**SIDRIG** THE SCOTTISH INFLAMMATORY DISEASES AND RHEUMATOLOGY INDUSTRY GROUP

# Delivery of RA Services in Scotland: The View of Healthcare Professionals

## A REPORT OF A SURVEY OF SERVICE PROVISION FOR PATIENTS WITH RA AND ASSOCIATED CONDITIONS

Morhamburn
The Scottish Policy Practice

abpi
THE SCOTTISH INFLAMMATORY DISEASES AND RHEUMATOLOGY INDUSTRY GROUP

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# ABPI SCOTLAND - DISEASE SPECIFIC INDUSTRY GROUPS

ABPI Scotland currently runs 9 disease specific industry groups covering a growing spectrum of conditions.

These industry groups work collaboratively at a national level with the NHS, the SGHD & patient groups to deliver improved patient outcomes in the specific disease area.

ABPI Scotland's industry groups form the backbone of its activity in Scotland: working to develop and deliver collaborative projects, giving support to patient organisations and informing policy by responding to relevant consultation documents issued by the Scottish Government and NHSScotland.

# THE SCOTTISH INFLAMMATORY DISEASES AND RHEUMATOLOGY INDUSTRY GROUP (SIDRIG)

SIDRIG works with a number of patient groups (e.g. NRAS, Arthritis Care, PSALV) to increase awareness of politicians, senior managers and health care professionals about the key issues (e.g. employment) faced by patients with Inflammatory Arthritis in Scotland.

The group aims to improve understanding that new cases of inflammatory arthritis should be considered as 'acute inflammatory emergencies' which, if treated promptly with more aggressive newer therapies, can result in the long term impact being minimised.

# AIMS & OBJECTIVES

To represent the pharmaceutical industry, operating wherever possible in partnership with all relevant agencies to:

- Raise the standards of evidence based patient care
- Improve outcomes for people with inflammatory arthritis and its related conditions
- Ensure people with inflammatory arthritis have equitable access to the best available medicines and services
- Highlight opportunities for aligning plans and policies across national groups and related disease areas at both strategic and tactical levels

Member Companies: Abbott, Bristol-Myers Squibb, Merck Serono, Roche, Schering-Plough, UCB Pharma, Wyeth

# FOREWORD

ARTHRITIS IS AN INFLAMMATION OF THE JOINTS. IT AFFECTS AN ESTIMATED 9 MILLION PEOPLE IN THE UK, INCLUDING AROUND 12,000 CHILDREN.

The Information Services Division (ISD) of NHS National Services Scotland estimates that between 152,000 and 217,000 people in Scotland have rheumatoid arthritis or osteoarthritis based on prevalence rates of 0.5-0.9% and 2.5-3.3% respectively, these being 2007 statistics being attributed to Scotland NHS Quality Improvement Scotland.

No cure exists at present but treatment is available to alleviate pain and some of the misery caused by joint stiffness. (NHS QIS) (2007)

This is the report of a survey of service provision, and the opinions of those delivering services, for patients with RA and associated conditions. It is a snapshot of this area of patient care that is felt by many of those involved to have a lower priority in terms of policy and resources than it should.

The survey was commissioned by the Scottish Inflammatory Diseases and Rheumatology Industry Group (SIDRIG) within ABPI (Association of British Pharmaceutical Industry) Scotland. Its publication coincides with the official launch of the Group.

As the voice of the pharmaceutical industry in Scotland, ABPI Scotland works to ensure that the industry is recognized as a partner in provision of healthcare and to work with clinicians to ensure that Scotland's patients have access to the best available medicines. SIDRIG is one of nine industry groups within ABPI Scotland that help promote best practices and opportunities for further development within their healthcare area.

This study into Rheumatoid Arthritis and its related conditions in Scotland is directly in keeping with the aims of SIDRIG to:

- Raise the standards of evidence based patient care
- Improve outcomes for people with inflammatory arthritis and its related conditions
- Ensure people with inflammatory arthritis have equitable access to the best medicines and services available
- Highlight opportunities for aligning plans and policies across national groups and related disease areas at both strategic and tactical levels

The survey responses have created some interesting food for thought. Whilst illuminating many positive examples of best practice that are to be found throughout Scotland's Health Boards, the survey also prompts questions of how best we can move forward and increase cooperation and communication both within and between the Health Boards so as not to miss opportunities. The survey also illustrates that further attention should be given to the mechanisms that assist healthcare professionals both in regard to resources and information.

I would like to take this opportunity to thank all those who took the time to respond to the survey. I would commend the real enthusiasm with which it was received as evidenced by the detailed responses we received.

Undoubtedly for suffers of RA today things are much brighter than they were in previous generations. Nevertheless, however far we have come in terms of better treatment and service provision, we still have more to learn.

I would therefore urge that studies like this one should be acknowledged as an opportunity to take stock of the current situation and as a signpost to the next steps ahead along the road towards achieving excellent outcomes for patients.

## Diane Thomson

CHAIR OF SIDRIG

## THERE ARE ABOUT TWO HUNDRED DIFFERENT KINDS OF ARTHRITIS.

## COMMON TYPES ARE:

### OSTEOARTHRITIS

where the cartilage protecting the bones is worn away. About 5 million people in the UK have osteoarthritis, mainly elderly but it can also affect younger people through sport injuries.

### RHEUMATOID ARTHRITIS (RA)

is a more severe but less common condition. The body's immune system attacks and destroys the joint lining, making the joints painful, unstable and deformed. This type of arthritis tends to affect younger people and is more common in women than in men. It affects about one in 100 people.

### ANKYLOSING SPONDYLITIS

is the third most common type of arthritis in the UK. Inflammation occurs in the spine and pelvis causing the joints to stiffen and sometime 'lock'. This disease affects more men than women.

### GOUT

caused by uric acid crystals forming in the joints, particularly the big toe, ankles, hands and wrists. It can be very painful, but is easily controlled by medication and a change in diet.

# INTRODUCTION

## RHEUMATOID ARTHRITIS (RA) IS A CHRONIC, PROGRESSIVE AND DISABLING AUTO-IMMUNE DISEASE WHICH CAN CAUSE INCREDIBLE PAIN AND SEVERE DISABILITY.

RA and its associated conditions affect an estimated 9 million people in the UK, including around 12,000 children. The National Rheumatoid Arthritis Society believes RA alone affects 0.8% of adults across the UK, estimating that it effects some 52,000 Scots. No single official statistic exists for the prevalence of RA in Scotland. ISD Scotland (Information Services Division of NHS Scotland) quotes the NHS QIS estimate of 152,000 – 217,000 people in Scotland with either rheumatoid arthritis or osteoarthritis.

For all affected there is pain and, through swollen joints, restrictions in movement. For some it can rob them of their independence. Fatigue is common for RA patients and some can suffer from depression following diagnosis.

Although no cure exists at present, treatment is available to alleviate the pain and some of the misery caused by the condition. Though it is a long term condition, advances in treatment have made it possible for most suffers to enjoy a much better quality of life than was previously possible.

It is widely accepted that early diagnosis and intervention can often hold back the progress of the disease and prolong the time that people affected can continue to work and live independently.

In the interest of improving knowledge and understanding in relation to the care and management of RA and its related conditions in Scotland, SIDRIG (the ABPI Scottish Inflammatory Diseases and Rheumatology Industry Group) commissioned Morhamburn Limited to conduct a survey of healthcare professionals in Scotland.

The Long Term Conditions toolkit was introduced in February 07 with the objective of improving the management of Long Term Conditions. In particular it sought to look afresh at conditions that may have had less attention in the past. As RA is a marker condition within this toolkit, SIDRIG identified that a survey of those involved in delivering care for patients with these conditions would be beneficial to explore further this condition in Scotland.

The aim of the survey was to examine the current situation in Scotland with regards to RA and its related conditions specifically in the areas of diagnosis, treatment and long term care. Those invited to complete the survey were those with first hand experience of the current situation in Scotland: rheumatology consultants, specialist nurses, Community Health Partnership (CHP) general managers and clinical leads.

*"The earlier diagnosis is made and treatment initiated the more promising the outcome for the patient." (NURSE)*

# EXECUTIVE SUMMARY

THE RESULTS FOR THIS SURVEY ARE BASED ON A MULTIPLE CHOICE ON-LINE QUESTIONNAIRE WHICH WAS SENT TO 88 SELECTED HEALTHCARE PROFESSIONALS.

## THE SURVEY

Recipients came from four data sets:

1. Consultant rheumatologists
2. Specialist nurses
3. Clinical leads and
4. CHP general managers.

Two members of each data set from the 11 mainland Health Boards were chosen using random sampling methodology. The survey was conducted between 31st January and 13th February 2008.

All 11 mainland Health Boards were covered: Ayrshire and Arran; Borders; Dumfries and Galloway; Fife; Forth Valley; Grampian; Greater Glasgow and Clyde; Highlands; Lanarkshire; Lothian; and Tayside. As Orkney, Shetland and the Western Isles do not offer RA services to their population they were excluded from this survey.

48 responses were received: 16 from specialist nurses; 13 from consultant rheumatologists; 13 from clinical leads; and 6 from CHP general managers.

Over 60% of respondents had been in their current position for 5 years or more, whilst nearly 40% of this group had 10 or more years of service.

## THE FINDINGS – AN OVERVIEW

The survey was broken down into 4 main sections: *Early Diagnosis; Intervention; Provision of Services; and Auditing of Services.* Though the majority of questions provided multiple choice options for the answer, space was provided for recipients to elaborate on or clarify their responses. Free text commentary spaces were also provided at the end of each section.

### EARLY DIAGNOSIS

In the treatment of rheumatoid arthritis and its related conditions early diagnosis and initiation onto a treatment pathway dramatically impacts upon the long term outcomes for patients. It is evident from the survey responses that a number of excellent examples of best practice are occurring throughout the Health Boards in Scotland but, unfortunately, these instances are not being shared consistently. The survey illustrated that divergences occur not only between Health Boards but also within Health Boards.

According to the perception of 48% of respondents to the survey, a low priority status is given to RA and its related conditions by Health Boards.

*"[Early diagnosis] remains difficult due to limited access to tests such as anti-CCP and diagnostic ultrasound. Access varies across Health Boards depending on local interests and studies / service developments." (CONSULTANT)*

## INTERVENTION (INCLUDING HOW LONG PEOPLE WAITED FOR A DIAGNOSIS)

Two themes emerged from the survey responses in regard to timely intervention:

Waiting times – Over 65% of those surveyed stated that on average patients waited eight weeks or more between GP referral and their first consultant appointment. The need to achieve targets and the subsequent impact on the service provided was raised by respondents, in particular the perceived inability to prioritise cases.

Resources – This was a concern for recipients, particularly staff shortages. It was also evident from the survey responses that the issue of budgetary implications does require further attention as 24% thought there were no limits in place and 24% thought that budgetary restrictions existed.

*"While no budget restrictions, the limited access to advanced treatment is currently caused by low staffing levels in nursing in general and specially in biologics nurses" (CONSULTANT)*

## SERVICE PROVISION

Service provision and the standard provided are undoubtedly important for all healthcare areas. From the survey, funding and resources emerged as two intrinsic topics of concern for healthcare professionals involved in the treatment of patients. Respondents illustrated that staffing levels were 'less than adequate' and that it was 'difficult' to make the case for new post within their service.

When questioned on budgetary limitations, respondents again identified staff limitations as an issue. Answers within this section also pointed to the possible emergence of a two-tier service with 'core' and 'additional' services not experiencing the same availability.

*'BSR and ARMA guidance recommend that all patients with RA should have access to a rheumatology nurse specialist. Access does not mean to see the nurse once but rather to be able to have input from the nurse whenever needed. The current situation is patients do see the nurse only after being diagnosed but there is no continued nursing input because of the low staffing levels' (CONSULTANT)*

## AUDITING OF SERVICES

Tied to the continual improvement of service provided is the question of change, in terms of amenability to new methodologies arising and implementation of new practices including the flexibility to change and adapt.

Overwhelmingly recipients of the survey acknowledged the excellent work of their nursing team, often against numerous hurdles (staff shortages, paperwork, expectations). Whilst funding for medicines was not identified as a major concern by half of the respondents, the level of funding available for staffing was raised. Respondents found it often difficult to make the case for new positions and there was a widespread lack of knowledge about future RA changes planned within their Health Board.

For continual improvement and enhancement of services regular auditing is necessary. A rigorous auditing process helps to identify successful practices and also those that are not working as efficiently and effectively as they should be. Respondents displayed a lack of knowledge of standards and quality control issues within their Health Board. Monitoring that did exist was deemed to be "average" whilst often there was either none or respondents were unaware of any that existed.

*"I suspect the only thing they monitor is the waiting time to be seen as an OP [out patient] and the new review ratio, neither of which has any relevance to quality of care" (CONSULTANT)*

Attitudes to change by the Health Board, as perceived by respondents, were "average" or "slow". There was no identification that Health Boards were dynamic or proactive in their attitude to change.

Costs were seen to affect decision making sometimes, while very few thought such concerns were not an issue.

Within the scale of priorities RA came 7th behind cancer, unscheduled care, cardio vascular disease, chronic obstructive pulmonary disease, mental health, and alcohol / drug misuse related conditions. RA was seen however as a higher priority than degenerative neurological disease and sexual health services.

# COMMENTARY ON FINDINGS

THIS SURVEY IDENTIFIED THOSE HEALTHCARE PRACTITIONERS THAT HAVE FIRST HAND EXPERIENCE OF THE TREATMENT PACKAGE PROVIDED TO SUFFERERS AND POTENTIAL SUFFERERS OF RA AND ITS RELATED CONDITIONS. THEREIN OUR RESPONDENTS SHOULD BE REGARDED AS BEING BEST PLACED TO COMMENT ON CURRENT PRACTICES.

*"Diagnosing RA early is only half the battle. Where do we put all the return patients once diagnosed? The system is saturated" (NURSE)*

*"Consultants have lost control of their waiting lists and the priority is to see all patients within 18 weeks. This takes away the ability to see the most urgent patients ideally within 6 weeks of onset" (NURSE)*

*"It [early diagnosis] needs to be considered a priority in the community, we therefore need to take the message, education and diagnostic tools to that level to fast track referral" (CONSULTANT)*

It should be noted that in addition to possible sampling error, that question wording and practical difficulties in conducting the survey can introduce error or bias into the findings, though all appropriate steps have been taken within the context of this survey to ensure this was not the case.

## (I) PERSONAL INFORMATION

- 88 recipients were targeted for this survey.
- Of the 48 respondents, over 83% were clinicians with daily contact with patients, 12.5% identified themselves as managers.
- Responses from all 11 mainland Health Boards were received and over 60% of respondents had been in their current position for 5 years or more, whilst nearly 40% of this group had 10 or more years of service.

## (II) EARLY DIAGNOSIS & PATIENT INFORMATION

In respect to services offered by Health Boards:

- 56.1% stated that their Board offered ultrasound.
- 24.4% acknowledged that they were unaware what early diagnosis services was offered and
- 9.8% stated that no services were offered.
- 34.1% of those who identified that ultrasound was offered stated that this happened during a specialist visit to radiography.
- 31.7% were unaware when this service was available.
- 80.5% of respondents stated that RA and its related conditions were most likely to be diagnosed at secondary care, though a number of those surveyed did acknowledge the prompt role that GPs played in passing on suspected cases to secondary care for diagnosis.

It was evident from the survey that patients access information on their condition from a range of sources: internet and media, GP surgery, specialist booklets, RA clinics, friends, specialist nurses, resource centres, education afternoons and charitable bodies. Patients also receive a variety of materials from their healthcare professionals including specialist reading materials on their condition, contact information, information on their medicine and exercise plans.

Evidence provided in the survey illustrated that a number of examples of best practice in patient information provision exist within the Health Boards and there are opportunities that could be developed to share these practices. Increased communication within and between boards should be more fully explored and promoted.

- 48% of respondents thought RA was attributed a low / fairly low priority status
- None of the respondents to the survey identified that RA and its related conditions was a funding priority within their NHS board.

In addition to the core questions offered by the survey, respondents were keen to raise additional issues in the comments section.

- As early diagnosis is heavily dependent on a prompt referral by GPs and though guidelines were issued to GPs in 2007 for early referral that undoubtedly have had an impact, it was suggested that a follow-up on this practice was urgently required to stress the importance of early referral.
- The healthcare professionals were eager to raise awareness within the survey of examples of best practice within their Health Boards. One example put forward was that a protocol based on research conducted in Bristol which tackles the high level of RA follow-up caseload by allocating selected patients two yearly appointments be replicated. Another was a call for the development of a protocol to use anti-ccp testing in primary care.
- A number of respondents did express concern about the post-diagnosis situation in respect to dealing with the high case load and also the implications of waiting times, in that the 18 week time frame often meant that consultants had lost the ability to prioritise the most urgent patients as all patients must be seen within 18 weeks.

*"I strongly believe that diagnostic ultrasound should be included within the rheumatology service to enable early diagnosis and prevent long term morbidity" (CONSULTANT)*

## (III) INTERVENTION

- 24.4% of respondents stated that waiting times were more than 12 weeks between referral from their GP and their first consultant visit.
- 41.5% of respondents stated that patients waited on average between 8 and 12 weeks.
- 4.9% stated that patients waited less than 2 weeks for the appointment.
- 58.5% said that the current trend in waiting times displayed either a downward pattern or had remained static.
- 17.1% felt waiting times appeared to be increasing.

Supplementary comments from respondents discussed how the drive to achieve waiting time targets impacted upon service. It was questioned whether in the drive to ensure that patients were seen within the 18 week 'target' that consultants had lost the ability to prioritise patients as effectively as possible. The impact of the 18 week push meant that possible RA patients had to wait as long as non-RA patients.

Additional pressures were also felt by the impact of the early referral guidelines issued and the subsequent increase in referrals, and the extra waiting lists being generated by 'out of hours' clinics.

In regard to funding for advanced treatments for new patients:

- 24.4% stated that there was no budgetary limits in place,
- 43.9% identified that there were budgetary restrictions.

Through their additional comments respondents expressed the opinion that funding for medicines was not a particular problem but rather that a lack of specialist nursing support to administer the medicines was a greater concern. Respondents emphasized the time consuming nature of initiating anti-TNF therapy.

*"In ensuring access for all patients within 18 weeks we have lost the ability to prioritise patients as effectively, so now 'possible' inflammatory arthritis patients wait as long as clearly non-inflammatory" (CONSULTANT)*

*"The main restriction is related to a lack of specialist nurse time for initiating anti-TNF therapy' (CONSULTANT)*

*'We need to be able to prescribe anti-TNF drugs to more people and the budget will need to be reviewed" (CONSULTANT)*

*"The specialist nurse service has developed clinics in addition to the telephone helpline and is only maintained by the enthusiasm and unpaid efforts of the staff" (CONSULTANT)*

*Funding provision is "very uneven across the board who are keen to aggregate numbers and provision [is] very uneven"(CONSULTANT)*

*Comment on specialist nurses - "Excellent staff but very hard pushed"(CONSULTANT)*

*"Funding is based on quantity [waiting times] rather than quality"(NURSE)*

## (IV) PROVISION OF SERVICES

The section on provision of services looked at issues such as the support available within the team, funding and service development.

Within the support provided among the team, respondents illustrated the high regard with which rheumatology specialist nurses are regarded by their colleagues.

- 27.6% of respondents acknowledged that the provision of specialist nurse support was average.
- 27.6% of respondents said the provision of specialist nurse support was below average.

However it should be stated that this is a fairly new role and rheumatology teams are still possibly in an adjustment phase.

Respondents drew attention to the excellent standard of nurses despite the low staffing levels. Examples were given as testament to the continuing hard work and effort of the nursing team often outside their working hours. Specialist nurses had developed clinics in addition to the telephone helpline which were 'only maintained by the enthusiasm and unpaid efforts of the staff'.

- 44.8% of respondents were unable to identify the ratio of specialist rheumatology nurses to consultant rheumatologists within their Health Board.

In respect to the other components of the team:

- 51.7% of respondents knew who their long term conditions lead is.
- 48.3% did not know who their long term conditions lead is.
- 44.8% of respondents were unaware at which point in a patient's treatment path that he or she was seen for the first time by a junior doctor or a dedicated AHP.
- 48.3% of respondents were unaware at which point in a patient's treatment path that he or she was seen for the first time by a training medic or a career grade medic.
- 55.2% felt that present staffing levels within their team were 'less than adequate' or 'insufficient'.
- 3.4% stated that levels were 'more than adequate'.
- 58.6% of respondents felt that making the case for new posts was 'difficult' or 'extremely difficult',
- none thought it was 'very easy' and
- 3.4% thought that it was 'easy'.

In regard to the actual service provided, a two-tier level of service was apparent from the survey. Core services such as access to a rheumatology specialist nurse (93.1%), consultant rheumatologist (100%), physiotherapist (96.6%) and occupational therapist (93.1%) are routinely available according to those surveyed. However, additional services were less universally available and were subject to regional differences:

- 37.9% reported offering dietary support
- 34.5% counseling / advice support
- 17.2% offered access to specialist pharmacy advice.

In relation to the funding provision of services
- 6.9% of respondents rated their Board as 'excellent',
- 24.1% as 'above average',
- 20.7% 'average' and
- 31% felt that their board was 'below average / poor'.

Comments for this question again remarked on the divergences that existed within Health Boards. Respondents stated that funding support for staff was not adequate.

Differences emerged between respondents when questioned on whether there was adequate budgetary provision to deliver ARMA standards of care:
- 34.5% felt that this was not the case for multi-disciplinary working
- 34.5% felt that this was not the case for podiatry and
- 37.9% felt that this was not the case for AHPs
- 13.8% felt that this was not the case for anti-TNF medication:

compared to
- 31.0% who identified that there was adequate provision for multi-disciplinary working
- 27.6% identified that there was adequate provision for podiatry and
- 24.1% identified that there was adequate provision of AHPs
- 55.2% identified that there was adequate provision for anti-TNF medication.

- 35.5% stated that they did not know about budgetary provision for multi disciplinary working
- 37.9% stated that they did not know about budgetary provision for podiatry and
- 37.9% stated that they did not know about budgetary provision for AHPs
- 31% stated that they did not know about budgetary provision for anti-TNF medication.

When asked to elaborate on why they felt there was not an adequate budgetary provision, respondents stated that there were insufficient staff levels available to ensure standards were met.

On the issue of development of services:
- 55.2% identified that RA had been included in their Health Board's long term conditions priority list,
- 6.9% said it had not and
- 37.9% did not know.
- 55.2% of respondents were unaware of any planned service changes as a result of the inclusion. Those changes that were identified included: plans to commence an enhanced service in primary care; plans to introduce a patient initiated review which would thereby cut the level of follow-up in formal OPD sessions; increased review intervals; and self management programmes.

Respondents also used the opportunity to comment on inequalities that existed within Health Boards and attention was drawn to the importance of correct data and statistics. In particular ISD intransigence, changes in working practices and inadequate IT provision all impacted upon the accuracy of figures available. Without accurate figures and data it was felt that provision would always suffer.

*"Restrictions on staffing prevent adequate frequency of patients review. Restrictions of DCU staffing restrict access to anti-TNF therapy"(CONSULTANT)*

*"We have a good team but still not sufficient in numbers to see all new patients like ARMA standards" (NURSE)*

*"[Service] provision is crucially dependent on knowing accurate figures. This is not currently available" (CONSULTANT)*

*"Huge inequalities exist within different units even within the same health board" (CONSULTANT)*

## (V) AUDITING OF SERVICES

From the survey it was evident that a large proportion of respondents (48.1%) were not aware of what standards of care their Health Board worked toward.

A lack of awareness was also evident in respect to existing quality control measures:

- 55.6% did not know what audit measures were in place to ensure standards were being met and
- 29.6% stated that there were no measures in place.
- 3.7% of respondents identified their board's ongoing monitoring of services as excellent
- 18.5% stated that it was average
- 11.1% stated ongoing monitoring was below average and
- 37% said they did not know how to rate the ongoing monitoring.

When asked to rate their Health Board's attitude to new evidence and its ability to accept these conclusions within working practices:

- 11.1% felt their Health Board was prompt and proactive
- 44.4% stated it had an average response and
- 18.5% felt response was slow to accept and amend accordingly.

From the survey it is apparent that clinical decision making is affected by cost considerations:

- 81.4% of those surveyed stated that cost was a factor;

of these:

- 7.4% responding 'yes, always'
- 48.1% 'yes, sometimes' and
- 25.9% 'yes, rarely'.

- 51.9% of respondents felt that the cost of medicines was important when choosing treatment options for patients, whilst
- 88.9% stated that likely compliance and concordance was important in choosing treatment options.
- 85.2% listed patient choice as an important factor in choosing treatment options and
- 74.1% said latest advances was an important factor.

*"On the ground, the hard core data is flawed" (CONSULTANT)*

*"Unable to achieve all standards due to staffing levels" (NURSE)*

# ISSUES FLAGGED BY THE RESEARCH

## EARLY DIAGNOSIS & PATIENT INFORMATION

- Just under 10% of respondents stated that early diagnosis services were not available and only 56% stated that they knew ultrasound was available.
- None of the respondents felt that services for RA and associated conditions were a funding priority for their Boards while nearly half suggested it was a low or fairly low priority.

## INTERVENTION

- A quarter of respondents stated that waiting times between GP referral and first consultant visit was in excess of 12 weeks.
- 43.9% of respondents stated that there budgetary restrictions on funding for advanced treatments for new patients.

## PROVISION OF SERVICES

- 55.2% of respondents said specialist nurse provision was average or below average (27.6% average and 27.6% below average).
- Nearly half of respondents were unable to identify who their long term conditions lead is.
- 55.2% felt that present staffing levels within their team were 'less than adequate' or 'insufficient'(41.4% less than adequate and 13.8% insufficient).
- 58.6% of respondents felt that making the case for new posts was 'difficult' or 'extremely difficult' (41.4% difficult and 17.2% very difficult).
- 55.2% identified that RA had been included in their Health Board's long term conditions priority list, but the same proportion were unaware of any planned service changes as a result of the inclusion.

## AUDITING OF SERVICES

- 55.6% did not know what audit measures were in place to ensure standards were being met.
- 81.4% of those surveyed stated that cost was a factor in clinical decision making while
- 51.9% of respondents felt that the cost of medicines was important when choosing treatment options for patients.

# RECOMMENDATIONS

## BEST PRACTICE

From the survey a number of excellent examples of best practice have emerged from the various Health Boards. SIDRIG recognize that, though this survey was in no way exhaustive, it was illustrative in identifying a few examples that are working successfully in regions of Scotland. SIDRIG would therefore encourage the Scottish Government to reexamine how best practice is exchanged both within and between Health Boards so as to allow better facilitation of appropriate mechanisms for the exchange and promotion of models that work.

## COMMUNICATION – BETWEEN AND WITHIN HEALTH BOARDS

Within Health Board areas it is evident that a long term communication strategy is required to link and reinforce the relationship between primary and secondary care. Though the early referral message did get out to primary care practitioners, as evident in the higher number of referrals, the survey would suggest that a continual communications process is required rather than having a one-off drive for early referral as was seen in 2007. Early referral leads to better long term outcomes for patients with RA. At no point in any of the responses was there any mention of managed clinical networks for RA. SIDRIG would suggest that the Scottish Government might wish to give further consideration to regional or inter-regional forums which could be hubs for best practice exchange and awareness raising.

A clear indication from the survey was the need for further attention to the issue of information sharing within hospital teams. On a range of topics including standards of care, monitoring procedures, staff provision, and service development / future changes, a large proportion of respondents were unable to answer questions. SIDRIG believes this finding should encourage the Scottish Government to consider strategies to facilitate and improve the exchange of knowledge.

## EQUITY OF SERVICE

A core aim of SIDRIG is to ensure that patients receive equitable access to the best medicines and services. From the survey it is evident that there is a two-tier system in operation between 'core' services that are routinely available and additional services which are less routinely available. SIDRIG would encourage the Scottish Government to address this situation and ensure that service and medicines are available to all patients no matter their locality.

## RESOURCES

SIDRIG would encourage the Scottish Government to take note of the comments provided by health care professionals across Scotland on the issue of resources, with particular reference to staff and limitations on staffing.

## ATTITUDE

Undoubtedly RA sufferers now are in a much better position than a generation ago. In pursuit of continuing improvement now and for future generations, SIDRIG would encourage the Scottish Government to promote and foster an atmosphere of innovation and receptivity to new evidence and practices within the health service to ensure the continual improvement of RA treatment strategies.

# CONCLUDING REMARKS

This survey was designed to help establish an overview of RA services in Scotland both from the perspective of those in regular contact with patients and from those developing the services.

This survey has been informative and illustrative by uncovering the issues that are currently affecting RA services in Scotland. As evidenced by respondents, a number of excellent examples of best practices are occurring. The health care professionals working in RA departments across Scotland are enthusiastic and passionate and are to be commended for their hard work and dedication.

SIDRIG would encourage the Scottish Government to take the time to consider fully this report, the issues that it flags up and its recommendations and use this study as a practical tool providing concrete information on the current status of RA services in Scotland. We hope that it can be the basis of a debate on the future design and direction of services in NHSScotland for people with RA and associated conditions.

# SURVEY RESPONSES

## PERSONAL INFORMATION

**1. What is your current position?**

| | Response Percent | Response Count |
|---|---|---|
| **Doctor** | **52.1%** | 25 |
| Nurse | 31.3% | 15 |
| Manager | 12.5% | 6 |
| Other (please specify) | 4.2% | 2 |
| Other (please specify) | | 3 |

**2. Which Health Board region are you based?**

| | Response Percent | Response Count |
|---|---|---|
| Ayrshire & Arran | 6.3% | 3 |
| Borders | 10.4% | 5 |
| Dumfries & Galloway | 6.3% | 3 |
| Fife | 8.3% | 4 |
| Forth Valley | 2.1% | 1 |
| Grampian | 8.3% | 4 |
| **Great Glasgow & Clyde (GGCHB)** | **27.1%** | 13 |
| Highlands | 6.3% | 3 |
| Lanarkshire | 4.2% | 2 |
| Lothian | 6.3% | 3 |
| Orkney | 0.0% | 0 |
| Shetland | 0.0% | 0 |
| Tayside | 14.6% | 7 |
| Western Isles | 0.0% | 0 |

# SURVEY RESPONSES

**3. How long have you been in your current position?**

| | Response Percent | Response Count |
|---|---|---|
| Less than 6 months | 2.1% | 1 |
| Over 6 months but less than 2 years | 20.8% | 10 |
| 2 years or over but less than 5 years | 16.7% | 8 |
| 5 years or over but less than 10 years | 20.8% | 10 |
| **10 years or more** | **39.6%** | 19 |
| Other | 0.0% | 0 |
| Other (please specify) | | 1 |

## EARLY DIAGNOSIS

**4. What services are currently available to the population in your NHS Board area? (Please tick ALL relevant boxes)**

| | Response Percent | Response Count |
|---|---|---|
| Predictive Testing | 34.1% | 14 |
| **Ultra Sound** | **56.1%** | 23 |
| Other | 12.2% | 5 |
| None | 9.8% | 4 |
| I Don't Know | 24.4% | 10 |
| Other (please specify) | | 7 |

**5. At which clinic appointment is ultra sound available to patients? (Please tick ONE box)**

| | Response Percent | Response Count |
|---|---|---|
| 1st consultant visit | 7.3% | 3 |
| 2nd consultant visit | 2.4% | 1 |
| **Specialist visit to radiography** | **34.1%** | 14 |
| Other | 9.8% | 4 |
| Not available | 14.6% | 6 |
| I don't know | 31.7% | 13 |
| Other (please specify) | | 9 |

# SURVEY RESPONSES

**6. In your opinion what funding priority is placed on RA and its related conditions in your NHS Board area? (Please rate from 1 to 10, with 1 indicating that it is a very low priority and 10 a very high priority)**

| | Response Count |
|---|---|
| | 41 |

**7. Where is RA and its associated conditions most likely to be first diagnosed? (Please tick ONE box)**

| | Response Percent | Response Count |
|---|---|---|
| Primary care | 17.1% | 7 |
| **Secondary care** | **80.5%** | 33 |
| Other | 2.4% | 1 |
| I don't know | 0.0% | 0 |
| Other (please specify) | | 4 |

**8. Where do patients usually access information on their condition? (Please tick ALL relevant boxes)**

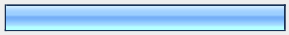
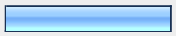
| | Response Percent | Response Count |
|---|---|---|
| Internet and media | 78.0% | 32 |
| GP surgery | 36.6% | 15 |
| Specialised booklet | 78.0% | 32 |
| Friends | 29.3% | 12 |
| **RA clinic** | **92.7%** | 38 |
| Other | 19.5% | 8 |
| Other (please specify) | | 11 |

# SURVEY RESPONSES

| 9. What type of information do patients usually receive on a visit to your team? (Please tick ALL relevant boxes) | | Response Percent | Response Count |
|---|---|---|---|
| General booklet |  | 46.3% | 19 |
| Specialised booklet |  | 68.3% | 28 |
| **Contact information for other agencies and groups** |  | **75.6%** | 31 |
| Other |  | 22.0% | 9 |
| I don't know |  | 4.9% | 2 |
| | Other (please specify) | | 14 |

| 10. Please provide any additional comments you may have in regards to the early diagnosis of RA and its related conditions | Response Count |
|---|---|
| | 19 |

## INTERVENTION

| 11. What is the average waiting time to be seen between GP referral and first consultant visit? (Please tick ONE box) | | Response Percent | Response Count |
|---|---|---|---|
| Less than 2 weeks |  | 4.9% | 2 |
| 2-4 weeks |  | 2.4% | 1 |
| 5-7 weeks |  | 14.6% | 6 |
| **8-12 weeks** |  | **41.5%** | 17 |
| More than 12 weeks |  | 24.4% | 10 |
| I don't know |  | 12.2% | 5 |

# SURVEY RESPONSES

**12. Which one of the following boxes describes best the overall trend in waiting times in your department? (Please tick ONE box)**

| | Response Percent | Response Count |
|---|---|---|
| **The current trend shows a downwards pattern in waiting times** | **34.1%** | 14 |
| The current trend shows an upward pattern in waiting times | 17.1% | 7 |
| The figures largely remain static | 24.4% | 10 |
| None of the above | 4.9% | 2 |
| I don't know | 19.5% | 8 |
| None of the above (please specify) | | 5 |

**13. Which best describes the process of seeking funding for advanced treatment for each new patient? (Please tick ONE box)**

| | Response Percent | Response Count |
|---|---|---|
| **Budget in place, no limits** | **24.4%** | 10 |
| Must go through on a named patient basis | 19.5% | 8 |
| **Budgetary restrictions though not on a named patient basis** | **24.4%** | 10 |
| Other | 9.8% | 4 |
| I don't know | 22.0% | 9 |
| Other (please specify) | | 11 |

**14. Please provide any additional comments you would like to make in regard to the availability of medicines for patients**

| | Response Count |
|---|---|
| | 16 |

# SURVEY RESPONSES

## PROVISION OF SERVICES

**15. How many consultants specialising in RA and its associated condition are there in your NHS board?**

| | Response Count |
|---|---|
| | 29 |

**16. How would you rate the provision of specialist nurse support in your unit? (Please tick ONE box)**

| | Response Percent | Response Count |
|---|---|---|
| Excellent | 6.9% | 2 |
| Above average | 24.1% | 7 |
| **Average** | **27.6%** | 8 |
| **Below average / poor** | **27.6%** | 8 |
| None of the above | 3.4% | 1 |
| I don't know | 10.3% | 3 |
| None of the above (please specify) | | 5 |

**17. Please give an example of evidence to support your choice in Question 2 (provision of specialist nurse support in your unit)**

| | Response Count |
|---|---|
| | 29 |

**18. What is the ratio of specialist rheumatology nurses to consultant rheumatologists in your Health Board? (Please tick ONE box)**

| | Response Percent | Response Count |
|---|---|---|
| 1:1 | 24.1% | 7 |
| 1:2 | 10.3% | 3 |
| 1:3 | 13.8% | 4 |
| 2:1 | 6.9% | 2 |
| 3:1 | 0.0% | 0 |
| Other | 0.0% | 0 |
| **I don't know** | **44.8%** | 13 |
| Other (please specify) | | 4 |

# SURVEY RESPONSES

**19. Which services are routinely available to patients in your unit? (Please tick ALL relevant boxes)**

| | Response Percent | Response Count |
|---|---|---|
| Rheumatology Specialist Nurse | 93.1% | 27 |
| **Consultant Rheumatologist** | **100.0%** | 29 |
| Physiotherapy | 96.6% | 28 |
| Occupational Therapy | 93.1% | 27 |
| Podiatry | 79.3% | 23 |
| Dietary support | 37.9% | 11 |
| Counselling / Advice service | 34.5% | 10 |
| Access to specialist pharmacy advice | 17.2% | 5 |
| Other | 17.2% | 5 |
| I don't know | 0.0% | 0 |
| Other (please specify) | | 9 |

**20. Do you know who your long term conditions lead is?**

| | Response Percent | Response Count |
|---|---|---|
| **Yes** | **51.7%** | 15 |
| No | 48.3% | 14 |

**21. At which point in a patient's journey is he or she seen for the first time by the following health professionals? (Please place a tick in each row)**

| | Diagnosis | 1st Consultant Visit | 2nd Consultant Visit | Never | I Don't Know | Response Count |
|---|---|---|---|---|---|---|
| Training Grade Medic | 10.3% (3) | 3.4% (1) | 10.3% (3) | 27.6% (8) | **48.3% (14)** | 29 |
| Junior Doctor | 3.4% (1) | 6.9% (2) | 17.2% (5) | 27.6% (8) | **44.8% (13)** | 29 |
| Career Grade Medic | 20.7% (6) | 13.8% (4) | 0.0% (0) | 17.2% (5) | **48.3% (14)** | 29 |
| Dedicated AHP | 20.7% (6) | 20.7% (6) | 13.8% (4) | 0.0% (0) | **44.8% (13)** | 29 |
| Specialist Nurse | 24.1% (7) | 24.1% (7) | 17.2% (5) | 0.0% (0) | **34.5% (10)** | 29 |

# SURVEY RESPONSES

| 22. How would you rate the funding provision of services linked to RA in your Health Board? (Please tick ONE box) | | | |
|---|---|---|---|
| | | Response Percent | Response Count |
| Excellent | | 6.9% | 2 |
| Above average | | 24.1% | 7 |
| Average | | 20.7% | 6 |
| **Below average / Poor** | | **31.0%** | 9 |
| Other | | 0.0% | 0 |
| I don't know | | 17.2% | 5 |
| | Other (please specify) | | 6 |

| 23. Please give an example of evidence to demonstrate your choice for Question 8 (funding provision) | |
|---|---|
| | Response Count |
| | 29 |

| 24. How do you regard present staffing levels within your team? (Please tick ONE box) | | | |
|---|---|---|---|
| | | Response Percent | Response Count |
| More than adequate | | 3.4% | 1 |
| Adequate | | 24.1% | 7 |
| **Less than adequate** | | **41.4%** | 12 |
| Insufficient | | 13.8% | 4 |
| Other | | 3.4% | 1 |
| I don't know | | 13.8% | 4 |
| | Other (please specify) | | 2 |

# SURVEY RESPONSES

**25. In regard to making the case for new posts within your service, how do you find this? (Please tick ONE box)**

| | Response Percent | Response Count |
|---|---|---|
| Extremely difficult | 17.2% | 5 |
| **Difficult** | **41.4%** | 12 |
| Neither difficult nor easy | 6.9% | 2 |
| Easy | 3.4% | 1 |
| Very easy | 0.0% | 0 |
| Other | 6.9% | 2 |
| I don't know | 24.1% | 7 |
| Other (please specify) | | 2 |

**26. Is your budget provision adequate to support the delivery of ARMA standards of care for: (Please place a tick in each row)**

| | Yes | No | Don't Know | Response Count |
|---|---|---|---|---|
| Multi-Disciplinary Working | 31.0% (9) | **34.5% (10)** | **34.5% (10)** | 29 |
| Podiatry | 27.6% (8) | 34.5% (10) | **37.9% (11)** | 29 |
| AHPs | 24.1% (7) | **37.9% (11)** | **37.9% (11)** | 29 |
| Anti TNF Medication | **55.2% (16)** | 13.8% (4) | 31.0% (9) | 29 |
| Access to Preventative Testing | 10.3% (3) | 20.7% (6) | **69.0% (20)** | 29 |

**27. For those that you have identified as not having adequate budgetary provision (Question 12) please explain why**

| | Response Count |
|---|---|
| | 9 |

**28. Has RA been included in the long term conditions priority list by your Health Board?**

| | Response Percent | Response Count |
|---|---|---|
| **Yes** | **55.2%** | 16 |
| No | 6.9% | 2 |
| I Don't know | 37.9% | 11 |

# SURVEY RESPONSES

**29. Are there planned changes in service provision as a result of RA being a long term conditions priority?**

| | Response Percent | Response Count |
|---|---|---|
| Yes | 34.5% | 10 |
| No | 10.3% | 3 |
| **I don't know** | **55.2%** | 16 |
| If 'yes' please specify what changes are planned | | 11 |

**30. Please provide any additional comments you would like to make in regard to the provision of services for patients**

| | Response Count |
|---|---|
| | 7 |

## AUDITING OF SERVICES

**31. What standards of care does your Health Board work to? (Please tick ALL relevant boxes)**

| | Response Percent | Response Count |
|---|---|---|
| BSR (British Society for Rheumatology) | 44.4% | 12 |
| ARMA Standards of Care | 29.6% | 8 |
| EULAR Guidelines (European League Against Rheumatism) | 11.1% | 3 |
| Other | 11.1% | 3 |
| **I don't know** | **48.1%** | 13 |
| Other (please specify) | | 5 |

**32. Are there audit / quality control measures in place to ensure these standards are met?**

| | Response Percent | Response Count |
|---|---|---|
| Yes | 14.8% | 4 |
| No | 29.6% | 8 |
| **I don't know** | **55.6%** | 15 |
| If 'yes' please explain what measures are in place | | 5 |

# SURVEY RESPONSES

**33. How would you rate your Health Board's ongoing monitoring of services to ensure that patients receive the optimal level of care? (Please tick ONE box)**

| | Response Percent | Response Count |
|---|---|---|
| Excellent | 3.7% | 1 |
| Above average | 7.4% | 2 |
| Average | 18.5% | 5 |
| Below average / poor | 11.1% | 3 |
| No ongoing monitoring exists | 18.5% | 5 |
| Other | 3.7% | 1 |
| **I don't know** | **37.0%** | 10 |
| Other (please specify) | | 3 |

**34. How would you rate your Health Board's attitude to new evidence and its ability to accept these conclusions within your working practices? (Please tick ONE box)**

| | Response Percent | Response Count |
|---|---|---|
| Prompt and proactive in using new information | 11.1% | 3 |
| **Average response to new information** | **44.4%** | 12 |
| Slow to accept new evidence and amend practices accordingly | 18.5% | 5 |
| Other | 3.7% | 1 |
| I don't know | 22.2% | 6 |
| Other (please specify) | | 2 |

# SURVEY RESPONSES

**35. Does the cost of treatment affect your clinical decision making? (Please tick ONE box)**

| | Response Percent | Response Count |
|---|---|---|
| Yes, always | 7.4% | 2 |
| **Yes, sometimes** | **48.1%** | 13 |
| Yes, rarely | 25.9% | 7 |
| No, never | 11.1% | 3 |
| Other | 0.0% | 0 |
| I don't know | 7.4% | 2 |
| Other (please specify) | | 1 |

**36. Which of the following are important considerations when choosing treatment options for patients? (Please tick ALL relevant boxes)**

| | Response Percent | Response Count |
|---|---|---|
| Cost of medicines | 51.9% | 14 |
| Latest advances | 74.1% | 20 |
| **Likely compliance and concordance** | **88.9%** | 24 |
| Patient choice | 85.2% | 23 |
| Other | 11.1% | 3 |
| I don't know | 0.0% | 0 |
| Other (please specify) | | 4 |

# SURVEY RESPONSES

**37. Please rank the following disease areas on the basis of how your NHS Board identifies the funding priority of these conditions o to 9, where 1 is the top priority and 9 bottom priority**

| | 1 Top Priority | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 Bottom Priority | Rating Averag |
|---|---|---|---|---|---|---|---|---|---|---|
| Cancer | **42.9% (9)** | 33.3% (7) | 19.0% (4) | 4.8% (1) | 0.0% (0) | 0.0% (0) | 0.0% (0) | 0.0% (0) | 0.0% (0) | 1.8 |
| Cardio Vasular Disease | 11.1% (2) | 22.2% (4) | **44.4% (8)** | 22.2% (4) | 0.0% (0) | 0.0% (0) | 0.0% (0) | 0.0% (0) | 0.0% (0) | 2.7 |
| Rheumatoid Arthritis | 0.0% (0) | 0.0% (0) | 4.5% (1) | 9.1% (2) | 18.2% (4) | 9.1% (2) | **36.4% (8)** | 22.7% (5) | 0.0% (0) | 6.3 |
| Mental Health | 18.8% (3) | 6.3% (1) | 25.0% (4) | 6.3% (1) | 6.3% (1) | **31.3% (5)** | 0.0% (0) | 0.0% (0) | 6.3% (1) | 4.0 |
| Alcohol / Drug Misuse related conditions | 0.0% (0) | 0.0% (0) | 11.1% (2) | 16.7% (3) | 16.7% (3) | **22.2% (4)** | **22.2% (4)** | 5.6% (1) | 5.6% (1) | 5.6 |
| Degenerative Neurological Disease | 0.0% (0) | 0.0% (0) | 0.0% (0) | 5.6% (1) | 5.6% (1) | 11.1% (2) | 5.6% (1) | 11.1% (2) | **61.1% (11)** | 7.9 |
| Unscheduled Care | 29.4% (5) | **35.3% (6)** | 5.9% (1) | 5.9% (1) | 11.8% (2) | 5.9% (1) | 0.0% (0) | 5.9% (1) | 0.0% (0) | 2.8 |

**38. Please provide any additional comments you would like to make in regard to the auditing of services**

| | Response Count |
|---|---|
| | 2 |

**39. Please provide any additional comments you would like to make in regard to Rheumatoid Arthritis that have not been covered elsewhere in this survey**

| | Response Count |
|---|---|
| | 3 |

# FURTHER INFORMATION

FOR FURTHER DETAILS ON THE INFORMATION DISPLAYED IN THIS REPORT, PLEASE CONTACT **NIAMH HEGARTY** AT MORHAMBURN:

Niamh Hegarty
Senior Consultant
Level 2, 17 Waterloo Place,
Edinburgh, EH1 3BG

0131 556 0050

niamh@morhamburn.com