The State of Play in UK Rheumatology

Insights into service pressures and solutions
## Contents

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Foreword</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>Recommendations</td>
<td>5</td>
</tr>
<tr>
<td>3</td>
<td>Rheumatic and musculoskeletal disorders – the hidden burden in numbers</td>
<td>6</td>
</tr>
<tr>
<td>4</td>
<td>The current picture of rheumatology services in the UK: challenges and opportunities</td>
<td>8</td>
</tr>
<tr>
<td>4.1</td>
<td>NHS services</td>
<td></td>
</tr>
<tr>
<td>4.2</td>
<td>Early diagnosis – referral to treatment times</td>
<td></td>
</tr>
<tr>
<td>4.3</td>
<td>Service configuration</td>
<td></td>
</tr>
<tr>
<td>4.3.1</td>
<td>Delivering services in the community</td>
<td></td>
</tr>
<tr>
<td>4.3.2</td>
<td>Providing care across 7 days</td>
<td></td>
</tr>
<tr>
<td>4.4</td>
<td>Collaborative working</td>
<td></td>
</tr>
<tr>
<td>4.4.1</td>
<td>Multi-disciplinary team working</td>
<td></td>
</tr>
<tr>
<td>4.4.2</td>
<td>Care co-ordination</td>
<td></td>
</tr>
<tr>
<td>4.4.3</td>
<td>Working with primary care</td>
<td></td>
</tr>
<tr>
<td>4.5</td>
<td>Patient-centred care</td>
<td></td>
</tr>
<tr>
<td>4.5.1</td>
<td>Shared decision-making</td>
<td></td>
</tr>
<tr>
<td>4.5.2</td>
<td>Personalised care planning</td>
<td></td>
</tr>
<tr>
<td>4.5.3</td>
<td>Education and self-management</td>
<td></td>
</tr>
<tr>
<td>4.6</td>
<td>Work and health</td>
<td></td>
</tr>
<tr>
<td>4.7</td>
<td>Commissioning and tendering</td>
<td></td>
</tr>
<tr>
<td>4.7.1</td>
<td>Improving contracting processes</td>
<td></td>
</tr>
<tr>
<td>4.7.2</td>
<td>Commissioning of specialised services</td>
<td></td>
</tr>
<tr>
<td>4.8</td>
<td>Finances and funding</td>
<td></td>
</tr>
<tr>
<td>4.8.1</td>
<td>The Best Practice Tariff</td>
<td></td>
</tr>
<tr>
<td>4.9</td>
<td>Data challenges in rheumatology</td>
<td></td>
</tr>
<tr>
<td>4.9.1</td>
<td>Improving the quality of data underpinning commissioning decisions</td>
<td></td>
</tr>
<tr>
<td>4.9.2</td>
<td>Interoperability of records</td>
<td></td>
</tr>
<tr>
<td>4.9.3</td>
<td>Data collection burdens</td>
<td></td>
</tr>
<tr>
<td>4.9.4</td>
<td>Developing and promoting national metrics for rheumatology</td>
<td></td>
</tr>
<tr>
<td>4.10</td>
<td>Workforce</td>
<td></td>
</tr>
<tr>
<td>4.11</td>
<td>Education and training</td>
<td></td>
</tr>
<tr>
<td>4.11.1</td>
<td>Shape of training and dual accreditation</td>
<td></td>
</tr>
<tr>
<td>4.11.2</td>
<td>Spreading training to other care professionals</td>
<td></td>
</tr>
<tr>
<td>4.11.3</td>
<td>The importance of experiential, community based learning</td>
<td></td>
</tr>
<tr>
<td>4.12</td>
<td>Drug treatments</td>
<td></td>
</tr>
<tr>
<td>4.12.1</td>
<td>Better medicines management</td>
<td></td>
</tr>
<tr>
<td>4.13</td>
<td>Public health and primary prevention</td>
<td></td>
</tr>
<tr>
<td>4.14</td>
<td>Research and innovation</td>
<td></td>
</tr>
<tr>
<td>4.14.1</td>
<td>Embracing technology in the delivery of care</td>
<td></td>
</tr>
<tr>
<td>4.15</td>
<td>The devolved nations</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>References</td>
<td>40</td>
</tr>
</tbody>
</table>
1 Foreword

The State of Play in UK Rheumatology is the first major policy report from the British Society for Rheumatology (BSR). The report aims to capture the key challenges and opportunities facing rheumatology services and the patients they serve, with a view to bringing these to the attention of those bodies that can make a difference. For too long many of the issues affecting our patients have been overlooked, both at a national level by Government and its arm’s length bodies and at a local level by commissioners. We hope this report goes some way to address this, in conjunction with the publication of our recent statements on biosimilars and other key policy areas.

The NHS is currently experiencing the combined challenge of unprecedented constraints on finances and increased demand for services, due to the rising age profile of population, overall population growth and a greater number of people living with chronic long term conditions. There are more than 15 million people living with a long-term condition, accounting for half of GP appointments, almost two-thirds of outpatient appointments and seven out of ten of inpatient bed days. Chronic diseases are now the most common cause of death and disability in the UK. The number of people with multiple conditions is projected to grow to nearly three million by 2018, a rise of a million in a decade.\(^{(1)}\)

The changing needs of the population have been met by an evolution in the type of care delivered, from one-off interventions to longer term complex care across multiple conditions, involving a range of care sectors. Services for patients with rheumatic and musculoskeletal disorders (RMDs) have risen to this challenge, but we feel that there is still more that could be achieved to ensure that patients everywhere receive the high quality care they deserve. A starting point for this would be greater recognition of the personal and economic impact of RMDs in national policy frameworks.

This report was developed in partnership with our membership representing healthcare professions involved in the care of people with RMDs, including rheumatologists, nurses, allied health professionals, GPs and academics. This involved a policy survey to over 2,000 members, along with a series of focus groups with a broad range of clinicians and patients. The issues to emerge from these sessions have informed the report and the final recommendations, which we have termed BSR’s ‘15 for 2015’, as they represent the 15 key challenges that need to be addressed across the UK. We will use the findings to lobby for greater recognition of the challenges facing rheumatology and continue our work to improve patient care and share best practice.

Professor Simon Bowman
President of the BSR

Laura Guest
CEO of the BSR
2 Recommendations — BSR’s ‘15 for 2015’

1 Health system leadership bodies in the UK must give greater priority in national strategies to rheumatic and musculoskeletal disorders, due to their major health and socio-economic impact.

2 NHS England, and equivalent bodies in the devolved nations, should accelerate the spread of best practice in care co-ordination across the NHS, working with relevant bodies on training and capacity-building of specialist nurses to fulfil this co-ordinating role.

3 Health system leadership bodies in the UK should prioritise the implementation of personalised, written care and support plans for all patients with long term conditions.

4 Commissioners and health boards should give greater priority to education and self-management programmes in local plans for managing long term conditions, as set out in NICE recommendations.

5 Commissioners, health boards and providers should ensure that rehabilitation, re-ablement and mental health support are core to care pathways and properly resourced to help people return to work.

6 Commissioners should be required to conduct a rigorous impact analysis for any major commissioning decision, with meaningful consultation on the system-wide effects.

7 Commissioners, health boards and providers should ensure that proposals for new services include a thorough assessment of impact on education, training and research of the proposed service.

8 NHS England should ensure that its Local Area Teams incorporate the co-ordinated network approach into plans for 2015/16 to strengthen specialised care in rheumatology.

9 NHS England and Monitor should review the Best Practice Tariff offer to improve take-up and provide clear guidance on local pricing flexibility to support service and financial planning.

10 NHS England, the Health and Social Care Information Centre and equivalent bodies in the devolved nations should prioritise the collection of outpatient data for patients with RMDs and promote standardised coding.

11 NHS England should work in partnership with BSR to oversee the development of a suite of new metrics on RMDs for inclusion in national commissioning frameworks.

12 Health education bodies across the UK should work with the BSR on expanding training to identify early onset of rheumatic conditions to a wider range of health professionals including GPs, practice nurses, community nurses, AHPs and pharmacists.

13 UK health departments should commission a review of medicines approval processes, to improve access to biologics for all patients including those at the mild stage of the disease and those with rarer conditions.

14 Health departments in Northern Ireland and Scotland should engage with the national clinical audit for rheumatoid and early inflammatory arthritis in order to drive improvement in the quality of services.

15 The Welsh Assembly Government should update the 2007 Directive for Arthritis and Chronic Musculoskeletal Services, in order to improve the prioritisation of RMDs in Wales.
Rheumatic and musculoskeletal disorders (RMDs) encompass over 200 chronic conditions that affect joints, bones and muscles, rarer autoimmune diseases and back pain. The below provides a graphical guide to the main conditions in terms of volume of patients or cost of interventions.

These conditions are the biggest cause of the growing burden of disability in the UK, affecting over 10 million adults and 12,000 children.\(^{(2)}\) Recent research such as the Global Disease Burden Study illustrates the major personal, social and economic burden that RMDs can have, which is largely unrecognised by national policy.\(^{(3)}\)

### Rheumatology Musculoskeletal Medical and Long Term Conditions Framework

**Domains and Pathways – prioritised by value and volume**

<table>
<thead>
<tr>
<th>Domains</th>
<th>Inflammatory Arthritis/Disease</th>
<th>Diagnostics and Pain management</th>
<th>Auto-immune Rheumatic disease</th>
<th>Bone Conditions</th>
<th>Rare Conditions</th>
</tr>
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<tbody>
<tr>
<td>Rheumatoid Arthritis</td>
<td>Osteoarthritis</td>
<td>Systemic Lupus Erythematosus</td>
<td>Osteoporosis</td>
<td>Hereditary recurrent fevers</td>
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<tr>
<td>Spondarthrosis</td>
<td>Fibromyalgia</td>
<td>Sjögrens Syndrome</td>
<td>Paget’s disease of Bone</td>
<td>Sarcoidosis</td>
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<tr>
<td>Reactive/Septic arthritis</td>
<td>Inflammatory-Regional pain (e.g. Back, Limb)</td>
<td>Myositis</td>
<td>Regional bone disorder</td>
<td>Relapsing polychondritis</td>
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<tr>
<td>Gout/Crystal Arthritis</td>
<td>Mechanical Regional Pain (e.g. Back, Limb)</td>
<td>Systemic Scleroderma</td>
<td>Osteomalacia</td>
<td>Amyloidosis</td>
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<td>Polymyalgia Rheumatica</td>
<td>Hypermobility Syndromes</td>
<td>Vasculitis</td>
<td>Other metabolic bone disease</td>
<td>Rare arthropathies</td>
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\(^{(2)}\) The State of Play in UK Rheumatology
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<tr>
<th><strong>10 million</strong></th>
<th><strong>£5.3 bn</strong></th>
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<td>Over 10 million people in the UK are affected by RMDs</td>
<td>Annual NHS spend on RMDs is £5.3bn, the 4th largest programme budget behind mental health – £11.3bn, problems of circulation – £6.9bn and cancers and tumours £5.7bn</td>
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<table>
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<tr>
<th><strong>£31 million</strong></th>
<th><strong>8.3 million</strong></th>
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<tr>
<td>Reducing indirect costs, such as work limitations or loss of work, can save the economy £31 million a year for rheumatoid arthritis alone</td>
<td>RMDs were the main cause for working days lost in the UK in 2013/14. 8.3 million days in total</td>
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<tr>
<th><strong>1/3</strong></th>
<th><strong>40 days</strong></th>
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<tr>
<td>A third of people with rheumatoid arthritis will have stopped working within two years of onset, half unable to work within ten years</td>
<td>Each person suffering from an RMD took an average of 16 days off work a year, rising to 40 days on average for a patient with rheumatoid arthritis</td>
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<tr>
<th><strong>1 in 5</strong></th>
<th><strong>4 in 5</strong></th>
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<td>1 person in 5 consults with GP about a rheumatic or MSK problem</td>
<td>4 in 5 people with rheumatoid arthritis have at least one co-morbidity, and twice the risk of heart attack than people without the condition</td>
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</table>
The current picture for rheumatology services across the UK – challenges and opportunities

4.1 NHS services

How would you rate the quality of NHS/rheumatology services since 2010?

- Improved
- Stayed the same
- Worsened

Percentage of respondents:

- NHS services
- Rheumatology services
Six out of ten of respondents felt that NHS services had worsened since 2010. This reflects the budgetary constraints and increased demand for services driven by an ageing population with increasingly complex needs. To improve this, a number of key themes emerged that are applicable across the UK, such as the need to:

- Increase staffing levels and provide greater access to GPs
- Invest resources in social care
- Focus on prevention and improved self-management
- Undertake no further major reorganisation of the NHS

Although our members were slightly more positive about rheumatology services, with only three in ten believing that services had worsened, eight in ten still felt that services were no better now than in 2010. This is concerning, particularly as the National Audit Office report on services for people with rheumatoid arthritis, published a year before the election, revealed how many local services were already struggling to meet requirements on early diagnosis, treatment and regular review. Similar issues were identified in the Scottish Public Health Network report into Health Care Needs Assessment of Services for Adults with Rheumatoid Arthritis, published in 2012.

Despite the considerable personal and socio-economic impact of RMDs, outlined in the introduction to this report, it is clear that there is a lack of awareness of the conditions among commissioners, health boards and service planners. This was highlighted in the recent ABPI Raising the Game report that showed that only 5% of Joint Strategic Needs Assessments referred to rheumatoid arthritis. The BSR believes that policy makers and commissioners should recognise the impacts of these conditions and give them the same priority as other conditions such as cancer and cardiovascular disease. With greater recognition, rheumatology services and patient care could be improved further in many of the areas suggested by respondents such as resources for patient education, access to the multidisciplinary team (MDT) and appointing specialist nurses.

 Recommendation 1

Health system leadership bodies in the UK must give greater priority in national strategies to rheumatic and musculoskeletal disorders, due to their major health and socio-economic impact
4.2 The importance of early diagnosis: the 12-week window of opportunity

Alongside greater access to services and to the MDT, early diagnosis and treatment emerged as another important way in which patient care could be improved. This echoes guidance such as the NICE quality standard for rheumatoid arthritis\(^{(16)}\), the SIGN guideline on management of early rheumatoid arthritis\(^{(17)}\) and the BSR’s Simple Tasks campaign\(^{(18)}\). The latter sought to raise awareness of the concept of the ‘window of opportunity’, a 12-week period after the onset of symptoms, during which a referral to a rheumatologist would reduce the adverse impacts of the condition. There is strong evidence that patients treated within the 12-week window of opportunity stand a better chance of achieving remission, or low disease activity state, preventing damage to joints and organs and improving quality of life. In addition, mortality rates are significantly lower for those diagnosed and treated within this period.

Our analysis of NHS England Referral to Treatment Waiting Times shows that waiting lists for rheumatology services rose by 32% from August 2011 to August 2014, well above the average increase for all specialties of 18% in that period.\(^{(19)}\) The largest in-year increase took place in 2012/13. Despite this increase in demand, services have managed to keep the median waiting times down to four weeks throughout this period, which is a testament to the hard work and MDT approach taken by the services. It should be noted, however, that four weeks still falls short of NICE quality standard 2 recommending that people with suspected persistent synovitis are assessed in a rheumatology service within 3 weeks of referral.

Number of people on waiting lists in England

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<tr>
<th></th>
<th>Rheumatology patients on waiting lists in England</th>
<th>All patients on waiting lists in England</th>
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<tr>
<td>August 2011</td>
<td>44,661</td>
<td>2,535,628</td>
</tr>
<tr>
<td>August 2012</td>
<td>46,837</td>
<td>2,543,954</td>
</tr>
<tr>
<td>August 2013</td>
<td>56,289</td>
<td>2,833,998</td>
</tr>
<tr>
<td>August 2014</td>
<td>59,156</td>
<td>3,000,962</td>
</tr>
<tr>
<td>% increase</td>
<td>32%</td>
<td>18%</td>
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The first year reports of the Healthcare Quality Improvement Partnership (HQIP) national clinical audit for rheumatoid and early rheumatoid arthritis are due to be published in late 2015, with a focus on NICE quality standard 2. With over 200 rheumatology services participating across England and Wales, the reports will reveal the full extent of whether services have been able to meet this standard, in light of rising demand. The reports will also allow benchmarking of performance against regional and national comparators, but as set out in later sections, more work is needed on developing a range of indicators to be included in national frameworks and future audits.
4.3 Service configuration

Is your trust exploring new models of delivering care with local commissioners?

Over one third of respondents reported that their organisation was exploring new models of delivering care with local commissioners and health boards, with discussions focusing on enabling rapid access to treatment, integrating all musculoskeletal care into a single service, shared pathways with primary care and providing a wider range of services in the community. Respondents were also clear that the NHS should not undergo any further major top-down re-organisation but that service design should be driven by greater collaboration with primary care, integrated care pathways and evidence-based best practice.

The 12-week window of opportunity underlines the importance of facilitating rapid access to rheumatology services for patients with suspected persistent synovitis, rheumatoid arthritis, gout or other early inflammatory arthritis. Traditionally, the service models employed to enable early assessment and diagnosis involved dedicated sessions in clinics in the general rheumatology service, but in recent years more bespoke rapid access and treatment services have emerged. These are normally centred upon an inflammatory arthritis clinic to which GPs can rapidly refer people with undifferentiated arthritis to be initially assessed before the appropriate pathway for them is identified.

As the aforementioned National Audit Office report on rheumatoid arthritis found, these rapid access services inevitably have considerable costs in the initial stage, particularly as a result of the surge of GP referrals, sometimes inappropriately referred. But, given time and proper support, these can begin to generate substantial savings through reduced GP visits and unnecessary diagnostics tests. In Scotland, service planners are even exploring direct self-referral by patients to rheumatology services, to improve access. In 2013, the BSR evaluated a number of rapid access and treatment services as part of our Best Practice Awards, and further details can be found here: www.rheumatology.org.uk/publications/best_practice/default.aspx

The BSR is currently exploring how best to work with partners on disseminating best practice more widely across the NHS.
Delivering services in the community

Despite the ongoing drive to deliver more services in community settings, only half of those surveyed reported currently provide rheumatology services in the community. We are aware of an increasing number of outpatient clinics being delivered in the community, often in community hospitals led by nurse practitioners. In some locations community clinics are being provided in GP surgeries. These clinics are generally rheumatology-specific, but can be integrated with other complementary specialties, for example orthopaedics for fracture prevention and pain management and with dermatology.

Whilst the BSR advocates making services more accessible for patients, we counsel against moving services to the community without having the necessary infrastructure in place locally, as this can fragment care further and result in patients having to make more journeys. We have become aware of services being established in local GP practices, without consideration of the other service vital to patient care, such as diagnostics or access to therapies. This is why the BSR favours more collaborative, network approaches over major structural reform with potential unintended consequences.

There are a number of community based providers offering a range of services in people’s homes that would have once been treated as day cases. For instance, Pennine Musculoskeletal Partnership delivers a home administration service for subcutaneous biologics drugs and an infusion service for intravenous biologic therapies and has strong links with secondary care, enabling rapid access to beds where appropriate.

Providing care across seven days

Almost seven in ten of respondents reported that no aspect of their services was available across seven days. This reflects the specialty’s traditional delivery of care in outpatient and ambulatory settings, although most services had well established 24-hour on-call medical services for patients admitted out-of-hours and for urgent reviews. This is often complemented by telephone support services for GPs and patients out-of-hours.
4.4 Collaborative working

The diagram below illustrates the complex and multidisciplinary nature of the care pathways for people with rheumatic and musculoskeletal disorders. Collaboration is therefore key to managing this complexity and the following sections outline how this approach is being embraced by rheumatology services in the UK.

Components of a rheumatology musculoskeletal medical and long term conditions service

Multidisciplinary Teams

In addition to rapid assessment for patients with an undefined diagnosis, services offer swift access to advice or treatment for existing patients who may have flare ups of their condition, worsening pain or concerns about medicines. The multidisciplinary team approach is core to this, from the multi-professional triage system that assigns people to the appropriate part of the service, through to multidisciplinary joint care planning with the patient and the telephone advice and support provided by the members of the MDT when people experience adverse changes such as flare-ups. In some cases, the members of the multidisciplinary team can make a direct admission to hospital in case of an emergency. Integrated pathways, supported by standardised information and a single, shared clinical record are key to the MDT process.

The findings of our survey suggested that, in some areas, the MDT was under-resourced and not properly integrated into pathways, adding to unnecessary delays to patients. The results of the HQIP audit to be published later this year should reveal greater detail on the impact of these MDT issues at a local and national level.
Care co-ordination across settings

Care co-ordination led by a specialist nurse has become more common in rheumatology services, whereby a specialist nurse acts as a case manager to coordinate access to care across secondary, community and primary care for certain patients. These patients are often identified through a risk stratification process and case management is tailored to their needs with direct access and options for home visits according to their personal preferences. The service can include a phone line and direct access for GPs and patients, enabling self-management and rapid response to disease flares, whilst helping people stay in the community. Case management is founded on shared accountability between the patient and providers along the care pathway.

Despite local good practice in this area, involving partnerships between primary, secondary, social care and the voluntary sector, the BSR believes that more could be done, as many people with multiple, chronic care needs are being left to navigate the complex care system on their own. We call for best practice in care co-ordination to be spread more widely across the NHS and for investment in the training and capacity building of specialist nurses to provide this co-ordinating role on behalf of patients.

Recommendation 2

NHS England, and equivalent bodies in the devolved nations, should accelerate the spread of best practice in care co-ordination across the NHS, working with relevant bodies on training and capacity-building of specialist nurses to fulfil this co-ordinating role.
Working with primary care

Is your provider working more closely with primary care to provide integrated rheumatology services?

Whilst a third of those who responded reported working more closely with primary care to provide integrated rheumatology services, two-thirds rated their relationship with primary care colleagues at five out of ten or below, suggesting that more work needs to be done to improve collaborative care across the pathway.

There are multiple good examples of this collaborative approach such as the Haywood Hospital in Stoke which integrates GPsWs working alongside advanced practitioners to triage patients as cited in the King’s Fund report Specialists in out-of-hospital settings. (21)

The BSR believes that as the recommendations of the NHS Five Year Forward View are taken forward by providers and commissioners, there will inevitably be more and more opportunities for secondary and primary care to develop closer working. There could be closer collaboration on developing and managing standardised care pathways, including protocols for shared care and drug management across the pathway. Such an approach would reduce follow-up rates, improve rapid access for new patients or flaring patients, and could optimise under-resourced areas of the MDT team such as occupational therapy, podiatry or psychology.
How would you characterise your relationship with primary care?

Although there have been improvements in working with primary care, our members are still reporting difficulties in terms of poor two-way communication and co-ordination between GPs and rheumatology units, along with an overall lack of condition awareness by GPs. For example, although patients with osteoarthritis or osteoporosis are being diagnosed, members have reported that poor long-term condition management in primary care is resulting in these patients developing avoidable complications. This has prompted rheumatology services in many areas to address these challenges by investing in training of GP partners to identify symptoms and make more informed referrals. University Hospital Southampton has a well-established support and education scheme for general practice, which has trained over 2,000 GPs.
4.5  Patient-centred care

The Government’s Mandate for NHS England requires it to ‘ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment’.[22] This view is echoed in a range of other documents, including the Healthcare Quality Strategy for Scotland.[23] Although much has been achieved in taking this forward, our research suggests that more that needs to be done to empower health professionals to embed care planning and shared decision making and co-develop self-management models with their patients.

Shared decision-making

Whilst eight out of ten of our respondents believe that shared decision-making approach is embedded in day-to-day interactions between healthcare professionals and their patients, the BSR recognises that there could be a disparity between patient and professional interpretations of shared-decision making. Patient organisations such as National Voices have raised this issue, which is common across many medical specialties. The BSR is keen to work with patient groups and the Royal Colleges to develop common understanding and to incorporate shared decision making into training syllabuses for our members. This will need to be explored as part of the work around care planning, outlined in the following section.

Shared decision making has become a core principle in the management of rheumatic conditions, as evidenced by the 2013 update to the EULAR recommendations on managing rheumatoid arthritis, which placed it as the top priority for best care.[24] Shared decision making requires a fundamental transformation of the traditional relationship between the patient and their care-giver, from a traditionally paternalistic approach to a more collaborative one.
Doctors need to provide patients with information on the risk of the conditions and the relative merits of the different therapies, in order to support to them to develop personal preferences such as a therapeutic target and management plan.

**Personalised care planning**

The survey findings suggest that the introduction of care plans has become more widespread in the RMD community, with one in five of respondents reporting that personalised care planning had been implemented for their patients. However, three out of five said that they had not been implemented and, of these, more than 80% said there were no plans to do so in the near future, which suggests there is still a long way to go realising the ambitions of the Mandate to NHS England. The Government’s Mandate set out an aspiration that everyone with a long-term condition should be offered a personalised care plan that reflects their preferences and agreed decisions, however, the latest NHS England estimates suggest that fewer than 6% of people with long term conditions have a written care and support plan.

Care and support plans set out the overall plan for the care of a patient, outlining their ongoing needs and personal goals and the support they will need to achieve these. Care plans should reflect whole person care needs and not just clinical interventions, and thus should cover physical health, mental health and social care needs. Moreover, ensuring that there is a holistic care plan for all people with rheumatoid arthritis that includes a low disease activity target, is an integral part of NICE guidance on managing this condition.

**Recommendation 3**

**Health system leadership bodies in the UK should prioritise the implementation of personalised, written care and support plans for all patients with long term conditions**

**Education and self-management**

It is estimated that, across a year, the average patient will only have two hours of face-to-face contact with healthcare professionals, underlining how much patients rely on themselves and on their loved ones to manage their conditions. Four out of five of those surveyed outlined how their service was encouraging self-management in their patients. This reflects how important education and self-management programmes have become in managing long-term conditions, with estimates suggesting that the programmes cost £125 per person, but generate savings of £244 per person on average. Studies have shown that developing knowledge and understanding of their condition improves patient experience. Patients who are more activated to self-manage their condition will experience better health outcomes and with effective support and education, these skills can be developed even for those people with low initial confidence or levels of health literacy. Furthermore, self-management is the ultimate goal of the personalised care planning process, where people become confident enough in themselves and in the support available to them to manage their condition effectively.
Within the field of rheumatology, the MDT plays a crucial role in supporting education and self-management activities. For example, at University Hospital Southampton, self-management and shared decision making have been incorporated into a patient contract, not only setting out the MDT responsibilities to the patient, but also outlining the patient’s own responsibilities, such as their medicines management. At the same time, education events at the Manchester Royal Infirmary have resulted in five times as many patients coming into contact with the MDT in a third of the time, saving 510 minutes of clinical time each week.\(^{(29)}\)

Furthermore, the third sector has had an increasingly important role in empowering patients to manage their conditions, with the National Rheumatoid Arthritis Society (NRAS) and Arthritis Care being two of the more developed programmes. NRAS, for example, offers a six-week rheumatoid arthritis self-management programme, demonstrating how self-management can result in both excellent patient outcomes but also in cost savings. Economic analysis of the programme has estimated a potential saving of up to £54K per year per thirty patients enrolled in the scheme.\(^{(30)}\)

The NICE quality standard for rheumatoid arthritis states that people with rheumatoid arthritis are offered educational and self-management activities within 1 month of diagnosis, which should be reviewed frequently, including as part of the annual review.\(^{(31)}\) There is a diverse range of activities from telephone advice for flare ups; patient handheld records for blood results; 1 to 1 support by rheumatology health professionals, as part of routine monitoring; self study; computer-based interventions; peer support groups; use of shared decision aids. The national clinical audit for rheumatoid and early inflammatory arthritis will measure compliance with this quality standard.

In fact the NICE guidance goes even further as it calls for commissioners to consider including education and self-management of rheumatoid arthritis in their quality, innovation, productivity and prevention (QIPP) plans for managing long-term conditions.\(^{(32)}\) The BSR strongly supports this notion, as we believe that active support for education and self-management should be core to the care pathway and often these activities can be overlooked in service specifications, or removed in cost saving exercises. Moreover, our members have reported that they have insufficient capacity and time available for education and self-management support.

**Recommendation 4**

Commissioners and health boards should give greater priority to education and self-management programmes in local plans for managing long term conditions, as set out in NICE recommendations.
4.6 Work and health

Almost 9 out of 10 respondents reported that they actively advised their patients to help them achieve those outcomes important to them, such as continuing in employment. This shows how advances in treatment of rheumatic conditions over the last 20 years have broadened the scope of consultations from merely improving a patient’s mobility, to helping people live a full a life as possible, including supporting them to remain or return to work. With MSK conditions being the biggest cause of long-term sickness absence in the UK, the BSR welcomes the priority given to work and health by the NHS Five Year Forward View, although believes that more needs to be done to enable employee access to treatment and support. Through the BSR’s work with the Fit For Work UK Coalition, a multi-stakeholder network that aims to drive policy and practice change to support people return to work, we hope to achieve this. As a first step, the BSR has worked closely with four rheumatology units across the UK to commission pilots to evaluate the impact of face-to-face training in work and health on members of the MDT.

Our survey revealed that access to vital support such as rehabilitation and re-ablement, is still a major challenge with seven out of ten of our respondents reporting that these elements were not well integrated into the care pathway. This echoes studies suggesting that a third of patients with rheumatoid arthritis wait over a year for physiotherapy. The BSR believes that rehabilitation, re-ablement and self-management must be core to the care pathway and properly resourced. Moreover, the focus must be on mental health needs as much as physical health, with psychosocial support such as Cognitive Behavioural Therapy to help patients self-manage and remain in or return to work. By way of example, an integrated, whole person approach has been adopted at the Bristol Royal Infirmary with the implementation of an evidence-based, standardised, multidisciplinary care pathway, including psychosocial support to improve the ability of patients to self-manage and return to work. In terms of secondary prevention of disease progression, 65% of patients achieved a low disease activity state after 12 months on the integrated pathway with a 40% reduction in patients needing to go onto more expensive and complex biologic, generating a saving equating to 20% of the total cost of the service.

Recommendation 5

Commissioners, health boards and providers should ensure that rehabilitation, re-ablement and mental health support are core to care pathways and properly resourced to help people return to work.
4.7 Commissioning and tendering

The survey revealed some worrying challenges in relation to commissioning, with half rating their provider’s relationship with local clinical commissioning groups (CCGs) as five out of ten or below and eight out of ten suggesting that the interests of secondary care are not being adequately represented on CCGs.

How well would you say the interests of secondary care are represented in local commissioning?

This is a significant concern as over the last two years, there has been an unprecedented rise in the number of musculoskeletal services re-commissioned across England, with contracts totalling well over £1bn. Major contracts have been put out to tender in areas such as Bedfordshire, London and West Sussex, generating mixed reactions from patients and healthcare professionals in these localities. Many of these procurements have been beset by problems such as referrals to Monitor due to concerns over the impact on patient care of ‘cherry-picking’ only the most profitable parts of a service, or issues over the transparency in the tendering process. This has resulted in preferred providers withdrawing bids at a very late stage, or even pulling out of already established services, when faced with the financial realities of providing a comprehensive service for patients with RMDs.
There is also a need to strengthen the relationship between commissioners, providers and those affected by any proposals. This is particularly important in light of concerns about the lack of clinical and patient input in tendering processes, along with variable representation of secondary care on CCGs. Currently only 14% of respondents feel that there is sufficient clinical input into tendering processes and 7% that there was adequate patient input. Now that commissioning processes are fully embedded, these groups can also provide feedback to review the effectiveness of the commissioning process in meeting local needs and whether planned improvements in cost and outcomes have been achieved.

CCGs should ensure that they seek advice from their local clinical senates for any proposed service change, as part of a more proactive and collaborative approach which identifies shared priority outcomes, clear lines of responsibility, capacity building and well defined protocols on how associated risks and rewards will be shared. Commissioners should be required to take into account the full, system-wide consequences of any proposed commissioning decision, including a thorough financial impact analysis to assess the sustainability of the proposal.

**Recommendation 6**

Commissioners should be required to conduct a rigorous impact analysis for any major commissioning decision, with meaningful consultation on the system-wide effects.
Improving contracting processes

Over 85% of respondents believe that education, training and research are not being taken into account in tenders for new services. Local intelligence has revealed that, in many cases, the bidders are omitting these elements from their bids to make them appear more competitive and commissioners are not fully evaluating bids to test proposals for education, training and research. Such an omission is concerning, as these elements are crucial to the future of services for patients and should not be viewed as separate to service specifications. Furthermore, research can be a source of innovation and potential income, as well as providing development opportunities for staff.

Recommendation 7

Commissioners, health boards and providers should ensure that proposals for new services include a thorough assessment of impact on education, training and research of the proposed service.
Our members have also alerted us to issues that are hampering the delivery of effective services and impacting on the development of future services. These include overly complex tendering arrangements, short term contracts and having multiple commissioners with differing commissioning intentions. For example, some aspects of the Haywood Hospital’s rheumatology and musculoskeletal interface service are only available to patients from certain commissioning areas, creating potential for variations in care. The BSR welcomes the NHS Five Year Forward View proposals to simplify the NHS contract, and we suggest that there needs to be a greater emphasis on promoting longer term contracting and transparency to help achieve the NHS Forward View aims.\(^{[36]}\)

**Commissioning of specialised services**

Just under a third of our respondents felt that specialised care in rheumatology was not being adequately commissioned. With plans to devolve more specialised commissioning to CCGs, commissioners should be required to consult with Clinical Reference Groups (CRGs) on service specifications and to be open and clear for their reasons should they decide not to follow the clinical advice. Moreover, the BSR has long been calling for a multi-specialty co-ordinated network approach to help address variations in care and in access to drugs, particularly for patients whose co-morbidities cross over to other specialised areas of commissioning. In such an approach, a single clinical lead is identified to co-ordinate care, and the BSR believes that, in the case of patients with RMDs this should be a rheumatologist due to their clinical expertise in immunology. We are pleased that a co-ordinated network for specialised rheumatology has been agreed by NHS England for inclusion in local QIPP plans for 2015/16.

**Recommendation 8**

NHS England should ensure that its Local Area Teams incorporate the co-ordinated network approach into plans for 2015/16 to strengthen specialised care in rheumatology
4.8 Finances and funding

Although there were no specific questions on finances in our survey, a number of respondents noted that improvements in rheumatology services were being hampered by the lack of resources, leading many areas to explore different approaches to funding care. The BSR welcomes the move away from payment approaches that reward single episodes of care, to approaches that better reflect clinical complexity and pay for care over a longer duration, such as the year of care approach. These more flexible approaches are better aligned with the changing needs of patients with chronic conditions. The BSR is currently working on a commissioning currency for measurement and financial flows that reflects the complexity and multi-disciplinary nature of care for people with RMDs. We believe that this could be translated to a number of complex, chronic conditions.

Rheumatology services have traditionally been funded by Payment by Results, but with some local variation negotiated to provide scope for service innovations, for example lower rates for day cases. Our members have reported confusion over local pricing flexibility, which is hampering initiatives for better co-ordination between services and introducing the potential for variation between local health economies. This is causing difficulties for both commissioners and providers in terms of service design and financial planning.

The Best Practice Tariff

The BSR welcomes the introduction of a Best Practice Tariff for Early Inflammatory Arthritis to incentivise good practice and reduce variations in care, although implementation in the first year has been patchy. Feedback gathered from our members suggests that the fact that the Best Practice Tariff does not cover the full year and excludes drug therapy costs, has deterred providers from taking up the tariff. Furthermore, as it only covers hospital treatment, it helps reinforce barriers to co-ordinated care, making it difficult to implement shared care across the pathway.

Recommendation 9

NHS England and Monitor should review the Best Practice Tariff offer to improve take-up and provide clear guidance on local pricing flexibility to support service and financial planning.
health
4.9 Data challenges in rheumatology

Over eight out of ten of our respondents reported that their services were exploring various solutions to overcome data issues, such as the quality of data collection, interoperability of electronic records and access to crucial diagnostics data. Below is an outline of the key challenges:

Improving the quality of data underpinning commissioning decisions

It is widely recognised that to commission high quality services, commissioners require high quality information that is clear, accurate and timely. Rheumatic disorders, however, like many long term conditions, have traditionally been hampered by the dearth of activity data, mainly as a result of data collection practice not evolving in line with changes in treatment options. Patients with rheumatic disease once occupied a large number of hospital beds, but drug therapies have allowed the provision of care to become largely ambulatory in nature. Comprehensive data collection has been further compounded by the fact that there are over 200 rheumatic conditions, each with its own distinct set of symptoms, treatment options and pathways.

A BSR analysis of SNOMED shows that only 75% of rheumatic conditions are covered by existing codes and of those coded only 3% are actually collected. Most of the classifications in the MSK programme budgeting data relate to orthopaedics, with very few specific to rheumatology services. Furthermore, our members have reported that locally, whilst there appears to be good data collection for patients on biologics, disease activity data are not being systematically collected for those on other treatment options. It is difficult, therefore, to provide an accurate picture of the burden of rheumatic disease, or a robust assessment of demand on services. This means that rheumatology services are being tendered, without the data to guide the service specification, or to monitor the delivery of the service. This lack of information presents a significant risk to the quality of patient care, in addition to the potential financial risk of not having fully costed pathways. This also carries major consequences for the funding of services and for monitoring service effectiveness and efficiencies.

Locally, commissioners and providers should be restoring clinical input into costing by more robust engagement with clinicians. Professional bodies can offer support by developing these skills across their membership, using resources such as the Musculoskeletal Solutions Alliance and the BSR commissioning toolkit to design better rheumatology services for patients. At a national level, we believe that NHS England, the Health and Social Care Information Centre and the equivalent bodies in the devolved nations, should work with healthcare professional bodies to prioritise data collection in areas with significant data gaps, such as outpatient appointments and contacts in community settings for patients with RMDs. This needs to be complemented by efforts to improve clinical coding and costing of RMDs by working with professional leadership bodies to develop standardised coding for these conditions, which would be understood and implemented across primary, community and secondary care.
Interoperability of records

Despite many national initiatives to improve the interoperability between records systems in the NHS, to allow practitioners and patients access records across a variety of care settings, progress has been slow and fragmented. Our members have reported that many departments still use paper-based records and organisations are still reporting difficulties in accessing vital diagnostic data such as pathology results. These issues have prompted most areas to seek their own solutions to these issues, which has not only compounded the lack of interoperability but has been a major drain on NHS resources.

Data collection burdens

Whilst we recognise the impetus to extend data collection, member feedback suggests that more needs to be done to simplify collection to reduce the bureaucratic burden on practitioners and patients. This is in line with drives to reduce bureaucracy and improve efficiencies across the NHS. Ideally this should be through standardised collection that is seamlessly interwoven into routine care.

Developing and promoting national metrics for rheumatology

The lack of rheumatology specific metrics has hindered the local prioritisation of services for patients with rheumatic conditions, as highlighted in recent ABPI report that showed that only 5% of Joint Strategic Needs Assessments referred to rheumatoid arthritis. To address this, the BSR suggests that new metrics need to be developed to be included in national commissioning frameworks. Specifically NHS England should work with the BSR to conduct a review of metrics in relation to RMDs and develop new indicators to be included in the CCG Outcomes Indicator Set and the Quality and Outcomes Framework (QOF). Associated financial incentives will also need to be developed.

Recommendation 10

NHS England, the Health and Social Care Information Centre and equivalent bodies in the devolved nations should prioritise the collection of outpatient data for patients with RMDs and promote standardised coding

Recommendation 11

NHS England should work in partnership with the BSR to oversee the development of a suite of new metrics on RMDs for inclusion in national commissioning frameworks
4.10 Workforce

Our survey found that 60% of respondents reported that their units were experiencing significant recruitment gaps across all professions working in rheumatology services. This reinforces the findings of the last Royal College of Physician census report that projected a shortfall of 117 consultants across the UK in 2014.\cite{41} According to the RCP specialty guidance for rheumatology, it is recommended that there is one full time rheumatologist per 86,000 population, but as of 2014, only London, the South West and West Midlands were meeting that consultant requirement, with a UK average ratio of 1 rheumatologist per 115,000 of population.\cite{42} Furthermore, international comparisons show that only Germany, Ireland and Spain have higher ratio of patients to consultant rheumatologists than the UK.\cite{43}

Despite this, interest in the specialty is continuing to grow with more medical trainees, particularly female trainees, choosing to pursue a career in rheumatology. This trend has meant that rheumatology is one of the few specialties where there are more women doctors than men and has also contributed to the rise in less than full-time working. About three quarters of rheumatologists work purely in rheumatology and 1 in 6 undertake acute medicine. Three quarters of the respondents to our survey report to rheumatologists in their trust being asked to participate in the acute take.

With regard to nurses and allied health professionals, it is difficult to put an exact figure on the numbers working in rheumatology, however the last estimates suggested that the workforce was 94% female and 37% were older than 50 years of age, which rose to 42% for nurses. Furthermore, staff tended to stay in post for a longer time than medical colleagues, which reinforces the need for long term succession planning.\cite{44}
4.11 Education and training

Overall the findings of survey revealed positive messages in relation to training with two-thirds of respondents saying that they believed service delivery and training were properly aligned in their organisation. Interestingly, four out of five reported that rheumatologists were being adequately trained to deal with the rising number of patients with multiple morbidities, reflecting the specialty’s roots in general internal medicine and in dealing with multi-organ disease.

Shape of training and dual accreditation

As one of the core specialities in internal medicine, we have long advocated the need for a greater number of doctors to train in General Internal Medicine (GIM) to manage the growing number of older patients and those with multiple long-term conditions. This view is echoed in the Shape of Training review, which also called for greater flexibility so that individuals are able to train in a way that meet changing needs in their local health economy, as well as flexibility to change career path to other specialties and to academia, in line with their evolving career aspirations.\(^{(45)}\)

Whilst the BSR broadly agreed with the Shape of Training proposals, with about a third of rheumatologists already having dual accreditation in GIM, our members have expressed concerns particularly in relation to specialty training and dual accreditation. Although the six-year period to achieve specialty competences post foundation remains the same, the Shape of Training proposal that dual accreditation in GIM and a medical speciality
could also be achieved within the same six-year time-frame is unrealistic. The Royal Colleges and specialty societies have been clear that seven years is the minimum requirement for dual accreditation, otherwise training in both general medicine and the specialty will be compromised. Furthermore, the six-year specialty training would also be adversely affected by the proposed optional year for leadership or management training.

The BSR believes that length of specialty training should be determined by the specialties themselves, in partnership with the Royal Colleges. This includes training post certificate of specialist training, where many specialties are developing credentialed training driven by changing clinical needs. The BSR is exploring accredited special interest modules in areas such as sports and exercise medicine, metabolic bone disease, osteoporosis, MSK ultrasound, connective tissues disease/vasculitis, pain management.

Spreading training to other care professionals

Nine out of ten of survey respondents felt that it was vital to train a wide spread of care professionals to identify early onset of rheumatic conditions, particularly in primary care in light of the concerns raised about the lack of condition knowledge beyond the core professionals working in rheumatology. The BSR is heartened to see that almost three-quarters of our respondents were involved in training GPs or AHPs, but also that those who aren’t would welcome the opportunity to do so. The BSR suggests that this training could be expanded to include all professions that come into regular contact with patients in the community, including GPs, practice nurses, community nurses, AHPs and pharmacists. Finally, the BSR welcomes the development of the common competency framework for nurses and AHPS embarking on a career in MSK, as we believe this will be a key driver in helping reduce variation in the quality of care.
The importance of experiential, community based learning

The BSR strongly believes that it is crucial that experiential, service-based learning must be safeguarded, as not only is this crucial to the development of medical trainees, but to the future of services for patients. We also believe that it is important that trainees have opportunities to train within community settings during rotations, to give them exposure to a broad range of cases and develop awareness of the issues of working across the pathway. 55% of our respondents suggested that this isn’t happening in their localities and we urge deaneries to ensure that there are ample opportunities for experiential, community based learning.

Recommendation 12

Health education bodies across the UK should work with the BSR on expanding training to identify early onset of rheumatic conditions to a wider range of health professionals including GPs, practice nurses, community nurses, AHPs and pharmacists.
Improving access to biologics

Delays in access to biologics have been reported in a number of areas across all the home nations, which echoed the findings of the London School of Economics 2012 comparative study into access to innovative treatments for patients with rheumatoid arthritis across 12 EU nations. The study highlighted England as an outlier where "access to modern, biologic therapies is heavily restricted until a patient’s burden of disease has become severe." As discussed earlier, treatment with these specialist drugs at the mild stage of disease can prevent unnecessary disability. In light of this the BSR suggests that appraisal processes for new medicines may need to be reviewed. It is worth noting however that the majority of respondents noted that patients were able to access the range of drug treatments they required.

Intelligence gathered from our members suggests that Independent Funding Requests (IFRs) for drugs treatments not yet approved by NICE have proved to be problematic, particularly for patients with rarer conditions. The IFR application process is lengthy and very complex, with applications rejected for a variety of reasons from cost-effectiveness to the case not being deemed sufficiently urgent or exceptional. The development of a raft of NHS England commissioning policies for treatments in rheumatology has helped improve matters, but many members are still reporting access issues. Rural areas appear worst affected, where district general hospitals are not being permitted to deliver drugs locally, despite reaching agreements with local tertiary centre over safe administration.

**Recommendation 13**

UK health departments should commission a review of medicines approval processes, to improve access to biologics for all patients including those at the mild stage of the disease and those with rarer conditions

Better medicines management

Survey respondents, along with the wider membership have reported a push in many areas for more effective use of biologic drugs, driven by the growing cost burden of these medicines, which have become the highest pharmaceutical spend for some areas. It is estimated that, on average, biologic drugs cost around £9700 per patient per year, compared with around £450 per year for conventional therapy. This has prompted some areas to undertake reviews of biologics use, working with partners across the care pathway on better medicines management. Agreements have been drawn up across whole regions on reducing the use of biologics, with all CCGs and providers signing up to a common biologics pathways.
This has been complemented by the implementation of more effective personalised prescribing as part of ‘treat to target’, where a rheumatologist and patient agree on a treatment target and drug therapies are prescribed based on an assessment of how well the patient is managing their condition, rather than standard drug and dosage regimes. Treating to target has the dual benefit of ensuring that the therapy is more clinically effective for patients, in addition to being a more efficient use of biologics overall. For example at Guy’s and St Thomas’ Hospital treat to target patients are nearly six times more likely to reach disease remission compared to routine care resulting in a 7% fall in biologics use and saving an estimated £1 million a year. Similarly, at Aintree Hospital treat to target was introduced at no additional cost, resulting in £600k savings in biologics use and one in two patients being seen within three months of symptom onset, when previously no patients were seen within that window.\(^{(48)}\)
4.13 Public health and primary prevention

The BSR welcomes the NHS Forward View’s on a more radical approach to public health and prevention as it well documented that weight reduction and physical activity are crucial to diminishing the pain associated with rheumatic conditions or preventing their development. Respondents to our survey were clear that advising patients on losing weight and taking more exercise were core to their approach, with 97% reporting that they did this routinely. However, we are also aware from discussions with patient groups that this advice can be variable in terms of delivery and quality. The BSR recognises the importance of every patient contact to health promotion, but we also believe that that these conversations should always take place much earlier in the pathway, in primary care, where patient contact is more frequent and where the real differences can be made in prevention.

Do you actively advise your patients on weight reduction or physical activity?
4.14 Research and innovation

Despite the service pressures facing rheumatology units, seven out of ten of our survey respondents believed that their employer was providing sufficient opportunities for research. Ideally the BSR would have liked this figure to be higher if the UK is to fulfil the ambitions to lead the world in healthcare research and innovation. The NHS’s poor track record in translating research into changes to practice is well documented and has been attributed to many factors, not least of which have been the cultural barriers. It is crucial that research activities are viewed as an integral component of service delivery and not as a distraction, as not only can they provide innovative care for patients, but they can be a source of potential income, in addition to offering development opportunities for staff. Plans for research programmes must therefore be considered in service planning and in all contracts for new services. These need to be complemented by strong links with academia, enabling quick adoption of evidence-based practice and access to drug through clinical trials.

Despite the positive message overall, the survey did reveal disparities in terms of the resources and opportunities available for research into non-medical interventions such as therapies. The BSR is well aware of how important MDT working is to providing the care that our patients need and urges providers not to overlook this. The BSR is investing in a programme to examine the impact of MDTs in rheumatology, drawing upon the findings of the national clinical audit for rheumatoid and early inflammatory arthritis.

There are a growing number of localities where research is being properly resourced and integrated into pathways such as the rheumatology service at Imperial College Healthcare NHS Trust. This service provides a streamlined patient pathway from diagnosis to treatment and long term follow up care, which seamlessly integrates clinical care with patient education and clinical research. Each patient taking part in clinical trials can potentially save the service more than £15.5K per year. Patient education sessions score satisfaction ratings in excess of 96%.

Embracing technology in the delivery of care

Although there are pockets of innovation, overall technology is relatively underused to enhance the delivery of care in rheumatology. Less than a third of respondents reported that their unit was using technology to improve access to services and support the delivery of care. Much of the use of technology has centred upon enabling patients to self-manage their condition, starting from well-established telephone support lines, to more sophisticated telehealth services that facilitate continuous patient monitoring as part of the case management approach outlined earlier. The BSR is seeking to explore this area further, drawing upon international best practice on how to empower patients to monitor the progress of their disease and link this vital information to the services that are there to support them.
4.15 The Devolved Nations

The following represents a synopsis of the key issues raised by our members in the devolved nations:

Northern Ireland

- Waiting times for biologics are over three months, although there has been some success in reducing the waiting period for funding
- The transfer of a greater range of services to the community under the ‘transforming your care’ programme, has not disrupted the specialist care pathways
- There is currently no national clinical audit to drive quality improvement and development of national indicators
- There is a lack of resources to improve early arthritis services driving a desire for an incentive similar to the Best Practice Tariff in England in order to promote good practice

Scotland

- There is currently no national clinical audit to help drive quality improvement and promote development of national indicators
- There are delays in diagnosis and referral for specialist rheumatology assessment, along with service capacity issues for ongoing management of patients with established disease
- Specialist nursing and AHP shortages, along with poor succession planning mean that not all units have full MDT provision
- There are shortages evident in paediatric rheumatology impacting on the availability of transition services
- There are difficulties accessing services in rural and remote areas, especially diagnostics, along with vocational rehabilitation services, including mental health support

Recommendation 14

Health departments in Northern Ireland and Scotland should engage with the national clinical audit for rheumatoid and early inflammatory arthritis in order to drive improvement in the quality of services
Wales

• There is a lack of priority given to RMDs in Welsh policy frameworks
• There are consultant shortages adding to waiting times and follow-up delays, particularly in paediatric rheumatology, along with shortages in staff to administer medicines
• There is poor access to multi-disciplinary services and a lack of available clinic rooms
• Delays in access to biologics has been reported
• There has been an increase in outpatient appointments at English border hospitals

Recommendation 15

The Welsh Assembly Government should update the 2007 Directive for Arthritis and Chronic Musculoskeletal Services, in order to improve the prioritisation of RMDs in Wales
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