Rheumatology Nurse Specialists
Adding Value to Care

Report and results of a survey carried out by the National Rheumatoid Arthritis Society in collaboration with the Scottish Society for Rheumatology on Rheumatology Nurse Specialists in Scotland

21 RNS across Scotland took part in the survey which represents approximately two-thirds of the total number of experienced RNS in Scotland
Background

In January of this year, we were delighted to hear the announcement from the First Minister that an additional £2.5m will be invested in specialist nursing and care from 2015/16. At that time we immediately got in touch with the office of the Chief Nursing Officer to make the case for increased funding of Rheumatology Nurse Specialists (RNSs) in Scotland. We gave relevant statistics and information about the value of RNSs, and they have kept us updated since then on this spending announcement.

We are aware of workforce issues in regard to specialist nursing posts in rheumatology in some Health Boards (as we have received reports this year from areas where there is concern regarding lack of nurse specialist resource). We were notified in early July that the Chief Nursing Officer had written to Nurse Directors in the NHS territorial boards on 7th May 2015 to request that they carry out an initial scoping exercise of specialist nursing services to identify gaps and to inform local decisions on how the Specialist Nursing & Care Funding should be used. We wrote to all Nurse Directors advising that we would shortly carry out our own survey in collaboration with the Scottish Society for Rheumatology; this survey ran from 8th-20th August 2015.

With 22 respondents, more than two thirds of current RNSs in Scotland, we hope that the data from this survey will be helpful in creating a better understanding of the issues faced by people living with rheumatological and musculoskeletal conditions and how vital the role of the Rheumatology Nurse Specialist is to these patients. Each Health Board has the opportunity to allocate their share of the funding and we hope rheumatology nursing will be given the recognition it deserves. On this occasion, £0.9m of the promised £2.5m has been ring fenced at a Scottish Government level to fund additional specialist nursing for patients with motor neurone disease. We hope that this report will help to raise the profile of rheumatology. Rheumatological and musculoskeletal conditions are overdue equal recognition in the policy making process to other, higher profile long term conditions and this report is intended to ensure better recognition in future.

Role of Rheumatology Nurse Specialists (RNSs)

From the experience of our members, the National Rheumatoid Arthritis Society (NRAS) knows that Rheumatology Nurse Specialist care is central to the delivery of high quality care and improved patient outcomes for people with rheumatoid arthritis (RA).

Rheumatology Nurse Specialists carry out a wide range of activities as part of their role, including managing physical and psychological morbidity, alleviating physical and psychological suffering, rescue work and resolving unsatisfactory patient experience.¹ The Nursing and Midwifery Council identifies four main work domains: advanced clinical or

¹ Royal College of Nursing, Clinical nurse specialists: adding value to care, 2010
professional practice, facilitating learning, leadership and management and research practice.\(^2\)

"I am a safety net for my patients"

The current level of provision means that many RNSs are struggling to deliver even a core service and do not have sufficient time to innovate or develop professional practice. Our survey has shown that many RNSs are unable to deliver more than the core service expected from them of a Nurse Led Clinic and a Helpline service.\(^3\)

There is wide agreement about the very important role played in rheumatology care by RNSs. The Scottish Public Health Network’s Healthcare needs assessment of RA named specialist nursing as an ‘essential element’ of the specialist multi-disciplinary team (MDT).\(^4\) In addition, numerous academic and clinical studies have identified the

\(^{2}\) Nursing and Midwifery Council,  
\(^{3}\) NRAS RNS Survey 2015, Page 5.  
effectiveness of RNSs in treating and managing RA. Nurse Specialists have been shown to have a significant beneficial effect on patient outcomes. In particular, specialist nursing has been shown to improve patient satisfaction with care\(^5\), quality of life\(^6\) and fatigue.\(^7\) Having strong complementary care from specialist nurses and consultants is invaluable and whilst nurse led care alone will not lead to superior outcomes than consultant led care, it has been found to be equally effective.\(^8\)

One of the key responsibilities of the RNS is patient education and information. They are also an important conduit to helping to empower the patient to self-manage. It is widely known and indeed embedded within Government policy that enabling patients with long term conditions to self-manage more effectively is going to be key to reducing the burden on the health system of treating this large group who consume 70% of the health budget. In Scotland there are two rheumatology units who are successfully delivering the NRAS RA Self-Management programme and the results achieved to date, as measured by the Health Education Impact Questionnaire (HEIQ), have shown that the participants have achieved sustained improvement across a number of the domains measured which has been at a higher level than is currently being achieved when compared to ‘national’ statistics.

**Current Provision**

NRAS has concerns that RA patients in Scotland currently have inconsistent and at times inadequate access to RNSs. The Scottish Intercollegiate Guideline Network (SIGN) Guideline on RA sets out that all patients should have access to a specialist multi-disciplinary team including specialist nursing.\(^9\) However, the ScotPHN report found that provision of core multi disciplinary teams (MDTs) was ‘patchy’.\(^10\) SNARE audit data found that 18% of RA patients did not see a Rheumatology Specialist Nurse during the first 6 months of rheumatology care.\(^11\) In NRAS’s view, ensuring consistent and adequate provision of RNSs must be a priority. Additional resourcing of specialist nurses within rheumatology could facilitate a number of mechanisms and practices which would improve patient care and outcomes as well as reducing costs.

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\(^7\) Kosvik et al. ‘Patient Satisfaction with nursing consultations in a rheumatology outpatient clinic: a 21 month randomised controlled trial in patients with inflammatory arthritides, Annals of Rheumatic Disease, 2013, 72 836-843


\(^9\) SIGN Guideline 123, Management of early Rheumatoid Arthritis, 2011


Pleasingly, survey respondents reported that in their areas the vast majority of patients were seen within 1-2 days if they experienced a flare.\textsuperscript{12} When they are seen, these patients will, by and large, be seen by an RNS,\textsuperscript{13} further highlighting the need for consistent access to RNSs across Scotland and for investment to ensure their future provision, both for the benefit of patients being treated promptly and a reduced pressure on the (limited and expensive) time of consultants. In areas where there is no RNS, it is likely that the patient will not be seen until their next scheduled appointment which could be months away.

We have had reports of understaffing in units across Scotland. In some severe cases there were no RNSs within a Health Board area for years at a time; this understaffing has knock-on consequences. Our survey has found that the majority of clinics in Scotland are unable to offer community based care either in the form of primary care clinics or home visits.\textsuperscript{14}

Current staffing levels are worrisome but there is even further cause for concern in the future. Over half of RNSs in Scotland are over the age of 55\textsuperscript{15} and yet on self-reporting

\textsuperscript{12} NRAS RNS Survey 2015, Page 8
\textsuperscript{13} ibid. Page 9
\textsuperscript{14} ibid. Page 13
\textsuperscript{15} NRAS RNS Survey 2015, page 2
from RNSs, it would appear that no health board has a permanent, structured nurse training programme in place to address succession planning.16

**Helplines**

Our members throughout Scotland have told us that patient helplines are extremely important to their care. As resources have been squeezed, NRAS has seen such services be decommissioned, or reduce the number of patients who can access the service. This has been the case in at least one hospital in Scotland where the helpline was recently discontinued. Whilst it has now been reinstated, it is currently only available for the newly diagnosed. This has left those with established disease, who often need prompt treatment during a flare, or who have concerns about their RA in relation to co-morbidity or polypharmacy, without a crucial form of support.

Studies have shown the effectiveness of RNS-staffed rheumatology helplines. A review of the function of a telephone helpline in the treatment of outpatients with RA concluded that ‘the provision of the helpline service contributes to the quality of care provided by an outpatient department and provides benefit to the NHS’.17 The study found that over 95% of surveyed callers were satisfied with all aspects of the helpline service.18 In addition, 60% of surveyed patients said that had the helpline not been available, they would have made an appointment with their GP.19 The study extrapolated from this that the helpline produced a cost saving to the NHS, largely as a result of GP consultations which were avoided.20 NRAS believes that investment in RNSs to restore full provision of helpline service at each unit in Scotland would be of great benefit to service users and, combined with an increase in community care, could greatly reduce pressure on outpatient clinics and consultant time. The availability of a telephone helpline fits with current models of self efficacy and patient empowerment and is a crucial tool in helping patients manage their long term condition.

**Financial benefits**

As suggested by the findings highlighted above - that RNS-staffed helplines can help avoid GP consultations - there is strong evidence that RNSs provide very good value for money and can deliver significant savings. The Royal College of Nursing (RCN) estimate that outpatient work done by RNSs is worth £72,128 per annum per nurse but delivers savings of £175,168 per annum per nurse by freeing up consultant appointments.21

The economic burden of RA on the Scottish economy due to reduced productivity is significant. The 2009 NAO report puts the figure at £4.8bn per annum across the UK. They also state that the cost of treating RA in England alone is £580M and we therefore

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16 ibid. Page 18
18 Ibid.
19 Ibid.
20 Ibid.
21 Royal College of Nursing, Clinical nurse specialists: adding value to care, 2010
estimate the cost to health services in Scotland of treating RA is approximately £58 million per annum. Early intervention and treatment can minimise this burden significantly.

In addition to being crucial for improved patient outcomes, the provision of RNSs can help to avoid more costly NHS interventions, such as emergency admissions. A study comparing the effectiveness of RNS and consultant rheumatologist led care found that patients under specialist nurse led care had greater improvement in disease activity, despite fewer changes to their medication and fewer x-rays or steroid injections being ordered. Patients under nurse-led care also had fewer unplanned hospital admissions or visits to A&E.\(^{22}\)

Whilst not specific to the provision of RNSs, ScotPHN’s Health Care Needs Assessment does contain some estimate of the costs of its recommendations and the savings they could generate. These include the greater provision of members of the Multi-Disciplinary Team. ScotPHN sets out that the cost of a Clinical Nurse Specialist (AfC 7: point 31; 1WTE), including on-costs would be £44,834. ScotPHN HCNA emphasises that ‘access to a specialist MDT should promote more rational management of the disease and more effective prescribing of RA drugs, especially biologics…this may result in a future cost saving through reduction in more frequent and later intervention.’\(^{23}\)

**Future services**

It is the view of both our patient member and healthcare professional stakeholders, that adequate provision of RNSs is crucial to improving the quality of care experienced by patients with rheumatoid arthritis and other rheumatological conditions and can play a pivotal role in driving much needed service re-design and innovation in relation to more effective delivery of care.

Given the number of people living with serious rheumatological diseases (such as RA, psoriatic arthritis, ankylosing spondylitis, lupus and other auto-immune related conditions) which are followed up in specialist care, where the cornerstone of the multi-disciplinary team is the Nurse Specialist, we think it imperative that rheumatology is one of the beneficiary areas for consideration of this funding allocation in each Scottish Health Board, and the findings of our recent survey support this.


\(^{23}\) ScotPHN, Healthcare Needs Assessment for Adults with Rheumatoid Arthritis, Part D
Case for increased funding of Rheumatology Nurse Specialists in Scotland