

**Health Care Needs Assessment of Services for
Adults with Rheumatoid Arthritis**

**PART C: RA services in Scotland - Corporate &
Comparative Needs Assessment**

Scottish Public Health Network - July 2012

Contents

PREFACE	4
PROJECT GROUP MEMBERSHIP	5
ACKNOWLEDGEMENTS	7
1 Introduction	8
1.1 Background	8
1.2 Aim of HCNA	8
1.3 HCNA methods	9
1.4 Format of report	9
1.5 Scope of HCNA	9
2 Policy context	10
2.1 Scottish Government policy	10
2.2 Clinical guidelines for RA	11
3 Methods	13
3.1 The corporate assessment	13
3.2 The comparative assessment	14
4 Corporate needs assessment findings – current RA services in Scotland 16	
4.1 Overview of key issues	16
4.2 Early identification and triage	16
4.3 Initial Specialist Assessment	23
4.4 Chronic Disease Management	27
4.5 The Multi Disciplinary Team	33
4.6 Rational approach to drug prescribing in RA	40
4.7 Employment and societal impact of RA	45
4.8 Remote and Rural Provision	48
4.9 Training and Staffing	50
4.10 Research & Audit	55
5 Comparative needs assessment findings – comparison of RA services in Scotland with those elsewhere	58

5.1	Key documents identified	58
5.2	Comparison with RA services in England.....	58
5.3	International perspectives on the key components of an RA service	59
5.4	Service configuration.....	61
6	Conclusions.....	63
	Reference List.....	66
	ABBREVIATIONS USED.....	77
	GLOSSARY	81
	APPENDICES	82

PREFACE

This report forms part of a wider health care needs assessment (HCNA) of services for people with rheumatoid arthritis (RA) in Scotland.

This report forms [Part C](#) of the wider HCNA report and describes the corporate and comparative elements of the needs assessment. The following reports are also available:

- [Part A](#): which summarises the conclusions and recommendations of the HCNA;
- [Part B](#): which describes the epidemiology of RA in Scotland; and
- [Part D](#): which considers the cost implications of developing the delivery of RA services in Scotland.

PROJECT GROUP MEMBERSHIP

<i>Chair of Project Group</i>	Carol Davidson, Director of Public Health, NHS Ayrshire & Arran
<i>Lead Author</i>	Martin Perry, Consultant Rheumatologist, NHS Greater Glasgow & Clyde
	Ann Conacher, ScotPHN Co-ordinator
	Jane Gibson, Consultant Rheumatologist, NHS Fife / Hon Senior Lecturer, University of St Andrews
	Marie Kerrigan, ScotPHN Senior Administrator
	Phil Mackie, ScotPHN Lead Consultant
	Duncan Porter, Consultant Rheumatologist, NHS Greater Glasgow & Clyde / Senior Lecturer, University of Glasgow
	Lynne Shand, Consultant Rheumatologist, NHS Grampian (until August 2011)

Editorial Team

<i>Report editor</i>	Laura Hay, Public Health Researcher
	Liz Murphy, Consultant Rheumatologist, NHS Lanarkshire
	Project Group

Stakeholders - Report Contributors

Initial Specialist Assessment and Chronic Disease Management

Jane Gibson	Consultant Rheumatologist, NHS Fife
Mhairi Brandon	Specialist Physiotherapist in Rheumatology, NHS Greater Glasgow & Clyde
Neil McKay	Consultant Rheumatologist, NHS Lothian
Lynne Shand	Consultant Rheumatologist, NHS Grampian (until August 2011)
Jenny Snell	Government Affairs, National Rheumatoid Arthritis Society (until March 2011)

Rational approach to drug prescribing in RA

Duncan Porter	Senior Lecturer, University of Glasgow & Honorary Consultant Rheumatologist, NHS Greater Glasgow & Clyde
Carol Callaghan	Advanced Clinical Pharmacist, NHS Lothian

Employment and Societal Impact

Janet Harkess	Head Occupational Therapist, Fife Rheumatic Diseases Unit, NHS Fife
Angela Donaldson	Director, Arthritis Care
Katie McAlarey	Occupational Therapist, NHS Greater Glasgow & Clyde

Remote and Rural Provision

Keith Slater	General Practitioner, NHS Highland
Malcolm Steven	Consultant Rheumatologist, NHS Highland

Additional Stakeholder Contributors

Helen Harris	Consultant Rheumatologist, NHS Fife
Kym Hennessey	PhD Research Student, School of Health, Glasgow Caledonian University
Donna Hood	Clinical Nurse Specialist, NHS Greater Glasgow & Clyde
Liz McIvor	Clinical Nurse Specialist, NHS Greater Glasgow & Clyde
Mike McMahon	Consultant Rheumatologist, NHS Dumfries & Galloway
Jemma Pringle	Specialist Registrar, NHS Lanarkshire
Ailsa Bosworth	Chief Executive, National Rheumatoid Arthritis Society
Jamie Hewitt	Government Affairs Manager, National Rheumatoid Arthritis Society

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1 Introduction

1.1 Background

In 2002, the Public Health Institute for Scotland (PHIS) undertook a needs assessment of rheumatoid arthritis (RA).¹ Since then the evidence base and policy context have changed considerably. The Scottish Public Health Network (ScotPHN) was therefore asked by the Scottish Government to update the previous report to take account of the current epidemiology and recent advances in the understanding, treatment and care of people with rheumatoid arthritis.

Substantial gains have been made over recent years in the management of patients with rheumatoid arthritis. Early, intensive treatment has made remission a realistic prospect for some, and improved quality of life a reality for many. There is, however, still variation within Scotland in the pattern and quality of care, dependent on local systems, pathways and resources.^{2:3} Without timely assessment both the human and financial cost of rheumatoid arthritis can be high: delays in treatment are associated not only with greater joint damage and morbidity related to RA but also greater work instability and socioeconomic cost.⁴

Ensuring that patients throughout Scotland receive the best care is the responsibility of NHS Boards. It is hoped that this updated needs assessment will assist Boards in developing local services which meet the needs of those with rheumatoid arthritis and help ensure that both the individual and societal benefits of early diagnosis and treatment are realised.

1.2 Aim of HCNA

The aim of the updated health care needs assessment (HCNA) is to:

- review the epidemiology of rheumatoid arthritis in Scotland (including future trends);
- identify the views of stakeholders on current and future service provision;
- identify gaps in service provision and highlight priority areas for change; and

- make recommendations that will assist NHS Boards to plan and develop services for those with rheumatoid arthritis in their local area.

1.3 HCNA methods

The HCNA has been undertaken using the standard ScotPHN project methodology for health care needs assessment. The general principles of health care needs assessment are described in Appendix 1. This HCNA has used elements of the following three approaches to needs assessment:

- *Epidemiological Needs Assessment*: describing the incidence and prevalence of the disease and baseline service activity;
- *Corporate Needs Assessment*: reporting the views of interested parties and stakeholders (including professionals and service users and their carers); and
- *Comparative Needs Assessment*: comparing and contrasting current RA services in Scotland with those provided elsewhere.

This report describes the corporate and comparative needs assessment elements of the HCNA and forms Part C of the overall report. The epidemiological needs assessment is described in [Part B](#), the cost implications are described in Part D and the HCNA's conclusions and recommendations are summarised in [Part A](#).

1.4 Format of report

This report is intended to be a technical document. A patient version of the HCNA's overall findings will also be produced.

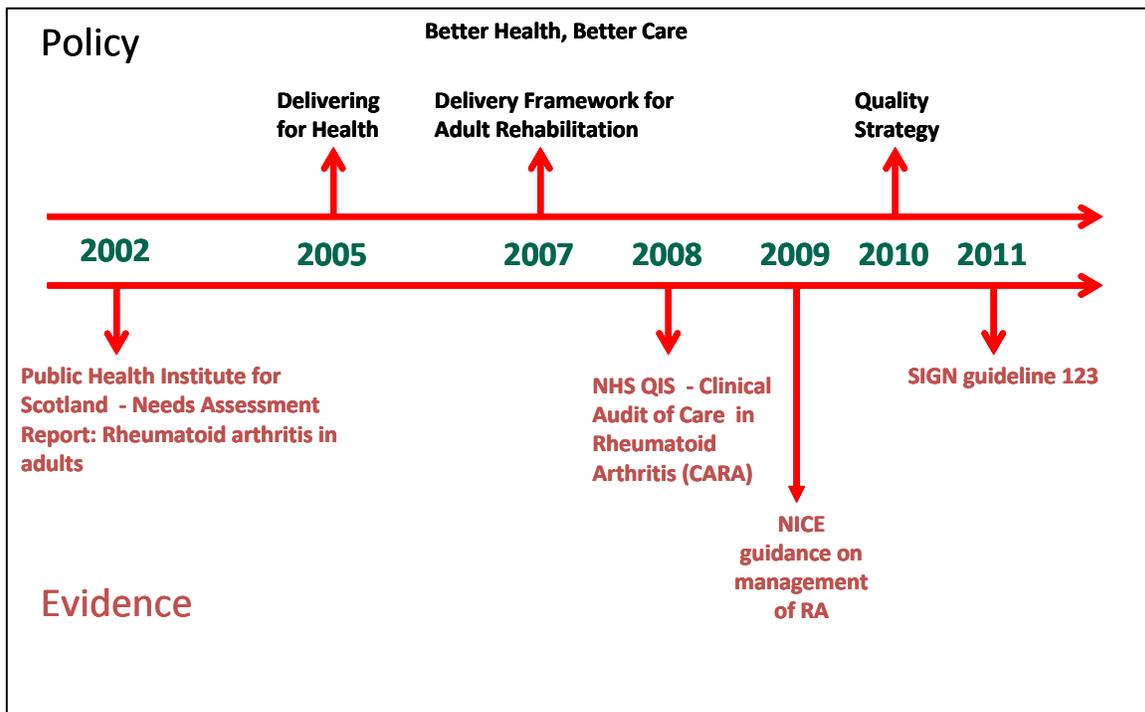
1.5 Scope of HCNA

The HCNA covers adults (aged 16 years and over) only. It considers rheumatoid arthritis only (and not other rheumatological or musculoskeletal conditions).

2 Policy context

Since the publication of the PHIS needs assessment of rheumatoid arthritis in 2002, both the evidence base and policy context have changed considerably. This chapter summarises the key recent policy documents (Figure 1).

Figure 1: Policy and evidence context for RA services since 2002



2.1 Scottish Government policy

Delivering for Health:

In 2005, the Scottish Executive published its strategy for the NHS in Scotland which aimed to provide care which is quicker, more personal and closer to home.⁵

Better Health, Better Care:

In 2007, the Scottish Government published its national strategy for a healthier Scotland.⁶ The central themes of the accompanying action plan included patient

participation, improved healthcare access and a focus on the twin challenges of improving Scotland's public health and tackling health inequalities.⁷

Delivery Framework for Adult Rehabilitation:

The importance of improving prospects for patients with long-term conditions was acknowledged in the *Delivery Framework for Adult Rehabilitation*, also published in 2007.⁸ The subsequent Long Term Conditions Action Plan has encouraged the development of self-management programmes, person centred care and greater integration of all stakeholders in policy decisions locally by promoting managed clinical networks (MCNs).⁹

Quality Strategy:

Published in 2010, the NHS Scotland *Quality Strategy* builds on the principles set out in *Better Health, Better Care*.^{6,10} Person-centred care, harm avoidance and providing appropriate treatment, interventions, support and services at the right time (with eradication of wasteful or harmful variation) are the three central themes of the strategy which aims to improve the effectiveness, efficiency and productivity of the health sector in Scotland.

2.2 Clinical guidelines for RA

NHS QIS Clinical Audit of Care in Rheumatoid Arthritis:

In 2008, NHS Quality Improvement Scotland (QIS) assessed the provision of care for people with rheumatoid arthritis across clinical care teams, hospitals and NHS Boards in Scotland.² The Clinical Audit of Care in Rheumatoid Arthritis (CARA) Report highlighted challenges in delivering high quality health care for patients newly diagnosed with rheumatoid arthritis, with considerable variation in time to treatment, the treatment employed and access to different members of the multidisciplinary team.²

NICE Guidance:

In England, the National Institute for Health and Clinical Excellence (NICE) published guidance on the management of RA in 2009 (NICE clinical guideline 79), with many of its recommendations endorsed by the Scottish Intercollegiate Guidelines Network (SIGN) for implementation north of the border.¹¹

SIGN Guidance:

In February 2011, SIGN published SIGN guideline 123 on the management of early rheumatoid arthritis in Scotland, which superseded SIGN guideline 48.^{12:13} SIGN 123 emphasises the crucial importance of early diagnosis and treatment, access to a multidisciplinary team and the adoption of a treat to target approach.

NICE Quality Standards for RA:

NICE Quality Standards are currently being developed for rheumatoid arthritis. A formal process to develop these by NICE is expected in 2012, with an anticipated publication date of June 2013.

In January 2012, the British Society for Rheumatology published a set of ten Quality Standards for RA (Appendix 2), which were developed with Arthritis Research UK and the National Rheumatoid Arthritis Society (NRAS) and have been submitted to NICE for consideration.¹⁴

3 Methods

This chapter describes the methods used for the corporate and comparative elements of the HCNA. The epidemiological needs assessment is described elsewhere (in [Part B](#) of the report).

3.1 The corporate assessment

The purpose of the corporate needs assessment was to identify the varying needs, demands, wishes and alternative perspectives of interested parties and stakeholders.

A key feature of this needs assessment has been the involvement of stakeholders in the process. The process has involved the following:

- A project sponsor was identified from within the Scottish Directors of Public Health as per ScotPHN's governance;
- A project group was established to represent key stakeholder interests chaired by the project sponsor;
- A lead author was identified from the field of rheumatology who worked with the project group;
- A stakeholder steering group was developed;
- 'Mini groups' were formed from the stakeholder steering group to look at specific issues in greater detail and to draft sections of this report;
- Regular update meetings occurred for both the project group and the steering group; and
- ScotPHN provided public health, project management, research and administrative support.

The views of service providers and health professionals were gathered by:

- Consultation and focus group work with the project stakeholders to identify the key issues and areas of work to consider.

- Establishing ‘mini-groups’ from within the stakeholder group to consider the areas identified in greater detail and explore the views of service providers and the voluntary sector in relation to each of the key strands identified. Five stakeholder ‘mini groups’ were established to consider the following specific areas:
 - Initial referral and assessment;
 - Chronic disease management;
 - Rational approach to drug prescribing;
 - Employment and societal impact of RA; and
 - Remote and rural provision of RA services.

- Semi-structured interviews were undertaken with health professionals working within rheumatology, the voluntary sector and with Directors of Pharmacy in NHS Boards. The interviews were undertaken by a ScotPHN researcher. The interview methods and findings are described in Appendix 3.

Public and service user views were identified through the involvement of the voluntary sector in the stakeholder group and ‘mini groups’. A full examination of public and service user views on current RA services in Scotland was not within the scope of this HCNA.

The findings from the corporate needs assessment are presented in chapter 4.

3.2 The comparative assessment

The purpose of the comparative needs assessment was to compare current RA services in Scotland with those provided elsewhere.

In undertaking the comparative analysis, the decision was taken to limit the analysis to published work on the scope of rheumatoid arthritis services. A rapid review of the literature highlighted four main reports relating to UK and international service configurations which were suitable for inclusion in the analysis. These were the:

- NICE commissioning guidance and clinical guidance on the diagnosis and management of rheumatoid arthritis;¹¹
- National Audit Office (NAO) report on services for people with rheumatoid arthritis;¹⁵
- Welsh Assembly Government's Service Development and Commissioning Directives: Arthritis and Musculoskeletal Disorders;¹⁶ and
- UK Department of Health's Musculoskeletal Service Framework.¹⁷

The key themes which emerged from the comparative analysis are described in chapter 5.

4 Corporate needs assessment findings – current RA services in Scotland

4.1 Overview of key issues

The following were identified as key issues in the corporate needs assessment:

- Early identification and triage (section 4.2);
- Diagnosis and initial specialist assessment (section 4.3);
- Chronic disease management (section 4.4);
- Access to the multi-disciplinary team (section 4.5)
- Developing a rational approach to drug prescribing (section 4.6);
- Employment and societal impact of RA (section 4.7);
- Remote and rural provision of RA services (section 4.8);
- Training and staffing needs (section 4.9); and
- Research and audit (section 4.10).

These issues are now discussed in turn.

4.2 Early identification and triage

4.2.1 Heterogeneity in presentation

The initial presentation of early disease in RA is variable. Some patients may develop sudden onset of numerous swollen and painful joints, others present with a single affected joint, while the elderly in particular may develop muscle ache prior to joint disease.¹⁸ This heterogeneity makes early triage and assessment challenging.

4.2.2 Delays in the time to diagnosis

During the first two years of RA, joint damage accrues rapidly.¹⁹ Early treatment is essential to reduce the activity of the disease and thereby reduce damage. Using a focus of treating to the target of remission, or using intensive therapy management in early RA, results in fewer erosions and less long-term disability.²⁰ The first 12 weeks of RA have been termed a 'window of opportunity' in which early and aggressive therapy can result in long-term, and in some, drug-free remission.^{21;22} However,

recent Scottish-wide audits have shown considerable delays in the time to diagnosis (Table 1).² Delays occur at several stages:

- The first delay arises because the patient does not seek advice from their General Practitioner (GP);
- The second delay occurs in Primary Care before referral to a Rheumatologist; and
- The third delay occurs in Secondary Care waiting for the first assessment by a Rheumatologist.

Table 1: Median delays in assessment from symptom onset to first Rheumatology appointment in Scotland (data obtained by national audit in 2003, 2005 and 2009-10)

Year	Source	1 st delay (weeks)	2 nd delay (weeks)	3 rd delay (weeks)	Total delay (weeks)
2003	CARA (n=252)	25 (1 st & 2 nd delays combined)		10	35
2005	CARA (n=229)	34 (1 st & 2 nd delays combined)		10	44
2009-10	SNARE (n=395)	9	8	7	24

1st Delay: from symptom onset to first GP consultation

2nd Delay: from first presentation at GP to referral to rheumatology

3rd Delay: from GP referral to first rheumatology outpatient appointment

CARA = Clinical Audit of Care in Rheumatoid Arthritis²

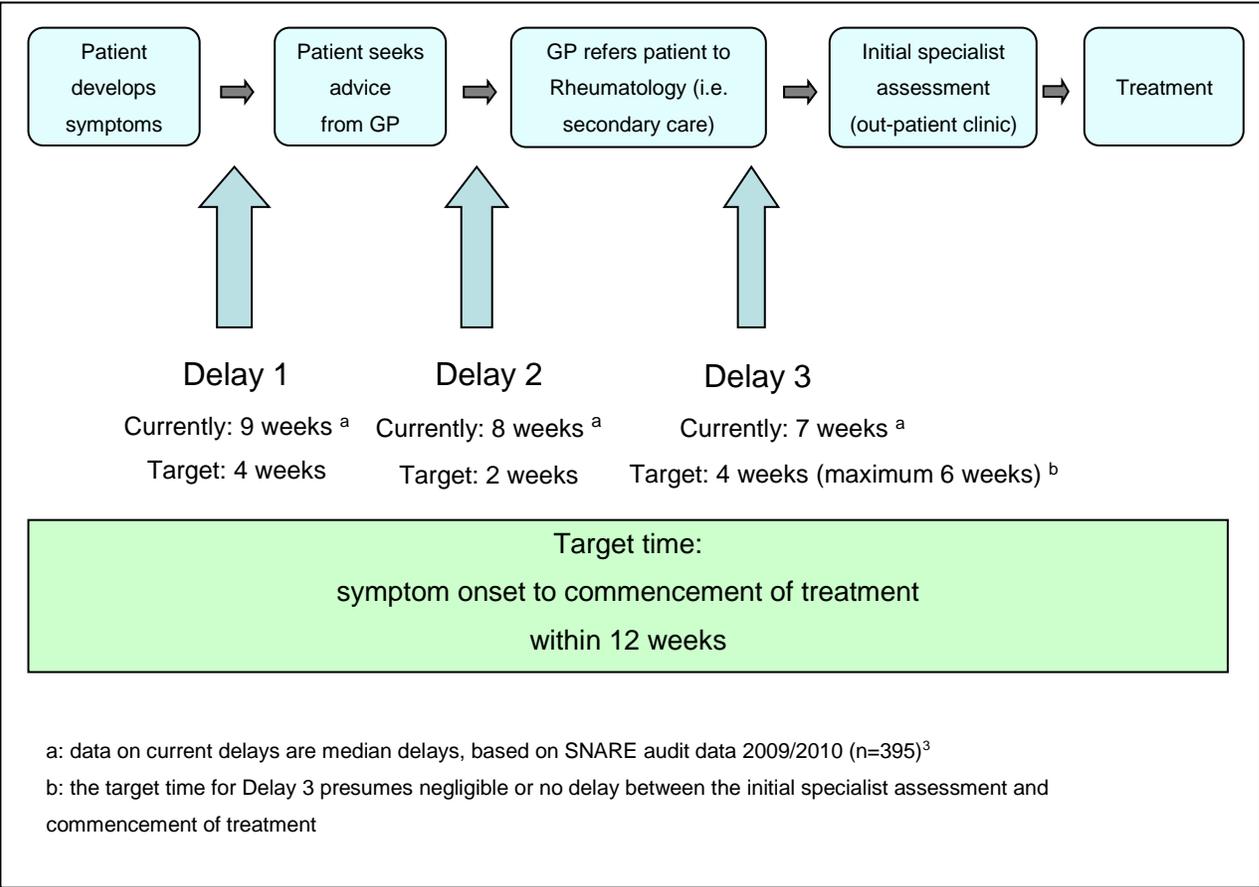
SNARE = Scottish National Audit of Early RA³

n = number of participants

Audit data from CARA found that only 6% and 8% of patients in 2003 and 2005 respectively were seen within 12 weeks of symptom onset.² Despite significant improvements in recent years, SNARE data shows the median time in 2009-10 from

symptom onset to assessment by a rheumatologist was 24 weeks, with only 25% of patients seen within 12 weeks of symptom onset.³ These results are consistent with a similar audit in Birmingham in 2007 in which only 30% of patients were seen within 12 weeks of symptom onset.²³ Figure 2 compares the 2009-10 SNARE audit results against the 12 week recommended target.

Figure 2: Comparison of current delays in referral against target time for symptom onset to start of treatment



4.2.3 Improving public awareness of RA

The greatest delay in diagnosis occurs during the time between symptom onset and the patient’s first presentation to their GP. Research into the decision-making process in patients with early RA has shown that the reasons for patients failing to seek medical advice are multi-factorial and relate not only to the severity of the initial

symptoms but also to the knowledge of patients regarding RA and their previous healthcare experience.²⁴

This first delay represents the most challenging dynamic to address: informing the general public of the need to seek healthcare advice when symptoms of RA develop, and ensuring that this translates into action. Health beliefs can be difficult to alter but it is likely that at least some of these in the Scottish population are socioeconomic and cultural. Similar populations in Norway, for example, where large scale public health campaigns have occurred, have a much shorter time from symptom onset to presentation of only four weeks.²⁵

Improving public awareness of RA is clearly needed but should be planned appropriately. For example:

- GP awareness of referral pathways must be clarified prior to any public awareness campaign (to ensure that those presenting with early RA as a result of the campaign are then referred on quickly and appropriately);
- The approaches to be used for raising awareness should be tried and tested first to check that they reach the right people; and
- Care should be taken to ensure that raising awareness does not inadvertently create problems elsewhere within the referral pathway (e.g. by 'flooding' the referral system with people who do not have RA, thus delaying the identification and treatment of those with RA).

4.2.4 Improving referral time from primary care to specialist assessment

The second longest delay in the diagnosis of RA occurs within primary care. The following issues were identified by the corporate needs assessment:

- GP awareness of current guidelines for the management of RA may be poor. Given that the number of new cases of RA that an individual GP will see each year is likely to be low, clear signposting is required for GPs to ensure timely referral.

In many sites across Scotland, patient pathways have been identified to allow rapid access to specialist care. Considerable variation exists but such access may take the form of: a flow diagram/protocol for urgent referral; allocation to urgent slots in general out-patients clinics; rapid assessment clinics; or consultation at an early arthritis clinic. The clinicians vetting the referrals are highly dependent, however, on the quality of the information given by the GP when determining how quickly a patient should be seen. Clarification in referral criteria is therefore cardinal if appropriate patient selection is to occur. The NICE guidelines for RA highlight criteria for referral but these may not be easily accessible to GPs.¹¹ The Primary Care Rheumatology Society has also promoted concise referral advice on its web-site which may be a useful guide.²⁶

- While GP to consultant remains the mainstay of referral for patients with early RA, it is important that all primary patient contacts (i.e. any health care staff to whom patients with potential joint disease might present) are aware of the importance of early recognition, assessment and treatment of RA. This includes: GPs; community and practice nurses; occupational therapists; physiotherapists; pharmacists; and podiatrists. Within hospital settings, this should extend to staff in Accident & Emergency, physiotherapy, orthopaedics and acute medicine. This also applies to patient pathways (e.g. musculoskeletal pathways) and not just professional groups.

Methods for raising awareness among staff will vary according to local circumstances but education must include both clinical aspects and clarification of lines of communication and referral.

- Community pharmacists are a potentially valuable untapped resource for raising awareness, identifying 'red flag' signs and expediting referrals (e.g. via

direct referral to rheumatology) for those with early RA. A pilot scheme of this nature is currently underway in NHS Fife.

- Concern was expressed that recent developments in musculoskeletal pathways may inadvertently lead to delays in the assessment of those with early RA. For example, new triage pathways for musculoskeletal presentations, using a telephone based system, are being piloted in Scotland. These will potentially by-pass GP involvement in a large number of patients with musculoskeletal symptoms and make greater use of Allied Health Professionals (AHPs) for treatment. While this may have benefits for many patients with mechanical musculoskeletal problems, inflammatory diseases such as RA are usually more difficult to detect and diagnose. There is therefore concern that the improvements that have occurred in RA referral times and GP education in recent years could be undone. Robust training will be needed for all AHPs in such pathways and direct rheumatology referrals will need to be possible for selected groups of patients, such as those with clinical synovitis.

Key points:

- Early treatment of RA significantly improves outcomes. However, there are currently considerable delays in the diagnosis of RA in Scotland.
- The greatest delay occurs during the time between symptom onset and the patient's first presentation to their GP. Delays also occur in the referral of patients from primary care to secondary care for specialist rheumatology assessment.
- There are concerns that recent developments in new triage pathways for musculoskeletal presentations may potentially inadvertently lead to delays in the assessment of those with early RA.

Recommendations:

- 1. Public awareness of rheumatoid arthritis should be raised in order to limit the delay in patients presenting to their General Practitioner (GP).**
- 2. Referral guidelines with clear referral routes should be agreed with GPs, encouraging urgent referral of patients with possible RA to a rheumatology specialist, ideally within 2 weeks of the patient presenting to primary care, in order to facilitate treatment commencing within 12 weeks of onset of symptoms.**
- 3. Protocols should be developed for physiotherapy triage services and other new models of care for musculoskeletal (MSK) conditions to facilitate the re-directing of patients with potential inflammatory joint disease. Regular auditing of time to specialist assessment should be undertaken to ensure no retrograde steps occur in time to treatment.**
- 4. Rheumatology departments should provide rapid access or urgent appointments for people with possible RA within 4 weeks of referral.**

4.3 Initial Specialist Assessment

4.3.1 Diagnosis

Rheumatoid arthritis is a multi-system disease that requires experience and expertise to diagnose. Careful history taking followed by a complete physical examination is required. There are no absolute diagnostic tests for RA and it is a clinical diagnosis made on the basis of a number of findings. Recent advances in imaging techniques and immunology can assist in making the diagnosis.

4.3.2 Diagnostic criteria

Patients with early RA may not present with the classical features of rheumatoid arthritis, making absolute certainty of diagnosis in early disease difficult. In 2010, the ACR and EULAR produced new guidelines for the classification of RA (Appendix 4) which should have greater sensitivity in detecting early disease due to the incorporation of synovitis imaging assessment.²⁷ Increased sensitivity of RA diagnosis could be obtained if the 2010 classification criteria are employed in clinical settings.

4.3.3 Disease activity scoring

A number of scoring systems exist to quantify the degree of active RA disease at time of diagnosis. The most commonly used is the DAS-28, a score which combines a clinical assessment of the number of swollen and tender joints, ESR level and the patients global assessment score which they volunteer on a visual analogue scale.

It is not known how extensively this scoring system is used in Scotland at time of diagnosis but there is evidence to show that using such an approach to target treatment improves outcomes.²⁸

4.3.4 Antibody testing

Previous classification of RA included the presence or absence of Rheumatoid Factor (RF). RF is an auto antibody (antibody directed against the body's own tissue, instead

of foreign material) but RF has relatively low specificity for RA. Another marker, anti-cyclic citrullinated peptide (CCP) antibody, has a higher specificity for RA (up to 95-98% in some studies) and has been shown to identify patients with a poorer prognosis.²⁹ It can be present in the blood for up to 10 years before diagnosis. It is also specifically correlated with smoking. However, sensitivity, as for RF, is only 60% so it cannot be used as a screening tool but it may be useful in secondary care. Anti-CCP antibody testing is more expensive than RF, however, and so will incur costs unless used in place of RF or as part of an algorithm.

4.3.5 Ultrasound and magnetic resonance imaging

The presence or absence of joint inflammation (synovitis) is key in establishing a diagnosis and formulating a management plan with patients. This can be difficult to ascertain clinically but ultrasound scanning (USS) of joints, particularly using Power Doppler has increased sensitivity compared to clinical examination.³⁰ Ultrasound machines are relatively cheap and portable so scanning can be performed in any outpatient clinic by the examining rheumatologist. Disadvantages of USS are that it is heavily operator dependent, there is often poor objective documentation and reproducibility can be difficult. EULAR has recommended the use of ultrasound in the diagnostic process for those patients where there remains diagnostic doubt.³¹ At present in Scotland there is variability of access to ultrasound and ultrasound availability at diagnosis is currently rare. Problems include:

- A lack of skilled operators;
- A lack of skilled mentors;
- Expense of machines;
- Creating capacity within job plans to facilitate use; and
- A lack of agreed quality assurance measures.

Consideration should therefore be given to the development of formalised training in musculoskeletal ultrasound in Scotland, possibly as part of an accredited qualification. This is now potentially being addressed by the Scottish Rheumatology

UltraSound Group (SRUG), but not within mainstream funding and so sustainability is an issue.

Magnetic resonance imaging (MRI) is even more sensitive than USS but is not immediately available in the outpatient clinic, is time-consuming to perform and interpret and is expensive. Choosing which joints to scan can also be difficult as the MRI imaging acquisition of multiple joint areas (e.g. hand, foot and knee) is time consuming and not practical. It does provide better information on deeper structures and can image all the small hand joints in a single image acquisition. MRI scanning can also be used to predict and assess response to therapy. However, neither USS nor MRI are included in the diagnostic criteria and therefore give information which has to be applied to the rubric of clinical examination when making a diagnosis.

4.3.6 Multi-disciplinary assessment

The effective management of early RA requires access to and coordination between the various members of the MDT (Appendix 5). The importance of the MDT is discussed further in section 4.5.

Key points:

- The diagnosis of early RA can be difficult. Recent advances in imaging techniques and immunology can assist in making the diagnosis. Ultrasound scanning can be useful for those patients where there is diagnostic dubiety but access to ultrasound is currently variable across Scotland.

Recommendations:

- 5. Patients referred to rheumatology with a possible diagnosis of inflammatory arthritis should be seen by a rheumatology consultant on the specialist register, or a doctor with experience and expertise in the assessment and management of early RA but under the overall**

supervision and responsibility of a consultant rheumatologist.

- 6. Assessment tools should be applied from the outset to enable monitoring of progress and treatment to target. Examples of appropriate tools are: DAS; DAS28; HAQ; HAD; RA-WIS; and SDAI. The use of such tools should be regularly audited.**

- 7. Imaging facilities for ultrasound examination by either a clinician or technician with experience and expertise in musculoskeletal ultrasound scanning of inflammatory arthritis should be available if required, preferably at the initial consultation.**

- 8. A concerted effort should be made to facilitate training in ultrasound for trainee rheumatologists and AHPs. Recognised trainers in Scotland should be identified and a structured training programme based on the EULAR model or postgraduate certificate developed.**

4.4 Chronic Disease Management

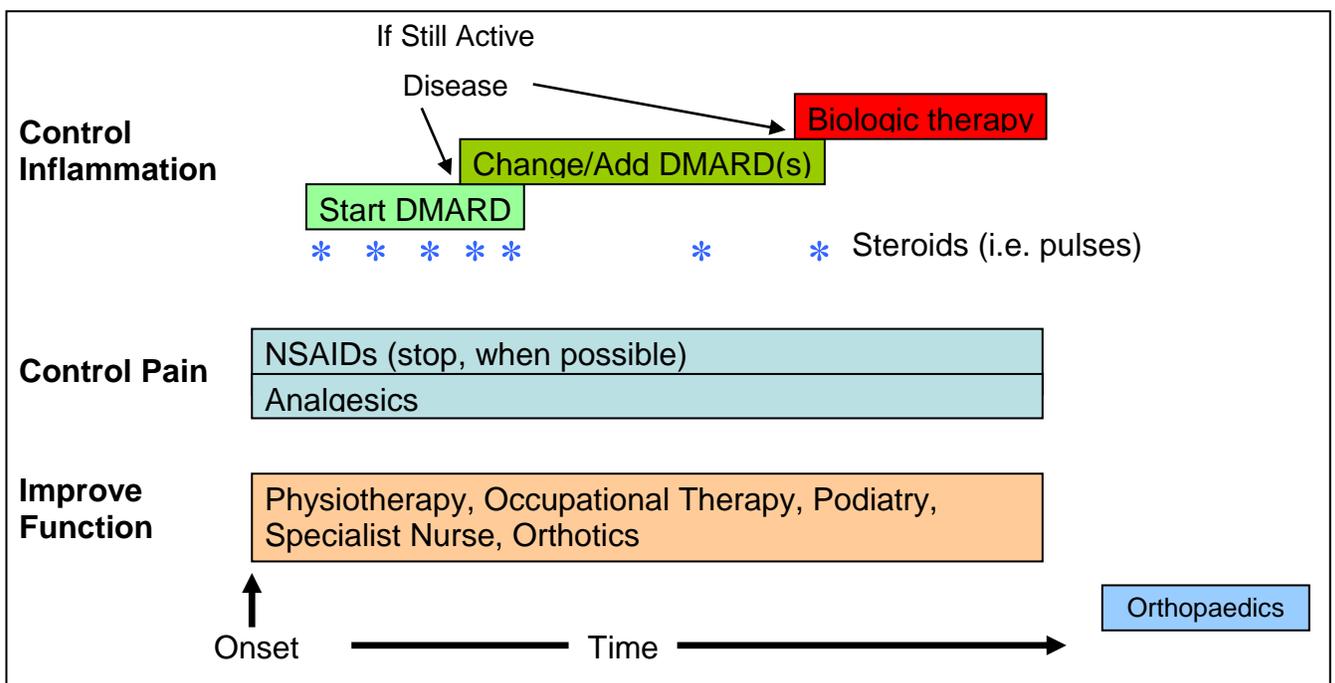
Although there has been an increased focus on the early diagnosis and treatment of rheumatoid arthritis, the majority of patients have established disease which has been present for many years. It is in this group of patients that there is an increased likelihood of complexity in drug therapy, requirement for advice from the MDT members and financial support from disability benefits.

Equally, many patients with established disease will have become very knowledgeable regarding self management of problems. Expectations vary considerably with some patients resigned to expect little improvement, others eager to seek new options.

4.4.1 Overview of RA Treatment

The aims of RA treatment include symptom relief, maximising function and slowing the progression of disease. The range of treatments used in RA is summarised in Figure 3.

Figure 3: Overview of the treatment of RA



Disease Modifying Anti-Rheumatic Drugs (DMARDs) control inflammation. These include methotrexate, sulphasalazine, hydroxychloroquine and leflunomide. One DMARD may be sufficient but where the disease remains active other DMARDs are added. Steroids have a role in active disease and can be given into joints, muscle or as tablets. Biological drugs are used for people who have active disease despite use of at least two DMARDs. Biological drugs work to switch off inflammation and include a number of different drugs such as TNF-alpha inhibitors (adalimumab, certolizumab, etanercept, golimumab and infliximab), rituximab and tocilizumab. Patients with chronic disease are more likely to be taking a biologic agent than those with early disease. Biologics are given either by injection by the patient or as an infusion in hospital.

Pain control is the priority for most patients. Non-steroidal anti-inflammatory drugs (NSAIDs) are effective as topical or tablet therapy but have significant adverse effects. Painkillers such as paracetamol or cocodamol are important in long-term pain management.

Improving the function of joints means better quality of life for many patients. The multi-disciplinary team plays an important role which may include advice regarding exercise, goal setting, assistive devices, dietary advice, improving the work environment, foot care and education. Orthopaedic surgery may be required, usually later on in the disease process.

4.4.2 Smoking and RA

Smoking increases the risk of developing RA (described in more detail in Appendix 6) and can also have a negative impact on the effect of RA treatment.³²⁻³⁷ Smoking can reduce the effectiveness of RA treatments including anti-TNF agents and DMARDs, for example. A recent survey of RA patients in Fife, however, found that few patients were aware of the links between smoking and RA (Appendix 6).

4.4.3 Vascular risk

People with RA have increased cardiovascular and cerebrovascular risk (in addition to any increased vascular risk caused by smoking) and increased mortality compared with the general population. People with RA should therefore be given necessary health promotion advice by health professionals, including aerobic exercise activities to assist in pain management and improve physical and psychological wellbeing.³⁸

The issue of medical therapy to address cardiovascular risk in established RA patients has been well described and the disease mechanisms outlined.³⁹ The inflammation of uncontrolled disease promotes atherogenesis, with subsequent increased risk of ischaemic heart disease and myocardial infarction. Patients with RA may not present with symptoms until late in the disease process as their exercise tolerance may be reduced, thus masking the disease until it declares itself on minimal exertion. Drugs that have been used to treat high cholesterol and blood pressure such as statins and angiotensin receptor blockers may have anti-inflammatory effects too.^{40;41} However, there is variability in practice regarding initiation of such drugs; GPs are remunerated under the Quality and Outcomes Framework to address such issues but may be less aware than rheumatologists regarding the adverse risk profile in RA and so the potential for undertreating exists. EULAR evidence-based recommendations for cardiovascular risk in RA have been established and provide a useful framework for assessment.⁴² RA is not currently captured within the ASSIGN cardiovascular risk score, however, and will therefore be 'missed' by ASSIGN. A close relationship with cardiovascular specialists/MCNs is therefore needed to ensure vascular risk among RA patients is appropriately managed.

4.4.4 Osteoporosis risk

RA is a major risk factor for osteoporosis and fragility fractures and all RA patients aged 50 years and over should have this evaluated as part of their treatment.

4.4.5 Role of self-management

Informed self-management should be a cornerstone of chronic disease management in RA. The Scottish Government's self management strategy for long-term conditions in Scotland ('Gaun Yersel') identifies various hallmarks of self-management (Appendix 7) many of which apply to rheumatoid arthritis.⁴³ Translating the 'Gaun Yersel' principles into the RA context might include:

- Ensuring patients have access to information about DMARDs and biologic therapies via an accessible medium;
- Support from a named member of the team (usually specialist nurse) as per NICE guidance;¹¹
- Support access to the local MDT including telephone, text, email or (in some cases) telehealth;
- Use of community nurses for pain management and disease management to supplement the role of the specialist nurses;
- Ensuring that arrangements are in place to facilitate rapid access in the event of disease flare or drug reactions;
- Care plans for RA, including aspects such as 'navigating the system', medication, employment, diet, exercise, smoking, osteoporosis prevention and benefit support; and
- Structured consults with shared goals, decision making, clarity, written & verbal feedback and action planning.

4.4.6 Multi-disciplinary team

The effective management of chronic RA requires support from the various members of the MDT (Appendix 5). The importance of the MDT is discussed further in section 4.5.

4.4.7 Communication and specialist support for Primary Care

Minimum waiting time targets have created pressures to increase the new: return ratio (i.e. to increase the proportion of new patient appointments) for outpatient

appointments and have, in some areas, hampered the ability to prioritise early or urgent appointments for RA. Access to return appointments is limited in most services which means that patients with established disease are waiting longer for return appointments and may find it difficult to be seen urgently. This is also a barrier to developing effective shared care – primary care teams need to be confident that they can access secondary care expertise when required if they are to contribute to the management of patients with stable disease. Primary care teams need support for issues such as flare management, drug problems or toxicity and result interpretation. This necessitates clarity regarding where, when and how this is available.

4.4.8 Orthopaedic surgery

RA may lead to a requirement for orthopaedic surgery, in particular joint replacement surgery, synovectomy (removal of the inflamed joint lining), tendon repair and carpal tunnel release. The main aims of surgery are to relieve pain, restore function and correct deformity. Good relationships between rheumatology and orthopaedics are therefore required, to ensure optimum management of those requiring surgery.

Key points:

- Smoking increases the risk of developing RA. It can also adversely affect the effectiveness of RA drug treatment. However, patient awareness of the links between smoking and RA is low.
- People with RA are at increased risk of cardiovascular disease but there is currently variation in the initiation of medical therapy to address cardiovascular risk.
- The majority of RA patients have established disease, requiring both informed self-management and MDT support. In some areas, pressure to reduce outpatient waiting times for new patients has resulted in patients with established disease waiting longer for return appointments, emphasising the

need for good communication and specialist support for primary care to support issues such as flare management and drug problems.

Recommendations:

- 9. Smoking cessation should be part of the management plan of all RA patients who smoke.**

- 10. A management plan should exist for addressing co-morbidities. This may take the form of a structured annual review assessment and should make clear the contributions of primary and secondary care, encouraging collaboration whilst minimising duplication of effort.**

- 11. Informed self-management should be a cornerstone of chronic disease management in RA.**

- 12. Patients and primary care teams should have easy access to the Rheumatology team between scheduled appointments when required for drug information and rapid assessment in event of flare in disease. People with RA should know how to access specialist care promptly, with rapid access for appropriate interventions available for persistent disease flares within 48 hours of first contact.**

- 13. Close working relationships should be developed between RA services and GPs/cardiovascular specialists/MCNs to ensure that the increased vascular risk among RA patients is appropriately managed.**

4.5 The Multi Disciplinary Team

Management of RA in both early and chronic disease stages is enhanced by intensive engagement with a specialist multidisciplinary team (MDT). Essential elements of the team are specialist nursing, physiotherapy, occupational therapy (OT), podiatry and pharmacy. Valuable additions are psychology, dietetics and social work. Skillmix changes, for instance using rehabilitation support workers, can enhance the ability of each unit to provide a broad spectrum of care. Good clerical support for these teams is essential so that clinical time is not spent on clerical work.

Most rheumatology departments in Scotland now have at least some elements of a multidisciplinary team but provision is patchy and most units do not have all professions attached to their Unit. Data from SNARE 2011 showed that only two thirds of patients saw a physiotherapist or OT during the first 6 months of rheumatology care, less than half saw a podiatrist and 18% did not see a specialist nurse.³ Only one Unit in Scotland has a psychologist attached to it. No data was collected for the number of patients who required psychological support.

Not only does the MDT ensure that patient outcomes are maximised but it is also essential in helping to develop services and expand the spectrum of treatments available to each patient.

4.5.1 Staffing levels and training

AHP staff shortages were identified as an issue of concern in some areas during the interviews undertaken by ScotPHN as part of the corporate needs assessment (Appendix 3). This is discussed further in section 4.9.4.

There is a lack of specific training programmes for Rheumatology Specialist Nurses and AHPs in Scotland. This has required staff to attend training courses elsewhere in the United Kingdom. In addition, staff do not usually rotate through Rheumatology as part of their training and therefore exposure to this specialism is limited and affects

succession planning. AHP training and the need for succession planning is discussed further in section 4.9.4.

4.5.2 Rheumatology Specialist Nurses

The role of the Rheumatology Specialist Nurse (RSN) has rapidly expanded and now includes patient education and empowerment, outpatient clinics, running a biologic service, steroid injection therapy, telephone helpline services, day intervention units and advanced practitioner skills such as ultrasound. The structure of the RSN service within each department varies widely according to the individual requirements of each unit but shortages of staff in some areas were identified during the interviews undertaken by ScotPHN for this HCNA (Appendix 3) which can make delivery of adequate support difficult.

The European League Against Rheumatism (EULAR) has recently published recommendations for the role of the rheumatology nurse in the management of RA and these give ten recommendations which are applicable to Scottish Rheumatology Specialist Nursing.⁴⁴

Patient Education

Patients who have had education and support from specialist nurses have been shown to have greater empowerment and self-reliance.⁴⁵ Those who understand their disease and take an active role in their own care tend to have better self-efficacy, coping strategies and overall satisfaction than those who have not received nurse specialist intervention. Patient education is therefore a key part of RSN work. This may be delivered individually or in small groups through a formal patient education programme. Education is particularly important shortly after diagnosis but ongoing support and advice is required throughout the chronic stages of disease. Patients are able to establish a long-term relationship with their RSN and are often able to discuss issues and beliefs that they will not raise with their rheumatologist.

Helpline services

Access to help and advice has traditionally been provided by a telephone service but greater use is being made of on-line services although confidentiality remains a source of concern. Telephone helpline services are valued by patients but are time-consuming, with a recent Royal College of Nursing (RCN) survey finding that running a telephone support advice line can take up to 10 hours per week of an RSN's time.⁴⁶

Outpatient Clinics

Rheumatology nurses spend up to 50% of their time in outpatient clinics which can be new or review clinics.⁴⁶ They may also be specific to biologic therapy or annual review clinics and are usually run according to protocols developed from national or international guidelines. Ongoing education and training of nurses is required to ensure high standards of care. Patients who are monitored by nurses have been found to have lower levels of pain and fatigue and higher levels of satisfaction compared to those who are seen by a doctor,⁴⁷ although a more recent meta-analysis has shown that better research is required to substantiate such claims.

Other activities

The RCN survey identified a wide range of other services provided by RSNs which reflect the diverse structure of individual departments.⁴⁶ Such activities include managerial roles, business development, ward and day-case care, staff education and clerical work.⁴⁶

4.5.3 Physiotherapy

Physiotherapy treatment enables patients with RA to improve physical function to maximise personal goals.

Adults with well controlled RA have a 13% reduction in body mass, which is accompanied by a decrease in muscle bulk, and consequently strength and endurance.⁴⁸ A combination of skeletal muscle strength training and aerobic exercise is therefore an important part of physiotherapy treatment for RA. Physical exercise

improves performance capacity, cardiovascular fitness and muscle strength in RA patients and reduces joint pain, early morning stiffness and fatigue.

Higher intensity exercise (HIE) programmes are more effective in increasing physical capacity (muscle strength, fitness) and have no detrimental effects on disease activity, or additional joint damage.⁴⁹⁻⁵¹ Higher intensity exercise has also been shown to decrease the use of glucocorticoid, improve functional ability, emotional status and bone mineral density.^{51;52} Recent long-term (two year) follow-up of an HIE programme concluded that patients continued to exercise and preserved muscle strength without disease progression.⁵³ New evidence from a three year follow up of an HIE (progressive resistance training programme) showed a relatively long term benefit in reduction of obesity (fat mass) and improved walking ability.⁵⁴

4.5.4 Occupational therapy

The role of the Occupational Therapist (OT) in rheumatology is to: improve a person's occupational performance carrying out valued life activities and roles; facilitate successful adaptation to disruption in lifestyle; prevent loss of function; and improve psychological status.⁵⁵ The need for early specialist rheumatology OT in reducing functional limitations is clear particularly in view of the high work disability rates that occur early on in the disease process.^{56;57}

Day to Day Function

A number of randomised controlled trials (RCTs) have demonstrated improved functional ability following OT interventions. Delivering comprehensive occupational therapy in the community improved people's ability to carry out activities of daily living.⁵⁸ An eight hour educational behavioural joint protection programme delivered by an OT for people with early RA also improved functional outcomes.⁵⁹ The improvement lasted four years and the experimental group had fewer deformities.⁶⁰ In addition, timely targeted comprehensive OT improves functional outcomes in employed patients with RA.⁶¹

Vocational Rehabilitation

Vocational interventions can improve work outcomes in RA.⁶² For example, timely vocational rehabilitation interventions provided as part of a comprehensive patient-centred OT programme have been shown to help promote job retention and work productivity in employed patients with RA.⁶¹ This is discussed further in section 4.7.6.

Fatigue Management Groups

Fatigue is an important consequence for patients with RA but is often not evaluated well in the outpatient clinic. It is a source of discordance between doctor and patient expectations of outcomes.⁶³ A recent RCT demonstrated that group Cognitive Behavioural Therapy (CBT) for fatigue self-management in RA, delivered by an OT and psychologist, improves fatigue impact, coping and perceived severity, and well-being.⁶⁴

Joint Protection Programmes

Improvements in hand pain, general pain and early morning stiffness can be achieved through joint protection group programmes.^{59;60} Working wrist supports have shown to improve pain and gross hand function. However, there is conflicting or low quality evidence concerning resting splints and other splints.

4.5.5 Podiatry

Foot involvement is a major feature of RA resulting in considerable functional disability due to pain, stiffness and ultimately damage and deformity. Deformity can occur at the rear foot, mid-foot or forefoot or in any combination of these. Over 90% of patients with long-standing RA will develop foot disease.

In early RA, more than 35.4% report foot pain as the presenting symptom and up to 93.5% will already have experienced foot pain.⁶⁵ Most (68.2%) reported moderate or severe foot pain daily. Pain affects the forefoot most with the ankles the next most commonly affected. However, data from the recent SNARE study in Scotland showed that only 46% of patients with early RA were referred to a podiatrist.

Turner et al (2006) compared clinical disease activity, impairment, disability and foot function between normal matched control subjects and early RA subjects and revealed moderate-to-high foot impairment and related disability amongst the RA subjects. In comparison to the control group, the subjects with early RA walked more slowly, had lower medial arch height and greater foot eversion in stance. In addition a patient's assessment of changes in the shape or appearance of their feet is a better predictor of loss of valued life activities than self-reported changes in the shape or appearance of the hands.⁶⁶

4.5.6 Psychology

In keeping with other long term conditions, levels of psychological distress are elevated in patients with RA compared to the general population. Estimates of heightened levels of depression and anxiety in patients with RA range from 20 to 40%.⁶⁷⁻⁶⁹ A study conducted in Scotland determined the prevalence of emotional disorders (depression, anxiety and panic disorders) amongst patients referred to a regional rheumatology service as 36% in those diagnosed with an inflammatory arthritis⁷⁰ but in those identified as having an emotional disorder by questionnaire, 82% of cases were either missed or not commented upon by the rheumatologist. Mood is a predictor of poor functional ability in RA and has been shown to prospectively predict poorer RA disease outcomes.⁶⁹

Evidence supports the effectiveness of psychological interventions such as Cognitive Behaviour Therapy for improving psychological functioning in RA⁷¹ and these can play an important adjunctive role in the comprehensive treatment of RA. In early RA (within the first two years) CBT can prevent psychological and physical morbidity as indicated by reduced depression and joint inflammation scores.⁷²

Despite the evidence highlighting the potential benefit of provision of psychological interventions for patients with RA such services, in the main, do not exist. Patients with long term conditions (including RA) have highlighted this gap and advocated for a more holistic approach that also addresses their psychosocial needs.⁷³

Furthermore, NICE Clinical Guideline 79 recommends that patients should be offered psychological interventions to help adjustment to living with RA.¹¹

Key points:

- The effective management of both early and chronic RA requires access to a specialist multidisciplinary team, comprising specialist nursing, physiotherapy, occupational therapy, podiatry and pharmacy with access to psychology, dietetics and social work, as appropriate.
- Most rheumatology departments in Scotland now have at least some elements of a multidisciplinary team but provision is patchy and most units do not have all professions attached to their Unit.

Recommendations:

- 14. All patients with RA should have access to assessment by a full multidisciplinary team (MDT), via clear referral pathways. The configuration of the MDT should take into account local circumstances (such as rurality) but members of the MDT must have specialist training in Rheumatology and should preferably be attached to the Rheumatology Unit.**

4.6 Rational approach to drug prescribing in RA

4.6.1 Introduction

Considerable changes have occurred in the pharmacological therapy of rheumatoid arthritis since the previous RA needs assessment in 2002. In particular, the earlier use of DMARDs, including combination therapy, and the introduction of biologic therapies have made significant changes to the drug regimens used. It is not the remit of this report to provide updated guidelines on drug therapy. However, the standards of care based on current recognised guidelines should be clearly set out. These have important implications for ensuring quality and appropriate use of financial resources. A summary of the guidelines' recommendations can be found in Appendix 8.

4.6.2 NSAIDs

Non-steroidal anti-inflammatory drugs continue to be widely prescribed. They are helpful in reducing pain and stiffness but can be associated with serious drug-related toxicity, including an increased risk of cardiovascular events and peptic ulceration. Current recommendations state that NSAIDs should be used in the lowest possible dose for the shortest duration of time but that, where long term use is required, patients with risk factors should be co-prescribed a proton pump inhibitor (PPI).¹³ National audit data (CARA) indicates that a significant minority of RA patients receiving NSAIDs are not co-prescribed a PPI.²

4.6.3 DMARDs

Disease modifying anti-rheumatic drug therapy is the mainstay of drug treatment in RA. Current guidelines recommend that DMARD therapy be instituted as soon as possible after diagnosis, preferably in combination, because delays in therapy have long deleterious impacts on outcome.⁷⁴⁻⁷⁶ There is also evidence that adopting an 'intensive' strategy of care – reviewing patients frequently, formally assessing their disease activity using well-validated outcome measures such as the DAS28, and escalating therapy in patients with persistent disease activity – results in superior outcomes to standard care and is cost neutral in the short term.⁷⁷ Early RA clinics

delivering 'intensive' management are being run in many, but not all, hospitals in Scotland. The reasons for the failure to deliver this service in all services are diverse and include lack of prioritisation, insufficient staffing, pressure on out-patient accommodation or a combination thereof. While monthly review of patients with newly diagnosed RA is recommended and cost effective, it is currently difficult to implement in some areas.

Particular issues may arise (and are presently doing so in many areas) over the re-negotiation of contractual arrangements for DMARD monitoring remunerated through enhanced service agreements under the GP contract. The number of DMARD and biologic therapies has increased substantially and will continue to do so (including increased use of combination therapies) but many enhanced service agreements have failed to keep pace with this and continued testing can be variable depending on how far it has become embedded within local general practice.

4.6.4 Biologic therapy

Biologic therapy has revolutionised the treatment of RA over the past decade, leading to significant improvements in health-related quality of life, physical function and work productivity. However, the costs to the NHS are substantial: the current annual costs of biologic drugs for all purposes have been identified by National Procurement within NHS National Services Scotland as being in excess of £50M in 2011.⁷⁸

Benchmarking data from NICE suggests that roughly 45% of these costs are likely to be attributable to RA, making an estimated cost of £22.5M.⁷⁹ NHS Boards expect the budget to grow by ~10% per annum. While known to be clinically effective, there is little data on current prescribing practice which limits the ability to plan for the future. In view of the large expenditure, better information collection to aid planning should be a priority.

At present, the use of anti-TNF therapy following the failure of conventional DMARD therapy is covered by NICE MTA 130, which defines the eligibility criteria for use*. NICE MTA 195 addresses the question of sequential biologic drug use and recommends the use of rituximab in patients who have failed to respond to initial anti-TNF therapy. Further guidance concerning the use of other biologic drugs in common use, such as Adalimumab; Etanercept; Infliximab; Abatacept; and Tocilizumab has also been issued (NICE MTA 198). The service implications of this guidance will depend on three factors: 1) whether the use of rituximab as the biologic 'drug of choice' would represent a change of practice; 2) the number of patients who require a second (or subsequent) biologic drug; and 3) the administration and monitoring requirements that are needed for patients. Cost savings may accrue from reduced drug acquisition costs, but this will critically depend on the frequency of re-administration of each drug. In addition, TNF inhibitors are largely administered by the patient at home, using home care delivery services. In contrast, rituximab, for example, is administered by intravenous infusion and requires admission to a day unit; other biologics also have administration and monitoring requirements. Therefore, significant investment to increase capacity in pharmacy and rheumatology day wards may be required to realise these savings. Most Boards have indicated that they do not believe that they currently have sufficient capacity in pharmacy and day wards to implement the guidance, but it is not known how robust this assessment is, nor what additional resources would be required to rectify the situation.

In some areas, the burden of acute medical admissions, particularly during winter months, can lead to infusion facilities being closed and used as acute medical beds. However, cancellation of infusions leads to waste in drug costs, administrative burden and patients not receiving timely therapy. Some hospitals admit these patients as in-

* NICE recommendations do not have any formal status in Scotland. However, NHSQIS (now HIS) has endorsed the NICE Technology Appraisal Guidance No. 130 and NICE (Multiple) Technology Appraisal Guidance No. 195 for use in Scotland, as mentioned in SIGN Guideline 123.

patients, a costly and unnecessary procedure, simply due to the lack of an alternative. Year-round, consistent access to dedicated infusion facilities is therefore required.

Agreement on a core dataset to be collected on all patients being treated with biologic drugs would assist the process of budget planning, audit, clinical governance and ensuring equity of access. A National web-based Biologic Management Database could be created and hosted in a Safe Haven to achieve this.

Key points:

- Considerable changes have occurred in the pharmacological therapy of RA since the previous RA needs assessment in 2002, with important implications for the delivery of services and the resources required.
- The intensive, early management of those with newly diagnosed RA results in superior outcomes and is cost neutral in the short term. Early RA clinics delivering 'intensive' management are being run in many, but not all, hospitals in Scotland.
- The number of DMARD and biologic therapies has increased significantly (and will continue to do so) but many enhanced service agreements to remunerate GPs for monitoring such treatments have failed to keep pace with this.
- While biologic therapy has revolutionised the treatment of RA, it is costly with expenditure expected to continue to rise. National data on biologic drugs use is currently limited.
- NICE recommends the use of rituximab and other biologics in patients who have failed to respond to initial anti-TNF therapy but most Boards have indicated that they do not believe they currently have sufficient capacity in pharmacy and day wards to implement this.

Recommendations:

- 15. All Boards should ensure that Early RA clinics or similar service arrangements are in place to deliver 'intensive, treat to target' management of patients with newly diagnosed RA.**

- 16. Each rheumatology unit should have access to an infusion facility, with adequate capacity, staffing, equipment and protected from seasonal closures.**

- 17. Boards should ascertain the capacity of their day ward and pharmacy services to identify what resources (if any) would be required to expand them to accommodate a shift from community sub-cutaneous preparations to day ward intravenous therapies.**

- 18. Each Board should have local protocols in place for the monitoring of DMARDs, including parenteral methotrexate, by GPs.**

- 19. An annual review of drug therapy should take place in primary or secondary care. Where patients are receiving NSAIDs, the potential for stopping or reducing dose should be explored. Where this is not possible, a PPI should be co-prescribed.**

- 20. Consideration should be given to developing a National Biologics Database to assist Boards to predict future spending and infrastructure requirements.**

4.7 Employment and societal impact of RA

4.7.1 Background

RA has a considerable impact on people's families, social roles, leisure time and participation in community life.⁸⁰⁻⁹⁰

RA has a detrimental effect on both paid and unpaid work causing increased disability and further ill-health.^{83;91} People with RA in employment often lose their jobs very early on in the disease process, often before they are referred to hospital or started on treatment. About one in four patients with RA are work disabled at diagnosis, rising to 1 in 3 at 5 years and approaching 1 in 2 at 15 years.^{56;87;92-94} The number of people leaving work prematurely in Scotland due to RA has been estimated in Part B of this needs assessment.

4.7.2 Policy context

Scottish and UK Government policy is currently focused on ensuring that everyone with the potential to work has the support they need to do so.⁹⁵ As well as legislation such as the Equality Act 2010,⁹⁶ various *Welfare to Work* schemes have been introduced to help facilitate employment for those with disabilities. How far these will remain an effective mechanism to support people with disability to work is open to debate as access to such schemes may be affected by the introduction of the Welfare Reform Act 2012 which changes many aspects of UK benefits arrangements. The Scottish Government's *Health Works - A Review of the Scottish Government's Healthy Working Lives Strategy* highlights the need for multi-agency working and the roles of central and local government, the NHS, the public, private, voluntary/third sector and trade unions.⁹⁷ It also highlights the fact that early intervention provides the best opportunity for a speedy recovery and full return to work which is reinforced by the evidence base.⁹⁸

4.7.3 Economics of early coordinated intervention

The National Audit Office's (NAO) 2009 report on RA services in England included an economic analysis of the effect of RA which suggested that better coordinated

services would lead to earlier identification of new cases, productivity gains for the economy and improved outcomes for patients, although short term costs to the NHS would increase.¹⁵ Achievable productivity improvements were estimated by the NAO to be in the region of £31 million each year, provided that additional investment was made in NHS services.

4.7.4 Work disability – predictors and management

The strongest predictors for work disability include Health Assessment Questionnaire (HAQ) and job physical demands rather than disease activity⁵⁶ suggesting a biopsychosocial approach is required.^{98;99}

4.7.5 Early intervention

To prevent work disability and to improve productivity patients need to be screened regularly for work issues and particularly at diagnosis.^{98;100} Screening includes asking ‘the work question’ and using tools such as the Rheumatoid Arthritis Work Instability Scale (RA-WIS).^{61;101;102}

4.7.6 Team Vocational Rehabilitation and Occupational Therapy

Evidence from a systematic review of Vocational Rehabilitation (VR) found that a team approach (including medical and other disciplines) attached to a VR programme was the most effective way to reduce work disability.¹⁰³ Macedo et al (2009) in an RCT demonstrated that comprehensive Occupational Therapy improved functional and work outcomes.⁶¹ Ongoing work monitoring may however be difficult due to staff constraints – a survey in 2006 by the National Rheumatoid Arthritis Society (NRAS) found that only 4% of patients were reviewed annually by an Occupational Therapist and nearly 70% were reviewed less often.¹⁰⁴

4.7.7 Voluntary sector

Voluntary agencies such as Arthritis Care (www.arthritiscare.org.uk) and NRAS (www.nras.org.uk) can provide a wealth of support to patients with RA and employment and social issues. Voluntary sector agencies play an important part in

raising awareness and empowering patients to manage their employability and job retention problems.

Key points:

- Work disability is a common consequence of RA, with loss of employment often occurring early on in the disease process.
- To prevent work disability, patients need to be screened regularly for work issues, particularly at diagnosis. Team based Vocational Rehabilitation and Occupational Therapy can then be effective at improving work outcomes.
- Economic analysis by the NAO suggests that better coordinated services for RA would lead to earlier identification of new cases, productivity gains for the economy and improved outcomes for patients, although short term costs to the NHS would increase.

Recommendations:

21. Early use of DMARD therapy should be employed to minimise work disability.

22. All patients should be asked ‘the work question’ regularly by a healthcare professional and referred on for Vocational Rehabilitation/Occupational Therapy as necessary.

23. A team approach is required to optimise employment outcomes and the impact of disease on other functional areas. Rheumatology units should have a pathway for referral to local employability networks or similar.

4.8 Remote and Rural Provision

Delivering specialist health care services to those living in remote and rural areas is a challenge for many specialties including Rheumatology. The issues and challenges are well rehearsed and include:

- Access to training & Continuing Professional Development (CPD) for staff;
- Having sufficient caseloads to maintain specialist skill levels;
- Professional isolation;
- Developing the primary/secondary care interface to ensure continuity of care;
- Recruitment and retention of staff;
- Transport; and
- Promoting the use of tele-health.

These issues are discussed elsewhere and this HCNA report does not aim to discuss them further. This section does, however, aim to highlight issues specific to RA that need particular consideration in remote and rural areas.

Early identification of RA

As discussed throughout this report, the early identification of RA is key to improving patient outcomes. Early assessment by a specialist must therefore take priority over attempting to provide services locally.

Inpatient facilities

Particularly in the early stage of disease, regular assessment is crucial when aiming for remission. This may require more frequent blood monitoring, joint injection, therapy alterations including TNF blockade screening and use of ultrasonography, all of which may require more centrally based services.

The provision of day facilities or in-patient beds at a central hub should allow for patients to access facilities such as hydrotherapy, physiotherapy or other medical investigations such as neurophysiology. Although there has been a trend for a reduction in in-patient bed requirements in rheumatology due to the delivery of

therapeutic advances in recent years, having such a facility in more rural areas remains important to avoid lengthy transportation issues and allow for a fuller assessment.

Key points:

- Delivering specialist health care services to those living in remote and rural areas is a challenge for many specialties including Rheumatology. Key issues for RA services include ensuring that early diagnosis is possible and that there is sufficient access to day facilities or in-patient beds to allow for appropriate assessment and early treatment.

Recommendations:

24. Avoidance of delay should take priority over attempting to provide services locally. Boards should assess whether peripherally or centrally provided early assessment clinics will provide the most secure and expeditious route to ensure early diagnosis of RA. This will vary according to local conditions.

25. Boards should ensure they have sufficient provision of rheumatology in-patient beds to facilitate the appropriate assessment and early treatment of those with RA from remote and rural areas.

4.9 Training and Staffing

4.9.1 The importance of training

As with other specialties, education and training of health care staff is a key part of delivering quality care. A skilled workforce is important for rheumatology for the following reasons:

- Musculoskeletal complaints are one of the commonest reasons that a patient attends a GP, accounting for 25% of consultations;¹⁰⁵
- Early referral, diagnosis and treatment are essential for maximising patient outcome;
- For 'shared care' between primary and secondary care to be effective, adequate skills and knowledge are required in primary care;
- There is scope to improve the quality of care for patients with RA by nurses and AHPs adopting extended roles – this will require investment in training; and
- If training in RA is given greater curriculum time and assessed at an undergraduate level, it is likely to assume a greater level of importance and result in better understanding and retention among new doctors.

4.9.2 Rheumatology exposure for trainee doctors

The change in working patterns for trainee doctors (especially core trainees and those in the initial phase of specialty training) required as a result of the European Working Time Directive has impacted on training in Rheumatology as these doctors now spend a greater proportion of their time in acute medicine and less in out-patient specialties. The proposed reduction in specialty trainee numbers will also impact on trainee access to out-patient clinic settings where the bulk of rheumatology experience is gained. These factors are likely to cause an overall reduction in rheumatology exposure at various stages of training and remain a concern for the quantity and quality of future practitioners.

4.9.3 Ultrasound training

The need to facilitate training in ultrasound scanning for trainee rheumatologists and AHPs is discussed in section 4.3.5.

4.9.4 Specialist training & succession planning for AHPs

The RA AHP community in Scotland is not large and the care of a large number of patients depends on the training and dedication of a relatively small number of individuals. The availability of accredited courses for nurses and AHPs is limited in Scotland. There therefore remain several barriers to education for staff with an interest in further education in rheumatology. Although generic training structures exist, formalised specialty training for rheumatology does not and this produces a number of problems:

- Releasing time for apprenticeship in an environment where financial constraints and service provision have become stretched is difficult to achieve; and
- Formalised training requires some degree of curriculum planning which might best be achieved at a national level for economies of scale given the relatively small numbers of staff. Consideration might be given to a more UK wide training structure for Rheumatology AHPs. NHS Education for Scotland (NES) might be a suitable source from which to access monies and has a track record of providing for similar projects in other specialties but to date rheumatology has not been successful in bidding for grants.

Some units currently do not have dedicated AHP support despite large catchment areas. Data from the 2007 SSR Manpower Audit was incomplete and so it is difficult to draw firm conclusions from it regarding AHP staffing levels. However, AHP staff shortages were identified as an issue of concern during the interviews undertaken as part of the corporate assessment for this HCNA (Appendix 3). The perceived reasons for staff shortages cited during the interviews included:

- Resource constraints;

- RA is largely an outpatient specialty and is therefore perceived as lower priority than other acute, in-patient based specialities;
- Delays in staff recruitment with no additional cover for absence/retiral; and
- Down-banding of retiral posts.

Looking to the future, succession planning was highlighted as lacking in some AHP teams. RA services rely on a small number of highly experienced staff (e.g. Clinical Nurse Specialists) who have 'learnt on the job' but there is currently no provision for training their successors. This is a significant risk to future services which needs to be addressed urgently (e.g. in discussion with NES and the Scottish Government).

4.9.5 Medical staffing

It is not the remit of this report to undertake a comprehensive staffing review of RA services. However, as staffing and needs may be linked some comment is required. The British Society for Rheumatology (BSR) and Royal College of Physicians (RCP) have advised on a recommended ratio of one rheumatologist to 85,000 in the general population.¹⁰⁶ To move towards this target there has been an expansion in the number of rheumatologists in Scotland over the last four years. However, the Scottish average is 1 rheumatologist per 128,000 population (Appendix 9) and a further 20 new WTE consultant posts would be required to meet the RCP/BSR recommendations. The BSR/RCP recommended staffing ratios may be difficult to achieve in the current difficult financial climate and are therefore likely to remain as an aspirational target only. However, there appears to be variation in rheumatology consultant staffing levels across Scotland and this does require to be reviewed and addressed now.

ISD workforce data for 2011 is shown in Appendix 9. Workforce data collected by the SSR (for March/April 2012) is presented in Appendix 10. The SSR workforce data is thought (by the HCNA editorial group) to be the more accurate. However, both sources show variation by Health Board in the provision of consultant rheumatologists per 100,000 population (although this variation reduces when Associate Specialists

are included) with some geographical regions having medical staffing shortages that would appear difficult to ameliorate simply by service reconfiguration. There are no anticipated rises in medical trainee rheumatologist numbers and limited succession planning. There is therefore concern over the ability to fill future vacancies.

Key points:

- There is concern that recent changes in trainee doctor working patterns and the proposed reduction in specialty trainee numbers will reduce rheumatology exposure during training and affect the quantity and quality of future practitioners.
- There are currently several barriers to formal specialist training for AHPs and nurses with an interest in rheumatology. Some rheumatology units do not currently have dedicated AHP support and the lack of succession planning in some areas is a significant risk to the future resilience and sustainability of services.
- The provision of consultant rheumatologists per 100,000 population currently varies between Boards, with an apparent shortfall of consultants in some areas.

Recommendations:

26. The development of Rheumatology training programmes for Nurses and AHPs should be encouraged through links with Universities.

27. The current and future staffing needs for AHPs should be determined. Succession planning for AHPs should be addressed as a matter of urgency.

28. A review of the adequacy of medical staffing levels for RA services should be undertaken with the aim of addressing the apparent consultant shortfall in targeted areas.

4.10 Research & Audit

4.10.1 Research in Scotland

Scotland has played a full and active part in research into RA, including landmark trials such as the Tight Control for Rheumatoid Arthritis Trial (TICORA), and has the Scottish Collaborative Arthritis Research Network (SCAR). There are four principle academic centres which have helped co-ordinate research; the universities of Aberdeen, Dundee, Edinburgh and Glasgow. Many peripheral hospitals out with these centres also recruit for clinical trials and patients benefit from the close association of research and clinical care.

For research to continue to be a positive aspect of RA care provision in the coming years, Scotland needs to continue to have an environment where research is encouraged. Based on the emerging and well funded programme at Glasgow Caledonian University, for example, health professional research and training should be encouraged, fostered and developed in partnership with clinical and academic centres.

4.10.2 Audit in Scotland

Many Rheumatology units carry out local audit which is frequently presented at regional and national meetings. In addition, one of the major aims of the Scottish Society for Rheumatology's multidisciplinary Clinical Standards Group is to promote national audit and there has been a coordinated system of national audit since 2006. There is thus an established network for national audit with a track record of multidisciplinary involvement, data collection from most but not all units in Scotland, and a robust mechanism for reporting back results to local teams. Recent audit results show considerable geographical variation in case mix and outcomes.³

With the evidence that a "treat to target" approach delivers better outcomes in early RA, the recent publication of several national standards of care and the imminent publication of NICE quality indicators for rheumatoid arthritis, there is an opportunity

to build upon the existing network and strengthen national audit of outcomes in RA in Scotland and to use this as a tool to improve quality and reduce variation in clinical care.

4.10.3 Disease registration

The imminent development of paperless and paper light systems of working allow for a change in rheumatology working practice, with the potential to use database developments to improve disease registration. Some units in Scotland have used databases to collect and hold patient information; others are in the process of implementing new systems. Databases have several advantages including:

- Data retrieval is easier and multiple users can access data for the same individual from different geographical sites;
- Potential for swifter communication with primary care, and shared data;
- Provides easy access to clinical scoring systems to assess disease activity;
- Allows for monitoring of clinical activity; and
- Allows a facility for audit and can act as a research tool (with patient consent).

Collaboration between Rheumatology Units when developing local disease registers would help maximise the opportunities to facilitate audit, research and national data collection.

Key points:

- Scotland has played a full and active part in RA research, with patients benefiting from the close association of research and clinical care.
- There is an established network for national audit of RA services in Scotland, with data collection from most but not all units in Scotland. Recent audit results show considerable geographical variation in case mix and outcomes. Opportunities exist to strengthen national audit of outcomes in RA in Scotland to improve quality and reduce variation in clinical care.

Recommendations:

29. Key national agencies should support Scotland wide audit. This should focus on evidence based practice and the three domains in the NHSScotland *Quality Strategy* of person centredness, safety and effectiveness and be closely allied to SIGN Guideline 123.

30. Rheumatology Units should collaborate on a national basis when developing local disease registers so that opportunities to facilitate audit, research and national data collection are maximised.

5 Comparative needs assessment findings – comparison of RA services in Scotland with those elsewhere

5.1 Key documents identified

The purpose of the comparative needs assessment was to compare current RA services in Scotland with those provided elsewhere. The comparative analysis was limited to an analysis of recently published work on the scope of rheumatoid arthritis services.

A rapid review of the literature highlighted four main reports relating to UK and international service configurations which were suitable for inclusion in the analysis. These were the:

- NICE commissioning guidance and clinical guidance on the diagnosis and management of rheumatoid arthritis;¹¹
- National Audit Office's report on services for people with rheumatoid arthritis;¹⁵
- Welsh Assembly Government's Service Development and Commissioning Directives: Arthritis and Musculoskeletal Disorders;¹⁶ and
- UK Department of Health's Musculoskeletal Service Framework.¹⁷

These key documents were reviewed to identify similarities and differences between RA services in Scotland and RA services elsewhere.

5.2 Comparison with RA services in England

The National Audit Office published a major review of RA services in England in 2009.¹⁵ This review highlighted that whilst there was international consensus relating to the need for health care services to provide rapid assessment, diagnosis and treatment initiation, supported by ongoing management of people with RA, the availability of the necessary multi-disciplinary services to provide such care was limited. Specific areas in need of further consideration included:

- improving the recognition of RA presentation in primary care to improve the speed of referral for specialist assessment;
- the availability of specialist rheumatology led multidisciplinary teams to diagnose and initiate appropriate treatment in a timely manner;
- mechanisms to allow ongoing monitoring of the condition; and
- the development of self-management programmes.

The findings from the corporate needs assessment of this HCNA (described in chapter 4) would suggest that the situation in Scotland is not dissimilar to that in England.

5.3 International perspectives on the key components of an RA service

There is a broad consensus of what the major aims of an RA service should be. For example, the Welsh Assembly Government's Service Development and Commissioning Directive on Arthritis and Musculoskeletal Conditions considers service requirements within the context of four broad areas:¹⁶

1. health promotion and prevention;
2. diagnosis and assessment;
3. treatment and management; and
4. facilitating independence.

This approach is echoed in the NICE commissioning guidance which describes the key components of an RA service to be: early identification and referral for specialist treatment; treatment availability; and access to a high-quality, multi-disciplinary care team for ongoing care.¹¹ The NAO report indicates that there is international consensus on the need for each of these components, though differences were noted between countries and the specific approaches used to implement them (as described below).

- *Early identification and referral for specialist treatment*

There is general, international consensus that early identification and rapid referral for assessment and diagnosis is necessary. Many countries identify the need for general practitioners to be able to identify RA effectively (USA, Australia and Canada), though all agree on the need for specialist assessment by Rheumatologists. The need for diagnosis to be confirmed by a specialist Rheumatologist is also noted as there are no internationally agreed criteria for the diagnosis of RA.

- *Treatment availability*

Early initiation of treatment is seen as paramount with better outcomes being observed with early treatment. The international consensus is that access to the full range of drug treatments, both disease modifying anti-rheumatic drugs and the newer biologic drugs, is needed. There are differences between country-specific guidelines as to the speed of initiation of drug treatment, though all agree that treatment should be initiated within three months of symptom onset. Surgery remains a potential treatment option in cases of irreversible joint damage.

- *Access to a high-quality, multi-disciplinary care team for ongoing care*

Whilst all countries agree on the need for multi-disciplinary care, the specific configuration of disciplines involved and the locus of such care is more variable. For example, ongoing care led by specialist Rheumatologists is recommended in the Nordic countries and the Netherlands, whilst GP led care is recommended in France and Germany. Shared care approaches are also noted. Nurse led clinics and ongoing care approaches are in place in some countries. The need for psychological therapies to deal with depression associated with RA is noted in many countries. The need for wider disciplinary involvement to deal with other forms of co-morbidity are identified in a number of countries.

- *Self management*

Self-management approaches to support treatment efficacy and psychological wellbeing are recommended in all countries. How these are delivered, however, vary from country to country.

5.4 Service configuration

There is no internationally agreed service configuration. NICE has identified that the elements of a service may include:¹¹

- *“early” arthritis referral clinics*, possibly specialist nurse-led, and supported by a multi-disciplinary team (including physical and occupational therapy, pharmacy, podiatry and psychology) and providing a basis for shared care arrangements for monitoring and ongoing management;
- *community-based services*, providing GP or consultant-led services with MDT support to provide joint injections, patient monitoring, patient education, support for local primary care teams within shared care arrangements and screening/prioritising specialist referrals; or
- *self-management programmes*, supported by patient initiated direct-access services that can provide monitoring or a rapid response to symptom “flare ups”. Structured patient education and self-management guidelines can help people with RA know when to seek further support to manage their condition.

However, NICE also clarified that whatever the configuration of a service, the clinical aims of the service should be to achieve early identification of RA, treatment initiation for arresting disease progression/symptom management and improving quality of life.

It is of interest that both the NICE commissioning guidance, the UK Government Musculoskeletal Service Framework and the Welsh Assembly Government’s Service

Directive all locate these RA services within the context of an overall approach to the management of long-term conditions.^{11,16,17}

Key points:

- A National Audit Office review of RA services in England in 2009 identified many of the same issues as those identified in Scotland in the corporate needs assessment of this HCNA.
- While there is broad consensus internationally of what the major aims of an RA service should be, there is no internationally agreed service configuration.

6 Conclusions

The current era of austerity makes for challenging times in healthcare, yet innovation and service improvements often occur during periods of necessity. In recent years, patients with RA have seen the biggest therapeutic advances for over a generation. For many people with RA, improvements in treatment mean that improved quality of life, and even remission, is now a reality. However, the human and financial cost of RA in Scotland is high and substantial need remains. The corporate needs assessment undertaken as part of this HCNA has highlighted several key needs that should now be addressed.

As emphasised throughout this report, early treatment of RA improves outcomes. However, significant delay in diagnosis currently exists in Scotland, with many people with early RA delaying seeking medical help from their GP and subsequent additional delays in the referral of patients onto secondary for specialist assessment. There are considerable opportunities to improve the time to treatment for those with early RA which would improve both efficiency and outcomes.

Scotland needs to prioritise specialist early management of RA given the current evidence that this improves outcome. Ensuring year-round infusion and day facilities for those who require this form of treatment and assessment has become essential, as patients have moved from in-patient assessment to largely out-patient management.

The findings from this needs assessment also emphasise the importance of the primary-secondary care interface. For patients with stable established disease, most care can occur in primary care but for this to happen effectively, primary care teams must have the knowledge to know when specialist input is required and both primary care teams and patients must have clear routes for rapid advice and assessment when flares occur, and confidence that this will be available when needed. Specialist teams must have the flexibility and capacity to respond promptly.

Most patients prefer to be seen locally by an experienced practitioner. Developing strong links with primary care should be encouraged, and the long term conditions project should actively support education of primary care teams to ensure maximally effective care, recognising that different structures may be required in remote and rural locations from those that work in urban areas.

Without timely assessment both the human and financial cost of rheumatoid arthritis can be high. RA is an important cause of work disability and Scotland compares poorly with England regarding workplace retention in RA. We can do better. Clarification of referral routes to appropriate vocational rehabilitation, and audit of the process and outcome, is required.

The effective management of RA requires access to all members of the MDT. However, access to MDT members remains an issue in some areas with an urgent need to address current issues of succession planning to ensure the resilience and sustainability of future services.

Both research and audit play an important role in improving clinical care for patients. A national database with capacity to link with local IT systems would provide an important repository for comparative audit, clinical effectiveness and research. A national research collaborative already exists and establishing a similar collaborative network with central support would facilitate sharing of good practice and minimise variation in care.

While such measures may seem expensive, the burden of untreated disability and requirement for increased hospitalisation or longer term care should not be forgotten. Moreover, the economy of scale provided by possibilities such as national procurement of biologic therapy or 'preferred' choice therapy may significantly off-set such initial outlay.

The needs identified in this report are by no means comprehensive (and this report should be read alongside Parts A, B & D of the HCNA). We now have an opportunity to respond. There is no reason why Scotland cannot be a world leader in RA health if there is a collective desire to attain the best we can for all who suffer this condition.

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ABBREVIATIONS USED

ACR	American College of Rheumatology
AHP	Allied Health Professional
ARMA	Arthritis and Musculoskeletal Alliance
BSR	British Society for Rheumatology
CARA	Clinical Audit of Care in Rheumatoid Arthritis
CBT	Cognitive Behavioural Therapy
CCP	anti-cyclic citrullinated peptide
COX-2	Cyclo-Oxygenase-2
CPD	Continuing Professional Development
DAS	Disease Activity Score
DMARD	Disease Modifying Anti-Rheumatic Drug
ESR	Erythrocyte Sedimentation Rate
EULAR	European League Against Rheumatism
FOI	Freedom of Information
FRDU	Fife Rheumatic Diseases Unit
GI	Gastrointestinal
GP	General Practitioner
GPWSI	General Practitioner with a Special Interest

HAD	Hospital Anxiety and Depression scale
HAQ	Health Assessment Questionnaire
HCNA	Health Care Needs Assessment
HCQ	Hydroxychloroquine
HIE	Higher Intensity Exercise
IA	Intra-articular
ISD	Information Services Division
IV	Intravenous
LTCAS	Long Term Conditions Alliance Scotland
MCN	Managed Clinical Network
MDT	Multi-disciplinary Team
MRI	Magnetic Resonance Imaging
MSK	Musculoskeletal
MTA	Multiple Technology Appraisal
MTX	Methotrexate
NAO	National Audit Office
NES	NHS Education for Scotland
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence (previously

	known as the National Institute for Clinical Excellence)
NOAR	Norfolk Arthritis Register
NRAS	National Rheumatoid Arthritis Society
NSAID	Non-steroidal anti-inflammatory drug
NTN	National Training Number
OT	Occupational Therapy
PHIS	Public Health Institute for Scotland
PPI	Proton Pump Inhibitor
PTI	Practice Team Information
QIS	NHS Quality Improvement Scotland
QOF	Quality and Outcomes Framework
RA	Rheumatoid Arthritis
RA-WIS	Rheumatoid Arthritis Work Instability Scale
RCN	Royal College of Nursing
RCP	Royal College of Physicians
RCT	Randomised Controlled Trial
RF	Rheumatoid Factor
RSN	Rheumatology Specialist Nurse
SCAR	Scottish Collaborative Arthritis Research Network

ScotPHN	Scottish Public Health Network
SDAI	Simplified Disease Activity Index
SERA	Scottish Early Rheumatoid Arthritis inception cohort and biobank
SIGN	Scottish Intercollegiate Guidelines Network
SLA	Service Level Agreement
SMC	Scottish Medicines Consortium
SNARE	Scottish National Audit of Early RA
SRUG	Scottish Rheumatology UltraSound Group
SSR	Scottish Society for Rheumatology
SSZ	Sulfasalazine
STA	Single Technology Appraisal
TEAR Trial	Triple Therapy in Early Active Rheumatoid Arthritis Trial
TICORA	Tight Control for Rheumatoid Arthritis Trial
TNF	Tumour Necrosis Factor
USS	Ultrasound Scanning
VR	Vocational Rehabilitation
WTE	Whole Time Equivalent

GLOSSARY

Need	The capacity to benefit from an intervention.
Sensitivity	<p>The sensitivity of a test is the proportion of people who have the disease who test positive for it.</p> <p>For example, a sensitivity of 80% means that for every ten participants with the disease, eight will test positive and the other two will be false negatives.</p>
Specificity	<p>The specificity of a test is the proportion of patients who do not have the disease who will test negative for it.</p> <p>For example, a specificity of 90% means that nine out of ten people who do not have the disease will have a negative result. One out of ten will have a false positive result and require further assessment.</p>

APPENDICES

Appendix 1: The General Principles of Health Care Needs Assessment

Purpose of HCNA

The objective of any health care needs assessment (HCNA) is to specify services and other activities which impinge on health care relating to a specific disease or diseases. In general, the principal activities involved in HCNA are:

- an assessment of incidence and prevalence;
- an analysis of the effectiveness and/or cost-effectiveness of services; and
- establishing the existing service baseline to help guide service development and redesign.

From these three components, health care planners and commissioners, together with other stakeholders, can determine the policy direction they wish to pursue. There can also be other objectives in HCNA. These might include:

- improving access and the allocation of resources at local, regional and national levels;
- targeting resources at area(s) of highest need; and
- securing the active participation of key stakeholders and players in understanding the need for change and how it can be achieved.

Types of assessment

Undertaking such work usually requires a collaborative approach bringing together people with the necessary knowledge base and those with the appropriate technical skills. Broadly speaking, this requires that there is an:

Epidemiological Needs Assessment:

- incidence and prevalence;
- effectiveness and cost effectiveness of services; and
- description of baseline services.

Corporate Needs Assessment:

- reporting the demands, wishes and alternative perspectives of interested parties, for example service users and their carers and stakeholders including professional, political and public views.

Comparative Needs Assessment:

- comparing and contrasting the services in the population under study with those provided elsewhere.

This HCNA of RA services has used elements of all three of these approaches.

Using the findings from HCNA

Taken together a HCNA should, insofar as there is appropriate data available, describe the capacity of the population to benefit from a service or intervention and to make suggestions as to how such benefits can be delivered. Health care need is not, however, the only important factor in planning and delivering health care.

Consideration may be given to, for example, political direction, health care costs, legislation, competing NHS priorities, patient voices and public involvement, professional opinion, scarcity of resources or expertise and the existing pattern of services. Given the NHS is a public-funded institution, it is also important to recognise the importance of population perceptions and the impacts of political processes.

Appendix 2: BSR Top Ten Quality Standards for RA¹⁴



JAN 2012

Top Ten Quality Standards for RA

1. People presenting in primary care with a suspected persistent synovitis affecting the hands or feet to be offered a specialist opinion within 6 weeks of symptom onset.
2. People with active RA to have access to specialist prescribed and monitored evidence based disease-modifying anti-rheumatic drug regimens within 3 months of the onset of persistent symptoms
3. People with recent onset active RA are reviewed monthly with validated measures of disease activity (e.g.DAS28) until treatment has induced remission, or minimal disease activity where this is not achievable.
4. People with rheumatoid arthritis are cared for by a specialist-led multidisciplinary team consisting of professionals with appropriate knowledge and skills from primary and specialist care, and are given a single point of contact responsible for co-ordinating their care (for example a specialist nurse).
5. People with rheumatoid arthritis are offered personalised information, education, support and opportunities for discussion throughout their care to help them understand their condition and be involved in their own self-management.
6. People with RA should be asked about the impact the disease is having on their ability to work, and treatment and support should be offered throughout their disease to ensure that their chances of maintaining employment are optimised.
7. People with RA are offered an annual holistic review to assess and record the effect the disease is having on the person's quality of life, with an action plan to address issues identified. This will include social roles and work, disease activity, pain, mood, joint damage,

Page 1 of 2

functional ability, review of diagnoses, co-morbidities (including cardiovascular disease), extra-articular disease, and the need for referral to members of the multi-disciplinary team.

8. People with RA to be given knowledge of how to access specialist care promptly with rapid access for appropriate interventions for persistent disease flares within 48 hours of first contact, and appointments at a frequency and location suitable to their needs.
9. People with RA should be offered the opportunity to participate in national and local audit and research projects to improve their quality of their care, and that of others.
10. People with RA should be offered biologic therapy as soon as possible after their condition fulfils NICE Technology Appraisal criteria, and should have their relevant clinical data on response and side effects recorded and shared with appropriate national databases.

Source:

http://www.rheumatology.org.uk/includes/documents/cm_docs/2012/t/top_10_quality_standards_for_ra.pdf

Accessed 12/3/12

Appendix 3: Summary of semi-structured interviews undertaken by ScotPHN as part of the corporate needs assessment

Aim

The purpose of the interviews was to develop an understanding of the current needs regarding the treatment of patients with rheumatoid arthritis (RA) in Scotland, as part of updating the previous needs assessment undertaken by PHIS in 2002.

Methods

A purposive sample of key players from NHS health care, the voluntary sector and pharmacy staff was selected. Telephone interviews were carried out, recorded and transcribed. Analysis was supported using a computer package for qualitative data. All the GPs and AHPs interviewed were either specialist rheumatology staff or had a special interest in Rheumatology as senior AHP staff or GPs. A list of interviewees is given in the casebook at the end of this Appendix. The interviews were undertaken during January/February 2011.

Key findings

1. Accessing the health system
 - General public awareness of RA is poor - greater awareness is needed.

2. Pathways, assessment & triage
 - GP to consultant remains the mainstay of referral for new cases of RA.
 - Referral matrix amongst AHPs exists (i.e. AHPs can refer to each other).
 - GP access to guidelines may be poor and caseload light for RA (making keeping up-to-date more difficult).
 - Patient direct access can occur to AHPs.

3. Barriers to initial care
 - Lack of patient awareness of RA (and the need for/value of treatment) e.g. 'it's just my age'.

- Referral to a non-specialist AHP can delay the start of specialist treatment.
- Condition heterogeneity i.e. initial symptoms may not be easily recognisable as RA.
- Financial barriers e.g:
 - Travel costs in remote areas
 - Prescription costs (if on multiple drugs/low income)
 - Worries about how taking time off work for appointments might affect job security
- No formalised GPWSI role in Scotland.
- Lack of specialist AHPs in the community (particularly in rural areas).

4. Tools to assess severity & progression

- Podiatry used Leeds Impact Scale & pain scoring.
- OT using COPM, Quick DASH and modified Barthel Index but highlighted that recommended outcome measures change quickly and focusing on a patient's functional issues is often more useful than having a scale.
- GPs & Physiotherapists did not feel it was their remit to assess severity & prognosis.
- DAS/DAS28 used infrequently.

5. Prescribing and monitoring

- Rheumatologists recommend and GPs prescribe most DMARDs. GPs get an enhanced payment for this work. Pharmacists felt no postcode lottery exists for biologic prescribing.
- High degree of patient choice re DMARDs was reported.
- Pre-prepared cytotoxics and biologics for self administration are often delivered by a private contractor. Administrative complications can exist regarding lab monitoring and access to results, and paperwork for secondary care pharmacists and nurses.

6. Adherence to standards of care

- Most healthcare professionals were aware of guidelines. However, nothing was really known as to whether these were adhered to. Patchy use of audit.

7. Impact of increased infusions

- A lack of 'bed' or chair capacity in some areas has limited the use of infusion biologics due to lack of capacity and has moved second choice biologics to subcutaneous preparations.
- The capacity for making the infusions by pharmacy is limited (since it requires technical staff, cabinets, clean rooms to keep the cabinets in etc).

8. Value of an MCN for RA

- Perceived by some as helpful to bridge the gap between primary and secondary care: but finance for staff to bridge the gap may be a barrier.
- GPs generally enthusiastic with an MCN perceived to: raise the profile of RA; optimise management; improve communication between and education of healthcare professionals; set local standards; and promote greater uniformity across Scotland.
- Rheumatologists were more sceptical. Many AHPs were unclear what a MCN would entail.

9. Solutions to budgetary pressures for RA prescribing

- The budget pressures posed by RA drugs were perceived to be a major issue.
- National procurement of RA drugs appeared favourable.
- National protocol was more contentious, and audit of effectiveness had variable support.
- Cheaper drugs (e.g. rituximab) were commented to be not a clear solution due to the frequency of use and need for infusion facilities and staffing.

10. Changing models of care since 2002

- More day case and less in-patient care.
- Greater involvement of healthcare at home.
- GPs learning intra-articular (IA) injections.
- Waiting time targets.
- Combined clinics by AHPs.
- AHP direct access clinics set up in some areas.
- Greater use of specialist nurses & nurse led clinics.
- Telemedicine for remote areas.
- Many changes in models of care were noted to depend considerably on local staffing, especially specialist nurse support.

11. Managerial support

- Some AHPs felt they had a lack of involvement at the initial assessment and many felt they had inadequate administrative and clerical support.
- Some geographical areas had issues with secretarial/clerical support and accommodation.
- Accommodation can be commandeered for 'winter beds'.

12. Patient databases

- Generally reserved for specific groups of patients such as those on biologics.
- Little inter-connectedness of such facilities between primary and secondary care.
- Rare to have administrative lead for RA in primary care.

13. Gaps in training compromising care

- Diagnostic scanning using ultrasound (USS).
- IA injections.

- Lack of local courses & formalised training programme for specialist nurses/AHPs.
- Recognition of early RA among GPs, physiotherapists and orthopaedics.

14. Voluntary sector role

- Providing education, support, advocacy and signposting.
- Peer support/education.
- Greater partnership in service design, planning, delivery and audit.
- Promotion of self-management courses.
- Facilitating work adaptations.

15. Opportunity for ongoing learning/access to journals & databases

- Generally not a problem to access time or finances from study leave budget or endowment funds.
- On-line access to journals usually available.

16. Barriers to maintaining & supporting people in the workplace

- Variable occupational health coverage.
- Docking of pay for attending health appointments.
- RA associated depression and anxiety / lack of access to psychological support.
- Poor employer/colleague understanding (e.g. re flare ups and the need to take time off work, early morning stiffness and the need for flexible working).
- Pressures from childcare (e.g. fatigue brought on by child care affecting work and vice versa).
- Physical barriers – although there's a need for workplace assessments they do not need to be acted on by employers.
- Time and resource limitation for adequate Occupational Therapy work screening, assessment and rehabilitation.

- Fear of employers knowing about their illness and redundancy.

17. Access to information on benefits

- OTs, social workers, specialist nurses & voluntary sector help with this.
- Literacy may be a barrier – Citizens Advice may help.
- Community based services (run by the local council, Citizens Advice Bureau or local community centre, for example) may also be available to help review benefits and assist with paperwork.

18. Targeted funding

- The specialist nurse role could be extended to create RA specialist nurses in primary care (e.g. to manage ‘flares’).
- The lack of specialist training in rheumatology for AHPs was felt to lead to a less effective service.
- Lack of access to MDTs can lead to inadequate monitoring and further costs later on (e.g. due to work disability).
- Drugs funding currently sufficient (but see cost pressures mentioned in (9) above).
- Specific areas for targeting funding included:
 - Staffing: consultant and specialist nurse, secretarial and AHP
 - MDT development
 - Early diagnosis and treatment
 - Mental health needs/psychological support
 - Pain management
 - Vocational rehabilitation

19. Availability of staffing

- Clinical teams often require inter-site travel, which can be time-consuming.
- Need for AHP staffing ratio recommendation – inadequate provision in some areas.

- Need for review of AHP skill mix e.g. OT assistants/support workers skill mix.
- Inadequate number of consultants for some areas.
- BSR/RCP recommendations on consultant staffing not being met.

20. Reasons for staff shortages

- Staff shortages were not universal. Where they existed, reasons included:
 - Resource constraints
 - Rheumatology is an outpatient specialty and therefore perceived as lower priority (in comparison with specialties requiring large numbers of inpatient beds)
 - Delay in recruitment with no additional cover for absence/retiral
 - Downbanding of retiral posts

21. Research & Audit

- Variable between units. Generally audit is undertaken.

22. Links with orthopaedics

- No-one commented on awareness of orthopaedic surgeons with a special interest in RA.
- Referrals have to go via rheumatologist.
- General feeling of reduced referrals to orthopaedics now (due to earlier identification and treatment of RA).
- Combined orthopaedic/rheumatology clinics are rare.

23. Co-operative working within the voluntary sector

- No consensus from respondents on how well this is working.
- No links with the physical activity task force were reported (the 2002 PHIS needs assessment had recommended that 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).¹

24. Miscellaneous

- Lack of national policies. Lack of follow-up from QIS, audit and projects into concrete action. MCNs only of use as a local tool.
- Selected patients in some sites offered exercise classes for cardiovascular disease risk reduction.

Casebook of interviewees

Role	NHS Board/voluntary organisation
Specialist Rheumatology Nurse	Greater Glasgow & Clyde
Specialist Rheumatology Nurse	Greater Glasgow & Clyde
GP	Forth Valley
GP	Lothian
Consultant Rheumatologist	Tayside
Consultant Rheumatologist	Lanarkshire
Consultant Rheumatologist	Forth Valley
Voluntary sector	NRAS
Voluntary sector	ARMA
Voluntary sector	Arthritis Care
Physiotherapist	Orkney
Physiotherapist	Greater Glasgow & Clyde
Occupational Therapy	Greater Glasgow & Clyde
Occupational Therapy	Highland
Occupational Therapy	Tayside
Podiatry	Fife
Podiatry	Highland
Podiatry	Greater Glasgow & Clyde
Pharmacy	Highland
Principal Pharmacist	Tayside
Pharmacy	Greater Glasgow & Clyde
Lead Clinical Pharmacist	Greater Glasgow & Clyde
Clinical Psychologist	Fife

Appendix 4: The 2010 ACR-EULAR classification criteria for rheumatoid arthritis

	Score
Target population (Who should be tested?): Patients who 1. have at least 1 joint with definite clinical synovitis (swelling) [*] 2. with the synovitis not better explained by another disease [†]	
Classification criteria for RA (score-based algorithm: add score of categories A–D; a score of $\geq 6/10$ is needed for classification of a patient as having definite RA) [‡]	
A. Joint involvement [§]	
1 large joint [¶]	0
2-10 large joints	1
1-3 small joints (with or without involvement of large joints) [#]	2
4-10 small joints (with or without involvement of large joints)	3
>10 joints (at least 1 small joint) ^{**}	5
B. Serology (at least 1 test result is needed for classification) ^{††}	
Negative RF <i>and</i> negative ACPA	0
Low-positive RF <i>or</i> low-positive ACPA	2
High-positive RF <i>or</i> high-positive ACPA	3
C. Acute-phase reactants (at least 1 test result is needed for classification) ^{‡‡}	
Normal CRP <i>and</i> normal ESR	0
Abnormal CRP <i>or</i> abnormal ESR	1

D. Duration of symptoms §§	
<6 weeks	0
≥6 weeks	1

* The criteria are aimed at classification of newly presenting patients. In addition, patients with erosive disease typical of rheumatoid arthritis with a history compatible with prior fulfilment of the 2010 criteria should be classified as having RA. Patients with longstanding disease, including those whose disease is inactive (with or without treatment) who, based on retrospectively available data, have previously fulfilled the 2010 criteria should be classified as having RA.

† Differential diagnoses vary among patients with different presentations, but may include conditions such as systemic lupus erythematosus, psoriatic arthritis, and gout. If it is unclear about the relevant differential diagnoses to consider, an expert rheumatologist should be consulted.

‡ Although patients with a score of <6/10 are not classifiable as having RA, their status can be reassessed and the criteria might be fulfilled cumulatively over time.

§ Joint involvement refers to any *swollen* or *tender* joint on examination, which may be confirmed by imaging evidence of synovitis. Distal interphalangeal joints, first carpometacarpal joints, and first metatarsophalangeal joints are *excluded from assessment*. Categories of joint distribution are classified according to the location and number of involved joints, with placement into the highest category possible based on the pattern of joint involvement.

¶ "Large joints" refers to shoulders, elbows, hips, knees, and ankles.

"Small joints" refers to the metacarpophalangeal joints, proximal interphalangeal joints, second through fifth metatarsophalangeal joints, thumb interphalangeal joints, and wrists.

** In this category, at least 1 of the involved joints must be a small joint; the other joints can include any combination of large and additional small joints, as well as other joints not specifically listed elsewhere (e.g. temporomandibular, acromioclavicular, sternoclavicular etc).

†† Negative refers to IU values that are less than or equal to the upper limit of normal (ULN) for the laboratory and assay; low-positive refers to IU values that are higher than the ULN but ≤ 3 times the ULN for the laboratory and assay; high-positive refers to IU values that are >3 times the ULN for the laboratory and assay. Where rheumatoid factor (RF) information is only available as positive or negative, a positive result should be scored as low-positive for RF. ACPA = anti-citrullinated protein antibody.

‡‡ Normal/abnormal is determined by local laboratory standards. CRP = C-reactive protein; ESR = erythrocyte sedimentation rate.

§§ Duration of symptoms refers to patient self-report of the duration of signs or symptoms of synovitis (e.g. pain, swelling, tenderness) of joints that are clinically involved at the time of assessment, regardless of treatment status.

Reference:

The American College of Rheumatology

http://www.rheumatology.org/practice/clinical/classification/ra/ra_2010.asp

Appendix 5: The Multidisciplinary Team in RA

The 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 health outcomes. The other 'players' share skills to improve health and reduce disability. This synergism helps optimise outcomes.

The main features of this approach include:

- Focus on outcomes not processes;
- Outcomes viewed from multiple perspectives;
- Sharing of goals information, decisions and skills;
- Communication and clarity; and
- Involvement of specialist AHP, medical and nursing support.

There are many key 'players' in the management of RA:

- Patient;
- Family and social network;
- Primary care: GP, practice nurse, pharmacy, physiotherapy, occupational therapy and podiatry;
- Secondary care: rheumatologist, specialist nurse, orthopaedic surgeon, pharmacy, physiotherapy, occupational therapy, podiatry, orthotist, dietician and psychology;
- Voluntary sector: with an important role in education;
- Complementary and alternative therapists;
- Local authority – social work, housing; and
- Work and Pensions – employment, training, benefits advice and employers.

Appendix 6: Fife RA and smoking disease awareness campaign

Rheumatoid Arthritis & Smoking – A Joint Problem

Prepared by Dr Helen Harris

Consultant Rheumatologist Fife Rheumatic Diseases Unit

24th January 12

We are all familiar with the risks associated with smoking, such as heart disease and lung cancer. You may not be as aware however of the impact smoking has on the development of Rheumatoid Arthritis (RA). Cigarette smoking causes citrullination of proteins in the body which can result in the production of anti cyclic citrullinated protein (CCP) antibodies that are strongly associated with the development of RA. Smoking more than 20 cigarettes a day for 20 years (20 pack-years) has been demonstrated to double the chances of developing RA. In addition, smoking can have a negative impact on the effect of RA treatment. Smoking can reduce the effectiveness of RA treatments including anti-TNF agents and disease-modifying anti-rheumatic drugs (DMARDs).^{32;35;37} Consequently, patients with RA who smoke may find that certain medications do not have the benefits they may provide to a non-smoker.

RA & Smoking - The Facts

- Smoking can increase the risk of developing RA by 50%
- Heavy smoking (>20 pack-years) can double the risk of developing RA
- Smoking can lessen the effect of RA treatments
- RA may be more severe in smokers than non-smokers

A survey of the attitudes and beliefs about cigarette smoking of 320 Fife RA patients was undertaken in September 2011. The results showed that only 5% of respondents were aware of a link between RA and smoking and 4% knew that smoking could interfere with treatment of RA. 1 in 5 RA patients surveyed in Fife currently smokes cigarettes and more than half of the RA smokers were thinking about quitting. The most common motivating factor for ex-smokers when quitting was a major health scare.

In September 2011 a RA and smoking disease awareness campaign was launched in Fife to raise awareness of the risks of smoking in the general public and amongst patients with RA. The campaign aimed to educate RA patients and the general public on the links between RA and smoking and how it may reduce the effectiveness of some RA treatments such as anti-TNF agents and disease-modifying anti-rheumatic drugs (DMARDs). Materials (see below) approved by RA patients were used to prepare the campaign posters, leaflets and flyers. The campaign was reported by local newspapers and radio stations. In addition all Fife Rheumatic Diseases Unit (FRDU) RA patients were posted a flyer summarizing the campaign. A second survey to measure the impact of the awareness campaign on Fife RA smokers is currently being undertaken.



There is a “Golden Moment” for doctors and other health care workers to give advice on smoking cessation at the time of RA diagnosis. The Fife Rheumatology multidisciplinary team plan to refer all smokers to local smoking cessation services

with the option to “opt out” rather than to “opt in”. Smoking cessation advice is now part of the treatment plan for all patients with seropositive RA in Fife.

Appendix 7: Role of self-management - 'Gaun Yersel'

In 2009 the Scottish Government published 'Gaun Yersel', a self management strategy for long-term conditions in Scotland, developed by people with long-term conditions in partnership with the Long Term Conditions Alliance Scotland (LTCAS).⁴³

Within the document, self management is described as 'the successful outcome of the person and all appropriate individuals and services working together to support him or her to deal with the very real implications of living the rest of their life with one or more long term conditions'. Ten areas were identified which represent the hallmarks of self-management. These include:

- Empowering patients to have more control and choice;
- Promoting better mental health and wellbeing;
- Enabling better access to information, advice and support;
- Care plans to support people to self-manage;
- Support people to understand their medication;
- Provide telehealth support for self-management;
- Support carers in their role;
- Commission resources to help people to manage their conditions;
- Use information systems to create person held records; and
- Train staff to enable people to manage their conditions.

Appendix 8: Rational approach to drug prescribing in RA

Introduction

Considerable changes have occurred during the time period from the previous RA needs assessment in 2002 with regards to the pharmacological therapy of rheumatoid arthritis.

In particular, the earlier use of DMARDS including combination therapy and the introduction of biologic therapy have made significant changes to the drug regimen which may be used.

It is not the remit of this report to provide updated guidelines on drug therapy. However, the standard of care based on current recognised guidelines and where possible informing of current Scottish practice should be clearly set out. These have important implications for ensuring quality and appropriate use of financial resources.

Non-Steroidal Anti-inflammatory Drugs and Analgesics (NSAIDs)

National Guidance

NICE Clinical Guideline 79:¹¹

- Offer analgesics (for example, paracetamol, codeine or compound analgesics) to people with RA whose pain control is not adequate, to potentially reduce their need for long-term treatment with non-steroidal anti-inflammatory drugs (NSAIDs) or cyclo-oxygenase-2 (COX-2) inhibitors.

- Oral NSAIDs/COX-2 inhibitors should be used at the lowest effective dose for the shortest possible period of time.

- When offering treatment with an oral NSAID/COX-2 inhibitor, the first choice should be either a standard NSAID or a COX-2 inhibitor. In either case, these should be co-prescribed with a proton pump inhibitor (PPI), choosing the one with the lowest acquisition cost.

- If NSAIDs or COX-2 inhibitors are not providing satisfactory symptom control, review the disease-modifying or biological drug regimen.

Clinical Audit of Care in RA (CARA):

CARA was a multi-centre Scottish audit of the care of 465 patients with newly diagnosed RA conducted in 2005-8, and published in 2009.²

- NSAID use in patients with early RA was widespread, and a significant proportion of patients had additional risk factors for developing NSAID-induced peptic ulcer disease. A majority of these patients were prescribed gastrointestinal (GI) protection, but 42% patients at high risk of GI toxicity continued on NSAID therapy without GI protection.
- Recommendation: Rheumatology Units should be supported to undertake review of their use of NSAIDs to ensure safe practice.

Glucocorticoids

National Guidance

NICE Clinical Guideline 79:¹¹

- Offer short-term treatment with glucocorticoids for managing flares in people with recent-onset or established disease to rapidly decrease inflammation.
- In people with established RA, only continue long-term treatment with glucocorticoids when:
 - the long-term complications of glucocorticoid therapy have been fully discussed, and
 - all other treatment options (including biological drugs) have been offered.

Disease Modifying Anti-Rheumatic Drugs (DMARDs)

National Guidance

SIGN Guideline:¹³

- Early initiation of treatment with DMARDs is recommended to control the symptoms and signs of RA as well as limiting radiological damage.

- Patients with moderate to severe disease activity should:
 - be assessed for disease activity using a standardised scoring system such as DAS/DAS28.
 - be reviewed monthly until remission or a low disease activity score is achieved.
 - treatment with DMARDs should be adjusted with the aim of achieving remission or a low DAS/DAS28 score.

- Methotrexate (MTX) and sulfasalazine (SSZ) are the DMARDs of choice due to their more favourable efficacy and toxicity profiles.

- DMARD therapy should be sustained in patients with early RA to control the signs and symptoms of disease.

- A combination DMARD strategy, rather than sequential monotherapy, should be considered in patients with an inadequate response to initial DMARD therapy.

- There is no consistent evidence that any combination strategy (step-up, step-down or parallel treatment) is superior to another.

NICE Clinical Guideline 79:¹¹

- In people with newly diagnosed active RA, offer a combination of DMARDs (including methotrexate and at least one other DMARD, plus short-term

glucocorticoids) as first-line treatment as soon as possible, ideally within 3 months of the onset of persistent symptoms.

- In people with recent-onset RA receiving combination DMARD therapy and in whom sustained and satisfactory levels of disease control have been achieved, cautiously try to reduce drug doses to levels that still maintain disease control.
- In people with newly diagnosed RA for whom combination DMARD therapy is not appropriate, start DMARD monotherapy, placing greater emphasis on fast escalation to a clinically effective dose rather than on the choice of DMARD.
- In people with established RA whose disease is stable, cautiously reduce dosages of disease-modifying or biological drugs. Return promptly to disease-controlling dosages at the first sign of a flare.
- When introducing new drugs to improve disease control into the treatment regimen of a person with established RA, consider decreasing or stopping their pre-existing rheumatological drugs once the disease is controlled.
- In any person with established rheumatoid arthritis in whom disease-modifying or biological drug doses are being decreased or stopped, arrangements should be in place for prompt review.

Summary of National Guidance:

- DMARDs should be introduced as early as possible in the disease course, and should be used singly or in combination with the aim of achieving low disease activity or remission.
- Patients with early RA should be reviewed frequently (monthly), with a formal assessment of disease activity (e.g. DAS28), and have their treatment

adjusted if there is persistent disease activity until low disease activity or remission are attained.

National Audit

CARA audit:²

- The audit showed that DMARDs are prescribed in more than 90% of patients with early RA. There was a continuing preference for mono-therapy but with a gradual switch from SSZ to MTX, mirroring world-wide trends. Clinicians choose alternatives, such as HCQ or combination therapy for those perceived as having less or more severe disease, respectively.

- SSZ and MTX are both reasonable options for patients' initial DMARD therapy, but it is also reasonable to offer patients initial combination therapy if poor prognostic indicators are present. Patients with early RA should be assessed frequently, ideally every 4–6 weeks in the first year of their disease, ideally using DAS or DAS28.

- Treatment should be tailored to individual patients' requirements, with the aim of achieving a low disease activity state or remission.

- Combination DMARD therapy should be used in patients not achieving a low disease activity state despite monotherapy. Initial combination DMARD therapy may be considered in patients with high baseline disease activity and other poor prognostic indicators.

- Early RA clinics are not run in every rheumatology unit, and patients are not reviewed as often as national guidelines recommend. Investment in Early RA clinics to optimise drug therapy yields very substantial improvements in health-related quality of life, physical function and remission rates and is highly cost effective.

Biologic therapy

Budget & Market Growth

- Data from National Procurement indicates that ~£22.5million is spent in Scotland each year on biologic drugs for the treatment of RA (section 4.6.4). Historical data to indicate the rate of growth of the market is not available nationally, but individual Boards may have collected these data locally. Boards expect the budget to grow by ~10% pa.
- Most Boards know how much is being spent on biologic drugs in total, but in many Boards only composite data is collected such that the spend on individual drugs for specific conditions is not readily available.
- Many clinicians are not informed about the expenditure (and its growth) on biologics.

National Guidance

NICE Clinical Guideline 79:¹¹

- The tumour necrosis factor alpha (TNF) inhibitors adalimumab, etanercept, golimumab, certolizumab and infliximab are recommended as options for the treatment of adults who have both of the following characteristics.
 - Active rheumatoid arthritis as measured by disease activity score (DAS28) > 5.1 confirmed on at least two occasions, 1 month apart.
 - Have undergone trials of two disease-modifying anti-rheumatic drugs (DMARDs), including methotrexate (unless contraindicated). A trial of a DMARD is defined as being normally of 6 months, with 2 months at standard dose, unless significant toxicity has limited the dose or duration of treatment.
- TNF inhibitors should normally be used in combination with methotrexate. Where a patient is intolerant of methotrexate or where methotrexate treatment

is considered to be inappropriate, adalimumab and etanercept may be given as monotherapy.

- Treatment with TNF inhibitors should be continued only if there is an adequate response at 6 months following initiation of therapy. An adequate response is defined as an improvement in DAS28 of 1.2 points or more.
- After initial response, treatment should be monitored no less frequently than 6-monthly intervals with assessment of DAS28. Treatment should be withdrawn if an adequate response is not maintained.
- An alternative TNF inhibitor may be considered for patients in whom treatment is withdrawn due to an adverse event before the initial 6-month assessment of efficacy, provided the risks and benefits have been fully discussed with the patient and documented.
- Escalation of dose of the TNF inhibitors above their licensed starting dose is not recommended.
- Treatment should normally be initiated with the least expensive drug (taking into account administration costs, required dose and product price per dose). This may need to be varied in individual cases due to differences in the mode of administration and treatment schedules.
- Use of the TNF inhibitors for the treatment of severe, active and progressive rheumatoid arthritis in adults not previously treated with methotrexate or other DMARDs is not recommended.
- Initiation of TNF inhibitors and follow-up of treatment response and adverse events should be undertaken only by a specialist rheumatological team with experience in the use of these agents.

SMC guidance on Biologic drugs:

Anti-TNF therapy:

- the use of infliximab, adalimumab and etanercept as initial biologic therapy is covered by the NICE MTA 130.
- certolizumab is recommended for use in Scotland, contingent upon the continuing availability of the patient access scheme in NHS Scotland (SMC advice 590/09).
- golimumab has been recommended.

Rituximab:

- Rituximab (in combination with methotrexate) is recommended for use in Scotland following an inadequate response to anti-TNF therapy (SMC advice 323/06).

Tocilizumab:

- Tocilizumab (in combination with methotrexate) is recommended for use in Scotland following an inadequate response to conventional DMARD or anti-TNF therapy (SMC advice 593/09).

Abatacept:

- Abatacept was not recommended for use in Scotland (SMC advice 400/07) but this advice has been partly superseded by the NICE MTA 195 which recommends that abatacept may be used following the failure of anti-TNF therapy in patients who cannot receive rituximab.

NICE Health Technology Appraisals

Single Technology Appraisals (STAs):

- STAs have no formal standing in Scotland, and all drugs that have been appraised by NICE in an STA have also been reviewed by SMC.

Multiple Technology Appraisals (MTAs):

- The use of anti-TNF therapy, following the failure of conventional DMARD therapy is covered by NICE MTA 130.

- NICE MTA 195 & 198 recommends the use of rituximab in patients who have failed to respond to initial anti-TNF therapy. Patients who have a contraindication to rituximab or intolerance of rituximab or methotrexate should be considered for treatment with abatacept, tocilizumab or a second anti-TNF inhibitor. The guidance does not address the issue of which drug(s) to consider in the event of a patient failing to respond to rituximab.

Of note:

- The service implications of this guidance will depend on several factors: 1) the number of patients who require a second biologic drug; 2) whether the use of rituximab as the second line biologic 'drug of choice' would represent a change of practice

 - Cost savings may accrue from reduced drug acquisition costs, but this will critically depend on the frequency of re-administration of rituximab

 - TNF inhibitors are largely administered by the patient at home, using home care delivery services; in contrast, rituximab infusion requires a full day admission to a day ward unit. Therefore, significant investment may be required to realise these savings, to increase capacity in pharmacy and rheumatology day wards
-
- Most Boards have indicated that they do not currently have sufficient capacity in pharmacy and day wards to implement the guidance, but it is not known:
 - how robust this assessment is; and
 - what additional resources would be required to rectify the situation.

- Most rheumatologists agree with their Board's assessment of capacity, namely, that an increased volume of infusions in the day ward could not be accommodated without investment.

National Audit Office (England)

- Eighty six per cent of acute trusts in England are able to prescribe biologics to all patients in accordance with NICE technology appraisal guidance.¹¹ NICE recommends use of biologics for patients who have not responded to other treatments. Trusts estimated that around 11,900 patients were eligible to receive biologics in 2007-08. Of these, all but around 350 people across all acute trusts were receiving them. The NAO estimates that biologics cost the NHS around £160 million annually.¹⁵
- In Scotland most patients who are eligible for biologic therapy can be prescribed them, but in some NHS Boards barriers are in place which prevent free access to therapy – for instance, in one board all prescriptions have to be approved on a case-by-case basis which introduces delay. In another example, the day ward facility is running at capacity such that the commencement of a patient on an IV biologic drug requires another patient to discontinue treatment first.

Regional audits of Biologic Use

- A regional audit project has been running in NHS Greater Glasgow & Clyde since 2007, with the objective of collecting prospective data from patients starting biologic drugs in routine clinical practice. By December 2010, 746 patients had been recruited, with an average DAS28 of 6.4. Data on drug cessation, adverse events and disease activity are being collected. It is recognised that the audit does not capture all patients prescribed biologic therapy in the NHS Board. The Clinical Governance committee aspire to the development of a web-based data collection tool that could facilitate the capture of data.

- Data is routinely collected in most units regarding the number of patients treated, indication, drug prescribed, eligibility and response. In most cases this is collected by the Specialist Nurse.

Uncertainties & Risks

- Comparative efficacy, cost effectiveness and safety of different biologic drugs or drug strategies:
 - Relatively little is known about the comparative efficacy, cost effectiveness and safety of different biologic drugs, because virtually no head-to-head RCTs have been performed. Indirect comparisons have suggested that different biologic drugs have similar efficacy.
- Regional variations in clinical practice and Post Code prescribing:
 - Systematic collection of data to establish equity (or otherwise) of access to biologic therapy is not being undertaken
- Budgetary pressures:
 - Detailed regional and national data on the use and growth of biologic in the treatment of RA is lacking.
- Capacity issues:
 - The current capacity of pharmacy and rheumatology day ward services and the costs of, and constraints on, service expansion are not known,

Potential solutions

- National protocol for use of biologic therapy
 - The Clinical Standards Sub-Committee of the Scottish Society for Rheumatology could be approached to consider the development of a nationally agreed protocol for the management of RA patients requiring biologic therapy. Such a protocol would need widespread consultation to

ensure clinical 'buy-in', and flexibility to allow appropriate variations in practice that take account of patient choice, service constraints and clinical judgement.

- Potentially, a protocol could be useful in identifying (a) biologic drug(s) of first choice, and a preferred pathway for subsequent treatment choices in the event of inefficacy, contraindication or toxicity.

➤ National procurement

- Where there are equally appropriate drugs for any given stage of the National Protocol, national procurement may be able to secure savings for the NHS if one drug is used as the preferred option. In practice, industry's pricing structures are not determined locally, but globally. There is currently very little price competition in the market.

➤ National web-based Biologic Management Database

- A National web-based Biologic Management Database could be created and hosted in a Safe Haven. Standardised data collection of key data would facilitate audit of compliance with national guidelines.
- The system would enable analysis of drug use, growth in use and regional variations in biologic therapy. This would allow inequity of access to be identified and would facilitate budget modelling.
- The collection of key data in the routine clinical environment would allow prospective evaluations of comparative clinical effectiveness. Where there is equipoise between two treatment options, patients could be asked to be entered into a randomised prospective evaluation, that could be used to inform future SMC guidance.

- Capacity planning
 - Boards should ascertain the capacity of their day ward and pharmacy services to identify what resources (if any) would be required to expand them to accommodate the shift from community sub-cutaneous anti-TNF preparations to day ward IV rituximab

Appendix 9: ISD Rheumatology Workforce Data by NHS Board in 2011 - Rheumatology medical staff and clinical nurse specialists (all staff numbers stated are Whole Time Equivalents)

	Population Estimates (2010)	WTE Consultants per 100,000 population	Consultants ¹	Career Grade Specialty doctors ¹	Training Grades: Foundation year 2 doctors ¹	Training Grades: Doctor in Training (with NTN) ¹	Training Grades: Doctor in Training (no NTN) ¹	Other medical staff ¹	Clinical Nurse Specialists ²
SCOTLAND	5,222,100	0.78	40.6	8.4	3.0	22.6	1.0	1.1	31.3
EAST REGION	1,314,526	0.72	9.5	1.0	1.0	4.8	-	-	5.7
NHS Borders	112,870	0.75	0.9	-	-	-	-	-	1.2
NHS Fife	364,945	0.79	2.9	1.0	-	-	-	-	-
NHS Lothian	836,711	0.69	5.8	-	1.0	4.8	-	-	4.5
NORTH REGION	1,332,791	0.85	11.4	0.5	1.0	8.1	-	0.3	4.0
NHS Highland	310,830	0.63	2.0	0.5	-	0.6	-	0.3	2.0
NHS Grampian	550,620	0.94	5.2	-	1.0	4.9	-	-	-
NHS Orkney	20,110	0.00	-	-	-	-	-	-	-
NHS Tayside	402,641	0.79	3.2	-	-	2.6	-	-	2.0
NHS Western Isles	26,190	0.00	-	-	-	-	-	-	-
NHS Shetland	22,400	4.46	1.0	-	-	-	-	-	-
WEST REGION	2,574,783	0.77	19.8	6.9	1.0	9.7	1.0	0.8	21.6
NHS Ayrshire & Arran	366,860	0.27	1.0	1.0	-	-	-	-	2.0
NHS Greater Glasgow & Clyde	1,203,870	1.23	14.8	3.4	1.0	8.7	1.0	-	15.6
NHS Lanarkshire	562,477	0.53	3.0	0.3	-	1.0	-	0.8	2.0
NHS Forth Valley	293,386	0.34	1.0	1.0	-	-	-	-	-
NHS Dumfries & Galloway	148,190	0.00	-	1.3	-	-	-	-	2.0

- nil WTE = Whole Time Equivalent NTN = National Training Number

¹ Medical staff: staff in post as at 31st December 2011 (WTE)

² Clinical nurse specialists: staff in post as at 30th September 2011 (WTE)

Source of data: Scottish Workforce Information Standard System (SWISS). Accessed from ISD 28/3/12.

Appendix 10: SSR Workforce Data for Scottish Rheumatology Units, March/April 2012 ¹⁰⁷

UNIT	Population	Consultants	WTE Consultants	WTE Consultants per 100k	WTE Associate Specialists	WTE (incl SAS) per 100k	PAs Rheumatology	Specialist Nurses
Highland	310,000	2	1.8	0.58	0.5	0.74	18	2
Western Isles	26,000	0	0	-	0	-	0	0
Grampian	520,000 (incl Orkney)	8	5.7	1.1	0	1.1	62	?1
Orkney	20,000	0	0	-	-	-	-	0
Shetland	22,000	1	0.3	1.3	-	-	4	?
Tayside	405,000 (excl NE Fife)	5	3.95	0.98	-	0.98	41.5	2
Fife	352,000	4	2.9	0.82	1	1.1	31	4.6
Lothian	800,000	9	6.4	0.8	-	0.8	64.5	3.5
Borders	120,000	1	0.85	0.7	-	0.7	8.5	1.2
Dumfries & Galloway	148,000	1	0.5	0.33	1.35	1.25	6	2
Ayrshire & Arran	367,000	3	1.5	0.41	1	0.68	15	2
Argyll & Clyde	430,000	4	2.8	0.65	1.8	1.07	25	3.6
Lanarkshire	620,000	4	4	0.65	1.4	0.87	43	3
Forth Valley	290,000	1	1.1	0.38	1	0.72	11	2
North Glasgow	850,000	12	7.45	0.88	0.8	0.97	74.5	6.2
Gartnavel	300,000	5	3.1	1.04	-	1.04	31	2
Stobhill / GRI	550,000	7	4.35	0.79	0.8	0.93	43.5	4.2
South Glasgow	368,000	4	3.15	0.87	1	1.14	31.5	4
SGH	148,000	3	2.15	1.2	0?	1.2	21.5	3
Victoria	220,000	1	1	0.46	1	0.91	10	1
North & South Glasgow	1,220,000	16	10.6	0.87	1.8	1.02	106.5	?10.7
Greater Glasgow & Clyde	1,650,000	20	13.45	0.81	3.6	1.03	131.5	14.3
SCOTLAND	5,459,000	59	42.4	0.77	9.85	0.956	435.5	37.1

SSR = Scottish Society for Rheumatology

WTE = Whole Time Equivalent

PAs = Programmed Activities

SAS = Specialty and Associate Specialist

incl = including excl = excluding

GRI = Glasgow Royal Infirmary

SGH = Southern General Hospital



ScotPHN r e p o r t

For further information contact:

ScotPHN
NHS Health Scotland
Elphinstone House
65 West Regent Street
Glasgow, G2 2AF

Email: [\[add details\]](#)

Web: www.scotphn.net