Royal College of Nursing

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Contents

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BHPR British Health Professionals in Rheumatology

ACUMeN

KEELE UNIVERSITY

This report outlines the results of the performance and activity of the rheumatology nurse. Allied Healthcare Professional evidence should be sought from the British Health Professionals in Rheumatology (BHPR) **www.rheumatology.org.uk**

Foreword

The RCN Rheumatology Nursing Forum (RCNRF) joined forces with the British Health Professionals in Rheumatology (BHPR) and the Nurse Consultant Group in Rheumatology to identify the contribution that nurses and allied health care professionals (AHPs) make to delivering effective high quality care to patients. A previous report by Carr (2001) outlined nurse and AHP activity and scoped the extended roles. Since 2001 there have been significant changes to health care delivery and there is a pressing need to evaluate high quality care and workforce planning needs to ensure the future delivery of care outlined in the *Next stage review* (Department of Health, 2008a, 2008b).

The collaboration included nurses, AHPs and academic leads in education, who worked together to prepare the questionnaire. It is thanks to the expertise of a these specialists and the time that they have given in the questionnaire preparation, together with permission to adapt original questionnaires, that it has been possible to develop a tool for nurses and AHPs.

Health policy and evidence on the provision of services has failed to capture adequately the hidden benefits of specialist nurses and AHPs (Leary et al., 2008). Patients have highlighted the value of the multidisciplinary team, and how support from the team has the potential to improve self-management and ultimately long-term outcomes (King's Fund, 2009).

High quality care for all (Department of Health, 2008) highlights a number of work streams to improve quality within the National Health Service (NHS). The drive to improve care focuses on improving leadership, workforce planning, and a renewed focus on quality combined with better metrics to identify evidence based effective care that is valued by patients. *World class commissioning* has outlined the importance of working with specialist teams to understand the service needs and plan future services if high quality care is it to be delivered (Department of Health, 2008c). This report provides an up to date snapshot of rheumatology nursing services and identifies the scope and breadth of nursing activity. As a result it should prove an important resource for commissioners seeking to understand and plan the provision of the specialist support and the workforce needs to commission and deliver high quality care (DH, 2008c).

Susan Oliver
Chair of the RCN Rheumatology Nursing Forum

Executive Summary

There has always been a challenge in describing the complex nature of nursing care and how to measure the vital components patients value and need. (Royal College of Nursing, 2003) In recent years with a renewed focus on cost effectiveness and a wish to identify metrics that demonstrate quality outcomes it is vital that nurses can describe and clearly define what they are delivering.

Rheumatology services have to date never been included in any national policy initiatives. It is therefore rewarding to see that many rheumatology nurses have developed to provide for the needs of the service. This is of particular importance as currently community expertise for rheumatological conditions is somewhat limited. This has resulted in strong although not always fully resourced reliance on the nurses working in this specialist field. In addition, nursing curricula include minimal, if any, content related to rheumatological conditions, so much of the expertise in this field has been developed after qualifying.

Patients who receive care from a rheumatology service with nursing and multidisciplinary team support report greater satisfaction with care and confidence in managing their condition (King's Fund, 2009). Patient outcomes are enhanced as a result of good communication between community and specialist teams, particularly with the use of telephone advice line services which provide vital contact for patients and community teams. These activities often go unrecognised in terms of activity data and funding. Because of the limited data collection and lack of targets it has been difficult to demonstrate how nurses aspire to deliver high quality care for those with rheumatological conditions. It is hoped this survey can provide a greater insight into the roles and responsibilities nurses undertake and outline some important workforce issues that need to be considered when planning future services.

This survey is one component of work to demonstrate the value of rheumatology nursing. A pilot study has been commissioned by the RCN Rheumatology Nursing Forum using a computer software programme (Pandora) to capture the essence of specialist nursing using eight specific dimensions that demonstrate how 'rescue work' and 'brokering care needs' across organisations can improve patient outcomes and reduce health care costs (Leary et al, 2008). The results of this pilot project will be published in December 2009.

Key findings

This report provides preliminary data about the work and activity profile of nurses working in the rheumatology field. The survey results explore the qualifications, training needs, self-reported perceptions of competency and work productivity of rheumatology nurses.

The survey has provided some valuable insights into the role of the nurse. Some examples of the information collected outline the significant nursing activity undertaken, and the challenges to future service provision. They include:

- this is an ageing workforce (mean age 48 years)
- the majority of nurses held a Band 7 post.

Qualifications

- thirty three per cent held a teaching qualification
- twenty six per cent were nurse prescribers
- twenty two per cent held a Masters qualification.

Clinics and day care

- forty eight per cent of nurses were carrying out administrative, non-clinical tasks that could be delegated to clerical staff.
- forty four per cent of nurses stated they had changed their usual work pattern or taken on extra hours. The reasons for these changes included:
  - extra clinic/hours required
  - changes in the role/service
  - loss of staff or extra staff
  - increase patient caseload and biologic therapies
  - increased administrative duties.

- nurses provided care to a wide range of rheumatological conditions
- the majority of nurses ran between four to five clinics per week
- the majority had new and follow-up appointment slots for 30 minutes. Although further sub-analysis is required to identify nurses who work full or part time, this needs to be considered when looking at some of the results (for example tables 3, 6 and 10)
- one or two extra patient appointments were added to each clinic session
- nurses ran telephone support advice lines for between 3-10 hours per week
- day case activity has increased and the majority of nurses managed between 1-10 patients per week
- eight per cent of nurses were currently carrying non-specialist, ward-based activities. The amount of time spent on these activities ranged from 2-72 hours
- the range of additional tasks undertaken by the nurse was significant and included: subcutaneous injections; intra-articular and intra muscular injections; cognitive behavioural therapy; and biomechanical assessments.

Education

- nurses played an active role in educating trained nurses, nursing students, allied health care professionals and a proportion (49%) also trained medical students.

The service needs – high quality care

Nurses work as part of a multi-disciplinary team and as part of this team they provide a valued component of care for patients with rheumatological conditions. In order to sustain and enhance high quality care, tools to evaluate the nursing contribution must measure the meaningful outcomes that identify the benefits to patient care and strive to attract high calibre candidates to the nursing profession. This can only be achieved if there are cohesive career pathways and core professional values that enable nurses to develop and focus on outcomes that enhance the patient experience and long term outcomes (Framing the Nursing and Midwifery Contribution, Department of Health, 2008).

1 Introduction

This report provides evidence to help nurses compare their skills and competences against other specialists in their field of practice. The report discusses evidence in relation to the nurses' roles. A similar document will be published by the BHPR to outline the evidence in relation to the AHPs skills and competences.The reports provide commissioners and nurse directors with a great understanding of the role and core components for service provision and workforce planning if high quality care is to be delivered (High Quality Care for All, The Next Stage Review, Department of Health, 2008).

In addition, if the valued aspects of care are to be maintained for people with rheumatological conditions three additional factors should be considered:

- there is still a lack of clarity about what skills make up the role. This raises concerns from professionals and the public about role standardisation, which professional bodies understandably are keen to address
- evidence is needed to outline which aspects of the role are essential to provide in different care settings
- it is important to benchmark the skills and competences against other roles to provide a template for peer evaluation. This should ensure high quality nursing care is identified and valued and maintained for the care of people with long term conditions.

It has been widely acknowledged that a multidisciplinary approach is required to provide effective care for the diverse needs of patients with chronic rheumatological conditions. Over the past decade there has been an expansion in the number and roles and responsibilities of nurses and AHPs working in rheumatology. Previous work by Carr (2001) identified specific tasks and role responsibilities of nurses and AHPs to inform education training provision.

This survey builds on Alison Carr's earlier work, and provides information on the following:

- demographic data including banding/grading of roles
- organisation, structure and time allocation of clinical sessions
- nature of clinical and non-clinical activities
- changes in working practises
- perceived confidence of nurses and AHPs in carrying out specific role aspects.

There are a few caveats about the data presented in this survey. Some questions containing free text have been excluded from the initial analysis because of the absences of theme cohesion. There is also a lack of clarity about the exact numbers of nurses working in the field of rheumatology. It is believed that the vast majority of nurses belong to the RCN Rheumatology Nursing Forum and/or British Health Professionals in Rheumatology, but there is limited knowledge about the numbers who belong to neither. Therefore, the survey may not be representative of all rheumatology practitioners. In addition, not all questions were answered by all the respondents, and some questions/responses have been excluded from the analysis because results were inconsistent or handwritten responses which made analysis difficult.

This report provides the preliminary analysis of the data. The next step is to undertake a more detailed sub-analysis and publish further papers. A number of reports and policy drivers have stressed the need to identify the core components of care that patients value and need to manage their long-term condition (King's Fund, 2009; Department of Health, 2008b). It is also recognised that quality is at the heart of patient care, yet cost effectiveness also impacts significantly on nursing roles.

Demonstrating nursing skills and competences and the benefits to patient care have always presented challenges. Data on what makes up the core components of nursing care, and failure to recognise its complex nature, has resulted in poor and limited information. The Pandora software programme was developed to enable nurses to collect evidence of their activity based upon eight dimensions specifically designed to capture dimensions of the specialist nurse role. Analysis allows scrutiny of a number of aspects of care such as proportion of time spent in clinical practice, education or research but more importantly demonstrate the essence of specialist nurse and can describe emotional labour, use of expertise to intervene and 'rescue' the patient from other unplanned events (Leary et al, 2008). To build on work from the King's Fund (2009) and evidence from this report, the RCN Rheumatology Nursing Forum has commissioned a pilot project for 200 nurses to use the Pandora software system. It is proposed that this will outline the essence of rheumatology specialist nurse roles and describe key components of care delivered (Leary et al., 2008). The report from the Pandora project will be available in December 2009, together with the more detailed sub-analysis from this report. This will provide an outline of cost effectiveness of the rheumatology nurse specialist, and other nursing roles in rheumatology.

Developing the questionnaire and data collection

The questionnaire was developed in two parts. This first part was devised from an original template used by the Royal College of Physicians (RCP). The second part was made up of a modified version of the Specialist Nurse Activity Profile (SNAP) questionnaire developed by Keele University to explore the confidence and competences of nurses in rheumatology (Ryan et al, 2006).

A small task group of consultant nurses, a community specialist nurse, senior lecturer, and consultant rheumatologist wrote and revised the original RCP questionnaire to ensure consistent formatting. The questions were written to reflect current work-related activities for rheumatology AHPs and nurses. Demographic questions were also included to add context and to make comparisons.

The modified SNAP questionnaire consisted of a shortened version of the original survey, for which the group was granted permission. The working group included some additional questions to capture data of AHPs activity and additional areas of practice, which will be published by the British Health Professionals in Rheumatology. The SNAP questionnaire assesses individual confidence in relevant practical aspects such as carrying out joint examination (Ryan et al., 2006). The two draft questionnaires were amalgamated and duplications removed. Once the draft was finalised a larger group of BHPR, RCN Rheumatology Nursing Forum and Nurse Consultant group members agreed the contents and format. A pilot was then undertaken, and the random sample of 60 rheumatology nurses and AHPs were surveyed achieved a total response rate of 38%. The respondents were asked to:

- complete the questionnaire
- give general comments
- highlight any potential gaps
- comment on clarity.

The pilot questionnaire responses/comments were confidential and anonymous. However, respondents were also able to ring in with questions, and a number of similar comments were made. They included changes to the terms used to reflect multi-professional factors. For example, clinics became clinical sessions.

The task group then revised and agreed the questionnaire in light of the pilot findings, prior to distribution.

The questionnaire and sample

The two-part questionnaire, with seven sections in the first section and four in the second, was sent to nurses and AHPs who were BHPR and RCN Rheumatology Nursing Forum members. This publication focuses on the results of the nurse data. Information in relation to the AHPs publication can be sought from the BHPR (www.rheumatology.org.uk)

The membership of the RCN Rheumatology Nursing Forum consists of a wide range of nurses working in various fields of practice. They could be based in a hospital or community services, and working in a different ways; their roles might include; clinic support, running outpatient clinics – including nurse-led services, ward nurses (medical and surgical) as well as specialist nurse roles. The RCN Rheumatology Nursing Forum has 1,216 members, of which 476 said that they worked in the rheumatology field as their main area of practice.

The BHPR has 554 members, and 185 nurses were members of both the BHPR and the RCN Rheumatology Nursing Forum. Duplicate names were removed from the database to ensure only one questionnaire was sent to nurses with dual membership.

Results

In total 1,545 questionnaires were posted to nurses and AHPs, and 623 (40%) were returned. Of these 20 were blank; 16 recipients provided a reason for non-completion; nine were not working in rheumatology; five had retired; one declined to complete; one replied that it was not relevant to clinicians; and four gave no reason.

The results focus initially on information about completing the questionnaire, then looks at nurses' training and development. The survey finally explores the role of the nurse in their current post and in their main area of work.

Age, gender and professional details of the nurses

The questionnaire was completed by 274 nurses who worked in the field of rheumatology (missing data n=3). Of the 272 nurses who gave their age, the mean age was 48 years (range of 26-71 years), while two of the respondents did not state their gender.

2 Survey

Part 1

Table 1: Years worked in present post

Over 40% of the nurses were ≥50 years (n=113) and the mean years since qualified was 24 years (Standard Deviation (SD) 8.3 years). Nurses reported that the number of years they had worked in their current post ranged from < 5 years to >25 years. The majority of nurses questioned worked full-time (64%).

Years working in present post	N=	%
<1-5	105	38.3
6-10	90	32.8
11-15	46	16.8
16-20	21	7.7
21-25	4	1.5
>25	1	0.4
Total	**267**	**97.5**

Table 2: Post-graduate qualifications

Many nurses had undertaken at least one post-graduate qualification. Of the 274 nurses surveyed, 33% had a teaching qualification and 28% had undertaken a prescribing course. Other qualifications or training courses completed were in: rheumatology; counselling; joint injection; and a range of previously classified English National Board (ENB) courses.

Diploma	Undergraduate	Masters degree	PhD	Teaching qualification	Prescribing course
131 (48%)	100 (36%)	61 (22%)	2 (0.2%)	90 (33%)	71 (26%)

Table 3: Hours worked

The median number of hours per week worked by the 261 nurses who replied to the question is 37 (range 5-72hrs). One full-time nurse told the survey that she worked 72 hours a week and that she also worked for an agency.

N =	Median	Minimum	Maximum
261	38	5	72

Missing data 13

Further sub-analysis needs to be considered to take into account nurses who work full or part time.

Table 4: Post funding source

The NHS was the major source of funding for the nurses' current posts. Other funders came from patient organisations such as Lupus UK, general practice or independent organisations.

Major funding source	Number
Acute NHS trust	217
Primary or community care trust	18
Academic with Hon NHS contract	6
University	3
Pharmaceutical company	3
Other	13
Total	**260**

Table 5: Banding

The majority of the nurses are on grade 7 – the grades are shown in table 5 below. Other nurse grades reported included: an I grade and an F grade; two advanced nurse practitioners; one academic grade 8; one lecturer B; two unspecified university grades; one senior staff nurse; one self–employed; and one Ministry of Defence grade.

Nurses band/grade	Band 5	Band 6	Band 7	Band 8A	Band 8B	Band 8C	Band 8D
Number	33	70	131	14	7	1	1
Total responses 255							

Missing data 7

Table 6: Number of clinics/sessions

The nurses were asked to report on their rheumatology clinics at their main work location. Nurses were asked how many clinics or sessions per week they held. Those that provided this information are outlined below showing clinic sessions ranged from 1-10 with the majority having 4-5 clinics per week.

Number of clinics/sessions	Number/nurses
1	19
2	24
3	37
4	67
5	46
6	15
7	11
8	4
9	2
10	1

Further sub-analysis needs to be considered to take into account nurses who work full or part time.

Table 7: Types of rheumatology conditions routinely assessed

Table 7 outlines the range of conditions rheumatology nurses routinely assess. Other conditions mentioned included: adult stills disease; hypermobility syndrome; complex regional pain; eye conditions; dermatomyositis; metabolic bone disease; soft tissue conditions; Paget's disease; vasculitis; and neck and thoracic pain.

Routinely assessed conditions	Nurse	
	Yes	%
Rheumatoid arthritis	213	78
Psoriatic arthritis	199	73
Seronegative rheumatoid arthritis	196	72
Ankylosing spondylitis	168	61
Other seronegative arthritis	152	55
Systemic Lupus Erythematosus	116	42
Osteoarthritis	109	40
Osteoporosis	106	39
PMR/temporal arthritis	105	38
Other connective tissue diseases	98	35
Fibromyalgia	86	31
Gout	72	26
Juvenile idiopathic arthritis	58	21
Back pain	45	16

Table 8: Minutes allocated for a newly-diagnosed patient

The number of newly-diagnosed patients on a 'usual' clinic list or in a session ranged from 1-23. The majority of nurses saw between two and six new patients per clinic.

Time for new patient appointments	15 minutes	30 minutes	45 minutes	60 minutes	90 minutes	Total
Nurse	11	150	22	24	0	207

The majority of nurses had a 30 minute slot for new patients.

Table 9: Minutes allocated to a follow-up patient

The numbers of follow-up patients per clinic/session ranged from two to 35 per clinic – although the majority ranged from 4-10 patients per clinic. The majority of nurses had a 30 minute slot for follow-up patients.

Follow-up appointment time	15 minutes	30 minutes	45 minutes	60 minutes	Total
Number	56	162	5	3	226

Table 10: Number of extra or urgent patients added to a clinic or session

Table 10 shows the number of extra or urgent patients who were slotted into their clinics/sessions. Of those who responded, 204 nurses said that on average one or two patients tended to be slotted in.

Number of patients	Nurse
0	15
1-2	117
3-4	45
5-6	17
7-8	2
9-10	5
12-14	2
24	1
Total	**204**

Further sub-analysis needs to be considered to take into account nurses who work full or part time.

Table 11: Authority to undertake specific activities

Nurses with the authority to undertake specific tasks is shown in the table below.

	Responders	Missing	Grade 5	Grade 6	Grade 7	Grade 8A	Grade 8B	Other
Do you have the authority to admit patients from clinics or sessions?								
Nurse	230	40	(4 did not give their grade)					
Yes			2	18	73	9	7	6
No			11	42	53	4	0	5
Do you have the authority to discharge patients from clinics or sessions?								
Nurse	231	39	(4 did not give their grade)					
Yes			3	20	93	10	7	7
No			10	40	34	3	0	4
Do you have the authority to refer patients to other members of the rheumatology team?								
Nurse	232	38	(4 did not give their grade)					
Yes			9	58	126	13	7	10
No			4	2	2	0	0	1
Do you have the authority to refer patients to non-rheumatology colleagues e.g. orthopaedic surgeon?								
Nurse	232	38	(4 did not give their grade)					
Yes			1	22	77	10	7	5
No			12	38	51	3	0	6
Do you have the authority to request radiological investigations?								
Nurse	230	38	(4 did not give their grade)					
Yes			1	26	70	11	5	5
No			12	33	57	2	2	6
Do you have the authority to undertake pre-treatment tests e.g. pre biologic TB testing?								
Nurse	230	40						
Yes			2	39	96	12	7	6
No			11	19	32	1	0	5

When considering the workload of the rheumatology nurse it was important to scope the range of services provided in their current post.

Telephone advice lines

One hundred and sixty seven of the nurses reported they provided a rheumatology telephone help/advice line as part of their current post. The number of hours 'allocated' for answering these calls ranged from 1-16 hours per week, with the majority (n=103) of nurses allocating between 3-10 hours per week.

Home visits

When asked about home visits and how frequently they were undertaken, 42 nurses responded to this question and, as expected, those respondents employed by primary or community trusts undertook the most home visits. The majority (n=27) undertook one to three home visits a month. However, one nurse undertook approximately 128 home visits per month in her 30 hours per week as a Grade 6, but undertook no other clinics or ward work. Another full time Grade 7 nurse made about 60 home visits per month in addition to seven clinic session per week. The Grade 7 full time nurse who made 45 home visits per month also undertook one eight-hour clinic session per week. Of the three respondents who made 30 visits per month, one had an acute NHS contract, one a primary or community care trust contract and one had a dual contract.

Table 12: Different disciplines taught by nurses

Teaching

Who do you teach?	Nurse	
	Yes	%
Qualified nurses	208	76
Nursing students	209	76
Allied health professionals	131	48
Allied health professional students	88	32
Medical students	134	49
General practitioners	64	23
Junior doctors	97	35

Table 13: Number of day cases

Nurses were asked if they managed day case patients as part of their current role and if so how many cases were allocated to their care per week.

Number of day cases	N =
<5	54
6-10	25
12-15	10
6-20	6
25	1
50-60	2

The latter two nurses were working full-time for an acute NHS trust.

Table 14: Main day case activities

There were 58 nurses who stated that they managed ward-based patients. Of the other nurses who responded, 84 saw patients in a day case unit, and 60 (70%) saw all their patients in this setting. Day case patients were seen on the ward by 26 nurses, and 14 said that the percentages differed from week-to-week. The main day case activities are outlined in Table 14 below.

Infliximab infusions		Rituximab infusions		Methyprednisolone infusions		Cyclophosphamide infusions		Blood transfusions	
Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
92	182	74	200	71	203	59	215	17	257

Table 15: Number of hours allocated to in-patient non-specialist ward-based activities

Nurses were asked whether their role involved non-specialist ward-based activities such as regular shifts on a general medical ward or covering for non-specialist staff, and how many hours each week were allocated to this work. The nurse who spent 72 hours per week on these activities has two roles as an academic with an honorary NHS contract, and as an agency nurse.

Hours	Nurse
2	2
3	1
7.5	1
8	1
10	1
15	1
20	1
37	1
37.5	1
72	1
Total	**11**

Table 16: Main other duties undertaken

When nurses were asked if their routine workload was captured electronically by their employers (e.g. on an OASIS or PAS type system) 249 nurses answered: 201 said yes; 39 said no; and nine replied that they did not know.

Nurses (82%) were often involved in other clinical or non-clinical duties according to the 258 nurses who responded. They said that they routinely undertook service development, business cases, protocols, guidelines, audit, standards, BHPR or committee work. When asked on average how many hours this involved per working week, the vast majority (87.5%) undertook < 1 hour to 5 hours per week.

Other activities

In addition, respondents were asked to identify the other main clinical and non-clinical duties that they were involved in, and estimate the number of hours per week devoted to these activities. Nurses answered with a large volume of handwritten responses that focused on administration, team and personal development. The definitions used to code the responses are:

1. **Administration essential specialist clinical**
   Requires specialist expertise of the clinical area and cannot be administered by a non-specialist or clerical member of staff.
   This category includes activities such as service development, liaising with the multidisciplinary team and clinic-related correspondence.
2. **Administration essential non-specialist clinical**
   Does not require specialist expertise in the field of rheumatology but requires a practitioner. Could not be delivered by a lay clerical member of staff.
   Examples include line management, infection control and supervising the outpatient area.
3. **Administration non-essential non-clinical**
   Does not require a clinician or expertise in the field of rheumatology. Can be delivered by a lay clerical member of staff.
   This category includes setting up and inputting data onto databases, typing letters and arranging appointments.
4. **Team and personal development**
   Developing the clinical team and undertaking personal development activities.
   Examples include clinical supervision, student co-ordination and preceptoring.

Of the nurses surveyed, 195 responded. Administration 3 is an important category because these tasks could be delegated to clerical staff. Unfortunately, because the respondents had outlined a number of activities together it was not possible to calculate the number of hours spent on these duties.

Category	%
Admin 1	62%
Admin 2	12%
Admin 3	48%
Team & PD	14%

Table 17: Estimated time spent on different activities each week

Respondents were asked to estimate the proportion of time spent on a number of different activities. The majority of time is spent undertaking clinics. This section covers activity and procedures in relation to team work in their current post at the main work location.

Activity	Nurse	
	Yes	Median %
Clinics	231	50
Day-case patients	105	10
One-to-one patient education	222	10
Staff education	203	5
Ward-based activities	83	5
Completion of BSR registry forms	121	5
Telephone help or advice	233	10
Other administration	192	10
Continuing professional development	206	5
Evaluating blood results	220	7
Other	52	10

Table 18: Professional colleagues in the MDT

Ninety nine per cent (262/265) of nurses worked in a multi-disciplinary team.

Profession	Missing value	Yes	No
Consultant rheumatologist	27	347	4
Junior doctors in rheumatology	52	283	43
Specialist nurses in rheumatology	31	314	33
Health care assistants in rheumatology	90	137	151
Physiotherapists	58	291	29
Occupational therapists	49	292	37
Podiatrists	71	195	112

Table 19: Frequency of procedures undertaken

In relation to specific questions on procedures, which included AHPs and nurses, data was not included for 30 respondents who simply specified 'other', and who did not state profession or grade.

The majority of nurses (86%) undertook intra-muscular injections. About a third (32%) undertook intra-articular steroid injections.

	Responders	Yes	Median number per week	Range	Grade 5	Grade 6	Grade 7	Grade 8A	Grade 8B	Other	Total (nurse grades)
Do you perform intra-muscular steroid injections?											
Nurse	266	228	4	1 - 80	24	57	115	14	7	7	224
Do you perform intra-articular steroid injections?											
Nurse	262	85	5	1 – 90	1	15	52	10	2	3	83
Do you perform subcutaneous injections?											
Nurse	262	201	3	1 - 50	22	56	98	12	4	6	198
Do you perform acupuncture?											
Nurse	265	2	8		0	1	1	0	0	0	2
Do you provide exercise classes?											
Nurse	266	7	2	1 - 3	0	2	3	0	0	2	7
Do you provide TENS treatment?											
Nurse	265	15	1		3	4	6	0	0	2	15
Do you perform manipulation?											
Nurse	266	0									
Do you perform massage?											
Nurse	266	0									
Do you perform ultrasound treatment?											
Nurse	266	3	0		0	2	0	0	0	1	3
Do you perform laser treatment?											
Nurse	266	0									
Do you perform hydrotherapy?											
Nurse	266	5	10		1	3	0	0	0	1	5
Do you perform relaxation therapy?											
Nurse	266	6	2.5	1 - 10	0	0	1	4	0	1	6
Do you undertake cognitive behavioural therapy?											
Nurse	266	11	2	1 - 5	1	3	2	1	0	0	7
Do you undertake work based vocational assessments?											
Nurse	265	8	1	1 - 6	1	2	2	1	0	1	7

	Responders	Yes	Median number per week	Range	Grade 5	Grade 6	Grade 7	Grade 8A	Grade 8B	Other	Total
Do you undertake callus reduction?											
Nurse	266	2	0		0	1	0	0	0	1	2
Do you undertake ulcer management?											
Nurse	265	38	2	1 - 21	17	10	7	1	1	1	37
Do you undertake biomechanical assessments?											
Nurse	265	15	5	1 - 30	0	7	6	1	0	1	15
Do you undertake castings for arthoses?											
Nurse	265	4	2		0	3	0	0	0	1	4
Do you undertake podiatric surgical procedures?											
Nurse	263	3	1		0	2	0	0	0	1	3

Table 20: Other procedures

Nurses were asked to list others not covered in the survey and the approximate number undertaken each week; 68 responded.

Profession	Procedure	N=
Nurse	Intravenous Infusion (for example cyclophosphamide, etanercept)	7
	Intramuscular injections (gold, depomedrone), soft tissue injections	4
	Intravenous cannulation	5
	Venepuncture	6
	DAS 28	7
	Blood pressure monitoring Leflunomide clinic	1
	Intra articular Injections	2
	Mantoux testing	2
	Assessing blood results	1
	Working on an orthopaedic ward	1
	Social care	1
	Arthoses	2

Table 21: Biologics waiting lists

This section of the report explored the demand of nurses in their current posts at their main work location. Nurses were asked to give an approximation of how many patients were managed by the rheumatology service and were currently prescribed anti-TNF drugs.

This question was answered by 197/274 nurses (72%) The median number of patients prescribed anti-TNF therapies was 170 but this ranged from just one to 2000. The majority of services (n=68) managed between one and 100 people, and this was followed by 104 to 200 (n=45). Three areas managed ≥1000 anti-TNF patients.

When nurses were asked if their service had a waiting list for biologics, 29 (12%) respondents did not know. Not all the nurses who said that there was a waiting list (n=101) (40%) could answer whether this was caused by funding issues (see table). Sixty (55%) respondents stated that the waiting list was caused by staffing issues. Only 12 (17%) of those who responded thought the waiting list for biologics was a result of infrastructure issues.

	Yes	No	Don't know	Total	Missing
Do you currently have a waiting list for biologics?	101	121	29	251	23
Is your waiting list for biologics as a result of funding issues?	54	34	21	109	165
Is your waiting list for biologics as a result of staffing issues?	60	28	22	110	164
Is your waiting list for biologics as a result of infrastructure issues?	12	36	21	69	170

Table 22: Reasons for changes in working patterns

A large number (121/44%) of nurses stated that they have been asked to change their usual working pattern, or take on extra work during the past 18 months. Nurses provided handwritten responses that were then collated into the following seven categories:

1. extra clinics/hours
2. changes in role/service
3. loss of staff
4. extra staff
5. increase in patients
6. biologic therapy
7. increased administrative duties.

By far the greatest changes given were in categories one and two. A number of respondents stated that they had to work unpaid overtime to cope with their clinical commitments and waiting list initiatives, and others had introduced weekend or evening clinics. Some had increased workloads due to extra/new consultants coming into post. A number of ward-based nurses had been asked to work extra shifts due to staff shortages or sickness, and a number of nurses working in outpatient departments had been asked to work on rheumatology or general medical wards. Some respondents stated that they were expected to cover for vacant posts in addition to their own roles. One nurse commented: "Increased activity without increased resources." This appeared to sum up many of the sentiments expressed by respondents.

Biologic therapies appear to have added greatly to the workload both clinically and administratively. One nurse's observation expressed the view of many others: "Anti-TNF therapies have escalated due to the numbers of patients needing assessment/follow up." She added: "No extra resources given."

Categories of changes	Nurse
1. Extra clinics/hours	56 (46%)
2. Changes in role/service	43 (36%)
3. Loss of staff	17 (14%)
4. Extra staff	1 (<1%)
5. Increase in patients	3 (2%)
6. Biologic therapy	18 (15%)
7. Increased administration	13 (11%)

(%) denotes the % of those who said yes, and who cited this category

Part 2

The second section of this questionnaire is based on the modified SNAP questionnaire, a shortened version of the original survey that includes additional questions about the professional practice of AHPs.

Table 23: Non-patient clinical and professional activities

The majority of nurses were involved to some degree in producing protocols/guidelines; audits; in-service training; giving talks in the department; providing mentorship and research. The majority are rarely or never involved in writing business cases, giving talks to internal or external groups at their trusts. However, the majority (63%) of nurses teach nursing students regularly or as the lead in their team.

		Yes, as lead	Yes, contribute regularly	Rarely	Never
	(responders/missing)	**N = (%)**	**N = (%)**	**N = (%)**	**N = (%)**
Are you responsible for producing protocols					
or guidelines?	(263/11)	104 (38)	82 (31)	49 (19)	28(11)
	(responders/missing)	**N = (%)**	**N = (%)**	**N = (%)**	**N = (%)**
Do you conduct audit projects?					
Nurse	(251/13)	94 (36)	99 (38)	50 (19)	18 (7)
	(responders/missing)	**N = (%)**	**N = (%)**	**N = (%)**	**N = (%)**
Do you write business cases?					
Nurse	(263/11)	39 (15)	49 (19)	66 (25)	109 (41)
	(responders/missing)	**N = (%)**	**N = (%)**	**N = (%)**	**N = (%)**
Do you run in service training sessions?					
Nurse	(260/14)	46 (18)	58 (22)	96 (37)	60 (23)
	(responders/missing)	**N = (%)**	**N = (%)**	**N = (%)**	**N = (%)**
Do you teach nursing students?					
Nurse	(263/11)	64 (24)	103 (39)	83 (32)	13 (5)
	(responders/missing)	**N = (%)**	**N = (%)**	**N = (%)**	**N = (%)**
Do you give talks in your department?					
Nurse	(262/12)	47 (18)	101 (38)	84 (32)	30 (11)
	(responders/missing)	**N = (%)**	**N = (%)**	**N = (%)**	**N = (%)**
Do you give talks to other departments in your trust?					
Nurse	(263/11)	39 (15)	54 (20)	112 (43)	58 (22)
	(responders/missing)	**N = (%)**	**N = (%)**	**N = (%)**	**N = (%)**
Do you give talks to groups outside your trust? (e.g. PCTs, GP practices)					
Nurse	(264/10)	46 (17)	51 (19)	79 (30)	88 (33)

	Yes, as lead	Yes, contribute regularly	Rarely	Never
(responders/missing)	**N = (%)**	**N = (%)**	**N = (%)**	**N = (%)**
Do you participate in research?				
Nurse (264/10)	39 (15)	113 (43)	75 (28)	37 (14)
(responders/missing)	**N = (%)**	**N = (%)**	**N = (%)**	**N = (%)**
Do you provide mentorship for colleagues in your trust?				
Nurse (263/11)		87 (33)	115 (44)	61 (23)

N =total population

Table 24: Professional activities/membership

The majority of respondents were members of their regional rheumatology society. Most nurses (92%) were members of the RCN Rheumatology Nursing Forum, and 63% were also members of BHPR.

	Responders	Missing	Yes		No	
Are you a member of your regional rheumatology society?						
	N =	N =	N =	%	N =	%
Nurse	261	13	162	62	99	38
Are you a member of British Health Professionals in Rheumatology?						
	N =	N =	N =	%	N =	%
Nurse	261	0	165	63	96	36
Are you a member of RCN Rheumatology Nursing Forum?						
	N =	N =	N =	%	N =	%
Nurse	262	12	240	92	22	8

Table 25: Professional meetings

	Responders	Missing	Frequency		Occasionally		Rarely		Never	
	N=	N=	N=	%	N=	%	N=	%	N=	%
Do you attend your regional Rheumatology society?										
Nurse	247	27	79	32	68	28	48	19	52	21
Do you give presentations at your regional Rheumatology society?										
Nurse	247	27	12	5	56	23	44	18	135	55
Do you attend BHPR meetings?										
Nurse	256	18	50	20	95	37	53	21	58	23
Do you give presentations or present posters at BHPR meetings?										
Nurse	259	15	20	8	37	14	37	14	165	64
Do you attend RCN Rheumatology Nursing Forum meetings?										
Nurse	263	11	22	8	97	37	70	27	74	28
Do you give presentations or present posters at RCN Rheumatology Nursing Forum meetings?										
Nurse	261	13	5	2	23	9	35	13	198	76

Table 26: Qualified prescribers

Nurses were asked about whether they were qualified prescribers, and 32% (n=84) said that they were either supplementary or an independent prescriber, or both. One physiotherapist is a supplementary prescriber.

	Responders	Missing	Supplementary		Independent		Both		Not a prescriber	
	N =	N =	N =	%	N =	%	N =	%	N =	%
Are you a qualified prescriber?										
Nurse	262	12	14	5	12	5	58	22	178	68

Table 27: Frequency of prescribing

Nurses were also asked if, as a qualified prescriber, whether they prescribed. Of the 108 nurses who responded, the majority (63%) frequently prescribe. Interestingly, 31 (29%) never prescribe.

	Responders	Missing	Frequently		Occasionally		Rarely		Never	
	N =	N =	N =	%	N =	%	N =	%	N =	%
If you are a prescriber, do you prescribe?										
Nurse	108	166	68	63	9	8	0	0	31	29

Table 28: Competences in patient-based practice

Nurses were asked questions evaluating their competence in various patient-based practice activities, and 91% responded. The majority said that they were very confident in their ability to counsel a patient with rheumatoid arthritis starting methotrexate therapy. Nurses were also confident, or fairly confident about their ability to perform an active joint count, assess disease activity and assess function in a patient with rheumatoid arthritis. Some 70% of nurses were very confident that they could calculate a disease activity score and were confident, or very confident that they could manage the ongoing care of a rheumatology patient.

However, the ability to support a patient with chronic pain syndrome was less consistent, with only 50% of nurses confident or very confident. The same kind of pattern emerged when nurses were asked about running a clinic on new referrals from their GP. Only 27% of nurses were confident or very confident about this activity.

Most nurses (85%) said that they were confident, or very confident that they could provide telephone advice to patients. The vast majority (89%) also said that they were confident, or very confident that they could educate a patient to manage their own disease. Confidence in their ability to present the results of audit to their department was reported by 67% of the nurses in the survey. However, nurses reported lower confidence about their ability to present audit results to the local PCT board, an audit to BHPR or co-ordinating the writing of a business case for a new nurse specialist was low. Half (50%) of respondents said that they were confident or very confident.

Table 29: Competences in relation to clinical activity

Nurses were asked to tick the descriptors that best fits each activity, outlining whether it was a major component or ticking 'not at all' where this was not undertaken. The majority of the nurses (91%) who responded signified that counselling regarding drug treatment comprised a significant or major proportion of their activity. Educating patients about the disease and its management was a major or significant activity for 95% of nurses. This was also true of two of the three 'other' categories. Joint counts and joint examination were a major or significant activity for many nurses (73%).

Few nurses (16%) made a diagnosis in new patients. However, managing patients with a known diagnosis such as rheumatoid arthritis was a major or significant activity for 93% of nurses. Administering intramuscular or infused drugs was also a major or significant activity for most nurses (72%). But, the same was not the case for joint or soft tissue injections, which was a minor activity or not undertaken by the majority of nurses. Only 42% of nurses allotted prescribing medications as major or significant activity. Assessing co-morbidities is a major or significant activity for over half (53%) of the respondents. Managing biologic therapies was a major or significant activity for most nurses (73%). Providing psychological support was seen as a major or significant activity for the majority (95%). Finally, monitoring Disease Modifying Anti-Rheumatic Drugs (DMARD) was a primary concern for most nurses, and 84% said that this was a major or significant activity for them.

	Responders	Missing	Not confident at all		Fairly confident		Not sure		Confident		Very confident	
	N =	N =	N =	%	N =	%	N =	%	N =	%	N =	%
Counselling a patient with rheumatoid arthritis who is starting treatment with methotrexate												
Nurse	250	24	10	4	19	8	2	1	36	14	183	73
Dealing with patients with possible anti-rheumatic drug-related side-effects												
Nurse	252	22	6	2	21	8	5	2	68	27	152	60
Performing an active joint count												
Nurse	245	29	18	7	13	5	7	3	45	18	162	66
Assessing disease activity in a patient with rheumatoid arthritis												
Nurse	246	28	18	7	13	5	1	0	56	23	158	64
Assessing function in a patient with rheumatoid arthritis												
Nurse	247	27	16	6	20	8	12	5	78	32	121	49
Calculating a Disease Activity score in a patient with rheumatoid arthritis												
Nurse	246	28	19	8	10	4	11	4	34	14	172	70
Managing the ongoing care of a patient with rheumatoid arthritis												
Nurse	251	23	7	3	15	5	6	2	69	27	154	61
Supporting a patient with a chronic pain syndrome												
Nurse	254	20	19	7	50	20	57	22	89	35	39	15
Performing a clinic on new patients freshly referred by their GP												
Nurse	225	49	67	30	36	16	61	27	36	16	25	11
Altering drug treatment in a patient whose rheumatoid arthritis is poorly controlled												
Nurse	234	40	36	15	20	9	17	7	69	29	92	39
Providing telephone advice to patients												
Nurse	253	21	5	2	18	7	4	2	60	24	166	61
Educating a patient to manage their own disease												
Nurse	255	19	4	2	19	7	5	2	75	29	152	60
Designing and implementing an audit to establish whether patients are being adequately monitored with respect to DMARD safety												
Nurse	246	28	32	13	26	11	42	17	78	32	68	28
Presenting the results of an audit to your department												
Nurse	251	23	26	10	29	12	28	11	85	34	83	33
Presenting the results of an audit to the local PCT board												
Nurse	247	27	59	24	27	11	54	22	62	25	45	18
Presenting the results of an audit to BHPR												
Nurse	242	32	81	33	24	10	55	23	54	22	28	12
Asking a question at a plenary session of BHPR												
Nurse	241	33	72	30	32	13	50	21	59	24	28	12
Co-ordinating the writing of a business case for a new AHP or nurse specialist colleague in your department												
Nurse	244	30	81	33	33	14	47	19	52	21	31	13

	Responders	Missing	Major		Significant		Minor		Not at all	
	N =	N =	N =	%	N =	%	N =	%	N =	%
Counselling regarding drug treatment										
Nurse	242	32	175	72	50	21	10	4	7	3
Educating regarding the disease and its management										
Nurse	241	33	170	71	57	24	9	4	5	2
Performing metrology such as joint counts										
Nurse	241	33	111	46	66	27	36	15	28	12
Carrying out a joint examination										
Nurse	241	33	113	47	82	34	25	10	21	9
Making diagnoses in new patients										
Nurse	240	34	18	8	19	8	75	31	128	53
Managing patients with a known diagnosis such as rheumatoid arthritis										
Nurse	241	33	180	75	44	18	10	4	7	3
Administering drugs such as IM injections and infusions										
Nurse	239	35	87	36	87	36	52	22	13	5
Giving joint or soft tissue injections										
Nurse	240	34	33	14	38	16	40	17	129	54
Prescribing medication										
Nurse	240	34	44	28	34	14	15	6	147	61
Assessing co-morbidities such as BP, ECG and cholesterol										
Nurse	240	34	48	20	79	33	85	35	28	12
Other	3	0	0	0	0	0	1	33	2	67
Q84k. Managing patients on biologic therapy										
Nurse	239	35	122	51	52	22	29	12	36	15
Q84l. Providing psychological support										
Nurse	240	34	129	54	98	41	12	5	1	0
Q84m. Referring to other health professionals										
Nurse	240	34	70	29	129	54	34	14	7	3
Q84n. Monitoring patients on DMARDs										
Nurse	239	35	147	62	52	22	25	10	15	6

Other activities

Respondents provided 44 responses to outline other activities that they undertook, which were categorised by an independent assessor. None of the categories identified were unique and had been captured elsewhere in the survey and have been omitted.

3 Discussion

There are many policy documents available that have discussed the changing role of the nurse, and what needs to be considered to identify the future direction of the profession. They include:

- Department of Health (2000) *The NHS plan*, London: DH.
- Scottish Government (2008) *Supporting the development of advanced nursing practice. Modernising nursing careers: advanced practice*, Edinburgh: Scottish Government.
- Department of Health (2008) *Implementing the White Paper, trust, assurance and safety: enhancing confidence in the regulation of health professionals in healthcare professionals' regulator*, London: DH.
- Department of Health (2006) *Modernising nursing careers: setting the direction*, London: DH.
- Department of Health (2008) *The next stage review. High quality care for all*, London: DH.
- Department of Health (2009) *Inspiring leaders. Leadership for quality*, London: DH.
- King's College (2008) *High quality nursing care – what is it and how can we best ensure its delivery? Policy +*, London: National Nursing Research Unit, King's College.
- Department of Health (2009) *High Quality Workforce. The NHS Next Stage Review*, London: DH.
- Department of Health (2008) *Framing the Nursing and Midwifery Contribution. Driving up the quality of care*, London: DH
- Maben J and Griffiths P, (2009) *Nurses in Society: starting the debate*, London: King's College London.

Key findings

This report provides preliminary data about the work and activity profile of nurses working in the rheumatology field. The survey results explore the qualifications, training needs, self-reported perceptions of competency and work productivity of rheumatology nurses and AHPs.

The survey has provided some valuable insights into the role of the nurse. Some examples of the information collected outline the significant nursing activity undertaken, and the challenges to future service provision. They include:

- this is an ageing workforce (mean age 48 years)
- the majority of nurses held a Band 7 post.

Qualifications

- thirty three per cent held a teaching qualification
- twenty six per cent were nurse prescribers
- twenty two per cent held a Masters qualification.

Clinics and day care

- forty eight per cent of nurses were carrying out administrative, non-clinical tasks that could be delegated to clerical staff
- forty four per cent of nurses stated they had changed their usual work pattern or taken on extra hours. The reasons for these changes included:
  - extra clinic/hours required
  - changes in the role/service
  - loss of staff or extra staff
  - increase patient caseload and biologic therapies
  - increased administrative duties.
- nurses provided care to a wide range of rheumatological conditions
- the majority of nurses ran between 4-5 clinics per week
- the majority had new and follow-up appointment slots for 30 minutes
- one or two extra patient appointments were added to each clinic session

- nurses ran telephone support advice lines for between 3-10 hours per week
- day case activity has increased and the majority of nurses managed between 1-10 patients per week
- eight per cent of nurses were currently carrying non–specialist, ward-based activities. The amount of time spent on these activities ranged from 2-72 hours
- the range of additional tasks undertaken by the nurse were significant and included: subcutaneous injections; intra-articular and intra muscular injections; cognitive behavioural therapy; and biomechanical assessments.

Education

- nurses played an active role in educating trained nurses, student nurses, allied health care professionals and a proportion (49%) also trained medical students.

Roles and training

The nurses who responded to this survey described different roles and bandings. Data was analysed from all the nurses who reported that they worked in the rheumatology field (63%). Nurses may be working on a rheumatology ward or in day care, or they could be an infusion nurse or providing specialist outpatient support and continuing care for patients with rheumatological conditions. A key finding in this report is that there is a crucial need to consider succession planning of specialist nursing support for rheumatology patients because the nursing workforce is an ageing one.

Carr (2001) scoped the extended clinical roles of nurses and AHPs in rheumatology. She outlined the activities commonly undertaken and explored role definitions and training needs. Since 2001 there have been significant changes in rheumatological treatment strategies and health policy. The emphasis is now on managing long-term conditions and enhancing patient empowerment and self-management. This is complemented by the extended role of the nurse, which provides care and pay structures (National Audit Office, 2009). Nurses in this survey have demonstrated a real commitment to enhancing their post-graduate qualification. A high number of nurses held additional qualifications, which included 28% who had a prescriber qualification.

There have also been significant challenges in demonstrating the cost effectiveness of nurse activity. There is limited data available on basic issues such as number of patients seen, length of appointments, activity related to enhancing self-management and reducing the need for additional health care resources. The survey has provided some insights into what rheumatology nurses are delivering in daily patient care. However, there remain questions about how to define activity, roles and responsibilities and the pre-requisite qualifications required. This is a particular problem when there are a too many different nursing titles used in different care settings.

Lastly, there are still issues about how to obtain the information that reflects the true breadth and value of nursing care, and the failure to use the most appropriate tools to measure effectiveness and patient outcomes. Leary et al. (2008) has demonstrated that clinical nurse specialists are cost effective, and undertake specific roles that are valued by the patient and use less health care resources.

Conclusions

The results of this survey show that rheumatology nurses provide a wide range of activities to improve patient outcomes. Much of their workload is in complex long term conditions management working in extended roles.

The Department of Health has highlighted the importance of high quality care and the need to develop and support nursing leadership. Nurses in rheumatology have set their sights high and have achieved some important milestones in demonstrating their competencies. For example:

- the reported number of nurse prescribers was 26% in this survey, higher than the national average of 12%. (Duffin, 2009)
- twenty two per cent of nurses hold a masters level degree an impressive percent compared to other specialist fields.
- thirty three per cent of nurses had a teaching qualification.

The Next Stage Review (2008) has highlighted the need to drive up the quality of care and enhance leadership (2009) across the NHS in England and Wales. If these goals are to be achieved for those with rheumatological conditions consideration must be given to:

- the development of expertise within the community. The current rheumatology workforce is an aging one with minimal expertise in the community
- nurses need to identify ways of developing their services and communicating the breadth and depth of the activities they undertake to ensure positive impact on the patient experience and health outcomes
- clinical time should be enhanced by the adequate provision of administrative and secretarial support
- adequate coding and reimbursement of nurse activity needs to be improved.

The policy drivers outlined by Lord Darzi in The Next Stage Review (2008) should empower nurses to maintain a high standard of care for patients. However community teams and specialist services must work together to ensure that there is adequate provision of expertise at all stages of the patient journey through health care.

This report provides a valuable picture of the current activity and competencies of nurses working within the field of rheumatology. This report will be supported by a pilot project using the Pandora software system to explore and define in even greater detail the true value of the nurse specialist by providing high quality care for people with rheumatological conditions. This information should help to inform commissioners, directors of nursing, professional colleagues and patient and voluntary sector organisations highlight the components that should be considered when planning a high quality service.

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