

RA and Physiotherapy: a national survey



The National Rheumatoid Arthritis Society in collaboration
with the Chartered Society of Physiotherapy.





Contents

1	Introduction	3
2	Background to this survey	5
2.1	Physiotherapy and rheumatoid arthritis – evidence and policy	5
2.2	The value of physiotherapy in the treatment of RA	5
2.3	Access to physiotherapy	6
2.4	Government policies	7
2.5	The survey and its methodology	9
3	Key findings	10
3.1	The survey respondents	10
3.2	Access to physiotherapy	11
3.2.1	Time to referral	12
3.2.2	Time to treatment	12
3.3	Pathway to referral	13
3.3.1	Initiation	13
3.3.2	Self-referral	14
3.4	Level of integrated care	14
3.4.1	The multidisciplinary team	15
3.4.2	Style of intervention	15
3.5	Impact of physiotherapy	16
3.5.1	Function	16
3.5.2	Mobility	17
3.5.3	Quality	17
3.6	Responsiveness to the patient	18
3.6.1	Location of Physiotherapist	18
3.6.2	Ease of contact	19
4	Conclusions and recommendations	20
4.1	Survey findings	20
4.2	Recommendations	21
5	More information	22
5.1	Thank you	22
6	Reference	23

Introduction

From Ailsa Bosworth, Chief Executive,
National Rheumatoid Arthritis Society



Keeping mobile is a major challenge for people with rheumatoid arthritis, owing to the pain, stiffness, joint damage and deformity the disease can cause. I know from my own hard fought experiences the considerable effort required to keep joints supple and muscles strengthened sufficiently to minimise some of the physical effects of the disease.

For example, when I was diagnosed in my early 30s, I very swiftly had my first operation and needed ongoing physiotherapy for 18 months, which was quickly and readily available at the time and really helped me to build up the strength in my leg and get mobile again. I had a small baby at the time and couldn't afford to be off my feet.

In hindsight, I count myself to be very fortunate, but here at NRAS we receive large numbers of calls from people struggling to cope physically and emotionally with the disease and the resultant loss of function and mobility. This is much more profound and wide-ranging than just discovering one day you can no longer walk large distances. There is also the enhanced risk to cardiovascular health that immobility poses for a category of individuals already placed in a higher band of risk, due to the other known life-limiting effects of the disease.

Equally as powerful, I would say, are the effects the disease has on the everyday tasks that healthy people normally take for granted, like being able to open a door, or being able to cook for one's self, or even simply being able to go to the toilet unaided.

These physical effects have powerful emotional side effects, robbing individuals of their independence and, ultimately, their dignity.

In response to the many requests we receive, NRAS consistently highlights the important role physiotherapy can play in helping to ameliorate some of the physical effects of the disease, reducing chronic pain and restoring people's overall quality of life. As part of this year's theme for World Arthritis Day, 'Move to Improve', we thought it would therefore be an appropriate juncture to survey our members to explore the value of physiotherapy and its availability to people with rheumatoid arthritis.

What we discovered was to some extent unsurprising. On the one hand, our findings suggest that the majority of people who receive physiotherapy rate the quality of the service highly and report seeing moderate benefits to their joint function and mobility. On the other hand, respondents report a more haphazard approach towards provision and access to physiotherapy services, with waits of between 1 and 2 months not uncommon.

Shockingly, nearly a third of people who responded to the survey said they had to wait over a year to be referred for physiotherapy and almost another third had never been referred to a physiotherapist at all. There was also roughly a fifty-fifty split between those who regarded their physiotherapy treatment as a 'one-off' and those who said they were offered the treatment whenever they needed it.

Although the aggressiveness of the disease can vary from person to person, we would not normally expect medical reasons alone to account for such low referral rates, suggesting that some services are being rationed.

As keen proponents of the multidisciplinary team model, NRAS was also particularly concerned to note that a little over a third of respondents said the physiotherapy service they encountered was working as part of a multidisciplinary team, which does not comply with medical guidelines for RA and the aims of many strategies designed to improve treatment of long-term conditions.

At a time of economic austerity, with the NHS in England for example expected to save £20bn over the next four years and subject to large scale reorganisation, we are understandably somewhat pessimistic about the prospect of improving access rates to physiotherapy (both early access and overall access). We are also, therefore, downbeat about the prospect of embedding greater numbers of physiotherapists into the structure of the multidisciplinary team, which we believe still offers the best means to achieving optimal clinical outcomes for people with rheumatoid arthritis.

This survey forms part of NRAS's on-going commitment to campaign for equal access to good care and services for all.

From Phil Gray, Chief Executive, Chartered Society of Physiotherapy



The Chartered Society of Physiotherapy (CSP) is delighted to be working with NRAS on this report into physiotherapy services for people with rheumatoid arthritis (RA).

People with RA live with debilitating pain, stiffness and joint damage, which can make the most routine parts of daily life painful, difficult or even impossible. World Arthritis Day is a key opportunity to highlight the concerns of those living with RA, and their friends, families and carers. This year's theme 'Move to Improve' exemplifies the importance of keeping active as part of the effective management of RA.

Research supports the experience of those living with RA, that physical activity and exercise can help to reduce pain and make movement easier. People with RA regularly stress the important role that physiotherapy has in supporting them to maintain their levels of movement and physical activity, reducing pain, fostering independence and in many cases allowing people to remain in work.

Physiotherapy enables people to move and function as well as they can, maximising quality of life, physical and mental health, and wellbeing. Physiotherapists work across sectors and care pathways, providing the bridge between hospital, primary and community care; and physiotherapists are central to the delivery of integrated care and keeping patients out of hospital.

Whilst we are, of course, delighted that the majority of those responding to this survey who receive physiotherapy rate the service highly, and experience improvement in their mobility as a result of it, we remain concerned that this benefit is not equally available to everyone with RA when it is needed.

The results of this survey demonstrate the 'postcode lottery' that still exists, with different people, in different areas experiencing different levels of access and service provision. This cannot be acceptable in a National Health Service.

The CSP is particularly concerned about reports that some people are waiting for long periods of time, in some cases over a year, for a referral to physiotherapy. Delaying access to treatment is costly – to the individual, whose condition deteriorates while they wait, and to the NHS, which will incur increased healthcare costs from this deterioration.

People with RA are experts in their own condition, they know how to manage their symptoms and when they need access to physiotherapy. The CSP is calling for the extension of patient choice through a greater adoption and roll out of the patient self-referral model for physiotherapy. Self-referral is a system which empowers patients to better manage their condition by allowing them to make an appointment direct with their local physiotherapy department, without seeing their GP first. It has demonstrated success in improving outcomes for patients through

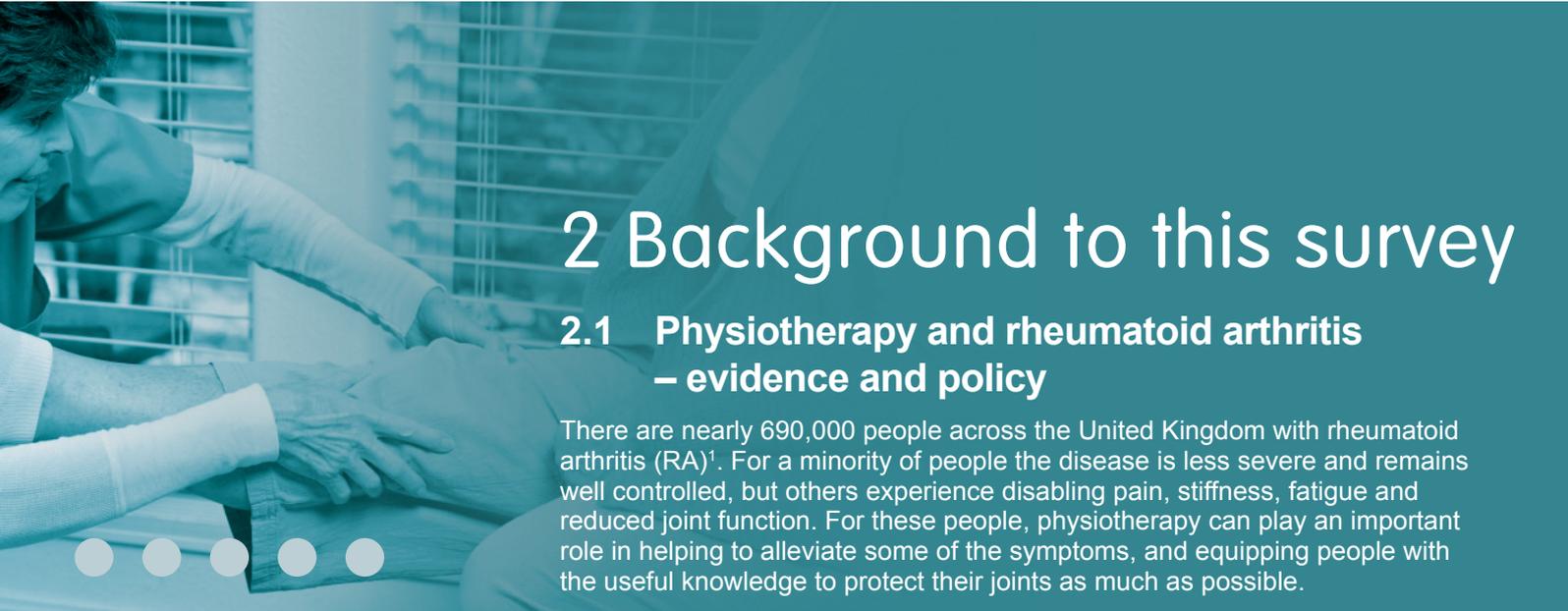
early intervention and by avoiding unnecessary referral to specialists in secondary care.

At a time when the NHS, in all four UK countries, faces tighter budgets, innovative models of care – such as patient self-referral to physiotherapy – which have been shown to save the NHS time and money, as well as delivering improved outcomes for patients, are essential to deliver the efficiency savings that need to be found.

The CSP is gravely concerned that, instead of adopting these efficient systems, some services are simply being cut to meet financial targets. Physiotherapy departments across the UK are struggling to meet patient demand as commissioners reduce the physiotherapy workforce by implementing recruitment freezes, cutting vacant posts, not allowing the backfilling of positions for maternity care or long term sick leave and in some cases, making redundancies.

This report makes essential reading for healthcare professionals and commissioners involved in the provision of services for people with RA. We call upon Government and decision makers at the national and local level to ensure that people with RA have appropriate and fast access to specialist physiotherapy as part of their ongoing treatment and care pathway.

A handwritten signature in black ink that reads 'Phil Gray'.



2 Background to this survey

2.1 Physiotherapy and rheumatoid arthritis – evidence and policy

There are nearly 690,000 people across the United Kingdom with rheumatoid arthritis (RA)¹. For a minority of people the disease is less severe and remains well controlled, but others experience disabling pain, stiffness, fatigue and reduced joint function. For these people, physiotherapy can play an important role in helping to alleviate some of the symptoms, and equipping people with the useful knowledge to protect their joints as much as possible.

“It has given me more general overall strength to help protect my joints and do things without pain.”

2.2 The value of physiotherapy in the treatment of RA

People with RA tend to be less active than the general population² and have an increased chance of developing cardiovascular disease³, cachexia⁴ and osteoporotic fracture⁵.

However, research shows that exercise can reduce these risks⁶ by boosting cardiovascular health, promoting muscle strength and bone mineral density⁷. Well designed physical exercise programmes have also been shown to help reduce obesity⁸ and improve physical function⁹. Strength-based and aerobic activities, such as walking, cycling and water-based exercise, are deemed to be effective, without being harmful to peoples’ disease activity¹⁰. There is also some evidence to suggest that strength training programmes can reduce impairment¹¹.

Patients are also aware of the benefits of exercise¹² and know about its potential to increase mobility, strengthen muscles and reduce pain¹³. However, research also shows that many people with RA do not exercise for fear of causing damage to their joints and that continuous emphasis and education about the benefits of exercise are needed to overcome this reluctance¹⁴.

Overall, there is broad agreement within the medical community about the importance of exercise in treating RA. Recommendations about aerobic, strengthening and mobility exercises are present in key medical guidelines about the treatment of RA, produced by the British Society of Rheumatology and British Health Professionals in Rheumatology¹⁵, National Institute for Health and Clinical Excellence¹⁶, the Scottish Intercollegiate Guidelines Network¹⁷ and the European League Against Rheumatism¹⁸.

These guidelines also make specific reference to the importance of giving RA patients access to specialist physiotherapy with periodic review. Indeed, physiotherapists can play an important role in the treatment of RA, as they can help to prevent disability, increase functional capacity, provide pain relief and patient education¹⁹. A survey conducted in 2009 by PatientView for the National Audit Office supports this from the patient perspective, with around 35% of respondents saying that physiotherapy helped them a lot and a further 40% saying it helped them a little²⁰.

Before starting treatment, physiotherapists will perform a physical assessment of the RA patient to test function, range of joint motion, muscle strength, posture and respiratory function²¹. Once this has been determined, they will devise a personal treatment plan and may prescribe treatments, including exercises, hydrotherapy, manual therapy, acupuncture and pain relief techniques (including the use of TENS (transcutaneous electrical nerve stimulation)²². In addition, they can offer general advice about increasing activity levels, avoiding exercise-related injuries and provide walking aids or splints to help individuals with their mobility²³.

“Yes physiotherapy has helped me, especially hydrotherapy, which has helped immensely with regaining mobility. This in turn has given me a greater quality of life. The downside is that I find it difficult to access hydrotherapy at the point of need, as the general waiting list time is 6 months for an appointment.”

2.3 Access to physiotherapy

Access to physiotherapists typically is via three routes: referral by a GP or consultant to the local community service or hospital physiotherapy department; self-referral to see an NHS physiotherapist, available only in areas where the local NHS physiotherapy department participates in this scheme; or by self-referral to see a private physiotherapist²⁴.

There is scant public information about approaches to referral for RA-related physiotherapy. One of the few examples is a survey conducted in 2009 by Medix, commissioned by the National Audit Office (NAO) in England. In the survey results, physiotherapy was found to be the type of support to which doctors most commonly referred patients with RA, with 13 per cent of respondents saying they always referred people with RA for physiotherapy, 62 per cent saying they frequently did, 22 per cent saying they sometimes did, and 2 per cent saying they rarely did so²⁵. Taken at face value, these figures imply that in 2009 almost a quarter of GPs in England were not adopting best practice by giving all patients with RA access to specialist physiotherapy with periodic review, as set out in the relevant RA medical guidelines.

Moreover, there is evidence that issues are being compounded by the restricted provision of services. Scotland's *Clinical Audit of Care in Rheumatoid Arthritis*, published in 2008, concluded that there were significant variations in the availability of physiotherapy services in different rheumatology units and that all RA patients should have rapid access to all members of the multidisciplinary team²⁶. A census of acute trusts in England, published in 2009 by the NAO, also concluded that under 75 per cent of trusts were actually able to provide access to a physiotherapist for all patients who need them²⁷. A report by the UK Parliament's Public Accounts Select Committee in 2010 also concluded that there was inconsistent provision of multidisciplinary services by Primary Care Trusts in England²⁸. Given these constraints, it is therefore unsurprising that recent research has shown that general waiting times for physiotherapy can range from less than 1 week to over 52 weeks, with the majority of patients waiting 4-5 weeks for treatment, and significant variation in the referral to treatment targets set by NHS provider Trusts of between 2 to 19 weeks²⁹. Despite these challenges, the PatientView survey commissioned by the NAO, found that apart from medicines and surgery, the most common therapy received by people with RA is still physiotherapy (44%)³⁰.

The NAO also produced census findings about RA-related physiotherapy staffing levels in acute trusts and concluded that the mean Whole Time Equivalent (WTE) for physiotherapists at December 2008 was 1.2 with mean vacancies of 0.08. 104 trusts claimed that staffing levels were unchanged compared to 2007-08, with 14 trusts claiming that the number was higher and 15 saying that the number of physiotherapists had decreased. For those acute trusts that went outside to access physiotherapists the main explanations were that physiotherapy services were provided by, or accessed by the PCT (24), the trust only employed a generalised physiotherapist (7), or that the trust did not employ a physiotherapist (1). When asked what would improve the outpatient experience of people with RA, the seventh highest response (8 trusts out of 173) was an increase in access to physiotherapy services³¹.

“I have just started physio and it has given me hope that I will be able to be more mobile and carry out tasks that I cannot currently do.”

The final factor affecting the provision of physiotherapy services concerns workforce planning. For example, research by the Centre for Workforce Intelligence in England concluded that demand for physiotherapists in the NHS is likely to at least remain stable, or slightly increase going forward³². The Scottish Government’s *Long-term Conditions Action Plan* also acknowledges that workforce capability is critical for success³³.

2.4 Government policies

While the role of physiotherapy in the treatment of RA has been well acknowledged in the medical field³⁴, it is clear that actually measuring compliance and imposing best practice remains difficult, particularly as none of the medical guidelines concerning the management of RA are legally binding. However, rather than moving to make medical guidance obligatory, governments in England, Scotland, Wales and Northern Ireland have attempted to improve standards through developing strategies for the management and treatment of long-term conditions.

These strategies express universal desires to deliver high-quality services, like physiotherapy, to patients with long-term conditions in the community. This vision is strongly articulated in the *Musculoskeletal Services Framework*³⁵ (England), *Delivering for Health*³⁶ (Scotland), the *Service Development and Commissioning Directives: Arthritis and Chronic Musculoskeletal Conditions*³⁷ (Wales) and *Caring for People Beyond Tomorrow*³⁸ (Northern Ireland).

Other strategies also seek to give patients with long-term conditions greater choice and control over their care. In England, proposals in the *World Class Commissioning Vision* and *The NHS Next Stage Review* led the Department of Health to embark on a series of self-referral pilots for musculoskeletal physiotherapy³⁹. The pilot evaluation concluded that self-referral could help reduce waiting times across a pathway, support self-management, and produce cost savings for the NHS⁴⁰. Despite the success of these pilots, self-referral is still not comprehensively available around the UK with recent research indicating that self-referral is now available in just under 50% of NHS physiotherapy departments⁴¹.





However, the principles concerning greater choice and control continue to move forward and have been adopted in England by the Coalition Government within its health White Paper, *Equity and Excellence: Liberating the NHS*⁴². Meanwhile, Scotland's *Better Health, Better Care* strategy has echoed this with its commitment to launch a dedicated Long Term Conditions Collaborative to support NHS Scotland improve patient-centred services⁴³ and *The Healthcare Quality Strategy for NHS Scotland* committed the Scottish Government to implementing a *Long-Term Conditions Action Plan* to provide care that is responsive to the individual⁴⁴. The draft *Strategy for the Allied Health Professions in Northern Ireland 2011 – 2016*, published in 2011, also contains a goal that the AHP workforce will engage effectively with service users as partners in the planning and delivery of their care⁴⁵.

The concept of integration and the related importance of the multidisciplinary team is another recurrent theme. In Scotland, the *Delivering for Health* strategy and *The Delivery Framework for Adult Rehabilitation in Scotland* commits the Scottish Government to delivering integrated care⁴⁶, focusing on the roles of AHPs and asking NHS Boards and local authorities to identify how rehabilitation and integrated care services can be developed to meet the needs of people with long-term conditions⁴⁷. This included a commitment to develop new data sets for community based musculoskeletal rehabilitation to help healthcare professionals collectively map the patient journey⁴⁸. In Wales, the *Designed to Improve Health and the Management of Chronic Conditions in Wales: Service Improvement Plan 2008-11*, published in 2008, also flagged the importance of better anticipating the needs of individuals and ensuring that services are proactively coordinated⁴⁹. Northern Ireland's *Quality 2020 - A 10 Year Quality Strategy for Health and Social Care in Northern Ireland* and the draft *Long Term Conditions Policy Framework for Adults in Northern Ireland*, both published in 2011, also profess to want to enhance continuity⁵⁰ and promote holistic needs assessment for people with long term conditions⁵¹.

Another theme running through these strategies is speed of access. For example, the Scottish Government's *The Healthcare Quality Strategy for NHS Scotland* stresses the importance of a Long Term Conditions Mutual Care Model which cites faster access to healthcare for people with long term conditions as a goal⁵². In Northern Ireland, *A Healthier Future: A 20 Year Vision for Health and Wellbeing in Northern Ireland* also set out a vision of people being able to have immediate access to health and social services in their communities⁵³.

We hope this survey will be able to shed light on some of these key themes and provide valuable information for:

- Individuals with RA, about others' experiences of physiotherapy
- Policy makers, about the important contribution that physiotherapy services make to the treatment of RA and what can be done to improve services across the UK
- Service providers, about the quality of physiotherapy services being provided to patients and how this complies with the best practice identified in RA medical guidelines.

2.5 The survey and its methodology

The questions in the survey were developed from issues raised by NRAS members and calls to the NRAS helpline about problems accessing physiotherapy services and information requests about the reported benefits of this type of treatment.

A questionnaire was selected as the preferred method of data collection to be distributed to NRAS members. It was designed in conjunction with a university lecturer in physiotherapy and clinical physiotherapist, and a NRAS medical advisor. This was subsequently reviewed by a panel of NRAS members with RA. Questions and design were then subsequently amended to take account of these comments.

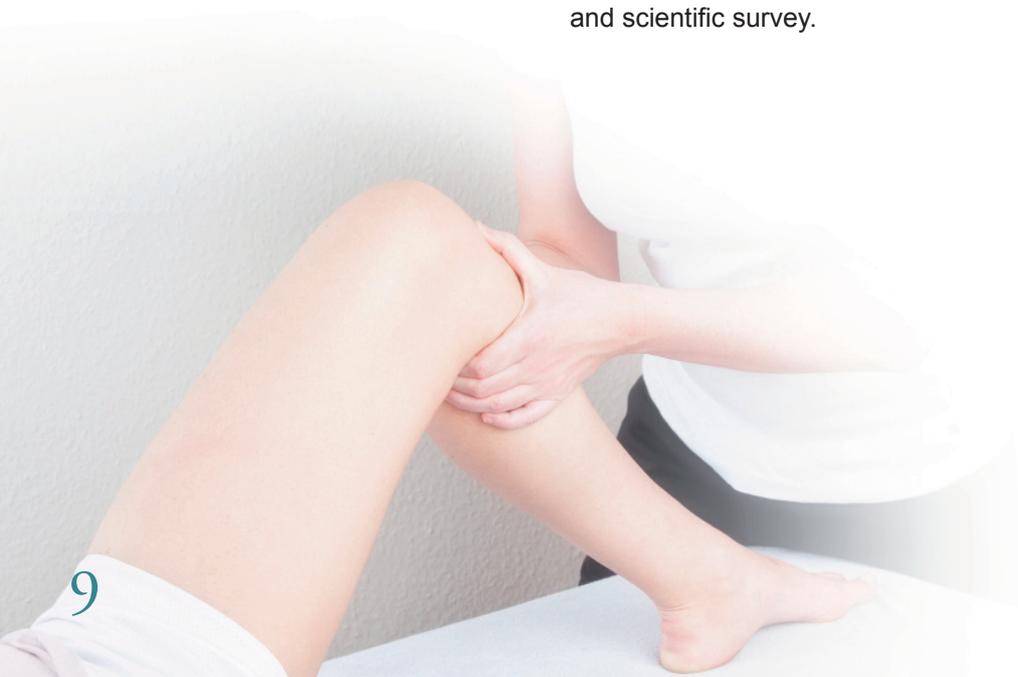
A series of closed questions were used in order to produce statistical evidence. In addition, an open question was included to give respondents the scope to express their own opinions.

NRAS sent out 2,303 electronic questionnaires to NRAS members with RA who had email addresses in August 2011. This excluded 771 healthcare professional members. A hard copy version of the questionnaire was then sent to a randomly selected NRAS community-based group during September 2011, where NRAS staff encouraged members to fill in survey responses.

Data that fell into discreet categories was analysed by coding the data and transferring it to Excel software for analysis. Percentages of particular groupings were then subsequently calculated and tabulated. Since NRAS did not have the scope to fully analyse the qualitative data produced by the survey, a small sample of these comments have been included throughout the report.

In total 248 questionnaires were returned. 3 questionnaires and incomplete responses were cleansed from the data. This meant that the total response rate of useable questionnaires was 10.6% out of 2,303. We would expect the response rate for this kind of survey to be about this. Assuming the respondents are representative of the sample then, with 95% confidence intervals, this gives an error range of $\pm 6\%$ in the worst possible case when calculating proportions.

This survey is therefore intended to yield suggestive rather than conclusive evidence, since NRAS does not have the resources available to execute a full and scientific survey.





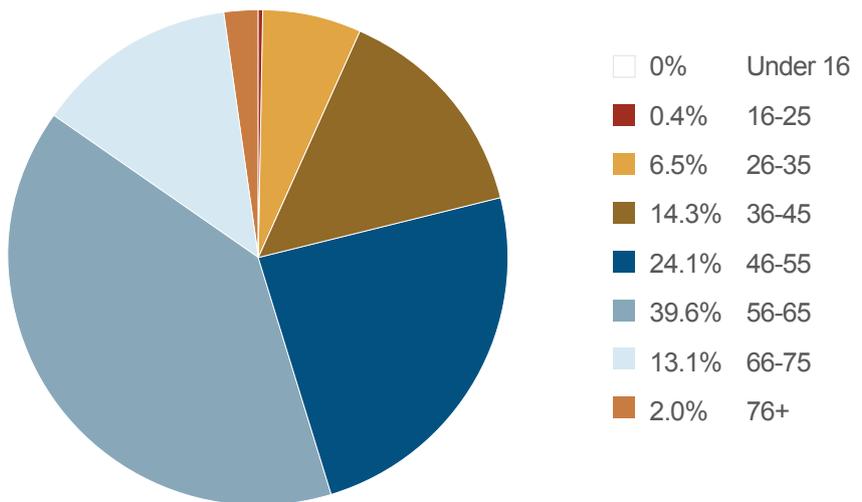
3 Key findings

3.1 The survey respondents

A total of 248 questionnaires were returned to NRAS. Of these, three responses were excluded because they were either incomplete or filled in incorrectly. Therefore, 245 respondents were included at the beginning of the survey. All the respondents who completed the survey have been diagnosed with RA.

Figure 1: Respondents' age

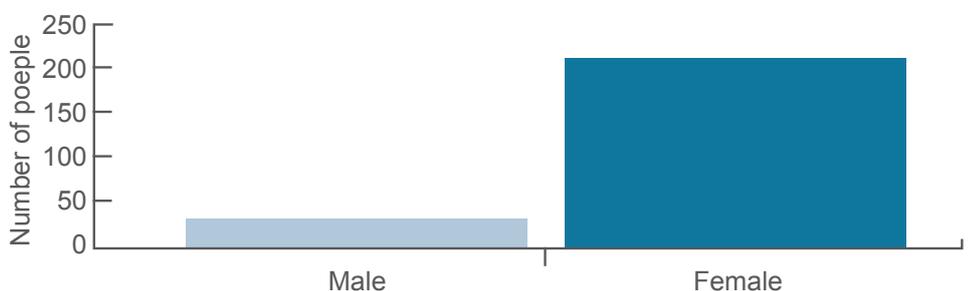
How old are you?



Of the 245 respondents, the largest age category were 56-65 year olds (39.6%). The next biggest age categories were 46-55 year olds (24.1%) and 36-45 year olds (14.3%). The sample population reflects the distribution we would expect to see in the general population. Although the disease can occur at any age, onset is usually between the ages of 30 to 55⁵⁴.

Figure 2: Respondents' gender

Are you male or female?

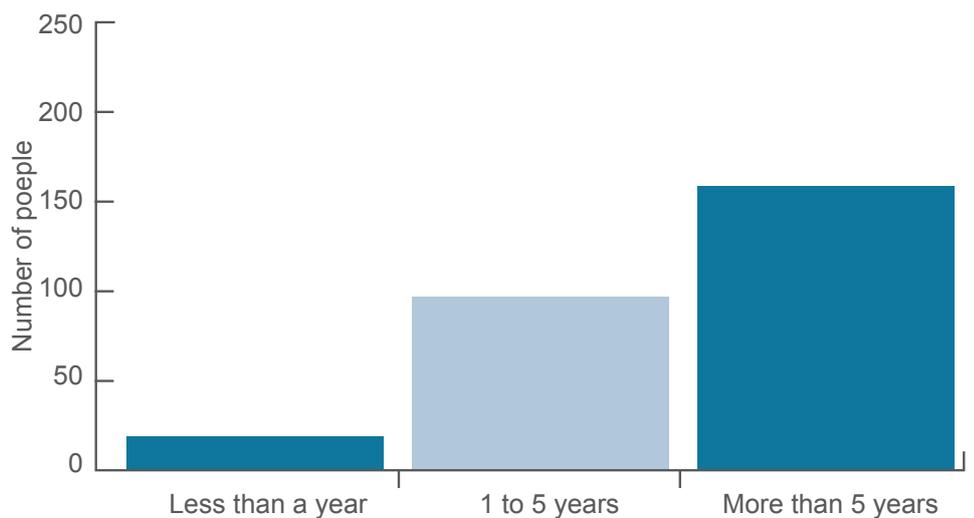


86.1% of the respondents were female and 13.9% were male. The proportion of women to men was slightly higher in the sample than we would expect to see in the RA population as a whole, where the ratio is estimated to be closer to 3:1 in favour of women⁵⁵. This gender bias is a recognised phenomenon in surveys of patient organisations, where group membership, regardless of medical condition, tends to be dominated by women⁵⁶.

“It has allowed me to do more exercise without the thought I would make it worse. I learnt how I could self assess so that I would perform more exercise and increase my strength.”

Figure 3: Respondents’ length of time living with RA

How long have you been diagnosed with Rheumatoid Arthritis?



The vast majority of respondents to the survey have been diagnosed and living with RA for over five years (62.4%). Almost another third of respondents had been diagnosed and living with the disease for between 1-5 years (31.4%). On the whole, the respondents in the sample population are relatively experienced at living with the disease. As a result, over time they will have had ample opportunity to discuss treatment strategies with clinicians and healthcare professionals involved in the management of their disease.

3.2 Access to physiotherapy

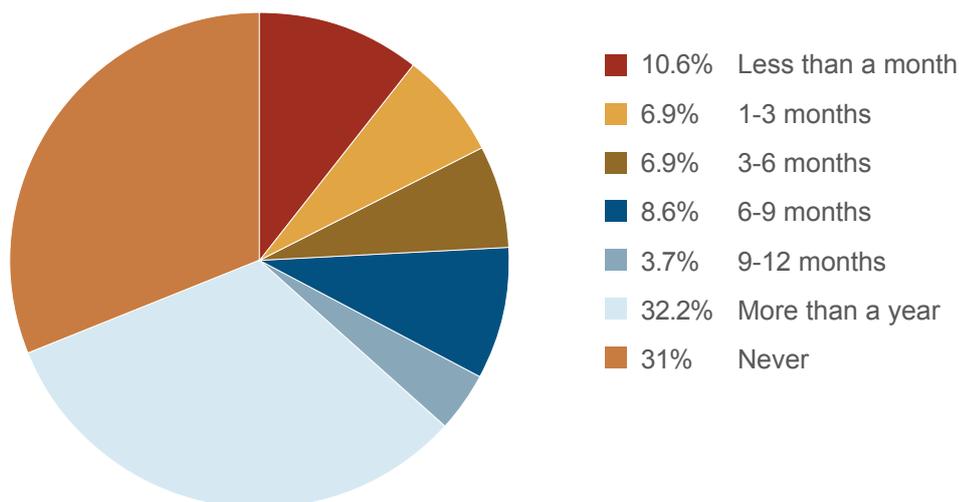
The data from this survey showed clear evidence of substantial delays in the time taken to refer patients with RA for physiotherapy. Most worryingly, a large portion of the sample population reported never having been referred to a physiotherapist for treatment. Of those who were referred, just over half the sample population waited 2-4 weeks or 1-2 months for treatment.

3.2.1 Time to referral

32.2% of respondents to the survey said they waited over one year for a referral from a medical practitioner to see a physiotherapist, while 31% of respondents said they had never been offered a referral to a physiotherapist. Only 10.6% of respondents reported waiting less than one month for a referral.

This survey data conflicts with the Medix research in 2009, that around a quarter of GPs were not complying with the medical guidelines, and referring only rarely. The NRAS data suggests that nearly a third of medical professionals, including GPs, are not adhering to medical guidelines. If figures for more than 1 year are taken into account, then the total number could be as high as nearly two-thirds.

Figure 4: How soon after being diagnosed with RA were you referred to a physiotherapist for treatment?



3.2.2 Time to treatment

76 respondents were excluded from this point forward because they had never been referred for physiotherapy on the NHS.

The data from the remaining 169 respondents found that 26.6% waited on average 1-2 months, followed closely by 24.9% who reported waiting 2-4 weeks. Strangely, 18.9% of the sample population responded that they didn't know how long they waited for treatment. This might be because there are very large discrepancies between the times taken for the same individual to obtain treatment, or that these individuals may have only had one short course of physiotherapy treatment. An equal number of people (10.7%) reported waiting times of 1-2 weeks or 2-4 months. However, the overall data complies with the average reported waiting lists for physiotherapy described in the literature review⁵⁷.

Figure 5: How long do you have to usually wait to see your physiotherapist?

Less than 1 week	6.5%
1-2 weeks	10.7%
2-4 weeks	24.9%
1-2 months	26.6%
2-4 months	10.7%
More than 6 months	1.8%
Don't know	18.9%

“A physiotherapist taught me how to get up from the floor, be more mobile and more confident in my ability to do things without more damage. I have had RA for 16 years but have always had to ask for physio even when a disc in my spine collapsed and they could not operate, they only offered opiates.”

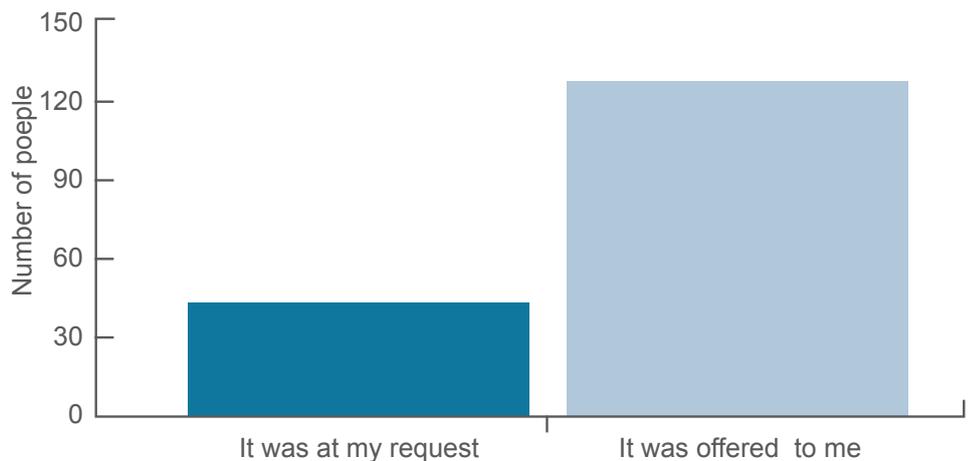
3.3 Pathway to referral

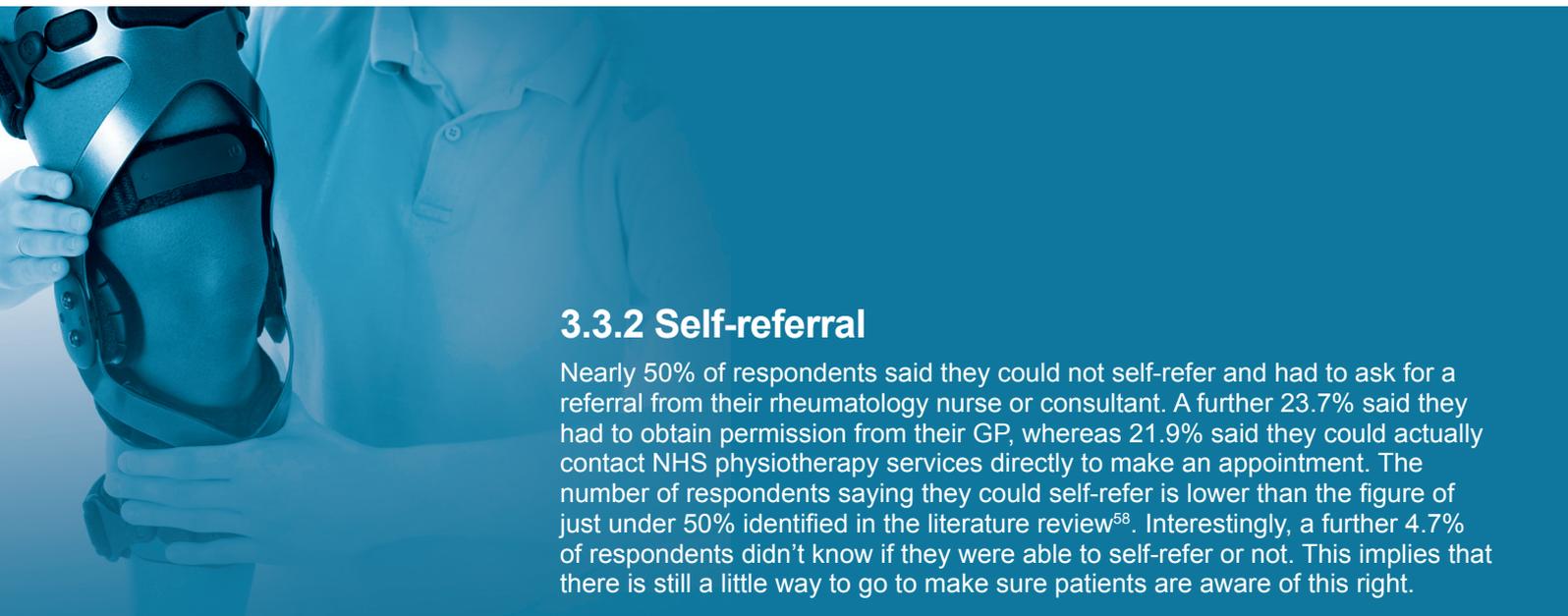
Strategies for managing long-term conditions focus on trying to increase patient involvement in decisions about their care and increase the ability to self-refer. The evidence from this survey suggests that referrals are still largely being directed by medical professionals and that opportunities for self-referral are not widely available.

3.3.1 Initiation

Nearly 75% of respondents said that the referral was offered to them and just under 25% said the referral for physiotherapy was at their request.

Figure 6: If you were referred to a physiotherapist, who prompted the referral?

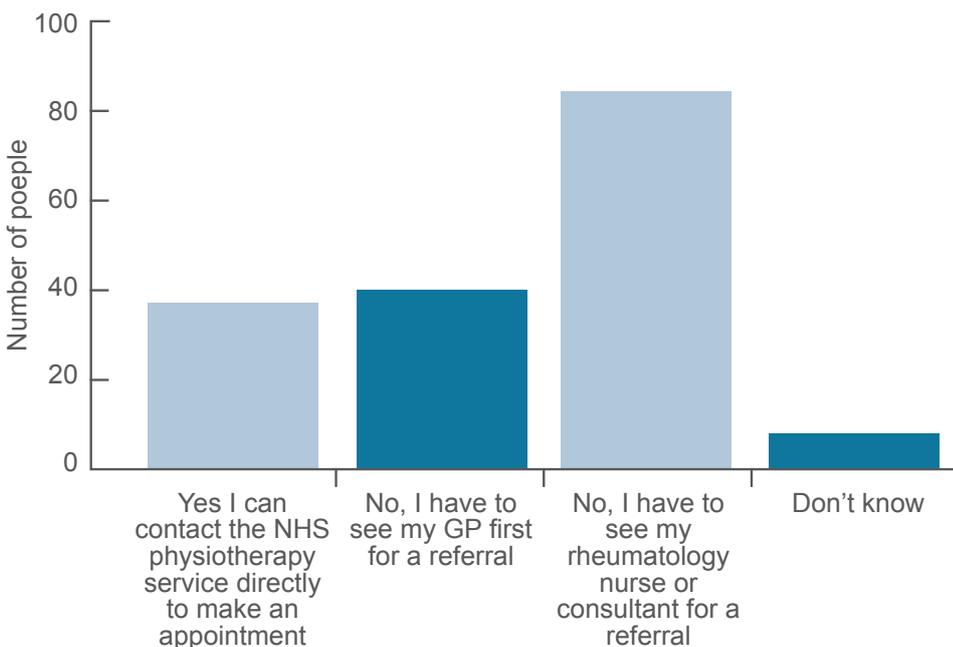




3.3.2 Self-referral

Nearly 50% of respondents said they could not self-refer and had to ask for a referral from their rheumatology nurse or consultant. A further 23.7% said they had to obtain permission from their GP, whereas 21.9% said they could actually contact NHS physiotherapy services directly to make an appointment. The number of respondents saying they could self-refer is lower than the figure of just under 50% identified in the literature review⁵⁸. Interestingly, a further 4.7% of respondents didn't know if they were able to self-refer or not. This implies that there is still a little way to go to make sure patients are aware of this right.

Figure 7: Can you self-refer to an NHS physiotherapy service if you need further treatment?



3.4 Level of integrated care

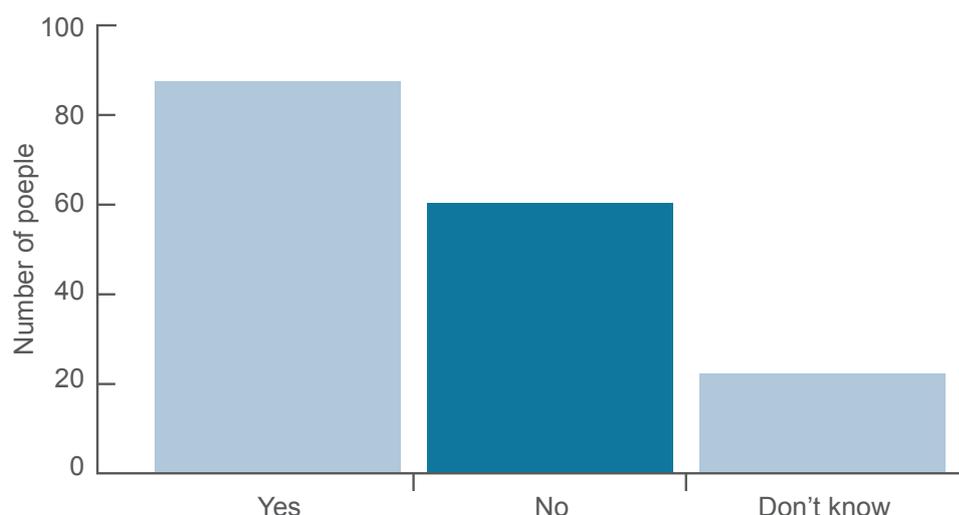
Medical guidelines for the treatment of RA and government strategies for people with long-term conditions both stress the importance of providing integrated care and making best use of the multidisciplinary team to deliver this. The evidence from this survey suggests there is still a sizeable gap between best practice and the patient experience on the ground, with an alarmingly high number of respondents reporting that their physiotherapy treatment was a 'one-off', which could be due to a variety of factors including onward referral, inappropriate referral, or forced rationing of services.

3.4.1 The multidisciplinary team

Just over half of respondents (51.5%) thought their physiotherapist was working as part of a consultant-led multidisciplinary team and, worryingly, a further 13% were not sure whether this was the case. This data would suggest that over a third of services being provided to RA patients contravene the medical guidelines on the treatment of RA, despite the best efforts of governments in England, Scotland, Wales and Northern Ireland to encourage this model of treatment.

“I have a lot of knee problems but physio has meant that I can undertake moderate cycling and hill walking. At one time I thought I would have to stop these activities.”

Figure 8: Does your physiotherapist work as part of a consultant-led specialist multidisciplinary team?

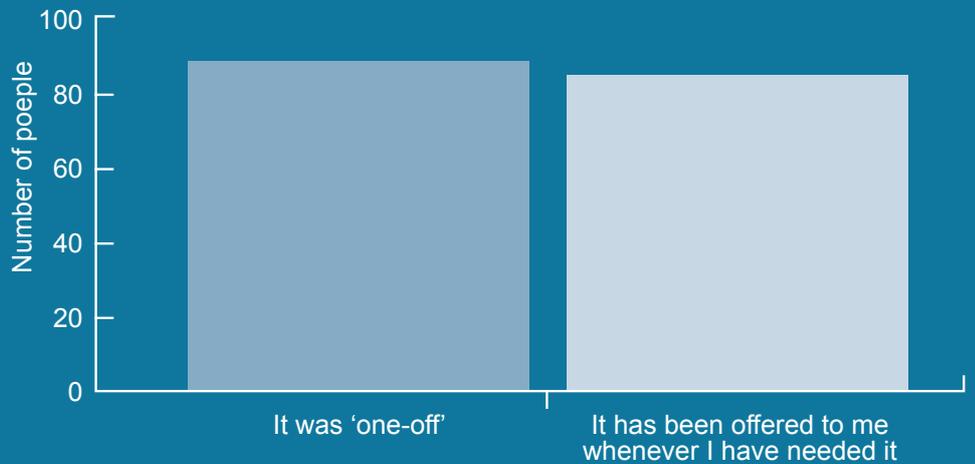


3.4.2 Style of intervention

Just over half of respondents (52.1%) regarded their experience of treatment as being a 'one-off' intervention prescribed as part of their rehabilitation following a specific medical event, such as RA-related surgery. However, the remainder of respondents did regard the service as part of the ongoing management of their disease.



Figure 9: Was your physiotherapy treatment ‘one-off’ or has it been offered to you whenever you needed it?



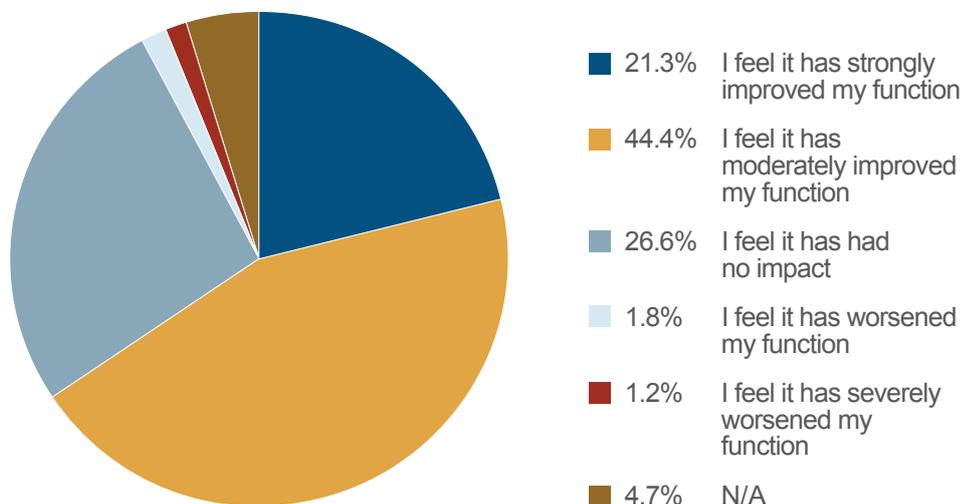
3.5 Impact of physiotherapy

The evidence from the survey supports the medical view that physiotherapy improves both function and mobility in the majority of people with RA, with a large proportion of the respondents reporting moderate improvements. However, the reported benefits of physiotherapy in this survey were slightly lower than the combined benefits reported in the PatientView survey (75%)⁵⁹. Despite this, the overall quality of physiotherapy services offered to people with RA was perceived to be of good quality.

3.5.1 Function

Nearly two-thirds of respondents (65.7%) felt physiotherapy either moderately or strongly improved the function of the parts of their body affected by RA. A mere 3% of the sample population thought physiotherapy had resulted in a worsening of their function.

Figure 10: Do you feel physiotherapy has had an impact on your function?



3.5.2 Mobility

Well over half of respondents (58.6%) felt physiotherapy either moderately or strongly improved their mobility. Again, a mere 2.4% of the sample population felt physiotherapy had resulted in a worsening of their mobility. 10.7% ruled the question inapplicable because the treatment did not have the potential to affect their mobility in the first place.

“It has provided education on joint protection and it has partially helped me perform tasks, my upper limbs have benefitted the most, unfortunately it has had little effect on my lower limbs as I still have poor mobility”

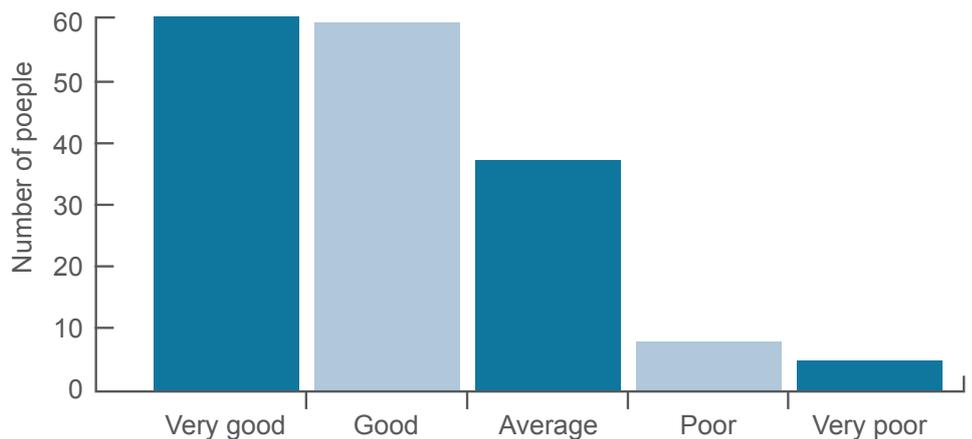
Figure 11: Do you feel physiotherapy has had any impact on your mobility?

I feel it has strongly improved my mobility	13.6%
I feel it has moderately improved my mobility	45%
I feel it has had no impact	28.4%
I feel it has worsened my mobility	1.8%
I feel it has severely worsened my mobility	0.6%
N/A	10.7%

3.5.3 Quality

Nearly three-quarters of respondents (70.4%) rated the quality of the physiotherapy they received as good or very good. Whereas less than one tenth (7.7%) rated their treatment as being of poor quality.

Figure 12: How do you rate the quality of the physiotherapy services you received?



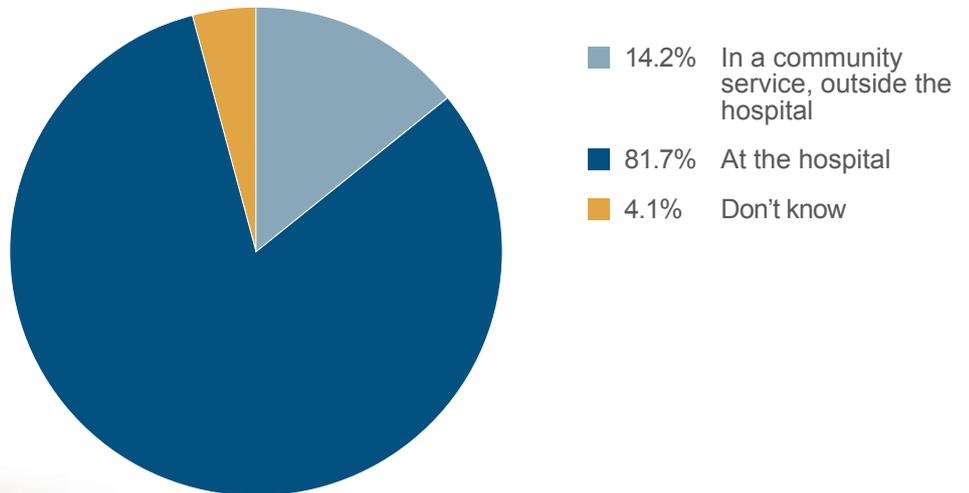
3.6 Responsiveness to the patient

Strategies for managing long-term conditions focus on trying to increase the amount of services provided by Allied Health Professionals in the community setting in an effort to be responsive to the patient. The evidence from the survey suggests that in the vast majority of cases this is not happening yet for physiotherapy services. Once referred, the survey suggests a mixed picture over the ease of contacting their physiotherapist with well over a third of respondents reporting that it is straightforward for them to contact their physiotherapist.

3.6.1 Location of physiotherapist

The overwhelming majority of respondents (81.7%) said their physiotherapist was hospital-based, with only 14.2% saying their physiotherapist was based in a community service outside of the hospital. This is clearly at odds with the vision for the management of long-term conditions articulated in government strategies. However, the survey does not reveal how many of these hospital-based services are operating as part of a multidisciplinary team.

Figure 13: Where is your physiotherapist located?

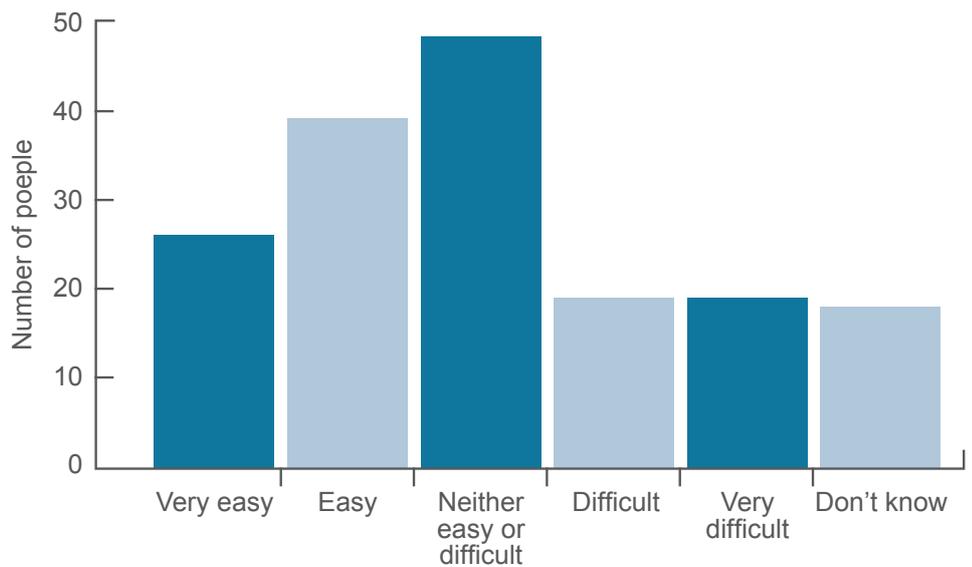


3.6.2 Ease of contact

38.5% of respondents said it was either easy or very easy to contact their physiotherapist, if required. The next largest category were those who said it was neither easy nor difficult (28.4%), with just under a quarter (21.9%) saying that it was either difficult or very difficult to contact their physiotherapist.

“I went initially after having operations on both knees. Unfortunately I was discharged and no longer go. I would of preferred to have continued to go for the extra support even if it was only every 6 months or so.”

Figure 14: How easy is it for you to contact your physiotherapist?



4 Conclusions and recommendations

4.1 Survey findings

- The data from this survey suggests there are substantial delays in the time taken to refer patients with RA for physiotherapy. Most worryingly, a large portion of the sample population reported never having been referred to a physiotherapist for treatment. In line with other published evidence, the survey suggests that a significant proportion of medical practitioners are not complying with best practice and failing to give all patients access to specialist physiotherapy with regular review, as stipulated in RA medical guidelines.



“I feel more regular reviews would be helpful as physiotherapy was only offered at an assessment appointment. The follow up never happened.”

- Strategies for managing long-term conditions focus on trying to increase patient involvement in decisions about their care and increase the ability to self-refer. The evidence from this survey suggests that referrals are still largely being directed by medical professionals and that opportunities for self-referral are not widely available.
- Medical guidelines for the treatment of RA and government strategies for people with long-term conditions stress the importance of providing integrated care and making best use of the multidisciplinary team to deliver this. There appears to be a sizeable gap between best practice and the patient experience, with an alarmingly high number of respondents reporting that their physiotherapy treatment was a ‘one-off’, which may be due to a variety of factors including onward referral, inappropriate referral, or forced rationing of services.
- The majority of our respondents support the view that physiotherapy can improve both the function and mobility of people with RA, and that the overall quality of physiotherapy services offered to people with RA is perceived to be of good quality.
- Strategies for managing long-term conditions focus on trying to increase the amount of services provided by Allied Health Professionals in the community setting in an effort to be responsive to the patient. However, this survey suggests that in the vast majority of cases it is not happening for physiotherapy services. However, once referred, a significant percentage of respondents do report that it is straightforward for them to contact their physiotherapist.

4.2 Recommendations

- There is limited public information available about provision and access to RA-related physiotherapy services around the UK. Governments in England, Scotland, Wales and Northern Ireland are urged to publish more information to enable a comprehensive assessment about the uptake of these services and referral practice.
- Depending on the results of a comprehensive audit, the governments of England, Scotland, Wales and Northern Ireland should consider bringing forward new measures to encourage best practice in referral for physiotherapy, including more information for RA patients about self-referral and expansion of its availability, and appropriate training for medical practitioners, particularly GPs.
- In addition to government actions, service providers must also do more to ensure that patients are given the right information soon after diagnosis about the importance of exercise in helping to strengthen muscles and keep joints supple, and how and when to contact a physiotherapist. It is vitally important that patients are given the opportunity to see a physiotherapist early on so these messages can be reinforced.
- We remain concerned that economic pressures being faced by these governments may result in indiscriminate cuts to physiotherapy services, with dire consequences for people with RA. Governments in England, Scotland, Wales and Northern Ireland are therefore urged to honour the pledges set out in their respective strategies for long-term conditions and to protect, or where possible, expand RA-related physiotherapy services.

“It has only been offered at times when there have been specific problems such as post-operative knee debridement and cartilage repair, neck mobility problems, trochanteric bursitis, post operative wrist replacement, post operative thumb joint fusion. In an ideal world it would be good to have some physio that aims to improve mobility such as gait, posture etc.”

5 More information

5.1 Thank you



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

Lindsay Bearne, Lecturer in Physiotherapy, King's College London

Becca Bryant, Head of Press and Public Relations, CSP

Ailsa Bosworth, Chief Executive, NRAS

Cathy Cameron, Physiotherapy Advisor, NRAS

Donna Castle, Head of Public Affairs and Policy, CSP

Katy Cooke, former Membership Manager, NRAS

Sarah Drew, Social Scientist and Data Analyst, NRAS

Phil Gray, Chief Executive, CSP

Linda Griffiths, Information Officer, CSP

Ruth Grosart, Online and Social Media Coordinator, NRAS

Tracey Hancock, Director of Development, NRAS

Jamie Hewitt, Government Affairs Manager, NRAS

Clare Jacklin, Director of External Affairs, NRAS

Becki Law, Doctoral Student, Bangor University

Victoria Manning, Research Associate, King's College London

Anne O'Brien, Lecturer in Physiotherapy, Keele University

Lorraine Tanner, Helpline Manager, NRAS

Steve Tolin, Professional Advisor, CSP

Editorial: Jamie Hewitt, Government Affairs Manager, NRAS

Design: AIT Marketing Associates www.ait-uk.com

6 Reference

“Physiotherapy has improved my sleep due to the advice given on positioning pillows and aids.”

- ¹ “The Economic Burden of Rheumatoid Arthritis” (March 2010) National Rheumatoid Arthritis Society: Maidenhead
- ² Sokka T, Hakkinen A, Kautiainen H, Maillefert JF, Toloza S, Mork hansen T, Calvo-Alen J, Oding R, Liveborn M, Huisman M, (2008) “Physical inactivity in patients with rheumatoid arthritis: Data from twenty-one countries in a cross-sectional, international study.” *Arthritis Care and Research* 59 (1): 42-50.
- ³ Metsios GS, Stavropoulos-Kalinoglou A, Veldhuijzen van Zanten JJCS, Treharne GJ, Panoulas VF, Douglas KMJ, et al. (2008) “Rheumatoid arthritis, cardiovascular disease and physical exercise: a systematic review.” *Rheumatology* 47(3):239-48.
- ⁴ Walsmith J & Ronenn Roubenoff R (2002) “Cachexia in rheumatoid arthritis.” *International Journal of Cardiology* (85): 89–99.
- ⁵ Van Staa TP, Geusens P, Bijlsma JWW, Leufkens HGM, Cooper C (2006) “Clinical assessment of the long-term risk of fracture in patients with rheumatoid arthritis.” *Arthritis & Rheumatism* 54 (10): 3104–3112.
- ⁶ Cooney JK, Law R-J, Matschke V, Lemmey AB, Moore JP, Ahmad Y, Jones JG, Maddison P & Thom J. (2011) “Benefits of Exercise in Rheumatoid Arthritis.” *Journal of Aging Research* 2011: 1-14.
- ⁷ Hurkmans E, van der Giesen FJ, Vliet Vlieland TPM, Schoones J, Van den Ende ECHM (2009) “Dynamic exercise programs (aerobic capacity and/or muscle strength training) in patients with rheumatoid arthritis.” *Cochrane Database of Systematic Reviews* No. 4. Art. No.: CD006853. DOI: 10.1002/14651858.CD006853. pub2.
- ⁸ Marcora SM, Lemmey AB, Maddison PJ (2005) “Can progressive resistance training reverse cachexia in patients with rheumatoid arthritis? Results of a pilot study.” *Journal of Rheumatology* 32(6):1031-9.
- ⁹ Lemmey AB, Marcora SM, Chester K, Wilson S, Casanova F, Maddison PJ (2009) “Effects of high-intensity resistance training in patients with rheumatoid arthritis: A randomized controlled trial.” *Arthritis Care and Research* 61(12):1726-34.
- ¹⁰ Vliet Vlieland TP, van den Ende CH (2011) “Nonpharmacological treatment of rheumatoid arthritis.” *Current Opinion in Rheumatology* 23 (3): 259-64.
- ¹¹ Bostrom C, Harms-Ringdahl K, Karreskog H, Nordemar R (1998) “Effects of static and dynamic shoulder rotator exercises in women with rheumatoid arthritis: a randomised comparison of impairment, disability, handicap, and health.” *Scandinavian Journal of Rheumatology* 27(4): 281-90.
- ¹² Law R-J, Breslin A, Oliver EJ, Mawn L, Markland DA, Maddison P & Thom, JM (2010) “Perceptions of the effects of exercise on joint health in rheumatoid arthritis patients.” *Rheumatology*, 49 (12): 2444–2451.
- ¹³ Ibis
- ¹⁴ Neuberger GB, Aaronson LS, Gajewski B, Embretson SE, Cagle PE, Loudon JK, et al. (2007) “Predictors of exercise and effects of exercise on symptoms, function, aerobic fitness, and disease outcomes of rheumatoid arthritis.” *Arthritis Care and Research* 57(6): 943-52.
- ¹⁵ R. Luqmani R, Hennell S, Estrach C, Birrell F, Bosworth A, Davenport G, Fokke C, Goodson N, Jeffreson P, Lamb E, Mohammed R, Oliver S, Stableford Z, Walsh D, Washbrook C, Webb F (2006) “British Society for Rheumatology and British Health Professionals in Rheumatology Guideline for the Management of Rheumatoid Arthritis (The first 2 years)”
- ¹⁶ “Rheumatoid arthritis: the management of rheumatoid arthritis in adults” Clinical Guideline 79 (February 2009) National Institute for Health and Clinical Excellence: London.
- ¹⁷ “Management of early rheumatoid arthritis: A national clinical guideline” Guideline 123 (February 2011), Scottish Intercollegiate Guidelines Network: Edinburgh.
- ¹⁸ Combe B, Landewe R, Lukas C, Bolosiu HD, Breedveld F, Dougados M, et al. (2007) “EULAR recommendations for the management of early arthritis: report of a task force of the European Standing Committee for International Clinical Studies Including Therapeutics (ESCI-SIT)” *Annals of the Rheumatic Diseases* 66 (1): 34-45.
- ¹⁹ Sandy B, Ganz PT, Harris LL (1998) “General overview of rehabilitation in the rheumatoid patient.” *Rheumatic Disease Clinics of North America* 24 (1): 181-201.
- ²⁰ “Patient Groups on Rheumatoid Arthritis and the NHS: A national survey of patient organisations and other health campaigners.” (February 2009) PatientView: Powys.
- ²¹ Kavuncu V & Evcik D (2004) “Physiotherapy and Rheumatoid Arthritis.” *MedGenMed* 6(2): 3
- ²² “Rheumatoid arthritis: the management of rheumatoid arthritis in adults” Clinical Guideline 79 (February 2009) National Institute for Health and Clinical Excellence: London.
- ²³ “Physiotherapy and Arthritis” (April 2011) Arthritis Research UK: Derbyshire.
- ²⁴ Ibis
- ²⁵ “Survey of general practitioners about the diagnosis and management of rheumatoid arthritis” Market research report prepared for the National Audit Office (February 2009) Medix UK: Hertfordshire.
- ²⁶ Porter D & McEntegart A “Clinical Audit of Care in Rheumatoid Arthritis” (December 2008) NHS Quality Improvement Scotland: Edinburgh.
- ²⁷ “Services for People with Rheumatoid Arthritis” (February 2009) National Audit Office: London.

6 Reference

“After hand surgery, I regained function back in my right hand rather quickly. It was great to have the support from physiotherapists at this time. I’m right handed, which needed the surgery to save the function of it – it was a rather stressful time, but the physiotherapists helped me so much. I am eternally grateful.”

- ²⁸ “Services for People with Rheumatoid Arthritis” (February 2010) Tenth Report of Session 2009–10, House of Commons Committee of Public Accounts: London.
- ²⁹ Jones, R, Jenkins, F (2011) “A survey of NHS Physiotherapy Waiting times and musculoskeletal workload in England 2009-2010 report”, CSP: London.
- ³⁰ “Patient Groups on Rheumatoid Arthritis and the NHS: A national survey of patient organisations and other health campaigners.” (February 2009) PatientView: Powys.
- ³¹ “Services for people with rheumatoid arthritis: Background and main findings from National Audit Office (NAO) census of NHS rheumatology units” (February 2009) National Audit Office: London.
- ³² “Physiotherapy Workforce Review” (24 August 2010) The Centre for Workforce Intelligence: London.
- ³³ “Improving the Health & Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan” (16 June 2009) The Scottish Government: Edinburgh.
- ³⁴ Dziedzic K, Hammond A (2010) “Rheumatology: Evidence-Based Practice for Physiotherapists and Occupational Therapists” Elsevier: Edinburgh
- ³⁵ “Musculoskeletal Services Framework” (12 July 2006) The Department of Health: London.
- ³⁶ “Delivering for Health” (02 November 2005) The Scottish Executive: Edinburgh.
- ³⁷ “Designed for People with Chronic Conditions - Service Development and Commissioning Directives: Arthritis and Chronic Musculoskeletal Conditions” (May 2006) Welsh Assembly Government: Cardiff.
- ³⁸ “Caring for People Beyond Tomorrow” (October 2005) Department of Health, Social Services and Public Safety: Belfast.
- ³⁹ “High quality care for all: NHS Next Stage Review final report” (30 June 2008) The Department of Health: London.
- ⁴⁰ “Self-referral pilots to musculoskeletal physiotherapy and the implications for improving access to other AHP services” (21 October 2008) The Department of Health: London.
- ⁴¹ Jones, R, Jenkins, F (2011) “A survey of NHS Physiotherapy Waiting times and musculoskeletal workload in England 2009-2010 report”, CSP: London.
- ⁴² “Equity and excellence: Liberating the NHS” (12 July 2010) The Department of Health: London.
- ⁴³ “Better Health, Better Care: Action Plan” (12 December 2007) The Scottish Government: Edinburgh.
- ⁴⁴ “The Healthcare Quality Strategy for NHSScotland” (10 May 2010) The Scottish Government: Edinburgh.
- ⁴⁵ “A Strategy for the Allied Health Professions in Northern Ireland 2011 – 2016: Consultation Document” (June 2011) The Department of Health, Social Services and Public Safety: Belfast.
- ⁴⁶ “Delivering for Health” (2 November 2005) The Scottish Executive: Edinburgh.
- ⁴⁷ “Co-ordinated, integrated and fit for purpose: A Delivery Framework for Adult Rehabilitation in Scotland” (February 2007) The Scottish Executive: Edinburgh.
- ⁴⁸ “Consultation on Recommendations for a Scottish minimum data set for community based musculoskeletal rehabilitation” (11 June 2010) The Scottish Government: Edinburgh.
- ⁴⁹ “Designed to Improve Health and the Management of Chronic Conditions in Wales: Service Improvement Plan 2008-11” (January 2008) Welsh Assembly Government: Cardiff.
- ⁵⁰ “Quality 2020 - A 10 Year Quality Strategy for Health and Social Care in Northern Ireland” (January 2011) The Department of Health, Social Services and Public Safety: Belfast.
- ⁵¹ “Living with Long Term Conditions: A Policy Framework (Consultation Document)” (February 2011) The Department of Health, Social Services and Public Safety: Belfast.
- ⁵² “The Healthcare Quality Strategy for NHSScotland” (10 May 2010) The Scottish Government: Edinburgh.
- ⁵³ “A Healthier Future: A Twenty Year Vision for Health and Wellbeing in Northern Ireland 2005-2025” (December 2004) The Department of Health, Social Services and Public Safety: Belfast.
- ⁵⁴ “Patient Groups on Rheumatoid Arthritis and the NHS: A national survey of patient organisations and other health campaigners.” (February 2009) PatientView: Powys.
- ⁵⁵ Symmons DP, Barrett EM, Bankhead CR et al. (1994) “The incidence of rheumatoid arthritis in the United Kingdom: Results from the Norfolk Arthritis Register.” *British Journal of Rheumatology* 33(8): 735–739
- ⁵⁶ “Patient Groups on Rheumatoid Arthritis and the NHS: A national survey of patient organisations and other health campaigners.” (February 2009) PatientView: Powys.
- ⁵⁷ Jones, R, Jenkins, F (2011) “A survey of NHS Physiotherapy Waiting times and musculoskeletal workload in England 2009-2010 report”, CSP: London.
- ⁵⁸ Jones, R, Jenkins, F (2011) “A survey of NHS Physiotherapy Waiting times and musculoskeletal workload in England 2009-2010 report”, CSP: London.
- ⁵⁹ “Patient Groups on Rheumatoid Arthritis and the NHS: A national survey of patient organisations and other health campaigners.” (February 2009) PatientView: Powys.



nras

National Rheumatoid
Arthritis Society

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

Telephone: 01628 823 524
0845 458 3969
Freephone Helpline: 0800 298 7650

Email: enquiries@nras.org.uk
www.nras.org.uk

A private company limited by guarantee.
Registered in England and Wales Number: 7127101
Registered Charity Numbers: 1134859 SCO39721