Rheumatology in Scotland
The State of Play
# Rheumatology in Scotland
## The State of Play

## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>3</td>
</tr>
<tr>
<td>Executive Summary</td>
<td>4</td>
</tr>
<tr>
<td>Key Findings from the BSR and SSR members survey</td>
<td>5</td>
</tr>
<tr>
<td>Recommendations</td>
<td>8</td>
</tr>
<tr>
<td>Methodology</td>
<td>9</td>
</tr>
<tr>
<td>Prevalence and Diagnosis</td>
<td>10</td>
</tr>
<tr>
<td>Delivering Care</td>
<td>11</td>
</tr>
<tr>
<td>Primary Care</td>
<td>13</td>
</tr>
<tr>
<td>Secondary Care</td>
<td>14</td>
</tr>
<tr>
<td>Case Study: Rural Services</td>
<td>15</td>
</tr>
<tr>
<td>Specialist Services</td>
<td>16</td>
</tr>
<tr>
<td>Collaboration between Health and Social Care</td>
<td>19</td>
</tr>
<tr>
<td>Workforce and Training</td>
<td>19</td>
</tr>
<tr>
<td>Person Centred Care</td>
<td>20</td>
</tr>
<tr>
<td>Work</td>
<td>20</td>
</tr>
<tr>
<td>Quality and Standards</td>
<td>21</td>
</tr>
<tr>
<td>Public Health</td>
<td>22</td>
</tr>
<tr>
<td>Diagnostics and Drugs</td>
<td>23</td>
</tr>
<tr>
<td>Research</td>
<td>24</td>
</tr>
<tr>
<td>Data</td>
<td>28</td>
</tr>
<tr>
<td>Technology and Innovation</td>
<td></td>
</tr>
<tr>
<td>Conclusion</td>
<td></td>
</tr>
<tr>
<td>Appendix</td>
<td></td>
</tr>
<tr>
<td>References</td>
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Introduction

The British Society for Rheumatology (BSR) and the Scottish Society for Rheumatology (SSR) have developed this report to generate a picture of rheumatology services in Scotland. In addition to highlighting best practice, the report aims to develop recommendations 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.

To complement this work, the BSR published in 2015 *The State of Play in Rheumatology: Insights into service pressures and solutions* which highlighted the condition of services throughout the UK. The BSR intends to publish separate reports on rheumatology services in Wales and Northern Ireland, which, in addition to this Scottish report, will provide an opportunity to explore similarities and differences across the UK.

Health and social care have been the responsibility of the Scottish Government since 1998, though ultimately the health budget is still dictated by Westminster. Recent legislation which has aimed to improve the health service includes the Scottish Government’s *2020 Vision, The Healthcare Quality Strategy for NHS Scotland* and the *Public Bodies (Joint Working) (Scotland) Act 2014*. Specifically related to the speciality and patients with RMDs, publications have included the *Impact of the Health Care Needs Assessment of Services for Adults with Rheumatoid Arthritis* reports conducted by the Scottish Public Health Network (Scot PHN). This report will explore the success of such work, its impact on rheumatology services specifically, and outline recommendations to ensure the needs of Scotland’s population are met.
Executive Summary

Key Findings from the BSR and SSR members survey

92% said that their services were not sufficiently staffed. Understaffed roles included specialist nurses, rheumatology trainees and allied health professionals.

26% of respondents believed their service ensured that accurate and detailed data were collected about patient activity, diagnoses and outcomes.

88% said Scotland’s rural geography impacted on patients’ accessibility to rheumatology services.

62% said their provider was not embracing the use of technology to improve access to services.

57% said care pathways for patients were not better co-ordinated since 2011, with 26% acknowledging that rheumatology services worked with community healthcare, and 9.1% with social services.

31% believed that patients with rare rheumatic conditions were being adequately treated by services in their area.

A majority of respondents believed research was not being given adequate consideration in their service and organisation. 27% felt research was given wider consideration in the wider design of services.

89% believed that rheumatology training needed to be spread more widely to other health and care professionals.
### Executive Summary

**Recommendations**

<table>
<thead>
<tr>
<th><strong>Primary Care</strong></th>
<th><strong>Secondary Care</strong></th>
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<tbody>
<tr>
<td><strong>NHS Education for Scotland</strong></td>
<td>The Scottish Government, working with relevant professional bodies and Specialty Training Committees, should ensure undergraduate, junior doctor and GP training programmes incorporate RMDs.</td>
</tr>
<tr>
<td><strong>Local Health Boards</strong></td>
<td>Local Health Boards should facilitate a review of local shared care agreements and actively support their continuation, utilising the Primary Care Fund.</td>
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<tr>
<th><strong>Specialised Services</strong></th>
<th><strong>Collaboration between Health and Social Care</strong></th>
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<tbody>
<tr>
<td><strong>The Scottish Government</strong></td>
<td>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 encourage national collaboration on quality improvement and outcome measurement, which should inform incentives.</td>
</tr>
<tr>
<td><strong>NHS National Services Scotland National Specialist and Screening Services Directorate</strong></td>
<td>NHS National Services Scotland National Specialist and Screening Services Directorate should formalise regional speciality services and their networks and if gaps are identified, commission services.</td>
</tr>
</tbody>
</table>

| **Healthcare Improvement Scotland** | Healthcare Improvement Scotland should support the development and dissemination of referral and treatment pathways, with Local Health Boards supporting their implementation. |
| **Local Health Boards** | The local Integration Joint Board or the Local Health Board and the Local Authority should set out requirements for how secondary care services should engage with other health and social services. This should be regularly audited and developed in partnership with professional bodies. |
| **Local Integration Joint Board** | **Local Health Board** | **Local Authority** |
### Executive Summary

#### Recommendations (continued)

<table>
<thead>
<tr>
<th>Workforce and Training</th>
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<tbody>
<tr>
<td>Rheumatology Specialty Training Committee</td>
<td>The Rheumatology Specialty Training committee and NHS Education Scotland should protect the exposure to rheumatology for junior doctors and medical students.</td>
</tr>
<tr>
<td>NHS Education Scotland</td>
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| Rheumatology Specialty Training Committee | As recommended by Scottish Public Health Network (ScotPHN), there should be a review of medical staffing levels addressing the apparent consultant shortfall in targeted areas [2]. |
| NHS Education Scotland |  |

| The Scottish Government | The Scottish Government should ring fence a proportion of the £2.5m to be invested in specialist nursing and care from 2015/16 for specialised rheumatology nurses [3], which should be used to meet Scot PHN’s training recommendations [2]. The Scottish Government should make similar commitments for AHPs. |
|  |

| NHS Education for Scotland | NHS Education for Scotland should replicate the Podiatry Development Group Rheumatology across all healthcare professionals working within the specialty [4]. |
|  |

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<thead>
<tr>
<th>Person Centred Care</th>
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<tbody>
<tr>
<td>NHS Scotland</td>
<td>NHS Scotland, Local Health Boards and services should ensure policies and programmes promote patient centred care are applicable for a secondary care setting and for the whole MDT.</td>
</tr>
<tr>
<td>Local Health Boards</td>
<td></td>
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<tr>
<td>Rheumatology Services</td>
<td></td>
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</tbody>
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<thead>
<tr>
<th>Work</th>
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<tbody>
<tr>
<td>Local Health Boards</td>
<td>Local Health Boards should enact Scot PHN’s recommendation that all patients should be asked the work question by all healthcare professionals [2].</td>
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<thead>
<tr>
<th>Quality and Standards</th>
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<tr>
<td>Scottish Intercollegiate Guidelines Network</td>
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**Executive Summary**

**Recommendations (continued)**

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<tr>
<th>Public Health</th>
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<tr>
<td><strong>Public Health Review</strong></td>
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<th>Diagnostics and Drugs</th>
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<tr>
<td><strong>NHS Education for Scotland</strong></td>
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<tr>
<th>Research</th>
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<tr>
<td><strong>Chief Scientist Office</strong></td>
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<th>Technology</th>
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<td><strong>The Scottish Government</strong></td>
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<th>Data</th>
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<tr>
<td><strong>National Services Scotland Public Health and Intelligence</strong></td>
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<tr>
<th>Local Health Boards</th>
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<tbody>
<tr>
<td>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.</td>
</tr>
</tbody>
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<tr>
<th>Rheumatology Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rheumatology units should collaborate on a national basis when developing disease registers to ensure opportunities to facilitate national data collection are maximised [2].</td>
</tr>
</tbody>
</table>
Methodology

We consulted BSR members based in Scotland and SSR members for a four week period in the autumn of 2015. The consultation process consisted of an online survey, the questions of which were based on those asked in the survey developed for the UK wide *The State of Play in Rheumatology* report and were further developed in consultation with the BSR Scotland Devolved Nation Chair and the SSR President (see appendix one). We received responses from a broad spectrum of healthcare professions, including consultants, trainees, generalist and specialist nurses, and allied health professionals (AHPs), all of whom are based across Scotland, working in a broad range of areas including secondary care, rheumatology and general internal medicine, primary care and academia. 49 responses were received, equating to a high percentage of BSR and SSR members.

**Please indicate your role:**

- Consultant: 58.3%
- Trainee: 6.3%
- Nurse (specialist): 10.4%
- Nurse (general): 2.1%
- Allied Health Professional: 14.6%
- Other: 8.3%

**What is the principal basis of your work?**

- Adult rheumatology: 91.7%
- General internal medicine: 4.2%
- Primary care: 2.1%
- Academia: 2.1%
Demographic detail

<table>
<thead>
<tr>
<th>Which Local Health Board(s) do you work in?</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ayrshire and Arran</td>
<td>6.4%</td>
</tr>
<tr>
<td>Borders</td>
<td>2.1%</td>
</tr>
<tr>
<td>Dumfries and Galloway</td>
<td>2.1%</td>
</tr>
<tr>
<td>Western Isles</td>
<td>0.0%</td>
</tr>
<tr>
<td>Fife</td>
<td>4.3%</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>2.1%</td>
</tr>
<tr>
<td>Grampian</td>
<td>6.4%</td>
</tr>
<tr>
<td>Greater Glasgow and Clyde</td>
<td>38.3%</td>
</tr>
<tr>
<td>Highland</td>
<td>6.4%</td>
</tr>
<tr>
<td>Lanarkshire</td>
<td>6.4%</td>
</tr>
<tr>
<td>Lothian</td>
<td>14.9%</td>
</tr>
<tr>
<td>Orkney</td>
<td>0.0%</td>
</tr>
<tr>
<td>Shetland</td>
<td>0.0%</td>
</tr>
<tr>
<td>Tayside</td>
<td>10.6%</td>
</tr>
</tbody>
</table>

Prevalence and Diagnosis

There are increasing rates of diagnosis of RMDs. In 2010/11 there were 85,964 diagnoses of musculoskeletal system and connective tissue disorders which increased to 94,377 in 2013/14, which is 6% of all episodes of diagnosis [6]. Similarly, new patients attending rheumatology outpatient appointments increased, from 23,218 in 2012/13 to 26,934 in 2014/15 [7]. Exact prevalence is hard to ascertain as it does not equate to statistics relating to diagnosis or outpatient appointments due to the delay between disease onset and seeking medical advice, and due to the diversity and number of RMDs, which total over 200. Looking at specific diseases, rheumatoid arthritis (RA) is one of the major chronic diseases in Scotland, with the number of adults with RA in Scotland expected to rise from 37,539 in 2010 to 42,505 in 2020 [8].
Delivering care

Primary care

The ability of GPs to appropriately refer has been cited as a key factor of delayed diagnosis and treatment. One respondent commented ‘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’. This is due to the heterogeneity of RMD symptoms and limited exposure to rheumatology throughout medical degrees and subsequent training. One respondent noted they ‘would like to see rheumatology appear in more GP training programmes and/or as part of FY1 or 2 posts’. Similarly, 89% of respondents to our survey believed rheumatology training needed to be spread across other professions. Such training should utilise the secondary care workforce, as 70% of respondents indicated they were willing to be involved in the training of other organisations, and research has found that GPs regard rheumatology consultants to be a valuable resource in meeting their learning needs [9].

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

- Yes 89.4%
- No 10.6%

Primary care could play an instrumental role in the shared care of RMD patients, monitoring the condition of the patient and their treatment without the patient having to attend outpatient appointments in a secondary care setting. This is specifically relevant for conventional DMARD therapy. This complements the Scottish Government’s policy for patients to be cared for in their community [10].

Funding for this should be redirected from the First Minister’s plans to create a new network of elective treatment centres [10] and federated structures of medical practice. This is part of the Scottish Government’s aim to provide opportunities for specialist services to be provided in primary care [11].

Recommendations for Primary Care

- NHS Education for Scotland, working with relevant professional bodies and Specialty Training Committees, should ensure undergraduate, junior doctor and GP training programmes incorporate RMDs.
- Local Health Boards should facilitate a review of local shared care agreements and actively support their continuation, utilising the Primary Care Fund.
Rheumatology services are provided in secondary care so 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. Secondly, RMDs can impact on the whole body and so access to specialist services such as renal, dermatology or thoracic are imperative. Additionally, there has been an increase in the number of rheumatology beds available in Scotland and their occupancy, with 24 beds and 89% occupancy in 2012/13 compared to 2013/14 with 37 beds and 94%, emphasises the acute nature of the speciality [12]. It is concerning the number of rheumatology beds have decreased to 31 by September 2015.

The SSR and BSR members highlighted the severe pressure rheumatology services are experiencing in Scotland, as one respondent commented ‘our clinics are running >100% capacity’. Such assertions are supported by statistics which demonstrate increased total attendances to rheumatology outpatient appointments. In 2005/06 there were 84,776, yet in 2014/15 this had increased to 118,581 [6]. Increased attendances seem to have not been met with resources, as NHS Scotland figures show the median waiting times for a new rheumatology outpatient appointment have increased since 2010 from 49 days to 56 in 2015. It must be acknowledged this is an improvement from the median time in 2013 of 62 median wait days [13]. Additionally, those waiting over 16 weeks have steadily increased from 9.69% of patients seen in 2013 to 15.31% in 2015, and for over 12 weeks 17.73% in 2013 and 20.29% in 2015 [13]. This is despite the Scottish Government’s commitment that no patient should wait longer than 12 weeks for a new outpatient appointment at a consultant-led clinic [14].

Such statistics do not include the potential delays in primary care, and so do not represent the total length of the patient has waited. Such delays are a concern as prompt access to services for patients with RMDs is essential, as for RA there is a 12 week window of opportunity after the onset of symptoms, during which a referral to a rheumatologist could reduce the adverse impact which result in disability and work limitations [15]. This recommendation is echoed in the National Institute for Health and Care Excellence’s (NICE) Quality Standard Rheumatoid arthritis in over 16s and the Scottish Intercollegiate Guidelines Network Management of early rheumatoid arthritis: A national clinical guideline. Rare RMDs, such as vasculitis or lupus, have also increased mortality rates in comparison to the general population and so prompt treatment is imperative.
Delivering care
Secondary Care (continued)

Table One: Waiting Times for a New Outpatient Appointment – Rheumatology

<table>
<thead>
<tr>
<th>Health board</th>
<th>Indicator</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
<th>2015 (until Sept)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS Scotland</td>
<td>Number seen</td>
<td>22000</td>
<td>22748</td>
<td>24372</td>
<td>24541</td>
<td>27087</td>
<td>18946</td>
</tr>
<tr>
<td></td>
<td>Median wait (days)</td>
<td>49</td>
<td>51</td>
<td>59</td>
<td>62</td>
<td>61</td>
<td>56</td>
</tr>
<tr>
<td></td>
<td>90th Percentile wait (days)</td>
<td>79</td>
<td>83</td>
<td>87</td>
<td>111</td>
<td>113</td>
<td>141</td>
</tr>
<tr>
<td></td>
<td>Of which: number who have waited over 12 weeks</td>
<td>446</td>
<td>961</td>
<td>2609</td>
<td>4350</td>
<td>5031</td>
<td>3844</td>
</tr>
<tr>
<td></td>
<td>Of which: number who waited over 16 weeks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2377</td>
</tr>
</tbody>
</table>

The Local Health Boards have sought short term solutions to this problem. For example NHS Lanarkshire appointed Medinet for three months to support their rheumatology out-of-hours clinics [16]. Prioritisation of particular conditions and patients has occurred as a result of initiatives and services introduced at a national and local level to improve waiting times. For example, the Scot PHN reports on RA has resulted in the creation of further early arthritis clinics [17]. However our respondents noted such behaviour has negatively impacted other patients, with one respondent stating the ‘MSK strategy specifically excludes inflammatory arthritis and this has skewed local services to favour non-inflammatory joint pain at the expense of services for inflammatory joint diseases’. Another respondent noted that ‘seronegative arthopathies [are] not being seen as quickly as those with conventional RA’. Initiatives have also 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’.

To improve access, the Scottish Government plans to introduce a seven day NHS [18]. Yet a majority of respondents, 77%, said they did not provide rheumatology services across seven days, which is 10% more than from our UK wide The State of Play in Rheumatology survey. The policy is inappropriate for rheumatology services, and, as articulated by the BMA, currently resources would not be available to deliver routine and elective services seven days a week [19].

Recommendation for 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 encourage national collaboration on quality improvement and outcome measurement, which should inform incentives.
Case Study: Rural Services

Scotland’s rural geography impedes accessibility to services. 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.’

Does Scotland’s rural geography impact on patients’ accessibility to services?:

- Yes: 88.1%
- No: 11.9%

Previous methods used to overcome Scotland’s rural geography have included the introduction of peripheral clinics. Yet respondents found such clinics do not provide access to diagnostics and testing, can lead to professional isolation and impact on the service. An additional concern is that such clinics do not necessarily provide the same specialist multidisciplinary approach, due to staffing shortages in rural settings, most notably among specialist AHPs [20]. In A Stronger Scotland: The Government’s Programme For Scotland 2015-16 [21] the Scottish Government, which aims to work with NHS Boards to develop networks between rural and urban hospitals, attempts to resolve the staffing issue via ensuring the maintenance and development of rural doctors’ skills and rotating health professionals between rural and urban settings. Yet the document does not explore the implications such policies may have on healthcare professionals, nor does it appear to tackle the issue that diagnostics and certain treatments are location specific or address the possibility of utilising technology and innovation.

The rural recommendations in A Stronger Scotland should be developed within a document which also provides an update on and an audit of the commitments of the Delivering for Remote and Rural Healthcare: The Final Report of the Remote and Rural Workstream [22]. The North of Scotland Planning Group (NoSPG) should explore developments in relation to each speciality. The utilisation of stakeholders including the Scottish Paediatric and Adolescent Rheumatology Network Remote (SPARN) and Rural Healthcare Educational Alliance is imperative to prevent professional isolation. In addition, Local Health Boards in rural areas should explore how to implement innovative technologies, outlined below, into rheumatology services.
Do you believe that the needs of patients with rare rheumatic conditions are being adequately met by the services in your organisation?:

<p>| | |</p>
<table>
<thead>
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<tbody>
<tr>
<td>Yes</td>
<td>31.1%</td>
</tr>
<tr>
<td>Occasionally</td>
<td>44.4%</td>
</tr>
<tr>
<td>No</td>
<td>24.4%</td>
</tr>
</tbody>
</table>

Though, by definition, the number of those with individual rare diseases is small, one in seventeen people in Scotland will be affected by a rare disease in their lifetime [23]. 69% of our respondents believed the needs of patients with rare rheumatic conditions in their care were occasionally or 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. Examples of best practice are the creation of formal and informal network that have developed in Scotland including the Scottish Lupus Exchange Group and the Scottish Paediatric and Adolescent Rheumatology Network (SPARN).

**Case Study: SPARN**

Prior to the creation of the SPARN in 2009, equality and accessibility of paediatric rheumatology services throughout Scotland was limited. There is now a SPARN clinic in each area of Scotland. The model of care is based around developing local expert multidisciplinary teams supported by clinics delivered by visiting tertiary centre paediatric rheumatologists. The network promotes education and training, such as enabling MDT training on joint injections, and paediatricians undertaking competencies to become a paediatrician with a special interest. The network has created an audit, and in terms of patient and carer involvement, SPARN have developed a parallel parent network, Scottish Network for Arthritis in Children).

The report from the UK Rare Disease Forum should provide an update on the progress in Scotland and highlight areas of collaboration across the four nations. We hope future areas of collaboration include Scottish involvement in Public Health England’s National Congenital Anomaly and Rare Disease Registration Service (NCARDS).

**Recommendations for Specialised Services**

- The Scottish Government should implement *It’s not rare to have a rare disease’s recommendation to seek input from health professionals, in the development of rare disease software systems and training of health professionals based on guidelines [1].*

- NHS National Services Scotland National Specialist and Screening Services Directorate should formalise regional speciality services and their networks and if gaps are identified, commission services.
Delivering care

Collaboration between Health and Social Care

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

- Yes 43.2%
- No 56.8%

Table Two

<table>
<thead>
<tr>
<th>Is your service working collaboratively with services in:</th>
<th>Yes</th>
<th>Occasionally</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute?</td>
<td>38.6%</td>
<td>54.5%</td>
<td>6.8%</td>
</tr>
<tr>
<td>Community healthcare?</td>
<td>26.2%</td>
<td>45.2%</td>
<td>28.6%</td>
</tr>
<tr>
<td>Primary care?</td>
<td>59.1%</td>
<td>36.4%</td>
<td>4.5%</td>
</tr>
<tr>
<td>Social care?</td>
<td>9.1%</td>
<td>43.2%</td>
<td>47.7%</td>
</tr>
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</table>

Table two demonstrates the lack of collaboration across the care pathway. Of additional concern is that there have been limited attempts to improve this, as 57% of respondents 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.’

Community Services

Patients in Scotland can have direct access to a physiotherapist without a referral [24]. Yet Chronic Pain Services in Scotland: Where are we now? highlighted the variability of chronic pain services in terms of access, type and scope of services across all levels of care [25].
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’[21]. This overlooks the importance of secondary care’s involvement in collaborative care between health and care services. Developing pathways specifically for rheumatology has also been overlooked, this is reflected by the exclusion of rheumatology in the Allied Health Professional (AHP) Musculoskeletal Pathway Framework (National Minimum Standard) report [26]. Transition between paediatric and adult services can also be a key problem, as explored by the Health and Sport Committee in 2014 [27]. Access to mental health services for patients with long term conditions is also limited, despite a research study finding one third of new rheumatology referrals had an emotional disorder [28].

Respondents noted where good collaboration had occurred with local services was 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. The Public Bodies (Joint Working) (Scotland) Act 2014 covers the integration of health and social care across the whole of Scotland, determined by each region’s Health Board and Local Authority, and will hopefully provide an incentive for services to collaborate [29].

Recommendations for Collaboration between Health and Social Care

• Healthcare Improvement Scotland should support the development and dissemination of referral and treatment pathways, with Local Health Boards supporting their implementation.

• The local Integration Joint Board or the Local Health Board and the Local Authority should set out requirements for how secondary care services should engage with other health and social services. This should be regularly audited and developed in partnership with professional bodies.

**Workforce and Training**

Please indicate which roles are most understaffed:

- Consultant: 16.7%
- Trainee: 20.2%
- GP: 2.6%
- Nurse (general): 6.1%
- Nurse (specialist): 29.8%
- Allied Health Professional: 20.2%
- Other: 4.4%
Ninety two per cent of our respondents considered their service to not be sufficiently staffed, in comparison to 62% of respondents to the UK wide *The State of Play in Rheumatology* survey. ScotPHN noted the presence of the core MDTs was limited and inconsistent [1]. Roles considered understaffed included specialist nurses (76%), AHPs (51%), trainees (51%) and consultants (42%). Recruitment gaps were cited as a key factor for rheumatology services worsening since the last election.

Our survey 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’. In the quarter June 2015 to September 2015, there was a 3.4% increase in the number of rheumatologists [30]. Statistics from 2012 found there was one consultant rheumatologist per 128,000, despite the RCP’s recommendation of one rheumatologist per 86,000 [17]. Respondents felt this was a consequence of junior doctors receiving little exposure to rheumatology during core medical training, leading to poor recruitment. The assumption of a medical workforce oversupply in Scotland has impacted all specialities and this is likely to be a continuing problem.

### 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>47.8%</td>
<td>52.2%</td>
</tr>
<tr>
<td>The organisation in which you work?</td>
<td>45.5%</td>
<td>54.5%</td>
</tr>
<tr>
<td>The wider design of services?</td>
<td>27.3%</td>
<td>72.7%</td>
</tr>
</tbody>
</table>

As table three demonstrates, the majority of the BSR and SSR members believed services and organisations were not providing adequate consideration to training. Due to the falling recruitment in general internal medicine (GIM), respondents felt potential rheumatology trainees have to undertake a broader GIM role. The consequences on training of a limited rheumatology MDT was articulated by one respondent – ‘we are currently running an essentially consultant and specialist nurse-led service with no time to provide training for the very few trainees we have’.

Figures released in June 2015 demonstrated that, despite NHS Scotland nursing figures increasing by 1.7%, there were increased vacancy rates [31]. In terms of AHPs, between September 2014 to September 2015 the number of occupational therapist stayed the same, physiotherapy 0.5%, and podiatry reduced by 1.2% [30]. The lack of these professionals was attributed by respondents to limited training and succession planning, and as AHP’s and nurses do not rotate through rheumatology during training therefore their exposure to the speciality is reduced [1]. Scot PHN similarly noted there are few training programmes for rheumatology specialist nurses and AHPs in Scotland [1].

### Case Study: BSR Travelling Fellowship

The BSR coordinates an annual Travelling Fellowship for UK trainees and newly appointed consultants to visit other rheumatology departments to study their resources and activities first hand. In 2015 the Travelling Fellowship took place in Scotland, at the Aberdeen Royal Infirmary, the Institute of Medical Sciences and the Institute of Applied Health Sciences at the University of Aberdeen.
In SIGN’s guidance on the Management of early rheumatoid arthritis [33], it states that ‘the multidisciplinary team has been shown to be effective in optimising management of patients with RA’. Rheumatology nurses, physiotherapists and podiatrists can assist in self-management and provide patient education, helpline services, outpatient clinics, vocational rehabilitation, fatigue management groups, joint protection programmes. Specialist nurses can also undertake the function of a care coordinator. There are cost benefits of employing these roles, outpatient work done by RCN is worth £72,128 per annum per nurse but delivers savings of £175,168 [34]. In light of this, it is concerning the nurse and AHP roles continue to be understaffed.

Case Study: Associate Rheumatology Nurse Specialist Training Post

NHS Greater Glasgow and Clyde developed an Associate Rheumatology Nurse Specialist Training Post. The 10 month training post rotated through three rheumatology units, with experiential training provided by the rheumatology consultations and experienced specialist nurses, and the academic element supported by Glasgow Caledonian University. At completion of the post, a Clinical Assessment and Management (Joint Injection) Honours Level Post Graduate Certificate was awarded. Consisting of case presentations, discussion and supervised practice, the course would result in the production of case studies, an essay and a learning log. The initiative is cost effective and [32], a second Associate CNS Rheumatology Training Post, for twelve months has now been developed.

Recommendations for Workforce and Training

- The Scottish Government should ring fence a proportion of the £2.5m to be invested in specialist nursing and care from 2015/16 for specialised rheumatology nurses [2], and should be utilised to meet Scot PHN’s training recommendations [1]. The Scottish Government should make similar commitments for AHPs.

- NHS Education for Scotland should replicate the Podiatry Development Group Rheumatology across all healthcare professionals working within the speciality [3].

- The rheumatology Specialty Training committee and NHS Education Scotland should protect exposure to rheumatology for junior doctors and medical students.

- As recommended by Scot PHN there should be a review of medical staffing levels addressing the apparent consultant shortfall in targeted areas [1].
The Patient Rights (Scotland) Act 2011 ensures patient centred care in practice, requiring a patient’s healthcare professional to consider their needs and encourages and supports them to participate in their care [35]. As highlighted in table four, feedback from respondents highlighted 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.’ This bias is demonstrated on an institutional level as the Act ensured the Key Information Summary (KIS) is used in only all GP practices in Scotland.

Recommendation for Person Centred Care

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

In Scotland, work related musculoskeletal disorders accounted for 41% of all days lost due to work related ill-health in 2014/15 [36]. Within two years of onset one third of people with RA will have stopped working [37]. Our survey found that rheumatology healthcare professionals were engaging in their patient’s 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’.

The BSR is piloting a course which encourages healthcare professionals to engage with patients regarding their employment which should assist in this recommendation being taken forward. It is hoped the SSR’s work and employment audit will also inform future work.

Recommendation for Work

- Local Health Boards should enact Scot PHN’s recommendation that all patients should be asked the work question by all healthcare professionals [1].
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 55.6% of Scottish Inflammatory Diseases and Rheumatology Industry Group’s (SIDRIG) respondents did not know what audit measures were in place, with 29.6% believing there were none [38]. Since 2009, the SSR has developed web based audit to monitor the standards patients receive. The audit consists of 6 modules on podiatry, RA, vaccination practice in immunosuppressed patients, giant cell arteritis and work related RA. 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.

Recommendation for Quality and Standards

• Healthcare Improvement Scotland and Scottish Intercollegiate Guidelines Network should promote existing networks, audits, guidelines and standards to ensure consistency nationally and across the UK. To support this Scottish Government should timetable a review of the Healthcare Quality Strategy for NHSScotland 2010.

Public Health

Our respondents noted the mixed impact of the Scot PHN report [17]. Many respondents commented that services have incorporated elements which support public health, including smoking cession and exercise. Sites such as NHS Inform are vital to inform the population about their health, but only reach those actively seeking information, therefore resources such as Leaflet Recognise, Respond, Relieve,- Rheumatoid Arthritis produced by the Scottish Government, Arthritis Care and NRAS are vital. [39]

Recommendation for Public Health

• The upcoming Public Health Review, should expand on the Scot PHN recommendation of a public awareness initiative on RA to include all RMDs [1].
SIDRIG found that 34.1% of those who they surveyed stated that ultrasound happened during a specialist visit to radiography rather than in rheumatology [38]. 96% of our respondents stated they had access to a range of drug treatments, compared to the 89% from our UK wide The State of Play in Rheumatology survey. However 43.9% of SIDRIG’s respondents believed there were budgetary restrictions for treatments for new patients. Yet the SSR and BSR members noted patients’ ability to access these drugs was limited by staffing numbers or waiting times for follow up visits. Rituximab was cited as problematic due to lack of nurse support to deliver the therapy resulting in waiting lists. In terms of funding for drugs, suggestions included reviewing funding for drugs to increase access for new treatments, such as the development of a biologic step down treatment and biosimilar policy which would release funds and therefore access for newer drugs. Our respondents explicitly noted accessibility concerns related to diagnostics such as ultrasound and MRI.

**Recommendation for Diagnostics and Drugs**

- **Diagnostics and Drugs** NHS Education for Scotland 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.
A majority of the SSR and BSR 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.

**Recommendations for Research**

- *The Delivering Innovation through Research – Scottish Government Health and Social Care Research Strategy* from the Chief Scientist Office should explore the opportunity of integrating research into clinical practice.

### Technology and Innovation

62% of respondents stated that their providers were not embracing the use of technology, which was 10% more than our UK wide respondents. This demonstrates the failure of policies outlined in documents including the *National Telehealth and Telecare Delivery Plan for Scotland to 2015 – Driving Improvement, Integration and Innovation* [40]. Technologies suggested by respondents to be implemented included mobile DXA scanning, telerheumatology, databases such as Trakcare or Cellma, email advice services or telephone appointment reminders for patients. The SSR and BSR members were concerned technologies were being developed and implemented outside the clinical setting, and therefore limiting their applicability.

The BSR’s report *Integrated information to support transformational change – learning from the Swedish healthcare system*, highlights how technology can be utilised to collect data and as a result lever service change and should inform the Scottish Health Technologies Group future work.

**Recommendations for Technology**

- The Scottish Government should replicate the Welsh Government’s commitment to provide £10m for a technology fund [4]. The Scottish Health Technologies Group (SHTG) should ensure such technologies are developed with health professionals and funding provided for training to health professionals to use this equipment.
Data

75% of respondents said their service either occasionally, or did not, ensure 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 mandatorily requested to record data on the number of returning outpatient appointments, despite these appointments consisting of the majority of clinic time.

Additionally, respondents noted 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 [41]. 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 [42].

As outlined above, the SSR have successful 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.’

Recommendations for Data

- National Services Scotland (NSS) Public Health and Intelligence (PHI) when developing ICD-11 should collaborate with all of the specialities 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 [1].

Conclusion

The feedback we received from the BSR and SSR members demonstrated a committed workforce, working within a health system which was not completely meeting their or their patients' needs. The Scottish Government and its partners have made strides in developing policy, however the content or direction needs to be realigned to support the specialty to improve outcomes for the growing number of patients it treats.

This report will be utilised to highlight to the Scottish Government and Parliament, government bodies and Local Health Boards the value of Scotland’s rheumatology services but also indicate areas of improvement to ensure Scotland’s RMD patients receive the optimum care from their NHS.
Appendix 1

Please indicate your role:
- Consultant
- Trainee
- GP
- Nurse
- Allied Health Professional
- Other

What is the principal basis of your work
- Paediatric rheumatology
- Adult rheumatology
- General internal medicine
- Primary care
- Academia
- Industry
- Other

Which Local Health Board(s) do you work in?
- Ayrshire and Arran
- Borders
- Dumfries and Galloway
- Western Isles (Gaelic: Bòrd SSN nan Eilean Siar)
- Fife
- Forth Valley
- Grampian
- Greater Glasgow and Clyde
- Highland
- Lanarkshire
- Lothian
- Orkney
- Shetland
- Tayside

Rheumatology Services Overall

How would you rate the quality of rheumatology services overall in Scotland since the Scottish Parliament elections in 2011?
- Improved
- Stayed the same
- Worsened

If they have worsened please provide further detail:
[Free text]

Have any of the recommendations of the Scottish Public Health Network’s Health Care Needs Assessment of Services for Adults with Rheumatoid Arthritis report (July 2012) been enacted in your area?
[Free Text]

Priorities For Rheumatology Services

What should be the main priority for the Scottish Government to improve rheumatology patient care in the NHS?
[Free Text]

Please use the text box below either to highlight any additional challenges or opportunities for rheumatology services, or to expand on any points already made.
[Free Text]
**Patient Centred Care**

Do you, or your service:

- Have a shared decision making approach with patients? (Y/N)
- Encourage patients to self-care? (Y/N)
- Advise and support patients to help them remain or return to work? (Y/N)
- Advise your patients on weight reduction, or physical activity? (Y/N)

If you or your service has been unable to implement any of above, then please let us know here:

[Free Text]

Please provide detail on how your service is successfully implementing any of the above:

[Free Text]

**Data Collection**

Does your service ensure that accurate and detailed data are collected about patient activity, diagnoses, outcomes, etc? [Y/N]

If not, please inform us what difficulties your service has encountered in trying to do this:

[Free Text]

If yes, please provide detail on how your service is successfully collecting accurate and detailed data:

[Free Text]

**Drug Treatment**

Do your patients have access to the range of drug treatments that they require? [Y/N]

If no, please inform us why not:

[Free Text]

**Staffing**

Do you consider your service to be sufficiently staffed? (Y/N)

If not, please indicate which roles are most understaffed:

- Consultant
- Trainee
- GP
- Nurse
- Allied Health Professional
- Other

**Accessible Services**

Are any aspects of rheumatology services available across 7 days? [Y/N]

Does Scotland’s rural geography impact on patients’ accessibility to services? [Y/N]

If yes, how:

[Free Text]
Innovation And Technology

Is your provider embracing the use of technology to improve access to services?
[Y/N]

If yes, what types of technology:
[Free Text]

Coordinated Care

Are care pathways for your patients better co-ordinated now than since 2011?
[Y/N]

Is your service working collaboratively with services in:
- Acute care (Y/N)
- Community healthcare (Y/N)
- Primary care (Y/N)
- Social care (Y/N)

Please inform us why your service has encountered difficulties in working collaboratively with services across the above:
[Free Text]

Please provide detail of how your service has been able to work collaboratively with any of the above:
[Free Text]

How well integrated into the care pathway are rehabilitation and reablement for your patients?
- Poorly integrated
- Some integration
- Well integrated

Input Into Service Design

When new services are being considered, how well represented would you say the interests of the following groups are,

- Patients and carers (Poorly represented/Variable/Well represented)
- Rheumatology professionals (Poorly represented/Variable/Well represented)
- Specialised Rheumatology services (Poorly represented/Variable/Well represented)
- Primary care services (Poorly represented/Variable/Well represented)

Please provide examples of where this has worked well/or not well:
[Free Text]

Rare Conditions

Do you believe that the needs of patient with rare rheumatic conditions are being adequately met by the services in your organisation?
[Y/N]

If not, please provide detail here of what needs to be improved:
[Free Text]

If yes, please provide detail on how your service has been successful in addressing this need:
[Free Text]
Research

In your opinion is research being given adequate consideration in

- your service (Y/N)
- the organisation in which you work (Y/N)
- the wider design of services (Y/N)

Training

In your opinion is training being given adequate consideration in

- your service (Y/N)
- the organisation in which you work (Y/N)
- the wider design of services (Y/N)

Do you believe that rheumatology training needs to be spread more widely to other health and care professionals? (Y/N)

Are you or your service actively involved in training other health professionals? (Y/N)
References


23 Rare Disease UK. About Rare Diseases. [Internet]; 2016 [cited 2016 Jan 27]. Available from: http://www.raredisease.org.uk/about-rare-diseases.htm


References (continued)


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