Who Cares?

A report on the health and perceived social care needs of people living with rheumatoid arthritis in Scotland
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1.1 Foreword

by Prof Iain B McInnes
FRCP, PhD, FRSE, FMedSci
Muirhead Professor of Medicine and ARUK Professor of Rheumatology
Director
Institute of Infection, Immunity and Inflammation,
College of Medical, Veterinary and Life Sciences,
University of Glasgow

I am delighted to accept NRAS’ invitation to write a brief foreword for this vital report. Rheumatoid Arthritis (RA) is one of the major chronic diseases in Scotland; the number of adults affected by RA in Scotland is expected to rise from 37,539 in 2010 to 42,505 by 2020. The wider impact of RA will affect in consequence many more family, friends and work colleagues.

RA is a disease that is primarily treated in secondary care. There have been many government and health service drivers in recent years to integrate services more widely across acute, community, primary and social care. Thus far there is little evidence that pathways and collaborative working across boundaries are being successfully implemented by sufficient numbers of Health Boards across the country. In Scotland, the Public Bodies (Joint Working) (Scotland) Act 2014 which covers the integration of health and social care across the whole of Scotland, determined by each region’s Health Board and Local Authority, has required local authorities to draw up plans for integrating services from this year. With typical foresight, Ailsa has highlighted this in her executive summary. We must hope that this will provide a greater incentive for services to collaborate in times to come.

It is encouraging to see the voluntary sector collaborating with academia. It is self evident that the huge experience and knowledge of those who live with the disease and understand the support required to improve outcomes, can mightily complement the rigour of academic research and analysis provided by colleagues from the University of Aberdeen.

This survey provides new insight into key areas which impact on an individual’s ability to cope with their disease. Note for example the prevalence of co-morbidities; depression is cited more frequently than any other condition (over and above their RA) at just over 30% of participants. It also highlights the enormous contribution that the families and friends of those living with RA make by the provision of ‘informal care’ which in turn ‘protects government support spending to significant extent.

The impact on work is also highlighted by those participants who were in paid employment completing the Work Productivity and Activity Impairment Questionnaire: Specific Health Problem instrument which indicated that over 40% experience presenteeism, which is work productivity impairment due to their RA. We must do more to support our patients to remain in work. One of the simple ways that we, as clinicians, can do this is to ask about work at an early stage in the diagnostic process and direct people to NRAS for support.

The message is not all discouragement. Far from it! It is heartening to see that when adherence to medication was explored through a series of questions from the Compliance Questionnaire for Rheumatology, a high level of adherence was observed across RA medication types.

I wholeheartedly support the recommendations in this report and look forward to working with NRAS to encourage their adoption and implementation.
1.2 Executive Summary

by Ailsa Bosworth
MBE, Founder and CEO of NRAS

In light of the imperative to integrate health and social care across the UK, NRAS conducted this survey to gain greater understanding of the wider care and support needs of people with rheumatoid arthritis (RA) in Scotland, and the factors which contribute to them. Whilst NRAS has a very good understanding of the health needs of people with RA, and the healthcare system in Scotland, much less is known about their wider care and support needs and how well these are being met. Also the commitment to take forward the Smith Commission Agreement represents an extensive package of new powers in welfare for both the Scottish Parliament and the Scottish Government which will be relevant in the context of this work.

Recent legislation in both England and Scotland has made significant changes to how social care is delivered. Within Scotland, the Public Bodies (Joint Working) (Scotland) Act has required local authorities to draw up plans for integrating services from this year. Additionally, the Self Directed Support Act has given people a legal right to an independent budget and now allows people to make informed choices about how their support is provided to them.

In addition to the severity and types of social care needs, we also probed the factors which contribute to their development, in particular the prevalence of co-morbidities, impact of relative deprivation, educational attainment and levels of medicines non-adherence. We also explored the impact of RA on work using a validated measure, to gauge levels of presenteeism and absenteeism for those who were in paid employment.

NRAS is aware that the above factors can exacerbate the severity of a person’s RA, and so therefore increase their support needs. NRAS has found that up to 80% of people with RA within the UK have at least one co-morbidity, whilst treatment adherence is estimated to be low in RA patients, varying from 30-80%.

NRAS would like to understand how these factors interplay in shaping care and support needs amongst the RA population in Scotland, and how these needs are met.

At the end of 2015, NRAS undertook a brief survey of our membership in England to try and find out more about their care and support needs. This proved to be very useful as we expand our work in this policy area. Our survey across Scotland has been a much deeper dive into the drivers of social care need and we are delighted to have partnered with the University of Aberdeen in this exercise and would like to thank, in particular, Dr Kathryn Martin who has been the principal author of this report. The data provided through this survey will also provide further research opportunities for our friends at Aberdeen and additional collaboration in future, which we welcome.

NRAS will utilise the findings of this study to shape our lobbying work and provide an up to date evidence base to continue our call for access to better health and social care services in Scotland for people with Rheumatoid Arthritis, as well as to identify new areas for social research into inflammatory arthritis. Our recommendations can be found on page 48 of this report.
1.3 Background and aim

Background

Rheumatoid arthritis (RA) is a systemic, chronic inflammatory disease. It affects the synovial membrane of the joints and commonly presents with pain, joint swelling/stiffness and fatigue. Due to the systemic nature of the disease, it can also affect other organs, such as heart, lungs and eyes. RA is approximately three times more common among women than men. It can affect adults of any age yet is most common among those between the ages of 40 and 60 years. In the UK population 1% of the population (approximately 690,000 people), have RA. In Scotland, estimates suggest that nearly 60,000 people have RA, and that just over 2,500 people are newly diagnosed each year.

Treatment and Medication Non-adherence

A variety of strategies are used to treat RA and related symptoms. Treatment and care is usually highly individualised and modified during the disease-course. The NHS spends an estimated £560 million each year on direct RA-related treatment costs.

The majority of individuals with RA take medication to reduce pain and inflammation and a disease modifying antirheumatic drug (DMARD) or combination of DMARDs with Methotrexate being the anchor DMARD, to slow progression of the disease and prevent irreversible joint damage. Bridging steroids at diagnosis to control symptoms whilst DMARDs take effect are also often given and by intramuscular injection periodically to control flares. Disease modifying antirheumatic biological and biosimilar drugs are the next step for the majority of those for whom standard DMARD therapy fails. Inevitably some people can experience side effects from some of the drugs, such as headaches, and nausea, however, such issues can usually be successfully addressed in different ways. It’s also important for people to be aware that drugs which dampen down the immune system, raise the possibility of increased risk of infections. Surgery may be an option for those with severe joint damage. Attention to lifestyle activities, such as maintaining a balanced and healthy diet, getting exercise, practising good joint care and stress reduction are all important components of self-management which can help to improve outcomes.

Among those with RA, medication adherence has been found to range from 30 to 80%. It is often higher among patients when the treatment makes sense to them or when it is perceived as being effective. In addition, medication adherence is better in those who believe the benefits outweigh any cost or risk, be it financial, physical or emotional. Individuals who are confident they have the ability to successfully take medicines as prescribed also have higher adherence. Non-adherence in this population has been associated with poor patient-provider relationships and medication cost. Non-adherence is an important issue, as it can be the cause of increased disease activity, flares, joint damage progression, as well as increased pain and stiffness in those with RA, ultimately resulting in poorer long term outcomes.

Comorbidity

The individual burden of RA is significant and is added to by health issues that arise as a cause and consequence of the disease. Comorbidities, that is to say coexisting diseases or medical conditions, are common among individuals living with RA. It is not unusual for many individuals with RA to have at least one comorbidity from early diagnosis and to acquire more over time. While reports of comorbid conditions vary across different study populations, individuals with RA are at greater risk of systemic comorbidities such as cardiovascular disease, osteoporosis, respiratory disease and cancer. In addition, depression is a frequently reported comorbidity in this patient group, as well as issues around fatigue and cognitive dysfunction.

Functional and Work Limitations

Functional limitations can arise as a result of structural changes or pain, medication non-adherence and comorbid conditions. As a result, individuals with RA, particularly those who are older, may have problems with activities of daily living, including washing, getting dressed, and moving about. In addition to functional limitations, RA symptoms can also have a negative effect on health related quality of life and contribute to depression and anxiety. This further impacts on an individual’s ability to perform everyday tasks and take part in social and work activities.

Indeed, people with RA commonly experience low productivity and work limitations. A study examining work disability across 32 countries, including 16 EU member states found that, among 8,000 RA patients, 37% of work disability was due to their RA. Many may need to reduce their working hours or leave employment altogether because of RA-related symptoms and disability. It has been estimated that approximately 75% of the economic cost of RA can be attributed to work disability. Overall, RA-related sick leave and work-related disability add another £1.8 billion a year to the cost of our economy.
Social Care

Social care aims to enable an individual to maintain independence and a good quality of life. It is a broad term that includes support that comes from family members, friends, local authorities or private sources. It encompasses a range of services which include personal care, transportation and occupational therapy. Care delivery which includes multidisciplinary teams of health and social care professionals working together can provide individuals with RA access to essential services and support (e.g. personal care, medication education, rehabilitation after surgery) to compliment self-management activities so as to reduce the daily burden of RA. Functional limitations, work disability, and non-adherence to medications may be improved by supporting individuals to better self-manage their RA and comorbid condition(s).

NRAS has previously produced a briefing paper investigating the types of social care services people with RA living in England access, their satisfaction with services, and areas where improvements could be made. However, as social care is a devolved matter in Scotland, NRAS wished to take a country-specific focus. Recent legislation in Scotland, the Public Bodies (Joint Working) (Scotland) Act has required local authorities to begin integrating services as of 1 April 2016. Additionally, the Self Directed Support Act has given people a legal right to an independent budget and now allows people to make informed choices about how their support is provided to them.

Regardless of disease condition, individuals in Scotland may be eligible for social care after receiving a needs assessment. Adults over the age of 65 are typically eligible for free personal care (e.g., services supporting personal hygiene, continence, immobility inside/outside) if they have been assessed as having substantial or critical personal care needs. Necessary aids and devices (e.g. hand rails, shower seats, Zimmer frames) may also be provided free of charge by local authorities after a needs assessment, however individuals are expected to contribute towards non-personal care services (e.g. help with housework, laundry, shopping, day care, meals on wheels) after a financial assessment.

Personal care is not automatically free for those under 65 and additional non-personal care service costs are also charged for based on the outcome of a financial assessment. Many individuals with RA, particularly those who are younger, may have only moderate care needs thus making them not eligible for services. Others may be working and assessed above the financial threshold, making personal contributions to care a considerable burden. Such scenarios are the likely result of a number of innovative medicines and advanced RA treatment regimens, such as biologics therapy (and biosimilars) available and being embraced since 2000. Most of those newly diagnosed today will have a very different disease and care-need trajectory than those diagnosed 20 or more years ago, when RA was treated differently and with less sophisticated medicines. Despite the fact that social care needs may be varied at differing stages, it is imperative that all individuals with RA are well supported to have meaningful social engagement, work participation, and a high level of health-related quality of life.

Aim

The aim of this survey was to improve understanding of social care and support needs of people with RA in Scotland, the factors that contribute to them and how these needs are met. This is timely given the burden of musculoskeletal disorders is expected to grow in aging populations, and more specifically the numbers of individuals with RA in Scotland has been estimated to increase by 13% in the ten year period from 2010 to 2020. Most recently, assessments have focused on outpatient attendance, demands on rheumatology services and the benefits of early diagnosis and treatment. However identifying social care needs and priorities of individuals with RA in Scotland is exceedingly important as this knowledge can assist in policy planning and service development, as well as guide improvement in the delivery of health and social care services to those with RA.
1.4 Research Methodology

In 2014, NRAS carried out a small scale survey in England to find out more about people with RA and their social care needs. This survey was adapted, in collaboration with Research Resource, a research agency based in Glasgow and Dr Kathryn Martin (Epidemiologist, University of Aberdeen), to better suit a Scottish audience and to go into more depth in areas of particular interest.

Once the survey was agreed, Research Resource developed the online questionnaire using SNAP survey software and we conducted a pilot amongst our Scottish Ambassadors to sense check the survey. Modifications were made following feedback from the pilot and the final survey was uploaded and ‘live’ online from 11th November 2015 to 22nd January 2016. Three methods of recruiting potential participants were undertaken: 1) a link to the survey was distributed by email to the 820 contacts on the NRAS database who had a Scottish postcode, 412 of whom were known to have RA; 2) from mid-November, leaflets promoting the survey were distributed to rheumatology units in Scotland and we encouraged our healthcare professional contacts to pass these on to patients; and 3) the survey was promoted through NRAS social media channels and website. We also used a paid for Facebook advert targeted at people living in Scotland who liked or were friends with someone who liked pages related to rheumatoid arthritis.

The survey was accessed through the provided link and instructions indicated that the survey sought responses only from people with RA. Screening criteria were also applied so that only those that were aged over 16 years of age and had received a clinical diagnosis of RA were able to follow through and complete the survey. Overall, a total of 391 responses to the survey were received, however 4 of these respondents met the screening criteria but did not live in Scotland. The total number of eligible respondents was therefore 387.

Descriptive analyses were carried out using STATA v13.1 to examine available quantitative data (note: base number of respondents varies throughout the report, as respondents were allowed to skip questions they wished not to answer). Where appropriate, data is presented in percentages and averages, with further examination by sub-groups. Open text provided by respondents was thematically analysed and this qualitative data has been provided throughout to contextually reflect those respondents’ voices.
2

Respondent Sociodemographic Profile
2.1 Geographic profile

There were a total of 387 participants who took part in this survey. In terms of the geographical area in which respondents lived, as shown in the map below, responses were received from almost every Council area in Scotland, with the exception of the Shetland Isles. The greatest proportion of responses were received from Fife (n=38; 10%) and Aberdeenshire (n=33; 9%).

Note: Value given represents the total number of participants in each council area.
2.2 Age, Gender and Ethnicity

Of the 387 respondents, the majority (90%) indicated they were female. This is slightly higher than gender breakdowns in RA registries (drug or disease) in Europe and the US, where the percentage of women with RA ranges from 70% to 85%. 28,29

Respondents came from a spread of age groups with the greatest proportion (55%) being aged between 45 and 64 years of age. No one above the age of 85 took part in the survey.

Finally, of those providing information on ethnic origin (n=385) 96% of respondents were of White Scottish (80.8%) or White Other British (15.6%) ethnic origin.
2.3 Employment status

Almost half of the 326 respondents who answered this question (47%) said that they were either in paid employment or self-employed. A further 26% said they were retired and 23% (74) said sickness or disability meant they were unable to work (see Figure 3). The circumstances of those individuals in work are explored further in the Work and Productivity section on page 25.

The 74 respondents who were unable to work due to sickness or disability had an average of 5 comorbid conditions and 43 reported depression and anxiety.

FIGURE 3: EMPLOYMENT STATUS

Base: All respondents. n=326
2.4 Qualifications

In terms of qualifications, 37% had a Level 4 qualification or above, indicating a University degree or higher qualification.

FIGURE 4: HIGHEST EDUCATIONAL QUALIFICATION

Base: All respondents. n=314
2.5 Home ownership/rental status and Household composition

The majority of respondents (74%) own their home, whether owning it outright (39%) or buying it with a mortgage (35%). Almost a quarter (24%) said that they rent their home.

In terms of the household composition, one in five respondents (20%) stated that they lived on their own, versus the majority who lived with two or more people (45% two; 18% three; 18% four or more).

Almost half of 328 respondents to this question (42%) described their household composition as either a two parent (36%) or one parent (6%) family. However, 34% stated that their household composition was best described as a couple with no resident children and 22% described their household as a single adult household. A small percentage (3%) of respondents reported ‘other’ household composition arrangement, such as living with adult children, other family members or in a multi-generational household.
2.6 Income and Capital

One third of respondents stated that their approximate annual household income before tax was under £20,000, 27% indicated it was between £20,000 and less than £40,000 and 13% that it was between £40,000 and £60,000.
The majority of respondents (54%) stated that the approximate value of their total capital was below £23,000, while 34% indicated that they would rather not disclose this information.
Respondent Health Profile
3.1 Length of time since diagnosis with RA

Respondents were asked the length of time since their diagnosis. Approximately 17% of all respondents were diagnosed within the past two years, however the majority, 83%, reported well established RA (a diagnosis ≥two years ago).

Of those diagnosed less than two years, the majority (76%) were aged 35 to 64, whereas 10% were aged 15 to 34 and 13% were aged 65 to 84. This aligns with the most common age of onset, between 40-60.

Nearly all respondents (99%) indicated that they received treatment for their RA and a substantial proportion of respondents (88%) also indicated that their RA limited their daily activities.
3.2 Medication taken for RA

When asked which medications they currently take for their RA, 97% of all respondents reported taking some form of medication, either prescription or over-the-counter. The average number of medications taken by respondents for their RA was 3.2 (range 0 to 7), with 30% reporting taking 3 medications in total.

No correlation between length of time since RA diagnosis and the number of medications taken for RA was observed.

Paracetamol was most commonly used (61%), while methotrexate was the most used prescription drug (55%).

Of the 144 respondents indicating they take Naproxen or Diclofenac (anti-inflammatories), a quarter (24%) were not taking it in conjunction with stomach protection.

Furthermore, of 44 respondents indicating that they took oral steroids, only 20 (less than half) were taking bone protection.

In general, 155 respondents (40%) reported taking at least one form of steroid. Steroids are generally used at point of diagnosis as bridging medication whilst waiting for DMARDs to work and also in flares (intra-muscular injection) or when a particular joint is affected (intra-articular). It has been acknowledged that keeping people on oral steroids, even what might be considered a ‘low’ dose is not ideal due to the acknowledged adverse side effects.
3.3 RA-specific Medication Adherence

Respondents were asked a series of questions from the Compliance Questionnaire for Rheumatology30 to explore RA-specific medication adherence. Examples of questions include: ‘I take my anti-rheumatic medicines because I then have fewer problems’, ‘I take my medicines because I have complete confidence in my rheumatologist’, and ‘My medicines are always stored in the same place, and that’s why I don’t forget them’. Of the 319 participants who fully answered this set of questions, the majority – 74% – could be classified as ‘high adherers’31, and a high level of adherence was observed across prescription medication types. Of the 260 respondents reporting taking DMARDs, 188 were ‘high adherers’. Similar numbers of ‘high adherers’ were found among those taking biologics, (83 out of 113), and in those taking steroids, (101 out of 132). However, this still leaves 97% of those taking biologics who answered the question who were not high adherers and the cost of their medication is high and treatment is sub-optimal.

3.4 Self-report functional status (disability)

Respondents answered questions from the Health Assessment Questionnaire Disability Index (HAQ-DI)32,33 about the extent of their ability to engage in a variety of daily activities such as dressing and grooming, getting out of bed, eating, walking, hygiene, reach, grip and miscellaneous activities with or without any difficulty. They also indicated whether they typically used any aids or had help from another person to carry out these tasks. Scores for this instrument range from 0 to 3, with a higher score indicating severe functional disability.

In general, respondents’ functional ability was poor, with average score of 1.42 indicating overall moderate impairment in this population. The majority of 380 respondents, 94%, reported some impairment, whereas only the remaining 6% (21 respondents) reported full physical function (score of 0). This is in stark contrast to prevalence estimates found in the general population, where only one third (30%) have some functional impairment34 and estimated average score values were 0.25.

3.5 Self-reported comorbidities

Respondents were asked to indicate whether or not they had other health problems in addition to their RA by completing questions from the Self-Administered Comorbidity Questionnaire35. The average number of other health conditions was 2.8 among all 387 respondents, with the majority (78%) naming at least one other health problem in addition to their RA.

The most common health problems were:
- Depression (30%),
- Back pain (27%),
- High blood pressure (22%),
- Osteoarthritis (20%)
- Anxiety (19%).

Around one in ten respondents also reported lung disease (12%), digestive issues, including stomach ulcers (11%), anemia (11%), Sjogren’s Syndrome (10%), thyroid problems (9%), and osteoporosis (8%).
Overall, respondents with established RA had slightly higher number of comorbid conditions, 2.9, than those with early RA, 2.5.

Many people with long-term physical health conditions also have mental health problems such as depression and anxiety as can be seen from the above chart. These can lead to significantly poorer health outcomes and reduced quality of life. Costs to the health care system are also significant – by interacting with and exacerbating physical illness, co-morbid mental health problems raise total health care costs by at least 45 per cent for each person with a long-term condition and co-morbid mental health problem.
3.6 Self-Reported Pain and Self-Reported Health

Respondents were asked to quantify both the level of pain experienced in the past week, as well as their overall health status, using a standard numerical scale of 0 to 100. Figure 11 below depicts the average level of pain (ranging from 0: ‘No Pain’ to 100: ‘Severe Pain’) and global health status (from 0: ‘very well’ to 100: ‘very poor’).

Among 378 respondents, the average value of the pain assessment was 54, indicating a moderate presence and severity of pain. Only 3% reported a value of 0 for their pain assessment. Little difference was observed when examining levels of the pain experienced in the last week by length of time since diagnosis. Average pain scores for newly diagnosed respondents were 53, for mid-diagnosed they were 54, and for established RA they were 57. Individuals reporting taking pain medication (e.g. paracetamol or aspirin) had higher average pain scores than those not taking pain medication, 55 v 51 respectively.

Similarly, reports of global health status by 377 respondents indicated only a moderate sense of well-being, with the average value 52. Average health scores for newly diagnosed respondents were 51, for mid-diagnosed they were 53, and for established RA they were 51. Additionally, respondents’ health scores worsened, increasing by 3.3 points, for each additional comorbid condition reported.

![Figure 11: Self-Reported Pain and Self-Reported Health](image)
3.7 Respondent experience of the influence of RA on work productivity

Of the 326 respondents that provided information about current employment status, 174 (53%) reported not being in paid or self-employment. The majority, 69%, of these 174 respondents were of working age (20 to 64 years), 91% had established RA (2 or more years since diagnosis) and 44% reported being unable to work because of any sickness or disability.

There were 152 respondents (47%) who reported working for pay in the past week, and they were aged between 20 and 74 years. The majority of those working (73%) had established RA. We further used the Work Productivity and Activity Impairment Questionnaire: Specific Health Problem17 to explore issues of work in this population.

- The average hours worked over the last 7 days was 24.5.
- The average number of hours missed from work due to RA over the last 7 days was 4.9.
- The average hours missed from work due to other reasons was 2.7.

On average, absenteeism (work time missed) due to RA was 17.1% [Table 1]. Presenteeism (work productivity impairment) due to RA was a considerable 41.3%, and overall work impairment (combination of absenteeism and presenteeism) due to RA was 45.4%. The average non-work activity impairment (regular activities) due to RA, was also considerable at 51.3%.

### Table 1: Respondents’ experience of the influence of RA on work productivity

<table>
<thead>
<tr>
<th>Influence of Rheumatoid Arthritis on work productivity and non-work activity</th>
<th>Number of Respondents with Complete Data</th>
<th>Average %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Absenteeism (work time missed)</td>
<td>125</td>
<td>17.1</td>
</tr>
<tr>
<td>Presenteeism (impairment at work)</td>
<td>120</td>
<td>41.3</td>
</tr>
<tr>
<td>Overall work impairment (overall work productivity loss)</td>
<td>116</td>
<td>45.4</td>
</tr>
<tr>
<td>Activity impairment (productivity loss in regular activities)</td>
<td>151</td>
<td>51.3</td>
</tr>
</tbody>
</table>

The significant impact of RA on work productivity in this survey reflects similar findings from the Scottish work survey carried out by NRAS in 201018, where 18.5% respondents indicated they had to change occupations because of their RA, particularly due to physical limitations or fatigue. The survey also found that of those who left their job due to their RA, over half stated that they had stopped working within one year of diagnosis and 80% percent had stopped working within 6 years. Respondents in the 2010 survey cited fatigue, pain, physical limitations and having time off sick as their greatest barriers to being able to work to their full potential.
Social Care
4.1 Understanding of term ‘social care’

Respondents were asked to describe, in their own words, what immediately came to mind when they thought of social care. Of the 341 respondents’ who responded to this question, 15 (4%) indicated that they either did not know or were unsure of what social care encompassed.

Three main themes emerged from the remaining 326 respondents, indicating that respondents’ identify social care with very specific people, places and things:

- Social care was identified by many respondents as being delivered by health care professionals, including social workers, occupational therapists, physiotherapists, doctors, nurses and carers. In addition, they strongly identified social care as for older or elderly adults, as well as for those with disabilities or who are unable to care for themselves. They identified local councils, the NHS, and charities as organisations that are or should be responsible for provision of social care.

- Social care was described as involving outside help that was provided for in one’s own home, however respondents also associated social care with care homes or nursing homes.

- Social care was also about the provision of assistance and services, such as help with personal care and activities of daily living (e.g. washing, dressing, chores, meal preparation) and the provision of assistive devices and equipment.

In general, the words associated with social care were either neutral (expressing a pointed answer like ‘home help’) or they were positive, with respondents stating: “Help with daily chores, advising on things that make life easier all round”; “to help me keep a good level of independence”; Help with things I can’t do. Someone to listen to my concerns”.

The most common words used were counted and are illustrated earlier in a word cloud (page 26), which denotes the 50 most common words used within the description given. The size of the word correlates to how often the word was mentioned.

However some comments indicated that negative emotions or experiences were associated with social care by a few. For example, one respondent stated that social care was “Dependence, vulnerability and lack of ability”, while three gave one word responses: “Horror!”; “Scary”; “Disorganised”. Several respondents commented on the lack of funds generally available for social care: “Never enough funds so social services seem very parsimonious and sometimes surly”, “No service available due to cuts”, and “Underfunded”. Others commented on their perception of social care as intrusive: “People coming to try and tell me what to do, to take over my life” and “Strangers coming every day to help and not the same ones on a rota”.

4.2 Importance of aims of social care

People are not always aware of what social care offers and we wanted to gauge what people across Scotland living with RA thought about social care, irrespective of whether they currently received formal social care or had ever applied to do so.

Respondents were shown a list of 15 social care aims and asked to rate how important each was to them. All aims listed were considered either ‘Somewhat Important or ‘Extremely Important’ to the majority of respondents (range: 96%-74%). A list of the top ten social care aims emerging as ‘Extremely Important’ for more than 50% of respondents is below.

**Top Ten Importance of Social Care Aims as identified by the majority of respondents (≥50%) as ‘Extremely Important’**

1. Enabling you to maintain or re-acquire independence
2. Improving your quality of life
3. Enabling you to have choice/control over your life
4. Safeguarding you from abuse
5. Improving your health  
6. Improving the health of carers  
7. Supporting carers emotionally  
8. Relieving carers of care responsibilities so they can pursue personal goals  
9. Supporting you emotionally  
10. Supporting carers financially  

*note base number of respondents varies for these questions from approximately 340 to 352

### 4.3 Providers of Social Care

Respondents were asked who they thought provided the majority of social care for people in Scotland. They were able to choose more than one response category from a list of possible options, and 353 respondents provided at least one response to this question.

The chart below highlights that, from their perspective, the majority of social care is informal with 85% indicating ‘family’, 68% ‘Partner’, 46% ‘Friends/Neighbours’.

Just over half (55%) indicated the majority came from governmental organisations such as ‘the NHS’, 41% indicated from ‘local Council’ and 20% ‘Scottish Government’. A quarter of respondents (25%) indicated that private companies or charitable organizations provided the majority of care for people in Scotland.

![Perception of who provides the majority of social care in Scotland](chart.png)
4.4 Social Care Information

People often report that they would like more information that may be helpful to them in managing their condition. We reviewed the perceived needs of a sub-group of participants (n=88) who had experienced some difficulty with personal care (i.e. dressing) by asking them what type of information about social care they thought might be beneficial to them. In general, all types of social care information were perceived as beneficial to them with more than 50% of this sub-group stating that receiving information about the types of care and services they might need in the future and types of service available locally would be extremely beneficial.

Additionally, respondents indicated that they wanted to know more about organisations with specialist knowledge of RA, such as NRAS. Lower ranked was information related to entitlements, eligibility assessment procedures and local eligibility criteria, as these were perceived as less beneficial.

![Figure 13: Perceived Benefit to Self of Social Care Information](image-url)

Base: n=353
Care and Support: Personal Experiences
5.1 Care and Support currently received

Respondents were asked to indicate from a list which care and support they currently receive, regardless of who provided it (i.e. by family and friends, private companies, NHS or local authorities).

More than half of all respondents \((n=205)\) indicated that they did not receive any of the care and support listed. Of the remaining 182 respondents indicating that they did receive care, the average number of care and support services received was 3. The response range was between from 1 to 13, where 13 was the greatest number of care and support services reported being received. The majority of these 182 respondents had established RA (81%) and were aged 45 years or older (73%). Nearly one in four (24%) lived in a single adult household. Overall those receiving care and support reported nearly two additional comorbid conditions when compared to those not receiving care and support (average comorbid count 3.7) and also reported greater functional disability (HAQ-DI score 1.8).

In general, most services reported by the 182 respondents receiving care and support were related to the home:

- 65% reported home care (cooking, cleaning)
- 56% reported use of devices (equipment / adaptations)
- 35% reported adaptations to the home

Approximately one in three (36%) indicated that they received personal care (washing, bathing, toileting), as well as assistance with transportation outside the home (33%).

Less reported were care and support types relating to mobility inside the house (15%), mental health services (12%), professional/ workplace support (10%), care and advocacy (7%), residential care (2%) and day care (2%). Figure 14. (Note: the number of respondents reporting various types of care and support received are small in some categories, and data should therefore be interpreted with care).

Respondents specified the approximate number of hours per week that they received the relevant type of care and support. In general, the majority of respondents received between 1 and 5 hours of care per week for most types of care and support, including using professional services (83%), mental health services (77%), adaptations to the home (75%), devices (75%), personal care (68%), home care (64%), mobility (inside the house) (64%), and transportation (outside the house) (59%). The report of greater number of care and support hours received for home care and personal care was related to an increasing level of functional impairment rather than length of time since RA diagnosis.

The vast majority of care and support received was reported to be needed and / or related to RA. As Figure 14 illustrates, nearly all care and support services received were predominately reported as needed because of the respondents’ RA, with residential care (67%), day care (67%), and mental health services (57%) reported less frequently needed due to respondents’ RA. Reasons other than RA that were reported as to why care and support was needed included depression, fatigue, pain, recent surgery/ complications from surgery.
5.2 Providers of Care and Support

The table below highlights the type of care/support and the provider. Family members are the most common providers of Personal Care (97%), Home Care (86%), Transportation (70%) and general Mobility (59%). The NHS is the most common provider of Professional Services (75%), Devices (46%) and Mental Health Services (60%). Local councils are most common provider of adaptations to the home (47%) and devices (31%).

**TABLE 2: PROVIDERS OF TYPES OF CARE AND SUPPORT**

<table>
<thead>
<tr>
<th>Base: receive care and support</th>
<th>Family</th>
<th>Friends/ Neighbours</th>
<th>Private providers</th>
<th>Faith-based organisation</th>
<th>Local Council</th>
<th>NHS</th>
<th>Charities</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Care (n=115)</td>
<td>86%</td>
<td>14%</td>
<td>13%</td>
<td>–</td>
<td>1%</td>
<td>–</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Devices (n=95)</td>
<td>32%</td>
<td>6%</td>
<td>2%</td>
<td>–</td>
<td>31%</td>
<td>46%</td>
<td>–</td>
<td>3%</td>
</tr>
<tr>
<td>Personal Care (n=63)</td>
<td>97%</td>
<td>8%</td>
<td>3%</td>
<td>–</td>
<td>2%</td>
<td>–</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Adaptations to the home (n=62)</td>
<td>37%</td>
<td>3%</td>
<td>5%</td>
<td>2%</td>
<td>47%</td>
<td>16%</td>
<td>2%</td>
<td>3%</td>
</tr>
<tr>
<td>Transportation (n=58)</td>
<td>83%</td>
<td>22%</td>
<td>–</td>
<td>2%</td>
<td>3%</td>
<td>2%</td>
<td>3%</td>
<td>7%</td>
</tr>
<tr>
<td>Professional services (n=44)</td>
<td>25%</td>
<td>11%</td>
<td>–</td>
<td>2%</td>
<td>5%</td>
<td>75%</td>
<td>7%</td>
<td>5%</td>
</tr>
<tr>
<td>Mobility (n=27)</td>
<td>59%</td>
<td>19%</td>
<td>7%</td>
<td>4%</td>
<td>7%</td>
<td>19%</td>
<td>–</td>
<td>7%</td>
</tr>
<tr>
<td>Post-operative rehabilitation (n=20)</td>
<td>70%</td>
<td>10%</td>
<td>–</td>
<td>5%</td>
<td>–</td>
<td>30%</td>
<td>–</td>
<td>5%</td>
</tr>
<tr>
<td>Mental health services (n=20)</td>
<td>25%</td>
<td>15%</td>
<td>5%</td>
<td>5%</td>
<td>–</td>
<td>60%</td>
<td>5%</td>
<td>15%</td>
</tr>
<tr>
<td>Professional support (n=16)</td>
<td>6%</td>
<td>–</td>
<td>13%</td>
<td>6%</td>
<td>13%</td>
<td>31%</td>
<td>–</td>
<td>31%</td>
</tr>
<tr>
<td>Care advice and advocacy (n=9)</td>
<td>56%</td>
<td>22%</td>
<td>–</td>
<td>11%</td>
<td>22%</td>
<td>–</td>
<td>22%</td>
<td>22%</td>
</tr>
<tr>
<td>Day care (n=2)</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>50%</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>50%</td>
</tr>
</tbody>
</table>
5.3 Funding for care and support services

Funding for individual aspects of care / support is highlighted below. The vast majority of support is provided free by family and friends, in particular, 87% of Personal Care, 76% of Home Care, 64% of transportation, 56% of post-operative rehabilitation, 52% of Mobility.

The economic role of informal adult care has been explored by estimating the value of care received either from members of one’s own household or from members of other households. Estimates suggest that the gross value added (GVA) of informal adult care in the UK was approximately £56.9 billion in 2014, and this figure comprises costs relating to personal care (i.e. dressing, bathing, washing and feeding), practical care (i.e. help with mobility, paperwork or financial matters), or both. This is a significant cost that is not formally borne by society, rather it is absorbed by family or friends/neighbours and often goes unrecognised.

Anecdotally, many partners and family members of people living with RA provide significant amounts of support and yet do not consider themselves ‘carers’. Such a disconnect might lead them to not necessarily describe themselves as such in national surveys, and it is possible that the cost to families supporting people with RA may well be underestimated.

### TABLE 3: PROVIDERS OF FUNDING FOR SUPPORT AND CARE

<table>
<thead>
<tr>
<th>Base: receive care and support</th>
<th>Provided free by family and/or friends</th>
<th>Self-funded</th>
<th>Welfare benefits (eg. PIP or DLA)</th>
<th>NHS</th>
<th>Local Council</th>
<th>Other</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Care (n=110)</td>
<td>76%</td>
<td>17%</td>
<td>17%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Devices (n=90)</td>
<td>23%</td>
<td>21%</td>
<td>13%</td>
<td>39%</td>
<td>26%</td>
<td>1%</td>
<td>6%</td>
</tr>
<tr>
<td>Personal Care (n=61)</td>
<td>87%</td>
<td>5%</td>
<td>18%</td>
<td>–</td>
<td>2%</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Adaptations to the home (n=58)</td>
<td>21%</td>
<td>16%</td>
<td>7%</td>
<td>19%</td>
<td>41%</td>
<td>2%</td>
<td>7%</td>
</tr>
<tr>
<td>Transportation (n=56)</td>
<td>64%</td>
<td>5%</td>
<td>38%</td>
<td>2%</td>
<td>4%</td>
<td>7%</td>
<td>2%</td>
</tr>
<tr>
<td>Professional services (n=42)</td>
<td>19%</td>
<td>7%</td>
<td>7%</td>
<td>64%</td>
<td>10%</td>
<td>2%</td>
<td>7%</td>
</tr>
<tr>
<td>Mobility (n=27)</td>
<td>52%</td>
<td>15%</td>
<td>33%</td>
<td>4%</td>
<td>4%</td>
<td>4%</td>
<td>4%</td>
</tr>
<tr>
<td>Post-operative rehabilitation (n=18)</td>
<td>56%</td>
<td>11%</td>
<td>–</td>
<td>28%</td>
<td>–</td>
<td>11%</td>
<td>6%</td>
</tr>
<tr>
<td>Mental health services (n=18)</td>
<td>22%</td>
<td>6%</td>
<td>–</td>
<td>67%</td>
<td>–</td>
<td>17%</td>
<td>6%</td>
</tr>
<tr>
<td>Professional support (n=17)</td>
<td>12%</td>
<td>12%</td>
<td>–</td>
<td>29%</td>
<td>12%</td>
<td>29%</td>
<td>6%</td>
</tr>
<tr>
<td>Care advice and advocacy (n=10)</td>
<td>40%</td>
<td>30%</td>
<td>10%</td>
<td>–</td>
<td>20%</td>
<td>20%</td>
<td>10%</td>
</tr>
<tr>
<td>Day care (n=3)</td>
<td>33%</td>
<td>33%</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>33%</td>
<td>–</td>
</tr>
</tbody>
</table>
We further explored how easy respondents found it to obtain funding for their care and support from various sources. The ease of obtaining funding from the central government, a local authority or the NHS, explored in Figure 15, was reported by this smaller subset of the total respondents. As respondent numbers here are low, care should be taken when drawing any conclusions.

Funding for Home Care and Personal Care was considered relatively difficult to obtain from government agencies – both were rated 8.8 and 8.6 out of 10, where 10 was considered very difficult. Transportation was also deemed moderately difficult to obtain with a rating of 7.5.

Funding for professional services, devices and re-ablement/recovery after a stay in hospital or surgery were considered to be the easiest to obtain from the central government, local authority or the NHS.

FIGURE 15: MEAN SCORE FOR EASE OF OBTAINING FUNDS FOR CARE AND SUPPORT FROM THE CENTRAL GOVERNMENT, LOCAL AUTHORITY AND THE NHS

Base: Respondents received government, LA or NHS funding of care and support
5.4 Ways in which care and support services are helpful

The majority (90%) of respondents who indicated they currently received care and support (n=182) were asked to describe the ways their care and support services helped them by choosing from a list of common responses.

- Two thirds (63%) indicated that their received care and support services help them maintain their independence.
- 45% reported the services help to maintain their physical health.
- 44% reported the services give them choice and control over their life.
- Lower proportions of respondents indicated that care and support services they have received have helped them to stay in work (23%) or to look after their family (21%).

5.5 Extent to which current care and support needs are being met

Of the 182 respondents who indicated they were currently receiving care and support services, 156 (86%) reported approximately how much of their care and support needs were not being met on a scale of 0% to 100%.

Nearly one in four (22%) further indicated that all their care and support needs were being met. These individuals were generally those with established RA (74%), living in households with either one (19%) or two (59%) persons, and living in households with an annual income over £20,000 (42%). Additionally, this group (22% reporting care and support needs being met) had a lower functional disability (average HAQ-DI score 1.5 compared to an average HAQ-DI score 1.9 from those who reported that their care and support needs were not being met at any level, which is unsurprising to us. However despite reporting that their needs were met, eleven respondents also reported that they believed that one or more (range 1 to 7) care and support services (e.g., home care, devices, professional services, transportation) would help them.

The majority of respondents (66%) indicated that at least half of their care and support needs were being met, whereas 34% indicated that at least half (≥50%) of their care and support needs were not being met.

Respondents also provided additional information about the extent to which their current care and support needs are satisfactorily met, which allows insight into the perceived quality of care and support received. Few respondents (16%) stated that their care and support needs were 100% satisfactorily met, and 63% of respondents receiving care and support believe at that the majority of their needs were being satisfactorily met (>50%). Whereas a greater proportion (37%) of respondents reported that ≤50% of their care and support needs were being satisfactorily met.

Finally, respondents were asked whether in general, their experience of care and support services they have received have been positive or negative overall. On average, the majority (60%) of 167 respondents receiving care and support were either 'very' or 'fairly' positive with their experience [Figure 16]. Nearly one in four (24%) were neutral and did not report having a positive or negative experience. A minority indicated they had a negative experience, with 17% reporting 'fairly negative' or 'very' negative experiences.
This seems to indicate that while some respondents report care and support needs being met, they are not entirely as satisfied with how that care and support is provided as some experiences may even be negative. This data supports the value of regular audits and ongoing service delivery improvement among various providers (e.g., NHS, local authority), as well as scope for review of services among those receiving support provided by family, friends and/or neighbours.

**FIGURE 16: OVERALL EXPERIENCE OF CARE AND SUPPORT SERVICES RECEIVED**
Base: Receive care and support. n=167
5.6 Additional Support Services Required

Respondents were also asked to select from a list those care and support services which they were not currently receiving that they believed would help them.

Almost one third (31%) of 140 respondents reported that there were no other care and support services (that they weren’t getting) which they thought would help them.

Respondents who did say there were other services which they would find helpful, were most likely to state the following:

- Professional services such as occupational therapy or counselling (31%)
- Devices such as equipment or adaptations in their home (26%)
- Care advice and advocacy (20%).

Of those 19% indicating that they believed professional support (i.e., organising your work life around your needs) would help them, 17 respondents indicated they were in paid employment. Furthermore, these respondents had very high overall work impairment, on average 71.6% (range 20-99), as well as high non-work activity impairment, on average 72.9% (range 40-100). While this reflects a small number of respondents, provision of professional support services for these individuals may help to reduce work and activity impairment.

![Figure 17: Additional Care and Support Services Required](image-url)
Where respondents indicated that some form of care and support was needed, they were further asked what would keep them from asking for that help. As shown in Figure 18, the most common reason for not asking for help was that they did not want to rely too heavily on others (63%) and not being able to afford to purchase services for care and support (49%). Less often reported was that they could cope without these services (14%) or that they did not have friends or family who could help them (6%).

Individuals with RA may be reluctant to ask for assistance with day-to-day care and support, as indicated by their responses when querying about 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.

**FIGURE 18: BARRIERS TO ASKING FOR CARE AND SUPPORT**

- **63%** don’t want to rely too heavily on others
- **49%** cannot afford to purchase services for care and support
- **34%** have family and friends without sufficient time to meet all their needs* (due to other responsibilities)
- **28%** do not know where to go to get help
- **23%** have tried to get help in the past, but been unsuccessful
- **14%** can cope without these services
- **6%** do not have family or friends who can help them

Base: Receive care and support and gave an opinion. n=142
Care and Support: Relationship with Caregiver
6.1 Primary Caregiver

The next section of the questionnaire sought to understand the nature of the relationship with the primary caregiver. Firstly, respondents were asked to identify whom, from the range of providers that provide their care, they considered to be their primary caregiver. Of 101 respondents, the vast majority of respondents (93%) considered family to be their primary caregiver, followed by friends/neighbours (3%), private providers (3%), faith organization/other (1%).

6.2 Relationship with primary caregiver

Respondents were then asked to respond to a range of statements from the Self-Perceived Burden scale\(^4\), which aims to understand better the way they may or may not feel about their primary caregiver. Of the 97 individuals listing primary caregiver as family or friends/neighbours, 80 (82%) responded to the self-perceived burden scale. They were asked to state if they felt that way 'none of the time' through to 'all of the time' to better understand their relationship with their self-reported primary caregiver.

For example, items to which respondents were most likely to mostly or always feel:

- Guilty about the demands that they make on their caregiver (57%)
- Concerned that they are 'too much trouble' to their caregiver (48%)
- Concerned that because of their illness their caregiver is trying to do too many things at once (46%)
- Worried that their caregiver is overextending him/herself to help them (45%)
- That they are a burden to their caregiver (43%)
- Worried that the health of their caregiver could suffer as a result of caring for them (42%).

Approximately 76% of respondents answering these questions had an elevated level of self-perceived burden on their caregiver based on a previously reported meaningful value in the literature\(^4\). The overall average perceived burden score was 30 (median average = 31), which was higher than scores found in a chronic pain population (median average = 27)\(^4\) indicating a substantial self-perceived burden on their caregiver. Respondents who reported anxiety or depression had significantly higher average self-perceived burden scores when compared to those without a report of anxiety of depression, 33.0 versus 27.3.

That respondents perceive themselves, on average, as a greater burden to their caregiver than when compared to scores found in a chronic pain population may reflect the complexity of RA. Indeed, respondents in this survey with an elevated level of self-perceived burden had a significantly higher average HAQ-DI score of 2.0 when compared to a HAQ-DI score of 1.6 in those without an elevated level. Whether actual or perceived, those with high levels of functional impairment may have greater and more varied care needs and in turn be a source of concern for individuals with RA.

Caution must be taken against drawing a conclusion that a high sense of perceived caregiver burden causes anxiety or depression. This survey collected information on both at the same time, and therefore we cannot know whether one preceded the other.

Overall, such a high level of caregiver burden suggests that individuals with RA may benefit from more formal care and support services. Spreading caring roles between a number of informal caregivers may also help to alleviate this perceived burden.
Care and Support: Information and Eligibility Criteria
7.1 Information received from local Council since RA diagnosis

Since their RA diagnosis, only 10% of 307 respondents stated that they had received information about care and support from their local Council. The majority of these 31 respondents had established RA (74%) and were 45 years or older (87%). In general, those who reported receiving information from their local Council had higher functional impairment when compared to those not receiving information (i.e. Health Assessment Questionnaire Disability Index (HAQ-DI) average score 1.6) and had an average of 3 comorbid health conditions.

These 31 respondents were most likely to have received information relating to Disability Living Allowance (39%) or an assessment for help from the local Council with care and support (19%), see Figure 19. Information less often received was related to self-directed support (6%), funding for care and support services (3%), attendance allowance (3%) or personal budgets (0%).

Self-directed support allows people to choose how their support is provided and gives them as much control as they want of their individual budget – this is support a person purchases or arranges, to meet agreed health and social care outcomes.

selfdirectedsupportscotland.org.uk
Six respondents who had received information said that they had received some ‘other’ form, with four respondents offering additional information about what type of information this related to:

- “Occupational Therapy assessment”
- “Hand rail for outside steps”
- “Equipment”
- “Travel pass”

Of those who reported receiving information from the local Council, the majority (64%) were directed to the Council from a healthcare professional. Others were directed from family members (16%), friends or neighbours (10%) or another source, such as TV, newspaper or internet (10%). Note: these figures represent a very small number of respondents and as such should be interpreted with caution.

### 7.2 Needs assessment from local Council

When asked about whether they had ever had a needs assessment, 40 respondents reported that they had been assessed by their local Council to get support. While the majority of these respondents had established RA (83%) and were 45 years or older (68%), there was little variability between those who reported having had a needs assessment and those who did not by income or household composition. However, a greater number of comorbid conditions, as well as greater functional impairment was reported by those who reported having a needs assessment when compared to those who did not (average comorbid count 3.9 v 2.7; average HAQ-DI score 1.82 v 1.33, respectively).

Almost two thirds (n=24) of those reporting having had a needs assessment said that they felt the process allowed their assessors to take into account all relevant factors (e.g. that their care and support needs might vary according to their disease activity). Of those responding that they did not know or did not feel as if the assessment process took into account all relevant factors (n=16), four offered further comments for clarification:

- “Only assessment was after surgery on hip.”
- “Had one assessment a few years ago when I lived in another house.”
- “Previously assessed in Perth & Kinross. Very traumatic experience which needed to be continually challenged. Process from initial assessment to actual delivery protracted and person who carried out initial contact was completely unprofessional. Many carers were inexperienced and non-cooperative. Easier to get by without outside agency involvement in my life now.

- “I was not assessed for any financial help only occupational health for devices and a stair rail to my home. [from person saying don’t know]”

Just under half (n=19) said that they were deemed eligible, i.e. they received care and support or funding from their local Council. The majority of these respondents:

- had established RA (74%)
- were 55 years or older (58%)
- and in general, one (28%) or two (50%) individuals usually live in their household.
Those deemed eligible had moderate functional limitation (average HAQ-DI score 1.7 (range 0-2.5), although this was lower than those reporting that they were deemed ineligible (average HAQ-DI score 2.0 (range 1.2-2.7). The majority (56%) of these respondents lived in households with incomes less than £39,999, and 39% had a total capital (i.e. combined sum of savings and current account) below £23,000. Note: these figures represent a very small number of respondents and as such should be interpreted with caution.

Surprisingly, nine individuals who had a needs assessment reported that they did not know the result of their assessment. As these individuals are similar in age, time since RA diagnosis, household income, and also have a moderate comorbid condition count and functional limitation similar to those deemed eligible for care and support services (average comorbid count 3.7; average HAQ-DI score 1.9) we can find no viable explanation for why these individuals would not know the result of their assessment, except perhaps if the Council had recently conducted the assessment with a result still outstanding.

7.3 Eligibility criteria for help with care and support from local Council

Of the 331 responses to this question, the majority from (89%) responded that they did not know what types of circumstances might make them eligible for help with care and support for their local Council. Those indicating they were aware of the circumstances which would make them eligible for help with care and support from their local Council were fewer in number (11%; n=36).

Of the 36 respondents who indicated they knew of the types of circumstances that would make them eligible for help from the local Council, 26 provided more detailed and descriptive information. In general, responses indicated that many believed an inability to care for oneself, need for devices/equipment, or restricted mobility would make them eligible for care and support through the local Council. For example, respondents stated, “If unable to tend to my personal care, toilet needs, washing and dressing etc.”, “No longer being able to look after myself properly”, and “If I had no support and was unable to manage daily living tasks.” Another described, “Great difficulty climbing stairs, unable to stand for any period of time so required shower seat and perching stools.”

In addition, there were several participants who indicated that eligibility for care and support was determined by a professional assessment. One respondent stated “If you were deemed by a health care professional e.g. GP, district nurse, community based OT, to be having difficulty in doing personal care tasks and food prep, they can arrange for Home Care to be put in place”. Another stated “Mobility assessment usually involving physiotherapist/ or occupational therapist – if eligible provides help with transport e.g. taxi card, blue badge etc. Social Work Service carries out assessments for day care, home help/carers and personal services. OT’s can provide equipment and arrange for home adaptation.” Finally, a few participants also noted that financial need was a circumstance making one eligible for care and support from the local Council. One stated “Below a certain level of income/ living alone”, while another responded “If I was unable to work due to my illness I may be entitled to help, probably depending on income.”
7.4 Restrictions for Council help with care and support

Respondents were asked to indicate whether they believed that help with care and support should be restricted in any way by responding to five questions. Of 322 respondents to this question, the majority (66%) indicated that they did not think that Council help with care and support should be restricted in any way. Others believed that care and support restrictions should be to those with highest need (28%), those with low income (15%) and those with few assets (9%).

Only five respondents (3%) stated that they believed it should be provided in some other way. They provided more specific comments to further illustrate their position on whether care and support should be restricted:

“In Scotland everyone is entitled to free personal care. I think that other support such as house work, meals etc. should be means tested with the emphasis being on income. I keep hearing the average income is £25,000. I do not make anything like that, so an amount would have to be set that is realistic. I work with families and at times have had reason to be informed about what their disability benefits are for a month and I am always shocked that they have more income than me. I have not tried to claim a benefit as the stress of being made to feel like I am lying stops me.”

“Restricted to those who cannot live independently without it - not necessarily a high need.”

“Everyone should have their basic needs cared for. It should be done on a case by case basis. Everyone is different.”

“Each case looked at individually.”

“If the resources were there, more people could be helped. Sometimes it shouldn’t come down to criteria.”
Conclusions and Recommendations
8 Conclusions and Recommendations

In spite of an era of rising demand and austerity in recent times which has challenged the health service in Scotland, and indeed across the UK as a whole, the treatment and care available for those living with rheumatoid arthritis means that it is now possible to achieve remission or a low disease activity state, leading to many being able to achieve a much better quality of life than ever before with less disability. This is to be celebrated.

However, the variability of access to the best care remains significant, and early diagnosis and treatment within the ‘12-week window of opportunity’ doesn’t happen often enough1, as a consequence of which, the human and financial cost of RA in Scotland is high and unmet need is substantial. Interestingly, despite the high number of co-morbid conditions reported by those who took part in this survey, the principal cause of needing help and social care was related to their rheumatoid arthritis.

It is essential that early diagnosis and treatment is prioritised as part of service re-design so the potential for longer term disability and subsequent co-morbidity can be reduced, and the consequential burden on individuals, families and the cost to health and social care could be substantially less. One of the ways in which people with suspected early inflammatory arthritis could get into the system more rapidly once referred by GPs is to establish early arthritis clinics. These do exist in some health boards but are by no means available everywhere.

Social care cuts have been widespread across the UK, with Scotland being no exception. Back in February, Council Leaders had to sign off cuts to their budgets for 2016/17 as well as being in the eighth year of the council tax freeze, which means that councils’ only significant means of generating additional income has been effectively removed. This will all impact on those with long term conditions such as RA.

Earlier diagnosis and treatment

It cannot be stressed enough that more needs to be done to address the need for earlier diagnosis and treatment of RA in order to maximise the number of people achieving remission or a low disease activity state. This holds out the likelihood of less co-morbidity, less disability and a reduced need for early social care intervention with cost savings to the individuals, families and health and social care system.

One way to characterise this would be to encourage GPs to treat early inflammatory arthritis in the same way that cancer is dealt with – rapidly and as a priority. In England, the NICE Quality Standard for Rheumatoid Arthritis recommends that GPs should refer within 3 working days. The SIGN Guidelines for Scotland recommend that all patients with suspected inflammatory joint disease should be referred to a specialist as soon as possible to confirm the diagnosis and evaluate disease activity.

NRAS will continue to work through our Scottish Campaigns Network to highlight these issues in the Scottish parliament and with all policy makers, Health Boards and providers. We will continue to raise awareness amongst the general public in Scotland of the need to seek help quickly should they experience the symptoms of RA.

**Recommendation:** SIGN guidelines should align with NICE Quality Standard QS33 in regard to GP referral time of 3 working days where inflammatory arthritis is suspected.

**Recommendation:** GPs should be trained and supported to make 3 day referrals achievable.
Co-morbidities

The most common co-morbidity reported was depression (30%) closely followed by back pain (27%) and anxiety (19%). Many people with long term conditions also have mental health problems and these can lead to significantly poorer health outcomes and reduced quality of life, irrespective of severity of disease. Feeling low and anxious is particularly common at an early stage following diagnosis when the disease is not yet under control and the individual is understandably very worried about how this disease will affect their life and their family. Worries about job retention and job loss are also significant and people often see their life’s ambitions, hopes and dreams rapidly receding.

Often what they need at that early stage is exactly the kind of services which NRAS provides:

- emotional support to help them make sense of their diagnosis
- a safe space to talk about how this is going to impact their life and what it means to them
- help with translating the information that they have been given by the rheumatology team into information that is meaningful to them, in the context of their own life/work/family commitments etc.

When support is easily accessible and available early on, it can help to reduce low mood, feelings of anxiety and isolation.

Health Boards should prioritise integrating mental and physical health care more closely as a key part of their strategies to improve quality and productivity in health care for all people with long-term conditions such as RA.

**Recommendation:** Health care professionals should refer patients early to either NHS services or to community resources and patient organisations who can help.

More information from specialist organisations

Respondents indicated that they wanted to know more about organisations with specialist knowledge of RA such as NRAS. NRAS will continue to support rheumatology health professionals by providing our wide range of services to their patients, not only for the newly diagnosed, but for all people with RA, however long they have had the disease. NRAS’ Scottish Ambassadors will continue to be a key link between NRAS and local teams.

**Recommendation:** All health professionals involved in the care of people with RA in Scotland sign-post their patients to NRAS as soon as possible post diagnosis.

*An easy and efficient way to do this is to give out our Helpline business cards which are freely available on request. We can also supply ‘newly diagnosed’ packs on request.*
Importance of taking medication safely

Of the high number of people taking anti-inflammatories (144), nearly a quarter (24%) were not taking them in conjunction with stomach protection as recommended in national guidelines. Furthermore, of those indicating that they were taking oral steroids, a high percentage were also not taking stomach protection. We appreciate that we do not know how long respondents have taken each of the medications they indicate they currently use, however we felt that this was an important point to raise so that people taking anti-inflammatories and/or steroids for any length of time ask about stomach protection.

NRAS will do more to highlight the need for stomach protection when taking anti-inflammatories and oral steroids through their website, social media, e-news bulletins and member’s magazine. However, it is incumbent upon all rheumatology and other health professionals to ensure that appropriate proton pump inhibitors are co-prescribed with anti-inflammatories where necessary.

Work

A relatively high number of people were unable to work because of sickness or disability. Also for all respondents, the average number of co-morbidities was 2.8 with the majority naming at least one other health condition. The greater the number of co-morbidities, the greater the likelihood of one’s health impacting on one’s ability to remain in or get back to work. Work is hugely important for the majority of those of working age. Loss of one’s job may lead to mental health problems, financial difficulty, loss of pension (resulting in greater reliance on the State in older age), and can have a significant impact on personal relationships with family and friends. There is a widespread call for work to be a ‘health’ outcome because the benefits of work on health are well documented.

NRAS is addressing this in two key stages. We are currently preparing for a major UK wide survey on the impact of RA on work which will be sent out in the first quarter of 2017; and intend to follow the results of this with further provision of resources and campaigning on the issues.

Recommendation: We would urge all health professionals to ask their working-age patients, particularly at diagnosis and at annual reviews, if they have job-related concerns and need support and sign-posting to organisations that can help. This includes NRAS.
Caring, Carers and Support

The majority of social care is informal and supplied by family, friends and neighbours. This saves governments an enormous amount of money. It was clear from the survey that for many with RA there was a high perceived burden on their principal carer and it must be remembered that this can add to anxiety and depression. This awareness should also help to ensure that the needs of the carers are taken into account over the long term. NRAS’ Family Matters survey, published in 2012, also revealed the huge impact on relationships and the whole family providing informal care.

Participants also told us that their concern about relying too heavily on others would keep them from asking for help. It was also clear that a significant number of participants did not know what types of circumstances might make them eligible for help with care and support from their local council.

**Recommendation:** Local councils should ensure that information about help with formal social care is easily accessible to all people.

**Recommendation:** Local councils should ensure that health professionals know how best to sign-post people to relevant care services.

**Recommendation:** Health professionals should ensure that they involve close family members when determining care plans for the newly diagnosed so that a clear understanding of patients’ needs is recorded at an early stage and reviewed on a regular basis.

**Recommendation:** Investment in support for carers should be maintained and even expanded.

The benefit of the right care and support at the right time and what matters to patients

It was interesting to note that the majority of those receiving care and support felt that this enabled them to maintain their independence. Participants also reported that the services received helped them to maintain physical health and have more control of their life, staying in work and looking after their family.

These are all fundamental issues important to everyone, with or without RA and there is little doubt that a greater focus on the goals of patients to remain independent, in work (or doing what they want to do), in control of their lives and looking after their loved ones, should be a priority for everyone involved in the care and support of people with RA across Scotland.

*The findings and data explored in this report have many potential avenues for further exploration. NRAS and the University of Aberdeen look forward to collaborating further in the future.*

*All NRAS documents and reports referred to in this report can be accessed and downloaded from the NRAS website.*
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**Principal Author & Editor:** Dr Kathryn Martin, University of Aberdeen

**Authors and Editors:** Ailsa Bosworth MBE and Conn O’Neill, National Rheumatoid Arthritis Society
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