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Needs Assessment Report

# Rheumatoid arthritis in adults: Gaining health from effective treatment

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## Reference Group

The reference group which informed the development of this report had broad professional and geographical representation from the health care and voluntary sectors. The membership of the group is detailed below:

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  - Roger Sturrock, Professor, Centre for Rheumatic Diseases, Glasgow Royal Infirmary
  - Joy Tomlinson, Clinical Research Fellow, Department of General Practice, Glasgow University.
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## Acknowledgements

The group members wish to express their thanks to the many people who contributed to the report including those who took time to speak to Ron Gray personally. These

individuals are named in Appendix 1 and included a number of specialist nurses, rheumatologists, orthopaedic surgeons, and primary care professionals from across Scotland. Thanks are also due

to the many people who provided extensive and constructive comments on the draft report. The full list of those who responded is in Appendix 2.

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## Note

It was initially considered important to have representation on the group from nurse specialists.

However, after careful consideration it was decided that, given the range of ways of working in existence in Scotland, it would be more

appropriate to meet and interview a number of these professionals in order that the different patterns of working could be reflected.

# Executive Summary

- Rheumatoid arthritis is one of the major chronic diseases in Scotland and affects an estimated 35,000 Scots, most of whom are over 45.
- Rheumatoid arthritis can cause considerable disability and premature death.
- Though it is not curable, early and appropriate treatment can modify the disease progression significantly and improve the patient's quality of life as a result.
- Developments in the understanding and treatment of rheumatoid arthritis mean that better outcomes than at any time in the past are now possible for those who have access to effective care.
- This needs assessment reports builds on the recently published Scottish Intercollegiate Guidelines Network (SIGN) guidelines on the early management of rheumatoid arthritis by providing further information on how to plan and deliver services for all rheumatoid arthritis patients.
- Current evidence strongly suggests that better outcomes can be achieved through:
  - a structured proactive approach to disease management
  - access to a well coordinated team of skilled professionals
  - an informed, empowered patient working as part of that team
  - accurate, early diagnosis and initiation of appropriate treatment to reduce inflammation and damage
  - prompt relief of pain and other symptoms
  - appropriate and timely interventions, including surgery, to minimise disability in established disease
  - a focus on outcomes rather than process
  - adequate systems to measure, record and evaluate outcomes.
- A checklist for local services has been developed as part of this report, based on the experience and knowledge of the reference group and others consulted.
- No one model of service provision is advocated over another. The most appropriate model will depend on local circumstance. The key point is that any service should contain the essential components of effective services outlined in this report, and be suitable and acceptable locally.
- The 'Eight E's' below summarise the key themes that arose during this needs assessment process and are the basic principles which should inform modern services.

## DEVELOPING SERVICES FOR RHEUMATOID ARTHRITIS: THE 8 'E's

Evidence based early treatment  
Extended care approach  
Equity  
Established disease  
Empowerment  
Exercise  
Education  
Employment

- There are ten recommendations in this report which cover: service commissioning and provision; quality standards; training and education; and improving information and awareness. These should assist the evolution of services to ensure that, in the future, patients with rheumatoid arthritis in Scotland have an equal opportunity of a good outcome and are prevented from the type of disability that can result from progressive, untreated or poorly managed disease.

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# One.

## Introduction

Continuing developments in the understanding, treatment and care of people with rheumatoid arthritis (RA) mean that better outcomes can be expected for those who have access to effective care in the early stage of their disease.

Translating advances achieved in science and clinical trials into everyday clinical practice in Scotland is the responsibility of our 15 NHS Boards. However, many service planners may be unclear how to provide appropriate services for RA to achieve the best results for their local populations. Recently published guidelines (developed by the Scottish Intercollegiate Guidelines Network (SIGN)<sup>1</sup>) summarised the evidence for improved outcomes and made specific recommendations for the treatment of early RA<sup>i</sup>. The current report builds on these guidelines by providing further information on how to plan and deliver services for RA patients.

This report offers information to help evaluate and plan local services to optimise health gain for people with RA. It provides an estimate of the number of new and existing adults with RA in Scotland. It also contains a template for local services,

suggests ways to improve them and illustrates an evidence-based model of care.

We are concerned not only with the needs of newly diagnosed people with RA, but also with those patients with severe, established RA. This latter group remains important in terms of service provision as these patients require the greatest amount of professional support and treatment.

From the outset it is important to acknowledge that the ultimate goal of RA services must be to achieve the best health outcomes for RA patients. Presently, outcomes are poorly measured and one of the recommendations of this report is that an expert working group considers which measures, targets and performance indicators should be adopted.

Implementation of the recommendations in this report should assist the evolution of services to ensure that, in the future, patients with RA in all parts of Scotland have an equal opportunity of a good outcome and are helped to avoid the type of disability that can result from progressive, untreated or poorly managed RA.

<sup>i</sup> The SIGN guidelines specifically address the treatment of early RA. The treatment of established disease and surgical management were outwith the remit and not covered.

### **Treat early to minimise later disability**

This picture illustrates the importance of early care and treatment in minimising the devastating effects that RA can have. For the patient opposite, delayed referral and treatment have resulted in deformed, painful, misshapen hands with reduced function. The picture below illustrates how, with early referral and early treatment, the inflammation has been controlled and there are fewer problems other than some swelling and stiffness.

Whilst we would not wish to underestimate the devastating effect that RA can have on some people, advances in its treatment mean that we should expect better outcomes for those newly diagnosed with the disease. Though a good outcome depends on many factors and cannot be guaranteed, the outlook is better than at any time in the past. In fact, with treatment started soon after diagnosis, there is real hope of an independent life for many people. In other words, RA should not result in low expectations by patients or practitioners and, in most cases, it should not adversely impact on an otherwise active life. Even in those with established disease, joint replacement can minimise disability and help maintain or restore independence.



These developments have led to a growing sense of optimism and increasing expectations from patients and professionals in the field of rheumatology. Disappointingly, the public generally, some health professionals and many service planners remain unaware of the potential improvements in pain relief, function and outcome that can be achieved. Services in Scotland are therefore not consistently delivering the optimum level of care.

The following case histories are included to illustrate how advances in treatment over the last 30 years have improved the outlook for patients with RA.



## RA THEN

### Case study 1

Seventy years ago doctors weren't able to stop RA damaging people's joints.

Mrs McCallum's joints were swollen and painful and she relied on her family to help her in day to day activities.

Most people with RA were unable to work and had problems walking.

### Treatment

When Mrs McCallum first had painful joints, her teeth were extracted to see if that would help! It didn't.

Next, hot baths and aspirin were advised but that didn't stop the joints being damaged either.

Gradually, she could do less and less.

## RA NOW

### Case study 2

When Liz started to have pains in her hands, she remembered how her gran had been affected.

When she found out she had RA she was really worried she might lose her job.

### Treatment

Modern treatments for RA work by reducing the inflammation. For Liz, like most people, it took some time for the treatment to work.

Rheumatoid arthritis hasn't seriously damaged her joints.

This type of response can be achieved with most patients presenting with rheumatoid disease.

A whole team of people saw Liz when she went to the specialist clinic. They helped her find the best way for her to manage things while her joints were sore.

### Case study 3

Jane was diagnosed with RA 2 years ago. She obtained good general control of the disease with modern drug therapy.

However, despite aggressive treatment she developed a painful right hip which limited her during normal activities of daily living (walking, sleeping, dressing, etc.) See above left for an example of a collapsing right hip.

### Treatment

A number of professionals worked together with Jane to ensure that she received prompt treatment to improve her quality of life and minimise her pain.

Following a hip replacement she returned to full activities and was able to care for her young family without pain or disability within 6 weeks. (see above right: total hip replacement)

She continues to maintain general disease control on her drug therapy.



## Two.

# What is rheumatoid arthritis?

Rheumatoid arthritis (RA) is amongst the most common, potentially treatable causes of disability in the Western World. It is one of the major chronic diseases and affects up to 35,000 people in Scotland. At least one person on your street is likely to be affected. Rheumatoid arthritis can cause considerable disability and premature death. Though it is not curable, early and appropriate treatment modifies the disease progression significantly, and improves the patient's quality of life as a result.

Appendix 3 contains more information on the impact of RA on the population and Appendix 4 has details on the treatments available for RA.

Rheumatoid arthritis can have a profound effect on day-to-day life. The symptoms of pain and stiffness in joints mean that even the most basic of activities of daily living (such as washing, dressing and housework) may be affected. These problems can lead to uncertainty or hopelessness about the future and may result in loss of employment, low self-esteem, depression and disempowerment.

The exact cause of RA is not yet known. What is known is that the body's immune system seems to turn against itself (autoimmunity) leading to inflammation. The main sites affected are the thin layers of tissue (synovial membranes) lining the inside of the joints and around the tendons. The main features of arthritis (pain, stiffness and swelling) are due to the inflamed joints. The disease typically affects the small joints of the hands and feet and the resulting loss of function can be severely debilitating. However, the most serious disability is associated with disease affecting the large weight-bearing joints, such as the knee and ankle.

Early treatment minimises loss of cartilage, erosion of bone and tendon damage but if left untreated, the disease takes a progressive course. Over a number of years more joints become affected leading to more severe disease. The rate of progression varies. In some people the condition may be mild and have periods of remission, but in many people it progresses rapidly.

There has been a lot of progress in recent years in the understanding of RA and appropriate care and treatments. Most treatment will involve medications to suppress disease activity and in some cases surgical procedures will be necessary. Early treatment with disease-modifying drugs can improve the outlook considerably, even for those worst affected. Appendix 4 has more detail on the effectiveness of the main treatment methods. The evidence strongly suggests that better outcomes can be achieved by:

- a structured proactive approach to disease management
- access to a well coordinated team of skilled professionals
- an informed, empowered patient working as part of that team
- accurate, early diagnosis, initiation and maintenance of appropriate treatment to reduce inflammation and damage
- prompt relief of pain and other symptoms
- appropriate and timely interventions, including surgery, to minimise disability in established disease
- a focus on outcomes rather than process
- adequate systems to measure, record and evaluate outcome.

Although RA mainly affects the joints, it can involve other tissues and organs. This is known as rheumatoid disease and tends to

## The majority of people with RA in Scotland are over 45 years old and therefore face additional problems of aging

occur in people with long standing RA. Patients with rheumatoid disease present with complications which require input from other specialists as they may have disease affecting the eyes, lungs, heart, skin, kidneys or other tissues.

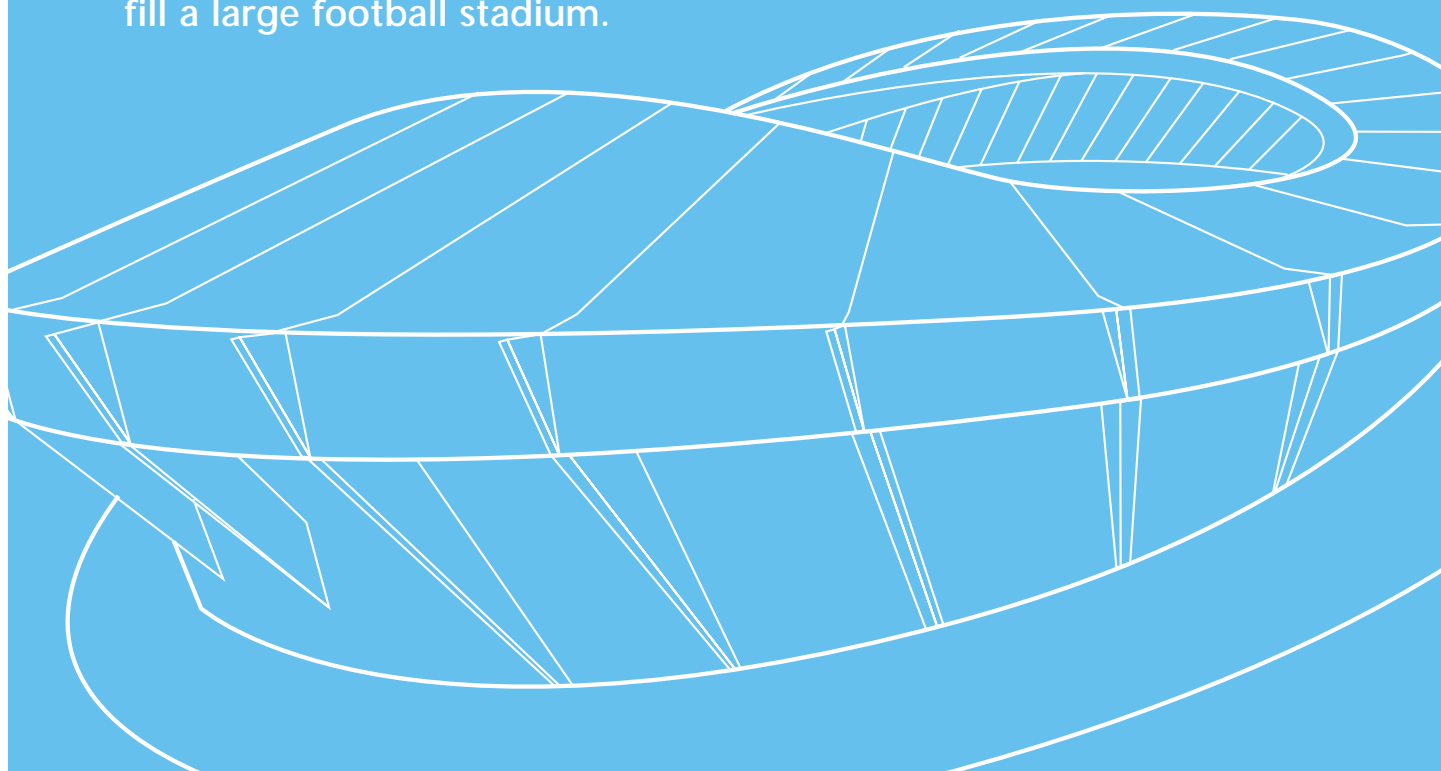
The majority of people with RA in Scotland are over 45 years old and therefore face additional problems of aging such as co-existing chronic diseases (for example, hypertension, diabetes) in addition to their RA. Many, however, are also of working age and so are particularly concerned about the impact of the condition on their employment status.

Recently an association with increased mortality from coronary heart disease (CHD) has been noted in patients with RA. Therefore, aerobic exercise programmes will also benefit RA patients in terms of a number of outcomes associated with cardiovascular health<sup>2</sup>.

## Three.

# Reducing the impact of rheumatoid arthritis in Scotland

The estimated 35,000 people with RA could fill a large football stadium.



We have estimated that up to 35,000 people in Scotland have RA. However, RA does not only affect those with the illness. It has a major impact on their partners, children, family and sometimes their close friends, neighbours and work colleagues. For every person with the illness there may be a number of others affected indirectly, meaning that RA impacts on a considerably larger number of people than those with the illness.

The estimated 35,000 people with RA could fill a large football stadium. If we looked round that stadium we would see that

about two thirds of these people are female and most are in middle to late life<sup>ii</sup>.

The case studies on page 8 illustrate how developments in care and treatment have improved the outcome for patients with RA. Twenty years ago more than half of those with the disease would have been unable to continue in employment compared to less than a third now.

Similarly, around a third would have been severely disabled compared to only about a sixth of RA patients today<sup>iii</sup>.

ii There would also be a few children and young adults. However, juvenile RA is a highly specialised area and will not be dealt with in this needs assessment document.

iii This popularisation is based on Capell et al<sup>6</sup>, Young et al.<sup>7</sup>, and Jacoby et al<sup>8</sup>.

## Four.

# Improving services for people with rheumatoid arthritis in Scotland: what needs to be done?

Based on our knowledge of the evidence base for interventions in RA we can predict that current services will be effective in so far as they:

- allow for early diagnosis and treatment by a rheumatologist
- have a well-developed multidisciplinary team approach
- aim for good control of disease
- are responsive enough to accommodate a whole spectrum of need
- have close liaison with, and prompt access to, orthopaedic services from a surgeon with an interest in RA
- collaborate with, rather than 'process', the patient
- are focussed on patient outcomes and improving these outcomes
- acknowledge the importance of primary care in chronic disease management.

### Scope for improvement in current services

Existing services in Scotland have evolved from historical patterns of provision developed in the light of experience of delivering these services. Increasingly attempts are being made to translate the growing evidence base into practice on the ground, delivered equitably across Scotland. However, there is still scope for improvement. Current services are described in more detail in Appendix 5.

Problems with existing services include the following:

- there is an insufficient knowledge and skills base amongst many professionals

- secondary care currently carries out many functions which might be better suited to primary care (e.g. some routine monitoring)
- there is poor coordination and integration between primary and secondary care
- waiting times are seen as a secondary care issue rather than a whole system problem
- current services are not as patient-centred as some patients would like
- services are often more focussed on process than outcome
- services are not consistently integrated with patient self-management
- each surgical episode is treated as a new episode for waiting list purposes
- standards of care vary throughout Scotland.

These problems are compounded by the fact that not only the public, but also some health professionals and many planners and policy makers, are poorly informed about RA and what can be done to improve the patient journey and health outcomes.

### The way forward

Eight key themes arose in the development of this needs assessment report. These are encapsulated in 'Developing services for rheumatoid arthritis: the 8 'E's'. (see Box A opposite). These can be seen as the basic principles which should inform modern services for RA in Scotland. They are all necessary and are, to a large extent, interdependent.

## BOX A Developing services for rheumatoid arthritis: the 8 'E's

### EVIDENCE BASED EARLY TREATMENT

- SIGN guidelines<sup>1</sup>
- Cultural shift – earlier assessment by rheumatologist
  - earlier introduction of disease-modifying anti-rheumatic drugs (DMARDs)
  - raised awareness and expectations

### EXTENDED CARE APPROACH

- Using the multidisciplinary approach
- Extending the use of nurses and allied health professionals (AHPs)
- Focus on outcomes supported by high quality information systems

### EQUITY

- Access, flexibility and choice
- Geographical consistency
- Economics
  - Health Technology Board for Scotland (HTBS) advice (and National Institute for Clinical Excellence (NICE) guidance)<sup>iv</sup>
  - Scottish Medicines Committee (SMC) guidance

### ESTABLISHED DISEASE

- Surgical intervention
- Patients whose disease responds poorly or not at all to treatment
- Use of newer ('biological') drugs

### EMPOWERMENT

- Self-management programmes including empowerment training
- Holistic model of care centred on the 'expert' patient
- Therapeutic alliance

### EXERCISE

- Changing culture
- Changing expectations
- Promoting health

### EDUCATION

- Education of people with RA
- Education of the public about RA and the needs of people with RA
- Educating employers
- Training and education of health professionals

### EMPLOYMENT

- Advice and retraining schemes
- Supported employment programmes
- Sensitive flexible employers

<sup>iv</sup> See Appendix 6

## Five.

# Checklist for local services

In each NHS Board area there needs to be universal access to a comprehensive service for people with RA. In some areas of Scotland this may require joint planning of services between NHS Boards to deal with issues such as geographical remoteness and cross boundary flows.

Based on the experience and knowledge of members of the reference group and information obtained from a variety of other sources<sup>v</sup>, including a comprehensive review of the existing literature, a checklist for local services has been drawn up and is detailed below.

Due to differences in geography, resources and organisational structures of NHS Board areas in Scotland, this checklist should be considered as a guide on which to base local discussions about local service development, rather than as an audit tool.

In addition, consideration should be given to the development of a Managed Clinical Network (MCN) for RA. Such an approach would support the development of a common database and the sharing of information and good practice between disciplines, primary and secondary services and geographical areas.

Appendix 7 provides more information about what patients with RA should expect from local services.

### In General

- 1 A multidisciplinary team of professionals, which includes appropriate allied health professionals (AHPs) and which has adequate clerical support, is essential for the delivery of an efficient, effective and timely service to RA patients. All patients should have access to such a team. (The team approach to chronic disease is explained further in Appendix 8).
- 2 People with RA should be regarded as key players in producing health gain both at an individual and service level. This means that people with RA should:
  - feel empowered in their contact with local services
  - have a major input to the commissioning and development of local services.
- 3 People with recently diagnosed RA should be offered:
  - user-led self-management courses
  - information on RA in primary and secondary care
  - relevant information on local services.
- 4 Relevant Health Technology Board for Scotland (HTBS) and Scottish Medicines Committee (SMC) advice should be considered when planning local services<sup>vi</sup>.
- 5 Pain management should be an integral part of the treatment process for patients with newly diagnosed RA and for those with established disease. (Pain may be

<sup>v</sup> This section draws on specific advice from members of the reference group as well as:

- The British League against Rheumatism – Standards of Care for Osteoarthritis and Rheumatoid Arthritis
- British Society for Rheumatology published advice on service planning

<sup>vi</sup> HTBS Comment on NICE Guidance No 27 on the use of cyclo-oxygenase (Cox II selective inhibitors) for osteoarthritis and rheumatoid arthritis, and HTBS Comment on NICE Guidance No 36 on the use of etanercept and infliximab for the treatment of RA. (see Appendix 6) . The SMC issues guidance at the point of licensing of new drugs.



multifactorial and has to be addressed on a multidisciplinary basis).

- 6 Access for physically disabled people and appropriate facilities for car parking should be available in all services attended by people with RA.
- 7 Up to date knowledge of the range of therapeutic options, including surgery, should be included in training, and continuing professional development for all members of the multidisciplinary team.
- 8 There should be regular educational events and opportunities for primary and secondary care professionals to make each other aware of developments.
- 9 The facilities for patient examination, combined clinics, patient and professional education, and technical procedures such as joint injections, should be considered adequate or better by professionals and service users.
- 10 The management infrastructure should be adequate. In particular there should be:
  - dedicated secretarial and clerical support.
  - telephone, fax and email facilities.

### Early rheumatoid arthritis

- 11 The SIGN guidelines on the management of early RA<sup>1</sup> should be implemented – and in particular the guideline relating to early referral which states that patients should be seen by a rheumatologist within twelve weeks of

the onset of symptoms. (Appendix 9 gives more detail on the classification criteria for RA).

### Information

- 12 There should be a comprehensive register of patients in each NHS Board area. It should allow linking of data between primary and secondary care and enable comparisons across NHS Board areas. This will require core data to be collected in all areas. In addition, the register should contain information on outcome, particularly patient centred outcomes, and be designed to enable:
  - clinical audit<sup>vii</sup>
  - patient recall
  - monitoring of individual care plans
  - service planning
  - improved resource allocation and planning.

### Primary care

- 13 Each local health care cooperative (LHCC) should recognise RA as a clinical priority and appoint a lead person for coordinating RA services locally. This person's brief would be administrative rather than clinical and would be likely to include the following:
  - acting as administrator for a local managed clinical network (MCN)
  - arranging locally agreed protocols and clinical guidelines
  - assessing local needs in the light of this document
  - monitoring waiting times within their LHCC

<sup>vii</sup> HTBS Comments and the corresponding NICE guidance have specific criteria for audit (See Appendix 6). Appendix F of the NICE Guidance on the use of etanercept and infliximab provides a detailed list of suggestions for audit.

- informing local decisions about referral pathways.

Where LHCCs are small there may be a case for having a lead person for a group of LHCCs.

- 14 General practitioners (GPs) should be aware of the need for early diagnosis and early referral to secondary care for confirmation of diagnosis, early assessment and initiation of disease-modifying anti-rheumatic drug (DMARD) therapy as appropriate. Patients suspected of having RA should be seen by a rheumatologist within twelve weeks of the onset of symptoms.<sup>1</sup>
- 15 Patients should be able to access, through the primary care team and without delay, the wide range of community support services required (including physiotherapy and occupational therapy).
- 16 A major role of primary care services for RA, as for any other chronic disease, is for psychosocial support and management.
- 17 General practitioners and community pharmacists should counsel patients to promote concordance with prescribed medicine and self-management of their condition.
- 18 Community pharmacists should check that patients are aware they should seek a pharmacist's advice before purchasing any over-the-counter medicines which might interact with prescribed medicines.
- 19 Since regular, moderate physical activity reduces the risk of developing CHD, patients should be encouraged and given support and advice to increase their activity levels<sup>2,4,5</sup>. Physiotherapists have an important role in the development of aerobic exercise programmes (which may include staff training) and, where appropriate, have an advisory role in service delivery.<sup>viii</sup>

#### Rheumatology services

- 20 All patients referred by their GP with suspected RA should be assessed by a rheumatologist. The rheumatologist and, where appropriate, the multidisciplinary team should then formulate a management plan agreed with the patient.
- 21 Patients started on DMARD therapy should be regularly reviewed in secondary care, as part of a shared care programme, with the GP usually monitoring drug side effects and the rheumatologist monitoring response to therapy.
- 22 There should be established multidisciplinary care with appropriate staffing. Clinical nurse specialists in rheumatology and AHPs are considered to be integral to well-managed, high quality clinical care. The numbers of these professionals should therefore be expanded.

viii The Physical Activity Task Force in Scotland recently published their consultation document. In it they outline a broad framework of objectives and priorities for developing physical activity in Scotland, which strongly support the recommendations about physical activity made in this needs assessment. It describes the vision, goals, strategic objectives and priorities and seeks comments on whether the proposed national and local infrastructure is appropriate for the development of further action plans. See: 'Let's Make Scotland More Active'. A strategy for physical activity – a consultation. Physical Activity Task Force. June 2002. Edinburgh: HMSO. Available at <http://www.show.scot.nhs.uk/sehd/patf/>





- 23 Workforce requirements may vary according to local models of service, local need and geographical variability. For these reasons for most health professions it is currently not possible to stipulate an ideal number of staff per head of population. However, local service planners should be aware of guidance published by professional bodies. A range of suggested figures based on expert opinion have been published (see Appendix 10) but the British Society for Rheumatology (BSR) recommend one whole time equivalent rheumatologist for every 85,000 population. The Senate of Surgery of the UK and Ireland recommends one whole time equivalent orthopaedic surgeon per 30,000 population<sup>ix</sup>. Service planners should be aiming for the recommended ratios, but in the short term there will be practical problems in achieving these. The most important point is that there should be established multidisciplinary care with staffing levels considered appropriate to meet the needs of patients locally by professionals working in the area.
- 24 There should be effective and close collaboration with orthopaedic surgeons. Where surgery is coordinated by a rheumatologist, regular meetings should take place with surgical colleagues to discuss clinical cases<sup>x</sup>.
- 25 Adequate inpatient<sup>xi</sup> and day patient facilities should be provided. These units should be staffed by a multidisciplinary team with specific skills and experiences of caring for rheumatoid patients, some of whom will be critically ill. Such units should act as a focus for severely affected patients who may require repeated treatments.
- 26 Facilities for injections into joints (or soft-tissues) should be available in both secondary and primary care. Only those with appropriate training and experience should give these injections, and should do so in an appropriate, clean environment.
- 27 Safe, supervised aerobic activity programmes, tailored to suit individual needs and preferences, should be available for RA patients. These programmes should link with community leisure services and GP Exercise Referral schemes. State-registered physiotherapists should have a role in the development and provision of such programmes and, where appropriate, be involved in the training of community service personnel.
- 28 All professionals should have access to up to date copies of the main rheumatology textbooks, major professional journals and an on-line library with access to clinical databases and electronic journals.
- 29 Units should engage in regular audit and most should participate in clinical research.

ix Senate of Surgery of the UK and Ireland document, Consultant Surgeon Practice and Training in the United Kingdom June 1997. Advisory Handbook on Consultant and Trauma Services. British Orthopaedic Assoc 1999.

x Ideally this should happen fortnightly

xi Ideally within a designated rheumatology ward or a general ward with designated rheumatology beds.

## Orthopaedic surgery

- 30 Local orthopaedic surgical services should include a surgeon with a sub-specialty interest in RA, and with access to a clinical network which ensures that cases requiring unusual or complex surgery (e.g. ankle, elbow, or neck surgery) receive adequate care.
- 31 There should be effective and close collaboration between orthopaedic surgeons and rheumatology services. The way of doing this may vary according to local circumstances, but may include a multidisciplinary assessment which incorporates surgical and functional priorities for surgery and patients' potential to comply with post-operative therapy.
- 32 The waiting time from initial referral by an experienced member of the team, when joint replacement may be considered, to actual surgery for patients with RA should be as short as possible and compatible with clinical need. Ideally it would be no more than eight weeks.
- 33 Surgery should be coordinated by a surgeon with specialist training, or a rheumatologist who meets regularly with his or her surgical colleagues to discuss clinical cases<sup>xii</sup>.
- 34 As outlined in point 23 above, workforce requirements may vary according to local models of service, local need and geographical variability. However, local

service planners should be aware of guidance published by professional bodies and be working towards these.

- 35 Patients with multi-joint disease requiring complex reconstruction should have their surgery regarded as a series of planned linked therapies and not as separate episodes for waiting list purposes.
- 36 Access to surgical services should be monitored to ensure availability and timely access.

## Services for other rheumatological conditions

- 37 In some parts of Scotland, specialist rheumatology services have had inappropriate referrals for soft tissue conditions and osteoarthritis on a routine basis. This has led to longer waiting lists for secondary care. To minimise this, adequate provision in primary care should exist for the treatment of all but the most severe cases of soft tissue conditions and osteoarthritis. Physiotherapists and community pharmacists can play a major role and should be easily accessible to the primary care team. Pain management must also be routinely available and an integral part of the care package.

<sup>xii</sup> Ideally this should happen fortnightly.

# Six.

## Training and education



Training and education for front line health professionals is important for a number of reasons:

- consultations related to musculoskeletal disorders make up a high proportion of GP caseloads
- early referral, diagnosis and treatment are vital for maximising patient outcome
- all members of the health care team need to have sufficient and up to date knowledge in the care and treatment of RA to deliver optimum patient care. For example, in order that patients have access to injections into joints or soft tissues in both primary and secondary care, relevant training should be made more widely available
- shared care is widely accepted as best practice but to be effective, it requires the presence of adequate knowledge and resources in primary care
- the development of new clinical roles (such as specialist health professionals (nurses or therapists)) brings the potential for important improvements in patient care, but also a requirement for appropriate training
- good undergraduate and postgraduate education of AHPs and medical

undergraduates and postgraduates is vital to help increase understanding about the management of RA and other rheumatic diseases. In addition, it can help to increase the importance that this group of conditions is given by the professions.

It is recognised that there is a need to increase the number of specialist rheumatologists and orthopaedic surgeons in Scotland. However this will take some time, as more doctors will be required to embark on training in this field. Therefore, pragmatic developments are required to address current service needs and these should include imaginative education programmes designed to encourage and improve multidisciplinary working. For example, in a rural area with a relatively small population, the involvement of GPs trained in rheumatology might help to provide a more effective service.

In addition, there is a need for increased training opportunities for specialist health professionals, yet there is little funding available for relevant specialist courses and a lack of availability of such training in Scotland.

## Seven.

# Examples of possible models of care

The reference group considered a number of service delivery models for rheumatoid arthritis care. It was deemed inappropriate to recommend any one model although the 'chronic disease management model' had significant support.

This model, which is being considered in some areas and which has a strong evidence base, has been successfully used for a number of chronic conditions such as diabetes, coronary heart disease and depression. Although there are no current working examples of this model specifically for RA, some details of the components of the model are outlined in Appendix 11.

The model currently adopted by most services in Scotland is a 'shared care' model, where primary and secondary care services work together to provide the patient with optimum care.

The choice of service models will depend to a great extent on local circumstance and should be agreed by all local partners. The key point is that any service should contain the essential ingredients of effective services.

These are outlined in Chapter 4 and summarised again below.

Services should:

- allow for early diagnosis and treatment by a rheumatologist
- have a well-developed multidisciplinary team approach
- aim for good control of disease
- be responsive enough to accommodate a whole spectrum of need
- have close liaison with, and prompt access to, orthopaedic services from a surgeon with an interest in RA
- collaborate with, rather than 'process', the patient
- be focused on patient outcomes and improving these outcomes
- acknowledge the importance of primary care in chronic disease management.

# Eight.

## Report recommendations

The recommendations below are based on 'Developing services for rheumatoid arthritis: the 8 'E's' outlined in Box A on page 13.

### 1. Service commissioning and provision

- a. Each NHS Board planning or commissioning department should provide resources for a designated lead person to bring together relevant local stakeholders in RA service provision (see Appendix 8: The team approach) as a planning and implementation group for local RA services. This should include patient representation. Links should also be established with the Board's public health department. These planning and implementation groups should include the following as part of their core remit.
  - i Identification of the strengths and weaknesses in local services using the checklist provided in this report (see Chapter 5).
  - ii Consideration of local prevalence and staffing numbers for all relevant health professionals, comparing with national guidance (where it exists<sup>xiii</sup>), and the addressing of any shortfalls.
  - iii Ensuring that there is appropriate and equitable access to services and treatments for all patients with RA.
  - iv Reviewing the services provided for people with established disease (as the existing SIGN guidelines largely deal with acute and newly presenting cases).
  - v Taking account of advice and evidence from HTBS on recommended drugs or treatments (see Appendix 6).
  - vi Ensuring the availability of good

quality information for the planning, delivery and monitoring of effective local services. Information systems should include:

- a local register of adults with RA. This register should include nationally agreed measures and indicators as a core, to permit area comparison<sup>xiv</sup>
- standards of care (including outcome measurements e.g. by patient derived disability and dependency scores, quality of life questionnaire, and mortality in the years following diagnosis)
- systems of recall
- means to share clinical information electronically between primary and secondary care.

The data collected by these information systems should be audited regularly to allow for identification of weaknesses in the system and continuous quality improvement (and particularly improvement in patient outcomes).

- b. NHS Boards, such as those in the north and west of Scotland and the island boards, should consider planning services jointly to deal with the issues of geographical remoteness and cross boundary flows. This might be done by the establishment of regional managed clinical networks (MCNs).
- c. When the current SIGN guideline on early management of RA is reviewed SIGN should be requested to consider widening the scope of the current guideline, or developing a new

<sup>xiii</sup> See Appendix 9.

<sup>xiv</sup> This should observe standard procedures about consent, confidentiality and data protection.

guideline, to cover the management of established disease, including surgical management.

- d. The needs of the minority of patients with progressive disease should be dealt with promptly and as fully as newly diagnosed patients. Each service should offer comprehensive care (involving the multidisciplinary team) to ensure appropriate and cost-effective care for these, the most disadvantaged patients.

## 2. Quality Standards

- a. NHSScotland Quality Improvement should be invited to formalise standards for RA services (the SIGN guidelines and this needs assessment report may be useful in informing this process).
- b. Information systems should be adopted in each NHS Board area (see recommendation 1a(vi) above) which allow for comparisons across areas. This would mean the development of a national dataset. It is therefore recommended that appropriate outcome measures targets and performance indicators are considered and identified by the Scottish Society for Rheumatology in consultation with the Rheumatoid Arthritis Surgical Society and the relevant voluntary organisations. These should be incorporated into local NHS Board information systems in order to allow comparison across NHS Board areas.

## 3. Training and education

- a. Improving training and education for front line health professionals is crucial to delivering better quality services. It is

therefore recommended that the Scottish Society for Rheumatology and the Rheumatoid Arthritis Surgical Society should work together with relevant Royal Colleges, patient organisations and other bodies, including NHS Education Scotland (NES), to develop plans to deliver improved training for all relevant disciplines. This may include multidisciplinary or multi-agency training or training delivered by people with RA themselves.

## 4. Improving information and awareness

- a. Those organisations working in the voluntary sector on RA issues should work together to raise awareness amongst the public and employers, in both the public and private sectors, of the importance of early treatment and access to surgery, as well as the needs of people with RA more generally.
- b. Voluntary organisations should link with the Physical Activity Task Force in Scotland to raise awareness, improve access and develop systems to promote physical activity and mobility in RA patients.
- c. The Scottish Society for Rheumatology (SSR) and relevant voluntary organisations should work together to develop balanced information for newly diagnosed RA patients and for primary care professionals. This information should cover the risks and benefits of disease modifying drugs and the availability and value of aids and appliances. This information should also provide details of support and voluntary services and reflect local circumstances and provision.

# Glossary

AHPs	Allied health professionals
ARA	American Rheumatism Society
BSR	British Society of Rheumatology
CAM	Complementary and alternative medicine
CMR	Continuous morbidity recording
CRAG	Clinical Resource and Audit Group
DMARD	Disease-modifying anti-rheumatic drugs
GHH	Glasgow Homeopathic Hospital
GPs	General practitioners
HTBS	Health Technology Board for Scotland
ISD	Information and Statistics Division
LHCC	Local health care cooperative
MCN	Managed Clinical Network
NES	NHS Education Scotland
NICE	National Institute for Clinical Excellence
NOAR	Norfolk Arthritis Register
NSAID	Non-steroid anti-inflammatory drugs
RA	Rheumatoid arthritis
RASS	Rheumatoid Arthritis Surgical Society
SIGN	Scottish Intercollegiate Guidelines Network
SSR	Scottish Society for Rheumatology
TNF	Tumour necrosis factor

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# Appendix one.

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- Lyndsay Harkins, Statistician, Information and Statistics Division, Common Services Agency.
- John Hunter, Consultant Rheumatologist, Gartnavel General Hospital, Glasgow.
- Rachel Logie, Health Economist, Arthritis Research Council Epidemiology Research Unit, School of Epidemiology & Health Sciences, University of Manchester.
- Alison Low, Rheumatology Specialist Nurse, Woolmanhill Rheumatology Clinic, Aberdeen.
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- Fiona McGhie, Nurse Specialist in Rheumatology, Raigmore Hospital, Inverness.
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- Robert Miller, LHCC Manager, Glasgow.
- Caroline Morrison, Consultant in Public Health Medicine, Greater Glasgow NHS Board.
- Stan Murray, Consultant in Public Health Medicine, Greater Glasgow NHS Board.
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- David Reid, Professor of Rheumatology, University of Aberdeen.
- Catriona Renfrew, Director of Planning and Community Care, Greater Glasgow NHS Board.
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- Deborah Symmons, Professor of Rheumatology and Musculoskeletal Epidemiology, Arthritis Research Council Epidemiology Research Unit, School of Epidemiology & Health Sciences, University of Manchester.
- Wilma Waugh, Rheumatology Specialist Nurse, Woolmanhill Rheumatology Clinic, Aberdeen.

# Appendix two.

## Consultation responses

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	Director of Reviews	
Ms Jan Warner	Fellow & Secretary	Clinical Standards Board for Scotland
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Ms Katie McAlary	Fife Rheumatic Disease Unit	Southern General Hospital
Ms Janet Harkness	Honorary Secretary	Cameron Hospital
Mr Andrew Thomas	NAROT Chairperson	Rheumatoid Arthritis Surgical Society
Ms Dawn Stobbs		National Association of Rheumatology
		Occupational Therapists
Ms Mel Miller	Health Planning & Quality Division	Scottish Executive Health Department
Ms Darryl McGhee		Southern General Hospital
Ms Sue Oliver		

## Appendix three.

# The impact of rheumatoid arthritis on the Scottish population

This section describes the impact of rheumatoid arthritis in Scotland. Estimates of the incidence and prevalence of the disease in each NHS Board area are given in Appendix 10.

### Rheumatoid arthritis in the context of rheumatic diseases

Rheumatoid arthritis is one of a group of disorders known as the rheumatic diseases<sup>i</sup>. Together they are the most frequently self-reported causes of ill-health and disability in the UK<sup>1</sup>. There are over 200 disorders in this group. They include some disorders which are more common (but generally much less disabling) than RA, for example:

- osteoarthritis
- soft tissue disorders (e.g. tennis elbow, frozen shoulder)
- back pain
- osteoporosis

They also include disorders which are much less common than RA, for example:

- inflammatory arthritis associated with psoriasis or bowel disease
- gout
- connective tissue diseases (e.g. scleroderma)

### Key issues in the epidemiology of rheumatoid arthritis

#### Unknown cause

The cause of RA is not yet fully understood. Like many other chronic diseases it seems likely that both genetic endowment and, as yet unknown, environmental agents are important.

#### Main risk factors –

##### age, gender and family history

The prevalence of RA is very low in childhood and early adult life, starts to increase markedly towards middle age and peaks between ages 50 and 70. The disease is two to three times more common in females than in males. Although family history is a risk factor, at least 80% of those with RA will have no other family members affected.

#### Effect of ethnicity

No studies of RA in Scottish Asian or other ethnic minority groups have been performed. However studies conducted in England have shown a lower prevalence of RA in those of both Pakistani<sup>2</sup> and Black-Caribbean origin<sup>3</sup> than white caucasians living there.

#### Prevention of disease is not yet possible

As the cause is unknown and the risk factors are fairly non-specific there is currently no way to prevent the disease from occurring and no screening test to detect it pre-symptomatically.

#### How many people with RA can we expect in Scotland?

Incidence refers to the number of new cases arising annually in a population; prevalence refers to the number of existing cases. There are a number of ways to estimate incidence and prevalence:

- numbers attending rheumatology clinics give rough estimates but are inaccurate
- number of new and existing consultations in primary care give more accurate

<sup>i</sup> The terminology can be confusing. Essentially, RA is one of the rheumatic diseases. Rheumatoid disease is when rheumatoid arthritis affects tissues and organs other than the joints.



estimates but tend to miss those who have mild disease or who are in remission. A small scale Scottish prevalence study<sup>4</sup> and data from a sample of Scottish general practices<sup>5,ii</sup> estimate adult prevalence at between 330 and 550 per 100,000 population

- the best method of establishing incidence and prevalence is to use a prospective system of registering and evaluating all new cases in the community. In 1989 such a system, the Norfolk Arthritis Register (NOAR), was set up in Norfolk Health Authority: an area with 286 GPs in 77 practices looking after around 485,000 patients. Figures now available for the 1990 cohort of incident cases suggest an incidence rate of 56 per 100,000 in adult women and 27 per 100,000 in men aged 16 and above<sup>6</sup> with a prevalence rate of 810 per 100,000<sup>7</sup>.

Estimates of incidence and prevalence for Scotland by NHS Board area are given in Appendix 10 based on figures from the NOAR. Though the characteristics of this population may differ from the Scottish population, in the absence of large well-conducted studies in Scotland, these give our best estimate.

### **How disabled are people with rheumatoid arthritis in Scotland?**

Generally, the longer you have RA the more disabled you become. Outcomes are much better in those who use disease modifying drugs than in those who do not – especially when treatment is started early (see Appendix 4). A study of 732 patients with

RA in England<sup>8</sup> examined five years after the onset of RA found:

- 40% of people had minimal or no impairment
- 16% were severely disabled
- 10% had home adaptations or were wheelchair users
- 17% had undergone surgery for RA
- 9% had joint replacement surgery
- 27% of those in work had work disability
- severe disablement was associated with female gender, age over 60 at presentation and moderate to severe disablement at presentation.

### **Deprivation predicts poorer outcome**

There is evidence from studies conducted in Glasgow that socio-economic deprivation is an important predictor of worse outcome in RA<sup>9:10</sup>. The reasons for this are as yet unclear but may include:-

- co-morbid disease
- lifestyle factors (e.g. diet, exercise, smoking)
- poorer self-management skills
- later presentation with disease
- access to health care services.

Anecdotal evidence from Highland NHS Board suggests that those living in rural deprivation similarly fare worse. Physical disability causes disproportionate problems for those patients who make a living in manual occupations.

### **Life expectancy is shortened**

The life expectancy of the most disabled patients with RA is similar to patients suffering from triple vessel coronary artery disease or stage 4 Hodgkin's disease<sup>11</sup>. The main causes of death in people with RA are

ii We would like to thank Mathew Armstrong and Lindsey Harkins of ISD for further analysis of this data.

heart disease and cancer. Indeed heart disease is said to be twice as common in people with RA as in the general population. After taking classical cardiovascular risk factors into account, RA is an independent risk factor for coronary heart disease<sup>12</sup>.

A relationship was found between socio-economic status and mortality rate in a group of 200 patients attending a Glasgow clinic. Forty eight per cent were dead at 12 year follow up. However, only 36% had died in the most affluent groups compared to 62% in the more deprived groups<sup>13</sup>.

#### **Geographical variation**

There is insufficient evidence to comment on the disease spread or variability between NHS Board areas.

#### **Time trends**

Consultation rates in primary care for RA in the UK appear to be declining. The Royal College of General Practitioners surveys of consultations for different disorders which took place in 1981-2<sup>14</sup> and 1991-2<sup>15</sup> show a decline in consulting prevalence for RA in all age groups and both sexes. This decline is consistent with recent trends in other Western European countries and the United States<sup>16</sup>. Although these figures are suggestive of a reduction in incidence and prevalence, they may be explained by other factors such as better disease control. Therefore, no firm evidence currently exists to show any changes over time in incidence and prevalence. Despite this, there is no evidence of a reduction in the numbers of patients requiring joint arthroplasty for RA<sup>17</sup>.

#### **Economic burden of disease**

There have been no studies to date estimating the total costs of RA in Scotland. The burden of RA in England has been estimated at £1.256 billion<sup>18</sup>, over half of which results from lost earnings. The major healthcare costs of RA come from long-term institutional care and admission to hospital. The cost of drugs (including monitoring and management of toxicity) accounts for only around 15% of the total costs. This again emphasises the importance of early diagnosis and treatment.

# Appendix four.

## What helps in rheumatoid arthritis?

There are a number of possible interventions that can increase health gain<sup>iii</sup>. These range from treatment of individual patients to interventions which improve public awareness. Here we consider interventions by their primary target group, but bear in mind that they usually have ramifications beyond this. In the final section we review economic evaluation of interventions in RA.

### Interventions targeting the general public

We need to improve public awareness of RA, and the needs of those with RA, to create a more supportive environment. Key messages include:

- the need to consult early
- the better outcomes now available with treatment.

Interventions to improve public awareness may include advertising campaigns and the use of storylines about people with RA in popular television programmes<sup>iv</sup>. No systematic evaluations of either of these methods have been performed. However, we have good indirect evidence from the literature on the effectiveness of health promotion campaigns that they are likely to be effective<sup>19</sup>. Since such campaigns are most effective where there is a connection to local services, any national or local campaigns need to be planned in consultation with those who have RA and tied into offers of further information and help through help-lines, NHS 24 etc.

### Interventions targeting employers

There is considerable evidence that people with RA experience employment difficulties and often have to give up work<sup>20</sup>. There are

no specific studies looking at targeting employers, but it seems reasonable to accept that any measures to help retain and recruit people with RA are worthwhile. Details of government schemes such as 'Access to Work' and 'New Deal for Disabled People' can be obtained from disability employment advisers who can be contacted through local Job Centres.

### Interventions targeting health service workers and policy makers

To bring about the conditions necessary for change in health services, we need to improve awareness of RA amongst clinicians, managers, commissioners and policy makers. This involves:

- creating a vision of what can be achieved for people with RA
- showing how a few small but significant changes by individuals can make it happen.

Interventions to achieve this include this needs assessment process itself and advocacy/lobbying by voluntary organisations led by service users. There is good evidence that the involvement of service users can effectively influence policy and practice<sup>21</sup> – indeed service user involvement is now a major building block of the NHS in Scotland<sup>22</sup>.

### Interventions targeting clinical practice

These are interventions specifically designed to improve clinical practice. They may be codified in guidelines and protocols or form part of professional education programmes.

There is good evidence that using guidelines, protocols and educational

<sup>iii</sup> The interventions discussed below were those felt to be of most help by the reference group. Information on effectiveness was obtained from national experts, SIGN guidelines and reviewing the relevant literature.

<sup>iv</sup> For example the recent edition of 'Holby City', BBC1, February 2002.

interventions can improve clinical practice<sup>23</sup>. The evidence also suggests that the use of multiple strategies to change clinical behaviour is likely to be more effective than the use of single interventions<sup>24</sup>.

There is good evidence that the following educational interventions are generally effective<sup>25</sup>:

- educational materials and reminders
- outreach visits
- local opinion leaders
- continuing medical education.

However, educational interventions in primary care are hampered by the fact that rheumatology is not a core curricular subject in general practice training, despite rheumatic diseases being the commonest cause of disabling illness seen in primary care.

It is too early to assess the effectiveness of the recently produced SIGN guidelines<sup>26</sup> for early arthritis. Anecdotally, however, a number of rheumatology units are moving towards using some of them as service standards.

### **Interventions targeting individuals with rheumatoid arthritis**

The importance of good control of the disease process with disease-modifying

drugs (DMARDs) cannot be overemphasised, and the majority of patients will require sustained disease-modifying therapy. However, RA must also be seen in the context of the whole person: disease control is one aspect of a complex process leading to multiple outcomes, all of which need considered. This section considers the effectiveness of:

1. specialist treatment
2. collaborative approach
3. self-management and patient education
4. multidisciplinary team care
5. drug treatment
6. surgical treatment
7. complementary and alternative therapies
8. exercise.

Note: It should be noted that there are a number of interventions for which evidence does not exist. Often this is because the effectiveness is self-evident (e.g. supplying home equipment such as bath hoists), but sometimes it is because making a comparison with a different intervention or no intervention would be unethical.



### 1 Specialist treatment

There is strong evidence that specialist secondary care services give better outcomes than general services<sup>27</sup>. We might also expect nurse specialists, specialist physiotherapists, occupational therapists, surgeons and GPs with specialist skills in rheumatology to be more effective than their counterparts with generalist skills, but there is no evidence to support this at the moment.

### 2 Collaborative approach

The collaborative approach to the care of chronic illness sees the patient as working in partnership with the care team. The key elements are:

- patients and care providers have shared goals
- there is a sustained working relationship
- mutual understanding of roles and responsibilities
- appropriate skills to carry out roles.

This approach has been shown to be effective in a number of chronic diseases including arthritis<sup>28</sup>. It has similarities with the patient centred approach which has also been shown to be effective<sup>29</sup>. In both these approaches the essential

element is that the balance of power in the therapeutic relationship is shifted more towards the patient. However, with power comes responsibility, and the patient is encouraged to take a much greater role in self-management.

### 3 Self-management and patient education

This approach has been pioneered in the UK by Arthritis Care with the user-led 'Challenging Arthritis' course. The course is geared to help participants deal with the pain and psychological difficulties that often result from RA. It also enables participants to develop the skills required to manage arthritis more effectively and to make well-founded decisions about how to control their lives.

In Scotland each course is led by one of 79 accredited volunteer course leaders. Local training and quality assurance are supported by training services managers based across Scotland<sup>v</sup>.

There is evidence to support the effectiveness of this programme. It is reviewed in the recently published report on the 'Expert Patient'<sup>21</sup> which recommends that these courses become

<sup>v</sup> In the last three years 150 courses have been held throughout Scotland, funded (up to March 2000) by the national Lottery Charities Board. However, sources of funding in each NHS Board area now need to be identified to continue this service.



part of the mainstream services commissioned and provided for people with RA in England and Wales by 2007.

Patient education in Scotland takes a number of forms. In most centres, nurses, pharmacists, physiotherapists, occupational therapists or other members of the clinic team will provide information tailored to the individual, combined with leaflets containing more general information. In Aberdeen, a resource centre where patients can receive information and advice from a trained arthritis nurse has been set up near the town centre. Patients can also watch instructional videos and get leaflets. The centre also has a nurse-led helpline for patients in contact with the local service.

Patient education is both important and effective<sup>30</sup>. It is probably most effective when integrated with self-management.

#### **4 Multidisciplinary team care**

Multidisciplinary team care is now considered part of the standard approach to RA. No one discipline or professional has all the necessary skills to tackle the multiple, diverse and complex problems associated with RA. Pooling the skills and resources of different professional groups offers a way forward. Besides, the capacity of the team as a whole is often greater than the combined strengths of the individual team members (also see Appendix 8 on the team approach to RA).

The limited evidence available on effectiveness suggests that use of the multidisciplinary team improves outcome in the short term.<sup>31</sup> Longer term studies are now needed.

An increasingly common addition to the team has been the nurse specialist. These nurses tend to work fairly autonomously but are clinically accountable to the consultant rheumatologist. Their roles vary depending on local circumstances but mainly they provide:

- patient education, support and advice
- crisis management services e.g. helplines, nurse-led clinics
- co-ordination of other specialist input
- drug monitoring, metrology (clinical outcome measurement)
- they may also perform technical procedures such as removing excess fluid from joints and injecting joints with steroid drugs to reduce inflammation.

Studies of the effectiveness of nurse specialists have been limited but have shown promising results<sup>32</sup>. At the moment provision of rheumatology nurse specialists in Scotland is patchy.

Another recent development has been the use of physiotherapist led musculo-skeletal clinics to triage those patients who may need specialist rheumatology or orthopaedic services. These may impact indirectly on services for RA by reducing workloads in both rheumatology and orthopaedic surgery. These services have only been developed in a few areas in Scotland.

## 5 Drug treatment

The evidence for effectiveness of different drug treatments is well covered in the SIGN guidelines. All the drugs currently in use have been well studied and are of clearly proven benefit although all have some adverse effects.

The main groups are:

- **Non-steroid anti-inflammatory drugs (NSAIDs)**

These drugs relieve pain, swelling and stiffness but they do not affect the disease process. They can cause indigestion, heartburn and sometimes bleeding from the stomach as side effects. New drugs in this group have recently been developed. These are less likely to cause the digestive system side effects but they are more expensive and are only recommended for patients at high risk of developing these side effects (Appendix 6).

- **Disease-modifying anti-rheumatic drugs (DMARDs)**

These can modify the disease process, but they take some time to work. They may have serious side effects, but with regular monitoring these can be avoided or minimised. Two or more of these drugs are occasionally used together.

- **Steroids**

These can be given orally or injected into a painful joint to reduce inflammation. They can also be given intramuscularly for widespread flare or

predominantly multiple small joint flare. They do not affect the disease process. They are safe to use occasionally but, due to their side effects, are not suitable for long term use, unless in low maintenance doses.

- **Anti-tumour necrosis factor (TNF) drugs**

These drugs are new and expensive. They modify the disease process and result in improvements in those people who do not respond to DMARDs. Significant numbers have achieved responses previously not expected with DMARDs. They are useful second line drugs and recent guidance from NICE and HTBS recommends that their use be considered for the treatment of adults who have continuing clinical active RA that has not responded adequately to at least two DMARDs, including methotrexate (unless contraindicated). (See Appendix 6) At the moment they are prescribed according to a rigid protocol as part of a pragmatic Scotland-wide study (SPECTRA). Some NHS Boards have included funding of these drugs in their health plan, others have not.<sup>vi</sup>

## 6 Surgical treatment

Surgery is of use in established disease and may also be required early in the disease process. The aims of surgery in RA are to relieve pain, restore function and, occasionally, prevent or delay joint erosion or tendon rupture. It can be used to stiffen, resect (remove) or replace joints; to repair, release or realign soft tissues surrounding the joints; and to

<sup>vi</sup> The overall population health gain from these drugs is likely to be small, as relatively few people with RA are likely to need them. For those who do, the individual health gain may be quite considerable. NHS Boards are guided by local area drug and therapeutics committees and have to take account of the opportunity cost of prescribing these drugs.

remove synovitis (the inflamed joint lining) from joints or tendons to prevent soft tissue rupture when drug therapy has failed to obtain local control.

There have been relatively few procedures evaluated by randomised controlled trials (exceptions include hip and knee replacement surgery<sup>33</sup>). This is usually because the need for surgery is self-evident and it would be unethical to withhold it. However, there have been a number of long-term observational studies showing the benefits of surgical intervention.

Specific procedures relating to different joints are outlined in Box B.

Joint replacement can dramatically improve pain and function. Total hip replacement results in a significant and sustained improvement in the quality of life for the majority of patients<sup>34</sup>.

Patients with multi-joint disease requiring complex reconstruction should have their surgery regarded as a series of planned linked therapies and not as separate episodes for waiting list purposes. The benefits of surgery on one area may be lost if the associated corrective procedures are delayed by organisational requirements imposed by waiting list management. A full multidisciplinary pre-operative assessment can contribute to effective planning, timing and sequence of surgical interventions. Extended post-operative rehabilitation should be available for RA patients in view of their special needs.

## 7 Complementary and alternative (CAM) therapies

In a review of fourteen surveys on patients' use of CAM<sup>35</sup> in rheumatological conditions it was found that prevalence of use varies between 30% to nearly 100%. The patients' level of satisfaction with complementary medicine was often considerable and few adverse effects were reported. It has been argued<sup>36</sup> that in addition to the issue of finding additional or alternative therapies, these patients are often dissatisfied with the traditional medical approach to illness and are seeking a more patient focussed and whole person approach. In this approach the disease is not treated in isolation but considered in the context of the person, taking into account mind-body links. Most orthodox health professionals would also endorse such a holistic approach in principle and advocate a bio-psycho-social model, but point out that limitations on time make it impractical in conventional practice.

There is now mounting evidence that psychological factors may work on the immune system through neural and hormonal pathways (psychoneuroimmunology) and in this way alter disease progression and enhance healing<sup>37-39</sup>. The whole person approach accepts that the therapeutic encounter and process may be used to influence these pathways, to promote healing and modify disease activity.

However, the evidence for this holistic approach is currently general rather than specific to particular diseases such as RA.

## Box B: Surgical Interventions for RA by site

Site	Common Reasons For Surgery	Main Types of Intervention
Neck	<ul style="list-style-type: none"> <li>• Pain</li> <li>• Pressure on spinal cord</li> </ul>	<ul style="list-style-type: none"> <li>• Cord decompression,</li> <li>• Fusion of joint</li> </ul>
Shoulder	<ul style="list-style-type: none"> <li>• Pain</li> <li>• Local failure to respond to systemic therapy</li> </ul>	<ul style="list-style-type: none"> <li>• Arthroscopic subacromial decompression</li> <li>• Rotator cuff repair</li> <li>• Joint replacement</li> </ul>
Elbow	<ul style="list-style-type: none"> <li>• Pain, nodules, pressure on ulnar nerve</li> <li>• Local failure to respond to systemic therapy</li> <li>• Disability</li> </ul>	<ul style="list-style-type: none"> <li>• Removal of nodules</li> <li>• Freeing or moving ulnar nerve</li> <li>• Synovectomy</li> <li>• Radial head excision</li> <li>• Contracture release</li> <li>• Joint replacement</li> </ul>
Hand and wrist	<ul style="list-style-type: none"> <li>• Pain</li> <li>• Disability</li> <li>• Deterioration of function</li> <li>• Pressure on median nerve</li> <li>• Local failure to respond to systemic therapy</li> </ul>	<ul style="list-style-type: none"> <li>• Removal of part of ulna bone</li> <li>• Synovectomy tendon transfer</li> <li>• Fusion of joints</li> <li>• Joint replacement</li> <li>• Freeing median nerve</li> </ul>
Hip	<ul style="list-style-type: none"> <li>• Pain</li> <li>• Disability</li> <li>• Contracture</li> </ul>	<ul style="list-style-type: none"> <li>• Contracture release</li> <li>• Joint replacement</li> </ul>
Knee	<ul style="list-style-type: none"> <li>• Pain</li> <li>• Disability</li> <li>• Instability</li> <li>• Stiffness</li> <li>• Local failure to respond to systemic therapy</li> </ul>	<ul style="list-style-type: none"> <li>• Synovectomy</li> <li>• Arthrodesis</li> <li>• Joint replacement contracture release</li> </ul>
Foot and ankle	<ul style="list-style-type: none"> <li>• Pain</li> <li>• Disability</li> <li>• Deformity</li> </ul>	<ul style="list-style-type: none"> <li>• Fusion of joints</li> <li>• Removal of bone</li> <li>• Joint replacement</li> </ul>

While there is evidence<sup>40;41</sup> that patients having a longer and more individualised consultation, such as those at the Glasgow Homeopathic Hospital (GHH), feel more enabled than they did when attending their GPs, and have resultant health gains and reduction in analgesia, there is currently no hard evidence to prove that this results in disease modification<sup>vii</sup>.

vii GHH is an NHS integrative care unit combining orthodox and CAM therapy with a whole person approach.

Similarly, no disease-modifying impact from specific complementary treatment of RA has yet been proven. CAM therapies use and demand is well ahead of the creation of research infrastructure, but some emerging work is yielding mixed evidence for CAM as a symptomatic therapy. Many studies are too poor methodologically to make comment for or against the effectiveness of CAM



therapies. However, a systematic review of controlled trial evidence<sup>42</sup> noted that given the high rates of adverse effects of synthetic drugs used for RA, the following CAM modalities would seem to be reasonable therapeutic options: borage, fish oil, phytodolor thunder god vine, relaxation techniques. There is also suggestive but less developed evidence for other approaches such as homoeopathy and dietary/fasting regimes. No firm evidence has been found to support the role of diet in the management of RA, but anecdotal reports of specific diets affecting inflammation levels would suggest that further research is merited. Homoeopathy exemplifies the problem of evaluating evidence in this field. It has reasonable evidence of general effectiveness over placebo<sup>43</sup>, however what little specific testing there has been in RA<sup>44:45</sup> suggests a useful 'non-specific' impact but is insufficient to state confidently there is a specific effect. Yet other approaches – such as yoga – have encouraging but anecdotal evidence so far untested in rigorous clinical trials. In those therapies where a direct disease effect has been shown, the effect is usually moderate to small<sup>42</sup>, but the 'non-specific' impact may be useful<sup>44:45</sup>. Thus such CAM treatments may be useful as adjuvant treatments rather than true therapeutic alternatives.

## 8 Exercise

All people with RA should be encouraged to undertake regular exercise. Exercise is prescribed to relieve pain and to increase or maintain joint range of movement, muscle strength and functional ability. Increasing physical activity also has proven benefits in minimising the risk of coronary heart disease<sup>46</sup> which has recently been found to occur more frequently in those with RA<sup>12</sup>.

Traditionally exercise has been relatively low in intensity and undertaken in a position that would reduce pressure on the joints (for example,

seated, lying or in water). There is now strong evidence to support the effectiveness of more aerobic types of exercise (such as walking, cycling, dancing, and swimming). Aerobic exercise of low to moderate intensity can significantly improve general fitness and muscle strength without increasing pain or inflammatory activity<sup>47</sup>. This evidence demands a change in beliefs regarding exercise. It also requires alterations to service provision within the health service and the community.<sup>viii</sup>

Despite the popularity of hydrotherapy, the evidence showing physical benefit is limited<sup>48</sup> although it can improve self-efficacy<sup>26</sup>.

## Economic evaluation of interventions for rheumatoid arthritis

There have been few economic evaluations which would meet current quality standards<sup>49</sup>. However, there is reasonably good evidence to show:

- combination therapy of high dose steroids, and two DMARDs (Methotrexate and sulphasalazine) is more cost-effective than sulphasalazine alone<sup>50</sup>. However this combination is not recommended by the SIGN guidelines
- the DMARD cyclosporin is less cost-effective than the DMARDs azathioprine and penicillamine<sup>51</sup>
- while studies have shown the efficacy of biologic drugs, there are currently insufficient economic data to draw any firm conclusions
- despite the costs, surgery in RA can be extremely cost-beneficial<sup>52</sup>
- the cost utility of total hip replacement is estimated at £750 per Quality Adjusted Life Year (Qaly) gained. (£5000 for heart transplant)
- inpatient and daypatient care are equally cost-effective for uncomplicated active RA<sup>53</sup>
- user-led arthritis self-management courses reduce inpatient and outpatient use and costs, such that the benefits (in averted costs alone) far outweigh the costs<sup>54</sup>.

viii For example, GP exercise on referral schemes

## Appendix five.

# Current services available to people with rheumatoid arthritis in Scotland

A range of NHS and other services is currently available for people with RA in Scotland. Those consulted as part of this needs assessment process felt that these are generally of a high standard but that there is considerable scope to make them even better.

In this section we set out:

- the structure of the services available for people with RA
- the patient's pathway through the services
- information on service use
- what we know about effectiveness of our services
- scope for improvement in current services.

### **The structure of the services available for people with rheumatoid arthritis**

As with all chronic illnesses, services for people with RA are organised around the individual needs of a patient. These needs may change as time goes on. Services for people with RA are currently available in:

- primary care
- secondary and tertiary care
- the community.

Initially a patient may self medicate or may see someone other than their GP for advice, e.g. purchase painkillers from their pharmacist. The next point of contact is usually the GP who makes a provisional diagnosis and then refers to a rheumatologist for further assessment and treatment. The GP and other practice staff may then be involved in drug monitoring as part of shared care arrangements. This involves regular review of drug dose, response to treatment and side effects. It usually also involves discussion with the patient, an examination and blood testing. The GP sees the patient in the context of

their social, personal and medical background, not just in the context of the disease, and therefore plays a key role in integrating the management of the RA in the context of the patients other strengths and difficulties.

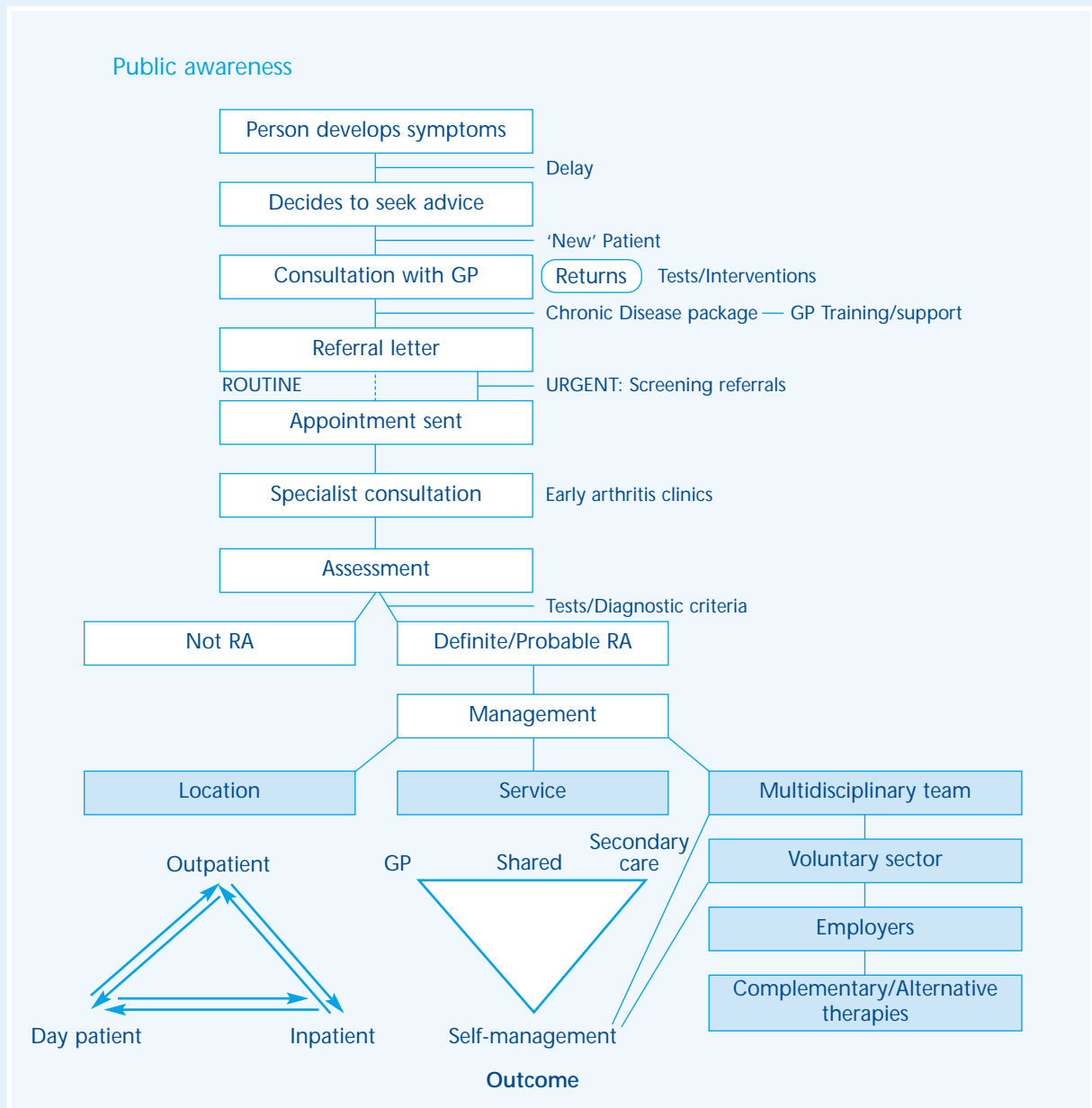
A number of professional groups offer services in primary care and in the community. These include allied health professionals, community nurses and social work. Voluntary organisations, such as Arthritis Care, base services in the community. Complementary and alternative therapists usually operate from a community base. These services are usually poorly coordinated internally and with primary and secondary care.

In the secondary care setting the rheumatologist is the first contact. Increasingly the rheumatologist is supported by a multidisciplinary team (although in many areas this approach is better developed for inpatients than for outpatients). Rheumatologists liaise with colleagues in orthopaedic surgery. Hospital based services usually operate through outpatient clinics, day patient services and inpatient beds.

A lot of routine monitoring is currently carried out in secondary care but may be more appropriately performed in primary care.

The multidisciplinary team in rheumatology involves ward, clinic and community-based staff. It may include some or all of the following professions: dietitians, nurses, occupational therapists, occupational therapists, orthotists, pharmacists, physiotherapists, podiatrists, rheumatologists, social workers, surgeons.

### Box C: The Pathway Through Services



### **The patient's pathway through the services**

The key issue is that all patients should be assessed by a rheumatologist and receive treatment as soon as possible after the onset of the disease. Therefore delay at any stage is potentially harmful and needs to be avoided. The pathway (shown in Box C) is not unduly complex but it is subject to delay at a number of points.

People with RA may present to the GP relatively late after the development of symptoms. This may be for a variety of reasons – including that they may feel little can be done to help or may have been self medicating.

There are also a number of patients who present to accident and emergency units or other orthopaedic services with one or more inflamed joints as their first presentation with RA. An awareness campaign both in accident and emergency and orthopaedics would help early diagnosis in such patients.

The GP should be able to refer the patient with suspected RA promptly (within 12 weeks of the onset of symptoms) for assessment by a rheumatologist. In some areas of Scotland waiting times for a new rheumatology appointment are long, so there are local arrangements with GPs to fast-track people with suspected RA.

Once disease modifying drug treatment has been started delays are less crucial to disease outcome, but can profoundly affect other outcomes such as psychological well-being, satisfaction with services and the relationship between the patient and the healthcare professional. Therefore, the next stage in the pathway (referral to other members of the multidisciplinary team, orthopaedic surgeons

and possibly social work) needs to happen promptly when required.

For all but those with mild disease who will be managed successfully in primary care, there should be regular review in secondary care or shared care between primary and secondary care. This regular review includes monitoring the effects of treatment, including being alert to adverse effects.

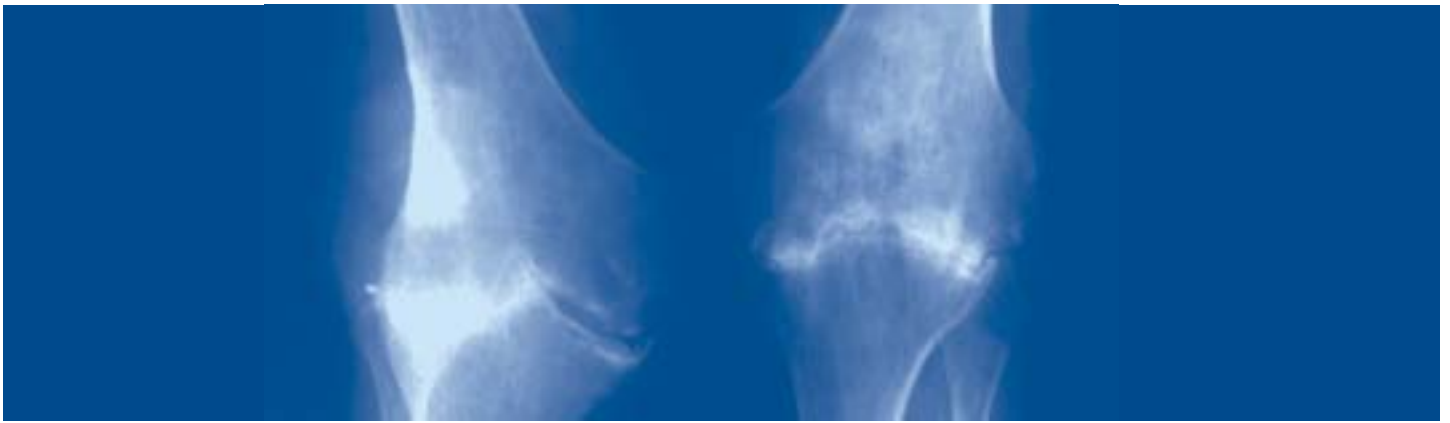
Crises such as sudden unexpected flare-ups in the disease or the development of severe or unusual side effects need prompt and competent help. While some GPs with a special interest or skills in rheumatology are able to handle these effectively on their own, in some areas of Scotland access to a specialist nurse-led clinic or helpline has been set up. In other areas, emergency admission or an urgent appointment with a rheumatologist is used.

Patients with rheumatoid disease present with complications which require input from other specialists. These include ophthalmologists, respiratory physicians, gastro-enterologists, cardiologists and renal physicians.

Pathways between health services and the voluntary sector, such as Arthritis Care, are currently not well established and individuals often have to find out about voluntary sector services for themselves. Some NHS Boards are willing to pay for the user-led self-management courses, such as those run by Arthritis Care, others are not.

Generally, there are no established referral pathways from health services to complementary and alternative therapists. However, a considerable number of people





with RA are using CAM services. This may be for a variety of reasons including, for example, increased patient choice or problems tolerating the side effects of conventional treatments. Given the high proportion of patients now using CAM in some way, and the possible implications for their conventional treatment, improved links between conventional and CAM services may be of benefit (see CAM section in Appendix 4).

#### Information on service use

The costs of treating RA are high. RA constitutes just over half of the rheumatology workload in secondary care and is responsible for about 54 GP consultations per year in the average general practice<sup>ix</sup>.

The Clinical Resource and Audit Group (CRAG) Scottish single-handed rheumatology audit in 1994 showed that RA accounted for half of all outpatient work and almost two thirds of all inpatient work<sup>55</sup>.

The direct costs of treating people with RA are two to three times higher than the healthcare expenditure on people of matched age and sex without arthritis<sup>18</sup>. In addition, one study showed increased costs for disease-related care and for other co-morbid diseases in this group<sup>56</sup>. This study also showed much higher medical costs for RA than a comparison group with osteoarthritis.

In the year 1999-2000<sup>x</sup> there were 66,931 rheumatology outpatient attendances at the 34 clinic sites in Scotland. Around a fifth of

these were new referrals. If we assume that RA accounts for half of these, then we can estimate that during this year RA accounted for approximately 33,500 attendances. The net cost for each attendance was on average £47, making a total cost of £1.5million for outpatient treatment of RA.

For the same year there were 2,760 discharges from the 13 Scottish rheumatology inpatient units, at an average net cost of £2,058 per case. If we assume that RA accounts for 60% of these discharges then this gives a total cost of £3.5 million for inpatient treatment of RA.

Also in this year there were a total of 1,585 rheumatology day patient cases at seven hospitals in Scotland at a net average cost per case of £276, which amounts to £437,000. If we assume conservatively that half these cases were of RA this adds another £0.2 million.

It is not possible to separate out those with RA receiving surgery from those with other disorders. However the costs for surgery in this group are likely to be substantial. Evidence from the Swedish national registries<sup>17</sup> would suggest that, despite the introduction of modern therapies over the last 10 years, the number of RA patients undergoing hip and knee joint replacement surgery has remained constant. The use of biological treatments such as anti TNF therapy will have an unpredictable effect on future requirements for surgery, and it should not be assumed that the need for surgical treatment will decrease. Indeed, if mortality is reduced, the requirement for surgery may increase.

ix This figure may be an under-estimate of actual consultations in primary care given that non-medical consultations are not recorded  
x The Scottish data referred to in this section are from ISD and are available on their website.

Patients who require surgery for RA often have been under medical treatment for some time. Because of the process of referral, the shortage of specialist clinicians and in-patient waiting lists for orthopaedics, these patients can often wait for up to two years for each joint replacement. This wait is unacceptable for people in pain with considerable disability, and unreasonable for patients for whom surgery should be an integral part of their care. Therefore, the waiting time from initial referral by an experienced member of the team, when joint replacement is considered, to actual surgery for patients with RA should be as short as possible, compatible with clinical need, and ideally no more than eight weeks.

While the majority of RA patients who need joint replacement surgery require only one or two joints replaced (often for osteoarthritis consequent to RA rather than for RA itself), around 5% of patients require surgery for multiple joint involvement. Planning surgery in these more complex cases is important but sometimes difficult<sup>xi</sup> (for example, lower limb surgery is usually carried out before upper limb surgery, as the use of walking aids may aggravate upper limb problems).

Use of primary care services can be estimated from the continuous morbidity recording (CMR) data submitted to ISD from the 75 Scottish practices involved in

this monitoring system. In the year from January to December 2000 there were, on average, 10.1 contacts per 1000 population for RA. This involved an average of 18 patients with RA in each practice making about three contacts each during the year i.e. about 54 consultations per practice per year<sup>xii</sup>. CMR data do not record consultations with non-medical staff in primary care.

#### **What we know about effectiveness of our services?**

We really know very little. Although there is a wealth of literature about the effectiveness of specific interventions for RA, there is very little on the effectiveness of the services themselves. Studies are often dependent on the nature of local services and cannot be generalised to other areas.

There have been studies comparing inpatient treatment with intensive outpatient treatment, which have shown inpatient treatment to be better<sup>57</sup>. A study from Edinburgh showed inpatient and daypatient care to be equal in terms of effectiveness and costs for uncomplicated active RA<sup>53</sup>.

<sup>xi</sup> This is because many orthopaedic surgeons are now regional specialists in upper limb, lower limb or back problems and deal with RA patients in their area of expertise. This means quality of individual procedures is high and cross-boundary referral low, however those patients requiring multiple surgeries may find no overall co-ordination or awareness of opportunities for surgery to less commonly operated joints. Surgeons with an interest in rheuma surgery are better placed to do this.

<sup>xii</sup> This figure may be an under-estimate of actual consultations in primary care given that non-medical consultation are not recorded.

## Appendix six.

# Health Technology Board advice

The Health Technology Board for Scotland (HTBS) has advised that the NICE Technology Appraisal Guidance – No.27: The use of cyclo-oxygenase (Cox) II selective inhibitors, celecoxib, rofecoxib, meloxicam and etodolac for osteoarthritis and rheumatoid arthritis (see [www.htbs.co.uk/htbsadvice/acoment.asp?did=346](http://www.htbs.co.uk/htbsadvice/acoment.asp?did=346)), and NICE Technology Appraisal Guidance – No.

36 Guidance on the use of etanercept and infliximab for the treatment of rheumatoid arthritis (see [www.htbs.co.uk/htbsadvice/acoment.asp?did=635](http://www.htbs.co.uk/htbsadvice/acoment.asp?did=635)) are as valid for Scotland as for England and Wales.

The full HTBS Comment on the NICE guidance can be found on the HTBS website ([www.htbs.co.uk](http://www.htbs.co.uk)).

# Appendix seven.

## What you should expect from your local services

### Setting the Standard

This section has been written by Arthritis Care Scotland to explain what you should expect from your health services and other agencies if you have RA. It also lets you know what you can do for yourself and other people with RA<sup>xiii</sup>.

It is necessary to acknowledge that the treatment of RA is not an exact science and that the disease and its progression impacts differently from person to person. In addition, because there is no cure as yet, health professionals do not and cannot be expected to have all the answers. That is why it is so important to set out minimum standards applying to the treatment of, and services to, people with RA to ensure a fair and equitable response no matter where you live.

It is also important to highlight, that all services received by a person with RA must place the patient within the context of their life. People with RA are not full time patients. They have jobs, families, responsibilities, sensitivities and pressures that do not disappear on diagnosis of RA, and these need to be taken into account if services are to adequately support the patient with RA to live a full and productive life.

### Disability Discrimination Act 1995

Section 21 imposes a duty on service providers to make adjustments to their premises to avoid discrimination against disabled people. This duty applies to all buildings to which members of the public

have access, and include:

- changing practices, policies and procedures that make it impossible or unreasonably difficult for disabled people to use a service
- provision of auxiliary aids or services which would make it easier for, or enable, disabled people to use a service
- overcoming physical features that make it impossible or unreasonably difficult for disabled people to use a service, by providing the service by a reasonable alternative method.

From 2004, service providers will have to take reasonable steps to remove, alter, or provide reasonable means of avoiding physical features that make it impossible or unreasonably difficult for disabled people to use a service.

The proposals outlined below are in addition to the responsibility of service providers to meet their obligations under the Disability Discrimination Act (1995).

### Primary care

- **Training** – should reflect the fact that 15% of all GP consultations are for arthritis related disorders, and should include an appropriate focus on rheumatology and disability awareness.
- **Appointments** – ideally GPs should be able to offer non-urgent appointments within 3 working days, especially in the early stages of diagnosis. Sufficient time for proper discussion of symptoms should be allowed for.

<sup>xiii</sup> This section was written by Angela Donaldson of Arthritis Care Scotland and aimed at people with RA. It is based on the current policy statements of Arthritis Care UK.

- **Information** – GP practice information booklets should include details of the accessibility of the surgery, including disabled parking spaces and access to all facilities within the surgery. Where GPs have several partners, information on each individual specialist medical interest should be declared, eg. Member of the Primary Care Rheumatology society.
  - **Home visits** – some people with RA have a difficulty in reaching the surgery, and may, at times, require home visits.
  - **Diagnosis of RA** – all people, both newly diagnosed and those with established RA should receive enough information to understand the condition and its likely progress together with information on how to manage their condition.
  - **Prompt referral** – referral to rheumatology specialist within 12 weeks of the onset of symptoms.
  - **Access to other health professionals** – physiotherapy, occupational therapy and podiatry etc should ideally be accessed from the GP practice. Where this is not possible or specialist rheumatology AHPs are considered more appropriate, prompt and timely referral to external services should be available.
  - **Self help organisations** – primary care services should be aware of and supply information on organisations providing support and information to people with arthritis. In addition, they should be able to directly refer people on to self-management and personal development courses, such as those run by Arthritis Care, within their area.
  - **Repeat prescriptions** – people with RA require long-term medication and this necessitates the need for repeat prescriptions. Systems should be set in place to minimise the number of journeys required to the surgery to obtain prescriptions. Either by using a postal system, at no expense to GPs, or partnership with a local pharmacy.
  - **Shared care** – most people with RA see a hospital based rheumatologist as well as their GP. The introduction of a Shared Care Card, to be retained by the patient should be encouraged. In addition, the patient should be encouraged to make their own notes on treatments received by either GP or consultant. This card can also be used to record the monitoring of drug side effects and disease activity.
  - **Supporting information** – GPs are frequently asked to provide letters of support, or complete claim forms for state benefit and other purposes. Where this occurs and if appropriate, consultation with the person concerned on the content of the response should take place.
  - **Consultation** – it is essential that patients be consulted when determining what services are provided and how their needs are to be met. Failure to do so will result in a meaningless partnership with the key partner absent.
- Secondary care**
- **Prompt referral to specialist rheumatologist** – people with suspected RA should be seen within 12 weeks of the onset of symptoms. These referrals should be prioritised for early appointments with a rheumatologist.

- **Access to multidisciplinary teams** – rheumatology departments should include the service of a multidisciplinary team, including; consultant, rheumatology nurse practitioner, physiotherapist, occupational therapist, podiatrist, dietitian and pharmacist. In order that the team can maximise their expertise and time with patients it is essential that adequate administration staff are made available to support all members of that team and their patients. Departments should regularly review their work practices and effectiveness monitored.
- **Hospital transport** – there should be a designated, named person who has responsibility on a day-to-day basis for ensuring that patients brought in for an appointment are also taken home again. The name and contact details of the person responsible should be prominently displayed. Where an unavoidable delay occurs this should be communicated to the person waiting via regular updates and staff should also ascertain what support is needed during the wait, eg. toilet facilities, telephone etc.
- **Waiting areas** – all waiting areas should have a variety of seating. In areas not designated for rheumatology a priority seating notice should be displayed.
- **Appointments** – the time allocated for appointments should be both genuine and achievable for patient and health professional. Block bookings for a number of patients at the same time for the same consultant are not acceptable. It should be made clear at the time of making an appointment, who should be contacted if a cancellation is necessary.
- **Patient education** – rheumatology departments should provide written material to back up the information given during the consultation, particularly in relation to the type of arthritis and the drugs used to treat it. Rheumatology nurse practitioners have been shown to be effective in this role. Other health professionals within the team should also provide written information on the specific treatments given to each patient. Departments should be aware of, and provide direct referrals to self-management programmes such as those provided by Arthritis Care.
- **Patient information** – each rheumatology department should have an information area providing basic information on the main Social Security Benefits and health benefits such as prescription charges and transport costs to hospital. Information on local support organisations and their services should also be made available, such as those provided by Arthritis Care. A designated person should be responsible for ensuring the information area is kept well stocked. These services can be provided in conjunction with organisations such as Arthritis Care, who are currently restructuring in order to better support such a service.
- **Surgery – combined clinics** – the ability to make an informed decision on whether or not a surgical procedure is necessary is of paramount importance. Consultation should therefore take place within a combined clinic involving the patient, consultant rheumatologist and orthopaedic surgeon. If significant input from other health professionals, such as physiotherapist or occupational therapist,

has been given or will be required post-surgery, they should also be in attendance.

- **Surgery – provision** – designated surgeons should have a specific interest, and continuing professional training in surgery for people with RA, although in most cases they will deal with people with other problems as well. There should also be centres which undertake highly specialised work including multi-joint surgery and surgery for problems which are uncommon <sup>xiv</sup>.
- **Surgery – process of care** – patients with RA who require a number of different surgical treatments should have their procedures seen as a process of care rather than a series of separate procedures.
- **Inpatient care** – some people with RA will require periods of hospitalisation during the course of their disease. Ideally this should be met by adequate provision of rheumatology beds within dedicated rheumatology wards. All inpatient facilities should be appropriate to the needs of all levels of physical impairment. Self-medication, which empowers people with RA to manage and retain control over their own condition, should be encouraged.
- **Hospital discharge** – to avoid unnecessary delays from hospital, a well coordinated approach, involving health professionals both in primary and secondary care is essential. There should be one named person who takes lead responsibility for

liaising with all health professionals and keeping the patient informed at all times.

### **Community care**

Community care services are vital to support people with RA to lead full and productive lives. These should be provided as part of a multi-agency response and according to the recommendations of the Joint Futures Group (2001) and include:

- an assessment process that is fair and followed in all cases
- clear objectives that promote the independence of an individual when assessing, devising, implementing and monitoring a care package
- carrying out regular reviews to ensure users needs are met
- an integrated approach to care with entitlement to services which support independent living irrespective of where a person lives
- a lead agency identified to take responsibility for ensuring that all appropriate services are commissioned
- a charging policy that is fair and equitable no matter the level of support required or where the person lives
- timely provision of equipment and adaptations to assist with daily living
- access to childcare where appropriate
- access to concessionary travel schemes
- access to money advice where appropriate
- access to respite care for people with severe disability.

### **Arthritis Care**

- Clear and accurate information about arthritis is available from Arthritis Care

<sup>xiv</sup> As advised in 'Rheumatoid surgery in the United Kingdom and Ireland. Proposals for future development and training in this subspecialty of orthopaedics.' Rheumatoid Arthritis Surgical Society, 2002. See: [www.bonejointdecade.org/news/default.html](http://www.bonejointdecade.org/news/default.html)

Helplines Service offering practical, confidential support. They also provide useful publications e.g. 'Arthritis News'.

- They provide a range of self-management and personal development courses, which are delivered locally and give people confidence and skills to manage their arthritis and improve their quality of life.
- They provide practical and social support through a network of nearly 600 branches and groups, Young Arthritis Care and local contacts. They also have offices throughout the UK.
- They campaign for greater awareness of the needs of everyone with arthritis, improved services and an end to discrimination.
- Four accessible hotels geared towards the needs of people with arthritis.
- They work closely with health professionals and other arthritis organisations in the UK and internationally.

### **Employment and Welfare Benefits**

Being able to gain and retain employment is not easy, and for people with RA there are a number of additional issues that make it particularly difficult. These are:

- lack of confidence and self-esteem
- unrealistic assessment of own strengths and skills
- lack of work experience
- breaks in career development
- lack of interview experience
- perception that all state benefits will be lost
- fear that benefits cannot be regained if job does not work out.

**The Disability Discrimination Act 1995** imposes duties on employers and these should be enacted in full. In addition:

- disability leave should be introduced for people with RA who need a period of rehabilitation following major surgery such as joint replacement or a flare – up of their arthritis
- personal capability assessment should take account of pain, fatigue, stress and the fluctuating nature of long-term conditions such as arthritis along with the qualification, experience and age of the disabled person
- discussions between employer and employee should take place at the earliest opportunity to establish what reasonable adjustments can be made to help a person with arthritis carry out the task of their job
- although for some people the impact of arthritis results in a long period (10 to 15 years) of being unable to work, during that time opportunities may arise that enable the individual to regain their self-esteem and confidence and explore alternative options. These include working as volunteer before returning to part or full-time employment
- for some people, the pain and fatigue associated with RA, often exacerbated by stress, can limit the number of hours they can work. In addition, the fluctuating nature of arthritis and the effects of the physical impairment most people with arthritis experience, may result in many deciding that, for them, work is simply not a viable option. This decision should be respected. It will have been made by someone with many years experience of managing their arthritis, and how they can best cope with it. Benefit recipients should not have their integrity questioned by being subjected to continual reviews of their benefit or treated as 'scroungers' on the state.





### What You Can Do

There are a number of things you can do to improve your local service.

By providing feedback to the staff you can:

- highlight problems and difficulties you experience with the service
- suggest improvements to the service.

It is helpful to feed comments back directly to staff or to your GP. However, in some cases it may be more appropriate to use complaints procedures – to do this contact your local NHS Board or your Local Health Council.

Some services are active in training and research. There is absolutely no obligation on you to take part in either of these activities. However, any help you are able to give by agreeing to take part in these if asked, can benefit others in the future and may be of some direct benefit to you.

Finally, it is worthwhile keeping yourself informed about RA and current developments in what can be done to help. This will help you to feel more in control and will help you to form realistic

expectations of what you can achieve by working with your local service.

Useful information is available at the following websites/helplines:

#### Arthritis Care

[www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)

0141 952 5433

020 7380 6500

#### National Rheumatoid Arthritis Society

[www.rheumatoid.org.uk](http://www.rheumatoid.org.uk)

01628 670666

#### Arthritis Research Campaign

[www.arc.org.uk](http://www.arc.org.uk)

0870 850 5000

#### British Society for Rheumatology

[www.rheumatology.org.uk](http://www.rheumatology.org.uk)

0207 242 3313

# Appendix eight.

## The team approach to chronic disease

Management of chronic disease involves a team approach. The key 'player' in the team is the patient, whose decisions and actions have a major effect on the health outcomes.

The other 'players' come from a variety of backgrounds including primary care, secondary care, and the voluntary sector. They share their skills to produce health and reduce disability. The effect of this combined team approach is much greater than the sum of the contributions of the different team members.

The main features of this approach are:

- health is seen as broadly determined
- a focus on outcomes not processes
- outcomes are viewed from multiple perspectives
- sharing of goals, information, decisions and skills
- communication and clarity
- different roles and levels of involvement
- mutual support
- increasing specialisation of nurses, AHPs and GPs.

The key 'players' in the management of RA are:

- patient
- family and social network
- primary care – GP, practice nurse, community physiotherapist, community pharmacist, specialist staff

- secondary care – rheumatologist, orthopaedic surgeon, nurse (specialist), physiotherapist, occupational therapist, dietitian, podiatrist, orthotist, psychologist, pharmacist, laboratory support
- pharmacy services – pharmacists have an important role to play in prescribing decisions, medicines management and patient education and empowerment
- voluntary sector – various organisations such as Arthritis Care (poorly integrated)
- complementary and alternative therapists (poorly integrated)
- local authority – social work, housing
- work and pensions – employment (re)training, benefits advice
- employers.

Just as a team needs a management structure to support it, so the team in RA needs strong management support from those planning, commissioning and implementing the service to make sure it is adequately resourced and properly integrated.

# Appendix nine.

## Classification criteria for rheumatoid arthritis

The American Rheumatism Association (ARA) criteria below are mainly used for research and are less useful in routine clinical practice.

Clinicians must therefore be aware of the need to investigate patients presenting with less specific symptoms and signs – typically pain, stiffness and swelling in the joints that is worse in the morning or after period of inactivity.

Symmetrical swelling and tenderness of the joints (particularly those of the hands or feet) should suggest the need for further investigations.

The SIGN guidelines are most useful in guiding clinical practice<sup>26</sup>.

It should be noted that the ARA criteria below are not helpful in distinguishing those patients with early arthritis who may turn out to have RA from those who turn out to have other forms of inflammatory arthritis<sup>59</sup>.

### AMERICAN RHEUMATISM ASSOCIATION 1987 REVISED CRITERIA FOR THE CLASSIFICATION OF RHEUMATOID ARTHRITIS<sup>60</sup>

Classification of rheumatoid arthritis requires four of the following seven criteria. In criteria one to four the joint signs or symptoms must be continuous for at least six weeks.

#### Signs and Symptoms

##### 1 Morning stiffness

Duration more than 1 hour, lasting more than 6 weeks

##### 2 Arthritis of 3 or more joint areas

\*Soft tissue swelling or effusion lasting more than 6 weeks

##### 3 Arthritis of hand joints

Wrist, metacarpophalangeal joints or proximal interphalangeal joints lasting more than 6 weeks

##### 4 Symmetric arthritis

\*At least one area, lasting more than 6 weeks

##### 5 Rheumatoid nodules

As observed by a physician

##### 6 Serum rheumatoid factor

As assessed by a method positive in less than 5% of control subjects

##### 7 Radiographic changes

As seen on anteroposterior films of wrists and hands

\* Possible areas: proximal interphalangeal joints, metacarpophalangeal joints, wrist, elbow, knee, ankle, metatarsophalangeal joints (observed by a physician).

# Appendix ten.

## Rheumatology services in Scotland – some relevant statistics

Figure 1.

NHS Board	Population 45+	Expected number of new cases per year <sup>xv</sup>			Expected number of existing cases per year <sup>xvi</sup>		
		Female	Male	Total	Female	Male	Total
Argyll & Clyde	169 542	102 (62-161)	41 (21-82)	143	2093	726	2819
Ayr & Arran	155 394	92 (55-144)	37 (19-73)	129	1858	636	2494
Borders	48 656	27 (16-42)	12 (6-23)	39	531	184	715
Dum. & Galloway	66 620	37 (22-58)	16 (8-31)	53	725	254	979
Fife	140 716	83 (50-131)	34 (17-68)	117	1715	599	2314
Forth Valley	109 633	66 (40-104)	27 (14-53)	93	1365	477	1842
Grampian	202 470	121 (73-191)	50 (25-101)	171	2520	923	3443
Greater Glasgow	327 162	209 (125-334)	81 (41-164)	290	4526	1538	6064
Highland	88 670	51 (31-79)	21 (11-42)	72	1006	360	1366
Lanarkshire	210 183	132 (79-208)	51 (26-104)	183	2737	960	3687
Lothian	286 222	179 (107-285)	71 (36-144)	250	3855	1359	5214
Orkney	8 491	5 (3-7)	2 (1-4)	7	93	34	127
Shetland	8 523	5 (3-8)	2 (1-4)	7	103	40	143
Tayside	164 005	95 (57-150)	40 (20-78)	135	1933	667	2600
Western Isles	12 335	7 (4-10)	3 (2-6)	10	132	49	181
<b>Total</b>	<b>1 998 622</b>	<b>1211 (728-1914)</b>	<b>488 (248-976)</b>	<b>1699</b>	<b>25192</b>	<b>8806</b>	<b>33998</b>

This shows estimates for incidence and prevalence in the adult population (with confidence intervals in brackets) by gender and NHS Board area. It should be noted that the prevalence estimates are

conservative and likely to underestimate the true figure. The population aged over 45 is also shown since this is the population most at risk of, and affected by, RA.

xv Figures (and 95% confidence intervals) obtained by applying NOAR revised age-specific incidence estimates<sup>61</sup> to mid-year population estimates at 30th June 1999 by age sex and NHS Board (Registrar General for Scotland).

xvi Figures are calculated using NOAR estimates of minimum prevalence of 1.16 % in females and 0.44% in males aged 16 and over<sup>7</sup>.

Figure 2.

British Society for Rheumatology suggests	1 whole time equivalent (WTE) per 85,000 population <sup>xvii</sup>
Royal College of Physicians, World Health Organisation and Department of Health suggest	1 WTE per 150,000 population
England mean	1 WTE per 162,752 population
Wales mean	1 WTE per 183,689 population
Scotland mean (note: there is a wide variation by NHS Board area)	1 WTE per 213,300 population

This shows different recommendations made regarding provision of consultant rheumatologists per head of population, as well as figures for current average workforce levels taken from the ARC-BSR Workforce

Register 2001. In general, Scotland has a level of provision lower than the rest of Britain and a wide range of levels of provision across NHS Board areas.<sup>xviii</sup>

<sup>xvii</sup> The justification for this can be found in the BSR publication , Musculoskeletal Disorders, Planning for the Patient's Needs. No 3. A basis for planning a rheumatology service. See especially Section 12.

<sup>xviii</sup> Dr McCarlie, Ayrshire and Arran NHS Board – personal communication.

# Appendix eleven.

## Chronic disease management model

### Background

There are no current working examples of chronic disease management (CDM) models for RA in Scotland. However, the evidence from recent research either shows, or strongly suggests, that better outcome in RA can be consistently achieved by:

- early diagnosis and intervention
- 'tighter' control and monitoring of disease
- the multidisciplinary team approach
- improved patient self-management skills
- greater collaboration between the patient and the healthcare team.

To maximise health gain it is therefore essential to refocus the healthcare delivery model to translate these findings from research into clinical practice.

The findings above are not exclusive to RA – they apply to a number of other chronic diseases as well. Furthermore, different models of healthcare delivery have been tried and in some cases tested for these chronic diseases. This is especially the case for diabetes. These models are collectively known as chronic disease management. It therefore makes sense to consider existing models and how they can usefully be applied or adapted to the care of RA.

Even if such models are used for RA then the main message must be re-iterated – all patients with suspected RA must be referred as soon as possible for a rheumatology opinion.

### General features of the CDM models

The models are all centred on the patient and firmly rooted in primary care. However, they involve a team approach which spans a number of organisations within and beyond the health service. The 'core' team for each

individual will, at a minimum, involve the patient and their GP, and in most cases the rheumatologist, nursing, and paramedical staff. The 'core' team may 'bring on' the orthopaedic surgeon, social worker, pharmacist and other professionals if necessary, particularly for those with more severe disease and disability. Those providing user-led self-management approaches are now becoming more integrated with the teams and it is likely that they will be recognised as key players in due course. All the professionals form part of an extended care team which should be led and managed by a lead clinician with appropriate management support.

The general features of the CDM models are as follows:

- focus on outcomes
- guided by evidence
- collaborative working – patient as part of the team
- use of coordinated, planned and proactive care
- incorporating a population perspective.

A lot of these features are also seen in managed clinical networks.

### Specific features of CDM model as applied to rheumatoid arthritis

Adapting the models to RA will depend to a great extent on existing patterns of local service. It is more important to see that the improved outcomes are achieved than to specify in fine detail the processes to achieve them. It is also important to make outcome measures relevant to the patient and their quality of life. Suggested features include the following:

- patient-held individualised care plan including

- guidance on what to expect from care
- guidance on how to 'navigate' the system
- advice on medication, diet, exercise, smoking, employment, benefits etc. (Something analogous to this has already been produced for the chronic disease management of CHD and heart failure in Glasgow).
- targeted case management (the team 'captain')
  - in most cases GP coordinates care
  - in moderate cases rheumatology specialist health professional with GP support
  - in severe cases a rheumatologist in collaboration with an orthopaedic surgeon
- regular reviews in primary care
  - overseen by GP
  - conducted by practice nurse, GP and relevant therapist
  - involving community pharmacists in medication review
- regular reviews in secondary care
- use of standards, protocols, guidelines (it is important not to overburden people with these – they should be integrated into care plan)
- universal access to self-management programmes
- structured effective consultations
  - shared goals, shared decision making
  - clarity and transparency
  - written and verbal feedback
  - action planning
- case registers
  - population, rather than clinic, based
  - integrated with care plan
  - outcome oriented
  - prompting call-back system
  - to improve:
    - > disease control/monitoring
    - > quality improvement/audit
    - > research and education
- assign larger responsibilities to non-medical members of team
- troubleshooting unexpected problems
  - role of rheumatology specialist health professional
  - helpline/nurse-led clinics
  - source of advice to GP/line of contact to consultant
  - educative role
  - role of community pharmacist

Experience from the implementation of CDM, and similar programmes elsewhere, has shown the following to be important:

- 'buy in' from GPs, commissioners, and secondary care professionals
- the need for sustaining momentum, after initial implementation
- adequate extra resources, including administrative support
- good project management.

Work is ongoing in Glasgow to construct such a model for RA.

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