



Bringing medicines to *life*

Rheumatology Initiative

# RAising the game:

translating national policy into  
local action for rheumatoid  
arthritis services

December 2014



RAising the game has been developed and funded by the Association of the British Pharmaceutical Industry (ABPI) Rheumatology Initiative (RI).

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## The ABPI Rheumatology Initiative

The ABPI Rheumatology Initiative (ABPI RI) was set up in 2012. The member companies have come together to work collectively on major strategic projects and in collaboration with those responsible for treating and supporting patients with rheumatological conditions.

The principal objective of the group is to work with stakeholders from the rheumatology community and policy makers to raise awareness and improve quality of care for people with inflammatory arthritis.

Our vision for the group is to be recognised by policy makers and the NHS as a valued contributor to initiatives relating to the care pathway, and access to effective medicines for rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis.

Current members include AbbVie Ltd, Bristol-Myers Squibb Pharmaceuticals Ltd, Merck Sharp & Dohme Ltd, Pfizer Ltd and UCB.



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## National Rheumatoid Arthritis Society and British Society for Rheumatology

The initiative has also been supported by the National Rheumatoid Arthritis Society (NRAS) and the British Society for Rheumatology (BSR). Both organisations reviewed and provided comment on the report.



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## Foreword

The National Rheumatoid Arthritis Society (NRAS) and the British Society for Rheumatology (BSR) are pleased to endorse this major new report by the Association of the British Pharmaceutical Industry Rheumatology Initiative (ABPI RI).

The chronic autoimmune disease, rheumatoid arthritis (RA), affects around 580,000 people in England and can occur at any age, from 16 years upwards. Many of those affected are of working age and, proportionately, RA affects more women than men.

If left untreated, RA can severely impact patients: causing bone erosion, destruction of joints and permanent disability. The systemic nature of the disease means it can also damage other internal organs of the body, such as the heart, eyes and lungs.

The costs of poor clinical outcomes are not just borne by the patients themselves. Families, carers, friends, work colleagues, the NHS and society all pay a heavy price. The National Audit Office estimates that RA costs the NHS £560 million a year and total costs which include the NHS, carers, nursing homes, private expenditure, sick leave and work related disability amount to £3.8 to £4.75 billion each year.

The report assesses progress towards implementing the new Best Practice Tariff for Early Inflammatory Arthritis (BPT), audits coverage of RA and musculoskeletal (MSK) conditions within key strategic policy frameworks, and surveys the opinions of clinicians and commissioners tasked with bringing about the change we so urgently require.

We have known for some time that the quality of care for people with RA varies tremendously across England. The introduction of the BPT, along with data from the national clinical audit, will enable us to both highlight areas of best practice and identify where further improvements need to be made.

Whilst these initiatives are positive steps, the report identifies a number of challenges, including the incoherent nature of the reforms to date, which may compromise their effectiveness. For example, the introduction of a Quality Standard for RA has been undermined by a refusal, to date, to introduce equivalent indicators within the Clinical Commissioning Group Outcome Indicator Set. Improving the range and quality of RA data remains a key challenge and there is a need to make greater use of existing resources, such as the BSR's biologics registers, and explore what other data is required.

As evidenced in the report, strategic planning and prioritisation of MSK (including RA) within Joint Strategic Needs Assessments also remains disgracefully low; especially when considering the high proportion of local GP appointments taken up with these types of conditions and the indisputably high impact they have on a person's quality of life.

We commend the report for meticulously detailing the challenges and solutions to the problems, and urge commissioners and policymakers to work with us to fully implement its recommendations, which we believe will substantively improve patient outcomes.



  
**Professor Simon Bowman,**  
**President,**  
**British Society for Rheumatology**



  
**Ailsa Bosworth**  
**Chief Executive,**  
**National Rheumatoid Arthritis Society**

**580,000** people affected  
in England alone

with an estimated  
**26,000**  
new cases each year

**3** times more common  
in women than men

**75%** of people  
with RA are  
of working age

Each year RA costs the NHS

**£560m**  
and the wider economy

**40%** lose their jobs  
within 5 years due  
to the condition

**£4.75bn** **4 in 5** patients do not  
have a care plan

## Executive summary

Almost 580,000 people in England have rheumatoid arthritis (RA),<sup>1</sup> a debilitating disease which has significant resource implications for the NHS and the wider economy. The total cost of RA in the UK, including indirect costs and work related disability, has been estimated at between £3.8 billion and £4.75 billion each year.<sup>2</sup>

In 2009 the National Audit Office (NAO) published *Services for people with rheumatoid arthritis* in which it said that “action needs to be taken to improve overall outcomes for people with rheumatoid arthritis”.<sup>3</sup> The Public Accounts Committee’s (PAC) subsequent recommendations<sup>4</sup> were, however, largely ignored by the Government. More positively, the Quality Standard for rheumatoid arthritis, published by the National Institute for Health and Care Excellence (NICE) in 2013 and the Best Practice Tariff for Early Inflammatory Arthritis (BPT), introduced in April 2013, both provide policy direction and aim to support improvements in service delivery.

The Secretary of State for Health has also identified long term conditions (LTCs) as a priority area for the NHS and a recent report from the Health Select Committee on LTCs emphasises the need to improve commissioning and management in order to address the strain they place on the health service.<sup>5</sup>

RAising the game draws on research carried out by the ABPI Rheumatology Initiative (ABPI RI), assessing the extent to which such policies are having an effect and, more broadly, the priority attached to RA by local commissioners. It concludes that whilst there have been some efforts to improve RA services, much remains to be done, with only 5% of Joint Strategic Needs Assessments (JSNAs) mentioning RA, and poor data acting as a significant barrier to taking action.

Against that background, and in the context of recent changes to health and social care policy, the ABPI RI makes the following recommendations:

**1. The National Audit Office (NAO) should revisit its 2009 report, *Services for people with rheumatoid arthritis* and the subsequent recommendations made by the Public Accounts Committee (PAC)**

Since publication of the original reports, the NHS has been subject to major reform. The NAO's review needs to consider whether these reforms necessitate changes either to the PAC's recommendations or the mode of their delivery. The review should also consider the need to update epidemiological data for RA, assess what progress has been made against the recommendations and identify areas where further action is needed.

**2. National Institute for Health and Care Excellence (NICE) and NHS England (NHSE) should take steps to improve awareness of RA and use of existing commissioning tools**

RA commissioning tools have been developed but ABPI RI research suggests that they are not being capitalised on locally. NICE and NHSE should consider taking additional steps to raise awareness of these initiatives to help drive improvements in services. This could include:

- Undertaking a NICE Implementation Collaborative (NIC) pilot focused on overcoming the systematic issues surrounding the implementation of guidelines relating to inflammatory arthritis. The pilot should dovetail with the ongoing Healthcare Quality Improvement Partnership (HQIP) audit on early inflammatory arthritis, in order to monitor commissioning compliance with NICE guidance.

**3. Local commissioners should take steps to assess the burden of disease associated with RA and prioritise accordingly**

RA is a long term condition, which can be life limiting and has a major impact on quality of life.<sup>6</sup> RA increases the risk of co-morbidities including cardiovascular disease, cancer, osteoporosis and depression.<sup>7</sup> Local authorities and Clinical Commissioning Groups (CCGs) have a responsibility to assess fully the impact that RA has on their local population and to commission accordingly.<sup>8</sup> Actions might include:

- Local authorities, Health and Wellbeing Boards (HWBs) and CCGs working together to ensure that JSNAs and Health and Wellbeing Strategies (HWSs) assess the burden of musculoskeletal disorders in their local populations, including RA.
- Ensuring expert clinical and patient input into service planning and design.
- CCGs and local authorities working with voluntary sector organisations, healthcare professional bodies, and initiatives such as the Musculoskeletal Support Alliance, to better understand RA and what steps should be taken to support the needs of local populations.

#### **4. The Department of Health (DH) and NHSE should work in partnership with the Health and Social Care Information Centre (HSCIC), the Healthcare Improvement Partnership and Right Care to improve the quality of data and develop national indicators for RA**

Data is a critical currency in the new NHS, but almost everyone that we spoke to highlighted challenges in collating RA data as a factor preventing prioritisation or making it more difficult. This gap should be addressed without delay. Actions could include:

- Promptly publishing interim findings from the HQIP audit of RA.
- Undertaking a review of the data that is currently available and making practical recommendations for its improvement. This might include the use of non-NHS data from research units, the British Society for Rheumatology (BSR) and the HQIP audit, to inform the development of national data and indicators.
- Establishing a minimum requirement for data collection that would allow data on long term or musculoskeletal conditions to be disaggregated to different conditions, such as RA.
- Extending Right Care's *Atlas of Variation on 'Problems of the Musculoskeletal System'* to include data on early initiation of disease modifying anti-rheumatic drugs (DMARDs).
- Making data available on ambulatory care provision for RA.

#### **5. NHSE should review its systems for measuring performance for RA under the overarching improvement areas of the NHS Outcomes Framework (NHS OF)**

RA runs the risk of falling under the radar in overarching improvement areas and the ABPI RI research suggests that the lack of RA specific metrics is part of the reason why the condition is not prioritised locally. Some work has been undertaken in the rheumatology community to address this gap but, to date, it has had limited impact. Actions could include:

- Working with NICE and the HSCIC to develop RA specific indicators within the CCG Outcomes Indicator Set (CCG OIS), which align with the BPT. These might include indicators previously put forward to the CCG OIS committee.
- Assessing the metrics that have been developed in the rheumatology community to identify whether they could be rolled out more widely, or promoted via NHSE networks.
- Developing metrics with the RA stakeholder community based on the available data.

#### **6. The DH's Payment by Results team should review the payment threshold for the BPT, working to ensure that the barriers to implementation identified in this report are minimised**

Respondents to our survey and interviewees were complimentary about the aims of the BPT but stated that there were too many barriers preventing its implementation spanning financial and administrative problems. The year one best practice tariff covers only three months and does not include drug therapy costs or some specialist therapies. A tariff that covered a full year would provide a comprehensive package that could help to optimise uptake.

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## Realising national policy ambitions at a local level

### Summary:

Recent NHS reforms have introduced a variety of policy measures which are focused on long term conditions.<sup>9</sup> However, they are generic in nature<sup>11</sup> and often lead to conditions being overlooked, such as rheumatoid arthritis (RA), which have significant impact on NHS resources and the economy.<sup>10</sup>

The ABPI RI suggests that RA should be used as an ‘exemplar’ for the health reforms as only by making progress on improving outcomes for “unnamed conditions” such as RA will the model be shown to work.

### Impact of health reforms on local prioritisation

The measures introduced through the Health and Social Care Act 2012 had bold ambitions to modernise the NHS and improve outcomes for patients.<sup>12</sup> Under the new arrangements it is for local commissioners and NHS England (NHSE) to establish what steps are needed to deliver improved outcomes for long term conditions (LTCs). In its leadership role, NHSE has already identified a number of areas for action:<sup>13</sup>

- Helping patients take charge of their care
- Enabling good primary care
- Ensuring continuity of care
- Ensuring parity of esteem for mental health
- House of Care – a strategic framework for integrated care for people with LTCs
- Reducing avoidable emergency admissions

These areas recognise the similarities between LTCs and suggest commissioning approaches that may help to improve services. However, although RA falls within the DH definition of LTCs, it has historically not been treated as such by commissioners.<sup>14</sup> Furthermore, these overarching statements do not take into account the co-morbidities that many patients with RA have to deal with on a daily basis.

In order to deliver against the LTC improvement areas in the outcomes frameworks, the ABPI RI suggests that actions will need to be tailored for different conditions. Aside from a few case studies setting out commissioning approaches,<sup>15</sup> NHSE has tended to leave prioritisation decisions up to CCGs as they are best placed to understand the needs of their local population. However, there are a number of factors which might influence prioritisation:

- **Financial:** The focus on short term efficiency savings means that commissioners may choose to focus on initiatives that will deliver a return on investment quickly, over longer term savings. Return on investment will also need to be recovered locally rather than taking into consideration the financial impact on the wider NHS or economy more generally.
- **Information:** Prioritisation is often driven by analysis of data. Where information is plentiful there is generally more prioritisation.<sup>16</sup>
- **Outcome measures:** Commissioners tend to focus on areas where specific outcome measures have been identified as they will be actively monitored by NHSE and the DH to assess local performance.
- **National strategies:** The existence of a national strategy or Strategic Clinical Network (SCN) with oversight and regular progress reporting is another factor that drives prioritisation.

For RA, a combination of these factors reduces the likelihood of prioritisation by commissioners, as evidenced in our discussions with CCGs, which are set out on pages 15-17.

## Why is it important to prioritise rheumatoid arthritis?

RA is a chronic and progressive autoimmune disease which affects approximately 580,000 people in England<sup>17</sup> with an estimated 26,000 new cases diagnosed each year.<sup>18</sup> Although RA is more common in older people, three quarters of those diagnosed with RA are of working age and it is, therefore, estimated to have a significant impact on the economy as well as costing the NHS approximately £560 million each year.<sup>19</sup>

### RA and unemployment

- 40% of people with RA lose their jobs within five years of diagnosis because of their condition.<sup>20</sup>
- Of this 40%, between 14% and 20% leave work within one year of diagnosis and between 25% and 33% leave work within two years.<sup>21</sup>
- Based on this information, Arthritis Research UK calculated that between 970–1,590 people will give up work in their first year after diagnosis each year in the UK because of their RA.<sup>22</sup>
- The total cost of RA in the UK, including indirect costs and work related disability, have been estimated at between £3.8 billion and £4.75 billion in the UK each year.<sup>23</sup>

Whilst often grouped under the MSK banner, the needs of this group of patients are distinct.<sup>24</sup> Further detail on the RA environment in England can be found in Appendix 1.

The reasons to prioritise RA are clear:

- By identifying people with RA and initiating treatment earlier, the chances of disease remission are maximised, greatly improving patient experience and outcomes.<sup>25</sup>
- Regular reviews and access to rheumatologists can help people to manage their condition and symptoms effectively.<sup>26</sup>
- 2009/10 reports from the National Audit Office (NAO) and Public Accounts Committee (PAC) identified that improving early diagnosis and treatment of people with RA would contribute significantly to the economy, and in the longer term, deliver savings for the NHS.<sup>27</sup>

Despite this, a report published by Arthritis Care in 2012 concluded that of the nine recommendations presented to the government in the PAC report, six were not delivered and of the three that were partially delivered, the impact was questionable.<sup>28</sup> Research carried out by National Rheumatoid Arthritis Society (NRAS) in 2010 also found that 12 months after the NAO review, only 27% of NRAS members had access to a personalised care and management plans.<sup>29</sup> The recommendations need to be revisited in the context of the new NHS arrangements. A full list of the NAO recommendations is available in Appendix 2.

Furthermore, the research set out below (pages 15-17) suggests that despite some efforts to prioritise RA nationally, it is not a condition that is prioritised on a local level. This lack of progress is disappointing given the long term pressures on the NHS and the potential improvements that could be achieved through earlier diagnosis and treatment. If NHSE is to secure improvements against the NHS Outcomes Framework and deliver the transformational change needed to fill the NHS funding gap, action on conditions like RA is essential.

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## Rheumatoid arthritis as a policy priority

### Summary:

Without the focus provided by a national strategy, Strategic Clinical Network (SCN) or specific outcomes measures, rheumatoid arthritis (RA) is faced with anonymity. While the appointment of a National Clinical Director for Musculoskeletal Conditions was a step in the right direction, this post covers over 200 conditions, raising the challenge of prioritisation.

Recent policy developments at a national level such as the Quality Standard for RA and the Best Practice Tariff for Early Inflammatory Arthritis (BPT) indicate an awareness of the need for action surrounding RA. How and whether such initiatives drive the necessary improvements will need to be assessed through their implementation on the ground.

### Impact of health and social care service reforms on RA

#### Outcomes frameworks

Health and social care service reforms have led to the introduction of a mixture of generic and condition-specific levers and incentives including outcomes frameworks across health, public health and adult social care. The generic nature of these frameworks means that while they include indicators that have relevance to RA, they do not identify the condition explicitly, raising concerns about whether this approach will lead to specific improvements in health and employment for people with RA. The relevant indicators for RA are set out in Appendix 3.

#### Clinical Commissioning Outcomes Indicators Set (CCG OIS)

The CCG OIS is intended to provide CCGs, Health and Wellbeing Boards, local authorities and patients and the public with information about the quality of health services being commissioned by CCGs. The measures are developed from NHS Outcomes Framework (NHS OF) indicators and are chosen on the basis that they contribute to the overarching aims of the five domains of the NHS OF. They also include indicators from NICE Quality Standards. A number of RA indicators were considered by the CCG OIS committee in 2013 including:

- Of people referred with suspected early inflammatory arthritis, the proportion who attend the rheumatology service within three weeks of the referral; and
- Of people with newly diagnosed rheumatoid arthritis, the proportion who receive short term glucocorticoids and (a combination of disease-modifying anti-rheumatic drugs) from a rheumatology service within six weeks of referral.

However, the CCG OIS committee decided not to recommend these indicators as it was felt that they were covered by other incentives such as the BPT, which missed an opportunity to align and strengthen the indicators for RA. The committee also stated that as this data was only collected locally, it could not support a national indicator. This raises concerns about the impact that poor data has on the potential to prioritise RA.

#### National strategies, SCNs and clinical directors

Therapy areas where additional guidance, incentives or national clinical directors (NCDs) are in place, may be more likely to be prioritised by commissioners. Figure 1 compares a range of long term conditions (LTCs), looking at whether a national strategy has been established and if an NCD has been appointed since 2010. These conditions and the number of people affected were identified in the Department of Health's (DH's) compendium of LTCs published in 2012.<sup>30</sup> Instructively, RA was missing from this compendium but the relevant information has been added to allow comparison.

**Figure 1: National prioritisation of long term conditions**<sup>31</sup>

Type of LTC	Number affected in England 2012 <sup>32</sup>	National clinical director (NCD)?	National strategy?	Strategic Clinical Network (SCN)?
Hypertension	7,460,000	Professor Huon Gray, NCD for Heart Disease	Cardiovascular disease (CVD) outcomes strategy: improving outcomes for people with or at risk of CVD (2013)	CVD
Depression	4,878,000	Dr Geraldine Strathdee, NCD for Mental Health	The Mental Health Strategy for England (2011), several DH driven policies have also been published	Mental health, dementia and neurological conditions
Asthma	3,273,000	Mike Morgan, NCD for Respiratory Services	An outcomes strategy for people with chronic obstructive pulmonary disease (COPD) and asthma in England (2011)	
Diabetes	2,456,000	Professor Jonathan Valabhji, NCD for Obesity and Diabetes	Cardiovascular disease (CVD) outcomes strategy: improving outcomes for people with or at risk of CVD (2013) and Action on diabetes (2014)	CVD
Coronary heart disease (CHD)	1,878,000	Professor Huon Gray, NCD for Heart Disease	Cardiovascular disease (CVD) outcomes strategy: improving outcomes for people with or at risk of CVD (2013)	CVD
Chronic Kidney Disease (CKD)	1,855,000	Richard Fluck, NCD for Renal Disease	Cardiovascular disease (CVD) outcomes strategy: improving outcomes for people with or at risk of CVD (2013)	CVD
Hypothyroidism	1,667,000			
Stroke / TIA	944,000	Tony Rudd, NCD for Stroke	Cardiovascular disease (CVD) outcomes strategy: improving outcomes for people with or at risk of CVD (2013)	CVD
Chronic Obstructive Pulmonary Disease (COPD)	899,000	Mike Morgan, NCD for Respiratory Services	An outcomes strategy for people with chronic obstructive pulmonary disease (COPD) and asthma in England (2011)	
Cancer	876,000	Sean Duffy, NCD for Cancer	Improving outcomes: A strategy for cancer (2011)	Cancer
Atrial fibrillation (AF)	791,000	Professor Huon Gray, NCD for Heart Disease	Cardiovascular disease (CVD) outcomes strategy: improving outcomes for people with or at risk of CVD (2013)	CVD
Rheumatoid arthritis	580,000 <sup>33</sup>	Peter Kay, NCD for Musculoskeletal Services		
Mental Health	438,000	Dr Geraldine Strathdee, NCD for Mental Health	The mental health strategy for England (2011), several DH driven policies have also been published	Mental health, dementia and neurological conditions
Heart failure	393,000	Professor Huon Gray, NCD for Heart Disease	Cardiovascular disease (CVD) outcomes strategy: improving outcomes for people with or at risk of CVD (2013)	CVD
Epilepsy	337,000	David Bateman, NCD for Chronic Disability and Neurological Conditions	NHS England-led Strategic Clinical Networks (SCNs) are in place for neurological conditions	Mental health, dementia and neurological conditions
Dementia	267,000	Alistair Burns, NCD for Dementia	NHS England-led Strategic Clinical Networks (SCNs) are in place for neurological conditions	Mental health, dementia and neurological conditions

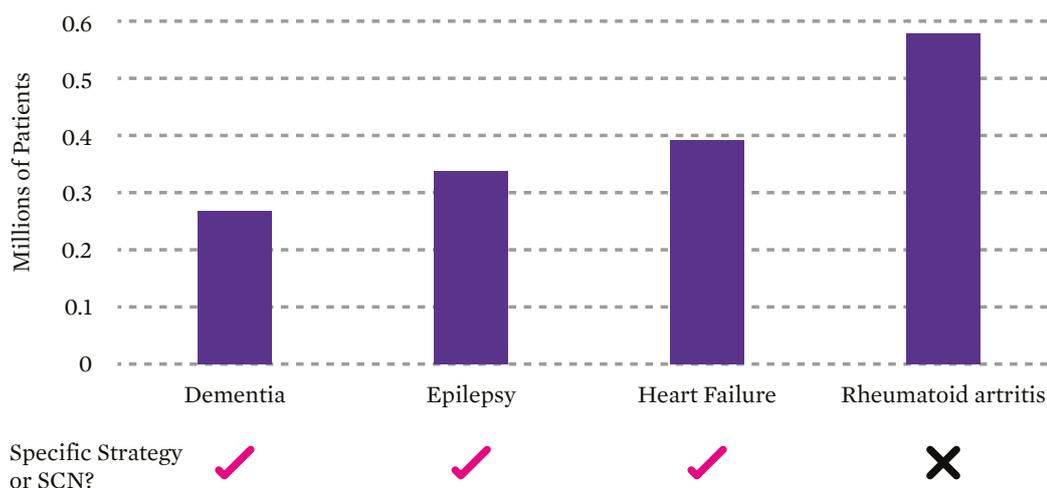
15 of the 16 LTCs above have an NCD. However, the number of conditions that fall within each NCD's remit vary significantly and the emphasis they are able to give to specific conditions within their remit will not be consistent. For example, the NCD for stroke will be able to adopt a focused approach to service improvement. Conversely, the NCD for musculoskeletal conditions covers over 200 conditions, making prioritisation challenging.

Where national strategies exist, these provide useful guidance for commissioners, especially where they include specific key performance indicators. Successive reports from the

rheumatology community have highlighted the need for a national strategy for musculoskeletal services.<sup>34,35</sup> Yet recent trends suggest that the introduction of new condition-specific strategies is increasingly unlikely. Analysis of the table above suggests that aside from respiratory conditions and hypothyroidism, MSK (including RA) is the only condition that is not covered by an SCN. In lieu of a nationally funded network, the Arthritis and Musculoskeletal Alliance (ARMA) is working in partnership with the NCD for MSK to look at the best ways of supporting the development of MSK clinical networks in England.<sup>36</sup> This work has had some early support from the Department of Health.

As Figure 2 shows, when compared to conditions with smaller populations, which have a strategy or an SCN, it is both surprising and concerning that MSK (including RA) has neither.

**Figure 2: Rheumatoid arthritis compared to other long term conditions**



### National recognition of need to prioritise RA

Although there is no national strategy for RA and poor progress has been seen against the PAC and NAO recommendations, there has been some notable action at a national level including:

- The development of a Quality Standard for rheumatoid arthritis, published in June 2013.
- The introduction of the Best Practice Tariff for Early Inflammatory Arthritis, introduced April 2013.
- The inclusion of indicators in the quality and outcomes framework (QOF), introduced in 2013/14 but reduced substantially in the 2014/15 QOF.
- A national clinical audit of rheumatoid and early inflammatory arthritis as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP), overseen by the Healthcare Quality Improvement Partnership (HQIP).

Further details on these initiatives are set out in Appendix 4.

### Commissioning support

A number of materials have been developed to support commissioners. For example, NHS England has produced Commissioning for Value packs, which provide CCGs with data showing where they can improve outcomes and make efficiency savings.<sup>37</sup> The main focus of these packs is to assess the top nine areas of programme budgeting expenditure and identify where a CCG can make savings across elective admissions, non-elective admissions and rescribing. Musculoskeletal conditions are included within this analysis but there is no breakdown of what elements of musculoskeletal care should be focused on to deliver these savings.<sup>38</sup>

Following the publication of Innovation, Health and Wealth in 2011, NICE also established the

NICE Implementation Collaborative (NIC) in order to drive implementation of NICE guidance where there was felt to be slow or inconsistent uptake across the NHS.<sup>39</sup> To date, pilots related to four specific pieces of NICE guidance have been progressed, although future work is likely to focus on systematic issues with regard to implementation.

Some RA specific resources have also been developed, some of which are listed in Figure 3. For example, the British Society for Rheumatology, the National Rheumatoid Arthritis Society and Arthritis Care also provide commissioning support in the form of the Musculoskeletal Solutions Alliance and Professor Peter Kay, the NCD for MSK has also undertaken to produce a commissioning resource which will be available on the NHS England website.

**Figure 3: Commissioning tools for RA**

#	Organisations	Document	Date
1	NRAS	Commissioning for Quality in Rheumatoid Arthritis (CQRA)	2014
2	BSR	Commissioning Toolkit for Providers	2013
3	NICE	Rheumatoid arthritis commissioning and budgeting tool	Jun-13
4	NICE	Support for commissioning for rheumatoid arthritis	June 2013
5	Right Care	Delivering an integrated Musculoskeletal Service in Oldham	2012

Despite the various efforts to provide guidance in this area, the information is diffuse and is yet to demonstrate tangible results.

### Data on RA services and outcomes

A lack of national data in RA means that it is difficult to develop an informed picture of the cost and quality of RA services as a discrete subset of musculoskeletal services. While Hospital Episode Statistics (HES) provide some insight, chronic and complex care with co-morbidities are not sufficiently addressed through the measurement of episodic care. For example, follow up ratios are not appropriate for people on lifelong drug therapy. Plans to move to Care Episode Statistics (CES) may help to develop a fuller picture of RA services, but only if this is accompanied by improved coding for RA.

Other relevant RA data which can be drawn on includes that collected by rheumatology units as part of their research, as well as the BSR's Biologics Register, which is the largest in Europe. The HQIP audit may also help to address this data gap, but the true value of such audits tends to be realised in the longer term once a bank of data has been developed to allow informed comparison. It is also important to consider that the audit only applies to the first three months of each newly registered patient. RA is a long term condition and it is, therefore, necessary to collect longitudinal data, reflecting different stages of the disease. Moreover, chronic and complex conditions with co-morbidities require measurements that are not focused on episodic care and are able to describe the management and costs of ambulatory conditions such as RA.

There is evidence to support the need for prioritisation of RA (NAO, PAC) but even in areas with significant local need, a lack of data may prevent commissioners from making a full assessment of RA services and taking necessary action.

## Local Reality

### Summary:

The ABPI Rheumatological Initiative (ABPI RI) has undertaken a range of research and analysis to better understand

- i) to what extent rheumatoid arthritis (RA) is being prioritised at a local level and
- ii) to what extent national initiatives such as the best Best Practice Tariff for Early Inflammatory Arthritis (BPT) and the Quality Standard for rheumatoid arthritis are having an impact on local services.

ABPI RI's assessment of Joint Strategic Needs Assessments (JSNAs) and Health and Wellbeing Board (HWB) strategies found that prioritisation of RA in these documents was very low. Less than 5% of JSNAs and less than 1% of HWB strategies mention rheumatoid arthritis specifically.

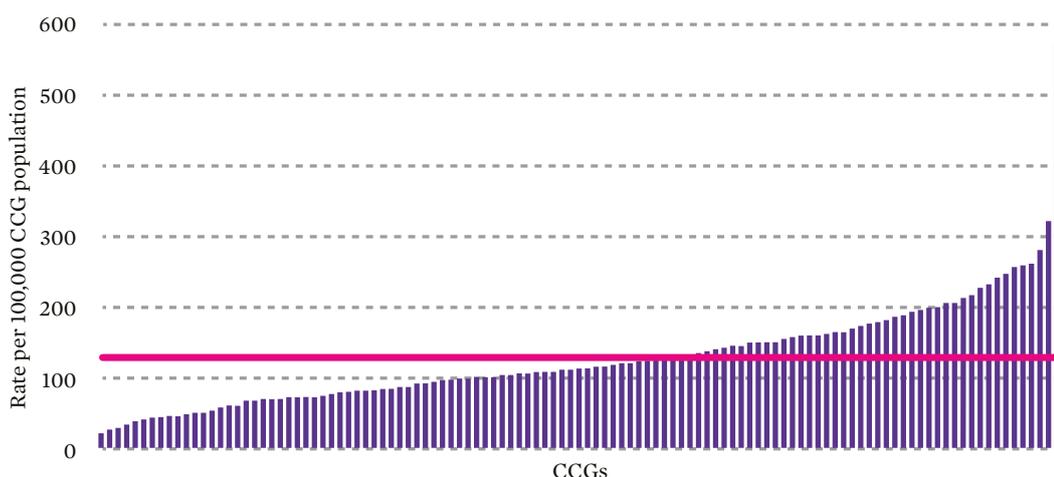
ABPI RI's research found that the decision to prioritise RA, usually as part of a larger musculoskeletal programme, was ad hoc. Awareness amongst commissioners of policies such as the Quality Standard and (BPT) was relatively low.

We also found that there is significant support for the BPT for EIA amongst clinicians. However, there are challenges facing broader implementation of the BPT for EIA.

To better understand the level of local prioritisation, ABPI RI looked to assess relevant data which was very limited in its scope.

The average admissions rate for RA across England is 127 per 100,000 population. There is a 27 fold variation between Clinical Commissioning Groups (CCGs) in the number of RA admissions per 100,000 CCG population – ranging from 21 per 100,000 in NHS Lancashire North CCG to 570 per 100,000 in NHS Walsall CCG. This significant variation is shown in Figure 4.

**Figure 4: RA admissions per 100,000 CCG population**<sup>40</sup>



It is unlikely that the differences in admission rates can be explained by solely demographic variations, suggesting that approaches to managing RA could vary significantly between CCGs. Furthermore, admissions data alone do not reflect the nuances of RA care. Data should be made

available on ambulatory care provision for RA and how this relates to other parts of the pathway such as emergency admissions.

Given the variation in RA admissions (page 13) and the lack of information available on RA services and outcomes set out above (page 12), the ABPI RI has undertaken a range of analysis to understand the extent that RA is being prioritised at a local level and the extent that national initiatives such as the BPT and the Quality Standard for rheumatoid arthritis are having an impact on local services.

The research includes:

- An assessment of JSNAs and HWB strategies.
- Telephone interviews with CCG representatives.
- A survey of rheumatologists on the BPT for EIA.
- Telephone interviews with rheumatologists on the BPT and viewpoints on commissioning.

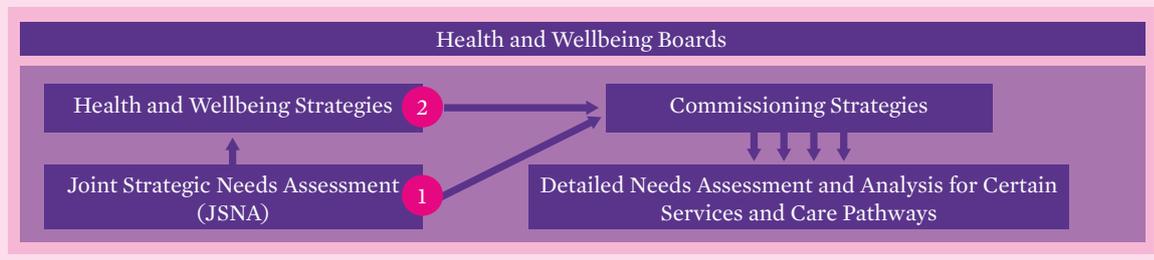
Further details of our methodology are set out in Appendix 5.

### Local needs assessments for RA

At a local level, prioritisation of particular conditions should be based on an assessment of local needs undertaken by local authorities through JSNAs and HWB strategies.

#### JSNAs and HWB strategies

JSNAs analyse the health needs of populations in order to inform and guide commissioning of health, wellbeing and social care services within a local authority area. The NHS and upper tier local authorities have had a statutory duty to produce an annual JSNA since 2007. HWB strategies set out a strategy for addressing the needs identified by the JSNA. They were introduced with the Health and Social Care Act 2012.



In 2008, the Department of Health and Association of Public Health Observatories published a JSNA core dataset to inform local JSNA development. This does include reference to musculoskeletal conditions and arthritis but no mention is made of RA.<sup>41</sup> The ABPI RI's assessment of JSNAs and HWB strategies found that prioritisation of RA in these documents is very low. Less than 5% of JSNAs and less than 1% of HWB strategies mention rheumatoid arthritis specifically. Details of some of these mentions are set out in the box below.

#### Rheumatoid arthritis in JSNAs and HWB strategies

- South Tyneside referred to RA in the context of residents of nursing homes with musculoskeletal and long term conditions (South Tyneside JSNA (2012-13), p11)
- Telford and Wrekin had a specific project for RA: Rheumatoid Arthritis Group / care pathway (map of medicine) listed in their JSNA. A new Community Rheumatology Service (CRS) opened in Telford in August 2010 (Telford and Wrekin JSNA (2009), p11)

- Waltham Forest included RA as an ambulatory care-sensitive condition in the context of musculoskeletal conditions (Waltham Forest JSNA (2012-13), p226)
- Liverpool reported that 463 Disability Adjusted Life Years (DALYs) were attributed to RA (Liverpool JSNA (2012), p15)
- Some plans recognised the effects of poor housing (damp, mould, poor heating and insulation, lack of handrails to stairs and structural defects) exacerbating long term conditions such a musculoskeletal conditions, rheumatism and arthritis. However, the use of these terms is vague and does not always identify RA specifically. (Blackburn with Darwen JSNA (2013), p73; Calderdale HWB strategy (2012-22), p23)

It was unclear whether the 10.5% of JSNAs and 3% of HWB strategies that mentioned arthritis more generally were referring to osteo or inflammatory arthritis, which is a very important distinction to make. Reference to arthritis was mostly made in relation to discussion of the burden of many different long term conditions (St Helens JSNA (2012), p21).

25% of JSNAs mentioned musculoskeletal conditions and the term was included in 8.5% of HWB strategies. Some referred to this in the context of public health and the need for physical activity to reduce the risk of developing musculoskeletal conditions (Durham, Central Bedfordshire and Cornwall). Others mentioned the impact that musculoskeletal conditions have on working and days lost due to ill health (Essex, Kirklees, and Nottinghamshire).

JSNAs and HWB strategies are developed with the intention of informing the provision of health and social care services which meet local need. The ABPI RI's analysis of these planning documents suggests that prioritisation of RA services based on these documents is highly unlikely. Although musculoskeletal conditions as a whole feature more prominently, the breadth of the conditions would make it difficult for commissioners to pinpoint what types of services would be required to meet that need. Moreover, as it is the responsibility of local authorities to undertake awareness raising campaigns,<sup>42</sup> it is concerning that MSK and RA in particular, have such a low profile.

## Commissioner approaches to RA

### Impact of local needs assessment on commissioner behaviour

In order to assess the impact that the JSNAs and HWB strategy have had on commissioning prioritisation, the ABPI RI has compared those areas that have identified musculoskeletal conditions within their JSNAs or HWB strategies with the areas where we know that CCGs have launched public tenders for musculoskeletal services. This was in order to assess whether JNSAs and HWB strategies have an impact on CCGs' planning and prioritisation.

It should be noted that this is a crude analysis as it does not take into account more informal changes that CCGs may have made to musculoskeletal services. Furthermore, tenders are often initiated as a result of other factors such as waiting times or when a provider states that they no longer wish to run a particular service.

Of the 54 local authorities that mentioned one of our search terms (rheumatoid arthritis, rheumatism, rheumatology, inflammatory arthritis, musculoskeletal) in either the JSNA, HWB strategy or both, only four corresponding CCGs have either begun work on or published a tender for musculoskeletal services. These are Bexley CCG, Bedfordshire CCG, Greenwich CCG and Sheffield CCG.

The ABPI RI is also aware of the following tenders for musculoskeletal services that have been initiated in areas where local planning documents do not highlight musculoskeletal or RA.

- NHS Brent CCG
- NHS Brighton & Hove CCG

- NHS Coastal West Sussex CCG
- NHS Crawley CCG
- NHS East Lancashire CCG
- NHS Eastbourne, Hailsham and Seaford CCG
- NHS High Weald Lewes Havens CCG
- NHS Horsham and Mid Sussex CCG
- NHS Newham CCG

This disparity indicates that JSNAs and HWB strategies do not have a significant role to play in influencing commissioner decisions on whether to prioritise RA or musculoskeletal conditions.

### Understanding commissioner approaches

In order to understand when and why commissioners prioritise RA and musculoskeletal services, the ABPI RI undertook telephone interviews with commissioners about the processes behind their decision making (see Appendix 5).

#### Reasons for prioritising

Among the commissioners that have chosen to prioritise commissioning in this area, it is often local, anecdotal evidence that has led to these decisions, for example:

*“The decision was largely based on anecdotal evidence from primary care clinicians and what we knew about the existing rheumatology service which was largely offered in one hospital.”*

**Dr Diane Bell, Bedfordshire CCG**

*“[RA was identified as a priority] partly because of pressures on finance and partly due to the number of referrals into rheumatology going up. Biologics have also been an increasing cost pressure that the CCG has been aware of.”*

**Dr Tim Wilkinson, Portsmouth CCG**

One CCG specifically stated that an approach by the British Society for Rheumatology (BSR) had led to prioritisation of rheumatology commissioning and that standard needs assessment tools had not identified a particular issue.

*“One of the reasons that RA wasn’t identified was that it was very difficult to get the data... the way in which RA is coded means that it can be very difficult to work out the costs of RA. It’s very difficult to unpick all the different tariffs.”*

**Lynn Talbot, Wiltshire CCG**

Where data and information were a contributing factor to the decision to prioritise, it was a result of further analysis rather than using standard information that is available, for example:

*“JSNA is a starting point that is used as a basis for drilling down to localities, looking at disease prevalence...Musculoskeletal review came out of this analysis. [Through] benchmarking against other systems, this area of Sussex was identified as a particular outlier in terms of secondary care referrals and spend for orthopaedics, rheumatology etc – higher even when taking [the] demographic profile into account.”*

**Ashley Scarff, High Weald Lewes Havens CCG**

In Brent CCG, the decision to focus on musculoskeletal conditions was based on awareness of the need for overarching change in the NHS. As a clinical area with a traditional outpatient service, musculoskeletal services were seen as an area where a move to a community setting might be beneficial. Interestingly, this was the only area that highlighted national tools as supporting the decision for prioritisation in our telephone interviews.

*“We have the DH framework for MSK services and a lot of guidance available from the NHS or Right Care about how services could be commissioned in a more effective way.”*

**Jatinder Garcha, Brent CCG**

Among the CCGs that we spoke to there was relatively low awareness of the national tools to improve RA commissioning, such as the Quality Standard and BPT for EIA. Although commissioners were aware of the need to follow NICE guidelines, many suggested that under their new prime contractor model this level of engagement on service content would now be undertaken by their new contractor in conjunction with providers.

### **Reasons for not prioritising**

Data was the main barrier to prioritisation identified by CCGs. This was also highlighted as making the commissioning process more difficult for those CCGs that had chosen to prioritise RA or musculoskeletal services.

Issues around coding means that drawing out data on RA can be very difficult. Concerns were also raised regarding legal restrictions introduced through the Health and Social Care Act 2012, which prevent commissioners from accessing patients’ identifiable data, making it more difficult to understand the situation on the ground, for example:

*“It’s now a lot harder for us to dig down and find out what has been going on with patients. That data was used for redesign – but [now] we’re not allowed to look at those patients and see what happened.”*

**Moneeza Iqbal, Manchester CCG**

*“The lack of local data for RA means that it is hard to see where patients get referred and where they end up. Our CCG routinely receives a number of freedom of information (FOI) requests for...long term conditions. Despite the best efforts of our analyst, who extracts information ranging from local risk management and hospital data to national-level datasets, we are still unable to provide adequate responses to some of those FOIs.”*

**Fiona Callaghan, Nottingham City CCG**

*“Access to benchmarking data would be a big part of that. There is a gap in quality data for these services...there is not that much out there.”*

**Jatinder Garcha, Brent CCG**

Conditions that have a shorter term impact on mortality are often prioritised over RA. CCGs that we spoke to had used the NHS England Commissioning for Value Packs<sup>43</sup> which tend to focus on conditions that impact on overall mortality rather than morbidity. It is likely that the problems that commissioners are encountering on a local level in terms of RA data also have an impact on the advice that is given on a national level.

### **Awareness raising**

Raising awareness of RA with the general public, as well as with clinicians, is important for driving up diagnosis. Among the commissioners we spoke to, none had formally assessed the awareness of RA in their local area. However, in those CCGs where RA had been prioritised, it was reported that some engagement activity had taken place around awareness of RA. This was particularly evident in those CCGs that were undergoing tender processes for their MSK services.

## Clinical responses to national policy

As outlined earlier in the report, there has been some notable action at a national level on rheumatology. Based on the ABPI RI's analysis of local planning and commissioning set out above, there was concern that national policy initiatives were not having the desired impact on the ground and would, therefore, be limited in their ability to drive up the quality of RA services.

In order to develop a better understanding of the implementation and impact of the BPT for EIA since its introduction in 2013, the ABPI RI carried out a short survey of rheumatologists and rheumatology nurse specialists in partnership with BSR (see Appendix 5). Alongside the survey the ABPI RI also spoke to a number of rheumatologists (see Appendix 5).

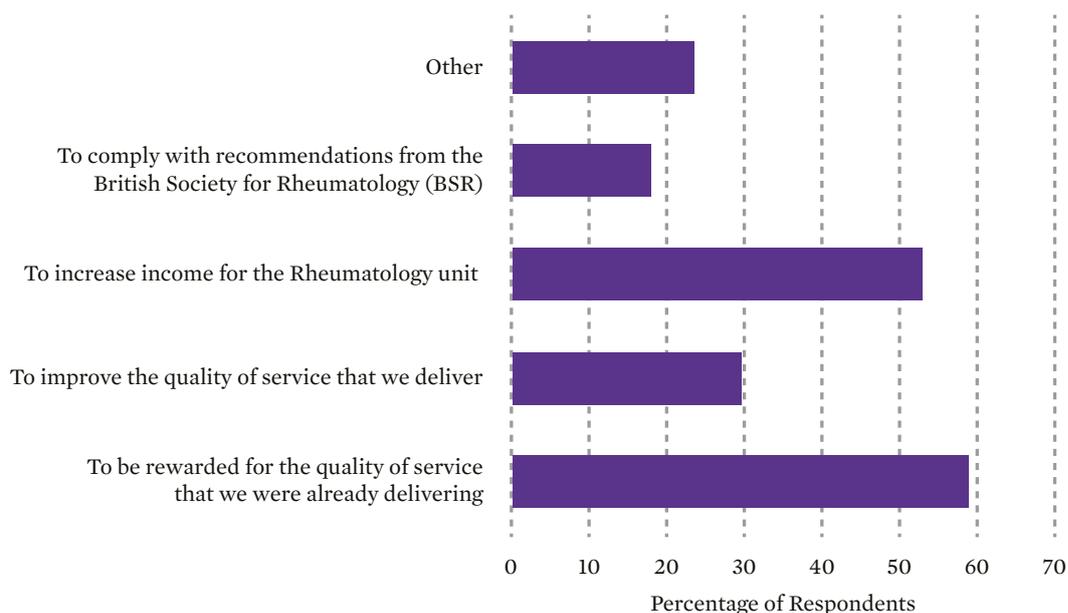
Having undertaken this research the ABPI RI has a better understanding of some of the real benefits that such policies have to offer RA, as well as uncovering some of the barriers to implementing national policies at a local level.

## Implementing the BPT

Of the 50 participants that responded to the survey approximately 57% reported that their rheumatology unit had not yet implemented the BPT and 36% reported that their unit had implemented the tariff.

For the 36% of respondents whose unit had opted into the BPT we asked what had driven this decision. The results are presented in Figure 5.

**Figure 5: Why did you decide to implement the BPT for EIA? (Please select all that apply)**



Almost 60% of respondents who had opted into the BPT answered that they did so because they were already delivering a high quality service which was in line with the BPT. This suggests that in these units, opting into the BPT would not necessarily deliver improvements to the service. However, opting into the BPT might help to ensure that standards remain high. Just under 30% of respondents indicated that they were implementing the tariff in order to improve the quality of RA services delivered.

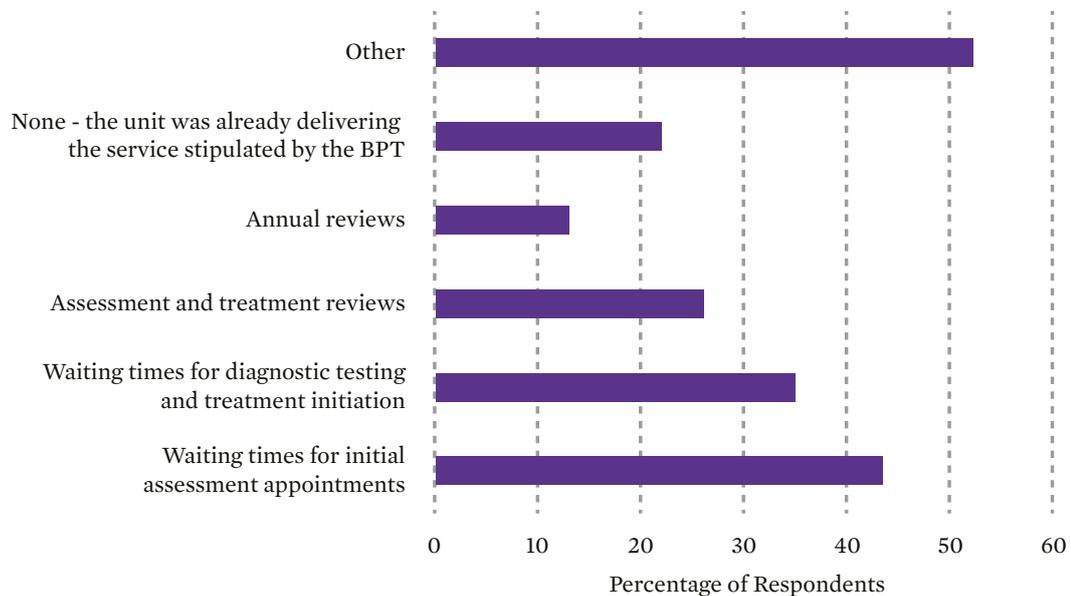
30% of respondents implemented the BPT for EIA to improve the quality of RA services delivered

23% of respondents stipulated other reasons for implementing the tariff. A number of these respondents reported that they were using the BPT as a lever to get managers to make changes to the service, in particular to introduce early inflammatory arthritis clinics.

**Improving services**

The survey also asked respondents what steps they had taken to improve services in order to qualify for BPT. The results are presented in Figure 6.

**Figure 6: What steps has your rheumatology unit taken to improve services in order to qualify for BPT for EIA payments? Multiple responses allowed.**



Respondents also identified a number of other improvements which had been made to their rheumatology service. These include improving access to ultrasounds to expedite diagnosis, and changes to coding to ensure that EIA was picked up. One unit had also moved its EIA clinic from Mondays to Wednesday in order to prevent patients from missing appointments due to bank holidays.

**Deciding not to implement the tariff**

Where respondents reported that their RA unit had not implemented the tariff we asked them why. 33.3% of respondents indicated that it was not financially viable to deliver the services as set out in the BPT for EIA, and 23.3% said that they already delivered a high quality services and were reimbursed via standard payment by results tariff. The survey also asked respondents to identify any other reasons why the BPT had not been implemented. Some of the key themes which emerged are outlined on the right.

## Financial incentives and limitations

Of the 33.3% of respondents who reported that the BPT was not financially viable for their unit, a number of respondents went on to elaborate in more details. For example, some felt that as their unit was already delivering a high quality service, the incentive provided by the BPT was not great enough:



33.3% of respondents indicated that it was not financially viable for their unit to deliver the services as set out in the BPT for EIA

*“[The] finance department don’t think it will be financially better off. We tend to see new patients pretty quickly anyway (5 weeks) but don’t have the facility to follow up as much as we ought to”*

**Response to survey on the Best Practice Tariff for Early Inflammatory Arthritis**

Others reported that the BPT would not guarantee that the unit was better off.

*“We already have monthly nurse led review clinics for early arthritis patients and so BPT would pay less than we receive through standard tariff.”*

**Response to survey on the Best Practice Tariff for Early Inflammatory Arthritis**

There was also some suggestion that where clinical teams might be interested in implementing the tariff, it was more difficult to convince management of the benefits brought about by the tariff.

*“Although we discussed it with the Trust, the Trust was not interested to help implement it, probably as it does not really provide a financial benefit, but we do deliver a high quality service in any case.”*

**Response to survey on the Best Practice Tariff for Early Inflammatory Arthritis**

## Challenge of service delivery

One of the reasons identified by respondents for not implementing the BPT was that they were unable to meet the necessary criteria. The BPT for EIA stipulates that people referred with suspected EIA should have their first specialist appointment within three weeks of the referral date. Meeting this target was identified as a significant challenge, for example:

*“Too stringent criteria regarding first appointment and subsequent follow up”*

**Response to survey on the Best Practice Tariff for Early Inflammatory Arthritis**

Another barrier raised in relation to delivering the BPT was the allocation of staff time and the need for additional members of staff to deliver the service, for example:

*“The main problem is that there is not enough staff. The business case made to the Trust was that they needed another consultant in order to perform in line with BPT.”*

**Response to survey on the Best Practice Tariff for Early Inflammatory Arthritis**

*“[We have] no resources available to deliver BPT, no full time rheumatology nurse having gone down from a full time band 7 and band 6 nurse to just one part-time band 5 nurse.”*

**Response to survey on the Best Practice Tariff for Early Inflammatory Arthritis**

## IT and processes

Organisational limitations were also identified as a barrier to successfully implementing the BPT for EIA. IT systems and data collection in particular were identified as barriers, particularly where new investment would be required in order to collect the relevant data, for example:

*“[We] can’t collect the relevant data as our IT systems aren’t up to it. There has been an effort by rheumatologists to implement [the BPT] but we can’t code for EIA patients. We are capable [of delivering the service] and probably do meet a lot of the standards but organisation isn’t good enough.”*

**Response to survey on the Best Practice Tariff for Early Inflammatory Arthritis**

### **Concerns regarding best practice**

Concerns were also raised about whether the BPT supported best practice, in particular, how and whether referrals were triaged and the impact this had on the service, for example:

*“Our pro forma is now not fit for purpose and the EIA service is full of inappropriate patients with not enough time in clinic for doctors and not enough practitioner support”*

**Response to survey on the Best Practice Tariff for Early Inflammatory Arthritis**

There were also some concerns raised about the frequency at which patients were seen, for example:

*“If all patients are sent to RA [services] that is not best practice. It’s important to be selective but the tariff doesn’t recognise that and increases mis-referral. It’s not cost effective to send everyone to RA - there should be a triage process.”*

**Response to survey on the Best Practice Tariff for Early Inflammatory Arthritis**

*“Our current arrangement gives us flexibility to see patients more frequently than the tariff allows if necessary.”*

**Response to survey on the Best Practice Tariff for Early Inflammatory Arthritis**

### **Improving the BPT for EIA**

The survey also asked respondents whether they had any suggestions as to how the BPT for EIA could be improved.

### **Funding and incentives**

Resource and funding issues again emerged as one of the biggest concerns with a significant number of respondents commenting that the financial incentives simply were not sufficient to incentivise Trusts to implement the BPT, even when clinical teams might still recognise and support it, for example:

*“Make it more financially attractive. At present we implemented it as a means of persuading our hospital to improve our services, but in reality it makes very little difference to our finances.”*

**Response to survey on the Best Practice Tariff for Early Inflammatory Arthritis**

*“The amount needs to be increased so that it pays at least the same amount as standard tariff if a clinic is delivering monthly reviews of EIA patients as per NICE [Quality Standard].”*

**Response to survey on the Best Practice Tariff for Early Inflammatory Arthritis**

### **Best practice**

Respondents also raised concerns about whether the tariff always supported best practice. The BPT for EIA stipulates that after six weeks, people who do not have EIA should be discharged back to the care of their GP, and people who have EIA should have received their first prescription for disease-modifying therapy. Some respondents felt that this did not always represent best practice, for example:

*“The six week discharge may not be reasonable. There are a lot of patients who are given a six month “open” follow-up if they have a convincing history but no clinical findings. The BPT would be detrimental to the interests of those patients.”*

**Response to survey on the Best Practice Tariff for Early Inflammatory Arthritis**

During a telephone interview with Professor Peter Taylor, Norman Collison Chair of Musculoskeletal Sciences, University of Oxford, he reinforced some of these concerns:

*“The focus of BPT is on securing the lowest common denominator of care. It is unlikely to improve outcomes in its current state as the focus is on meeting set standards which do not take into account the individual needs of patients.”*

## Awareness

Respondents to the survey also raised some concerns about the level of awareness of the BPT outside of the clinical community with implementation of the BPT almost entirely driven by clinicians. This was borne out in our conversations with commissioners who had relatively little awareness of the BPT for EIA. Moreover, it is important that commissioners are aware of BPT so that they are able to plan ahead. One survey respondent reported:

*“We had a meeting with the commissioners to talk about the BPT... The commissioner was a bit distressed that the provider might suddenly implement the BPT and charge lots of extra money. They quietened down when they realised that was not the case.”*

### **Response to survey on the Best Practice Tariff for Early Inflammatory Arthritis**

For this provider the BPT would not cost the commissioners more, but in some instances delivery of the BPT may cause budgeting issues for commissioners if they had not previously been made aware of the BPT for EIA and their responsibility to fund it.

During a telephone interview with Dr Bruce Kirkham, Guy’s and St Thomas’ NHS Foundation Trust, Dr Kirkham stated:

*“The real benefit of the BPT for EIA is to help units that struggled to set up a high quality service and to concentrate the minds of commissioners.”*

However, if commissioners are unaware of the BPT for EIA it is unlikely that it will be able to achieve the second half of this ambition.

## **Next steps for implementing the BPT for EIA**

In its 2012 report, *Best practice tariffs and their impact*, the Audit Commission suggests that BPTs have variable impact and that while the concept had strong support in theory, NHS organisations felt that BPTs were not themselves a driving force for local improvement, in part due to the lack of financial incentives.<sup>44</sup> However, the Audit Commission also recognised that BPTs can focus attention on an area of clinical practice saying that when aligned with strong clinical leadership at a national and local level, BPTs can help to bring about significant improvements.<sup>45</sup>

The ABPI RI’s research shows that there is significant support for the BPT for EIA particularly regarding its aims for improving the level of care. However, there are also some challenges facing broader implementation of the BPT for EIA, which will need to be addressed if it is to achieve its ambitions of driving up the quality of RA services at a local level. The year one BPT for EIA was designed to cover only the first three months of care and did not, therefore, include certain costs such as biologics. The BSR is working with the Payment by Results team at the Department of Health on a year two BPT for EIA. In order to be comprehensive, this will include all costs, which may go some way in addressing the financial challenges outlined above.

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## Conclusion

### Summary:

There has been some progress in improving services for RA but our research suggests that not enough is being done locally to prioritise and tackle RA. If NHS England (NHSE) is to secure improvements against the NHS Outcomes Framework (NHS OF), more needs to be done to drive change for “unnamed conditions” including RA.

The ABPI Rheumatological Initiative (ABPI RI) makes a number of recommendations, including that NHSE takes a more strategic approach in supporting local commissioners to make informed commissioning decisions about RA, accessing the tools that are already available and supporting improvements in data to help inform decisions about prioritisation. NHSE should work in partnership with the RA community, drawing on the significant expertise available within industry, patient groups and professionals, with leadership from the National Clinical Director.

Given the extensive evidence that supports action and prioritisation on RA, it is concerning that local progress to improve services in the new health and social care environment has been limited. Failure to improve services for this type of condition may raise questions over the ability of NHSE to oversee improvements in outcomes for the ‘unnamed’ conditions in the NHS OF.

NHSE should take a more strategic approach to support local commissioners to make informed commissioning decisions about RA, accessing the tools that are already available and supporting improvements in data to help to inform decisions about prioritisation. There is significant expertise available to support this work, including within industry and among patient groups and professionals.

ABPI RI understands that NHSE does not have the capacity to undertake significant activity in this area.<sup>46</sup> By working in partnership with the RA community, and with leadership from Professor Peter Kay, National Clinical Director for Musculoskeletal Conditions, we believe that improvements can be delivered that will help local commissioners to understand the importance of tackling RA and to access the tools that will support them to make improvements.

In order to support the prioritisation of RA and to address some of the concerns that were identified through, ABPI RI makes the following recommendations:

### Recommendations:

1. The National Audit Office (NAO) should revisit its 2009 report, *Services for people with rheumatoid arthritis* and the subsequent recommendations made by the Public Accounts Committee (PAC)

Since publication of the original reports, the NHS has been subject to major reform. The NAO’s review needs to consider whether these reforms necessitate changes either to the PAC’s recommendations or the mode of their delivery. The review should also consider the need to update epidemiological data for RA, assess what progress has been made against the recommendations and identify areas where further action is needed.

2. NICE and NHS England should take steps to improve awareness of RA and use of existing commissioning tools

RA commissioning tools have been developed but ABPI RI research suggests that they are not being capitalised on locally. NICE and NHSE should consider taking additional steps to raise awareness of these initiatives to help drive improvements in services. This could include:

- Undertaking a NICE Implementation Collaborative (NIC) pilot focused on overcoming the systematic issues surrounding the implementation of guidelines relating to inflammatory arthritis. The pilot should dovetail with the ongoing Healthcare Quality Improvement Partnership audit on early inflammatory arthritis, in order to monitor commissioning compliance with NICE guidance.
3. Local commissioners should take steps to assess the burden of disease associated with rheumatoid arthritis and prioritise accordingly

RA is a long term condition, which can be life-limiting and has a major impact on quality of life.<sup>47</sup> RA increases the risk of co-morbidities including cardiovascular disease, cancer, osteoporosis and depression.<sup>48</sup> Local authorities and Clinical Commissioning Groups (CCG) have a responsibility to assess fully the impact that RA has on their local population and to commission accordingly.<sup>49</sup> Actions might include:

- Local Authorities, Health and Wellbeing Boards and CCGs working together to ensure that JSNAs and Health and Wellbeing Strategies (HWSs) assess the burden of musculoskeletal disorders in their local populations, including RA.
  - Ensuring expert clinical and patient input into service planning and design
  - CCGs and local authorities working with voluntary sector organisations, healthcare professional bodies, and initiatives such as the Musculoskeletal Solutions Alliance, to better understand RA and what steps should be taken to support the needs of local populations.
4. The Department of Health and NHSE should work in partnership with the Health and Social Care Information Centre (HSCIC), the Healthcare Improvement Partnership and Right Care to improve the quality of data and develop national indicators for RA

Data is a critical currency in the new NHS, but almost everyone that we spoke to highlighted challenges in collating RA data as a factor preventing prioritisation or making it more difficult. This gap should be addressed without delay. Actions could include:

- Promptly publishing interim findings from the Healthcare Quality Improvement Partnership Audit of RA.
- Undertaking a review of the data that is currently available and making practical recommendations for its improvement. This might include the use of non-NHS data from research units, the British Society for Rheumatology (BSR) and the Healthcare Quality Improvement Partnership audit, to inform the development of national data and indicators.
- Establishing a minimum requirement for data collection that would allow data on long term or musculoskeletal conditions to be disaggregated to different conditions, such as RA.
- Extending Right Care's *Atlas of Variation on 'Problems of the Musculoskeletal System'* to include data on early initiation of disease modifying anti-rheumatic drugs (DMARDs).
- Making data available on ambulatory care provision for RA.

5. NHSE should review its systems for measuring performance for rheumatoid arthritis under the overarching improvement areas of the NHS OF

RA runs the risk of falling under the radar in overarching improvement areas and the ABPI RI research suggests that the lack of RA specific metrics is part of the reason why the condition is not prioritised locally. Some work has been undertaken in the rheumatology community to address this gap but, to date, it has had limited impact. Actions could include:

- Working with the National Institute for Health and Care Excellence (NICE) and the Health and Social Care Information Centre (HSCIC) to develop RA specific indicators within the CCG Outcomes Indicator Set (CCG OIS), which align with the Best Practice Tariff on Early Inflammatory Arthritis (BPT). These might include indicators previously put forward to the CCG OIS committee.
- Assessing the metrics that have been developed in the rheumatology community to identify whether they could be rolled out more widely, or promoted via NHSE networks.
- Developing metrics with the RA stakeholder community based on the available data.

6. The Department of Health's Payment by Results team should review the payment threshold for the BPT, working to ensure that the barriers to implementation identified in this report are minimised.

Respondents to our survey and interviewees were complimentary about the aims of the BPT but stated that there were too many barriers preventing its implementation, spanning financial and administrative problems. The year one BPT covers only three months and does not include drug therapy costs or some specialist therapies. A tariff that covered a full year would provide a comprehensive package that could help to optimise uptake.

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## Appendix 1: the rheumatoid arthritis environment

### What is rheumatoid arthritis?

Rheumatoid arthritis (RA) is a chronic and progressive autoimmune disease.<sup>50</sup> Typically RA causes pain and swelling in the joints, hands, feet and wrists are most commonly affected. The inflammation brought about by RA damages the cartilage and bones around joints and can also damage other parts of the body including the lungs, heart and eyes.<sup>51</sup> A report from the National Rheumatoid Arthritis Society (NRAS) found that 80% of people with RA have at least one co-morbidity as a result of their condition.<sup>52</sup> Indeed, 10% of people with RA will develop serious lung complications over the course of their disease.<sup>53</sup> They are more likely to suffer from a heart attack<sup>54</sup> and people with long-term conditions are twice to three times as likely to experience depression.<sup>55</sup> The severity and progression of RA varies between individuals and it can cause severe disability that affects the individual's ability to carry out everyday tasks.

Onset of RA usually starts between the ages of 40 and 60 but it can occur at any age.<sup>56</sup> The cause of RA is unknown although there are some established contributing factors in disease development and progression including genetic predisposition and smoking. Other less well established connections include infections, viruses and diet.<sup>57</sup>

### Rheumatoid arthritis in the context of musculoskeletal conditions

“Musculoskeletal (MSK) conditions” is a broad term used to describe around 200 different conditions affecting the muscles, joints and skeleton (including RA). Cumulatively, these affect about 10 million adults in England.

RA's inclusion in the musculoskeletal conditions category means that historically it has benefited from musculoskeletal focused policy and prioritisation such as the *Musculoskeletal Services Framework*<sup>58</sup> and more recently, the appointment of a National Clinical Director for MSK. However, RA's inclusion in the musculoskeletal umbrella may also make it more difficult to look at RA as a distinct condition.

For example, programme budgeting data (PBD) for 2012-13 includes spend in relation to “problems of the musculoskeletal system”. The average spend on problems relating to the musculoskeletal system was £10.09 million per 100,000. This amounts to approximately £5.35 billion, or 6% of the NHS budget, the 6th highest area of condition-specific spend in England. PBD also shows significant variation in spend across Primary Care Trusts (PCTs), the relevant commissioning bodies during this period of PBD, with Southwark PCT spending £5.83 million per 100,000 population and Stockport PCT spending £13.72 million per 100,000 population<sup>(i)</sup>.

While this provides a useful overview of MSK spend, unlike many of the other categories included in the PBD, problems of the musculoskeletal system is not broken down into sub-categories, making it difficult to assess what proportion of this related to RA specifically.

### Diagnosis and treatment

#### Diagnosis

Diagnosis of early RA can be difficult because overall awareness of its symptoms are low. Although there are specific symptoms associated with RA, including joint swelling, pain, fatigue, weight loss, morning stiffness and poor sleep, some people will only present with a few of these symptoms and not always the most common ones. These symptoms can also be confused with a number of other conditions such as osteoarthritis (OA) and fibromyalgia. The National Audit Office (NAO) report Services for people with rheumatoid arthritis reported that people with RA visit a GP on average four times before referral, and a fifth visit a GP eight or more times before they are referred.

(i) This analysis was conducted by JMC Partners based on NHS England Programme Budgeting data for 2012-13.

As set out in NRAS's report *Breaking Down Barriers*, it is important that people with RA are diagnosed as quickly as possible as therapeutic intervention early in the disease course can mean that the condition is easier to control and results in less joint damage.<sup>59</sup> Research shows there is a 'window of opportunity' for RA patients. Those diagnosed and started on optimal treatment using disease-modifying anti-rheumatic (DMARDs) within twelve weeks of symptom onset stand a much better chance of achieving remission or a low disease activity state.<sup>60</sup>

### Treatment

Although there is no cure for RA there are a range of treatment options which include medication and surgery. Surgery is usually conducted once damage to the joint has already occurred. However, as discussed above, early diagnosis and treatment can control symptoms and help to prevent or slow joint damage and reduce disability. Treatments include the following:

- **Painkillers** including non-steroidal anti-inflammatory drugs (NSAIDs) are used to relieve pain and swelling in the joints. Corticosteroids may be used if NSAIDs fail to provide sufficient pain relief.
- **Disease-modifying anti-rheumatic drugs (DMARDs)** help to ease symptoms and slow down the progression of rheumatoid arthritis by blocking the chemicals that cause damage to the bones, tendons, ligaments and cartilage.
- **Biologic DMARDs** are usually given as a second line treatment if DMARDs have not worked.

### Patient pathways

The NICE pathway and Quality Standard for rheumatoid arthritis (RA) suggests that any person with suspected persistent joint inflammation of undetermined cause should be referred to a specialist and that they should be referred urgently if any of the following apply:<sup>61</sup>

- the small joints of the hands or feet are affected
- more than one joint is affected
- there has been a delay of three months or longer between onset of symptoms and seeking medical advice

Once a patient has been referred to a rheumatology specialist and a diagnosis of active RA has been confirmed, monthly treatment escalation will be progressed until the disease is controlled to an agreed low disease activity target.<sup>62</sup> In people with established RA whose disease is stable, treatment dosage may be slowly reduced if there is no sign of flare ups.

Once treatment has been established and symptoms are under control, people with RA can expect to see their rheumatology team on an annual basis for an assessment of their treatment and general wellbeing.

### Commissioning overview

Since the introduction of the Health and Social Care Act 2012, Clinical Commissioning Groups (CCGs) have taken over from Primary Care Trusts (PCTs) in commissioning the majority of rheumatology services. This means that there are 200 separate organisations commissioning the majority of rheumatology services for their local populations. CCG services commissioned for RA will include those provided by rheumatologists and wider support services including those provided by physiotherapists, occupational therapists and specialist nurses.<sup>63</sup> CCGs will also need to commission services for people with RA who have joint damage and require surgery.

Some people with RA may experience severe manifestations of the disease such as rheumatoid vasculitis, an inflammation of the blood vessels. There are about 20 to 25 specialist rheumatology centres for the treatment of rarer rheumatic conditions or complex aspects of more common conditions such as rheumatoid vasculitis. NHS England is responsible for commissioning these

services at a national level.<sup>64</sup> NHS England is also responsible for commissioning paediatric and transitional services.

Local authorities have a responsibility to promote and protect health, tackle the causes of ill-health and address health inequalities. This includes assessing their populations' health in the form of Joint Strategic Needs Assessments (JSNAs) and through Health and Wellbeing Strategies (HWBSs).

The breakdown of these responsibilities is set out below. Co-ordination across these areas of commissioning is essential to ensure a smooth patient pathway.

Care setting	Primary	Secondary	Social Care
<b>Commissioning Responsibility</b>	CCGs	CCGs and NHS England	Local Authorities
<b>Details</b>	<ul style="list-style-type: none"> <li>Responsibility for core rheumatology services including physiotherapy, occupational therapy and medicines.</li> </ul>	<ul style="list-style-type: none"> <li>CCGs are responsible for RA services, the majority of which are Outpatient services.</li> <li>NHS England is responsible for commissioning services for severe manifestations of RA, paediatric and transitional rheumatology services.</li> </ul>	<ul style="list-style-type: none"> <li>Address health inequalities</li> <li>Raising awareness</li> </ul>

### Cost of RA

As well as the significant burden it places on the individuals it affects, RA also impacts on NHS resources and the economy. While RA is more common in older people, three quarters of people diagnosed with RA are of working age.<sup>65</sup>

40% of people with RA lose their jobs within five years of diagnosis because of their condition.<sup>66</sup> Of this 40%, between 14% and 20% leave work within one year of diagnosis and between 25% and 33% leave work within two years.<sup>67</sup> Based on this information Arthritis Research UK has calculated<sup>68</sup> that between 970–1,590 people will give up work in their first year after diagnosis each year in the UK because of their RA. In 2007 NRAS also published “I want to work” which reports that 64% of respondents who were not working felt they had given up work prematurely due to their RA.<sup>69</sup> In its 2010 report *Service for people with rheumatoid arthritis*, the National Audit Office (NAO) stated that each year RA costs the NHS £560 million and the wider economy at least £1.8 billion in sick leave and work related disability. The NAO calculated that increasing the number of people treated within three months of symptom onset from 10% to 20% would cost the NHS £11 million over five years but could result in productivity gains of £31 million for the economy.<sup>70</sup>

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## Appendix 2: List National Audit Office recommendations

1. **Recommendation:** The Department should run a campaign during 2010 to raise people's awareness of the symptoms of rheumatoid arthritis, highlighting the need to seek prompt medical attention.
2. **Recommendation:** The Department should, as a priority, launch a targeted campaign or guidance to raise the awareness of GPs and other primary care professionals of the importance of referring people promptly to a specialist, if rheumatoid arthritis or other forms of inflammatory arthritis are suspected.
3. **Recommendation:** The Department should encourage the Royal College of GPs to provide more training on rheumatoid and inflammatory arthritis when it implements its plan to extend the duration of training for GPs. Such training should help trainee GPs identify the early signs of IA and emphasise the importance of early referral to specialists.
4. **Recommendation:** The Department should write to this Committee by March 2010 setting out what it is doing to encourage take up of the Commissioning Pathway by primary care trusts, and how it intends to evaluate the impact on patients.
5. **Recommendation:** The Department should review the evidence on the need for better access to flare-up and pain management services for people with rheumatoid arthritis and produce an action plan by March 2010.
6. **Recommendation:** Strategic health authorities should clarify how they expect commissioners in primary care to ensure that sufficient follow-up appointments are available for people with rheumatoid arthritis in their local area, and should audit whether acute trusts are providing the number of follow-up appointments required to meet clinical need.
7. **Recommendation:** The Department should identify the reasons for variations in primary care trusts' spending, set national benchmarks, and require strategic health authorities to hold primary care trusts to account for the cost effectiveness of the services they provide.
8. **Recommendation:** Primary care trusts should obtain much better information about the numbers of people with rheumatoid arthritis, decide what services, including psychological services, they need to provide, and take action to ensure their services are configured cost-effectively.
9. **Recommendation:** It should agree with the Department for Work and Pensions how they will ensure that assessors have the knowledge they need to make proper judgments about the ability of people with rheumatoid arthritis to work.

### Appendix 3: Outcomes framework indicators that are relevant to RA

Framework	Relevant indicators			
<b>NHS outcomes framework 2013-14</b>	2.1 Proportion of people feeling supported to manage their condition	2.2 Employment of people with long-term conditionsd	4a Patient experience of primary care 4ai GP services	4.1 Patient experience of outpatient services
<b>Public health outcomes framework 2013-16</b>	1.8 Employment for those with a long term health condition			
<b>Adult social care outcomes framework 2013-14</b>	1a Social care related quality of life	1b Proportion of people who use services who have control over their daily life		

## Appendix 4: Rheumatoid arthritis policy initiatives

### Quality Standard (QS) for rheumatoid arthritis

A QS for RA was published in June 2013 and includes quality statements to support early diagnosis, appropriate escalation of treatment and details for annual reviews and ad hoc advice when required.<sup>71</sup>

It is one of the 49 standards that have been published to date.

### Best Practice Tariff for Early Inflammatory Arthritis (BPT for EIA)

The BPT for EIA was introduced in April 2013 and is designed to give a financial incentive to providers to ensure the delivery of high quality services across the country for people with early inflammatory arthritis. Its development was supported by the British Society of Rheumatology (BSR), Arthritis Research UK and the Department of Health.<sup>72</sup>

We understand that all rheumatology units have been encouraged to take part in the BPT for EIA.<sup>73</sup>

### Quality and outcomes framework (QOF)

A new clinical area for RA was added to the QOF in 2013/14.<sup>74</sup> This was a significant step forward as it should result in GPs being rewarded for playing a more active role in the management of RA. Unfortunately, the number of points and indicators for rheumatoid arthritis has already been decreased substantially in the 2014/15 QOF, as set out in Figure 7.

**Figure 7: Rheumatoid arthritis in the QOF**

Indicator	Points	2013/14 QOF	2014/15 QOF
RA001: The contractor establishes and maintains a register of patients aged 16 or over with rheumatoid arthritis	1	Included in the QOF	Removed from the QOF
RA002: The percentage of patients with rheumatoid arthritis, on the register, who have had a face-to-face review in the preceding 12 months	5	Included in the QOF	Removed from the QOF
RA003: The percentage of patients with rheumatoid arthritis aged 30 or over, and who have not attained the age of 85, who have had a cardiovascular risk assessment using a CVD risk assessment tool adjusted for RA in the preceding 12 months	7	Included in the QOF	Removed from the QOF
RA004: The percentage of patients aged 50 or over, and who have not attained the age of 91, with rheumatoid arthritis who have had an assessment of fracture risk using a risk assessment tool adjusted for RA in the preceding 24 months	5	Included in the QOF	Removed from the QOF

Included in the QOF
  Removed from the QOF

In addition to the deprioritisation of these indicators, much wider debate around the future of the QOF may result in the whole framework being redesigned or disbanded in favour of local schemes, led by CCGs.<sup>75,76</sup> The uncertainty of QOF and any replacement incentive schemes undermines the indicators that are in place and effectively means that the power of this lever in driving GP behaviour is weakened substantially.

## **Health Quality Improvement Partnership (HQIP) National audit of Rheumatoid and Early Inflammatory Arthritis**

In February 2014 the national clinical audit of rheumatoid and early inflammatory arthritis commenced. The audit examines the assessment and early secondary care management of EIA in all NHS secondary care settings in England and Wales. The audit intends to identify areas of RA services where improvements are required and will seek to measure services against a number of criteria derived from the NICE QS for RA and the BPT for EIA, as well as patient reported outcome and experience measures.<sup>77</sup>

It is anticipated that the audit will collect full data for all patients presenting from 1st October 2013 until the end of September 2015. Data is, therefore, currently being collected but it is unlikely that any information will be published for some time.

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## Appendix 5: Methodology

ABPI RI undertook various strands of research in order to generate insight into the current status of rheumatoid arthritis in the NHS.

### **1. Assessment of Joint Strategic Needs Assessments (JSNAs) and Health and Wellbeing Strategies (HWSs)**

The ABPI RI undertook an analysis of Joint Strategic Needs Assessments (JSNAs) and Health and Wellbeing Strategies (HWSs) to determine whether rheumatoid arthritis (RA) was being prioritised at a local level.

In November 2013 the ABPI RI used internet searches to identify JSNAs and HWSs for upper-tier local authorities (LAs). Of the 152 upper-tier local authorities in England, 143 JSNAs and HWSs were identified respectively. The JSNAs and HWSs identified do not necessarily correspond to the same 143 LAs.

Each of the JSNAs and HWSs were searched for the key terms:

- Rheumatoid arthritis
- Rheumatism
- Rheumatology
- Inflammatory arthritis
- Musculoskeletal

The majority of documents were PDFs but an increasing number of JSNAs and HWSs are presented in a web based format, bringing together a range of data sets and analysis. Where JSNAs or HWSs were web based, an advanced web search was carried out to identify the key terms set out above. However, ABPI RI is aware that these searches may not always have been comprehensive, especially where there was large amounts of data presented in a range of formats.

### **2. Survey of the Best Practice Tariff for Early Inflammatory Arthritis (BPT for EIA) in partnership with the British Society for Rheumatology (BSR)**

The ABPI RI worked in partnership with the BSR through a small working group to develop a survey for healthcare professionals (HCPs) in order to assess the initial experience of the BPT for EIA since its launch in April 2013.

A short electronic survey, set up via Survey Monkey, was initially circulated via the BSR through email and its newsletter. The ABPI RI also attended the BSR conference in April 2014 and completed surveys with rheumatology HCPs in attendance.

51 respondents from across the 10 geographical areas of the NHS, representing different sizes of unit, completed the survey.

Respondents completed the survey anonymously.

### **3. Interviews with commissioners**

The ABPI RI approached 40 Clinical Commissioning Groups (CCGs) and five Commissioning Support Units (CSUs) via email, inviting them to take part in a short telephone interview about the prioritisation and commissioning of rheumatology services in their area.

CCGs and CSUs were originally chosen to cover the 27 area teams in order to provide geographical representation. However, areas that had not prioritised rheumatology services or musculoskeletal services more generally were less inclined to participate. After an initial wave of invitations, ABPI RI narrowed its focus to areas where it was aware that musculoskeletal and

rheumatology services were being prioritised.

The ABPI RI conducted interviews with eight commissioners between March and May 2014. No CSUs agree to be interviewed.

The interviewees were not paid honoraria. Participants have all agreed to their names and quotes being published in the report.

A full list of interview participants is set out in Appendix 6.

#### **4. Interviews with clinicians**

The ABPI RI approached 16 rheumatologists and rheumatology nurses via email, inviting them to take part in a short telephone interview about the BPT for EIA and the NICE Quality Standard (QS) for RA. This was not intended as a representative sample but to provide qualitative data. The ABPI RI conducted three telephone interviews with rheumatologists between April 2014 and May 2014.

The interviewees were not paid honoraria. Participants have all agreed to their names and quotes being published in the report.

A full list of interview participants is set out in Appendix 6.

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## Appendix 6: list of contributors

<b>Name</b>	<b>Organisation</b>	<b>Position</b>
<b>Diane Bell</b>	Bedfordshire CCG	Director of Strategy & System Redesign
<b>Hazel Buchanan</b>	Nottingham North and East CCG	Director of Operations
<b>Fiona Callaghan</b>	Nottingham North and East CCG	Assistant Director of Commissioning
<b>Jatinder Garcha</b>	Brent CCG	Project Lead
<b>Clare Handley</b>	Southampton CCG	Commissioning Manager - Unscheduled Care Team
<b>Moneeza Iqbal</b>	North Manchester CCG	Programme Director - Planned Care, Long Term Conditions and Public Health
<b>Dr Bruce Kirkham</b>	Guy's and St Thomas' NHS Foundation Trust	Lead Rheumatologist
<b>Professor Robert Moots</b>	University of Liverpool	Consultant Rheumatologist
<b>Gillian Parker</b>	Southampton CCG	Senior Commissioning Manager for Adults Planned Care
<b>Ashley Scarff</b>	High Weald Lewes Havens CCG	Head of Commissioning and Strategy
<b>Lynn Talbot</b>	Wiltshire CCG	Interim Director of Transformation
<b>Professor Peter Taylor</b>	University of Oxford	Norman Collison Chair of Musculoskeletal Sciences
<b>Shelly Watson</b>	Wiltshire CCG	Project Manager
<b>Dr Tim Wilkinson</b>	Portsmouth CCG	Chair of Governing Board, Elected Clinical Executive

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## Appendix 7: list of acronyms

<b>Acronym</b>	<b>Related Term</b>
<b>BPT</b>	Best practice tariff
<b>CCG</b>	Clinical Commissioning Group
<b>CCG OIS</b>	Clinical Commissioning Group Outcomes Indicator Set
<b>CES</b>	Care Episode Statistics
<b>CSU</b>	Commissioning Support unit
<b>DMARD</b>	Disease modifying anti-rheumatic drug
<b>EIA</b>	Early inflammatory arthritis
<b>HCP</b>	Health care professionals
<b>HES</b>	Hospital Episode Statistics
<b>HWB</b>	Health and Wellbeing Board
<b>HWS</b>	Health and Wellbeing Strategies
<b>JSNA</b>	Joint Strategic Needs Assessment
<b>LAs</b>	Local authorities
<b>LTC</b>	Long term conditions
<b>NCAPOP</b>	National Clinical Audit and Patients Outcomes Programme
<b>NCD</b>	National Clinical Director
<b>NHS OF</b>	NHS Outcomes Framework
<b>NIC</b>	NICE Implementation Collaborative
<b>NSAID</b>	Non-steroidal anti-inflammatory drugs
<b>QOF</b>	Quality and Outcomes Framework
<b>QS</b>	Quality Standard
<b>RA</b>	Rheumatoid arthritis
<b>SCN</b>	Strategic Clinical Network

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## Appendix 8: list of organisations

<b>Name</b>	<b>Abbreviation</b>
Arthritis Research UK	ARUK
Association of the British Pharmaceutical Industry	ABPI
British Society for Rheumatology	BSR
Healthcare Quality Improvements Partnership	HQIP
Health and Social Care Information Centre	HSCIC
National Audit Office	NAO
National Clinical Director	NCD
National Institute for Care Excellence	NICE
National Rheumatoid Arthritis Society	NRAS
NHS England	NHSE
Rheumatology Initiative	RI
Public Accounts Committee	PAC
Public Health England	PHE

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