



# **The Impact of Rheumatoid Arthritis Co-morbidities**

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### **Foreword**

Rheumatoid arthritis (RA) is not well understood in general and as a result the co-morbid risks are overlooked by the public and policymakers alike. This report is an important means of spelling out the evidence of the severity of the risks associated with RA.

With an ageing population and the majority of people with RA being diagnosed between the ages of 40-60, dealing with people with a variety of co-morbidities will increasingly become an issue for the NHS.

It is very important to raise awareness of the co-morbidities linked to RA so patients have the ability to manage the risk factors more effectively. For example, if a patient does not know about cardiovascular and osteoporotic risks, they are far less likely to address factors such as smoking, weight and diet which are firmly within their control.

The sad reality is that it is not unusual to meet someone newly diagnosed with RA who does not realise that they are at an increased risk of heart disease, thus ignoring the fact that people with RA have the same cardiovascular risk as those with type-2 diabetes.

This report is timely because we are witnessing a shift in the way that long-term conditions are being viewed by policymakers, as they recognise that people often live with more than one condition over the course of their life.

The challenge is, therefore, increasingly about how best to treat somebody with two or three conditions, including RA, while also meeting their social care needs in a way that ensures they do not continually get passed between services. The presence of these risks reinforces the need for a case management approach with a key worker responsible for coordinating the patient's care, which includes holistic annual reviews.

There have been a number of significant policy announcements relating to the future treatment and management of RA and associated co-morbidities, including the potential introduction of new indicators

within the forthcoming Quality and Outcomes Framework (QOF) that will encourage GPs to undertake annual cardiovascular and osteoporotic assessments.

This is welcome news, but the policy framework is by no means complete. If implemented, the recommendations contained in this report will help to plug these gaps and ensure a much better, cohesive approach to the management of RA and associated co-morbidities, and go a considerable way to achieving the coalition government's aim of improving clinical outcomes for patients.

**Ailsa Bosworth**  
**Chief Executive**

## Executive Summary

Rheumatoid arthritis (RA) is a chronic, disabling autoimmune disease which affects approximately 580,000 people in England<sup>1</sup>. Around 80 per cent of these patients will have one or more co-morbidities, which means there are around 464,000 RA patients in England who have another long-term health condition<sup>2</sup>.

The report presents evidence about the range of co-morbidities that RA patients are at risk of developing, including problems with eye, heart, lung and bone health, as well as the psychological impact of living with a long term condition. The report highlights the following types of co-morbidities as being particularly problematic:

- Cardiovascular disease: The risk of heart attack is doubled for RA patients<sup>3</sup>. The risk of atrial fibrillation is around 40 per cent higher among RA patients than those without RA<sup>4</sup>. The risk of stroke is 30 per cent higher for RA patients<sup>5</sup>
- Interstitial lung disease: this disease associated with RA is a major cause of death amongst RA patients<sup>6</sup>
- Osteoporosis: rates of osteoporosis can be up to twice as high amongst RA patients than the general population<sup>7</sup>
- Cancer: leukaemia, lung cancer, lymphoma and multiple myeloma are all more common in people with RA<sup>8</sup>
- Depression: rates of depression are raised amongst RA patients<sup>9</sup>

Failure to manage these co-morbidities effectively will have a serious impact on the RA patient. For example, the presence of co-morbidities may add delays to the care pathway, and the co-morbidities themselves may increase the patient's overall levels of disability, or even their risk of mortality.

Although current NICE guidelines recommend some checks for co-morbidities among RA patients<sup>10</sup>, the report finds that their implementation is patchy and the range of conditions for which checks are recommended is too limited<sup>11</sup>.

The report goes on to recommend the introduction of a series of measures to improve awareness and effective management of co-morbidities by RA patients, healthcare professionals, commissioners and policymakers. If implemented in concert, we believe these measures will significantly enhance the patient journey while at the same time reducing the associated treatment costs to the NHS.

#### **Key recommendations**

- 1. Providers should fully implement the recommendation in NICE Clinical Guideline 79 that all RA patients should be offered annual checks for co-morbidities and have access to a consultant-led multidisciplinary team**
- 2. Providers should fully implement the Darzi recommendation that all people with long-term conditions should be given an annual personalised care plan, which is agreed with their healthcare professional**
- 3. The Information Prescription for RA should be overhauled to include further information about the range of co-morbidities that affect people with the disease**
- 4. The HQIP national clinical audit should make data available about the proportion of rheumatology teams that are offering care plans, conducting holistic annual reviews and co-morbidity assessments, and giving access to the full multidisciplinary team**
- 5. The forthcoming Long-Term Conditions Outcomes Strategy should include a section on effective management of co-morbidities, which promotes investment in self-management programmes, annual care plans and holistic annual reviews to manage these risks**
- 6. Additional outcomes strategies, including the forthcoming Cardiovascular Disease Outcomes Strategy, should include sections on effective management of co-morbidities and identify specific at risk populations, such as RA patients.**

- 7. The forthcoming NICE Quality Standard for the management of RA should include a quality statement on the requirement to screen for co-morbidities and establish a care plan for every patient, and equivalent Commissioning Outcomes Framework indicators should be developed for all long-term conditions**
  
- 8. The NHS Commissioning Board should establish a strategic clinical network for musculoskeletal conditions, which should advise clinical commissioning groups on the need to prioritise checks for co-morbidities, give access to multidisciplinary team services and assist with developing shared-care protocols**
  
- 9. Future iterations of the Quality and Outcomes Framework should include a commitment for GPs to conduct holistic annual reviews with RA patients that screen for co-morbidities**
  
- 10. The shortlisted early inflammatory arthritis best practice tariff for providers should be introduced as soon as possible and it should include an annual review as part of the configuration of the financial incentive**

## **1. Introduction**

It is estimated that there are nearly 580,000 people across England with rheumatoid arthritis (RA)<sup>12</sup>. For a minority of people the disease is less severe and remains well controlled, but others experience disabling pain and reduced joint function which is exacerbated by the presence of co-morbidities. For these people, better management of co-morbidities can help to alleviate some of the symptoms and ensure they have a better quality of life.

This report examines the impact of RA co-morbidities on both patients and the NHS, and makes recommendations targeted at improving clinical practice and NHS incentives related to the effective management of RA co-morbidities.

### **1.1 About Rheumatoid arthritis**

RA is a chronic autoimmune disease in which the immune system attacks the tissue within the joint, leaving it painful and inflamed. If left untreated, the joint can lose its shape and alignment, and can eventually be destroyed completely<sup>13</sup>. Patients with RA also experience symptoms that include pain and fatigue.

There is no known cure for RA and the symptoms fluctuate considerably from person to person, depending on the manner in which the disease progresses<sup>14</sup>.

RA is most common after the age of 40, but can affect people of any age. Around three quarters of people with RA are first diagnosed when of working age, and women are more than twice as likely as men to have the disease<sup>15</sup>. RA costs the NHS in England around £560 million a year in healthcare costs, with the majority of this in the acute sector. The additional cost to the UK economy, including carer costs, the costs of nursing homes, private expenditure, sick leave and work-related disability was estimated to be £3.8 to £4.8 billion a year in 2009<sup>16</sup>.

There is currently no accurate estimate of how much of this UK expenditure is related to the treatment of co-morbidities. However international studies have found that increases in mean and aggregate total healthcare expenditures for adults with arthritis are attributable to the increasing number of those with at least one co-morbid chronic condition<sup>17</sup> and that the presence of co-

morbid cardiovascular disease and/or depression significantly affects annual healthcare costs for RA patients<sup>18</sup>.

A five-year study of RA patients who had been given NICE-approved psychological therapies early on found that they used significantly fewer healthcare resources, with reduced admissions, injections, referral for physiotherapy and total healthcare costs<sup>19</sup>. A recent study conducted by the King's Fund on the broader subject of long-term conditions and mental health also found that co-morbid mental health problems raise total health care costs by at least 45 per cent for each person with a long-term condition and co-morbid mental health problem<sup>20</sup>.

## 1.2 Co-morbidities

Although several definitions are offered within medical literature, the term is most frequently defined as the presence of one or more disorders or diseases in the patient occurring in addition to the primary disease<sup>21</sup>.

There are broadly two types of co-morbidities affecting people with RA: those resulting directly from the disease (the inflammatory process, the physical effects of the disease, and the mental health issues arising from living with the disease on a daily basis); and those resulting indirectly from the treatments that are administered<sup>22</sup>.

If not managed effectively, these co-morbidities can have wide-ranging impacts on people with RA - worsening their levels of physical disability<sup>23</sup> (as well increasing their support needs and reducing their ability to work) and increasing their risk of mortality<sup>24</sup>. Co-morbid disorders in RA patients are also therefore associated with frequent medical consultations<sup>25</sup>.

Within the UK context, it has been noted that while inpatient admissions to rheumatology services have reduced significantly due to the introduction of earlier and more aggressive disease-modifying anti-rheumatic drug (DMARD) treatments as well as biologic therapies, many RA patients are still admitted to hospital for the treatment of co-morbidities, largely in other specialist areas such as cardiology, respiratory and oncology<sup>26</sup>.

Evidence from international studies suggests that some types of co-morbidities linked to RA, such as hypertension, are under-diagnosed and under-treated<sup>27</sup> and that patients with RA do not receive optimal health maintenance and preventive care services<sup>28</sup>. However, international studies have also shown that patterns of care that include relevant specialists are associated with substantially higher quality care<sup>29</sup>. Co-morbidities can also be of prognostic interest, allowing clinicians or patients to take preventative action to mitigate these risks.

A recent UK study found that significant co-morbidity was present at the outset for a sample of RA patients, which increased with follow-up<sup>30</sup>. The study went on to conclude that, since many of these co-existent conditions respond to preventative or therapeutic measures, co-morbidity needs earlier detection and management to reduce its impact on people with RA<sup>31</sup>.

The average RA patient has 1.6 co-morbidities and the number of co-morbidities increases with age<sup>32</sup>. In total, around 80 per cent of RA patients have one or more co-morbidity<sup>33</sup>. This means there are around 464,000 RA patients in England that live with a co-morbidity.

## 2. Extent and impact of RA co-morbidities

The following section identifies some of the most significant co-morbidities affecting RA patients and provides a series of case studies demonstrating their practical impact on patients.

### 2.1 Heart attack

The risk of heart attack is doubled for RA patients<sup>34</sup>. It is currently not well understood why those with rheumatoid arthritis have a greater risk of heart attack. However, it is thought that the disease may cause higher levels of inflammation in the body generally which can trigger plaque in the arteries to form blood clots<sup>35</sup>. In addition, some treatments used for RA may increase the risk of heart disease<sup>36</sup>. Mortality is significantly higher in heart attack cases affecting RA patients, with the risk of mortality at six months nearly doubled<sup>37</sup>.

#### RA patient experience of high blood pressure: Jean

Jean is in her early sixties and has been diagnosed and living with RA for about 20 years. She had no family history of high blood pressure but explains that *“my raised blood pressure began not long after taking large doses of DMARDs, which was prescribed more or less straightaway after I was speedily diagnosed by the GP.”* Although unaware of any symptoms at the time, Jean was informed that without taking action she would be at risk of cardiovascular damage and possibly transitory ischemic attacks. Both the GP and the hospital now monitor her blood pressure on a regular basis. Describing the impact, Jean said *“on more than one occasion I have also had to wear a heart monitor because of cardiac symptoms and I now take a pill every day for hypertension”*.

### 2.2 Congestive heart failure

Congestive heart failure is the inability of the heart to supply sufficient blood flow to meet the needs of the body. Studies have shown an increased risk of congestive heart failure for RA patients<sup>38</sup>. Again, it has been suggested that this might be as a result of the inflammation caused by RA<sup>39</sup>, however further research is required to fully understand the reasons for this increased risk.

### 2.3 Atrial Fibrillation

Atrial fibrillation (AF) is the most common type of irregular heart beat. It will not necessarily cause symptoms in the patient, but is associated with palpitations, fainting, chest pain or congestive heart

failure. AF is known to increase the risk of stroke<sup>40</sup>, leaving patients with subsequent disability and caring cost to society. The incidence of AF among RA patients is approximately 40 per cent higher than for those without RA<sup>41</sup>. Women with RA are at slightly higher risk of developing AF than men<sup>42</sup>. Research has shown the link between inflammatory processes and the development of AF<sup>43</sup> which might explain the higher risk for RA patients.

## 2.4 Vasculitis

Vasculitis is a condition in which blood vessels become inflamed. This can result in the blood vessels becoming weakened and increase in size, or become narrowed, sometimes to the point of stopping blood flow. The blood vessels most often involved are arteries that bring blood to the skin, nerves, and internal organs<sup>44</sup>. People with RA are at increased risk of developing vasculitis, particularly those with long-term, severe RA<sup>45</sup>.

### RA patient perspective of arrhythmia: Pat

Pat was first diagnosed with RA in 1989 and developed heart problems as a result of her condition as far back as 1992. *“Prior to being diagnosed I had no significant family history of heart problems,”* she explains. The arrhythmia led to Pat being fitted with a pacemaker and she has had to give up walking due to breathing problems – *“it affected me so much that I couldn’t do normal house work, gardening or even get up the steps to get to my work.”*

## 2.5 Stroke

Stroke is a serious medical condition that occurs when the blood supply to part of the brain is cut off. One of the major risk factors for stroke is AF; as set out in 2.3, the incidence of AF among RA patients is approximately 40 per cent higher than for those without RA<sup>46</sup>. Research has shown the link between inflammatory processes and the development of AF<sup>47</sup> which might explain this higher risk. A nationwide study of RA and non-RA patients found an increased risk for 30 per cent of stroke amongst RA patients<sup>48</sup>. This study found the risk of AF and stroke was even higher among younger patients – for both AF and stroke there were threefold increases in the relative risks to patients with RA younger than 50<sup>49</sup>.

## 2.6 Cancer

Some cancers are more common in people with RA<sup>50</sup>. Lung cancer, lymphoma and myeloma are thought to be more common as a result of the effects of RA itself (such as chronic stimulation of the immune system or excess antibody-related proteins in the blood)<sup>51</sup>, while skin cancer and leukaemia seems to occur as a consequence of treatment for RA<sup>52</sup>. Research suggests that patients with RA are at lower risk of developing bowel, breast and prostate cancer as result of taking long-term anti-inflammatory arthritis treatment<sup>53</sup>.

## 2.7 Interstitial lung disease

Interstitial lung disease (ILD) is a group of lung disorders that can cause scarring of the lung tissue, making it difficult to get enough oxygen into the body<sup>54</sup>. RA patients are at greater risk of developing ILD due to increased inflammation, and the disease is estimated to affect 20 to 30 per cent of RA patients<sup>55</sup>. This disease is a major cause of death for RA patients<sup>56</sup>.

## 2.8 Chronic obstructive pulmonary disease

Chronic obstructive pulmonary disease (COPD) is the name for a collection of lung diseases including chronic bronchitis, emphysema and chronic obstructive airways disease. People with COPD have difficulties breathing primarily due to the narrowing of their airways and typical symptoms including increasing breathlessness when active, a persistent cough with phlegm and frequent chest infections<sup>57</sup>. RA patients are at greater risk of COPD – the prevalence of COPD is twice as high in people with RA than in the general population<sup>58</sup>. The link is thought to be down to altered genetic and autoimmune processes<sup>59</sup>.

### RA patient perspective of lung co-morbidities: Catherine

Catherine is in her late 40s and has been diagnosed and living with RA for 25 years. About five years ago she began to have associated lung problems. *“The symptoms came on very suddenly and I started bringing up phlegm on a daily basis – up to 2 to 3 times a day,”* Catherine commented. She was at first just prescribed antibiotics by her GP but over 18 months later she was eventually able to see a specialist who conducted an MRI scan which found scarring on her lungs. She was then diagnosed with

early onset pulmonary fibrosis which could be stable or could progress further. The condition means she gets out of breath more easily and has a periodic cough.

## 2.9 Anaemia

Anaemia is a condition where the amount of haemoglobin in the blood is below the normal level, or there are fewer red blood cells than normal; the main symptoms are tiredness and lack of energy<sup>60</sup>. Anaemia rates are tripled in RA patients compared with the general population<sup>61</sup>. Over three-quarters of RA patients have chronic anaemia and nearly one-quarter have iron-deficiency anaemia<sup>62</sup>. This means around 435,000 RA patients in England have anaemia.

## 2.10 Infection

There is a strong association between people who suffer from RA and an increased risk of infection, with chest infection and generalised sepsis being particular risks<sup>63</sup>. In particular, RA appears to increase the risk of bacterial, tubercular, fungal, opportunistic and viral infections, with all infections being more common in active and severe RA<sup>64</sup>. This appears to be a consequence of changes to the immune system caused by RA, as well as a result of immunosuppressant therapy<sup>65</sup>. All marketed TNF inhibitors appear to also increase the risk of serious and non-serious infections compared with conventional disease modifying anti-rheumatic drugs (DMARDs)<sup>66</sup>.

## 2.11 Depression

People with rheumatoid arthritis are more likely to be depressed as those without the condition<sup>67</sup>. Studies indicate that 19 per cent of people with RA are formally diagnosed with depression<sup>68</sup> and those diagnosed with RA and depression can have suicidal ideation<sup>69</sup>. Although depression in RA patients can arise from living with a long-term condition that can be painful and debilitating, there is some research that suggests that inflammation as a result of the disease itself might also be a cause of depression<sup>70</sup>.

### RA patient perspective of depression: Sandra

Sandra is in her early sixties and has been diagnosed and living with RA for 5 years. The physical pain she experienced combined with a lack of mobility led to her experiencing depression. Sandra said that the depression *“had a sizeable impact on the relationship with my children”* due to her mobility

problems which “created a real barrier between us.” After receiving treatment with antidepressants, Sandra’s condition has improved and she has not had any relapses since.

### 2.12 Orthopaedic problems

RA patients can suffer from orthopaedic co-morbidities, including carpal tunnel syndrome, tendon rupture and cervical myelopathy (usually after severe and long-term RA)<sup>71</sup>. Osteoporosis is also a consequence of RA, resulting from decreased physical activity and treatment with corticosteroids<sup>72</sup>. A study of one patient register found a two-fold increase in osteoporosis among RA patients compared with the general population<sup>73</sup>. In addition, the rate of fracture is doubled among individuals with RA<sup>74</sup>. The consequences of fracture are potentially very significant for a person already disabled by RA.

### 2.13 Sjögren’s syndrome

Sjögren’s syndrome is a disorder of the immune system where white blood cells attack the body’s tear and saliva glands<sup>75</sup>. This causes a dry mouth and dry eyes, along with other related symptoms<sup>76</sup>. The disease is associated with RA, with one study finding a prevalence of 31 per cent amongst RA patients<sup>77</sup>, compared to three to four per cent in the general population<sup>78</sup>. The cause of Sjögren’s syndrome remains unknown, but research suggests that it is triggered by a combination of genetic, environmental and possibly hormonal factors, and that in about half of cases it develops in combination with another autoimmune disease such as RA<sup>79</sup>.

#### RA patient perspective of Sjögren’s syndrome: Martina

Martina has been diagnosed and living with RA for four and half years and had symptoms of Sjögren’s syndrome for several years. However it was four years post-RA diagnosis that her co-morbidity was first diagnosed. Martina was never asked about her eyes by the consultants and nurses she saw during her treatment for RA – highlighting the importance of clinical staff checking for the presence of co-morbidities in RA patients.

### 2.14 Inflammation of the eye

About a quarter of RA patients have RA which manifests itself in the eye<sup>80</sup>. This can be inflammation of the interior of the eye (uveitis), inflammation of the membrane covering the white part of the eye (episcleritis), or inflammation of the white part of the eye (scleritis)<sup>81</sup>. All of these conditions result in red

and painful eyes, and in the case of uveitis, can (in the most severe cases), reduce vision<sup>82</sup>. These conditions may warrant steroid use, which can, in turn, lead to the development of a cataract (an opacity in the lens of the eye) or raised pressure inside the eye (glaucoma) which has to be treated surgically or topically respectively<sup>83</sup>.

#### RA patient perspective of episcleritis: Allannah

Allannah is in her early fifties and has been diagnosed and living with RA for one year and three months, but had symptoms relating to her eyes for about two years. *“Very suddenly I developed red eye and suffered from a loss of vision and pain in both eyes. I went to the GP and he referred me to the emergency eye clinic,”* she said. Later suspecting an underlying illness, her ophthalmologist referred Allannah to see a rheumatologist. Eventually she was diagnosed with RA. Although with treatment her symptoms of RA are under control at present, Allannah still has flared eyes and has had to retire from work.

### 3. Evidence and policy

#### 3.1 Best practice

In light of these challenges, there is broad agreement within the medical community about the importance of effectively managing co-morbidities in RA patients and what best practice should look like. NICE Clinical Guideline 79 on the management of RA in adults recommends that co-morbidity checks are conducted in all patients and that patients should be offered an annual review, which should include checking for the development of conditions, “such as hypertension, ischaemic heart disease, osteoporosis and depression”<sup>84</sup>.

The Clinical Guideline also makes specific reference to the importance of giving RA patients access to a multidisciplinary team, including specialist physiotherapy and psychological therapy to help to keep RA patients active and manage issues such as depression<sup>85</sup>.

A separate report by The Royal College of Physicians, The Royal College of General Practitioners and The Royal College of Paediatrics and Child Health, suggested that jointly commissioned integrated health services should be provided by primary and secondary care working together for people with chronic medical conditions to deliver a locally designed care pathway<sup>86</sup>.

A King’s Fund report on RA published in 2009 also concluded that GPs and the wider clinical teams in primary care can play a major role in recognising RA co-morbidities and doing regular checks to support monitoring<sup>87</sup>.

Also in 2009 a Commissioning Pathway for Inflammatory Arthritis was produced by the Rheumatology Futures Group, and endorsed by the Department of Health<sup>88</sup>. The commissioning pathway focused on early recognition and integration of primary care and specialist management and reinforced the importance of giving RA patients access to the multidisciplinary team and promoting holistic assessments<sup>89</sup>.

#### 3.2 Public policy

Successive government approaches to tackling co-morbidities have been ad hoc and do not represent a coordinated approach.

The *Our health, Our Care, Our Say* white paper, published in 2006, committed the former government to making sure patients had the health and social care information they needed, when they needed it<sup>90</sup>. The white paper contained a specific commitment that by 2008 everyone with a long-term condition would be given an Information Prescription, which would provide information about their condition and tell them where to get further information<sup>91</sup>.

The *Musculoskeletal Framework*, also published by the Department for Health in 2006, made an initial attempt to articulate the vision for high-quality services for people with musculoskeletal diseases<sup>92</sup>. The framework advocated controlling co-morbidities through a proactive approach to management that involved regular evaluation of clinical indicators of disease progression<sup>93</sup>. It went on to say that good control of the disease could improve long-term prognoses and prevent additional health problems caused by inadequate management and also noted that shared care across primary and secondary care could significantly contribute to reductions in the number of inpatient episodes in the longer-term<sup>94</sup>.

Then, in 2008, Lord Darzi published the *High Quality Care for All* report, which contained a section focused on how to improve quality and access to care for people with long-term conditions<sup>95</sup>. Of particular note, the report advocated the use of personalised care plans for everyone with a long-term condition (noting that only one-fifth had access at the time)<sup>96</sup>. In addition to this, the report recommended that care plans should be agreed by the patient and a named professional to ensure services are organised around the needs of the individual patient<sup>97</sup>. Another theme outlined in the report was the need for true partnerships between people with long-term conditions and the professionals and volunteers that care for them, also underpinned by better patient information, health literacy, and a commitment to improve the Quality and Outcomes Framework for GPs to provide better incentives to prevent long-term conditions<sup>98</sup>.

Through the *Equity and Excellence: Liberating the NHS* white paper and the subsequent Health and Social Care Act, the present coalition government has elected to focus on measuring and improving clinical outcomes for patients<sup>99</sup>. The NHS's overall performance will be judged on a series of outcomes indicators published annually in the NHS Outcomes Framework<sup>100</sup>. The latest version of the framework includes a number of indicators geared towards improving outcomes for people with long-term conditions, which better management of co-morbidities can contribute towards:

- improving the health-related quality of life for people with long-term conditions
- the proportion of people feeling supported to manage their condition
- employment of people with long-term conditions<sup>101</sup>

As part of the reforms to the NHS, a new NHS Commissioning Board has been established, which will be nationally accountable for the outcomes achieved by the NHS, and provide leadership in the new commissioning system<sup>102</sup>. The Government has just published its mandate for the new organisation, setting out the objectives for the NHS and highlighting the areas of health and care where the Government expects to see improvements<sup>103</sup>. The mandate emphasises the importance of supporting and empowering people with long-term conditions and makes explicit reference to the fact that “by 2018 nearly three million people... will have three or more conditions all at once”<sup>104</sup>. The NHS Commissioning Board has an objective to ensure that the NHS becomes “dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment”, which includes all people with a long-term condition being offered a personalised care plan and everyone who wishes to have access to their GP record online<sup>105</sup>.

Another key element of the reforms is the desire to increase the number of NICE quality standards to 150 by 2014 and to strengthen their role as a key driver of quality in the new NHS<sup>106</sup>. Quality standards usually contain 10-15 statements describing what high quality care looks like for a given disease or topic area, based on the best available evidence. These sit alongside more detailed clinical guidelines and under the direction of the Health and Social Care Act commissioners will have a duty to have regard to quality standards when commissioning services<sup>107</sup>, although it is unclear what the sanctions will be if they are not met. In February 2012, NICE announced it would develop a quality standard for RA after the Department of Health made the decision to refer it to NICE alongside nine other new topics<sup>108</sup>. RA was selected because of the perceived burden of disease, the noted impact on resources, and in recognition of the inappropriate variation in practice across the country. A Topic Expert Group (TEG) has now been recruited by NICE to develop the quality standard, which consists of individuals drawn from across the rheumatology community (including an NRAS representative). The TEG has met twice so far, with further meetings planned before the quality standard is published some time in 2013<sup>109</sup>.

Quality standards will become even more important in the context of the Commissioning Outcomes Framework (COF) expected later this year<sup>110</sup>. The COF will be the main strategic document that the NHS

Commissioning Board uses to hold commissioners to account for the services they commission and will set out a series of specific indicators that Clinical Commissioning Groups will be measured against<sup>111</sup>. Once a NICE quality standard has been established for a disease it will then be eligible to have indicators included in the COF<sup>112</sup>. A draft consultation on potential COF indicators took place in February 2012 but did not elect to include a category for musculoskeletal conditions, including RA<sup>113</sup>. An appendix of draft COF indicators issued in an earlier consultation document provides a list of potential indicators for 'future development', which also did not include any mention of RA or musculoskeletal conditions<sup>114</sup>. The final COF document is expected to be published by the end of 2012.

The current government has made clear its commitment to supporting greater self-management for people with long-term conditions,<sup>115</sup> and the development of a specific self-management strand within the Quality, Innovation, Productivity and Prevention (QIPP) programme, which is aiming to make efficiency savings of £20 billion by 2014-15 in the NHS by providing more innovative, joined-up and high quality care<sup>116</sup>. This follows extensive research over the past few years which shows that supported self-management improves physical and mental wellbeing and changes how patients use services<sup>117</sup>.

Under the health reforms, the coalition government has also announced the introduction of a number of strategic clinical networks bringing together commissioners, providers and service users to help improve commissioning and deliver improvements to services<sup>118</sup>. The NHS Commissioning Board will be responsible for supporting and hosting these clinical networks and has recently announced that it will provide initial support to a small number of strategic clinical networks<sup>119</sup>, but decided not to establish a dedicated musculoskeletal clinical network, even though it represents the fourth largest area of spending in the NHS in England (accounting for £5.06 billion in 2011/12).<sup>120</sup>

In a separate development, there was an announcement in October 2011 that the Healthcare Quality Improvement Partnership (HQIP) would be taking forward a national clinical audit on early inflammatory arthritis and RA during 2012/13 to collect data and ascertain the level of service that is being offered to patients in hospital in relation to NICE Clinical Guideline 79 and the Inflammatory Arthritis Commissioning Pathway standards<sup>121</sup>. The audit will also examine cardiovascular risk factors for RA in conjunction with primary care and one of its objectives is to minimise cardiovascular and other co-morbidities by collaborative working involving specialists and GPs<sup>122</sup>.

Another way in which the government has sought to bring about improvements in care is through the introduction of a series of outcomes strategies. These have been documents with national reach, setting out how services in particular condition areas should be delivered across public health, the NHS and social care services. So far, strategies have been developed in cancer, mental health and chronic obstructive pulmonary disease. The King's Fund has pointed out that strategies such as these can bring about "real change and improvement for patients"<sup>123</sup>. Further strategies are being developed in the areas of liver disease and cardiovascular disease. However, the Government says that it has no plans to develop one for musculoskeletal conditions<sup>124</sup>, including RA, despite extensive campaigning on the issue from NRAS and others.

In March 2012 the Government announced it would be developing a new cross-government Long-Term Conditions Outcomes Strategy to set out a vision for how services such as health, social care, education, housing and others can work together to improve life chances and outcomes for people living with long term conditions, including RA<sup>125</sup>. A two-day accelerated learning event has been held in London and an online consultation on the themes for the new strategy has also been undertaken, which closed in June 2012<sup>126</sup>. The Government has said it intends to publish the Long-Term Conditions Outcomes Strategy by the end of 2012, but it has already said that the vision will cover helping to prevent or delay the onset of conditions, preventing deterioration of conditions and helping to develop joined up services to support people living with long term conditions<sup>127</sup>.

Another key lever for delivering improvements in the NHS is the Quality and Outcomes Framework (QOF), which is a voluntary incentive scheme for GP practices in the UK, rewarding them for how well they care for patients<sup>128</sup>. A NICE consultation on the latest round of QOF indicators took place on February 2012 and in June NICE recommended the inclusion, for the first time, of new RA indicators in the QOF 2013/14 that would incentivise screening of RA patients for cardiovascular risk and assessing fracture risk<sup>129</sup>. However, the menu of indicators is yet to be signed-off and will instead inform negotiations on the QOF between NHS Employers and the General Practitioners Committee of the British Medical Association as part of the wider General Medical Services contract negotiations this year.

Finally, the coalition government is supporting the development of best practice tariffs to promote better management of long-term conditions to reduce the risk of avoidable hospital admissions. Best practice tariff are financial mechanisms designed to incentivise the provision of higher quality services<sup>130</sup>. Arthritis

Research UK and the British Society for Rheumatology (with some input from NRAS), has worked with the Department of Health during 2012 to develop a proposed tariff for early inflammatory arthritis. Under the proposal, enhanced payments would be made for rapid assessment and appropriate treatment of people referred with suspected early inflammatory arthritis. The proposal is based on the NICE clinical guideline for RA, and aims to increase the proportion of people with early inflammatory arthritis who begin treatment within six weeks of GP referral and receive appropriate follow-up care, which might include a holistic annual review in the first year. The proposed tariff has been shortlisted for inclusion in the 2013/14 round, and is now under internal NHS consultation<sup>131</sup>. A letter was circulated by the Department of Health in September 2012 which confirmed its shortlisting<sup>132</sup>.

### **3.3 Implementation**

While the importance of managing co-morbidities is acknowledged in the medical guidelines and to a certain extent in public policy, measuring compliance and imposing best practice remains difficult particularly as NICE Clinical Guideline 79 on the management of RA and the Commissioning Pathway for Inflammatory Arthritis are not legally binding.

A King's Fund report, published in 2009, highlighted these challenges when it concluded that consistent monitoring of RA and its co-morbidities was poor and stated that quality of co-morbidity monitoring varied from "good, comprehensive, regular and evidence based assessment for the main health conditions associated with RA, through to virtually no active consideration of co-morbidities"<sup>133</sup>. The report pointed out that uncertainty arose concerning who was in the best position to monitor co-morbidities. The main examples of best practice cited in the report were located in specialist care, often provided by nurse specialists, though others claimed such monitoring and ongoing management should be conducted by primary care teams. A major constraint appeared to be the often limited knowledge among such teams of the specifics of RA and particularly the treatment regimens<sup>134</sup>.

As a result, the Rheumatology Futures Group, which commissioned the King's Fund report, published a series of recommendations to policy-makers and politicians. This included the recommendation that "a more comprehensive system of recording activity and coding data on RA patients who receive care is needed to capture the number of admissions through different specialist areas of the NHS for co-morbidities, such as cardiovascular disease. This will provide a greater understanding of the true economic and social costs of RA to the NHS and patients"<sup>135</sup>.

Meanwhile, a National Audit Office census conducted in January 2009 found that only 63 per cent of acute trusts were offering all patients an annual review and half reported that they provided care plans for all patients with RA, although 30 per cent did not provide a care plan for any<sup>136</sup>. Just 14 per cent at that time provided access to psychological services for all patients who needed them, even though depression is a common co-morbidity for people with RA.

A further report by the House of Commons Public Accounts Committee in 2010 also concluded that there was inconsistent provision of multidisciplinary services by PCTs in England and expressed particular concern about restricted access to psychological services<sup>137</sup>.

In 2010, NRAS conducted follow-up surveys with RA patients and healthcare professionals and found that 55 per cent of patient respondents claimed not to have had an annual review<sup>138</sup>. 57 per cent of consultant rheumatologists claimed to have seen no change in the past year in accessing a holistic annual review, and only 48 per cent of consultant rheumatologists' patients had access to a personalised care and management plan.<sup>139</sup>

A further report by NRAS in 2011, which examined access to physiotherapy services, also found that RA patients are getting limited access to allied health professionals working as part of multidisciplinary teams<sup>140</sup>. 35.5 per cent of survey respondents said they thought their physiotherapist was not working as part of a multidisciplinary team and, worryingly, a further 13 per cent were not sure whether this was the case<sup>141</sup>.

In respect of Information Prescriptions, a tool has since been produced for RA. It is available to access through the NHS Choices website and highlights the risks of developing a limited range of co-morbidities such as carpal tunnel syndrome, inflammation in the organs of the body, tendon rupture, cervical myelopathy, and vasculitis<sup>142</sup>. There is no public information available about how widely used this tool is.

### **3.4 Next steps**

We understand what good practice looks like in relation to the management of RA co-morbidities and section 3.2 outlines the ways in which better management can help to achieve care quality objectives for

people with long-term conditions as set out in the NHS Outcomes Framework, the NHS Commissioning Board Mandate, and the Commissioning Outcomes Framework.

Better management of RA co-morbidities can also contribute towards the target of achieving £20 billion of efficiency savings in the QIPP programme and this has been recognised by the coalition government<sup>143</sup>. RA patients with co-morbidities currently receive care that is funded by NHS budgets which cover musculoskeletal, cardiovascular and cancer services, receiving care from a total spending pot of over £13.11 billion a year<sup>144</sup>. As noted in the section 1.2, early detection and treatment of RA and its co-morbidities can reduce their impacts and enable better targeting of existing financial resources.

If we are to take determined action on RA co-morbidities then a first step must be to ensure that providers are fully implementing the recommendations of NICE Clinical Guideline 79 so that all patients are given an annual check for co-morbidities and access to consultant-led multidisciplinary team services. The baseline information collected through the forthcoming HQIP audit will also be particularly important in identifying gaps and applying pressure to providers to alter their practices where they are falling short. To reinforce the need for positive change, it will also be important that the newly proposed early inflammatory arthritis best practice tariff is introduced, and that it properly incentivises providers financially to conduct holistic annual reviews and ensures this is not just a 'tick-box' exercise.

To give clear direction to the NHS Commissioning Board, the Department of Health also needs to articulate a clear vision through its forthcoming Long-Term Conditions Outcomes Strategy (and any future outcome strategies that are pertinent to RA) on effective management of co-morbidities, which promotes investment in tailored self-management programmes, annual care plans and holistic annual reviews.

In turn, to support commissioners in implementing this vision locally, the NHS Commissioning Board should commit to assisting in the development of a musculoskeletal clinical network to help advise localities on good management of co-morbidities and the forthcoming NICE quality standard for RA must also include a quality statement on the need for holistic annual reviews and the development of annual care plans for patients. This will ensure that commissioners have both the necessary support structure and the sufficient legal duty to commission better care for RA co-morbidities. This could be even further augmented by including equivalent indicators for all people with a long-term condition in the forthcoming Commissioning Outcomes Framework.

Primary care must also play its full part too. The introduction of new QOF indicators relating to annual reviews for RA patients and the monitoring of cardiovascular and osteoporotic risks are absolutely vital, as is the need to develop shared-care protocols between primary and secondary care in local areas. This is something that the introduction of a musculoskeletal clinical network could help to facilitate.

Finally, to ensure patients are equipped to manage their health, we need to give RA patients better quality information about co-morbidities. This can be achieved through Information Prescriptions and provision of appropriate self-management programmes to educate newly diagnosed patients and those with established disease about the risks, so they can take active steps to manage their disease more effectively. It is also important that such investment should not be seen as a cost pressure in the system, as studies on economic effectiveness of self-management have concluded that it can lead to cost savings of £1,800 per patient per year<sup>145</sup>.

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