WorkMatters

A UK wide survey of adults with Rheumatoid Arthritis and Juvenile Idiopathic Arthritis on the impact of their disease on work
ABOUT US
The National Rheumatoid Arthritis Society (NRAS) is the only patient-led charity in the UK focusing specifically on rheumatoid arthritis (RA), and Juvenile Idiopathic Arthritis (JIA), and providing information, support, advocacy and campaigning for people living with RA and JIA, their families, carers and health professionals involved in their treatment and care.

ASK US
Our freephone helpline 0800 298 7650 is open from 9.30am to 4.30pm, Monday to Friday. Our trained helpline staff, supported by a team of medical and healthcare professionals, are there to answer your questions on all aspects of living with RA.

If you’d like to talk to someone else with RA, our colleagues can match you with one of our trained telephone support Volunteers, who will then call you back to discuss whatever aspect of living with RA most concerns you. To be put in touch with a Volunteer who has RA, please call the office and they will organise a mutually convenient time for the volunteer to call you.

Our website www.nras.org.uk has a wealth of information about all aspects of living with RA, treatments, the latest research and developments, as well as full details of other useful organisations and charities.

The website also links you to an NRAS online forum, NRAS HealthUnlocked, a safe space where you can get peer support and blog about your experiences.

If you don’t have access to the internet or prefer any helpful information sent in the post just call us on 0845 458 3969 or email enquiries@nras.org.uk.

MEET US
Local NRAS groups meet regularly around the country. To find out if there is a group near you visit www.nras.org.uk/groups, email volunteers@nras.org.uk or call 0845 458 3969.

JOIN US
To find out how to support the work of the charity by becoming a NRAS Member, visit www.nras.org.uk. You can make a real difference and help many others living with RA for as little as £20 per year.

CREDITS AND ACKNOWLEDGEMENTS
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Thanks to contributors: all 1534 people with Rheumatoid Arthritis and Juvenile Idiopathic Arthritis who responded to the survey

REFERENCES
For a full list of all the references (such as to articles in medical journals) used in compiling this booklet, please call NRAS on 01628 823524.
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Introduction

Ailsa Bosworth MBE
Chief Executive

I have been lucky in that I have been able to remain working full time since I got my first job, despite being diagnosed with severe polyarthritis when I was 31. Thanks to innovative new therapies and a radically different way of treating people now by comparison with the early 80s, I am able to work between 50 and 60 hours a week after living with inflammatory arthritis for 37 years and having undergone 19 operations to replace joints, repair tendons, fuse joints and vertebrae and manage my uveitis.

The only time I have had off during that period was when I was hospitalised, a frequent occurrence in the early years, and for the various surgical procedures. I had a wonderful boss at the time of my diagnosis who believed in me, saw potential and mentored me from his PA to becoming a Director. He supported me when I became very ill and as a consequence, I went more than the extra mile for him and the organisation. Since then, I have never had to reduce my working hours nor had any sabbaticals or extended periods off other than normal holiday allowance. But when I have needed to go to clinic appointments, have time off for surgery, go for the endless blood monitoring, imaging, managing co-morbidities etc., I have been able to do so without having to ask anyone’s permission and that makes a massive difference. I have more than made up for any time off due to ill health, but that’s not the point, when you have full autonomy it reduces the stress levels associated with managing your disease in the workplace.

Many people are fearful of telling their employer that they have rheumatoid arthritis (RA) because they worry it will at best reduce their chances of progression in their career and at worst, lead to losing their job. It seems so wrong on every level that in 2017 many people should be made to feel this way as employers can, if they are aware of the situation, do much to support staff living with long-term conditions like RA, who, like me, if well supported, would work incredibly hard on behalf of their employer.

We were delighted to partner with Dr. Suzanne Verstappen and Laura Lunt from the Centre for Musculoskeletal Research at the University of Manchester in this project and to have Professor Karen Walker-Bone, Director of the Arthritis Research UK/MRC Centre for Musculoskeletal Health and Work write the foreword for us.

We hope that this report will contribute to the body of research demonstrating that work must become an established health outcome for people with RA and JIA (and other long-term conditions) and we would like to thank all those who took the time to participate in the survey.

Ailsa Bosworth MBE
Chief Executive
Foreword

Professor Karen Walker-Bone BM, FRCP, PhD, Hon FFOM
Director, Arthritis Research UK/MRC Centre for Musculoskeletal Health and Work

“Work is central to human existence and the motive force for all economies. For individuals, it provides structure and meaning and is good for people’s health and wellbeing, as well as their financial health and prosperity. Moreover, work benefits families and is socially inclusive.”

Professor Dame Carol Black wrote these words in her report to Tony Blair’s government “Working for a healthier tomorrow” in 2008. Almost a decade later, “Work Matters” is a very important new survey of more than 1000 people with rheumatoid arthritis and juvenile idiopathic arthritis. Despite a number of government initiatives, the survey suggests that many people with inflammatory arthritis are struggling to find the type of work that they want and need. It is excellent that more than 60% of the respondents are currently participating in some sort of work. However, there were so many signals that things are far from easy for them. For example, many workers with rheumatoid arthritis report that they are having to accept lower expectations of promotion or job development; that they are fearful of changing their job if they currently have acceptable working conditions in case a future employer is less supportive; that they are struggling financially perhaps because of restricted working hours; and that they are using their annual leave to help them deal with their RA. Despite a high proportion of workers disclosing their arthritis to their employer, it is shocking how many still find their employer uninterested or ill-informed as to what is needed to help them work successfully despite their condition.

Loud and clear comes across the message that employers and line managers can make an enormous difference to work accessibility by being supportive of, and flexible with, their employees. Interestingly, the types of adjustments that employers need to make are often extremely cheap and easy and numerous research studies show that employers get back many £s for every £1 investment they make in their workforce. Ailsa’s own story and that of several of the case studies illustrate these points well. It is absolutely vital that we continue to empower people with RA and other long-term conditions to enable them to participate in work and that employers and line managers are given more advice and support to create flexible jobs in supportive working environments. Everybody is better off when this is achieved – employers get fiercely loyal and hard-working employees who are happy in their jobs, and people with RA can take their rightful places in society, supporting themselves and their families thereby reducing the disability employment gap to benefit all of society.

I would like to thank NRAS and the researchers for undertaking this important survey and all of the people with RA who provided us with their information. “Work Matters” will be really important for us to use to challenge Government and employers about their progress since 2008 and to point to the most important places to put their resources to make things better in the next decade.

Professor Karen Walker-Bone BM, FRCP, PhD, Hon FFOM
Director, Arthritis Research UK/MRC Centre for Musculoskeletal Health and Work
Methods

Ten years after the publication of the National Rheumatoid Arthritis Society’s (NRAS) survey “I Want to Work,” the 2017 NRAS work survey was designed together with Researchers from the Centre for Musculoskeletal Research at the University of Manchester and the Director of the Arthritis Research UK/MRC Centre for Musculoskeletal Health and Work, Professor Karen Walker-Bone. This collaboration has brought together an expertise in research into work related matters of adults with rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA) and the lived experience of people with RA and JIA. In order to draw comparisons with results from a decade ago, some questions were developed based on the 2007 survey, as well as others on current knowledge of the topic and current national policy relating to work and health. The survey included some validated questionnaires to draw comparison with other current research in this field. The study was approved by the University of Manchester Ethics committee (ref. 2017-2112-3266) and all participants gave consent by completing the survey.

The main aim of the survey was to gain an up-to-date understanding of the impact of RA on employment and understand the main challenges for people to remain in work. Understanding these challenges will help us to provide better information and support to people with these diseases and provide a steer about possible policies or interventions to prevent problems at work and future loss of work due to RA and JIA. The survey also provides an opportunity to compare results from the “I Want to Work” report in order to understand if there have been improvements (or not), to the challenges faced by people with RA in the workplace, and understand how national policy and modern treatment might have affected this. For young adults with JIA, decisions about their career start at school. Making the right choices at an early age will help them in their future career to find the job most suitable to them. Since there is limited information about career planning and applying for jobs for young adults with JIA, this survey also included questions for this group of people aged 16 to 30 years.

The survey was carried out using an online platform hosted by the University of Manchester. In order to find participants to complete the survey, NRAS sent an email to its membership and also used social media (Facebook, Twitter and HealthUnlocked) to ensure that non-members were given the opportunity to complete it. The survey was open for 6 weeks during June/July 2017 and generally took participants up to approximately 30 minutes to complete.

Participants

The focus of the survey was on people with RA who are currently or who were previously employed whilst having RA and young adults aged between 16-30 years with JIA living in the UK. We therefore excluded people living abroad, those who did not complete the question about their current working status, those who have never worked, those with a diagnosis of RA after stopping work and duplicates of IP addresses. A total of 1534 people completed the survey and 282 were excluded.
Results – Section 1
The survey respondents – rheumatoid arthritis

In total, data from 1222 people who stated that they had RA were used, and these people completed the majority of the questions in the survey. Everyone in this part of the survey had RA and JIA. The majority of the participants were female (90.8%) and 91.2% were aged less than 65 years. The ratio of women to men with RA is 3:1, therefore we would expect a greater number of responses from female participants. However, 90.8% is slightly higher than would be expected. The high percentage of respondents under the age of 65 can be attributed to the fact that most people are diagnosed when of working age1. Figure 1 shows the geographical location of where the participants live.

Figure 1: Geographical location of respondents

The average symptom duration was 12.7 years and time since diagnosis was on average 10.5 years. The majority of the participants took medication for their RA: 62.7% used pain medication (e.g. paracetamol), 49.6% used anti-inflammatory medication (e.g. naproxen), 81.5% used disease modifying drugs (DMARDs), 41.7% used biologics, and 15.8% used oral steroids. Participants were also asked to rate their physical, general and emotional wellbeing in the past week in order to set their responses in the context of how they are feeling (score 0 – 10). It is notable that fatigue scored most highly out of all the symptoms. (Figure 2)

Figure 2: Rating of physical, emotional and general wellbeing in the past week

Co-morbidities

Many participants reported having diseases in addition to RA (Figure 3). Most commonly participants reported having high blood pressure, back pain and osteoarthritis. Notably, a large proportion of the respondents also reported using medication for depression (17.4%) and for anxiety (10.9%). Mental health issues have been consistently reported as a significant co-morbidity in the social research undertaken by NRAS2 and others. Following the release of Government statistics showing that musculoskeletal and mental health illnesses are the first and second highest causes of lost work days in the UK3, this data raises particular concerns in relation to work for people with RA. Furthermore, given the high number of people with RA who develop heart disease, the importance of treating high blood pressure cannot be underestimated. It also underlines the importance of rheumatology units carrying out holistic annual reviews where co-morbidities are screened for in line with NICE guideline CG79 and NICE Quality Standards in RA.

Figure 3: % of respondents with co-morbidities

Employment

The majority of the respondents, 63.3%, were in paid employment (Figure 4) and 7.61% were self-employed. This is higher than in the 2007 survey when 54.8% of the participants were in employment. This may reflect a greater number of people whose disease is better controlled as a result of modern therapeutic approaches maximising disease activity control and use of biologics if the disease cannot be controlled, but may also include people who have applied for help under government policies such as the Access to Work scheme, enabling them to remain working. This policy was highlighted in NRAS booklets for employees and employers, developed in response to the survey from 10 years ago, and these booklets have been widely used by patients and rheumatology health professionals.

Figure 4: Employment status (%)
Population in employment

A high proportion of participants in employment work in offices (25.5%) (e.g. as secretaries, accountants, etc.) or as healthcare professionals (13.9%) (e.g. nurses, social workers etc.) (Figure 5) with the majority of people having a permanent contract (87.6%) (4.0% fixed term contract, 1.9% zero-hour contract and 6.5% other). The unemployment figures for those with RA, including those that stopped working or retired early due to RA, is 17.3%. This is in comparison to national figures at 4.3%4; a concerning statistic demonstrating that so many more people with the disease are currently out of work. This is reflected in other long-term conditions and disabled people and is why the Government aims to halve the disability employment gap5. This compares favourably to the survey in 2007, when 29.3% of participants had given up work early due to their RA and may, as mentioned above, be due to earlier access to effective treatments and greater awareness of policies that may help. Additionally, one of the reasons for lower employment in the industrial sector for people with RA can be attributed to the difficulty in undertaking manual labour.

Figure 5: Sector of main job (%)

38.7% have a part-time job and most people work day shifts (86.1%). The job requirements are shown in Figure 6, with many jobs requiring a lot of attention and use of computers for long periods of time. The high percentage of respondents with a part-time job may also be attributed to the disease, with people having to reduce hours due to their RA. The need to reduce working hours to accommodate the disease impacts on an individual’s salary as well as the ability to make adequate pension provision for retirement.

Support at work

It can be difficult for employers and colleagues to understand the variable nature of the disease. In general, colleagues and the immediate line manager were not often willing to listen to work-related problems (Figure 7). This can have a negative effect on relations with colleagues, particularly if there is a lack of understanding about the disease. This aligns with data from a report6 published by Business Disability Forum in June 2015, which cited ‘a lack of skilled and confident line managers’ as one of the biggest barriers to retaining and developing employees with disabilities.

Figure 7: Support colleagues and line manager at work (%)

Compared to previous research, the vast majority of the participants had told their employer that they had RA (96.7%) with 78.2% disclosing almost immediately after diagnosis, 12.5% within 6 months, 2.8% within 6-12 months, 2.3% within 1-3 years and 4% after 4 years. However, in spite of this, 38.7% said that their employer did not understand their disease at all, emphasising the importance of increasing awareness, particularly amongst Small to Medium Enterprises (SMEs) who are less likely (than larger/major corporates) to have internal HR departments or be aware of current legislation in regard to employment law. These figures have worsened since the 2007 survey, in which 29.5% said that the employer did not understand enough and 15.4% felt that their employer had no idea, which would indicate that successive

Table 1: Barriers to remaining in current or most recent job

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<thead>
<tr>
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<th>serious working</th>
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<th>neither serious nor non-serious working</th>
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<td>4.1</td>
<td>22.8</td>
<td>13.8</td>
<td>20.5</td>
<td>25.2</td>
<td>17.5</td>
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<tr>
<td>Time off for medical appointments</td>
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<td>6.9</td>
<td>21.8</td>
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<td>19.5</td>
<td>16.0</td>
<td>16.2</td>
<td>20.0</td>
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<tr>
<td>Lack of family support/understanding</td>
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<td>4.9</td>
<td>9.4</td>
<td>14.0</td>
<td>14.0</td>
<td>16.4</td>
<td>11.4</td>
<td>16.7</td>
</tr>
<tr>
<td>Time off when having a flare or unwell</td>
<td>25.4</td>
<td>14.0</td>
<td>31.6</td>
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<td>10.4</td>
<td>15.8</td>
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<td>14.0</td>
<td>17.5</td>
<td>9.1</td>
<td>13.0</td>
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NATIONAL RHEUMATOID ARTHRITIS SOCIETY
governments have not sufficiently raised awareness with, or put in place, policies to support employers in this area. NRAS, as a member of the Expert Advisory Group to the Work and Health Unit, hopes that with the data captured from the Green Paper (on disability) consultation, the work being done by the Government currently will address these issues.

Barriers and facilitators to remain in work

When asked whether participants in employment would be able to continue working in the next 12 months, 41.3% stated that they would certainly be able to continue in their current job. However, if the job became more physically, emotionally or generally demanding and more difficult, over 50% of people would find it hard to continue working (Figure 8, p10). It is a concerning statistic that the majority of people feel that they would be unable to continue in their current job if circumstances changed, which demonstrates the importance of the right support for people with RA in the workplace.

Barriers to remaining at work have remained the same since the 2007 NRAS work survey, which highlights the importance of early intervention and support following diagnosis to prevent the disease potentially leading to job loss. For those respondents who stopped working, a lack of understanding from colleagues/employers and time off when having a flare or for medical appointments were found to be major issues in their last job. (Table 1, below)

For those employed, we also asked what the Advantages and Challenges were to continuing work.

The main five most reported advantages were:
- Financial security
- Sense of purpose and achievement
- Reasonable adjustments
- Understanding employer
- Accessible and comfortable working environment

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**Table 1: Barriers to remaining at work (continued)**

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<th></th>
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<tr>
<td>Getting to and from work</td>
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<tr>
<td>Lack of understanding from colleagues</td>
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<tr>
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<tr>
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<tr>
<td>Lack of family support/understanding</td>
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<tr>
<td>Lack of support from employer or line manager</td>
<td>15.3</td>
<td>28.6</td>
<td>13.6</td>
<td>12.6</td>
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</tbody>
</table>
The main five most reported Challenges were:
- Demanding role
- RA symptoms
- No reasonable adjustments
- Commuting to work
- Lack of understanding employer and/or colleague

Some quotes of patients are included in Figure 9 (opposite).

"Due to my RA symptoms, especially the fatigue that is a result of the disease, I found it difficult to work the same hours I had previously."

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Figure 8: Will be able to continue working in the next 12 months (%)
Figure 9: The main challenges and advantages to remaining in work

### Challenges

“The nature of reception work with it’s constant interruptions of answering the front door and the telephone while trying to complete admin tasks that require accuracy and concentration…”

“All work is PC based which can be difficult during a flare when my hands and wrists are very painful.”

“The amount of stress created by my employer doubting my disability, questioning my need for time off – even when provided with a letter from the doctor and refusing to accommodate my need to change my hours has made my life hellish. I feel more ill as a result and have been suffering with anxiety to the point of becoming unable to cope.”

“The job is physically challenging particularly because the employer refused to upgrade the equipment or organise the warehouse area to make it easier to pull roll cages. The employer really cannot be bothered to support me at all and is looking to use the company’s disciplinary process to sack me!”

“Difficult commute (can take 40 to 60 minutes), long hours on my feet nearly all day, lots of twisting of my hands and lifting.”

“Getting to and from work during rush hour. Getting to different work sites for meetings…”

“The key challenge is making the chain of command understand invisible illnesses and overcoming stigma of ‘you don’t look ill’; there is work ongoing to address this.”

“Lack of understanding about the illness; employer pursuing capability following long term absence – stressful situation; threat of dismissal if further absence.”

### Advantages

“The pension scheme, life insurance and additional sick leave the longer I work for the company.”

“It pays the mortgage, I can afford to go on holiday, it sometimes keeps me going when I don’t feel like it…”

“Gives me a sense of purpose and makes me get going in the morning. Keeps me cheerful.”

“I retain a bit of independence and self respect.”

“Continue to be active, keeps mind active, socially, financially better off”

“I like the job, the company, colleagues and getting out of the house.”

“Flexibility when I do my hours. If I am stiff in the morning I can work in the afternoon when I feel better.”

“It is very physical and tiring, however I have requested that I do not work more than 2 days in a row, and this is working out ok.”

“Local, close to home. Park right outside the building. All on one level, no stairs.”

“Some equipment made available through Access to Work after first being diagnosed – office chair, electric desk.”

“Colleagues know and understand my limitations.”

“They are fully aware of my current health and needs. They have acknowledged my requirements to reduce hours and flexible working”
For the majority of people, limited adjustments, lack of understanding from work colleagues and employers and commuting were seen as challenges, suggesting that some of these issues are very much related to the type of job people do, whether they have disclosed their disease, the attitudes of employers and colleagues, and available options to adjust their working environment.

In this survey, separate questions were asked about flexible working. 63.9% of people mentioned that they have a fixed time that they need to begin work for all working days, and only 14.3% stated that they never had to be at work at a fixed time.

The majority of people travel to work by car (70.7%) and the distance to work is less than 20 miles for the majority travelling, perhaps indicating the difficulty for people with long-term conditions to use public transport. Schemes such as Transport for London’s ‘Please Offer Me A Seat’ badge can successfully raise awareness of invisible diseases such as RA, and are to be welcomed. Surprisingly, adjustments such as early retirement, a shorter working week, less demanding tasks or adaptations of the work environment are often not available in companies or people are not aware of the possibility of asking for such arrangements to be accommodated (Figure 10).

Sick leave and impact of rheumatoid arthritis on work performance

Of participants currently employed, self-employed or employed but currently on sick leave, the majority rated their performance at work somewhat or much worse compared to their performance prior to diagnosis (Figure 11). 59.8% have not changed their working hours, 38.7% are working less hours and 1.6% are working more hours now than before their diagnosis. If people feel that they are not performing as well as they did prior to their diagnosis, and the high number is very worrying, this situation is likely to contribute to anxiety and a lack of mental wellbeing, which will impact both the individual and the employer.

**Figure 10: Arrangements in company (%)**

<table>
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<th>Arrangement</th>
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<td>Re-education</td>
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<td>Less demanding tasks</td>
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<tr>
<td>Exemption from evening or night work</td>
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<tr>
<td>Shorter working week for people with disabilities</td>
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<td>Early retirement</td>
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</tbody>
</table>

265 (31.7%) people reported that they had been absent from work for an average of 7 days due to their RA in the past month. Some of the participants reported being on sick leave for more than one month. In addition, we asked about the number of hours people missed because of their RA during the past seven days (Work Productivity and Activity Impairment Questionnaire (WPAI)). The average percentage time missed due to inflammatory arthritis in the past week was 10.7%.

The survey asked how secure people would feel if illness prevented them from working for three months or more. 48.5% said that they would feel rather/very insecure. About 29% would get full pay for up to 4 weeks when on sick leave, 50% up to six months, 6% more than 6 months and 15% didn’t know. In general, nearly 30% mentioned that financially they were “just getting by” and 11.3% said that they found it (very) difficult to make ends meet. This demonstrates the negative impact that the disease can have on job security, particularly during a flare or at a time when it may be necessary to take time off for medical appointments etc.
This lack of security can contribute to feelings of anxiety or depression on a daily basis, which has a very negative impact on a person’s general wellbeing.

**Rheumatoid Arthritis affecting work whilst at work**

Figure 12 shows the percentage of people having no or some level of difficulty with various tasks at work (Work Activity Limitation Scale (WALS); range score 0-36, with 36 being the worst score). The average overall WALS score was 12.4 and more than 90% reported having medium difficulty (WALS score 5-8) to high difficulty (WALS score ≥ 9). In a separate question we asked how much their RA affected their productivity at work and any daily activities outside work (score 0-10, where 0 = no impact to 10, where their rheumatoid arthritis prevents working/performing daily activities (visual analogue scale WPAI)). The average score for productivity was 3.5 and for daily activities was 4.7.

### Figure 12: Difficulty performing tasks at work due to rheumatoid arthritis (%)

<table>
<thead>
<tr>
<th>Task Description</th>
<th>Difficulty Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much difficulty do you have getting to and from work (e.g. subway, bus, car, walking) and getting to and from work on time?</td>
<td>No difficulty</td>
</tr>
<tr>
<td>How much difficulty do you have getting around the workplace (e.g. stairs, hallway, furniture)</td>
<td>No difficulty</td>
</tr>
<tr>
<td>How much difficulty do you have sitting for long periods of time at your job (e.g. more than 20 minutes)</td>
<td>No difficulty</td>
</tr>
<tr>
<td>How much difficulty do you have standing for long periods of time at your job (e.g. more than 20 minutes)</td>
<td>No difficulty</td>
</tr>
<tr>
<td>How much difficulty do you have lifting, carrying or moving objects?</td>
<td>No difficulty</td>
</tr>
<tr>
<td>How much difficulty do you have working with your hands (e.g. writing, typing, grasping small objects, holding a phone)</td>
<td>No difficulty</td>
</tr>
<tr>
<td>How much difficulty do you have crouching, bending, kneeling or working in awkward positions?</td>
<td>No difficulty</td>
</tr>
<tr>
<td>How much difficulty do you have reaching?</td>
<td>No difficulty</td>
</tr>
<tr>
<td>How much difficulty do you have with the schedule of hours of work that you require?</td>
<td>No difficulty</td>
</tr>
<tr>
<td>How much difficulty do you have with the pace of work that your job requires?</td>
<td>No difficulty</td>
</tr>
<tr>
<td>Overall, how much difficulty do you have meeting your current job demands</td>
<td>No difficulty</td>
</tr>
<tr>
<td>As a result of your arthritis how much difficulty do you have concentrating or keeping your mind on your work?</td>
<td>No difficulty</td>
</tr>
</tbody>
</table>
Benefits

630 participants who reported being employed, self-employed or currently employed, but on sick leave answered questions about benefits. Of those who claimed benefits, the majority have claimed these benefits since their RA (or JIA) diagnosis. Of the 111 (17.8%) participants who claimed Disability Living Allowance (DLA), 72 (64.9%) received the higher rate of the mobility component, 14 (12.6%) received the lower rate, and 21 (18.9%) participants did not receive this component (n=4 (3.6%) not applicable). For those who claimed Personal Independence Payment (PIP) (n=116 (18.3%)) these numbers (%) were, respectively: 16 (13.8%), 38 (32.8%) and 46 (39.7%) (n=16 (13.8%) not applicable). Having a Motability car (n=125) made it significantly easier for people to get around independently (36.8%), knowing they could get around (24%), to go out and see friends and family (23.2%) and to get to medical appointments (29.6%).

Receiving either PIP and/or DLA (n=186) helped to pay for transport (95/186; 51.1%), to keep things people want (67/186; 36%), to improve work-life balance (90/186; 48.4%) and to reduce fatigue (52/186; 28%) or other (37/186; 19.9%) (22/186; 11.8% said it was not applicable). Accessing PIP/DLA was very important (46.2%) or important (32.2%) for most people to work. Only 11.8% said it was not directly relevant to staying in work (9.7% not applicable).

The results show that relatively low numbers of people with RA claim benefits, with the most commonly being those (just under 30%) who had claimed for a Blue Badge Allowance. However, it is clear that for the minority who need to claim DLA/PIP, that this represents a very important component to the majority of claimants being able to remain in work.

This perhaps shows that only people with RA that are the most in need are claiming benefits, however it may also indicate that insufficient awareness raising and advice is being provided to those that may be eligible for benefits. This would chime with the results of the NRAS Report, *Who Cares?* (health and social care needs of people across Scotland), where results indicated that only a minority were claiming health and social care benefits, but there was great reliance on family and friends to provide ‘informal’ support. Interestingly, the *Who Cares* report also identified that individuals with RA may be reluctant to ask for assistance with day-to-day care and support, as indicated by their responses when querying what may pose a barrier in asking for help. Carers, family, friends and neighbours and in particular health care providers should be aware that individuals with RA might not ask for help when they need it, and instead should begin a conversation to identify any unmet needs. The same situation is likely to occur in the workplace and this is something that colleagues and employers should be aware of.

In the transition from DLA to PIP, notable results show that under DLA, 17.6% of respondents were claiming DLA plus mobility component at a higher rate. However, under the PIP system, only 5.9% were claiming PIP plus mobility component at a higher rate, demonstrating that many people may be missing out on mobility vehicles under the new system. This can have a negative impact on people’s ability to commute to work, especially as a significant percentage of people with RA commute by car, as seen earlier in this report.

Figure 13: Benefits claimed by those in employment

![Bar chart showing benefits claimed by those in employment](chart.png)

- **Attendance allowance**
- **Access to work scheme**
- **Blue Badge Allowance**
- **Child benefit**
- **Child tax credit**
- **Council Tax Reduction scheme**
- **Working Tax Credit**
- **Disability Living Allowance (DLA)**
- **Personal Indepence Payment (PIP)**
- **Incapacity Benefit**
- **Employment Support Allowance (ESA)**
- **Motability**
- **Pensions Credit**
- **Universal Credit**

Legend:
- **Claimed before arthritis**
- **Claimed after arthritis**
- **Never claimed**
Job related changes due to RA in last year

Participants were asked about changes to work that had occurred in the last 12 months due to RA. Nearly 50% of respondents had had to use holiday allowance in order to deal with their RA (this could be several days when the disease is flaring or time required to attend hospital/medical appointments). People with long-term conditions need their annual leave equally as much, if not more than, healthy people, and to have reduced annual leave may add to the stress of managing the disease in the workplace, as well as impacting on family life. Nearly 55% felt unable to attend training days or meetings and over 37% felt unable to seek or accept promotion, thus limiting their career progression and potential future earnings.

Help and advice received about work since diagnosis

Less than 30% of working participants had received help or advice from an Occupational Health Advisor, which may reflect the lack of awareness of such health professionals and/or their availability across the UK. A very recent article in the British Medical Journal on this subject posited the argument that "integration of the clinical specialty of occupational health into the NHS is long overdue" and something for which the "UK economy, workforce, and healthcare system cannot afford to wait".

In June 2015 research was published on employer readiness to adopt the Department of Work and Pension’s (DWP) new Fit for Work occupational health service. Research was commissioned through YouGov to check awareness and engagement levels amongst both employers and General Practitioners (GPs). Worryingly, more than 75% of employers and 60% of GPs were not aware (at that time) of the DWP’s Fit for Work service, which provides free occupational health information and assessments. Even fewer are aware that the DWP scheme also allows tax relief up to £500 of medical treatment per employee each year.

“Despite reducing my hours of work, it proved difficult to arrange medical appointments outside of working hours. Three years after my diagnosis, my job was made redundant. I fear that this was due to the combination of missed work for medical appointments as well as substantial periods of sick leave.”
Case Study 1

Fiona, 31

Background
At the time of my rheumatoid arthritis diagnosis approximately 5 years ago, I was working as an outpatient musculoskeletal physiotherapist for two days a week, 48 weeks of the year, whilst raising my young children. The nature of my job combined with my condition meant that my joints could not cope with the regular joint pressures needed in my role. My employer was not very supportive and did not make attempts to facilitate changes in my workplace to help me continue with my job.

Job change
Faced with such extreme challenges, it seemed inevitable that I would have to leave my job. By chance, and very fortunately, a colleague who performed a different role was leaving, and I took the opportunity to take over that role. My employer helped me retrain for the role, however remained largely unsupportive in the workplace.

For family reasons, I then moved jobs. I told my new employer about my condition after being offered the role. They were immediately far more supportive, sending me to Occupational Health and facilitating me to work in conditions that were suitable for me.

Support from employer
Due to my RA symptoms, especially the fatigue that is a result of the disease, I found it difficult to work the same hours as I had previously. Despite compromises at home, such as hiring a cleaner and my husband working reduced hours, I requested a reduction of hours at work. My employer was very helpful, as they made it clear they valued me and wanted me to stay with them. They facilitated me working reduced hours and having a work pattern that gave me a week off every 7-8 weeks, working 32 weeks a year.

This proved to be very important as, coming up to the week break, the fatigue increased substantially which would result in a flare. The week break is vital for me to be able to continue working permanently. By doing this, I have been able to stay at work and in the career that I trained to do.

Summary
Although I have had a positive experience with my current employer, I feel that the disease has meant that I am unable to leave my job, as I know that other workplaces do not facilitate people with long-term conditions as well as my current employer. The disease has also affected my career progression, as I feel like I could and would have progressed further had I not been diagnosed with RA.
Changes to working conditions

A high proportion (41.5%) of participants mentioned that they had changed their job/role since the onset of RA. An overview of reasons is shown in Figure 14 (people could tick more than one reason). The main reasons for changing job was their RA, especially due to pain and fatigue, as well as the job becoming too demanding. For those who changed jobs, 49% stated that their current job was less demanding, 35% said the physical demands were the same and 13% had a more physically demanding job (2.5% didn’t know). 34% had a higher skilled job now and 19% a lower skilled job, meaning that changing jobs certainly does not mean that it will always be a lower skilled job, although for 50% it meant that there was a decrease in salary, either by moving to a different sector or reducing number of hours. A diagnosis with a debilitating disease like RA coupled with a change in job and reduction in salary can have a severely negative effect on an individual’s life and impact the whole family unit (financial security was top of the list of the main five most reported advantages to remaining in work). It is therefore crucial for employers to understand the nature of the disease and know how to reduce demand and make reasonable adjustments with appropriate support for someone who has been newly diagnosed in order for them to continue in their current role.

"There are lots of demands on my time physically and mentally, and this causes fatigue which is my biggest challenge"

Figure 14: Main reasons for changing job (%) (Respondents could tick all that applied)
Case Study 2

Pippa, 37

Background
I am a single parent of two young children. Prior to my diagnosis of rheumatoid arthritis, I was working full-time as a Health and Safety Officer, which involved both desk work and visits to building sites. Following my diagnosis in 2007, the pain and fatigue forced me into reducing my hours to part-time work. This enabled me to manage my condition and I hoped would also limit the effect of continual medical appointments on my employer’s perception of me.

Although my employer seemed supportive initially, it was clear that there was no understanding about rheumatoid arthritis. Unfortunately, a letter from my rheumatology nurse to my employer seemed to be taken the wrong way, and caused negative reactions towards me and my disease in the workplace. I did not receive any other additional support from my rheumatology team.

Job loss
Despite reducing my hours of work, it proved difficult to arrange medical appointments outside of working hours. Three years after my diagnosis, my job was made redundant. I fear that this was due to the combination of missed work for medical appointments as well as substantial periods of sick leave. I had to re-apply for my own job, which was re-created as a full-time position once again; it was made clear that my employer would not consider hiring another part-time person as part of a job share. I was therefore forced to accept redundancy.

Search for work
I have always been and remain keen to work. After accepting redundancy from my previous employer, I have stumbled from one temporary position to another during periods in which I am fit and well enough to work. These are all low-paid administrative jobs, unlike my previous permanent position. The benefits of temporary work are that I can choose to stop working when I am unwell at short notice, and I am treated as a more casual employee. However, these very minor benefits in no way outweigh the benefits of permanent employment.

My experience has resulted in a CV which has large gaps, meaning that finding permanent work has become increasingly difficult to find.

Summary
The nature of my condition has led me to having to live on credit cards, overdrafts and rapidly diminishing savings. I still have a strong desire of returning to a permanent job, despite the bad experience that I had in my previous workplace.
People no longer in employment

Of those who had stopped working due to their RA (over 15% of respondents), nearly 42% had had to stop due to their RA and nearly 33% retired early due to their RA. This compares favourably to the NRAS survey in 2007 when nearly 30% of participants had stopped work early and might indicate that people are being treated more effectively amongst other possible factors. Having to stop work or retire earlier than anticipated can have a major impact on family income and pension prospects. Little research has been undertaken on the impact of pension entitlement for people with long-term conditions, who have had to either reduce their hours or stop work early, despite the impact that this can have on the individual, their family, wider society and the economy; this is therefore an area that requires further research.

Pain and fatigue are the most common symptoms stated which cause barriers to employment, which has not changed since 2007. An inability to carry out duties due to physical limitations (61.4%) and fatigue affecting ability to work (63.5%) were cited by people who had left work due to their RA.

Worryingly, of those who had had to give up work early due to their RA, >15% said that their employer wanted them to leave their job once they were aware of the fact that they had a long-term condition. In the NRAS survey of 2007, this figure was 13%, which shows that not much has changed since the introduction of the Equality Act 2010 in this respect.

60% of people had stopped working more than 5 years earlier than they had anticipated if they had not been diagnosed, with findings showing that there was an overall estimated loss of earnings per year of more than £20,000 for the majority of those who stopped working. (Table 2)
Figure 17: Years stopped working earlier than expected (%)

Table 2: Estimated loss of earnings relating to Figure 17

<table>
<thead>
<tr>
<th>£</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 10,000</td>
<td>23</td>
<td>7.2</td>
</tr>
<tr>
<td>10,000 - 20,000</td>
<td>117</td>
<td>36.6</td>
</tr>
<tr>
<td>21,000 - 30,000</td>
<td>61</td>
<td>19.0</td>
</tr>
<tr>
<td>31,000 - 40,000</td>
<td>21</td>
<td>6.5</td>
</tr>
<tr>
<td>41,000 - 50,000</td>
<td>15</td>
<td>4.7</td>
</tr>
<tr>
<td>&gt; 50,000</td>
<td>37</td>
<td>11.5</td>
</tr>
<tr>
<td>Don’t know</td>
<td>35</td>
<td>10.9</td>
</tr>
<tr>
<td>NA</td>
<td>12</td>
<td>3.7</td>
</tr>
</tbody>
</table>

Less than 50% of those not working were offered changes to their working environment in their last job (n=127, 43.5%), including flexible working, working fewer hours or being provided with special equipment (Figure 18), indicating that it is necessary to raise awareness amongst employers of their duties and responsibilities under the Equality Act 2010.

Figure 18: Changes offered in working environment (participants could tick all that applied) (%)

"The company will only reduce working hours when the work is quiet, not to aid employees"
Approximately two-thirds of respondents were offered some help or given advice about their work in their last job. Most participants received some help from an occupational therapist or an occupational health advisor, and many had also read the NRAS publication about employment.

Figure 19: Received help/advice about work (%)

“After being offered the role, [my new employer] was immediately far more supportive, sending me to Occupational Health and facilitating me to work in conditions that were suitable for me.”
Return to work

Of the respondents not working (n=304), approximately one-third said they would be willing to return to work if they could find a suitable job that would accommodate their RA (18% full-time, 67% part-time and 16% either part-time or full-time) (Table 3).

<table>
<thead>
<tr>
<th>Return to work</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, full time</td>
<td>20</td>
<td>6.6</td>
</tr>
<tr>
<td>Yes, part time</td>
<td>76</td>
<td>36.6</td>
</tr>
<tr>
<td>Yes, either full time or part time</td>
<td>18</td>
<td>5.9</td>
</tr>
<tr>
<td>No</td>
<td>68</td>
<td>22.4</td>
</tr>
<tr>
<td>Not relevant, reached retirement age</td>
<td>95</td>
<td>31.3</td>
</tr>
<tr>
<td>Don’t know</td>
<td>27</td>
<td>8.9</td>
</tr>
</tbody>
</table>

A total of 60 participants (19.7%) mentioned that they had attempted to regain employment including those who had to retire early. This is higher than found in previous research and shows that more people have a desire to return to work whilst managing their long-term condition.

When applying for a job, two-thirds (66.7%) of people declare that they have RA, 25% sometimes do and 8.3% never do so. Of the 60 respondents willing to return to work, 31.7% said they needed assistance to return to work. To date, they had received assistance in at least one of the following: work programme (10.5%), job seekers allowance (26.3%), job centre (31.6%), professional advice (15.8%), and job training (5.3%). However, most people stated that they would have liked to have had some advice or help when seeking a new job.
When asked about the three main obstacles to returning to work, the three main reasons reported were having a flare, side effects and having applied for a job but been unsuccessful (Figure 21).

**Figure 21: Obstacles to regain work**
(Respondents had to tick the three main obstacles)

To accept a future job, most people trying to regain employment would like to have some flexibility in organising their tasks, control over pace of work and ability to make workplace adaptations.

**Figure 22: Minimum requirements to accept job (%)**

**Impacts of work and RA outside of the workplace**

Participants were asked whether the disease was impacting on aspects of their lives outside of work due to work. 63% of respondents stated that their social activities had been negatively impacted, which is an increase from 47% a decade ago. Other large increases from 2007 were an impact on family/partner relationships, 26% in 2007 to 49% this time, and impact on friendships, from 16% to 31%, demonstrating that working with RA is negatively affecting many people’s social lives. In 2007, 27% of respondents stated that the combination of the disease and working was impacting on their financial health. This year’s survey showed only a small increase to 30.6%, however this figure of almost one third of people stating that their finances are impacted by their disease remains a significant concern.
Conclusions – Section 1, RA

By comparison to the 2007 NRAS survey, fewer people seem to be losing their job or having to retire early due to their disease, which is an improvement on our 2007 survey. Whilst we cannot be certain about the reasons, it seems reasonable to suggest that this may, partly at least, be due to greater numbers of people whose disease is better controlled as a result of treat-to-target approaches, maximising disease activity control and use of biologics where disease is moderate to severe and cannot be controlled on standard therapy.

However, in spite of this apparent improvement, the survey revealed that for many, if the demands of the job became more physically, emotionally or generally demanding, they would not be able to continue in the job. People also indicated that they had to take annual leave in order to deal with flares and medical appointments. This demonstrates a level of fragility about employment for many people with RA/ JIA which can contribute to a consistent level of background anxiety, which can impact on physical and mental wellbeing. Added to this, employees (including those currently on sick leave) rated their performance at work ‘worse’ than prior to diagnosis which is also likely to increase stress levels.

There is no question that the attitude of employers and, in particular, line managers, can make an enormous difference (positive or negative) to an employee with a long-term condition like RA or adult JIA. Barriers to and the challenges of remaining in work were very similar to those in the 2007 survey. However, worryingly, the figures relating to employers who did not understand the disease at all have increased since the 2007 survey. The majority of people in the UK are employed by Small to Medium-sized Enterprises (SMEs), who are less likely to have internal HR departments or necessarily be up-to-date with current employment legislation and the requirements of the Equality Act 2010 as larger and corporate organisations.

In regard to co-morbidities reported, treated anxiety and depression were of similar levels to other research in this area. For some time, there has been a desire from many across the political spectrum to grant parity of esteem to mental health. This survey demonstrates that many people with RA also suffer from depression and anxiety. Combined with data from Public Health England showing that mental health issues and musculoskeletal conditions are the two highest causes of lost work days in the country, a high priority must be afforded to addressing these issues through combined approaches (health service, employers, social care), in order to reduce the number of lost working days. Parity of esteem for mental health should help this, however it is vitally important that musculoskeletal conditions are not overlooked in the process.

High blood pressure was another co-morbidity which was frequently mentioned. High blood pressure, if left untreated, can lead to heart disease and people with RA have the same increased risk of cardiovascular disease as those with Type 2 Diabetes. NRAS has highlighted this as a priority amongst its current work and has developed ‘Love Your Heart’, an on-line programme to raise awareness of and educate about the increased risk and impact of heart disease for people with RA. The interactive programme (launch autumn 2017) will enable participants to identify their own personal risks and set goals to mitigate such risks.

In regard to benefits, whilst relatively low numbers of people who participated in this survey were receiving benefits, the most frequently cited were Blue Badge, DLA and PIP. This correlates with calls to the NRAS helpline. In recent times, NRAS has seen an increase in calls and emails regarding people facing re-assessment as they transition from DLA to PIP. Many callers were extremely upset, having previously received the higher mobility component under DLA, to find that this was not the case when re-assessed for PIP and consequently lost their Motability vehicle, taking away their independence and ability to remain in work. It was clear from the survey that those who receive these benefits find that they are extremely important enablers to remaining at work.

As in the previous survey, it was unsurprising to find that having to work part-time or losing work/retiring early impacted negatively on finances and financial security. The impact on family and social life was also similar between surveys. One of the things that NRAS frequently hears from people with RA who are working is that so much effort and energy goes into ‘keeping working’, that there is little left over for family activities, socialising or for valued activities and hobbies.

In conclusion, whilst there are some differences, not a huge amount has changed between 2007 and 2017 when it comes to the impact that RA has on working life. Much more needs to be done by employers to support employees with RA and adult JIA to remain in the workplace (or get back to work). Employers need to understand that intervening at an early stage to create a flexible and supportive working environment, before things get to a crisis point for their employee, will be beneficial for both parties. Employees need access to a range of resources to inform them about their rights in the workplace and to feel supported and empowered to ask for reasonable changes and adaptations. Health professionals also need to do more to ensure that work is routinely considered as an important health outcome and services need to be responsive to people getting access to prompt help when disease flares to minimise presenteeism (identified as an issue in this survey) and absenteeism for this reason.
In the area of welfare to work, the ambitious aim of the Government is to halve the disability employment gap by 2020, which requires it to find jobs for about 1.2 million people with disabilities or long-term illnesses. This means it will need to provide a range of different types of help for people to get back into work. It is harder to get someone with a long-term condition back to work once they have lost their job than it is to prevent them from losing their job in the first place. As a member of the Expert Advisory Group to the Work and Health Unit, NRAS is aware of the amount of current work by the Government, following the consultation on the Green Paper earlier in the year, to address the challenge of getting such people back into employment. The 2017 NRAS survey had a greater focus on job retention for people with RA and adult JIA and it is with this in mind that the following recommendations are made, which NRAS and the University of Manchester believe will also help those with RA/JIA who want to, and are able to, get back to work, to do so.

- **Government should incentivise employers to incorporate training of workforce, particularly line managers, in how to support employees with long-term conditions/disabilities and ensure this is included in all new employee induction processes. The emphasis should be on providing early support to prevent employees getting to a crisis point where job loss or reduction of hours is more likely or inevitable.**

- **Greater awareness is needed about the DWP 'Fit-for-Work' Occupational Health Service and its provisions. All relevant stakeholders have a responsibility to raise awareness of this service and NRAS will ensure that all the charity’s resources include information and sign-posting to it where appropriate.**

- **Provision should be made for people with RA (and other long-term conditions) to be able to (easily) access free, tailored financial advice about future financial planning relating to retirement and old-age. Pensions are clearly impacted in circumstances where reduction in hours or leaving work early is the only answer for health reasons (potentially adding to the burden of anxiety) and NRAS will commit to undertaking further research in this area in order to understand the detailed needs of people with RA who have to stop work early due to their disease.**

- **People with RA clearly need access to good quality, accurate information about their rights in the workplace when they develop the condition and to be able to sign-post their line manager/employer to reliable sources of support and help. NRAS will develop further resources for publication in 2018 in response to this need.**
Results – Section 2
Adults with Juvenile Idiopathic Arthritis

The number of adults with JIA in the UK is unknown, with many people often being diagnosed as having RA in adulthood although symptoms began before the age of 16. A diagnosis of JIA as a child or young person under the age of 16 remains throughout your life, even if you take the disease into adulthood (about 50%). In the recent past such ‘re-diagnosis’ was due to NICE guidance relating to access to biologics. However, recent NICE guidance in JIA obviates the need for this practice to continue. There is relatively little data available on the impact that having JIA as a child/young person has on career prospects and subsequent entry into the adult workplace. Whilst the numbers of adult JIA respondents in this survey were relatively low, this data represents a valuable contribution to a knowledge base in this arena and paves the way for more detailed research in future.

Survey results
19 respondents reported having JIA between 16 and 30 years of age. The majority of these respondents were female (89.47%).

School and career plans
64.71% of respondents stated that their JIA had affected their school results. The most commonly reported reason for this was ‘difficulties to focus’ (42.11%), followed by ‘difficulties with writing’ (31.58%) and ‘time missed due to illness (e.g. your JIA)’ (31.58%). An impact on school results may mean a young person is unable to realise their ambitions and expected achievements, leading to disadvantages in finding a job or progressing along a career path.

Respondents were asked about the school they attended and if their school provided work-related experiences. Figure 23 shows the percentage of those who answered this question. The majority of people said work experiences were offered to pupils under 16 only (47.06%). In addition, participants were also asked if their school offered additional work-related activities to students with disabilities and/or special educational needs. Just over half of those who answered this question said their school did not offer such activities (52.94%). Participants indicated how much they agreed or disagreed with a number of statements relating to work experience support and advice they received from their school. 14 people completed this question (Figure 24). Answers varied across all statements however, over 70% of respondents felt their school did not provide advice about limitations they might face on a work-related placement or traineeship, due to their JIA. This is probably not surprising as our experience is that schools do not understand enough about JIA or the needs of those children and young people who live with it.

Figure 23: School provided work-related experiences (%)

<table>
<thead>
<tr>
<th></th>
<th>Under 16 only</th>
<th>Over 16 only</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>47.06</td>
<td>17.65</td>
<td>35.29</td>
</tr>
</tbody>
</table>

Figure 24: Work experience support and advice (%)

- My school provided advice about possible limitations about some placements/traineeships due to my arthritis
- My work experience placement/traineeship was easily accessible or near home
- My school identified placements that stretched/challenged my view of work
- My school matched my placement/traineeship based on my studies subjects
- My school encouraged me to try any work despite possible physical limitations due to my arthritis
- My school looked at my strengths and matched these skills with an employer willing to take on these skills
- My school offered a placement which matched my career ambitions

- **Strongly agree**
- **Agree**
- **Neither agree or disagree**
- **Disagree**
- **Strongly disagree**
- **Don’t know**
Further to this, 57.14% said their JIA was not taken into account when discussing career choices at school or university with an advisor.

The results indicate that a high proportion of respondents did think about their condition when considering their future career (78.57%).

**Career change/compromise**

8 out of 14 respondents said they had changed/compromised their career plans because of their JIA (57.14%). Many reasons were given and the top three most common were:

- Wanting to stay healthy
- Symptoms of JIA such as sore joints and fatigue
- Career path/role physically too demanding

Other comments related to the lack of advice given in the early stages of career planning and the lack of self-confidence. Some quotes from respondents are included in Figure 25.

**Figure 25: Reasons for changing/compromising career plans because of JIA**

"A compromise between comfort, maintaining good health while doing what I wanted to do."

"I had to cease my physiotherapy master’s degree as my arthritis got too bad to continue and change career choice. I wish there would have been more discussion about it not being a reasonable choice for me at the time as we just didn’t have the information then."

" Wanted to work as a ranger or similar for the National Trust but fairly physically demanding job and I knew my joints would suffer so changed track slightly."

"I wanted to become a medical doctor, but the fatigue I experienced meant I couldn’t put in the extra hours needed to get a sufficient grade in AS Chemistry to apply. I considered post-graduate medicine, but felt that my fatigue, problems with mobility, and pain would impair my ability as a doctor. I didn’t lack confidence in my academic abilities or patient skills (I am currently doing a clinical PhD), but it was my lack of confidence in my physical abilities that stopped me from applying. I think I will always regret that."
Paid employment

9 people reported being in paid employment, the majority of whom had been in employment for 5-10 years since leaving school (77.77%). Figure 26 shows the level of importance of specific aspects of work. All respondents reported the importance of work you like doing, a job where you can use your initiative and having good relations with your supervisor or line manager.

Figure 26: Important aspects of first job (%)

- Friendly people to work with
- A lot of variety in the type of work
- Good mental conditions
- Good physical working conditions
- Good training provision
- An easy work load
- Good fringe benefits
- The opportunity to use your abilities
- Choice in your hours of work
- Convenient hours of work
- Work you like doing
- A job where you can use your initiative
- A secure job
- Good relations with your supervisor or manager
- Good pay
- Good promotion prospects

Legend:
- Very important
- Important
- Neither important nor unimportant
- Unimportant
There is little epidemiological data available on the number of adults living with JIA in the UK, where the disease has either continued into adulthood or reappeared in adulthood following a period of remission, and the impact of their JIA on work. Whilst much of the section on conclusions in RA is similar and can be applied to adults with JIA, there are some distinct differences given that JIA starts in childhood and impacts education.

We appreciate that the number of participants in this survey who declared that they had JIA, as distinct from RA, was small (19). However, this data provides an insight into the issues which affect how disease has impacted their ability to transition successfully into adult working life which requires further research.

It’s clear that living with JIA has a significant impact on education. Missing school due to periods of disease flare and inability to focus or write easily when at school, impacts results (of exams and assessments) which can lead to stress for the child or young person which, in turn, can disrupt normal family life and relationships.

It was clear from the majority of those who answered the question, that many schools do not provide structured support and advice, including careers’ advice, for pupils with a long-term condition or special educational needs.

When it came to changing or compromising career choices or plans due to their JIA, the majority of participants who had answered the question, said the key reasons included managing symptoms and the physical demand of the job. We know from our close working relationships with paediatric and adult rheumatology teams across the UK that today, children and young people with JIA are encouraged to strive to achieve whatever their desired ambitions may be. The high proportion demonstrating that compromise was necessary may be an indication of the fact that when they were diagnosed years ago, treatment and drug therapy was less advanced than it is today.

Lack of confidence was cited as a factor in determining career choice. It was therefore unsurprising to see that of those who had been in employment for a number of years since leaving school, the aspects they felt were of key importance in a first job included doing work you ‘like doing’; ‘a job where you can use your initiative’; and ‘having good relations with your supervisor or line manager’.

This survey has provided a huge amount of new data and given both NRAS and its partners, the University of Manchester, a platform for further research into specific areas. This report could have generated a very long list of recommendations, however, the editors have tried to keep these to a minimum in order to focus on the key areas we can contribute to and influence the most.
Recommendations: Adult JIA

The recommendations from Section 2 apply equally to adults with JIA, however, more needs to be done to raise awareness of JIA in the educational environment so that when young people transition into the workplace they are not disadvantaged in the way participants in this survey have described. Schools are legally obliged to ensure that all children with health needs are properly supported, and schools, local authorities, health professionals and other support services are advised to work together to ensure that children with medical conditions receive a full education which should include support for planning their future. NRAS has already developed a publication for parents and teachers entitled ‘Managing JIA in School’ which was recently highly commended in the British Medical Association patient information Awards.

As an active member of the Health Conditions in Schools Alliance (HCSA), NRAS will:

- Address the issues raised in this survey with the HCSA and with relevant health professional associations such as the British Society for Paediatric and Adolescent Rheumatology.
- Continue to advocate for access to best evidence-based care for all children, young people and adults with JIA (so that potential for disability is minimised).
- Continue to raise awareness of JIA and the challenges young adults face with government and relevant government organisations.
- Undertake further research regarding the specific needs of young people with JIA entering the workplace.
- Provide additional resources for young people, parents and schools to support good transition from education to the workplace, including accessing suitable further education.
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Work Matters

A UK wide survey of adults with Rheumatoid Arthritis and Juvenile Idiopathic Arthritis on the impact of their disease on work

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