



Breaking Down Barriers: Rheumatoid Arthritis and Public Awareness

Embargoed: 00.01am 24 June 2013



nrAS
National Rheumatoid
Arthritis Society

Contents

1.	<i>Introduction</i>	<i>p 2</i>
2.	<i>Background to this survey</i>	<i>p5</i>
2.1	<i>Public awareness and rheumatoid arthritis – evidence and policy</i>	<i>p5</i>
2.2	<i>Signs and symptoms</i>	<i>p5</i>
2.3	<i>Impacts</i>	<i>p6</i>
2.4	<i>Risk factors</i>	<i>p7</i>
2.5	<i>The value of early diagnosis and treatment</i>	<i>p8</i>
2.6	<i>Delays due to lack of public awareness</i>	<i>p8</i>
2.7	<i>Calls for action</i>	<i>p10</i>
2.8	<i>Approaches to raising public awareness of RA</i>	<i>p11</i>
2.9	<i>Measuring levels of public awareness of RA</i>	<i>p11</i>
2.10	<i>Government policies</i>	<i>p13</i>
2.11	<i>The survey and its methodology</i>	<i>p15</i>
3.	<i>Key findings</i>	<i>p16</i>
3.1	<i>The survey respondents</i>	<i>p16</i>
3.2	<i>Symptoms of the disease</i>	<i>p16</i>
3.3	<i>Impact of the disease</i>	<i>p18</i>
3.4	<i>Risk factors</i>	<i>p21</i>
3.5	<i>Age</i>	<i>p23</i>
3.6	<i>Personal connection to the disease</i>	<i>p25</i>
3.7	<i>Understanding the symptoms</i>	<i>p25</i>
3.8	<i>Understanding the difference between RA and osteoarthritis</i>	<i>p27</i>
3.9	<i>Differences between England, Scotland and Wales</i>	<i>p27</i>
3.10	<i>Ethnicity</i>	<i>p29</i>
3.11	<i>Seeing information on the symptoms of RA</i>	<i>p31</i>
3.12	<i>Satisfaction with existing public awareness initiatives</i>	<i>p31</i>
3.13	<i>Appetite for further education</i>	<i>p32</i>
4.	<i>Conclusions and recommendations</i>	<i>p33</i>
4.1	<i>Summary of report findings</i>	<i>p33</i>
4.2	<i>Recommendations</i>	<i>p34</i>
5.	<i>Thank you</i>	<i>p35</i>
6.	<i>References</i>	<i>p36</i>

Introduction

From Ailsa Bosworth, Chief Executive
National Rheumatoid Arthritis Society



To coincide with the launch of our very first national Rheumatoid Arthritis Awareness Week we have collaborated with leading opinion polling company ComRes to survey the British population to try to better understand overall levels of awareness and misconceptions surrounding the chronic autoimmune disease rheumatoid arthritis (RA).

To our knowledge this is the first time a detailed survey of this type has been conducted, which analyses public perceptions of the disease, offering a real insight into people's awareness of the symptoms, the impacts and associated risk factors, and most importantly what they think about government attempts to raise awareness about the disease so far.

The results of the ComRes survey succinctly illustrate the scale of the challenge we face in getting members of the public to recognise the early symptoms of RA, understand the severity of the disease and to urgently seek out medical advice from their local General Practitioner.

I am very committed to the issue of public awareness having tried to make the case for a nationally funded campaign to the Department of Health in 2010 during my time as joint Chair of the Rheumatology Futures Project Group. The proposal was initially verbally supported by the Department before eventually being politely rebuffed.

The Group subsequently worked with stakeholders in the inflammatory arthritis community to develop the *S Factor* public awareness campaign. Then when funding for the Group eventually came to an end both NRAS and Arthritis Research UK continued to put in our resources to the *S Factor* campaign, to maintain the momentum which had been kick-started by its launch and promotion at the British Society for Rheumatology annual conference in 2010.

The *S Factor* campaign was undoubtedly an important piece of work, which received substantial backing from all our partners and did manage to raise a degree of public awareness – as told to us by our local NRAS groups. However, undoubtedly progress around this issue over the last three years has been hamstrung by our limited resources.

The results of the opinion poll are both surprising and predictable. For example, although younger survey respondents exhibited poorer levels of understanding about the disease compared to other age categories a very high percentage did manage to correctly identify the main symptoms of the disease – giving me some cause to hope.



I was nevertheless still extremely disappointed to discover that only around 10 per cent of survey respondents reporting having seen public information about the symptoms of early RA – despite recent attempts to engage the public through initiatives such as the aforementioned *S Factor* campaign and the Scottish Government’s new pamphlet on the early symptoms of RA.

Given what we know about the striking impact that early diagnosis and appropriate treatment can have on disease progression, public awareness needs to be much higher. Indeed, I have lost track of the number of times I have encountered people who have shown little or no understanding for the severity of my disease which, like many people with RA, I find deeply frustrating.

We hope *Breaking Down Barriers: Rheumatoid Arthritis and Public Awareness* will help to reinvigorate efforts to improve public awareness of RA and lead stakeholders within the health arena to create more targeted messages and adopt more innovative approaches when tackling this issue, because it is clear that current practices are inadequate.

This report forms part of NRAS’s ongoing commitment to campaign for equal access to good care and services for all.

Video wall on patient leadership
click here

News

Principles of Care and Support Planning – we welcome your views

National Voices is seeking views on its Principles of Care and Support Planning from patients, services users, commissioners, providers and health professionals about how to refine the Principles and develop an online...

From Jeremy Taylor, Chief Executive - National Voices



The future of the NHS will increasingly be about how society adapts itself to the needs of people with long term conditions. An estimated 15 million or more people are living in England with one or more chronic health conditions and about £7 in every £10 spent on healthcare goes towards their needs.

While great advances have been made in the last few decades in the prevention and treatment of major killers such as coronary heart disease and many cancers, there is a long way to go in creating a systematically excellent system for supporting people who live with chronic diseases.

The NHS has perhaps been better at saving and extending lives than in helping people live with a greater quality of life. Equally, the public debate still tends to focus on the “rescue” side of the NHS. The controversy is all about hospitals and emergency care, less about community based services to support people with continuing health needs.

Rheumatoid arthritis provides a perfect case example of the challenges. It can be a profoundly debilitating and disabling disease but it can also be successfully managed. Early diagnosis can make a big difference. It affects a large number of people yet manages to lurk below the radar of public consciousness and - some would argue - below the radar of many in the health professional community.

NRAS does a sterling job in classic health charity mode: providing information and support for people with RA and their families, and advocating on their behalf. But this is a job that needs to be shared more widely. The newly reorganised NHS in England has set itself the task of creating a better service for people with long term conditions. In doing that, it must understand the diversity of needs and conditions and avoid defaulting to a “one size fits all” model.

Equally, this is not just the task of the NHS. The government, health educators, other public services, the education sector and voluntary organisations all have a role to play to promote greater awareness of conditions such as rheumatoid arthritis; to convert that awareness into better tailored services, and to ensure a stronger voice for people living with these conditions.

Breaking Down Barriers: Rheumatoid Arthritis and Public Awareness is an important contribution to this debate.



Background to the survey

2.1 Public awareness and rheumatoid arthritis – evidence and policy

There are nearly 690,000 people across the United Kingdom with the chronic autoimmune disease rheumatoid arthritis (RA)¹. For some people, the disease is moderate or less severe and remains reasonably well controlled, but others experience chronic disabling pain, inflammation, stiffness, extreme fatigue and reduced joint function and impaired mobility. For these people, earlier diagnosis and effective treatment could have helped to reduce the long term impact of the disease by slowing or halting its progression at a stage when long term outcomes can be significantly influenced.

2.2 Signs and symptoms

RA is a chronic, progressive and disabling disease where the immune system attacks the synovial lining to the joints and other organs. If left untreated, the joint can lose its shape and alignment, cause bone erosion and ultimately lead to destruction of the joint and permanent disability. It is a systemic disease, which means it can also affect internal organs of the body such as the heart, eyes and lungs.

Only about 15 per cent of patients experience an explosive, sudden onset of RA, where the symptoms present themselves in a matter of days or weeks (generally described as “barn door” presentation). In 8 to 15 per cent of cases the symptoms may also begin within a few days of a specific ‘inciting event’, such as an infection².

In most other instances the symptoms develop gradually over a period of weeks or months and can either be palindromic - with patients describing symptoms that last a few days or weeks and then completely go away, only to return later with other manifestations that increase over time - or present with monoarticular symptoms, extra articular synovitis, or polymyalgic-like onset³.

Many early signs and symptoms – joint pain, stiffness, fatigue, fever, weight loss – are not specific to RA and can be attributed to other medical conditions, which makes it very difficult to diagnose the disease⁴. The lack of disease-specific diagnostic features means diagnosis is usually based on the opinion of a rheumatologist using relevant physical examination, classification criteria, blood tests and imaging⁵ and the patient’s own self reported history – because there is no single diagnostic test for RA, a clinical diagnosis by a skilled specialist is required.

“These results clearly show how few people are aware of the serious consequences of rheumatoid arthritis.”

Katharine Peacock,
Director of Research at
ComRes



“Early diagnosis and treatment is clearly vital in the treatment of RA, and raising public awareness of this disease is the first step.”

Patient with rheumatoid arthritis – response to a survey commissioned by the National Audit Office

RA is also a very individual disease with no universal pattern to the symptoms. Some people have ‘flares’, or periods when their symptoms are much worse, which then subside. Others can have periods when their disease is quieter and causes significantly less pain. The duration and impact of flares differs and nearly half of people with RA suffer flares over a six month period and nearly a quarter suffer flares on a weekly or daily basis⁶.

People with RA usually experience swelling in at least two joints, often the small joints of the hands, feet and wrists. In some patients however, RA will start in one or more larger joints before spreading to the smaller ones.

There can also be stiffness in the joints, particularly first thing in the morning or after sitting for some time. RA morning stiffness is distinguished from other types of morning stiffness because it usually lasts for 30 minutes or longer⁷. RA patients can also wake up in the middle of the night with joint pain and stiffness.

Extreme fatigue is pronounced in RA⁸, and there may be loss of weight due to poor appetite. Apart from joint pain, stiffness or swelling, some people have flu like symptoms.

2.3 Impacts

The impact of the disease is dependent upon numerous factors including the aggressiveness of the onset, how well controlled it is and how long a patient has had the disease for.

RA patients diagnosed and treated within the last decade are likely to experience less damage than those diagnosed between 15 and 30 years ago because of improved treatment and management of RA⁹, including the introduction of more aggressive use of Disease Modifying Anti Rheumatic Drugs (DMARD) therapy and the advent of new biologic drugs, which have significantly improved patient outcomes since the late 1990s¹⁰.

The disease can affect mobility. Many RA patients have severe difficulty walking because of foot pain and deformity, resultant foot operations, toe straightening, foot fusions, ankle replacements or knee and hip replacement operations, which are all common complications of the disease. It is estimated that 90 per cent of people with RA experience foot pathology, which creates restricted mobility and concomitant pain¹¹.

Further impacts of the disease relate to the concomitant risk of various co-morbidities. 80 per cent of RA patients have one or more co-morbidities with the average being 1.6.¹² People with RA have a higher risk of suffering a heart attack, atrial fibrillation and strokes compared to the general population¹³. Meanwhile, leukaemia, lung cancer, lymphoma and multiple myeloma are all more common¹⁴ and about a quarter of patients also have manifestations of RA in the eyes. This can be inflammation of the interior of the eye, which can in the most severe cases reduce vision¹⁵.



Furthermore, while the biopsychosocial impacts of the disease are also well understood they are not well addressed. Patients are sometimes reluctant to talk about personal issues and healthcare professionals often don't know how to open the door to these sensitive issues, which can impact greatly on people's lives. 79 per cent of respondents to an NRAS survey said that the disease had a negative impact on their confidence, 69 per cent said it negatively affected their mood some of the time and 68 per cent said the disease negatively affected how they feel about their appearance¹⁶.

The disease also has wide ranging impacts upon family members. Partners of RA patients report significant changes in responsibilities for household tasks, restrictions to social life and impacts of the disease upon their own mood or mental wellbeing, as well as negative impacts upon their relationship with their partner and concerns about how the disease will affect their children¹⁷.

Although RA can affect anyone from the age of 16 upwards, three quarters of people with RA are first diagnosed when of working age - with the largest cohort being over 40 years old¹⁸. RA is thus a major cause of sickness absence and worklessness and this is estimated to cost around £1.8 billion per year¹⁹. Almost a third of people with RA have given up work as a result of their condition, with well over a quarter doing so within one year of diagnosis, and over half doing so within six years²⁰.

Ensuring people are able to stay in work is absolutely vital. Not just in pure economic terms, but also because of the psychological impact on patients. In an NRAS survey of members with the disease, 88 per cent of respondents said that having a job helped them cope with the disease with incidences of depression significantly higher among non-workers than workers²¹.

2.4 Risk factors

Gender is a significant risk factor for RA with the overall occurrence of RA being around three times greater in women than men. This has been attributed in part to the female hormonal environment during pregnancy, breastfeeding, use of the oral contraceptive pill and menopause²².

There is also evidence of a genetic risk factor with two genes in particular having been identified – the HLA-DRB1 gene and the protein tyrosine phosphatase non-receptor 22 (PTPN22) gene – and believed to have varying degrees of correlation²³.

There is also a link between cigarette smoking to both the onset of symptoms and the intensification of symptoms, as well as reducing the efficacy of drugs among those already diagnosed with the disease²⁴.

Diet may also be a risk factor, with high caffeine, low antioxidants and high red meat consumption possible contributory risk factors²⁵.



Exposure to certain infections may also be an elevating risk factor, with the Epstein-Barr virus highlighted as one possible candidate²⁶.

The role of ethnicity may also be a risk factor as it has also been noted that the prevalence of RA is lower in people of Chinese, Pakistani or first and second generation African Caribbean origin compared to European Caucasians²⁷ with higher prevalence of RA noted in Native American populations²⁸.

2.5 The value of early diagnosis and treatment

In accordance with NICE Guidelines, research shows there is a 'window of opportunity' for RA patients. Those diagnosed and started on optimal treatment using DMARDs within twelve weeks of symptom onset stand a much better chance of achieving remission or a low disease activity state²⁹.

Even brief delays of as little as 8–9 months in starting DMARD therapy significantly affect disease outcomes years afterwards³⁰, even if more potent treatment strategies are applied³¹. For example, mortality among RA patients who present early is lower than in those who present late in the course of their disease³².

Erosive changes happen early on in disease that is inadequately treated. Radiographic evidence demonstrates that 90 per cent of RA patients have damage after 2 years³³ and evidence from magnetic resonance imaging and ultrasonography shows that damage can occur within weeks of symptom onset³⁴.

Early diagnosis and treatment does not just benefit the individual, it also has wider societal benefits. National Audit Office economic modelling predicts that doubling the proportion of RA patients treated with DMARDs within 3 months of symptom onset, from the current level of 10 per cent to 20 per cent, could result in productivity gains for the economy of £31 million over 5 years³⁵.

2.6 Delays due to lack of public awareness

Most GPs are likely to see an undiagnosed case of RA less than once a year, which means they will have few opportunities to improve their ability to identify the disease³⁶. Although serious issues remain, it has been noted that levels of GP education about RA have improved over the last 20 years and led to a shortening of out-patient waiting times for patients with new onset synovitis³⁷.

The failure of RA patients to consult their GP is therefore regarded as one of the principle reasons for delays in seeing a rheumatologist in the UK in comparison to other health systems³⁸. Research conducted to feed into the National Audit Office reported that 15 per cent of RA patients identified delaying to go and seek medical help as one of the main factors that could have led to a quicker diagnosis³⁹.



“There are too many people in the UK with the symptoms of rheumatoid arthritis who are not seeking treatment. Research shows that the earlier you visit your doctor the more successful your treatment is likely to be. The first 12 weeks of symptoms developing are critical - if rheumatoid arthritis is caught in this time and treated aggressively there is less joint damage and reduced chance of long-term disability.”

Professor Alan Silman,
Medical Director, Arthritis
Research UK

In the same year, a King’s Fund report on the perceptions of RA patients and healthcare professionals also concluded that low level of awareness of RA was a major cause of delay among the wider population, which may partly be related to not knowing the difference between RA and osteoarthritis and also to the incorrect assumption that ‘nothing can be done’⁴⁰.

As a result, the National Audit Office estimated that between half and three quarters of people with RA will delay contacting their GP for the first three months or more following symptoms, and around a fifth delay for a year or more⁴¹. A separate study in Birmingham also found that the median delay caused by patients failing to seek medical advice was 12 weeks⁴² and this was confirmed in another UK study⁴³.

Of particular concern, evidence from the Norfolk Arthritis Register (NOAR) data collected between 1995 and 2005 also suggests public awareness and public behaviour about the symptoms of RA has not improved over the last decade⁴⁴.

Reasons for delays are complex and include the type and severity of the symptoms. For example, studies have shown that patients with asymmetric or unilateral joint symptoms tend to seek attention earlier than those with symmetric arthritis or more gradual symptom onset⁴⁵.

Delays may also occur because of cultural differences. For example delays are significantly longer in RA patients of South Asian origin compared to other ethnic groups, with several factors being identified: symptom experiences, how they evaluated the symptoms, their existing ideas and level of knowledge about RA, and influence of friends and family⁴⁶.

A systematic review of qualitative peer-reviewed publications on help-seeking behaviour in adults with RA found that many patients had little knowledge of RA, sometimes attributed the disease to stressful life events, undertaking particular activities, or confused it with ageing and osteoarthritis, or believed the symptoms would eventually go away. Many patients often tried to normalise or ignore the symptoms and delayed seeking medical help because of factors including seeking out lay advice from friends, attempting to self-medicate or in some cases suffering because of difficulty accessing healthcare due to living in a rural area⁴⁷.

International evidence points to the value of public awareness in improving health outcomes. For example, a study in the United Arab Emirates partly attributed reductions in the lag time to diagnosis and initiation of DMARD therapy over a five year period to activities that increased public awareness⁴⁸.

A Norwegian study also found that the median delay on the part of the patient was 4 weeks, which is much shorter than in the UK patient population. The study hypothesised that this may be partly due to differences in how public health campaigns operate in these countries⁴⁹. While the situation in Norway is not optimal it does show that further reductions in patient-related delays are theoretically possible.



2.7 Calls for action

Evidence about the impact of poor public awareness has led a number of organisations to raise concerns and call for investment in public awareness campaigns.

Scotland's *Clinical Audit of Care in Rheumatoid Arthritis*, published in 2008, recommended that a further audit should take place identify if there are significant delays before patients with inflammatory arthritis present to their GP. If there is, a public awareness campaign should be considered to highlight the necessity for medical attention if joints become swollen and stiff⁵⁰.

In 2009, the National Audit Office (NAO) also recommended that the Department of Health explore the cost effectiveness of options for raising public awareness of the symptoms of inflammatory arthritis, including RA, to encourage people to present to the NHS promptly after symptom onset⁵¹.

In the same year, the Arthritis and Musculoskeletal Alliance also published research on the implementation of the *Musculoskeletal Services Framework* which recommended the introduction of a general programme of awareness-raising for the public about when to seek help and the need for improved information⁵².

Latterly, in response to the NAO report the House of Commons Public Accounts Committee undertook an inquiry on services for people with RA and published its own report in 2010 which recommended the Department of Health run a national campaign to raise people's awareness of the symptoms of RA, highlighting the need to seek prompt medical attention⁵³.

The UK Government responded by publishing a Treasury Minute which acknowledged that low public awareness was a barrier to the early diagnosis and treatment and committed to supporting charities to produce materials to raise awareness of RA⁵⁴.

The response from the UK Government drew criticism from NRAS for being inadequate and the charity continued to call for a public awareness campaign like those undertaken to tackle other common chronic diseases⁵⁵.

In a separate development, the Scottish Government asked the Scottish Public Health Network (ScotPHN) to undertake a revised Needs Assessment of RA, which reported in 2012. One of ScotPHN's main recommendations was that public awareness of RA should be raised in order to limit the delay in patients presenting to their GP⁵⁶.

NRAS welcomed the findings of the ScotPHN report⁵⁰. The report has been presented to the Scottish Government and is awaiting an official response.

"After both NAO (2009) and Public Accounts Committee (2010) reported serious shortcomings in health services for RA, Arthritis Care's 2012 "3 Wasted Years" report drew attention to, inter alia, the need for proper investment in raising public awareness of the signs and symptoms of rheumatoid arthritis. Another year on, we welcome the clear re-statement of that message in the Breaking Down Barriers report and hope that it will ensure attention is paid to this important issue right now."

Phil Baker, Interim Chief Executive, Arthritis Care



2.8 Approaches to raising public awareness of RA

Approaches to raising public awareness in the UK have been very sporadic with only Scotland electing to fund a national awareness campaign on RA so far. The campaign developed by the Rheumatology Futures Project Group to raise awareness of the early signs and symptoms of inflammatory arthritis, (“The S Factor”) for the UK audience is the only other notable example within Britain.

“The Breaking Down Barriers report confirms what our members are telling us, which is that people with RA are often presenting too late to receive the maximum benefit from the treatments available.”

Laura Guest,
Chief Executive, British
Society for Rheumatology

As mentioned in the foreword by Ailsa Bosworth, further additional funding was contributed by NRAS and Arthritis Research UK and the campaign received the endorsement of the Royal College of General Practitioners and the Primary Care Rheumatology Society. Focused around 3 “S” symptoms in the joints - Stiffness, Swelling and Squeezing - the campaign message to the public was that if you have any symptoms highlighted in the poster, then seek help from your GP, and crucially don’t delay.

Posters were rolled out throughout the UK during 2010 and a further national and regional media campaign was initiated in 2011 and fronted by television presenter Dr Hilary Jones. Although members have informed NRAS through its local networks that it had some impact, owing to resource constraints no formal evaluation has been conducted.

After publication of the ScotPHN Needs Assessment on RA, the organisation worked in partnership with NRAS and Arthritis Care to develop and distribute a new pamphlet targeted at the public to raise awareness of the signs of early rheumatoid arthritis. *Recognise, Respond, Relieve – Rheumatoid Arthritis* was published in March 2013 and sets out the symptoms members of the public should look out for and stresses the ‘window of opportunity’⁵⁸.

However, this pales into insignificance when compared to the comprehensive approach to raising awareness that is being adopted in Ireland, where a major public awareness campaign, including television advertising, has been launched in 2013 to alert the public to the symptoms and the importance of early treatment. The “Every Day Tasks” campaign highlights how difficult simple daily tasks can become and encourages members of the public to call Arthritis Ireland or visit their website to receive a free information pack⁵⁹.

2.9 Measuring levels of public awareness of RA

There is no consistent year on year data about levels of public awareness of RA among the British public. However, the vast majority of national polls and surveys show low levels of recognition and routine misunderstandings about the disease symptoms, which are accentuated in young adults. Across the board - RA patients, their families, healthcare professionals and patient organisations - all believe that greater public awareness is required.



An Ipsos MORI poll conducted in 2000 found that 48 per cent of adults surveyed about the different types of arthritis mentioned RA, but when asked more closely about the disease only 5 per cent specifically identified inflammation as a feature of RA⁶⁰ suggesting poor awareness of the symptoms. Levels of recognition of RA within the poll, while not good, still exceed those observed in other surveys of the British public.

For example in 2009 NRAS commissioned a ComRes poll of the British public and found that 62 per cent of people polled mistakenly thought that RA was caused by the wear and tear of joints over time with 75 per cent of young people aged 18-24 believing this to be true. 73 per cent of 18-24 year olds also didn't know RA is a systemic disease that can affect other internal organs⁶¹.

In the same year, the National Audit Office commissioned research into the attitudes of patient organisations which identified lack of public awareness as one of six factors responsible for prolonging the delay of RA diagnosis and suggested that speed and accuracy of diagnosis could be improved by promoting greater awareness of RA and using messaging to stress the importance of bone health, clarifying the difference between RA and osteoarthritis, emphasising the importance of early intervention and explaining that RA does not necessarily occur in old age⁶².

The extent of confusion over symptoms and possible conflation with osteoarthritis was underlined in a joint survey by NRAS and Arthritis Research UK published in 2011, which found that only 10 per cent of people were confident that they knew the symptoms of RA. 59 per cent of those surveyed experienced symptoms, yet many overlooked them. 42 per cent assumed pain, stiffness and swelling in the joints was a normal part of ageing and 32 per cent put it down to over doing it in the gym or garden. Crucially, 58 per cent of survey respondents said they would not consult a health care professional if they experienced pain, stiffness and swelling in the joints⁶³.

A recent survey of RA patients conducted by Arthritis Care in 2012 found that over three quarters of survey respondents rated the current level of public awareness of the condition as either 'poor' or 'very poor' with over 70 per cent of healthcare professional respondents also saying they felt public awareness of RA remained 'poor' or 'very poor'. A large number of these patients who provided supplementary comments felt there was a widespread misconception that RA is a condition that primarily affects older people⁶⁴.

In 2012, NRAS surveyed the family members of people living with RA about what they felt would be of most benefit to them and 93 per cent said running public awareness campaigns so that more people understand RA would either be 'helpful' or 'very helpful'. Interviewees went on to say that lack of awareness made it more difficult for them to cope and contributed to difficulties they experienced in talking about their partners' RA⁶⁵.



2.10 Government policies

With the partial exception of Scotland, successive governments in England and Wales have overlooked the potential of enhanced public awareness in achieving better outcomes for patients with long term conditions. Strategies concerning long term conditions, public health, and health promotion in secondary education all omit to include any reference to this issue.

Under the previous Labour Government *The Wanless Report* was published which set out the benefits of increased investment in health promotion and disease prevention on health status, its potential to increase productivity and reduce inactivity in the working age population, and reduce future demand for overall health resources⁶⁶. *Our Health, Our Care, Our Say* published in 2006 under the previous UK Government noted the need for high quality information to ensure people access the right service at the right time and set out a range of e-government objectives relating to the sharing of information, but nothing on health promotion⁶⁷. *The NHS Next Stage Review* published in 2008 also acknowledged the need for a greater focus on prevention of long term conditions rather than just management, but it did not come up with a convincing vision or recommendations of how this could be applied to public awareness of long term conditions⁶⁸.

A similar path has been followed by the present UK Government as none of the three key strategic documents that inform the present health reforms in England - the *NHS Outcomes Framework 2013-14* the *NHS Mandate* or the White Paper *Equity and Excellence: Liberating the NHS* – provide a clear steer on the role of health promotion and greater public awareness in achieving earlier diagnosis for people with long term conditions. The only mentions of early diagnosis are in relation to achieving better outcomes for dementia, and avoidance of preventable deaths through appropriate use of primary care, with the introduction of a performance indicator to measure the estimated diagnosis rate for people with dementia⁶⁹.

The issue is equally patchily addressed through long term condition and musculoskeletal strategies, where they exist. For example, the *Musculoskeletal Services Framework* in England, published in 2006, set out a vision for integrated care pathways with patients as active agents and seamlessly coordinated services from public health information onwards, but without referring to the issue of public awareness, even though it acknowledged that early diagnosis of these conditions would be cost effective, especially if it allowed people to remain in work for as long as possible⁷⁰.

By contrast there is a more developed vision in Wales. The 10 year vision for health and social care in Wales called *Designed for Life* was published in 2005 and set out a goal to ensure effective and rapid diagnosis is eventually available locally and committed to ensuring that all NHS Trusts will have an approved health promotion strategy covering services and staff in place. Building on this in 2006, the *Service Development and*



Commissioning Directives: Arthritis and Chronic Musculoskeletal Conditions in Wales set out a vision for early assessment and diagnosis of arthritis and musculoskeletal conditions to minimise physical and psychological impact and recommended that health promotion information and targeted campaigns should educate the public and contribute to a better understanding of how to prevent and manage musculoskeletal conditions. Of particular note, it said information should be focused on the whole population as well as targeted toward those at particular risk of developing arthritis and chronic musculoskeletal disorders⁷¹. The *Designed to Improve Health and the Management of Chronic Conditions in Wales: Service Improvement Plan 2008-11* also included references to the role of effective health promotion and the need for strong infrastructure to promote healthy lifestyles across communities⁷². Although there was no reference to the role of information campaigns about long term conditions.

Public health strategies are equally inadequate when it comes to identifying the role for increased public awareness of long term conditions. In England, the White Paper *Healthy Lives, Healthy People: Our Strategy for Public Health in England*, the *Healthy Lives, Healthy People: Update and Way Forward* and the *Public Health Outcomes Framework for England 2013-2016* focus to varying degrees on ensuring people can live healthy lifestyles, make healthy choices and reduce health inequalities with particular emphasis on prevention through lifestyle interventions. The potential of health promotion in schools is flagged up (better utilisation of the school nursing service around health reviews and key transitions and managing pupils' wellbeing) and it established an indicator to measure cancer diagnosed at stage 1 and 2, and committed the UK Government to explore the best place to locate commissioning responsibility for early diagnosis campaigns⁷³. The only notable reference to long term conditions in these documents is in relation to establishing an indicator for employment for those with these diseases⁷⁴. A not too dissimilar picture appears in Wales, where documents such as *Our Healthy Future* and the *Health Promotion Action Plan for Older People in Wales: A Response to Health Challenge Wales* focus the Welsh Government on prevention through lifestyle interventions and accompanying messaging with no reference to health promotion or public awareness of long term conditions.

Meanwhile in Scotland there has been a haphazard approach to tackling issues of public awareness of long term conditions. For instance, *Better Health, Better Care: Action Plan* published in 2007 focuses on boosting health promotion in schools through nutritional guidance and related measures⁷⁵. While *The Healthcare Quality Strategy for NHS Scotland* committed to the introduction of a *Long Term Conditions Action Plan*⁷⁶. The Plan acknowledged that NHS Scotland needed to provide a solid foundation of population-wide prevention, health promotion and targeted health improvement activity, through action to prevent disease, raise awareness of risks to health and support healthy lifestyle choices⁷⁷ – but again without mention of practical measures that could enhance public awareness with reference to long term conditions. Likewise, the publication of the *Long Term Conditions Collaborative – High Impact Changes* document in 2009 was supposed to set out a series of measures that the Scottish Government thought would lead to a big impact on the way people with long term conditions manage and experience their care. However it contained no recommendations relating to health promotion and public awareness⁷⁸.



2.11 The survey and its methodology

The questions in the survey were developed by NRAS and ComRes in order to explore people's perceptions of RA and the misconceptions around the condition. ComRes is a member of the British Polling Council and abides by its rules.

The questions were designed to support and provide insight for the national Rheumatoid Arthritis Awareness Week in June 2013.

A series of closed questions were used in order to produce statistical evidence of opinions and misconceptions. ComRes interviewed 2,074 British adults aged 16+ online between 10th and 11th April 2013. Data was weighted to be representative of all British adults aged 16-88.

A total of 58,051 invitations were sent, of which 2,074 completed the survey, and 131 clicked on the link but did not complete it.

ComRes tabulated the data electronically, including breaks by factors such as age, gender and region. The confidence interval was 95 per cent and the margin of error on the results is ± 2.15 per cent.

The results for the age group 16-18 were formulated from a sample size of 70 respondents. While this is representative of the population as a whole, owing to the relatively small sample size, any findings in the report about this age classification are therefore intended to yield suggestive rather than conclusive evidence.

The survey data initially found that 36 per cent of respondents said they had been affected by RA (either in person or through close friends and family). However on closer inspection this figure was believed to be inflated by those who confused RA and osteoarthritis.

The survey attempted to calculate a more realistic figure by cross-referencing answers by respondents to three questions: those that said they, or friends and family close to them, had been affected by RA; those that said they understood the difference between RA and osteoarthritis; and those that correctly identified 'crunching and grinding of the joints' as not a symptom of RA (6 per cent). Extrapolating this figure to the British population as a whole, using data from the 2011 census, the survey revealed that approximately 3.7 million people are affected by the disease. This means that for every person with the disease, approximately 4 others will also be affected.



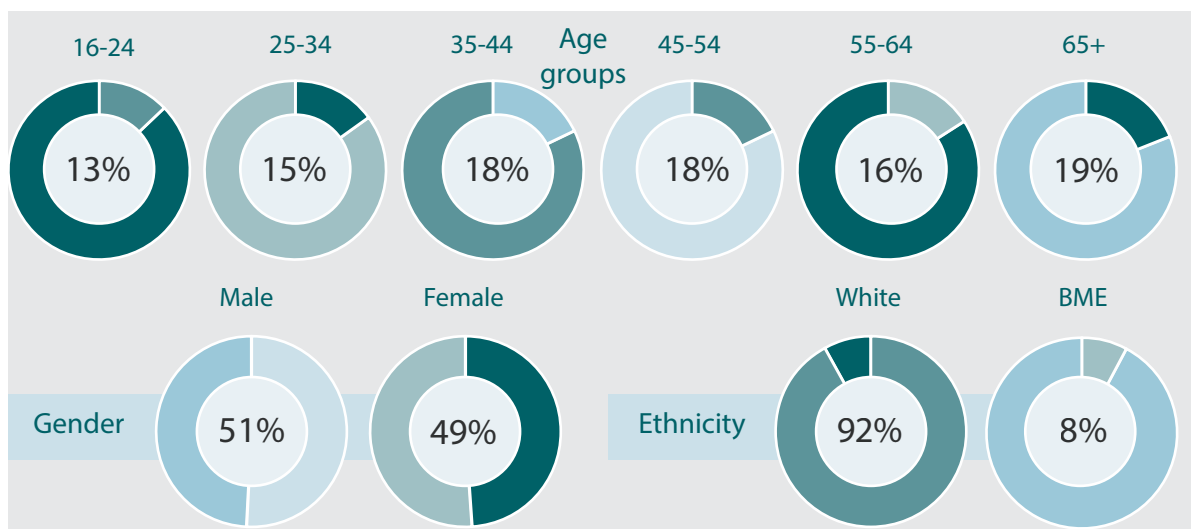
3. Key findings

3.1 The survey respondents

Of the 2,074 respondents, the largest age category was those over 65 years old (19 per cent). The next biggest categories were 35-44 year olds and 45-54 year olds, both making up 18 per cent of the total respondents respectively. The smallest group was the 16-24 year olds (13 per cent). These proportions roughly reflected those found in each age band of the general British population.

51 per cent of those who completed the survey were male and 49 per cent were female. The ethnicity of respondents was largely comprised of people who define themselves as 'white' (92 per cent), leaving the categories 'Mixed', 'Asian or Asian British', 'Black or Black British', 'Chinese' and 'other' to make up the remaining 8 per cent.

To ensure the results were statistically significant when conducting data analysis on ethnicity later in the report, it was decided to split this into two groups - 'white respondents' and 'Black and Minority Ethnic (BME) respondents'.



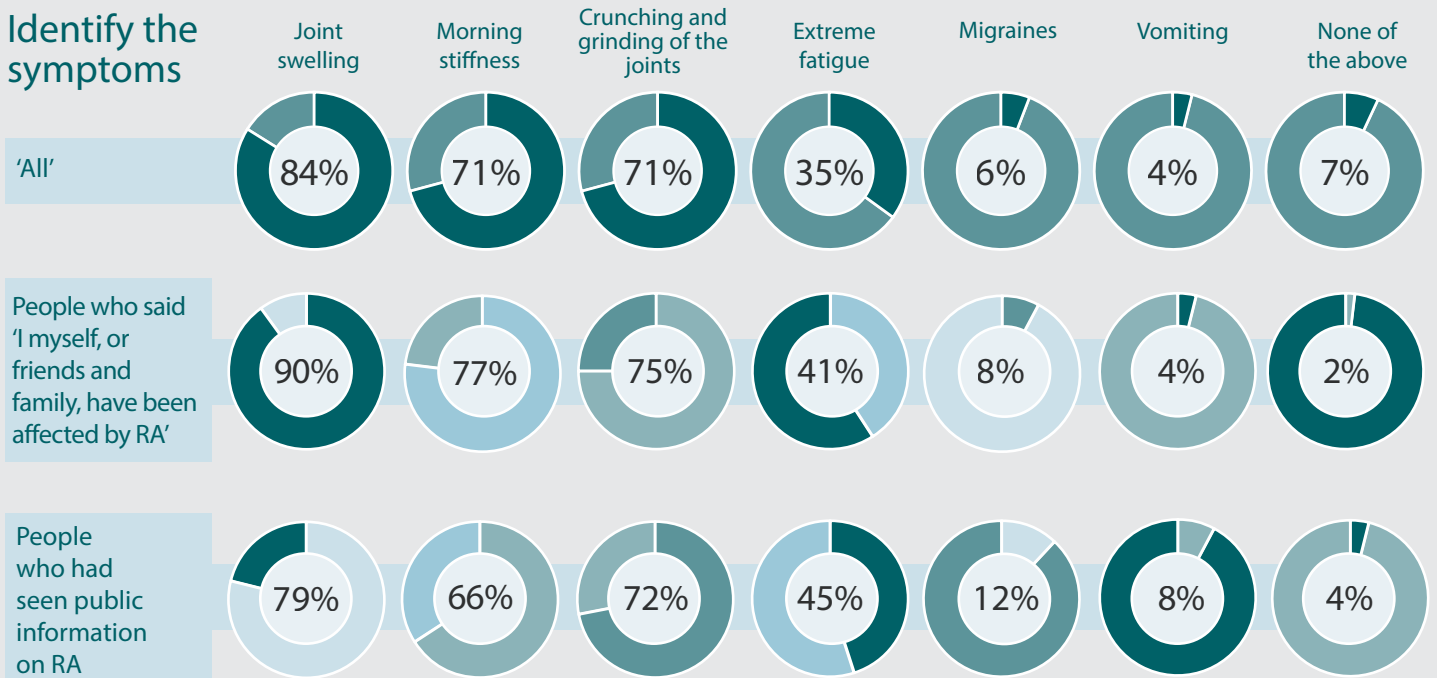
3.2 Symptoms of the disease

A large number of respondents recognised certain symptoms of RA (joint swelling and morning stiffness) although equally as many incorrectly identified crunching and grinding of the joints (associated with osteoarthritis) and very few identified extreme fatigue as a symptom.

The majority of respondents correctly identified joint swelling (84 per cent) and morning stiffness (71 per cent) as symptoms of RA – although an equivalent proportion of respondents also incorrectly identified 'crunching and grinding of the joints' as a symptom (71 per cent).



Identify the symptoms



Respondents who had a personal connection to the disease^[1], were more likely to identify joint swelling (90 per cent), morning stiffness, (77 per cent) and fatigue (41 per cent) as symptoms, but were almost as likely as other respondents to list crunching and grinding of the joints (75 per cent), migraines (8 per cent) and vomiting (4 per cent) as symptoms. The lack of knowledge about extreme fatigue among this group was lower than expected and indicates that even those with a personal connection with the disease are not fully aware of how it affects a person.

Even those claiming to know the difference in symptoms between osteoarthritis and RA, were less aware than they thought. Almost three quarters (71 per cent) of this group incorrectly identified 'crunching and grinding of the joints' as a symptom of RA.

Worryingly, those respondents who had seen information displayed in public about the symptoms of RA were often less informed about its symptoms than the general sample population. Only 79 per cent of those who had seen public information identified joint swelling as a symptom in comparison to 84 per cent in the general population.

Similar proportions of people who had seen public information mistakenly thought crunching and grinding of the joints was a symptom, and double the number of respondents incorrectly thought migraines and vomiting were symptoms in comparison to the general population. The notable exception was extreme fatigue, where those who had seen public information were more likely to recognise this as a symptom (a difference of 10 percentage points).

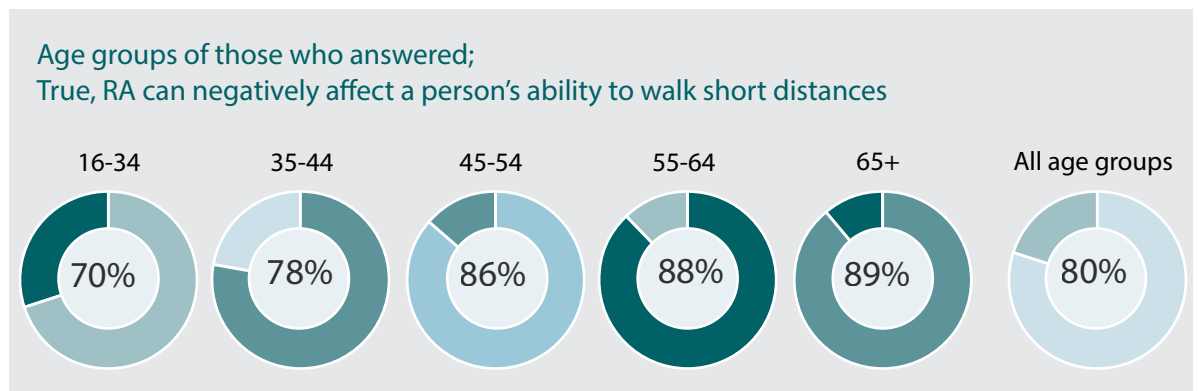


3.3 Impacts of the disease

The evidence from the survey indicates there is a significant shortfall in the public's knowledge regarding the impact of RA on the lives of people with the disease. Although many respondents were able to identify RA's negative effect on being able to walk short distances, the figures for those who knew its effect on life expectancy were very low. Moreover, very few noted the relationship between RA and the internal organs of the body and few women were aware of their increased susceptibility to the disease.

3.3.1 Walking

Although 80 per cent of people recognised that RA affects someone's ability to walk short distances, the age band least aware of this was the 16-34 year olds (70 per cent). This band lagged 10 percentage points behind the overall average and 19 percentage points behind the proportion of people over 65 who identified this as a symptom. Additionally, those in the 16-34 category were more likely to have answered 'don't know' (26 per cent), than those in the 65 and over category (9 per cent).





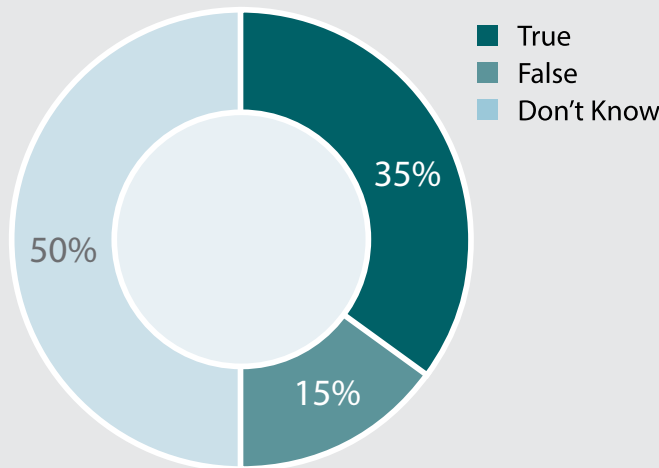
3.3.2 Life expectancy

Over half the respondents (52 per cent) were aware that RA affected life expectancy, but 48 per cent either didn't know or answered the question incorrectly. A surprising statistic is those with a personal connection to the disease were just as nearly poorly informed (58 per cent correctly identified this). Of concern, 19 per cent of those with a personal connection to the disease answered the question incorrectly, which was greater than the general population as a whole (15%). The group least likely to note the disease's effect on life expectancy were 16-18 year olds, as only 30 of the 70 surveyed said this.

3.3.3 Gender

A low number of people (28 per cent) were aware that women are more susceptible to developing RA than men. As might be expected, females were more aware of this than males. However, half the female respondents were still unaware and a further 15 per cent disagreed with the statement. Altogether more than three out of five women were unaware of their increased susceptibility to the disease, indicating that more needs to be done to raise awareness to this audience. The results were similar across all age groups.

Women are more likely to have RA than men. Female respondents



3.3.4 Diagnosis

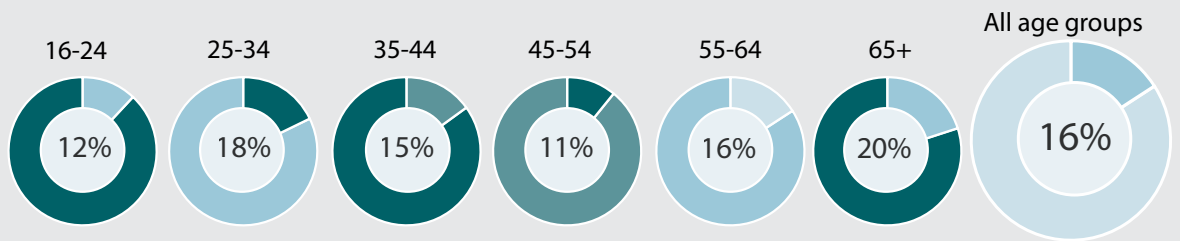
More than a quarter (27 per cent) of the British public incorrectly believed that 'GPs can diagnose RA easily'; which was a pattern repeated across genders and between age groups. Unexpectedly, those with a personal connection to the disease agreed marginally more with this false statement (32 per cent) compared to the general population. Only 29 per cent of respondents correctly identified RA as difficult for GPs to diagnose.



3.3.5 Internal organs

Only a very small proportion of people were aware that RA can affect the internal organs of the body (16 per cent), but 16-24 year olds were particularly bad at recognising this (12 per cent). Counterintuitively, those people who had a personal connection to the disease were also more likely to believe that RA did not affect the internal organs of the body compared to the general population - a difference of 7 percentage points.

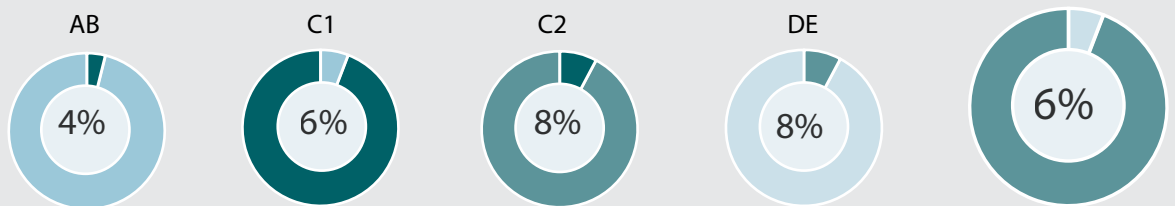
Age groups of those who answered; True, RA affects the internal organs of the body



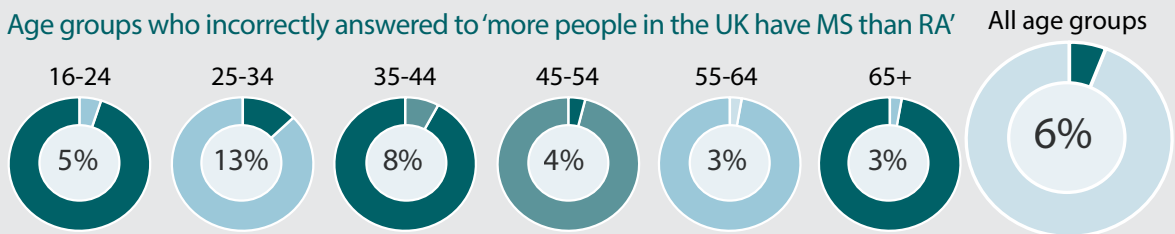
3.3.6 Comparison to other diseases

Encouragingly, only a small percentage of the public believed more people in the UK had multiple sclerosis (MS) than RA (6 per cent). Although the proportion who thought this statement was true was much higher among 25-34 year olds (13 per cent).

Social classes who incorrectly answered true to 'more people in the UK have MS than RA'



Age groups who incorrectly answered to 'more people in the UK have MS than RA'



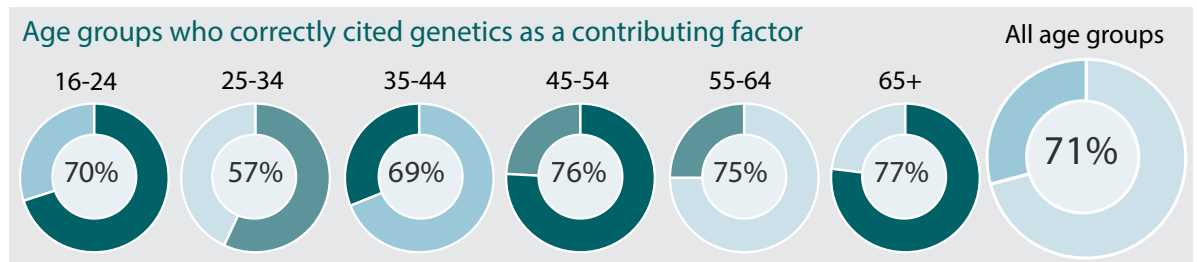


3.4 Risk factors

The survey data suggested that the British public was poorly informed about the risk factors that lead to the onset of RA. While many respondents realised genetics played a part, only a quarter were aware of the increased risk posed by smoking. Furthermore, a large proportion falsely believed that exercise and obesity could contribute to the onset of RA.

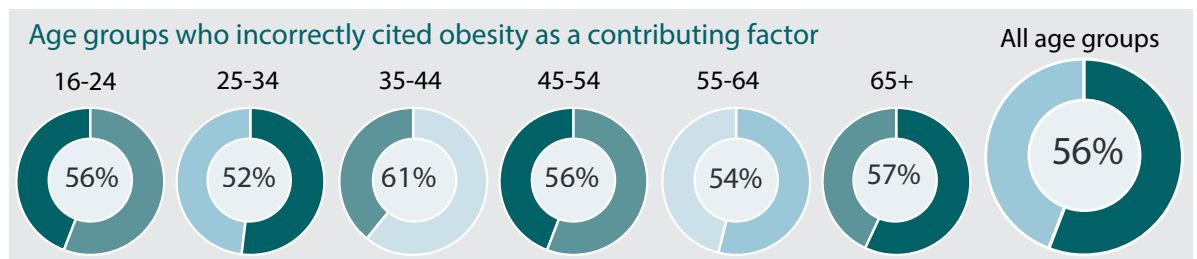
3.4.1 Genetics

Around seven in ten (71 per cent) of the British public correctly identified 'genetics' as a contributory factor in the development of RA, but significantly less 25-34 year olds correctly observed the link (57 per cent).



3.4.2 Obesity

Over half of respondents (56 per cent) incorrectly identified 'obesity' as a contributory factor in the development of RA. The age group most likely to incorrectly cite this were the 16-18 year olds, with 49 of the 70 surveyed getting this wrong.

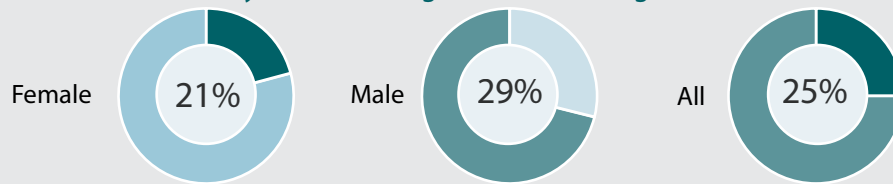




3.4.3 Smoking

25 per cent of the British public correctly noted that 'smoking' can increase the risk of developing RA. Women (21 per cent) were less likely than men (29 per cent) to answer this correctly, which is particularly concerning considering RA is around three times more common in women.

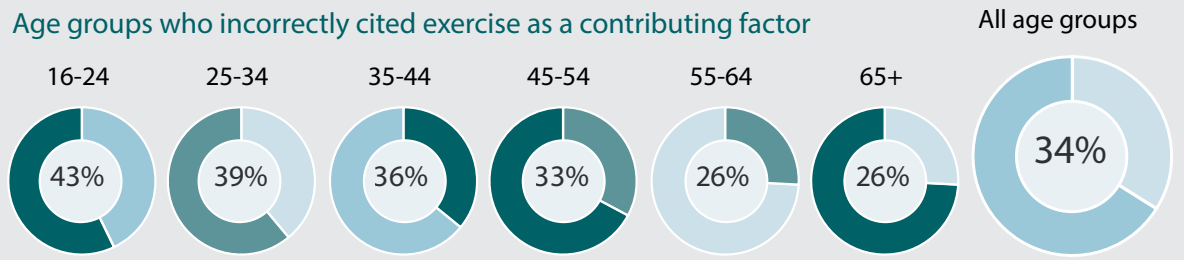
Genders who correctly cited smoking as a contributing factor



3.4.4 Exercise

Over a third (34 per cent) incorrectly attributed 'exercise' as a factor that can increase the risk of developing the disease. Those aged 16-24 were most likely to incorrectly observe this (43 per cent) compared to the general population (34 per cent). This misconception was pronounced in 16-18 year olds where 38 of the 70 surveyed believed exercise was a risk factor for developing RA.

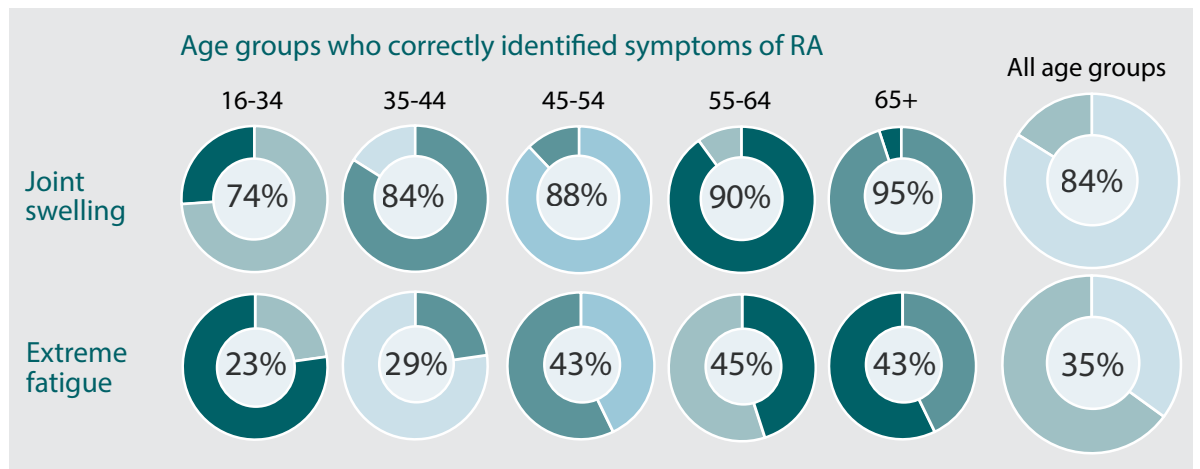
Age groups who incorrectly cited exercise as a contributing factor





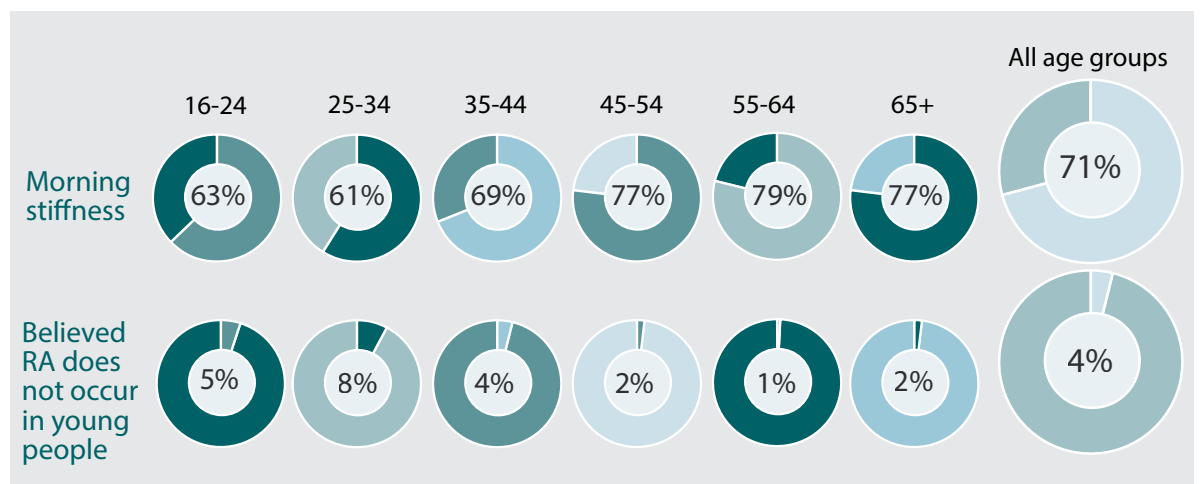
3.5 Age

The survey revealed significant differences between age groups regarding recognition of the symptoms and risk factors surrounding RA. Younger people were significantly less informed about the disease, which could affect their decision to seek early treatment should they present with symptoms.



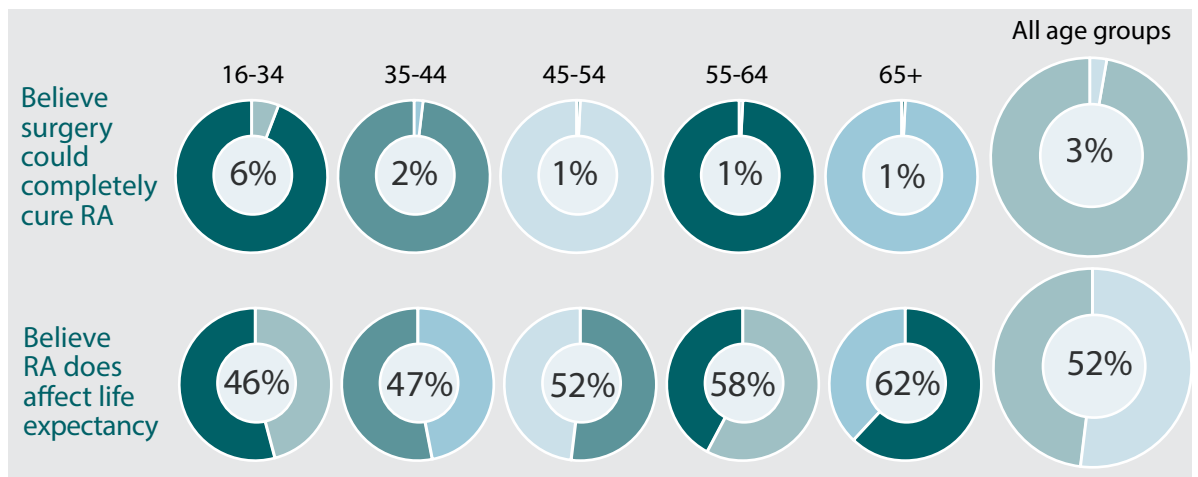
Those aged 45 and over were consistently more likely to recognise the symptoms of RA. Around nine in ten of those between 55-64 (90 per cent) and 45-54 (88 per cent) identified 'joint swelling' as a symptom of RA compared to nearly three quarters of those aged between 16-34 (74 per cent).

When looking at those who recognised morning stiffness as a symptom, only 61 per cent of 25-34 year olds acknowledged this compared to 79 per cent of 55-64 year olds. Additionally, just 23 per cent of the 16-34 age bracket recognised extreme fatigue as a symptom of RA compared with 35 per cent overall and 45 per cent in the 55-64 year old bracket.





Over half of those aged between 45-54 (52 per cent), and three fifths of those aged between 55-64 and 65+ (58 per cent and 62 per cent respectively) recognised the negative impact of RA on life expectancy, compared to less than half of those aged between 16-34 (46 per cent). Among 16-24 year olds, 42 per cent were aware of this link, which is still surprisingly high.



Many respondents correctly identified that young people could get RA (78 per cent) and that surgery could not completely cure the disease (68 per cent) with a negligible proportion of respondents believing the opposite to be true. Of those who thought surgery could completely cure RA, the age group most likely to falsely presume this were 16-34 year olds (6 per cent) and 25-34 year olds in particular (10 per cent). This pattern was repeated among those who thought young people could not get RA, with double amount of 25-34 year olds believing this to be true (8 per cent) compared to the overall average (4 per cent).

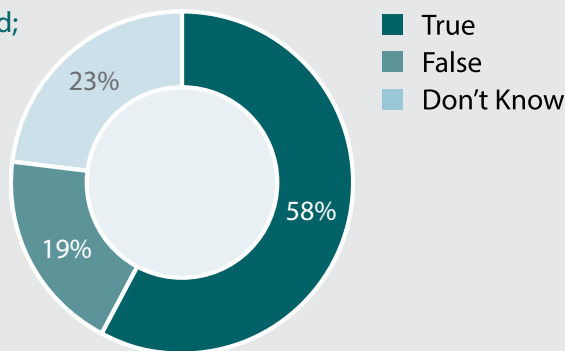


3.6 Personal connection to the disease

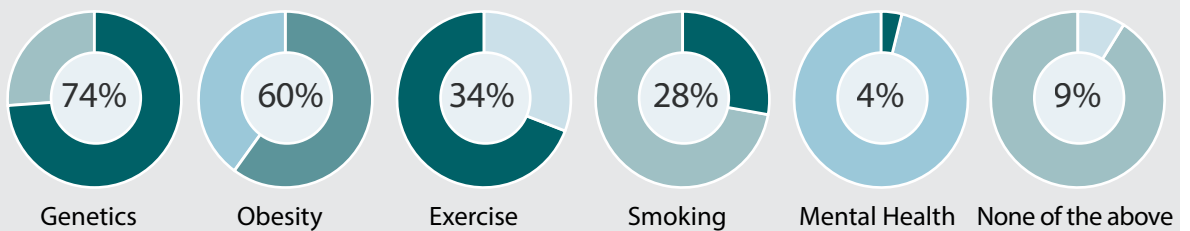
The results suggested those with a personal connection to the disease had a similar (or in some cases worse) knowledge of risk factors for the disease. The results from all respondents on whether genetics, obesity, exercise, smoking, mental health and none of the above never strayed more than 4 percentage points from the responses of those who identified a connection to RA.

Women were more likely than men to have a personal connection to the disease. However, the results of this indicate that those in the lowest social class (DE) were also more likely than any other to have a personal experience of the disease. In the social class band DE 44 per cent of respondents had personal experience of the disease in comparison with 36 per cent overall and 33 per cent in the highest social class bracket AB. This may have implications for raising public awareness of long term conditions and RA as this section of society is often the hardest to reach with information.

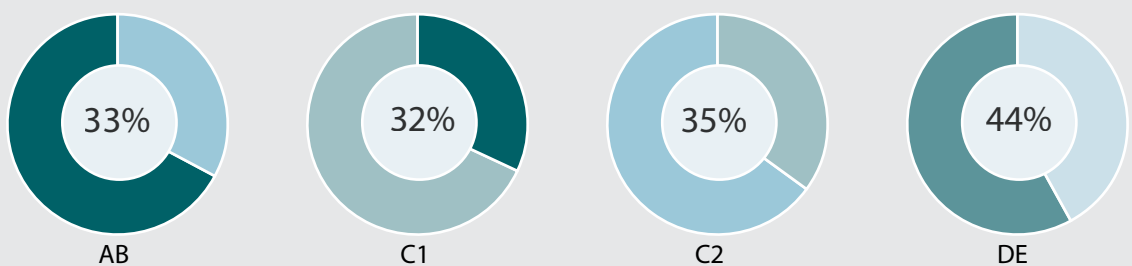
Those who answered; 'I myself, or friends and family close to me, have been affected by RA'



Contributing factors identified by those who said; 'I myself, or friends and family close to me, have been affected by RA'



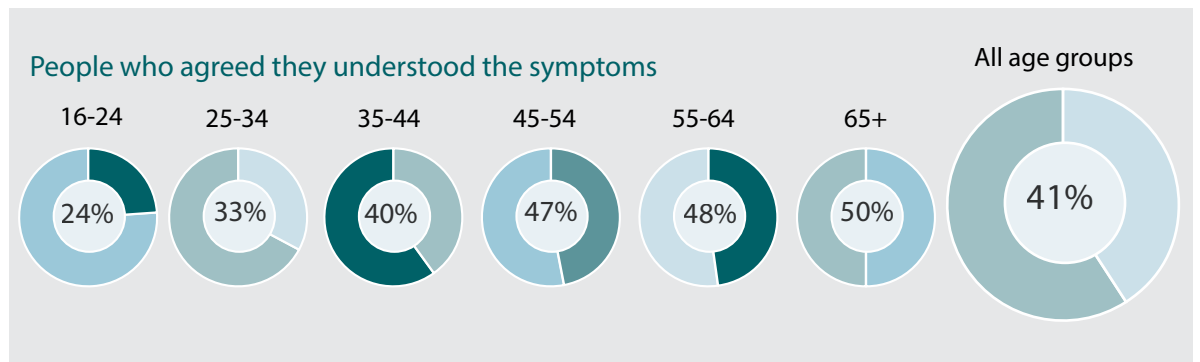
Social classes of those who said; 'I myself, or friends and family close to me, have been affected by RA'





3.7 Understanding the symptoms

The survey data suggests more has to be done to help people understand the symptoms of RA. A relatively small number of respondents were able to claim they understood the disease and worryingly few people were very confident about this. Younger people were less confident in this than older respondents and even those who had a personal connection to the disease struggled to fully understand the range of symptoms.



41 per cent of the surveyed British public said they understood the symptoms of RA and only 8 per cent agreed strongly with this statement. This was echoed in earlier survey results which found that 71 per cent incorrectly thought 'crunching and grinding of the joints' was a sign of the disease (a symptom more commonly associated with osteoarthritis) and the fact that only 33 per cent also claimed to know the difference between RA and osteoarthritis when asked directly (see section 3.8).

There was a direct correlation between age and understanding of the symptoms. 24 per cent of 16-24 year olds claimed to understand the symptoms of RA, compared to 41 per cent overall. Awareness increased incrementally with each age group and those aged over 65 were the best informed - half said they understood the symptoms. By comparison, only 17 per cent of 16-24 year olds said they understood the difference between RA and osteoarthritis, which rose to 47 per cent of those aged 65 and over (see section 3.8).

69 per cent with a personal connection to the disease said they understood the symptoms of RA, while more than a quarter of this group (27 per cent) said they did not understand the symptoms.

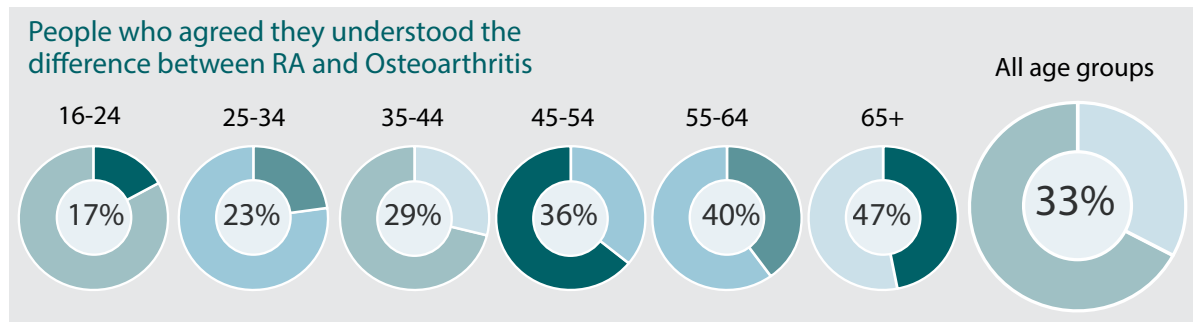


3.8 Understanding the difference between RA and osteoarthritis

The survey results revealed a correlation between age and understanding the difference between RA and osteoarthritis. Seeing public information on RA significantly increased a respondent's ability to differentiate between the two forms of arthritis.

Only 17 per cent of 16-24 year olds and 11 of the 70 16-18 year olds surveyed purported to know the distinction between the two forms of the disease. In fact, of those aged 16-18, none were very confident they knew the difference between RA and osteoarthritis.

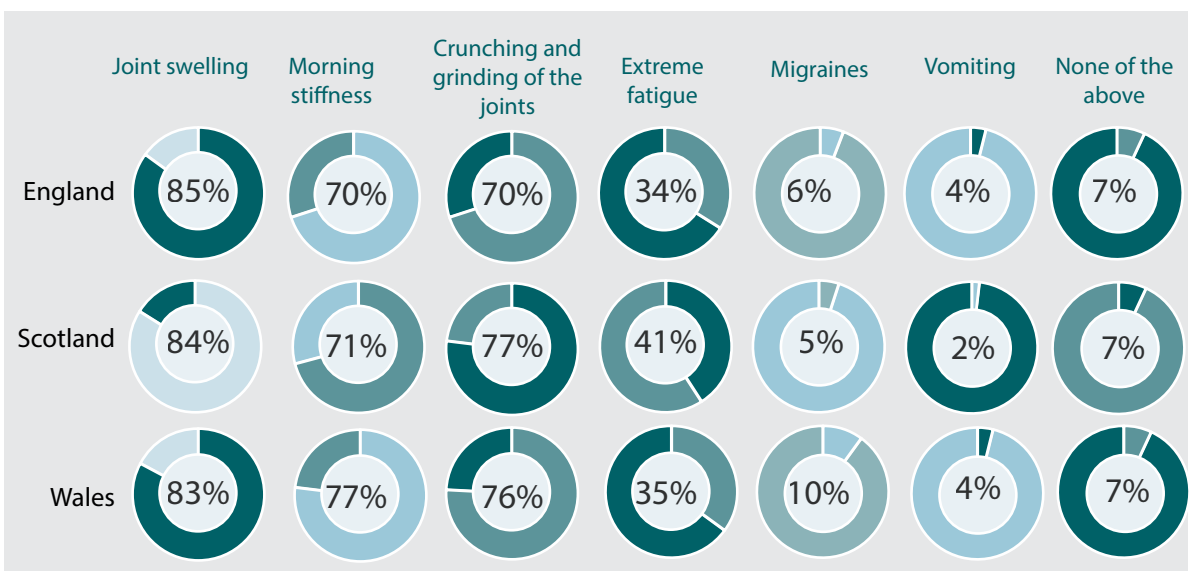
More than a quarter (27 per cent) of people with a personal connection to the disease said they did not understand the difference between RA and osteoarthritis.



Encouragingly, 24 per cent of those surveyed who said they knew the difference between the two types of arthritis had seen information displayed in public about the symptoms of RA, whereas only 10 per cent of respondents in general claimed to know the difference.

3.9 Differences between England, Scotland and Wales

There was little overall variation between the ability of each country's population to recognise the symptoms of RA and the risk factors involved in developing the disease. However, English and Scottish people were slightly better informed than Welsh people. There was a similar appetite for education around long term conditions including RA.

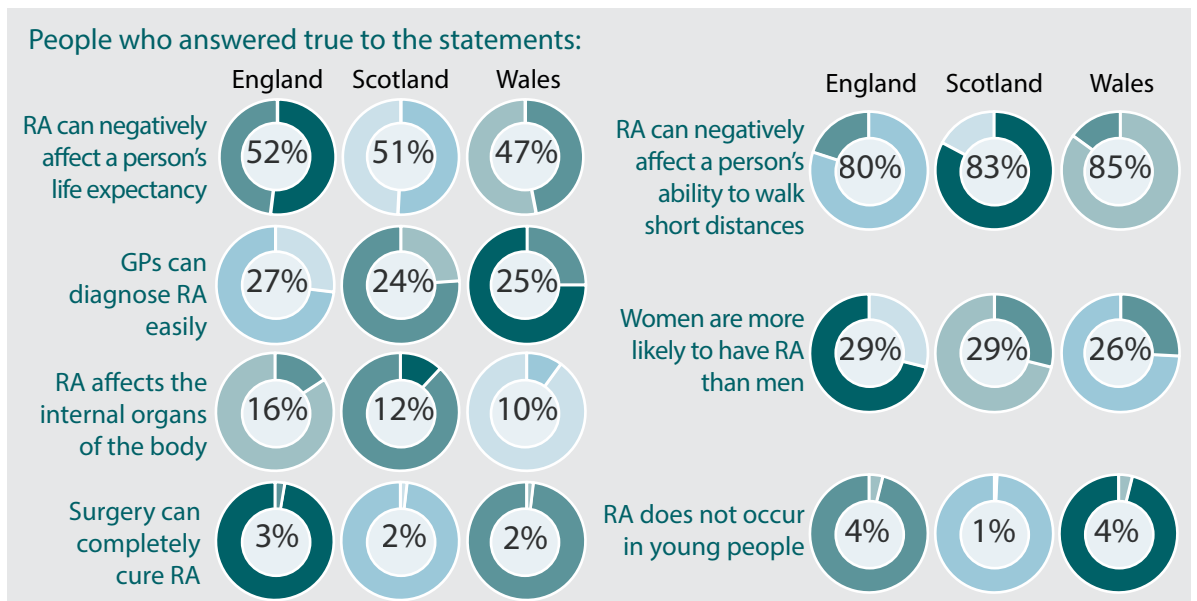




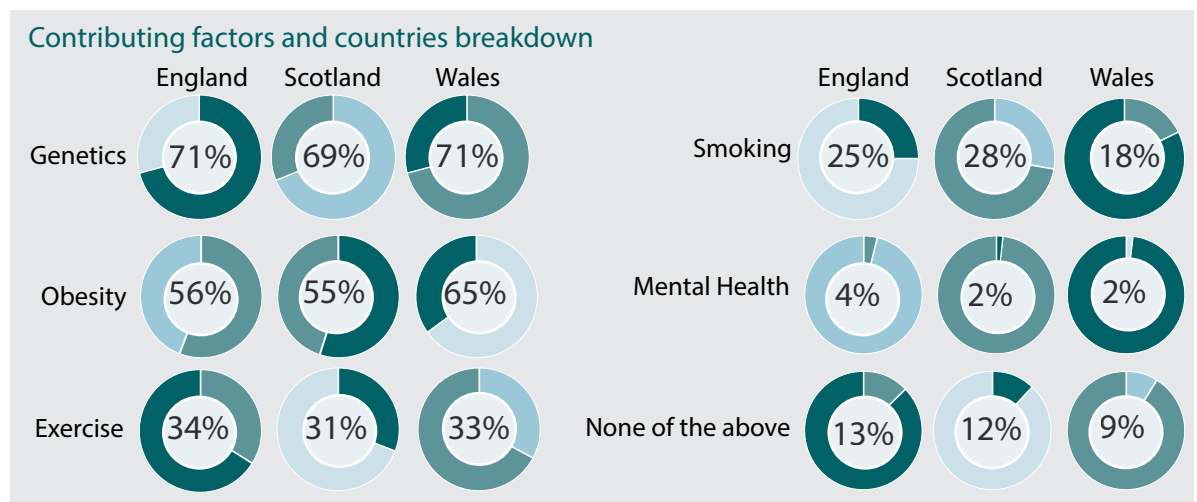
Scottish respondents were more likely to recognise extreme fatigue as a symptom of RA (41 per cent) compared to those in England and Wales. People in England (70 per cent) were less likely than those in Wales (76 per cent) and Scotland (77 per cent) to incorrectly identify crunching and grinding of the joints as a symptom of RA. However the degree of misconception around crunching and grinding of the joints was still universally high.

People in England were more likely to recognise RA's effect on the internal organs of the body, with 16 per cent recognising this in comparison with 12 per cent in Scotland and 10 per cent in Wales.

Encouragingly, only 1 per cent of Scottish people mistakenly thought RA did not occur in young people, however the figures of 4 per cent in both Wales and England were also low.



In terms of life expectancy, ability to walk short distances, ease of GP diagnosis, ability of surgery to completely cure RA and gender susceptibility to the disease, the results across all the countries were very similar to the general population average and no country fared worse.



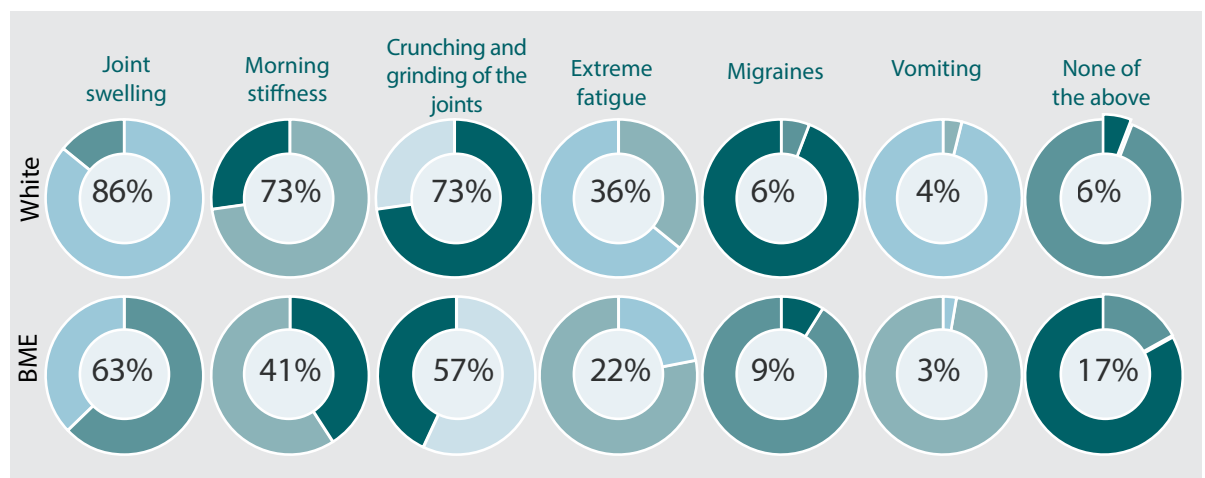


People in Wales were far more likely to falsely assume obesity played a role in developing RA (65 per cent) compared to those in England (56 per cent) and Scotland (55 per cent). Additionally, Welsh people were less likely to realise the impact of smoking in comparison to Scotland and England. 18 per cent of the Welsh noted this as a risk factor, whereas 28 per cent of Scottish people did and a quarter of English people (25 per cent).

Similar results were observed across all three nations regarding attitudes to genetics as a contributing factor. This was also the case in the number of people who incorrectly identified exercise and mental health as factors.

3.10 Ethnicity

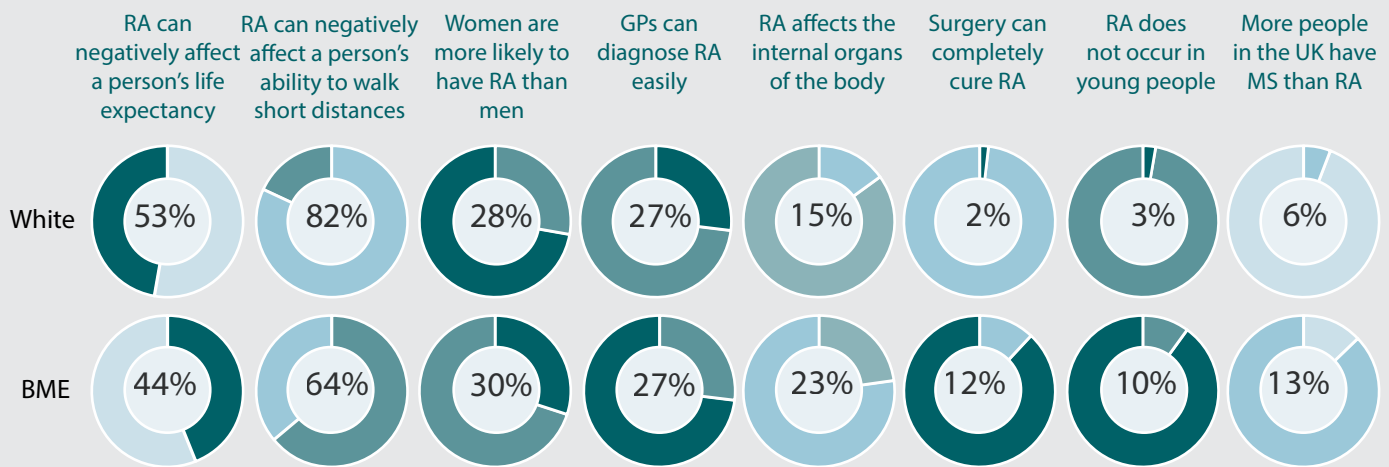
There were significant differences between ethnicities in terms of recognising the symptoms and impacts of RA. In the majority of cases BME respondents were less well informed than white respondents, even though more BME respondents claimed to have seen public information on the disease symptoms. This suggests that existing public awareness information campaigns targeted at these populations are ineffective.



86 per cent of white respondents recognised joint swelling compared to 63 per cent of BME respondents. 73 per cent of white respondents identified morning stiffness as a symptom compared to 41 per cent BME respondents, and 36 per cent of white respondents were aware of extreme fatigue as a symptom, in comparison to just 22 per cent of BME respondents.

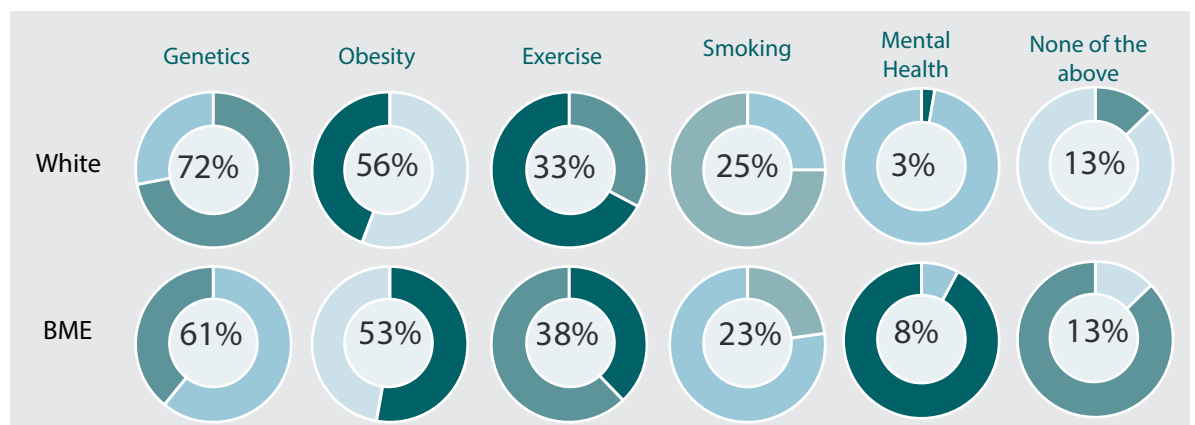
BME respondents were also less likely to realise the impacts of RA. For example fewer BME agreed that RA could negatively effect life expectancy (44 per cent) compared to white respondents (53 per cent). Fewer BME respondents also correctly identified RA's negative effect on a person's ability to walk short distances (64 per cent) compared to white respondents (82 per cent).

Furthermore, a greater number of BME respondents incorrectly believed surgery could completely cure RA (12 per cent) compared to white respondents (2 per cent). A greater number of BME respondents also thought that RA did not occur in young people (10 per cent) compared to white respondents (3 per cent). BME respondents were also twice as likely to believe that more people in the UK had MS as RA (13 per cent) compared to white respondents (6 per cent).



However, fewer BME respondents incorrectly identified crunching and grinding of joints as a symptom of RA (57 per cent) compared to white respondents (73 per cent). BME respondents were also more likely to realise that RA effects the internal organs of the body (23 per cent) compared to white respondents (15 per cent).

There were no differences in how different ethnicities viewed GPs ability to easily diagnose RA. While just under a third of white respondents (28 per cent) and BME respondents (30 per cent) thought women were more likely to have RA than men. Again, similar results were reported for the ability of both ethnicities to recognise obesity, exercise, smoking, or mental health. However, white respondents were more likely to acknowledge the effects of genetics (72 per cent) compared to BME respondents (61 per cent).



Interestingly, BME respondents were more than twice as likely to say they had seen information displayed in public about RA (20 per cent) compared to white respondents (9 per cent). Perhaps unsurprisingly, BME respondents were therefore also more than twice as likely to believe that government was doing a good job of raising public awareness of long term conditions (21 per cent) compared to white respondents (9 per cent).

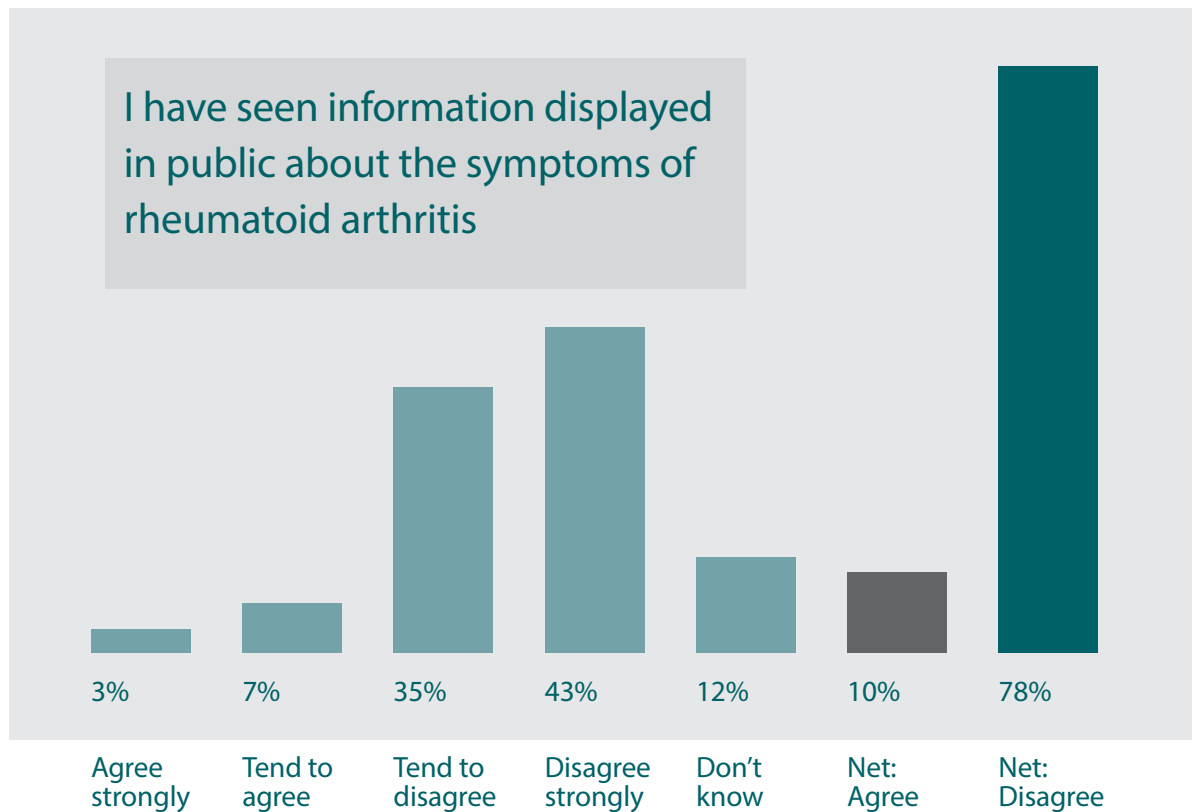
Marginally more white respondents said there should be greater education about long term conditions in secondary schools and colleges (67 per cent) compared to BME respondents (63 per cent).



3.11 Seeing information on the symptoms of RA

Very few respondents had seen information about the signs and symptoms of RA. This was reinforced by the alarmingly high number of people who had not seen public information and who said they did not understand the symptoms of RA and could not explain the difference between RA and osteoarthritis.

Only 10 per cent of British public said they had seen information displayed in public on the symptoms of RA. This dropped to only 5 per cent among those aged 16-18. More than half (57 per cent) of people who had not seen information displayed in public on RA also did not understand the symptoms of the disease and 65 per cent did not understand the difference between RA and osteoarthritis.

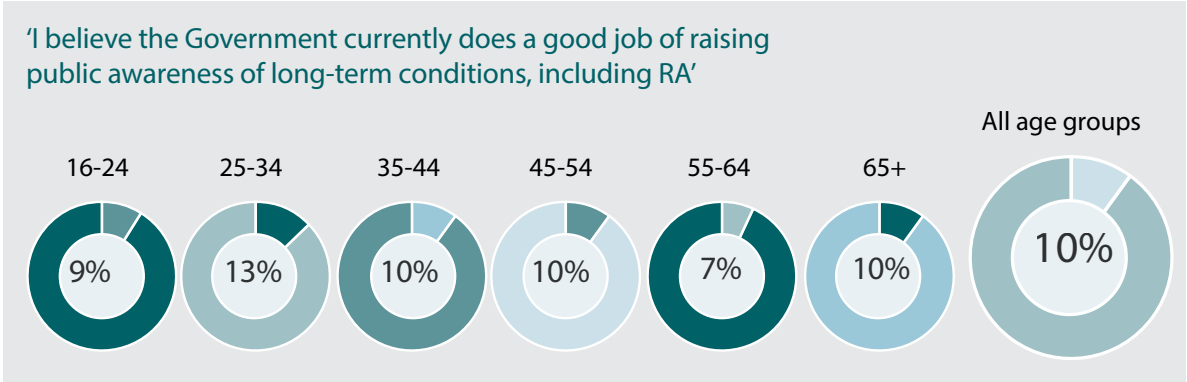




3.12 Satisfaction with existing public awareness initiatives

The data from the survey revealed that only one in ten of the British public believed their government was doing a good job of raising public awareness of long term conditions, including RA.

Less than a fifth of respondents with a personal connection to the disease believed their government was doing a good job of raising public awareness of long term conditions (17 per cent) and 73 per cent disagreed with this statement. A third of those who said they had been personally affected by the disease also strongly thought the government was not doing enough.

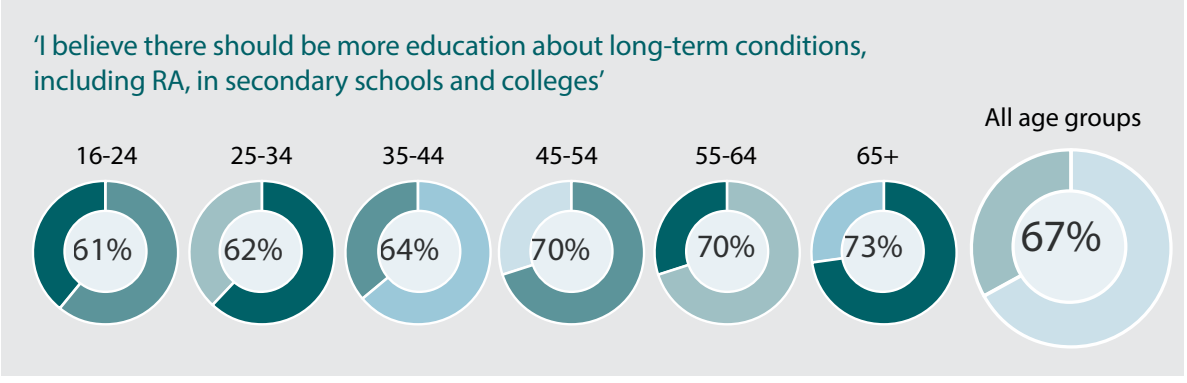


Just 1 of the 70 surveyed 16-18 year olds said they felt their government currently did a good job raising public awareness. 58 of the 70 surveyed in this age group expressed the view that their government had performed poorly in relation to this.

3.13 Appetite for further education

Owing to the lack of awareness of the symptoms of RA and risk factors for developing the disease, there was sizeable demand for greater education in schools and colleges on the issue of long term conditions, even among those 16-18 year olds that were surveyed.

Just over two thirds of the surveyed British public (67 per cent) believed there should be more education about long term conditions, including RA, in secondary schools and colleges, including 61 per cent of those aged between 16-24. 48 of the 70 16-18 year olds surveyed agreed with this statement.





4. Conclusions and recommendations

4.1 Summary of report findings

The medical evidence presented in the report clearly demonstrates the significance of public awareness as a both a barrier and an opportunity to improve clinical outcomes for RA patients. The literature review points out the extensive delays that are currently happening, which in many instances are jeopardising healthcare professionals best efforts to treat individuals within the 12 week 'window of opportunity', with data showing that the average delay in patients seeking help from their GP being 12 weeks alone and thus obliterating this target.

As evidenced in the literature review, and despite the documented calls from patients and healthcare professionals for greater public awareness of RA, none of the three countries have thus far managed to introduce a comprehensive approach. The closest candidate so far has been Scotland where a needs assessment has taken place and a national public pamphlet has so far been produced on the signs and symptoms of RA. However, it is unclear whether this is a standalone activity or not.

In contrast, although Wales has in the past attempted to develop a vision which includes reference to the role of enhanced public awareness there is no evidence of any planned activity by the Welsh Government or its institutions. The UK Government also has an unsatisfactory track record having rejected earlier widespread calls for a nationally funded public awareness campaign on RA and having failed to include any meaningful reference to the role of enhanced public awareness across its main strategic documents governing long term conditions and public health.

The results of the national survey generated some genuinely surprising information about the overall levels of public awareness. In line with some of the findings in the literature review, it was very apparent that the majority of respondents were not fully aware of the different forms of arthritis, with a great deal of confusion between RA and osteoarthritis. Only around two fifths of respondents understood the symptoms of RA and only one in ten were very confident they could identify them. Most surprisingly of all, the survey uncovered evidence that even those who have a personal connection to RA (through either themselves or family and friends having been affected by the disease), were still misinformed regarding some symptoms.

With regard to the impacts of the disease, general public awareness was high regarding the disease's impact on mobility. However, evidence around understanding of risk factors was mixed. For example a large proportion of survey respondents identified genetics as a contributory factor. However, of significant concern only a quarter of respondents understood the links between RA and smoking.



The survey revealed significant differences in the attitudes of different age groups regarding recognition of the symptoms and risk factors surrounding RA. Those in younger age groups were far less likely to be aware of the symptoms of the disease and the factors that could contribute to the possibility of them developing RA, while also incorrectly identifying factors that have no known correlation, such as obesity. Rising levels of awareness were observed with the rising age of respondents, suggesting that further work is required to engage people at an earlier age to avoid people learning about the disease symptoms too late.

Our survey results supported some of the findings in the literature review regarding different levels of public awareness among ethnic groups, with the results suggesting that BME respondents were less well-informed about the symptoms of RA and some of the impacts of the disease, such as the effect on mobility and life expectancy. This has implications for future public awareness campaigns because it indicates that a 'one size fits all' to devising public health messages around RA may not be appropriate and that additional forms of communication may be required to better inform the BME population.

In relation to the success of existing approaches, of deep concern, a very small number of people reported seeing public information about RA symptoms, yet the survey illustrated that seeing previous public information did little or nothing to increase a person's awareness of the disease symptoms (apart from helping people to differentiate RA from osteoarthritis) indicating that current public awareness information about RA may be ineffective. In support of this, only one in ten believed their government was doing a good job, with the most damning assessment coming from 16-18 year olds with only one individual agreeing that their government was doing a good job and tellingly a miniscule number of respondents in this age category claimed to have seen public information about RA.

4.2 Recommendations

Public awareness of RA among British survey respondents is very low with little public information about the disease having been observed by respondents. In light of existing calls for further investment by patients, healthcare professionals, and leading organisations, the governments of England, Scotland and Wales are urged to undertake reviews into the effectiveness of existing approaches towards raising public awareness of long term conditions, including RA, which should then be published to enable stakeholders to benefit from the findings.

Taking into account the results of these reviews, the governments of England, Scotland and Wales should then undertake activity to initiate more comprehensive approaches to raising public awareness of RA and other long term conditions which are less ad hoc, go beyond the provision of simple poster campaigns and instead engage in a fuller spectrum of the media. This should include plans for more co-ordinated and effective displaying of public information in GP surgeries, community pharmacies and other healthcare settings.

Not only do we remain concerned that existing approaches to raising public awareness of RA remain too simplistic, but that the types of messages employed are not sufficiently targeted and do not take account of significant variations in levels of understanding about the disease found



between different age groups, genders and even ethnic backgrounds. We therefore recommend that future public awareness campaigns around RA take into full account these differing population needs.

Given the low levels of satisfaction with existing approaches to raising public awareness to long term conditions, including RA, among the 16-18 year olds surveyed in the report we suggest that any co-ordinated plans brought forward by governments should include a more formalised component within secondary education in schools and colleges to alert young people to the risks of developing inflammatory arthritis and other significant groups of long term conditions.

Finally, we recognise that governments alone cannot deliver enhanced public awareness of these diseases. The voluntary and community sector has an important contribution to play through pooling its resources and bringing the additional insight of our members into the design and execution of these campaigns. Therefore our final recommendation is that governments in England, Scotland and Wales instigate high-level stakeholder dialogues with the voluntary and community sector as soon as possible to establish priorities and leverage appropriate resources.

5. Thank you

NRAS would like to thank the following individuals who played a part in the design and testing of the questionnaire, and the research and production of this report:

Ailsa Bosworth, Chief Executive, NRAS

Tracey Hancock, Director of Development, NRAS

Jamie Hewitt, Government Affairs Manager, NRAS

Oliver Hoare, Trust and Grants Fundraiser, NRAS

Clare Jacklin, Director of External Affairs, NRAS

Rachel Phillips, Quantitative Research Team Manager, ComRes

Karim Raza, PhD FRCP, Professor of Clinical Rheumatology & Honorary Consultant Rheumatologist, University of Birmingham & Sandwell & West Birmingham Hospitals NHS Trust

James Rentoul, Research Analyst, ComRes

Andrew Scott, Public Relations and Press Officer, NRAS

Lorraine Tanner, Helpline Manager, NRAS

Leo Watson, Government Affairs Officer, NRAS

Editorial: Jamie Hewitt, Government Affairs Manager, NRAS

Leo Watson, Government Affairs Officer, NRAS

Design: Fortune West Limited www.fortunewest.co.uk



6. References

- ¹ Given that the England population is 83.8 per cent of the UK total, and assuming that the burden of RA is directly proportional in all the UK's home countries.
- ² Rindfleisch, JA. & Muller, D. Diagnosis and Management of Rheumatoid Arthritis. *Am Fam Physician*. 2005; 72 (6): 1037-1047
- ³ Grassi W, et al. The Clinical Features of Rheumatoid Arthritis. *European Journal of Radiology* 1998; 27: S18–S24
- ⁴ Emery P & Symmons, DPM. What is Early Rheumatoid Arthritis?: Definition and Diagnosis. *Bailliere's Clin Rheumatol* 1997; 11: 13-26
- ⁵ Kary J, et al. Do We Still Miss the Chance of Effectively Treating Early Rheumatoid Arthritis? New Answers from a New Study. *Rheumatology* 2004; 43: 819–820
- ⁶ Bolge SC, et al. Patient Experience with Rheumatoid Arthritis Disease Flares, KantarHealth
- ⁷ Emery P, et al. Early Referral Recommendation for Newly Diagnosed Rheumatoid Arthritis: Evidence Based Development of a Clinical Guide. *Ann Rheum Dis* 2002; 61: 290 -7
- ⁸ Akil, M & Amos, RS. ABC of Rheumatology. Rheumatoid Arthritis—I: Clinical Features and Diagnosis. *BMJ* 1995; 310: 587–90.
- ⁹ Theodore P, et al. Patients Seen for Standard Rheumatoid Arthritis Care Have Significantly Better Articular, Radiographic, Laboratory, and Functional Status in 2000 than in 1985. *Arthritis & Rheumatism* 2005; 52 (4): 1009–1019
- ¹⁰ Siddiqui, MAA. The Efficacy and Tolerability of Newer Biologics in Rheumatoid Arthritis: Best Current Evidence. *Curr Opin Rheumatol*. 2007; 19 (3): 308-313
- ¹¹ Williams, AE & Bowden, AP. Meeting the Challenge for Foot Health in Rheumatic Diseases. *Foot*, 2004. 14(3): 154-158
- ¹² National Rheumatoid Arthritis Society, The Impact of Rheumatoid Arthritis Co-morbidities, 2012
- ¹³ Lindhardsen J, et al. Risk of Atrial Fibrillation and Stroke in Rheumatoid Arthritis: Danish Nationwide Cohort Study. *British Medical Journal*, 2012; 344
- ¹⁴ CKS Clinical Knowledge Summaries, Rheumatoid Arthritis – Management
- ¹⁵ National Rheumatoid Arthritis Society, Ocular Manifestations of Rheumatoid Arthritis, 2010
- ¹⁶ National Rheumatoid Arthritis Society, Relationships, Emotions and Sexuality, 2013
- ¹⁷ National Rheumatoid Arthritis Society, Family Matters Survey, 2012
- ¹⁸ National Audit Office, Services for people with rheumatoid arthritis, 2009
- ¹⁹ National Audit Office. Services for People with Rheumatoid Arthritis. 2009
- ²⁰ National Rheumatoid Arthritis Society, I want to work..., 2007
- ²¹ National Rheumatoid Arthritis Society. Beyond the Pain. 2004



- 22 Brennan, P & Silman, A. Why the Gender Difference in Susceptibility to Rheumatoid Arthritis? *Annals of the Rheumatic Diseases* 1995; 54: 694-695
- 23 Bowes, J & Barton, A. Recent Advances in the Genetics of RA Susceptibility. *Rheumatology* (2008) 47 (4): 399-402 doi: 10.1093/rheumatology/ken005
- 24 Hutchinson, D et al. Heavy Cigarette Smoking is Strongly Associated with Rheumatoid Arthritis (RA), Particularly in Patients without a Family History of RA. *Ann Rheum Dis.* 2001 Mar; 60 (3): 223-7
- 25 Oliver, JE & Silman, AJ. Risk Factors for the Development of Rheumatoid Arthritis. *Scandinavian Journal of Rheumatology*, 2006; 35 (3).
- 26 Costenbader, KH & Karlson, EW. Epstein-Barr Virus and Rheumatoid Arthritis: Is There a Link? *Arthritis Res Ther.* 2006; 8(1): 204. doi: 10.1186/ar1893
- 27 Molokhia, M and McKeigue, P. Risk for Rheumatic Disease in Relation to Ethnicity and Admixture. *Arthritis Res* 2000; 2: 115-125 doi:10.1186/ar76
- 28 O'Brien WM, et al. A Genetic Study of Rheumatoid Arthritis and Rheumatoid Factor in Blackfeet and Pima Indians. *Arthritis Rheum* 1967; 10: 163-178
- 29 National Institute for Health and Clinical Excellence, *Rheumatoid Arthritis: The Management of Rheumatoid Arthritis in Adults - Clinical Guideline 79*, February 2009
- 30 Emery, P. Evidence Supporting the Benefit of Early Intervention in Rheumatoid Arthritis. *J Rheumatol* 2002; 29 Suppl 66: 3-8
- 31 Van der Linden, MPM et al (2010) Long-Term Impact of Delay in Assessment of Patients with Early Arthritis. *Arthritis and Rheumatism* Vol. 62, No. 12, December 2010, pp 3537-3546 DOI 10.1002/art.27692
- 32 Symmons DPM, et al. Long-term mortality outcome in patients with rheumatoid arthritis: early presenters continue to do well. *J Rheumatol* 1998;25:1072-7
- 33 Lindqvist E, et al. Course of Radiographic Damage over 10 years in a Cohort with Early Rheumatoid Arthritis. *Ann Rheum Dis.* 2003 Jul; 62 (7): 611-6
- 34 Quinn, MA & Emery, P. Window of Opportunity in Early Rheumatoid Arthritis: Possibility of Altering the Disease Process with Early Intervention. *Clin Exp Rheumatol* 2003; 21 (Suppl. 31): S154-S157
- 35 National Audit Office, *Services for People with Rheumatoid Arthritis*, February 2009
- 36 National Audit Office, *Services for People with Rheumatoid Arthritis*, February 2009
- 37 Kumar K, et al. Delay in Presentation to Primary Care Physicians is the Main Reason Why Patients With Rheumatoid Arthritis Are Seen Late by Rheumatologists. *Rheumatology* 2007; 46 (9): 1438-1440
- 38 Kumar K, et al. Delay in Presentation to Primary Care Physicians is the Main Reason Why Patients With Rheumatoid Arthritis Are Seen Late by Rheumatologists. *Rheumatology* 2007; 46 (9): 1438-1440
- 39 PatientView, *People with Rheumatoid Arthritis, their Carers, and the NHS: A National Survey of Patients and their Carers*, March 2009
- 40 The King's Fund, *Perceptions of Patients and Professionals on Rheumatoid Arthritis Care: A Consultancy Report for the Rheumatology Futures Group*, January 2009
- 41 National Audit Office, *Services for People with Rheumatoid Arthritis*, February 2009



- 42 Kumar K, et al. Delay in Presentation to Primary Care Physicians is the Main Reason Why Patients With Rheumatoid Arthritis Are Seen Late by Rheumatologists. *Rheumatology* 2007; 46 (9): 1438-1440
- 43 Sandhu RS, et al. Comment On: Delay in Presentation to Primary Care Physicians is the Main Reason Why Patients with Rheumatoid Arthritis Are Seen Late by Rheumatologists. *Rheumatology* 2008; 47: 559–60
- 44 National Audit Office, *Services for People with Rheumatoid Arthritis*, February 2009
- 45 Emery, P. Evidence Supporting the Benefit of Early Intervention in Rheumatoid Arthritis. *J Rheumatol* 2002; 29 Suppl 66: 3-8
- 47 Stack, RJ, et al. Delays in Help Seeking at the Onset of the Symptoms of Rheumatoid Arthritis: A Systematic Synthesis of Qualitative Literature. *Ann Rheum Dis* 2012; 71: 493-497
- 48 Zafar S, et al. Efforts to increase public awareness may result in more timely diagnosis of rheumatoid arthritis. *J Clin Rheumatol*. 2012 Sep;18 (6): 279-82. doi: 10.1097/RHU.0b013e3182676975.
- 49 Kumar K, et al. Delay in Presentation to Primary Care Physicians is the Main Reason Why Patients with Rheumatoid Arthritis Are Seen Late by Rheumatologists. *Rheumatology* 2007; 46 (9): 1438-1440
- 50 Porter, D & McEntegart, A. *Clinical Audit of Care in Rheumatoid Arthritis*, December 2008
- 51 National Audit Office, *Services for People with Rheumatoid Arthritis*, February 2009
- 52 Arthritis and Musculoskeletal Alliance, *Joint Working? An Audit of the Implementation of the Department of Health's Musculoskeletal Services Framework*, June 2009
- 53 House of Commons Committee of Public Accounts, *Services for people with rheumatoid arthritis, Tenth Report of Session 2009–10*
- 54 Treasury Minutes on the Tenth to the Eleventh and the Fourteenth to the Thirty Second Reports from the Committee of Public Accounts Session 2009-10, July 2010
- 55 National Rheumatoid Arthritis Society, *The Year of RA: One Year On*, 2010
- 56 Scottish Public Health Network, *Health Care Needs Assessment of Services for Adults with Rheumatoid Arthritis: Part C - RA services in Scotland - Corporate and Comparative Needs Assessment*, July 2012
- 57 National Rheumatoid Arthritis Society, *Press Release: Scottish Public Health Network Publishes its Health Care Needs Assessment of Services for Adults with Rheumatoid Arthritis*, 17 September 2012
- 58 NHS Health Scotland, *Recognise, Respond, Relieve – Rheumatoid Arthritis*, March 2013
- 59 Arthritis Ireland, *Press Release: Arthritis Ireland Launches Major Awareness Campaign*, 28 May 2013
- 60 Ipsos MORI, *Low Public Awareness of Symptoms Of Arthritis*, 18 May 2000. Available at: <http://www.ipsos-mori.com/researchpublications/researcharchive/1461/Low-Public-Awareness-Of-Symptoms-Of-Arthritis.aspx>
- 61 Medical News Today, *Campaign Launched To Tackle 'Alarming Ignorance' About Rheumatoid Arthritis - Revealed In New Poll*, 17 March 2009. Available at: <http://www.medicalnewstoday.com/releases/142497.php>
- 62 Patient View, *Patient groups on rheumatoid arthritis and the NHS: A national survey of patient organisations and other health campaigners*, 2009



- ⁶³ Arthritis Today, Ignorance of rheumatoid arthritis puts thousands at risk, 10 November 2011
- ⁶⁴ Arthritis Care, Three wasted years: Evaluating progress in delivering improved rheumatoid arthritis services, 2012
- ⁶⁵ National Rheumatoid Arthritis Society, Family Matters: A major UK wide survey on the impacts on the family of living with rheumatoid arthritis, 2012
- ⁶⁶ HM Treasury, Securing our Future Health: Taking a Long-Term View – Final Report, April 2002
- ⁶⁷ Department of Health, Our Health, Our Care, Our Say: A New Direction for Community Services, January 2006
- ⁶⁸ Department of Health, High Quality Care for All: NHS Next Stage Review Final Report, June 2008
- ⁶⁹ Department of Health, The Mandate: A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015, November 2012
- ⁷⁰ The Department of Health, Musculoskeletal Services Framework, 12 July 2006
- ⁷¹ Welsh Assembly Government, Service Development and Commissioning Directives: Arthritis and Chronic Musculoskeletal Conditions, May 2006
- ⁷² Welsh Assembly Government, Designed to Improve Health and the Management of Chronic Conditions in Wales: An Integrated Model and Framework, March 2007
- ⁷³ HM Government, Healthy Lives, Healthy People: Update and Way Forward, July 2011
- ⁷⁴ Department of Health, Improving Outcomes and Supporting Transparency: Part 1A: A Public Health Outcomes Framework for England, 2013-2016, January 2012
- ⁷⁵ The Scottish Government, Better Health, Better Care, December 2007
- ⁷⁶ The Scottish Government, Improving Health & Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan, June 2009
- ⁷⁷ The Scottish Government, The Healthcare Quality Strategy for NHS Scotland, May 2010
- ⁷⁸ The Scottish Government, Long-Term Conditions Collaborative – High Impact Changes, March 2009



nras

National Rheumatoid
Arthritis Society

Contact us...

General: 0845 458 3969

Email: enquiries@nras.org.uk

National Rheumatoid Arthritis Society
Unit B4 Westacott Business Centre
Westacott Way
Littlewick Green
Maidenhead
Berkshire SL6 3RT

Follow us...



Join the NRAS Facebook page
www.facebook.com/nationalrheumatoidarthritisociety
& be part of the NRAS community



Follow us on Twitter
[Twitter@NRASociety](https://twitter.com/NRASociety)



To see what is happening on Helpline follow them
[Twitter@helpline_NRAS](https://twitter.com/helpline_NRAS)



For up to date membership information follow
[Twitter@members_NRAS](https://twitter.com/members_NRAS)

FREephone HELPLINE: 0800 298 7650 | WWW.NRAS.ORG.UK



NRAS is a private company limited by guarantee
Registered in England and Wales No 7127101
Registered Charity Numbers 1134859, SC039721