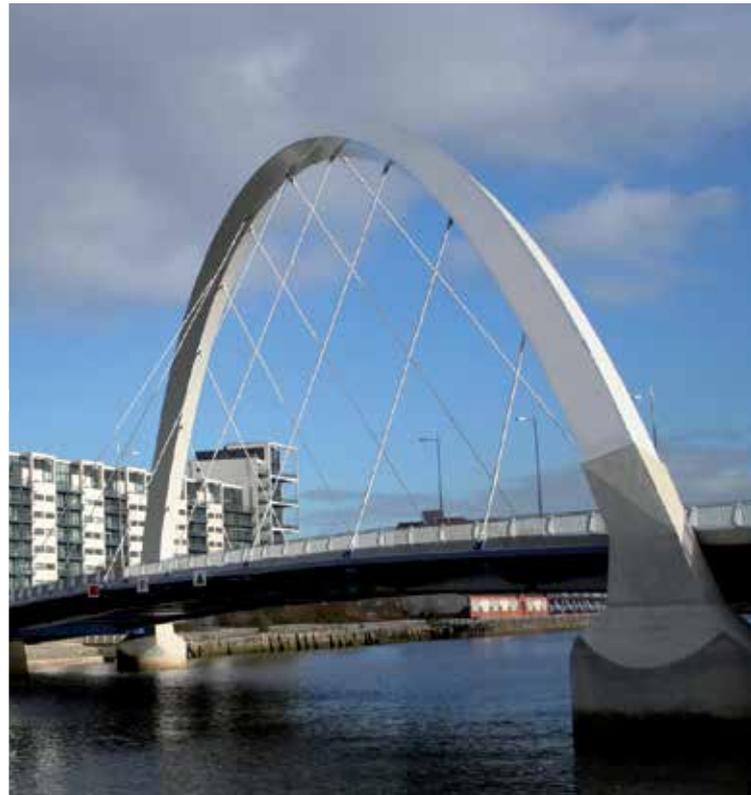


National Rheumatoid Arthritis Society Survey 2010

RA and Work



Employment and Rheumatoid Arthritis
in Scotland. A national picture.



nras
National Rheumatoid
Arthritis Society



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Introduction

From Ailsa Bosworth, Chief Executive, NRAS

Employment is a critical issue for so many people with rheumatoid arthritis, and it is one of the major reasons people ask NRAS for support. Some are worried about taking time off because of their rheumatoid arthritis; others are having difficulty getting the support they need.

It is not an overstatement to say that often people call us because they are in crisis: afraid they will lose their job or that they will be unable to continue working. They want to know what their options are, what the future might hold and whether they can realistically hope to maintain their career. Worries about the financial implications of not working only add to their stress.

And the costs of not working, or working less, are high, both for individuals and their families and for the economy overall. There is now a considerable amount of evidence about this, as well as the anecdotal evidence we and others have from the people we support. Traditionally, the costs of health and social care, the personal costs to individuals and the costs to economic productivity have been considered separately – but now we need to challenge that, and it is one of NRAS's priorities.



Ailsa Bosworth - Chief Executive

In this, our annual survey for 2010, we have aimed to bring together several aspects of employment and rheumatoid arthritis. We wanted to present, from Scottish patients' perspectives, the first national picture of the impact of rheumatoid arthritis on working lives in Scotland.

We began to think about this in 2007, when we conducted a UK-wide survey of the experiences of people with rheumatoid arthritis of employment.¹ NRAS members across the UK took part, including members in Scotland. The results showed that the experiences of members living in Scotland differed from those in the rest of the UK: higher percentages of people were losing their jobs within one year of diagnosis and within six years. We were clear at that time that we needed to survey a wider group of people in Scotland to get a more accurate picture. This is the report of that wider survey, which we conducted in 2009-2010.

We asked for people's views about the barriers to remaining in work, and what support they felt could help. Our findings – as in 2007 – suggest that large numbers of people with rheumatoid arthritis give up work or retire early as a direct result of their condition. They also shed light on some of the less visible costs of rheumatoid arthritis, which can often affect people's career progression and create uncertainty about their future.

Yet it also confirms that many of the barriers people experience in the workplace are not insuperable. Awareness and understanding from employers, specific adaptations and equipment can all be important, alongside greater government support, rapid access to the rheumatology team and effective pain control. We hope that these results will be helpful for government, employers, health professionals, people with rheumatoid arthritis and organisations that advocate for the rights of people with long-term health conditions.

When I was diagnosed in my early 30s, I was very ill and frequently in and out of hospital. But I was supported by a wonderful boss for whom I had worked since the age of 20. Without his help, particularly during the most difficult years following diagnosis, I would not have been able to continue in my job. He could see beyond the 'long term condition' that limited my physical usefulness but not my brain!

Unfortunately, not all employers are like my old boss. But I hope that this survey will help, together with NRAS's publications for employees and employers, which drew on our findings from the 2007 survey.

We believe that healthcare professionals need to treat 'work' as an important health outcome right from the point of diagnosis, whether it is paid work, voluntary work or work in the home. Our aims are to enable government, employers and health professionals to understand the difficulties people with RA face in the workplace, and to work together to help them remain in work, if that is their choice, for as long as possible.

NRAS Publications

There are NRAS employment publications available on our website, www.nras.org.uk.



¹ NRAS, 2007, I want to work... Employment and rheumatoid arthritis: A national picture. Available from www.nras.org.uk



2 Background to this survey

2.1 Employment: the costs of rheumatoid arthritis

There are nearly 60,000² people in Scotland with rheumatoid arthritis, and every year just over 2,500 people are diagnosed. For a minority of people the disease is less severe and remains well controlled, but others experience disabling pain, stiffness, fatigue and reduced joint function. This has a huge impact on their quality of life and their families'.³ One of the most significant impacts is the effect of RA on working life.

This survey aims, for the first time, to provide a national picture of the impact of RA on employment in Scotland, from the patients' perspective. It considers the barriers they perceive to staying in work, and their assessment of what would help to remove those barriers.

Rheumatoid arthritis represents a huge cost to the UK economy, both in terms of health costs and in terms of lost working days. The total costs in the UK of work related disability have been estimated at £8 billion per year.⁴

In August 2004, the Scottish Executive published *Healthy Working Lives*.⁵ This was a response to a growing body of evidence that improving the health and wellbeing of the working age population would increase sustainable economic growth. The report set out a strategy for improving the health of people of working age, by promoting health and wellbeing in the workplace and supporting people back into work who were unemployed with health conditions such as rheumatoid arthritis.

Subsequent policy developments on health and work across the UK prompted a review of this approach in Scotland, including: the publication of the *Health Work and Wellbeing* strategy for Great Britain⁶; a 2006 review of evidence about health and work⁷; and Dame Carol Black's review of the health of the working-age population of Britain, *Working for a Healthier Tomorrow*.⁸

The Scottish Government responded, and in *Better Health, Better Care: Action Plan*⁹ it made a commitment to re-energise the *Healthy Working Lives* agenda, to ensure that as many people as possible could contribute to and share in the economic prosperity of Scotland. The review, completed with the involvement of key stakeholders, led to the publication of *Health Works*¹⁰ in 2009. It sets out the reasons for changing attitudes to health and work amongst employers, workers and healthcare professions, and what action the Government will take to achieve this. Its action points challenge both the Scottish Government and employers, to jointly improve people's overall health and the competitiveness of Scottish industry.

Alongside developments in health and employment policy in Scotland, there have also been important developments in the management and care of people with rheumatoid arthritis. One of these has been the publication of a Clinical Audit of Care in Rheumatoid Arthritis (CARA).¹¹ The study team audited the implementation of the Scottish clinical guideline on the management of early rheumatoid arthritis¹², aiming to find out if there were significant variations in the care provided by clinical teams, hospitals and NHS boards.

² Figure for Scotland is calculated from data in National Audit Office (2009) *Services for people with rheumatoid arthritis*.

³ NRAS (2003) *Beyond the Pain. The social and psychological impact of RA*.

⁴ NRAS (2010) *The Economic Burden of RA*.

⁵ Scottish Executive (2004) *Healthy Working Lives – a plan for action*.

⁶ For details see <http://www.workingforhealth.gov.uk/Default.aspx>

⁷ Waddell, G. and Burton, K., (2006). *Is Work Good for Your Health and Well-being?* TSO (The Stationery Office).

⁸ TSO (2008) *Working for a healthier tomorrow*.

⁹ Scottish Government (2007) *Better Health, Better Care: Action Plan*.

¹⁰ Scottish Government (2009) *Health Works A Review of the Scottish Government's Healthy Working Lives Strategy*.

¹¹ NHS QIS (2008) *Clinical Audit of Care in Rheumatoid Arthritis (CARA) Final Report on behalf of the CARA study team*.

¹² *Management of Early Rheumatoid Arthritis*, SIGN Guideline 48, December 2000. Available at www.sign.ac.uk/guidelines (The Scottish Intercollegiate Guidelines Network, known as SIGN, develops evidence-based clinical practice guidelines for the NHS in Scotland).



The audit identified key challenges in providing high-quality care for people with newly diagnosed RA, addressing the following areas:

- access to rapid referral and assessment by the rheumatology multidisciplinary team and rapid treatment for patients with persistent inflammatory arthritis
- minimising the use of Non Steroidal Anti Inflammatory Drugs (NSAIDs) and reducing the risks of gastrointestinal problems associated with them
- staffing rheumatology units adequately, so that they can implement the principles of intensive management in providing therapy with disease modifying anti rheumatic drugs (DMARDs)
- providing steroid warning cards for patients on oral steroids and information about the increased risk of shingles
- ensuring that all RA patients have rapid access to all members of the multidisciplinary team.

It has been recognised by government that health services have an important contribution to make to this agenda. However, we are in a climate of increasing pressure on the NHS in Scotland, as elsewhere in the UK, and facing the likely prospect (as we go to press) of a new administration.

Many rheumatology health professionals who work with NRAS feel uncertain about the future, and report that they have seen reductions in service provision in recent years. These have included redundancies amongst specialist nurses and allied health professionals, and the failure to renew consultant posts: these factors create a difficult time for health professionals and have a negative impact on patient care.

We hope that this survey will provide valuable information for:

- individuals with RA, about others' experiences in the workplace
- employers, about the kind of problems people experience in the workplace
- health professionals, about how the disease affects people in relation to their work and about the importance of rapid access to expert help when they need it
- policy makers, about the vital contribution of healthcare services as well as employment support from both employers and government – all critical to enable people with rheumatoid arthritis to continue working.



2.2 The survey and its methodology

The survey questionnaire was designed by the NRAS team together with an independent market research company specialising in healthcare, specifically for NRAS's 2007 annual survey. The questions were developed from issues raised by NRAS members and calls to the NRAS helpline. The design was reviewed by three consultant rheumatologists, a rheumatology nurse specialist and a panel of NRAS members with RA. Amendments were made in the light of their comments. Employment is a huge subject and many areas deserve exploration in more depth than is possible in a survey. The questions are designed to provide data that builds a picture of RA's effect on employment, from patients' perspectives, and at the same time keep the questionnaire a manageable size for respondents to complete.

NRAS presented the results of the 2007 UK-wide survey at the Scottish Society for Rheumatology Annual Conference in 2008, keen to develop partnerships to conduct the survey in Scotland. Diane Crake, Nurse Specialist from Tayside, reviewed the survey for use in Scotland. The review found that it was robust and could be used without modification, which would also enable comparisons with the findings of the 2007 survey.

From November 2008 to autumn 2009, NRAS worked to secure funding and to identify units prepared to take part. It was agreed to distribute the survey through NHS outpatient clinics, to people who met the survey criteria: they had a confirmed diagnosis of RA and were of working age.

In August 2009, NRAS contacted lead nurses and allied health professionals in all hospitals in Scotland, to invite them to participate. Units that wished to distribute the survey had first to apply to their local Clinical Governance team to get the necessary approval. While the processes of approval differed from area to area, a total of 17 hospitals gained approval and took part. See page 23 for a list of the participating units.

NRAS sent hard copies of the questionnaire to each unit. Specialist nurses and allied health professionals distributed them to patients who attended for routine outpatient clinic appointments in each hospital within their NHS Trust. They encouraged patients to fill them in while at the clinic. The health professionals collected the surveys for their unit and sent them back to NRAS.

NRAS did not send the survey to NRAS members in Scotland, to minimise the chance of any respondents having also completed the 2007 survey.

In total 220 questionnaires were returned to NRAS.

NRAS contracted with the Early Rheumatoid Arthritis Network (ERAN) to analyse the data in Excel spreadsheet format and provide an initial written report.

Some of the questions included an option for respondents to give free comments. We have included a small, representative sample of these comments throughout the report.

We have made some comparisons in this report between the findings of this survey and the 2007 UK-wide survey. While the sample size of this survey is smaller (198 completed questionnaires were included, compared to a UK-wide total of 782 in 2007), this survey was designed to capture more of the Scottish data. The sample represents a larger percentage of the relevant population (around 0.4% of people with RA in Scotland, compared with around 0.2% of people with RA in the UK in 2007).

3 Key findings

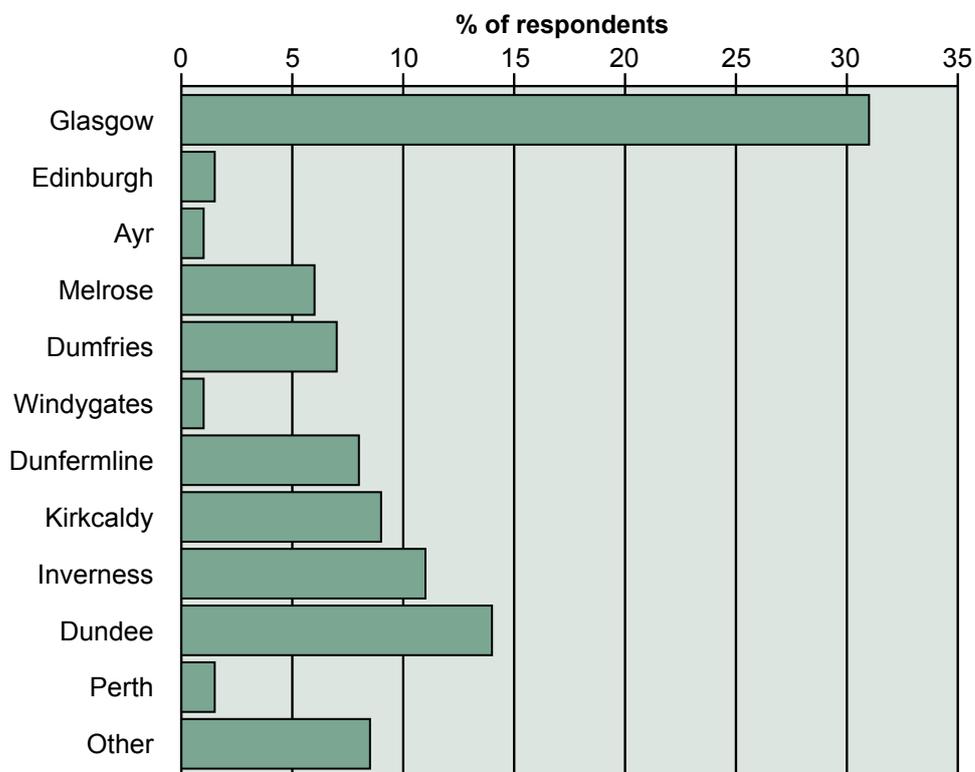
3.1 The survey respondents

A total of 220 questionnaires were returned to NRAS. Of these, four were not completed (the response to the first question Do you have RA? was no). A further 18 were either not completed or the respondent completed the wrong section, so these were excluded from the results. Therefore, 198 respondents were included in the survey.

The participants' geographical locations are shown at Figure 1. Around one third (31%) of respondents were from Glasgow.

Figure 1. Geographical location of respondents

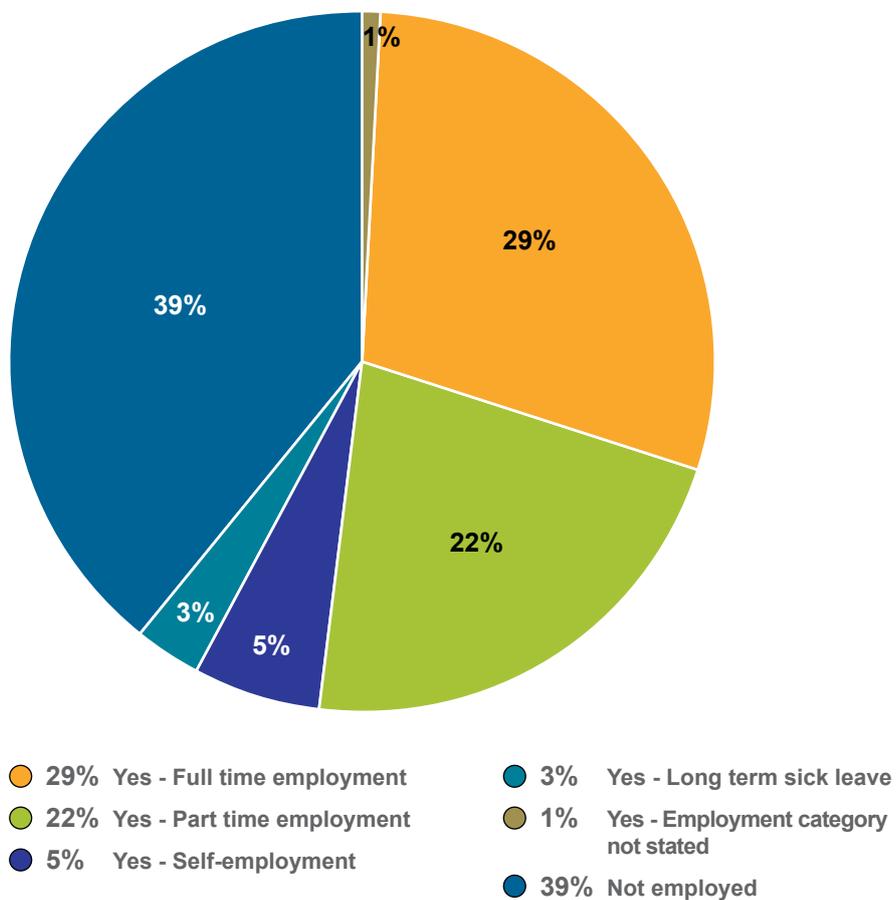
Geographical distribution



Their employment status is shown in Figure 2. Of the 198 respondents, 60.1% (119) were in employment. Over a quarter (29.3%) were in full time employment, 21.7% were in part time employment, 5.6% were self employed and a further 2.5% were employed though currently on long-term sick leave.

Well over one third of respondents were not currently working: 39.9% were not in paid employment. This is a slightly lower percentage than in our 2007 UK survey, which showed 45% of respondents not working. The different age distribution of this sample may be one factor contributing to this (see Figure 4).

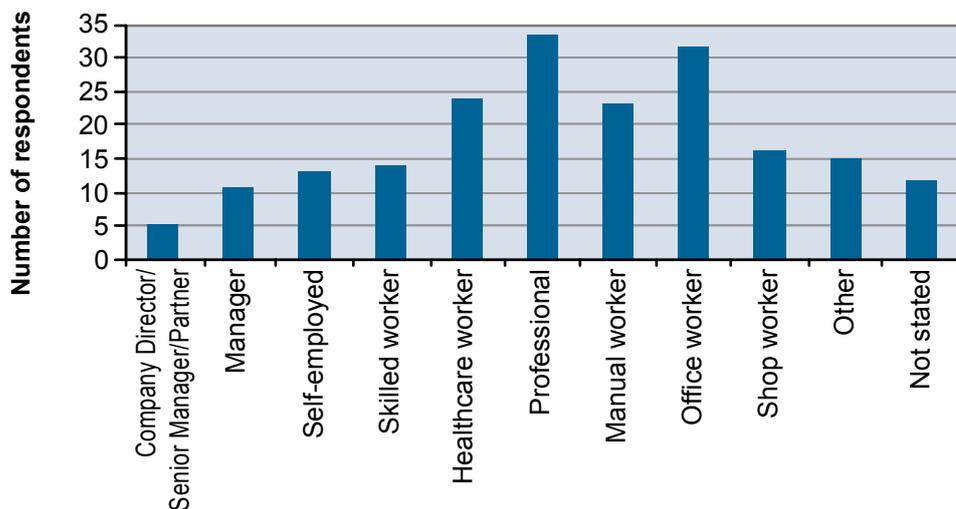
Figure 2. Respondents' employment status



Respondents came from a wide variety of employment backgrounds, as shown in Figure 3.

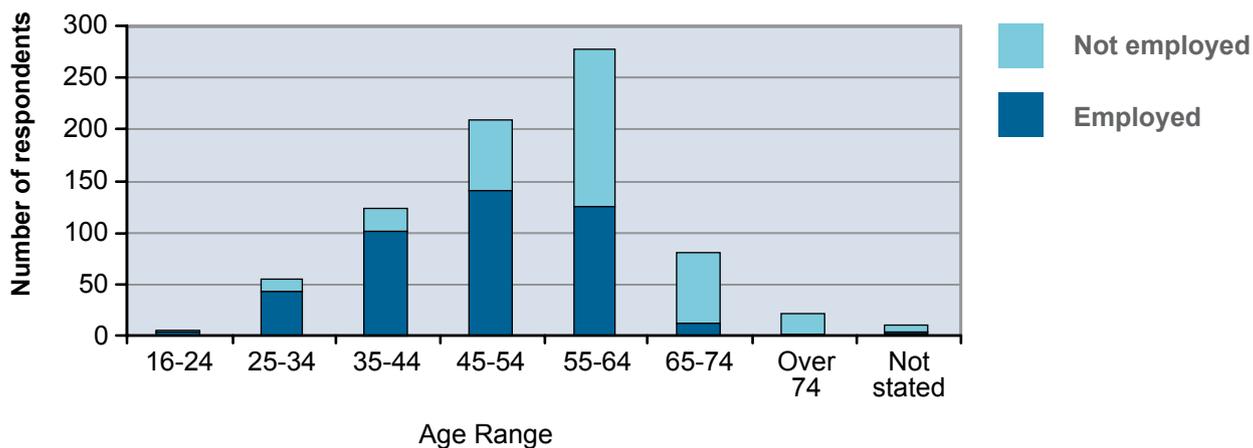


Figure 3. Types of employment



The distribution of respondents' ages and employment status is shown in Figure 4. Well over half of the respondents (56.6%) were aged 54 or under, less than one third (27.8%) were aged between 55 and 64, and 11.6% were 65 and over. This is a slightly different, younger profile than that of the 2007 survey: the age category with the most respondents in 2007 was 55-64. In the 2007 survey, 50.2% of respondents were aged 54 or under.

Figure 4. Respondents' age and employment status



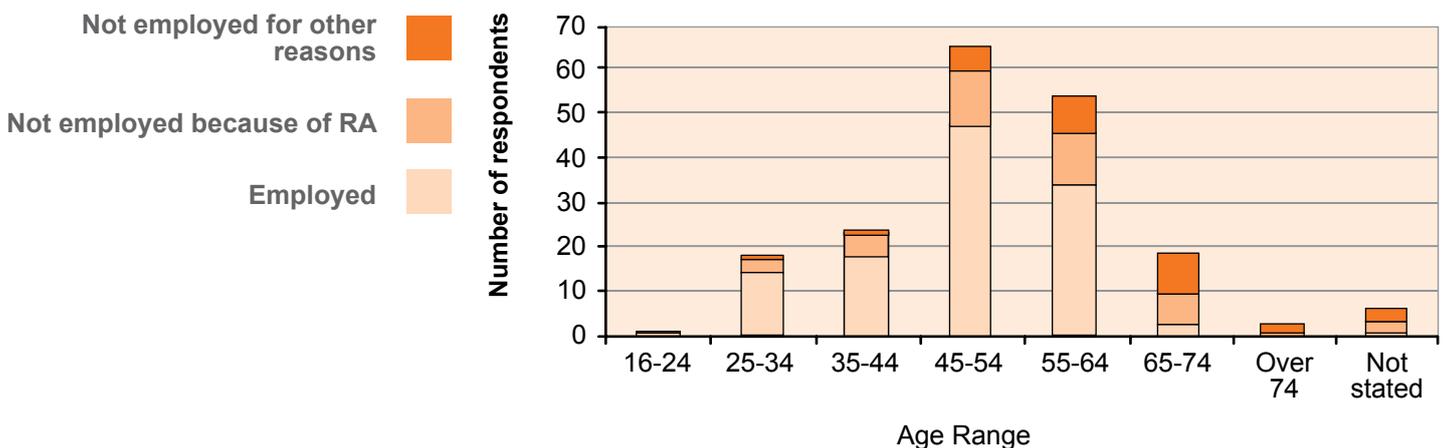
3.2 Effects of rheumatoid arthritis on employment

The data from this survey show that RA had a significant impact across all age groups, affecting both how long people could stay working and the type of work they were able to do.

3.2.1 Stopping work

The survey data indicate that people's working lifetimes in Scotland are very significantly curtailed because of RA. Of those respondents not working, over half (45 out of 79, or 57%) said that they were not in employment because they gave up work early as a result of RA (details in Figure 5). This includes people above and below the statutory retirement age, and represents 22.7% of all respondents (45 out of 198).

Figure 5. Not employed as a result of RA



“[I changed job because of a] decrease in strength, mobility and stamina for physical work”

It is likely that the impact and costs of early retirement will become more significant, as flexible retirement ages become more common and there are more opportunities for people to continue working beyond the statutory retirement age.

Of those 45 respondents who were not working because of their RA, over half (56%, or 25 respondents) reported that they had stopped working within one year of diagnosis and 80% (36 respondents) had stopped within six years (details at Figure 6).

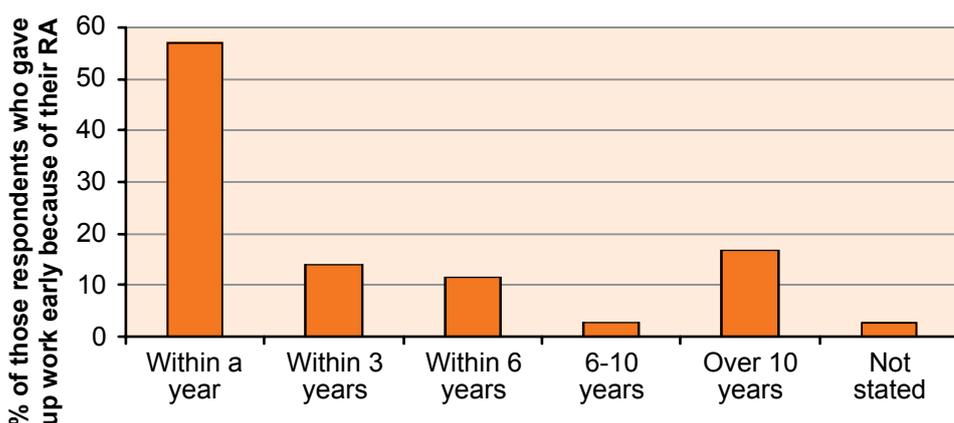
This confirms the 2007 findings, that the experiences of people with RA living in Scotland differed from those in the rest of the UK. The findings of this survey suggest an even more significant impact on working lifetimes than was found in the 2007 survey: the UK-wide survey in 2007 found that 28.4% of those who gave up work early because of RA had stopped within one year, and 59% within six years.

The data from this survey in Scotland highlight the very severe curtailment of working lifetimes that can result from RA and the urgent need for measures to address it. We feel that these results are likely to be more representative of all people with RA, as the survey sample was drawn from those attending clinics rather than from the membership of NRAS.

Of those 45 respondents who were not working because of their RA, over half (51.1%, or 23 respondents) said that they would like to return to work if they could find a suitable job that would accommodate their RA. This includes those who would like to return to work part-time, and those over the statutory retirement age.



Figure 6. How soon after diagnosis people stopped working as a result of their RA



3.2.2 Impact at work

The data indicate strongly that RA has an impact on the kind of work people can do, and therefore on their earning potential. Amongst the employed respondents:

- close to one fifth (18.5%) said they had had to change their occupation to something different because of their RA. All of these respondents stated that the reason for changing their jobs was the physical limitations of their condition, or fatigue
- nearly one third (32.8%) believed that RA had been detrimental to their career progression
- 62.2% thought they would continue in their current job for the next three years, but a sizeable minority (35.3%) either thought they would not or it was uncertain that they would do so.

“I was a hairdresser, now in sales and [have] little or no physical duties”

“I became a freelance based at home”

3.2.3 The costs

This survey sheds light on the financial costs both for individuals with RA and for their employers, though our focus here is the impact of RA on employment from patients' perspectives. This survey of 198 people clearly indicates that RA leads to a significant reduction in productive working years.

People are unable to work to their full potential, and the consequent loss of personal income has an impact both on them and on wider society. With many people forced to leave work in their 40s and 50s or even earlier, individuals cannot build up their pension contributions for income in retirement, and employers lose the valuable contributions of skilled and experienced people in their workforce.

These consequences are likely to become more significant in the future, as people work for longer and the numbers of older people with chronic disease increase.

In addition to early retirement, there are further 'hidden' costs for those people with RA who do remain in work, as the results show. People find that their earning potential can be affected by factors that include:

- having to change occupations to accommodate their RA
- finding that their career progression is hampered
- having to reduce their hours or work part-time.

While there is a growing body of research that is quantifying these costs, for individuals and for the economy, it is clear from these respondents that many people's personal circumstances are severely affected. In 'The Economic Burden of RA Report'¹³, the loss of productivity related to RA is estimated to be £666 million in Scotland.

3.3 Barriers to remaining in employment

When asked to consider the potential barriers to remaining in work, less than one fifth (17.8%) of employed respondents felt that their RA had not affected their employment at all.

The remainder had experienced, or anticipated that they would experience, barriers to remaining in employment. Overwhelmingly, the most important of these was fatigue: 81.1% of respondents in employment cited this as a major barrier. The other most significant factors were: pain; the inability to carry out duties due to physical limitations; and taking time off sick. Respondents in work and respondents not in work were largely in agreement about the factors they considered significant (see Table 1).

There are some differences between these results and those of the 2007 survey. Similar percentages of respondents identify pain and the inability to carry out duties as important, but a higher percentage of Scottish respondents see time off sick as a barrier: 55.6% of employed respondents compared to 32.9% of employed respondents in the 2007 survey. The importance attached by Scottish respondents to fatigue as a barrier to employment is also notable: identified by 81.1% of employed respondents compared to 59.8% in the 2007 survey. This highlights the need for strategies and management to reduce its impact. Healthcare professionals in Scotland have a vital role in enabling people with RA to manage fatigue as effectively as possible, reduce their time off sick and help them to remain in employment.

¹³ NRAS (2010) *The Economic Burden of RA*.



Table 1. Barriers to remaining in employment

Factors perceived as barriers to remaining in employment	respondents identifying this as a major barrier	
	% of employed respondents	% of respondents not in employment
Fatigue affecting ability to work	81.1	79.6
Pain affecting ability to work	64.4	68.5
Unable to carry out duties due to physical limitations	58.8	59.5
Time off sick	55.6	48.1
Problems with colleagues	4.4	3.7
Need specific adaptations at work to carry out current role	3.3	3.7
Lack of support and understanding from employer	2.2	9.3
Lack of family support/understanding at home	1.1	1.9
Unable to get to or travel to work	0	1.9

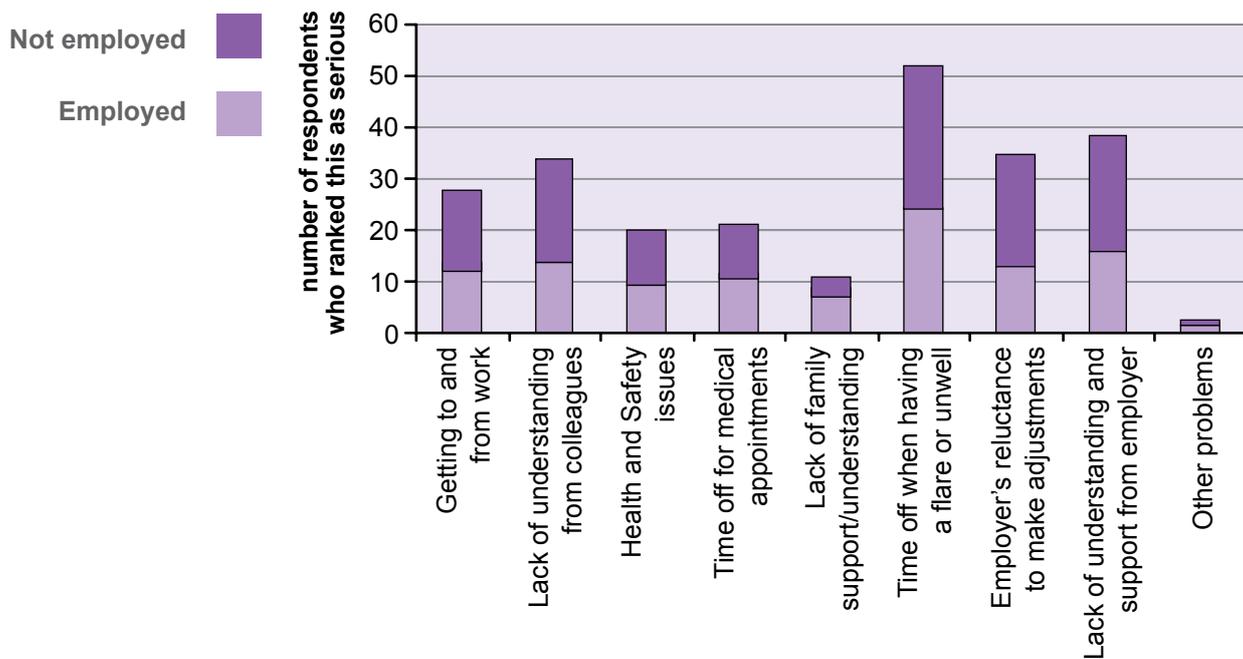
All respondents, whether in employment or not, were asked to rank the seriousness of problems they had experienced at work on a scale of 1 to 5, where 1 meant 'not at all serious' and 5 meant 'very serious' (see Figure 7). The problems that were considered by all respondents to be the most serious (i.e. those that were ranked 4 and 5) were:

- taking time off when having a flare or unwell (52, or 26.3% of all respondents)
- a lack of understanding and support from their employer (38, or 19.2)
- their employer's reluctance to make adjustments (36, or 18.2%)
- a lack of understanding and support from colleagues (35, or 17.7%)

"I was dismissed from previous employment on capability"



Figure 7. Seriousness of problems experienced at work



“Have to use holiday entitlement for medical appointments/blood tests”

It is clear from these responses that staying at work can itself be hard work for people with RA. However, the findings also suggest that many of the problems people experience are not insuperable: rapid access to health services when needed, more awareness from employers and colleagues, and more readily available adjustments at work could all play a role in improving the situation.

3.4 Employers' attitudes and support

Most respondents had told their employer or former employer that they had rheumatoid arthritis: 88.2% of those in work (105 out of 119) and 57% of those not who were not in work (45 out of 79). The majority of respondents (62%) stated that they had informed their employer within one year of being diagnosed.

However, these percentages are all a little lower than those found in the UK-wide 2007 survey. The comparable figures were: 90.1% of respondents in work had told their employer; 67.4% of those out of work; and 83.9% had done so within one year of being diagnosed.

Respondents in this survey also gave mixed assessments of their employers' awareness and understanding of RA.

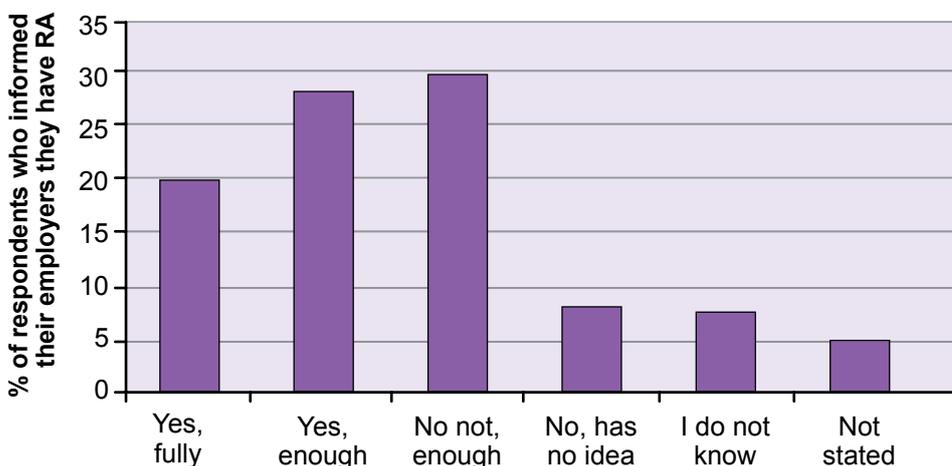
3.4.1 Awareness and understanding

It can be difficult for employers to understand the variable nature of rheumatoid arthritis. To the untrained eye there are often no physical changes visible in a person with RA, particularly in the first few years after diagnosis.

It is encouraging that, of those respondents in work who had told their employer of their diagnosis, one fifth (20%) felt that their employer fully understood RA, and a further 28.6% felt that they understood 'enough'. However, those who give positive reports account for less than half of those in work (details in Figure 8). Nearly one third (29.5%) felt that their employer did not understand enough, and a further 8.6% felt that their employer had 'no idea' at all.

The findings suggest that there remains a need to address the 'awareness gap' amongst employers, both about the RA itself and about the needs at work of people with the condition.

Figure 8. Does your employer understand RA?



"I do not take time off for my condition as this would go against my employment record"

"I am regularly told by patients to delay [methotrexate] treatment, as they won't be able to go to their GP fortnightly for bloods in the initial period: it would be too much time off work"

(Nurse Specialist from hospital participating in the survey)

3.4.2 Support to help people stay in work

There were mixed responses about the help people received from their employers in order to remain in their jobs.

Respondents had mixed views about how helpful their employers had been in assisting them to stay in work. A total of 150 respondents, employed and unemployed, had told their employer that they had RA. Of these, over a quarter (30.8%, or 61 out of 198 respondents) described their employer as 'helpful' or 'very helpful' (rating them 4 or 5 on a scale of 1 to 5). This is encouraging, although a sizeable minority, 16.6% (33 out of 198 respondents), said their employer was 'unhelpful' or 'very unhelpful' (ratings 1 and 2).

“I was refused flexible retirement by my employer”

45 respondents who were not employed had told their former employer of their diagnosis. Of these, only 8.9% (4 respondents) said that they had been offered support to help them make changes to working conditions or equipment to make their work easier.

105 employed respondents had told their employer of their diagnosis. Of these, over a third (36.2%, or 38) said they had been offered support to help them make changes to working conditions or equipment to make their work easier. The difference in their experience from that of those not working may be a welcome indication that support is becoming more widely available.

Only about one fifth of all respondents who were in work (25 out of 119, or 21.0%) felt that support from their employer was not needed. The data thus suggest that for the majority of people with RA, support from their employer is a significant factor in enabling them to remain at work.

Those respondents who did receive support mentioned several forms. Most frequently mentioned were: special equipment; reduced hours; and flexible working hours.

Table 2. Changes to working conditions

Type of support or change to working conditions	Total number of respondents who received this support	As % of all respondents who had received support (51 respondents)
special equipment/ changes to equipment	25	49
flexible hours	17	33.3
fewer hours	15	29.4
change in duties	13	25.5
improved accessibility	1	2
Other adjustments	30	10.8%
Help with transport	25	9%
Improved accessibility into the work place or in the work place	21	7.6%

“Not sure if employer fully understands RA implications”



3.4.3 What else would help?

All respondents were asked what else would help, or would have helped them to stay in employment for longer. The results are shown in Table 3. As this shows, the type of support that people need is often both practical and achievable: for many people with RA the barriers to remaining at work are not, or should not, be impossible to overcome.

Table 3. Factors identified that would enable people with RA to stay in employment for longer

Would any of the following help have helped you to stay in employment for longer?	% of all respondents who agreed
Availability of urgent access to rheumatology team when needed (e.g. for flare management)	49.0
Increased government priority for schemes to assist people with long term chronic health conditions to remain in work	46.0
Increased flexibility and knowledge of employer	39.9
Better awareness of schemes to assist disabled people at work	31.3
Better awareness of my rights at work	31.3
Good family support at home	26.3
Guaranteed assistance from an occupational health adviser	24.7
Easier access to buildings and better accessibility within the work place	15.2
Better assistance getting to and from work	11.1

The top five factors identified were thus:

- Availability of **urgent access to the rheumatology team** when needed (e.g. for flare management). Almost half of all respondents (49%) identified this: the prompt availability of healthcare was more important to people than any single employment-specific measure, when they assessed what would help them to stay in employment. This confirms that an integrated approach from government will be the most effective in reducing the numbers of people who are unnecessarily out of work because of rheumatoid arthritis. Improved access to rapid access clinics and prompt telephone helpline support will enable people to manage flares better and minimise their time off work.

“More understanding from employers [would help], to keep them off my back. They think I am okay because I look okay”



- Increased government priority for **schemes to assist people with long term chronic health conditions** to remain in work. Again, close to half of all respondents agreed that the government should give higher priority to this issue.
- Increased **flexibility and knowledge of their employer**. Well over one third (39.9%) of all respondents felt that higher levels of awareness and more flexibility from their employers was important. This indicates that improved awareness on the part of employers could help more people to remain productive members of the workforce.
- Better **awareness of schemes to assist disabled people at work**. Almost one third (31.3%) identified this as important, suggesting that improved information could enable people to access support.
- Better **awareness of my rights at work**. Many respondents indicated that they had felt unsupported at work and unsure of their rights and their employers' responsibilities. Almost one third (31.3%) identified this as important.

NRAS Publications

There are NRAS employment publications available on our website, www.nras.org.uk.



There was also interest in receiving specific materials to help inform employers about rheumatoid arthritis, the needs of people with RA and employers' obligations under the Disability Discrimination Act. 62% of respondents currently in employment, and 53.2% of those not in employment, said it would be useful to have such a booklet. This indicates that many people with RA may not have had access to such information, and there is a real need for practical support.

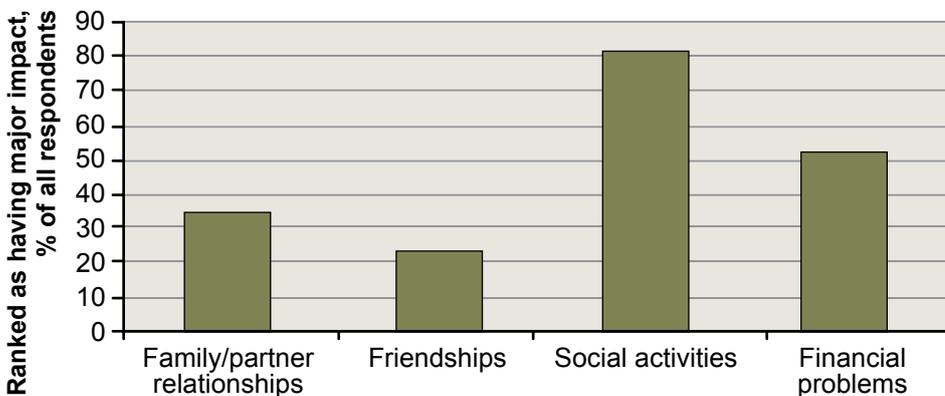
3.5 Social and emotional impacts

All the respondents were asked whether any problems they had experienced at work because of RA had an impact on other areas of their life. They were asked to rank them on a scale of 1 to 5, where 1 meant 'no impact at all' and 5 meant 'a major impact'. The problems considered most serious (i.e. ranked 4 and 5) are shown in Figure 9.

Over one third of respondents (81 or 40.1%) stated that the problems they experienced at work because of RA had an impact on their social life. Over a quarter (52 respondents or 26.3%) said that problems at work had had a major financial impact for them.

A smaller proportion, though still significant, also noted the effects of problems at work on their family relationships and friendships (17.2% and 12.1% respectively). This highlights the interconnected nature of work and different types of wellbeing. Once again, it shows how important it is for people with long-term conditions such as RA to have the support they need to remain economically active and productive.

Figure 9. Impact of problems at work due to RA on other areas of life



4 Conclusions and recommendations

4.1 Survey findings

- For many people, rheumatoid arthritis has a significant impact on their working life. Difficulties arising from this can extend beyond the work place and contribute to social and emotional as well as financial problems.
- People with RA are likely to have their working life cut short, at considerable personal cost. In this survey over half of those who gave up work because of their RA reported that they had stopped working within one year of diagnosis, and 80% had stopped within six years. These percentages are significantly higher than those in the rest of the UK, according to NRAS's 2007 UK-wide survey. The reason for these differences could be the basis for further research.

- Many people reported that they had had to change their occupation because of their RA. Close to one fifth of employed respondents had changed their occupation to allow for changes in their physical abilities.

- The most significant barriers to work identified by people with RA, were:

- fatigue
- pain affecting their ability to work
- being unable to carry out duties because of physical limitations
- having to take time off sick.

Fatigue is a considerable problem for people with RA, particularly for those who are working, and its impact can often be underestimated by health professionals. Over 80% of people in this survey identified it as a major barrier to staying in work. This is a strong message to multi-professional teams about the importance of addressing fatigue. Pain is also a symptom that patients often feel could be better managed; and the significance of pain as a barrier to employment, as perceived by respondents in this survey, confirms the need to focus on pain management.

- People with RA identified the following as the most important factors that would help them to remain working:

- urgent access to rheumatology team when needed
- increased government priority for schemes to assist people with long term chronic health conditions to remain in work
- increased flexibility and knowledge from their employer
- better awareness of schemes to assist disabled people at work
- better awareness of their own rights at work.

There is clearly a major need for greater investment in occupational health services.

- There remains an 'awareness gap' amongst some employers that needs to be addressed: Nearly one third of respondents felt their employer did not understand enough, and a further 8.6% felt that their employer had 'no idea' at all.

- Many of the barriers to work identified by this survey's respondents are not insuperable: with changes and more support, many more people with RA would be enabled to stay in work and contribute to the economy. Over a third (36.2%) of respondents in employment who had told their employer of their diagnosis, said that they had been offered some support to help make their work easier. Only about one fifth of all respondents who were in work (21.0%) felt that support from their employer was not needed. While many employers are supportive, a significant number are not: 16.6% of respondents who had told their employer of their diagnosis found them unhelpful or very unhelpful.

4.2 The way forward

4.2.1 Integrated government support

The health service has an important contribution to make for people with long term health conditions, and there is a strong focus in Scotland on long term conditions and the need for self management. However, without access to adequate rheumatology services that provide the right care at the right time, many people with RA will continue to face significant problems in the workplace, and some will face the possibility of having to give up work when, with the right help, could be supported to remain in work. Rheumatoid arthritis can start at any age, and giving up work because of a diagnosis of a long-term chronic condition can be traumatic.

- All government agencies need to work together, taking a proactive approach to helping people remain in work if possible and providing support and effective treatment at the right time. This will prevent people from needlessly moving onto benefits. There are additional challenges in Scotland, where some departments (such as health) are devolved and others (such as the DWP) are not – this continues to be a major focus for NRAS.
- There needs to be improved government priority for schemes to assist people with RA to remain in the workplace, and better advertising of those schemes that do exist. Current schemes must work to maximise the opportunities for people with rheumatoid arthritis. The quality of government schemes varies, as we know from talking to the many people who contact NRAS. A consistent approach is needed, drawing on the lessons of pilot schemes such as ‘Fit for work’.
- Government education and support needs to extend to both large and small employers.

4.2.2 Rapid access to the right services

Nearly half of all respondents (49%) agreed that urgent access to the rheumatology team, for example for managing flares and drug side effects, was an important factor in enabling them to remain at work. This survey also identified pain as a significant barrier to remaining in work, confirming the findings of a considerable amount of research¹⁴ that pain is a very significant problem for people with RA.

Over one fifth (22%, or 45 out of 198) respondents to our survey had given up work because of RA and over half of these 45 gave up within one year of diagnosis. This highlights the importance of prompt treatment and tight management of the disease, particularly in the early stage, in order to improve the long-term health outcomes as well as economic prospects for people with RA.

- There needs to be integrated government support for rheumatology services providing the right care at the right time. Commissioners of services must recognise this vital need, and that not all long term conditions require the same level of resource, if people with RA are to make the most of their potential in employment.
- Healthcare professionals at all stages of the patient journey need to have the expertise or resources to provide or refer patients for appropriate prompt pain relief. People with RA probably tolerate higher levels of pain than they need to because they believe it comes with the territory. Patients may need to be more proactive about seeking help with pain relief and health professionals may need to be more aware of the importance of effective pain management for patients, some of whom may have a tendency to minimise the impact of pain (‘putting on a brave face’) when discussing it in clinic.

¹⁴ E.g. Covic AI, Adamson B, Spencer D, and Howe G. (2003) ‘A biopsychosocial model of pain and depression in rheumatoid arthritis: a 12 month longitudinal study.’ *Rheumatology* [42] 11, 1287-1294; NRAS (2003) *Beyond the Pain. The social and psychological impact of RA.*

4.2.3 Further research on the costs of RA

Our survey has shed light on the considerable financial costs for individuals associated with having RA. There are also the less visible costs to the individual, such as slower career progression; to employers, such as the loss of staff with valued experience; and to the economy overall.

There is now an increasing body of research that is helping to quantify the full costs of rheumatoid arthritis. Research published by NRAS suggests that the total cost to the UK is in the region of £8 billion annually, including £666 million in Scotland.¹⁵

- The National Institute for Health and Clinical Excellence should, when assessing the value of new therapies, include the wider societal costs of work related disability in their cost effectiveness modelling. It is clear that patients with RA who are treated effectively, at an early stage in the disease, are more likely to remain in work and economically productive.

4.2.4 Education for employers and employees

The fluctuating nature of rheumatoid arthritis and its often invisible symptoms make it particularly difficult for people to understand. People with RA can experience problems both with colleagues and employers as a result. Some employers' lack of awareness may be contributing to the lack of support for individuals with RA. Employers may also be influenced by a range of other factors, including how long the person has been an employee, their particular skills and value to the organisation, and whether the employer is able to manage financially with a reduced staff team for some periods.

While the majority of employed respondents in this survey (88.2%) had told their employer about their diagnosis, just over a third of those (36.2%) had actually received support or adjustments to their working conditions. Employees may not know about their right to adjustments or may be unable to obtain them; employers may not be complying with their obligations under the Disability Discrimination Act 1995.

- There needs to be improved education for people with RA to help them become more aware of their rights in the workplace. The booklets we published for employees and employers in 2007 following the UK wide survey were intended to provide education and detailed information and sign-posting about work issues. Contact NRAS if you would like copies.

In 2010 NRAS is running a series of 'Workwise' employment workshops across the UK, designed to help people get the most out of work. For details call 0845 458 3969 or visit www.nras.org.uk Extracts and material from the workshops will also be available online from 1st May, 2010.

- Information needs to be readily available for employers that is specific to RA, in order to encourage employers' awareness, understanding and flexibility about people's needs.

¹⁵ NRAS (2010) *The Economic Burden of RA*.

5 More information

5.1 About NRAS

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