Introduction

In 2016, the British Society for Rheumatology (BSR) and the Scottish Society for Rheumatology (SSR) published Rheumatology in Scotland: The State of Play. This report presents a revised and updated picture of rheumatology services in Scotland, combining the results of our original survey with updated statistical analysis and recommendations. Through this, we seek to ensure Scotland’s health service is able to provide timely and effective treatment for patients with rheumatic and musculoskeletal disorders (RMDs), whilst supporting the rheumatology multidisciplinary team (MDT) delivering such care.

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In the autumn of 2015, we consulted BSR members based in Scotland and SSR members over a four week period via an online survey. We received responses from a broad spectrum of healthcare professionals, including consultants, trainees, generalist and specialist nurses, and allied health professionals (AHPs), 49 responses were received from BSR and SSR members. The opinions of the rheumatology workforce presented in our 2016 report stem from that survey, while numerous data sources, cited throughout, have been consulted to develop a complete picture of rheumatology in Scotland in 2018. In order to draw comparisons with results from our 2015 survey, we spoke to relevant stakeholders in Scottish rheumatology about developments in rheumatology services over the past three years. We received data from the Scottish Government and the Information Services Division (ISD) Scotland which is part of NHS National Services Scotland, in order to produce an updated report highlighting the key issues faced by healthcare professionals and patients and the services they work within or are treated by. This report, updated in autumn 2018, reflects changes within the NHS in Scotland, as well as to reference newer data and statistics where available.

Methodology

Please indicate your role:

- Consultant: 58%
- Trainee: 6%
- Nurse (specialist): 10%
- Nurse (general): 2%
- Allied Health Professional: 15%
- Other: 8%

What is the principal basis of your work?

- Adult rheumatology: 92%
- General internal medicine: 4%
- Primary care: 2%
- Academia: 2%
### Demographic detail

<table>
<thead>
<tr>
<th>Local Health Board</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ayrshire and Arran</td>
<td>6%</td>
</tr>
<tr>
<td>Borders</td>
<td>2%</td>
</tr>
<tr>
<td>Dumfries and Galloway</td>
<td>2%</td>
</tr>
<tr>
<td>Western Isles</td>
<td>0%</td>
</tr>
<tr>
<td>Fife</td>
<td>4%</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>2%</td>
</tr>
<tr>
<td>Grampian</td>
<td>6%</td>
</tr>
<tr>
<td>Greater Glasgow and Clyde</td>
<td>38%</td>
</tr>
<tr>
<td>Highland</td>
<td>6%</td>
</tr>
<tr>
<td>Lanarkshire</td>
<td>6%</td>
</tr>
<tr>
<td>Lothian</td>
<td>15%</td>
</tr>
<tr>
<td>Orkney</td>
<td>0%</td>
</tr>
<tr>
<td>Shetland</td>
<td>0%</td>
</tr>
<tr>
<td>Tayside</td>
<td>11%</td>
</tr>
</tbody>
</table>
# Rheumatology in Scotland

## Key Stats

In 2014/15, there were 85,889 new diagnoses of musculoskeletal system and connective tissue disorders which fell to 80,932 in 2016/17.¹

<table>
<thead>
<tr>
<th>Year</th>
<th>New Diagnoses</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014/15</td>
<td>85,889</td>
</tr>
<tr>
<td>2016/17</td>
<td>80,932</td>
</tr>
</tbody>
</table>

New patients attending rheumatology outpatient appointments largely stayed the same, with 26,934 in 2014/15 and 26,401 in 2016/17.²

<table>
<thead>
<tr>
<th>Year</th>
<th>New Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014/15</td>
<td>26,934</td>
</tr>
<tr>
<td>2016/17</td>
<td>26,401</td>
</tr>
</tbody>
</table>

Looking at specific diseases, rheumatoid arthritis (RA) is one of the major chronic diseases in Scotland. It was predicted in 2010 that the number of adults with RA in Scotland would rise from 37,539 in 2010 to 42,505 by 2020.³ However, that prediction has already been overtaken in 2018 with 44,000 individuals having a diagnosis of RA.⁴

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>37,539</td>
</tr>
<tr>
<td>2018</td>
<td>44,000</td>
</tr>
</tbody>
</table>

1 in 5 people in Scotland (approximately 800,000) live with chronic pain.⁵ ⁶

1 in 20 experience disabling chronic pain with the most common sites of chronic pain being the back and the joints.⁷

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¹ [Source](#)  
² [Source](#)  
³ [Source](#)  
⁴ [Source](#)  
⁵ [Source](#)  
⁶ [Source](#)  
⁷ [Source](#)
In 2012/3 there were over 600,000 consultations with a GP or practice employed nurse due to back pain in Scotland.¹

The number of people in Scotland having hip and knee joint replacements has grown from 7,000 to 15,000 in the last 10 years.²

In Scotland back and neck pain are in the top 10 most frequent conditions seen by GPs.⁵

48% of work-related illness in Scotland is of RMD origin.¹¹

The NHS spend on the annual musculoskeletal health budget in Scotland is £353 million (2011/2) out of a total of around £12 billion. ¹¹ This is the 10th largest NHS Annual Programme Budget in Scotland.⁴

600,000

Top 10

15,000

7,000

From 2008 to 2018

Economic impact of musculoskeletal conditions in Scotland:

£12 billion

£353 million

48%
As with all progressive conditions, early diagnosis is key to ensuring that people living with rheumatic and musculoskeletal conditions are able to access timely and appropriate care. For GPs, few of whom are specialists in RMDs, appropriately recognising symptoms and referring onward can understandably be a challenge, and has been cited as a factor in delayed diagnosis and treatment.

One respondent to our survey noted that, “I am concerned that the increase in referrals represents declining GP confidence among younger GPs in relation to the diagnosis and management of rheumatic diseases”. Many RMDs can have similar presenting symptoms. This can make the identification of those who need specialist care difficult, particularly given the limited exposure to rheumatology throughout medical degrees and subsequent training. One respondent noted that they, “would like to see rheumatology appear in more GP training programmes and/or as part of Foundation Year 1 or 2 posts”.

Similarly, 89% of respondents to our survey believed rheumatology training needed to be spread across other disciplines and specialties, in GPs for example. Training should utilise the secondary care workforce, as 70% of respondents indicated they were willing to be involved in the training of other practice areas (other specialties and general medicine), and research has found that GPs regard rheumatology consultants to be a valuable resource in meeting their learning needs.12

The Scottish Government said the following on GP training for RMD conditions.

“The General Practice Specialty Training (GPST) is based on the Royal College of Practitioners (RCP) curriculum which is approved by the GMC. Rheumatology awareness training is covered in the Curriculum Statement 3.20 Care of People with Musculoskeletal Problems. NES also supports Continuous Professional Development (CPD) activities for all GPs through a variety of means. Specific educational support of GPs to improve their awareness of rheumatology includes (a) Practice Based Small Group Learning (PBSGL) modules and (b) Taught courses on arthritis (along with Arthritis Care Scotland), joint injections and musculoskeletal medicine.”

Jeane Freeman MSP, Cabinet Secretary for Health and Sport, 28 August 2018.13

Our members continue to report challenges they face – understandably, many GPs do not have in-depth knowledge of the broad range of rheumatic conditions that they might come into contact with. Further, communication between GPs and specialists are an area where our members believe there could still be further improvements. GPs face severe time pressures, and often have limited exposure to RMD patients. This is not just a Scottish problem, as the England and Wales National Audit for Early Inflammatory Arthritis showed that only 20% of patients were referred by their GP within 3 days of first presentation.14

The role of primary care is pivotal in the management of people living with RMDs. For many conditions most or all management should be within the primary care setting. For more complex and inflammatory conditions shared care between primary and secondary care reduces the burden of hospital visits for the patient and helps to optimise the use of secondary care resources.
In 2017, the BSR and RCGP launched a joint Quality Improvement project to improve care for people living with inflammatory arthritis. It is an online resource designed to help improve pathways between primary and secondary care, with a focus on reducing delays to diagnosis and creating standardised shared care agreements. In February 2011, SIGN (The Scottish Intercollegiate Guidelines Network) provided a guideline on the treatment of early RA specifically targeted at GPs. This was due for revision in 2014, but to date, has not been carried out.

NHS Education for Scotland, working with relevant professional bodies and Specialty Training Committees, should ensure a greater RMD emphasis in undergraduate, junior doctor and GP training programmes, in order to support primary care management of MSK problems which do not need secondary care referral.

SIGN and Healthcare Improvement Scotland should look to gather new evidence to revise the ‘Management of early rheumatoid arthritis’ guideline, which was due for revision in 2014.

NHS Education for Scotland should work with BSR and the RCGP to promote the Inflammatory Arthritis Toolkit amongst GPs in Scotland.

Next Steps - Primary Care

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**Do you believe that rheumatology training needs to be spread more widely to other health and care professionals?**

- **89% Yes**
- **11% No**

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In 2017, the BSR and RCGP launched a joint Quality Improvement project to improve care for people living with inflammatory arthritis. It is an online resource designed to help improve pathways between primary and secondary care, with a focus on reducing delays to diagnosis and creating standardised shared care agreements. In February 2011, SIGN (The Scottish Intercollegiate Guidelines Network) provided a guideline on the treatment of early RA specifically targeted at GPs. This was due for revision in 2014, but to date, has not been carried out.

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- **89% Yes**
- **11% No**

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Many rheumatology services are provided in secondary care to ensure close proximity to appropriate diagnostic and monitoring services. This allows patients to attend their outpatient appointment and have subsequent tests without the need for additional appointments. Additionally, many RMDs can impact on the whole body and so access to specialist services such as renal, dermatology or respiratory medicine, which are only available in secondary care, are imperative. Accessing these services can however be challenging in more remote parts of the country, as highlighted in the case study below.

In our survey, BSR and SSR members highlighted the severe pressure that rheumatology services were experiencing in Scotland, with one respondent commenting, “our clinics are running at greater than 100% capacity”. Such assertions are supported by statistics that demonstrate increased total attendances to rheumatology outpatient appointments – in some cases, improvements in care (for example, increased therapeutic options and reduced premature mortality in some conditions) actually contribute to these increases. In 2016/17, there were 114,588 attendances of rheumatology outpatient appointments, markedly higher than a decade earlier in 2005/06, when only 84,766 rheumatology outpatient appointments were attended.¹

The Scottish Government has set a target that all AHP MSK service waiting times from referral to first clinical out-patient appointment will be 4 weeks for 90% of patients. This target took effect from the 1 April 2016, yet the percentage of patients seen within 4 weeks has remained around 50% over the last few years, leaving many patients waiting for appointments.¹

Waiting times are an issue across appointment types whether AHP or consultant led. Indeed, data from NHS Grampian in June 2018 has shown, that 75% of patients were waiting 13 weeks for a routine new outpatient rheumatology appointment and 9 weeks for an urgent appointment.

Such statistics do not include the potential delays in primary care, or in patients presenting to primary care and so do not represent the total length of time the

<table>
<thead>
<tr>
<th>Year</th>
<th>Median Wait (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>41</td>
</tr>
<tr>
<td>2011</td>
<td>51</td>
</tr>
<tr>
<td>2012</td>
<td>59</td>
</tr>
<tr>
<td>2013</td>
<td>62</td>
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<tr>
<td>2014</td>
<td>61</td>
</tr>
<tr>
<td>2015</td>
<td>56</td>
</tr>
<tr>
<td>2016</td>
<td>69</td>
</tr>
<tr>
<td>2017</td>
<td>79</td>
</tr>
<tr>
<td>2018 (until June)</td>
<td>79</td>
</tr>
</tbody>
</table>
Next Steps - Secondary Care

The Scottish Government should allow Local Health Boards to regionally determine local prioritisation and incentives to reflect the needs of the population and service. Local Health Boards should support national collaboration on quality improvement and outcome measurement, which should inform incentives.

Local Health Boards and departments should explore strategies for dealing with workload, such as the use of AHPs to see return patients and telephone consultations where the patient is stable.

(patient has waited. Delays are a concern as prompt access to appropriate services for people living with some RMDs is essential. For example, with RA there is a 12 week window of opportunity after the onset of symptoms, during which a referral to a rheumatologist can reduce current symptoms. Lack of action increases the risk of long term joint damage which can result in disability and work limitations. This recommendation is echoed by the National Institute for Health and Care Excellence (NICE) and SIGN. Rare RMDs, such as vasculitis or lupus, also have increased mortality rates in comparison to the general population and so prompt treatment is imperative.

Initiatives and services introduced at a national and local level to improve waiting times have at times resulted in the prioritisation of particular conditions and patients. For example, the Scottish Public Health Network report on rheumatoid arthritis has resulted in the creation of further early arthritis clinics. Our respondents noted, however, that this can negatively impact upon other patients, with one doctor stating that “seronegative arthropathies [are] not being seen as quickly as those with conventional rheumatoid arthritis”.

Initiatives have also, in some cases, been created for new patient referrals at the expense of existing patients. Funding, for example, “has been put into waiting list initiatives for new patient referrals, but this generates unfunded additional follow up work which is now also impacting on our ability to provide timely review for those patients who need it”.

Since the publication of the original “State of Play” document in 2016, there has been some expansion in consultant rheumatologist posts, but demand continues to exceed supply. As 2020 approaches, plans are still underway to introduce a seven day NHS, and yet still very little is known about how rheumatology departments will cope with these demands. A majority of respondents to our survey, 77%, said they did not provide rheumatology services across seven days, which is 10% more than shown in our UK-wide State of Play report. The seven day NHS policy may not be compatible with existing rheumatology services. With current resources it seems unlikely that seven day services for rheumatology can be provided.

The Scottish Government should allow Local Health Boards to regionally determine local prioritisation and incentives to reflect the needs of the population and service. Local Health Boards should support national collaboration on quality improvement and outcome measurement, which should inform incentives.

Local Health Boards and departments should explore strategies for dealing with workload, such as the use of AHPs to see return patients and telephone consultations where the patient is stable.

Case Study: Rural Services

Scotland’s rural geography impedes accessibility to services. Rural Scotland accounts for 98% of the land mass and approximately 20% of its population. There are many significant challenges of delivering health and social care in rural areas, including higher numbers of older people, longer distances to travel for health appointments and lack of available public transport.

88% of respondents believed rural or island based patients had difficulty accessing services, travelling excessive distances for clinics and diagnostic services. This problem is exacerbated as RMD conditions can often have a negative impact on patients’ mobility. Respondents informed us that the consequences of lengthy travel time can determine treatment, “Day unit services e.g. for infusional medicines, are only available on one site, which is not easily accessible for patients from East, West and Mid-Lothian”.
One in seventeen people in Scotland will be affected by a rare disease in their lifetime. Whilst rare diseases are individually rare, collectively they put a significant burden on the population and NHS, and can be life threatening to patients.

Rare RMDs can be categorised into two distinct groups, rare autoimmune rheumatic diseases which comprise systemic vasculitis, scleroderma, myositis and Sjögren’s syndrome, and rare non-autoimmune rheumatic diseases which includes osteogenesis imperfecta and fibrous dysplasia.

Following a European Union Council Recommendation on rare diseases, the four countries of the UK jointly produced a strategy for the UK in 2012. The Scottish Government published their implementation plan in 2014, which sets out how Scotland will deliver the 51 commitments in the period to 2020.

A progress report, published in February 2018, on the work carried out in Scotland against those commitments in the UK Strategy for Rare Diseases, outlined that access to specialist services are limited for rare autoimmune patients, with 75% of vasculitis patients (over 2200) in Scotland having no access to specialist services. A national managed clinical network or other officially endorsed network could facilitate access to specialist support and improve outcomes for all people who live with these conditions in Scotland.

More than two-thirds (69%) of our respondents believed the needs of patients with rare rheumatic conditions in their care were not being met. Respondents highlighted the inaccessibility of specialised services within Scotland and their inability to set up clinics, noting the need for regional or national services for connective tissue diseases.
Collaboration between health and social care

Are care pathways for your patients better co-ordinated now than since 2011?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>Occasionally</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>57%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>43%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table Two

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>Occasionally</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute?</td>
<td>39%</td>
<td>55%</td>
<td>7%</td>
</tr>
<tr>
<td>Community healthcare?</td>
<td>26%</td>
<td>45%</td>
<td>29%</td>
</tr>
<tr>
<td>Primary care?</td>
<td>59%</td>
<td>36%</td>
<td>5%</td>
</tr>
<tr>
<td>Social care?</td>
<td>9%</td>
<td>43%</td>
<td>48%</td>
</tr>
</tbody>
</table>

There has been a lack of collaboration across the care pathway, as shown in Table 2. There have also been, however, attempts to improve this, although 57% of respondents in 2015 stated that their pathways had not improved since 2011. Barriers to collaboration cited by the BSR and SSR members included little interest from management, insufficient staffing, incompatible IT systems, little understanding of other sectors and poor communication. There was also a distinction between collaboration within or outside the health service, with a respondent commenting “we work very closely with our acute and primary care services but have no collaborative working with social care. The routes to community health care are complex and not well signposted to secondary care providers”.

However, in a Health and Care Experience Survey for Scotland carried out in 2017/2018, 74% of patients stated that their services ‘seemed’ to be well coordinated, which may indicate improvements in care coordination since our 2015 survey.22
There has previously been a failure to recognise the need for secondary care services, and specifically those within rheumatology, to develop collaborative working arrangements with social care. A Stronger Scotland stated that the Scottish Government would “ensure that local community based services to patients are delivered by the appropriate range of health and social care professionals working together more effectively”[23]. The omission of secondary care overlooks the importance of its involvement in collaboration between health and social care services. Developing pathways specifically for rheumatology has also been overlooked, this is reflected by the exclusion of rheumatology in the Allied Health Professional Musculoskeletal Pathway Framework (National Minimum Standard) report.[24]

Respondents noted that good collaboration had occurred with local services as a result of local agreements and local initiatives, such as occupational therapists working with their counterparts in social care. An example of best practice is SPARN’s work collaborating with interested adult rheumatologists to develop a standard transition programme from paediatric into adult care.
Rheumatology services operate as a multidisciplinary team (MDT), which includes consultant rheumatologists, trainees, specialist nurses, physiotherapists, occupational therapists, podiatrists and pharmacists.

Consultants

Our survey in 2015 noted the limited number of physicians working in rheumatology departments in Scotland. One respondent noted “I now have no juniors or middle-grades attending my clinic so have a single consultant and an associate specialist serving a catchment area of 220,000 patients”.

Statistics from 2012 found there was one consultant rheumatologist per 128,000, despite the RCP’s recommendation of one rheumatologist per 86,000. Since our original report was published, the number of consultants per population has changed to one consultant per 95,000 as there are 62 consultants, 32% of the consultants are employed academically and 62% employed by the NHS. 47% of consultants reported that they have an additional specialty. This is a significant improvement from the 2012 data, however it still falls short of the RCP recommendations. Additionally, these figures do not take into account difficulties with provision of service in rural areas. Whilst numbers of consultants have improved, the vacancy rates of consultants is alarmingly high at 12% with 8 vacancies, 3 of which have been vacant for 6+ months. It has been reported that some advertised posts in the last 12 months have received no applicants. Only 2 vacancies have been filled by trainees in the last 12 months, others have been filled by rheumatologists within Scotland moving jobs. In 2013, the vacancy rate was 4% with 2 vacancies. Furthermore, there is a shortfall of trainees completing specialist training and ready to take up a consultant post, which could be addressed with an increase in training numbers.
The rest of the MDT

Rheumatology nurses, physiotherapists, occupational therapists and podiatrists can assist in self-management and provide patient education, helpline services, outpatient clinics, vocational rehabilitation, fatigue management groups and joint protection programmes. Specialist nurses can also undertake the function of a care coordinator. There are cost benefits of employing these roles, with a study undertaken by the Royal College of Nursing highlighting work worth £72,128 is delivered per annum per nurse but delivers savings of £175,168. In light of this, it is concerning that nurse and AHP roles continue to be understaffed and initiatives are required to address this.

Next Steps - Workforce and Training

The Scottish Government should look to replicate the Associate Rheumatology Nurse Specialist Training Programme across other health boards in Scotland, which will help Local Health Boards address shortfalls in the numbers of CNS in certain areas and allow for succession planning.

The Rheumatology Specialty Training committee and NHS Education Scotland should ensure that junior doctors and medical students continue to receive exposure to rheumatology throughout their training and development.

An additional training post in the specialty should be added each year to address the need for more rheumatology consultants.

Table Three

<table>
<thead>
<tr>
<th>In your opinion is training being given adequate consideration in:</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your service?</td>
<td>48%</td>
<td>52%</td>
</tr>
<tr>
<td>The organisation in which you work?</td>
<td>46%</td>
<td>55%</td>
</tr>
<tr>
<td>The wider design of services?</td>
<td>27%</td>
<td>73%</td>
</tr>
</tbody>
</table>

CASE STUDY: Winner of BSR’s 2017 Best Practice Award

Stobhill Hospital, Glasgow: Associate Rheumatology Nurse Specialist Training Programme

The Associate Rheumatology Nurse Specialist Training Programme, developed and employed in NHS Greater Glasgow and Clyde (NHSGGC) with academic links to Glasgow Caledonian University, is a one-year training programme for nurses with an interest in moving into a permanent rheumatology clinical nurse specialist (CNS) post. Rheumatology CNSs are highly skilled members of the multidisciplinary team, providing support with tasks that reduce burden on doctors and ultimately improve patient care. In total, three nurses have completed the training post and are now in substantive rheumatology CNS posts, and a fourth nurse started the training programme in early 2018. When trained, the rheumatology CNS can help with the return patient workload and importantly see patients quickly when they are having a disease flare. They are a consistent resource once trained, building up valuable experience which supports the MDT at a time when the availability of junior doctors in clinics is decreasing.

As well as improving the quality of patient care, recently appointed CNS have realised cost savings by facilitating the switching of biologics therapies with a cost saving of £112,590 over a 9 month period when 90 patients were switched from etanercept to benepali.
Person-Centred Care

The Patient Rights (Scotland) Act 2011 requires a patient’s healthcare professional to consider their needs, encouraging and supporting them to participate in their care. Respondents found that rheumatology services in Scotland were meeting this requirement, providing services such as self-management, smoking cessation, back to work support and exercise classes. However, there was an assumption by respondents that patient centred care occurs outside of the hospital and is undertaken by certain members of the MDT. As one respondent noted “all newly diagnosed patients with inflammatory arthritis see OT, physio and specialist nurse as a matter of routine. They are the main drivers in making sure that these issues are addressed.”

Throughout Scotland, there has been a move to practise ‘realistic medicine’ – health and social care that is sensible, practical and right for the person and their family receiving the care. This movement was launched by Dr Catherine Calderwood, Chief Medical Officer of Scotland with the publication of her annual report Realistic Medicine in January 2016. In the wake of this, the rheumatology department at NHS Grampian has been working collaboratively with psychologists and physiotherapists to develop care pathways that are more individualised to patients.

Next Steps - Person Centred Care

NHS Scotland, Local Health Boards and services should ensure policies and programmes promote patient centred care that is applicable to a secondary care setting and for the whole MDT.

Psychological support should be available at all Local Health Boards as part of the wider MDT to ensure that patients receive the appropriate mental as well as physical support.

Table Four

<table>
<thead>
<tr>
<th>Do you, or your service:</th>
<th>Yes</th>
<th>Occasionally</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adopt a shared decision making approach with patients?</td>
<td>75%</td>
<td>25%</td>
<td>0%</td>
</tr>
<tr>
<td>Encourage patients to self-care?</td>
<td>79%</td>
<td>21%</td>
<td>0%</td>
</tr>
<tr>
<td>Advise and support patients to help them remain or return to work?</td>
<td>90%</td>
<td>8%</td>
<td>2%</td>
</tr>
<tr>
<td>Advise your patients on weight reduction, or physical activity?</td>
<td>77%</td>
<td>19%</td>
<td>4%</td>
</tr>
</tbody>
</table>

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Work

In Scotland, work-related musculoskeletal disorders accounted for 34% of all days lost due to work related ill-health in 2016/17.\(^{28}\) Within two years of onset, one third of people with RA will have stopped working.\(^{29}\) Our survey found that rheumatology healthcare professionals were engaging in their patients employment status, however this is largely as a consequence of the inclusion of the occupational therapist in the MDT. A respondent noted “OTs have been developing their services to focus on work disability and encouraging and supporting return to work”, which has been supported in some areas by members of the voluntary sector, such as Arthritis Care’s vocational rehab programme. Consultants and all members of the rheumatology MDT have a role to play in ensuring that a patient’s work is not detrimental to their health. They also have a role in enabling patients to participate in work by maximising their function.

Quality and Standards

The assurance of quality and standards within rheumatology services was a key concern among respondents. Auditing is a key method of monitoring and ensuring standards, yet 56 of Scottish Inflammatory Diseases and Rheumatology Industry Group’s (SIDRIG) respondents did not know what audit measures were in place, with 30% believing there were none.\(^{30}\) Since 2009, the SSR has developed web based audit to monitor the standards of care. The audit consists of 6 modules on podiatry, RA, vaccination practice in immunosuppressed patients, giant cell arteritis and work related RA. In addition, networks such as the Podiatry Development Group Rheumatology, SPARN and Regional Rheumatology Managed Clinical Network NHS Greater Glasgow and Clyde have been created to promote quality across all forms of rheumatology services.
Diagnostics and Drugs

Next Steps - Diagnostics and Drugs

NHS Education for Scotland and/or Local Health Boards should audit services to assess the skills mix of their staff to ensure the appropriate numbers of staff are able to prescribe and provide injections. Patients on biologic drugs should remain under the care and supervision of their consultant and the multidisciplinary team.

Do your patients have access to the range of drug treatments that they require?

- Yes: 96%
- No: 4%

Of the top ten medicines by expenditure used in the hospital setting in Scotland in the year to March 2017, eight were biological medicines – some of which have lost patent protection within the last three years, with others approaching expiry. The availability of biosimilar medicines has enhanced competition within the marketplace – £46m of current biological medicine spend is expected to face biosimilar competition for the first time within the next 3 years.

There has been wide variation in the speed of uptake of available biosimilars in different health boards. Speed of uptake was highest in boards who provided some investment to support the change of product. NHS Scotland encourages the use of biosimilar medicines and recommends that they should be considered as a treatment option for patients for whom a biological medicine is being considered as part of their treatment pathway.

The vast majority (96%) of respondents to our survey stated they had access to a range of drug treatments, compared to the 89% from our UK wide State of Play survey. BSR and SSR members noted that patients’ ability to access these drugs was limited by staffing numbers or waiting times for follow up visits – Rituximab, for example, was cited as problematic due to lack of nurse support to deliver the therapy resulting in waiting lists. Health Boards should recognise that to realise savings from the use of biosimilars investment is required. Access to diagnostic tests such as ultrasound and MRI can help to facilitate dose reduction in patients who have achieved remission.
A majority of BSR and SSR members felt research was being given inadequate consideration in services and organisations, and recommended more should be done to recognise and value the importance of research as a marker of a quality service. Respondents believed there were significant threats to clinical research in Scotland due to lack of prioritisation, and that proposed disclosure requirements could act as a deterrent.

### Table Five

<table>
<thead>
<tr>
<th>In your opinion is research being given adequate consideration in:</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your service?</td>
<td>46%</td>
<td>54%</td>
</tr>
<tr>
<td>The organisation in which you work?</td>
<td>45%</td>
<td>55%</td>
</tr>
<tr>
<td>The wider design of services?</td>
<td>31%</td>
<td>69%</td>
</tr>
</tbody>
</table>

A majority of BSR and SSR members felt research was being given inadequate consideration in services and organisations, and recommended more should be done to recognise and value the importance of research as a marker of a quality service. Respondents believed there were significant threats to clinical research in Scotland due to lack of prioritisation, and that proposed disclosure requirements could act as a deterrent.

### CASE STUDY: Scottish RMD research

Despite reservations over the level of investment in research, Scotland continues to participate in and deliver world-class medical research within rheumatology. The Scottish Early Rheumatoid Arthritis Cohort was a pan-Scottish collaboration among most Scottish NHS consultants and biomedical Universities. The resulting biobank and clinical cohort has more than 1100 patients, whose care is followed up by virtue of the electronic Scottish NHS records system. Productivity is constantly increasing in terms of the use of this cohort, both for primary research outputs, and also through bringing together wider cohorts across the UK. The University of Glasgow leads the UK-wide IMID-Bio-UK Consortium, funded by the Medical Research Council, to bring together a meta-consortium of immune diseases including rheumatoid arthritis, psoriatic arthritis, lupus and Sjögrens. Recently the same Scottish consultant body has aligned to deliver the SOPHOS cohort with ongoing recruitment of patients with new onset psoriatic arthritis together with assembly of a complementary biobank.
Data

Three-quarters (75%) of respondents said their service did not, or only occasionally ensured that accurate and detailed data was collected about patient activity, diagnosis or outcomes. As in the rest of the UK, coding systems such as SNOMED and ICD-10 are not fit for purpose for rheumatology, as a BSR analysis of SNOMED found that only 75% of rheumatic conditions are covered by existing codes and of those coded only 3% are actually collected. Services are not required to record data on the number of returning outpatient appointments, despite these appointments consisting of the majority of clinic time.

Additionally, respondents noted that services do not have the infrastructure, hardware or software to support the input of data, with staffing shortages also preventing data input. The interoperability of different systems of data collection should occur as a result of the inclusion of data sharing in the arrangements between Health Boards and Local Authorities when integrating their services. The Person-Centred e-Health Strategy requirement for NHS Boards to progress the development of patient portals to give access to services in secondary care is a positive step towards engaging patients in their treatment.

As outlined above, the SSR have successfully implemented their web based audit into rheumatology services. In terms of rare diseases it is hoped that NHS Scotland participates in the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS). As noted by one respondent, “standards of care and access needs to be benchmarked across Scotland to ensure raising of standards to be the best possible”.

Next Steps - Data

National Services Scotland (NSS) Public Health and Intelligence (PHI) when developing ICD11 should collaborate with all of the specialties and their relevant bodies to ensure coding is fit for purpose.

Local Health Boards should ensure all their services are provided with sufficient resources to collect data, especially in the context of the upcoming Electronic Health Data Work’s pan-Scotland service for routinely collected electronic health data.

Rheumatology units should collaborate on a national basis when developing disease registers to ensure opportunities to facilitate national data collection are maximised.
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