impact (eg HAQ 2.37, PI HAQ 4.125) while others with lower disability had higher impact (eg HAQ 1.5, PI HAQ 4.25).
PI HAQ scores were significantly lower than baseline at weeks 2, 4, 6 and 8 (median changes: -0.63, -0.19, -0.5, -0.38, all $p<0.04$). Using the median % change from baseline, improvements at weeks 2, 4, 6 and 8 were greater for the impact of disability (PI HAQ 12.5%, 5.4%, 9.5%, 7.1%) than for disability alone (HAQ 4.3%, 3.8%, 9.1%, 4.3%).
Overall median change in PI HAQ was associated with change in the impact of disability as measured by the DRP function scale ($r=0.399$, $p<0.05$). Change in PI HAQ was associated only with change in HAQ ($r=0.606$, $p<0.01$) whereas change in DRP was associated with change in all symptoms.
A subset of 10 patients did not respond to i/m glucocorticoids (defined as a median improvement of <10% in the majority of variables, excluding PI HAQ). In the 26 patients who did respond, PI HAQ changes were more marked: median change from baseline at weeks 2, 4, 6 and 8: -0.69, -0.5, -0.63, -0.5, all $p<0.013$). Using the median % change from baseline, improvement in disability impact was greater for the responders at weeks 2, 4, 6 and 8 (PI HAQ 18.7%, 9.3%, 16.7%, 13.3%), which was also greater than the improvement in disability (HAQ 7.7%, 11.1%, 12.5%, 7.1%).
Conclusions: The PI HAQ is sensitive to change in RA patients and associated with changes in another disability impact measure (DRP). The PI HAQ provides a valid and useful measure of the impact disability in RA and suggests that i/m glucocorticoids may change the impact of disability more than they change disability.
References
[1] Hewlett et al. Ann Rheum Dis 2002; 61; 986-93

BHPR – research

414. SENSITIVITY TO CHANGE OF THE RHEUMATOID ARTHRITIS SELF-EFFICACY SCALE (RASE)

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Background: Patient self-management programmes in RA aim to improve outcome by prompting the patient to adopt self-management behaviours. Self-efficacy, or the belief that you can do a task, is believed to be a necessary precursor to initiating behaviour change. This study tests the sensitivity to change of a new scale to measure self-efficacy for self-management in RA patients in the UK (RASE).[1]
Methods: RA patients at 11 centres, who had been offered an education/self-management programme as part of routine clinical care, were invited to complete questionnaires at baseline, and 2 and 8 weeks after their programme. Programmes were not standardized as this was a pragmatic study of the RASE in current practice.
Results: 140 patients participated (79.7% female, mean age 56.6 years (SD 12), disease duration 5yrs (SD 8.6). Patients had moderate pain (mean 4.6/10, SD 2.8) and disability (HAQ 1.36/3, SD 0.71), little depression (HAD 5.7/21, SD 3.6), but moderate anxiety (7.26/21, SD 4.1) and helplessness (AHI 17.2/35, SD 4.6). Baseline self-efficacy was relatively high as measured by the RASE (106.8/140, SD 11.8) and General Self-Efficacy Scale (GSES 28.8, SD 5.7, scale 10-40), but moderate as measured by the Arthritis Self-Efficacy Scales (ASES pain 55, SD 18.1; ASES other symptoms 58.1, SD 19.3, scale 10-100).
The RASE showed small but significant improvements in self-efficacy 2 weeks after programme end (mean change 3.23, SD 9.38, $p<0.0001$), maintained at 8 weeks (mean change 2.77, SD 10.25, $p<0.003$). These changes gave effect sizes of 0.344 and 0.27 at 2 and 8 weeks. Changes in RASE were associated with behaviour initiation at week 2 ($r=0.419$, $p<0.001$) and week 8 ($r=0.342$, $p<0.001$). RASE change was also associated with a reduction in illness resignation at week 2 ($r=0.228$, $P=0.012$) but this effect was lost by week 8 (Medical Coping Modes Questionnaire).
The ASES showed similar effect sizes (ES). ASES pain: wk 2 ES 0.33 (mean change 5.97, SD 18.26), wk 8 ES 0.36 (mean change 6.31 SD 17.43); ASES other symptoms, wk 2 ES 0.42 (mean change 5.96, SD 14.23), wk 8 ES 0.41 (mean change 6.36, SD 15.61). GSES showed smaller effect sizes: wk 2 ES 0.24 (mean change 1.31, SD 5.42), wk 8 ES 0.27 (mean change 1.52, SD 5.52).
Conclusions: The RASE is sensitive to change in a cohort of UK patients receiving routine self-management programmes in normal care. Changes are associated with behaviour initiation and a reduction in illness resignation.
References
[1] Hewlett et al. Ann Rheum Dis 2001;40:1221-30

415. RHEUMATOLOGICAL EDUCATION FOR UNDERGRADUATE NURSING, PHYSIOTHERAPY AND OCCUPATIONAL THERAPY STUDENTS IN THE UK

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Background: Rheumatological conditions are common, thus nurses, physiotherapists (PT) and occupational therapists (OT) require knowledge and skills to assess and manage their impact on physical, psychological and social health.
This study examines rheumatological education of undergraduate nurses, PTs and OTs in the UK.
Methods: Curriculum organizers and clinical placement organizers for every undergraduate course in adult nursing, PT or OT in the UK were sent a questionnaire on the rheumatological content of their courses.
Results: 47 adult nursing courses, 30 PT, and 26 OT courses are being delivered in the UK. A curriculum questionnaire (teaching), clinical placement questionnaire (experience) or both, were returned for 40 nursing courses, 27 PT and 22 OT courses (85%, 90%, 85%).
Teaching about rheumatoid arthritis (RA) was moderate/in depth in only 52% of nursing courses (PT 96%, OT 91%) with probable/definite clinical exposure in 56% (PT 88%, OT 72%). Nursing courses were weaker for OA teaching (63%, PT 92%, OT 91%) and clinical experience (63%, PT 96%, OT 83%). Pain management and patient education teaching and experience were available for 78-100% of the professions (clinical experience for only 61-72% of OTs). Psycho-social issues were less frequently taught (nursing 61%, PT 77%, OT 77%) or covered clinically (nursing 61%, PT 67%, OT 56%).
Whilst 89-100% of respondents knew of local rheumatology services, only 57% of nursing respondents knew about local specialist nurses (90% of PT respondents knew of local PTs, OT's 87%). Use of local rheumatology practitioners to help educate their own profession was limited for teaching (nursing 19%, PT 27%, OT 52%) but better for clinical experience (nursing 54%, PTs 83%, OTs 82%). Teaching across disciplines (eg PT exposure to nursing) occurred in only 6-27% of disciplines, with only 8-42% given multi-disciplinary clinical experience.
Rheumatological undergraduate education provision was deemed about right by only 50% of nursing and 58% of PT respondents, but by 76% of OT respondents.
Conclusions: Undergraduate nurses, PTs and OTs have limited education in key rheumatological disorders and consequences, with limited use of specialist practitioners and cross-discipline exposure. Further work needs to identify core knowledge and skills for the professions at graduation, and ways to achieve them.

416. MEASURING PROTECTIVE SENSATION IN THE FEET OF PATIENTS WITH RHEUMATOID ARTHRITIS (RA)

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Background: Several authors have reported the presence of sensory neuropathy in the feet of patients with RA, but its incidence, prevalence and clinical progression are unclear. Using electromyography or nerve conduction techniques to assess sensation in the feet is time consuming, difficult and expensive. We therefore set out to validate of the use of sensitivity to monofilaments pressed against the skin as a method of assessing sensation in the feet of patients with rheumatoid arthritis (RA), to calculate initial estimates of prevalence of loss of sensation and to investigate its association with disease status.
Methods: Clinical examination of the feet of 51 patients with RA and 20 normal controls. 6 sites on each foot were tested twice with both 10g and 3g research grade monofilaments and this was repeated after 6 weeks. Disease status was measured using DAS, HAQ, visual analogue scales of pain, and the acute phase response using ESR and PV.
Results: Reproducibility was high for 3g (kappa = 0.73) and 10g (kappa = 0.75) monofilaments. The best balance between sensitivity (58.8%) and

specificity (92.3%) for distinguishing the feet of patients from the feet of controls was using the 3g filament and defining reduced protective sensation as being sensitive to less than 11 of 12 applications. Using this definition, the prevalence of reduced protective sensation is 12.5% in the feet of controls. There was some variation in sensation over 6 weeks in the patient group, but this was not related to measures of clinical status.
Conclusions: The use of monofilaments in assessing sensation levels in the RA foot is valid and reproducible, and requires only a short time to perform. The prevalence of reduced sensation in the feet of patients with RA was greater than previously reported. Future studies should be powered to assess relationships with disease duration and inflammatory status.

417. DISCRIMINATION OF THE NEUTRAL LOW BACK SITTING POSTURE IN PEOPLE WITH AND WITHOUT LOW BACK PAIN, BEFORE AND AFTER A SHIFT OF WORK

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Background: The "neutral" lumbar posture is considered the position least likely to cause low back pain, with errors as little as 2° from the neutral spinal posture substantially decreasing the axial compressive load capacity of the spine. Accurate sensory feedback from, and activation of, appropriate trunk muscles is essential for appreciation and maintenance of the neutral spinal posture. If these muscles are dysfunctional due to low back pain and/or work-related activity and fatigue, this might impair people's ability to discriminate the neutral spinal posture. This study investigated whether LBP or a shift of work alters people's ability to discriminate the neutral low back sitting posture.
Methods: Sixty one subjects with, and forty subjects without, a history of LBP were recruited. Each subject's spinal position sense was assessed before and after a shift of work by an electro-goniometer placed over the lumbar sacral spine. Subjects were blindfolded and instructed to actively locate the neutral low back sitting posture – the "test" position. They were then asked to flex or extend their low back and stop at a random position for 3 seconds, before returning to the neutral low back sitting position; the position they returned to was the "reproduced" position. This procedure was repeated 20 times in total. The absolute error between the "test" position and each "reproduced" position was calculated in degrees. The average mean error was then calculated and compared between the two groups using an independent-samples t test.
Results: Data was not normally distributed and therefore log-transformed before analysis. Anti-logged (returning data to original scale) values are also presented. LBP subjects had slightly higher average mean error values before work, showing that they found it more difficult than NLBP subjects to discriminate the neutral low back sitting posture, but the difference was non-significant (Table 1).

Table 1. Error in low back position sense when returning to the "neutral" sitting posture. Data presented in degrees as mean (SD)

	LBP subjects n=61	NLBP subjects n=40	Mean difference (95% CI)	P value
before work	4.83[a]	4.01[a]		
	1.58 (0.65)[l]	*1.39 (0.56)[l]*	*-0.19 (-0.44 to 0.06)[l]*	*0.137*
after work	4.38[a]	4.36[a]		
	1.48 (0.67)[l]	*1.47 (0.54)[l]*	*-0.004 (-0.26 to 0.25)[l]*	*0.973*

[a] = geometric mean; [l] = natural-logs value

Conclusions: The ability of people with and without LBP to appreciate the neutral low back sitting posture was similar, both before and after a shift of work.

418. A PILOT STUDY TO DETERMINE THE PREVELANCE OF ERECTILE DYSFUNCTION IN MEN WITH RHEUMATOID ARTHRITIS

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Background: Rheumatoid Arthritis (RA) is a chronic inflammatory joint disease associated with many extra-articular manifestations - all contributing to a high prevalence of disability. Erectile Dysfunction (ED) is a multifaceted problem caused by a combination of organic and/or psychological factors. It's true prevalence in the UK is not known. Despite recent developments in treatment for ED, the associated social stigma leads to very few men seeking medical help. Depression and cardiovascular disease are independently linked to the development of ED and both are more common in patients with RA.
Methods: Thirty male patients with a diagnosis of RA were recruited: 21 (67%) rheumatoid factor (RF) positive; mean age 58 yrs (range 39-79); mean disease duration 10 years (range 0.5 years – 42 years). A demographic questionnaire was completed and the following clinical data collected. Medical History, blood pressure, Body Mass Index (BMI), Disease Activity Score (DAS), Health Assessment Questionnaire (HAQ), smoking history (pack years). Sexual Health Inventory for Men (SHIFM), (a score of >21 = ED). Centre for Epidemiologic Studies Depression Score (CES-D), (score > 15 = depression). Visual Analogue Score for general health (VAS). Venous blood was drawn for C-reactive protein (CRP), rheumatoid factor (RF), fasting blood sugar (FBS), cholesterol, serum total testosterone, sex hormone binding globulin (SBGH), follicle stimulating hormone (FSH), luteininzing hormone (LH), testosterone free index (TFI). Bloods were all taken before 11am.
Results: Nine (30%) men had ED. There were significant correlations between ED and age (p=0.04) (t-test), depression (p=0.043) (Mann-Whitney), HAQ(p=0.045)(M-W) and alcohol intake (p=0.018)(M-W). Ten (33%) had a HAQ score between 0 and 1; 13 (43%) had a HAQ score >1 – 2, 7(23%) had a HAQ score >2 – 3. Twelve (42%) had a depression score greater than 15 (p=0.01) (Chi square). Seven (23%) drank 21 or more units of alcohol per week. When age was controlled for, depression (p=0.001) and diastolic BP(p=0.001) correlated with ED. When both age and depression were controlled for, ED correlated with LH (p=0.042)and FBS (p=0.037). We could not establish links between other variables and ED.
Conclusions: These data show that ED is prevalent in men with RA. Since the study excluded men with co-morbidities, such as diabetes or cardiovascular disease, the data are even more striking - and close to the prevalence of 50% in men with diabetes. Erectile dysfunction appears to be a significant health issue in men with RA and merits further study, focusing on potential mechansims and the results of therapeutic intervention.

419. AN ORIGINAL SPLINTING TECHNIQUE: BESPOKE NEOPRENE SPLINTS WITH THERMOPLASTIC SUPPORT

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Background: NAROT's (National Association of Rheumatology OTs) recent splinting guidelines recommend orthoses as a modality for patients with inflammatory arthritis. Commercial functional wrist splints are empirically used in clinical practice but there remains a paucity of controlled evidence to support their efficacy. Large numbers of these splints are worn incorrectly or issued inappropriately.
We have developed a novel splint made from neoprene with external thermoplastic support directly applied; this method of customising splints has potential advantages compared to ready made splints and we have therefore undertaken preliminary qualitative assessments.
Methods: Consecutive patients referred to the rheumatology service in Northumberland between April 2003 and August 2003 were included. Following assessment, all patients were issued *with both* ready made, Futuro-style, wrist splints and neoprene wrist splints customized to individual need. Patient satisfaction, perceived effectiveness of neoprene splints and the preferred splint were elicited in an unstructured interview with the Occupational Therapist. Cost estimates were made for the novel splint, compared to ready made splints.
Results: 79 consecutive patients were seen. The diagnoses were: Rheumatoid Arthritis 71%; Psoriatic Arthritis 23%; Fibromyalgia 5%; Raynaud's 1%. More than 90% of patients expressed a preference for neoprene splints. Patient's subjective responses were recorded: pain relief 68%; support 60%; comfort 56%; heat benefit 27%; reduced swelling 10%; problems with neoprene 7%.
Feedback from patients was very positive. Patients were able to contribute to the design and development of their own splints. The splints allowed greater flexibility with support and conformity.
Cost: ready made splints can be expensive to buy particularly if ordered through Orthotic companies e.g. up to £50 for the supply and fitting of one splint. The total material cost of a neoprene splint with thermoplastic reinforcement on both radial and ulnar borders of the wrist and hand is less than £1.50 but requires additional therapist time (estimated at 7-10 minutes per splint this equates to a total splint cost of ~£4).
Conclusions: The qualitative data does support the use of original bespoke neoprene splints rather than ready made splints. Patient satisfaction was considerable and patient preference overwhelming, supporting the use of these splints.

However, this was a pragmatic clinical study and the time, cost-effectiveness and benefits to patients provided by using neoprene splints would be best assessed in a controlled study.

420. THE PREVALENCE OF DISABLING FOOT PAIN IN PATIENTS WITH RHEUMATOID ARTHRITIS

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Background: Foot involvement is common in RA patients with pain being reported early in the disease process. Foot pain can lead to impairment of gait and disability and hence reduce quality of life. Data about the prevalence of foot pain and the degree of disability are essential to evaluate how serious these problems are in the group of early diagnosed RA patients. With this knowledge, a treatment strategy to prevent or ease foot pain can be developed. Therefore the aim of this study was to gather data about the prevalence of foot pain in early diagnosed RA patients and quantify its effect on disability.
Methods: Ethical approval was granted and written informed consent was given. Patients who were older than 16 years and diagnosed with RA up to 3 years prior to the survey were asked to complete a questionnaire which included demographic questions and questions about the prevalence of foot pain related to RA during the last month and at present. Participants with foot pain also filled in the Manchester Foot Pain and Disability Questionnaire (MFPDQ) which is a valid tool for quantifying disabling foot pain. It comprises 19 questions of 4 subscales with the following aspects: pain, ambulation, personal appearance and social life.
Descriptive statistics of the data were obtained with Microsoft Excel.
Results: The prevalence questionnaire was completed by 163 patients with a mean age of 52.2 years (16-84 years) and a mean disease duration of 20.3 months (1-36 months). Foot pain was reported in 64% of these patients during the last month and 59% experienced pain at the time of completing the questionnaire. 113 patients completed the MFPDQ and the results are illustrated in Table 1.

Table 1. Results MFPDQ

	Total score	Aambulation subscale	Pain subscale
No disability	0.0%	0.9%	0.9%
Mild disability	16.8%	14.1%	14.1%
Moderate disability	54.0%	41.6%	64.6%
Severe disability	29.2%	43.4%	20.4%

Conclusions: The survey found that around 60% of the sample had foot problems. These results show that foot pain is a serious problem that may occur early in the disease. The total and the pain score of the MFPDQ demonstrate a similar distribution with the majority of the patients having moderate disability, followed by severe and minor disability. The ambulation subscale shows a different picture with the greatest percentage reporting severe disability, followed by moderate disability and minor disability. These results show the high impact of foot pain on the patient's life and especially ambulation. It can be concluded that due to the high prevalence and the severity of foot pain in patients with RA there is a need for adequate treatment of this specific problem.

421. WHAT PATIENTS WITH RHEUMATOID ARTHRITIS REALLY WANT TO KNOW - AN ASSESSMENT USING THE EDUCATIONAL NEEDS ASSESSMENT TOOL

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Background: The Educational Needs Assessment Tool (ENAT) has been developed to quickly assess the educational and information needs of patients with RA. Using 1-5 likert scales it takes a few minutes for patients to complete and comprises 7 domains; managing pain, movement, feelings, arthritis process, treatments, self help and support. It is reliable (test/retest r=0.823: $p<0.01$) the Rasch analysis showed it to be robust, unidimensional and free from Differential Item Functioning.
Methods: The ENAT was completed by an opportunity sample of 125 RA patients attending either an outpatient clinic, a one day unit or were in-patients. They were asked to complete the ENAT anonymously, unaided and return it to the researcher.
Results: The majority of the cohort 99 (79%) were female. Age range was 19 - 86 years (median 57), median disease duration 12 years (range 0.2 - 47) and median age at leaving full time education was 16 years (range 14-19).
In the pain domain, knowing more about taking the best medication for them was thought to be extremely important by 81 (65%) patients. The use of acupuncture, ultrasound and hydrotherapy n=25 (20%) were thought least important. In the movement domain 75 (60%) thought it extremely important that they had more information about prevention of joint damage. Knowledge of practical aids was least important in this category (n=10; 8%). There was less consensus in the section on feelings, but 53 (42%) of the cohort wanted more information regarding tiredness. In the disease process section, 83 (66%) patients thought it extremely important to know more about treatments for their arthritis. Regarding treatments received from health professionals, 85 (68%) wanted more information about side effects from medications. The self treatments section showed 48 (38%) of the cohort felt that it was extremely important that they had further information about how much to exercise and in the final section about support from others, 48 (38%) felt it extremely important that they knew how to get the best from their consultations with their doctor or nurse.
Many patients commented on the ease of completion and pertinence of the questions.
Conclusions: Many of this cohort of RA patients had had their disease for many years, but they still had unmet informational needs. Most patients lacked information about medications and side effects, exercise, fatigue and how to to obtain the best from their consultation.
The ENAT is user friendly and enables health professionals to provide timely and meaningful education and information that is pertinent to the patient.

422. OUTCOME IN LOW BACK PAIN: WHAT MATTERS TO THE PATIENTS?

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Background: The ability of patients with low back pain to perform "usual" activities is frequently used as an outcome measure. "Usual" activity is a multi-dimensional concept, varies greatly between individuals and is poorly defined. We investigated the clinical usefulness of self reported ability to perform "usual" tasks as a patient centred outcome measure in low back pain. We explored the inter-relationship between this and a single individualised question relating to the ability to perform a specific usually enjoyed activity, self reported overall improvement in condition and general health status.
Methods: This was a secondary analysis of data recorded at baseline and 12 months from a randomised clinical trial comparing two physiotherapy interventions for low back pain (n=405) (Rheumatology 2004;43:ii86). At baseline, participants responded to the Euroqol "usual activities" item; were asked to identify a single activity that they enjoyed doing but were unable to do because of back pain and to rate the personal importance of this activity on a 10cm VAS. At 12 months participants were asked "Are you now able to do this activity?". General health status was self-rated from "excellent" to "poor" and overall improvement in condition from "completely recovered" to "much worse" using modified Likert scales. Associations between ability to perform "usual activities" and changes in these other outcomes were examined using correlation and inferential analyses.
Results: At baseline, 142 patients stated that they had "no problem" with usual activities but still identified a specific "enjoyed activity" they were prevented from doing because of back pain. This subgroup rated the importance of their enjoyed activity lower than patients who reported problems with usual activities ($p<0.001$). At 12 months, patients who reported "no problem" with usual activities were more likely to be able to perform their enjoyed activity than those who still had problems ($p<0.001$).
Change in ability to perform "usual activities" was associated with change in general health status (rho = 0.265, $p<0.001$) and overall improvement in condition (rho = 0.243, $p<0.001$) at 12 months.
Those who could perform their enjoyed activity at 12 months rated their general change in condition significantly better than those who were unable to ($p<0.001$).
Conclusions: There are clear associations between patients' responses to "usual activities", and ability to perform a specific important enjoyed activity, general health status and global improvement in condition. However this relationship is complex and depends on the degree of importance attached to specific tasks. Responses to questions about "usual activity" may be less meaningful than important task specific performance when assessing recovery in a low back pain patient.

423. MEASURING FATIGUE IN RHEUMATOID ARTHRITIS: A SYSTEMATIC REVIEW OF THE SCALES

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Background: Fatigue has far-ranging consequences on the lives of patients with RA and needs to be assessed accurately. The aim of this study was to identify fatigue measures currently used in RA and examine their validity.
Methods: Scales in current use were identified by systematically searching Medline, EMBASE, CINHAL, Psycho INFO, AMED, for papers containing the terms "rheumatoid arthritis", plus "fatigue" plus each of the following terms in turn: "scale" "questionnaire" "inventory" and "checklist". The searches were repeated substituting "tiredness" for "fatigue". The abstracts of the papers identified, were reviewed by two researchers and those reporting RA fatigue data seperately from other data were retained, and the full papers obtained. The fatigue scales used in these "index" papers were identified and the scale validation papers obtained. Scale validation papers were reviewed systematically by three researchers for evidence of content and face validity (comprehensiveness and credibility); criterion and construct validity (accuracy and biological sense); discriminant validity (sensitivity to change) and other elements of the OMERACT filter (truth, discrimination and feasibility).
Results: Of the 166 papers identified, 60 fulfilled the entry criteria of reporting RA fatigue separately. These 60 index papers used 19 different fatigue scales in RA: NIH (activity record) ACTRE, Composite Index Fatigue Impairment, Fatigue hours, Psychasthenia scale, Rating scale, Feeling tone checklist, Time to onset of fatigue, Morning fatigue, Multidimensional fatigue inventory, Chalder Fatigue Scale, Nottingham Health Profile, Checklist Individual Strengths, Profile of Mood States, 5 items modelled after Tack, Chronic Fatigue Index, Multidimensional Aspects of Fatigue, SF 36, Visual analogue scale, Likert Scale.
60 index papers used scales on 70 occasions but only 34 referenced them. 30/60 index papers used a VAS, 7 referenced it, and none actually related to validation of VAS for measuring fatigue in RA. Of the 30 index papers using a VAS, only 12 described them fully, and those 12 described 11 different versions. 10/19 scales had only the index paper as a validation scource. Using the agreed validation criteria, the first 8 of the 19 scales identified above did not achieve adequate validation for measuring fatigue in RA. The remaining 11 scales vary in the level of evidence of their validity.
Conclusions: Systematic analysis to identify the validity of scales used to measure RA fatigue has proved difficult and time-consuming. Despite the importance of accurate measurement, researchers often create new and unvalidated scales, or use existing unvalidated scales, or do not quote the validation papers.

424. A PRELIMINARY SURVEY OF PATIENTS' VIEWS IN RELATION TO THE USE OF SUBCUTANEOUS METHOTREXATE IN THE MANAGEMENT OF INFLAMMATORY ARTHRITIS

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Background: Methotrexate (MTX) is an antimetabolite, Disease Modifying Anti-Rheumatic Drug, which is widely used in the management of inflammatory arthropathies.
Parenteral administration of the drug is increasing in popularity due to the development of innovative service developments, which facilitate patients to self-administer MTX at home.
Current studies have examined the bioavailability and safety of the drug in parenteral form and patient satisfaction with the self-administration procedure.
This study examines the patients' lived experience of Parenteral MTX in relation to tolerability and efficacy in comparison to prior experience of the drug in tablet form.
Methods: The entire accessible population of a nurse-led service to facilitate patient self-administration of parenteral MTX was included in a patient survey. A self-administered questionnaire was given to a total of 58 patients within the clinic setting. Initially 45 (77.5%) questionnaires were returned, followed by a further 7 following a reminder letter. Therefore 52 (89.75%, women 67.3% n=35, men 32.7% n=17) of the total number of questionnaires were returned, and were included in the study. The age range of the sample was 30-79 years, length of disease 1-20yrs+.
The data collected was primarily quantitative although participants were encouraged to comment about side effects experienced yet not specified in the questionnaire and/or experience of MTX in general. Qualitative analysis of these comments was therefore also undertaken.
The questionnaire covered three main themes:-
1. The patients experience of oral MTX.
2. Side effects experienced with both routes of administration, including a comparison of severity since changing to injections.
3. The patients' experience of parenteral MTX, including impressions of tolerability and efficacy.
Results: The mean number of individual side effects experienced on oral MTX was found to be 3.7 (st dev. 2.57) and 2.5 (st dev.2.01) with parenteral MTX (P=.001, two-tailed significance, Wilcoxen Test). A one sample *t*-test was indicated the probability of patients experiencing an improvement in the severity of side effects following conversion to parenteral administration. Mean 3.4 (st dev. 5.9, 95% conf. int. of 1.78 - 5.1, P=.001). 67.3% participants reported being able to tolerate higher doses of MTX in parenteral form. 46.8% of participants reported "much better" disease control, and 34.6% "slightly better" control with parenteral MTX, with no negative responses.
Conclusions: Patients are likely to experience fewer and/or less severe side effects with parenteral MTX, allowing them to tolerate higher doses, which may lead to improved disease control.
Limitations of the study and implications for future practice and research are discussed.

425. WHY DO PATIENTS WITH RHEUMATOID ARTHRITIS USE COMPLEMENTARY THERAPIES?

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Background: It is becomming increasingly apparent that patients with Rheumatoid Arthritis are turning to forms of Complementary Therapy (CT) to supplement prescribed medication. The aim of this study is to (a) develop an understanding as to how the use of CT affects a patients perspective of health and well being, (b) to offer the rheumatology professional insight and understanding as to why a patient chooses to use a CT, and (c) to raise awareness as to the forms of CT most commonly used by patients with Rheumatoid Arthritis.
Methods: This qualitative study was based on phenomenological principles applied through focused inquiry to develop an understanding of the lived experience of the study participants. An inclusion criteria of an established diagnosis of Rheumatoid Arthritis, and known use of CT was applied to a convenience sample of patients attending Rheumatolgy Outpatient Department clinic on two consecutive days. Of the 15 eligible patients identified, 5 were randomly selected for inclusion in the study. Narrative data was collected through analysis of transcripts taken from audio tape recordings of unstructured interviews with study participants. A manual indexing system was used to develop 4 significant categorisation themes to reflect the findings (1) *incentives* to use CT, (2) *perceived benefits* of CT use, (3) the *choice of CT* used, and (4) *perceived disadvantages and risks* of CT use.
Results: *Incentives* to use CT included dissatisfaction with conventional treatment, often in the form of side effects and drug ineffectiveness. Social factors such as loss of employment and social activities were also indicated, as were psychological changes in the form of depression, hoplessness and fear. *Perceived benefits* were categorised as either physical or psychological with associated aspects of choice and control viewed as important elements of personal empowerment. The *choice of CT* used fell into 3 categories; physical, spiritual and herbal. The most commonly used of these were herbal remedies and supplements, closely followed by aromatherapy massage. *Disadvantages and risks* were identified as physical, (pain and discomfort), psychological (fear and uncertainty), and/or material (cost).
Conclusions: This study suggests that regular use of CT by patients with Rheumatoid Arthritis offers holistic benefits. Compared to conventional treatments, CT is seen to have advantages in terms of a lower incidence of adverse reactions, greater patient choice, psychological comfort and an increased quality of the patient/therapist realtionship. The evident use of CT by patients with Rheumatoid Arthritis indicates a need for evidence based information about its use and safety in order to direct practice within the Rheumatology Department.

426. PEER AND PATIENT PERSPECTIVES OF THE ROLE OF THE NURSE CONSULTANT IN RHEUMATOLOGY

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Background: The nurse consultant role was introduced in 1998 to expand the clinical career pathway and retain experienced nurses in clinical care. Role criteria include expert clinical practice, developing education and research initiatives and redefining services to improve patient outcome. We wished to explore the perceptions and experiences of peers and patients of

the role of the first Rheumatology nurse consultant appointed in the UK. This study contributes to a Royal College of Nursing (RCN) project exploring the effectiveness and impact of the nurse consultant.
Methods: A purposive sample of 6 peers (2 rheumatologists, 2 nurses, 1 manager and 1 consultant therapist) and 5 patients (attending the nurse consultant rheumatoid arthritis review clinic) participated in a semi-structured qualitative interview. A major aim of the interviews was to explore perceptions of the role of the nurse consultant. Interviews were conducted by a nurse researcher (CT) not involved with the patients' clinical care. The interviews were tape-recorded, transcribed verbatim and analysed using Colaizzis procedural steps. The analysis was peer reviewed to ensure that the results reflected the data.
Results: Four main functions of the nurse consultant emerged from the peer interviews:
1. Developing a new chronic pain service
2. Enabling colleagues to reach their potential
3. Providing clinical education
4. Participation in research

Patients focused on (i) their sense of being looked after, (ii) the consultant nurse's empathy and (iii) the consultant nurse's appreciation of the impact of their condition. Peers also commented on the patient-centredness of this nurse consultant. It is not clear whether these qualities are a virtue of the individual or a feature of the role.
Conclusions: The use of qualitative interviews has enabled perceptions of the role of the Rheumatology nurse consultant to be explored. The four key activities which emerged from the peer interviews were found to relate to the national criteria on role function. Patient perceptions of the role focused on personal attributes and suggest that the nurse consultant is impacting positively on the patient experience. Further exploration of the views of health professionals and patients on the role of the nurse consultant should contribute to our understanding of its impact.

427. A RANDOMISED CONTROLLED PILOT STUDY OF INFLAMMATORY ARTHRITIS PATIENTS ATTENDING AN INDIVIDUAL OR A GROUP SESSION FOR INFORMATION ON ANTI-RHEUMATIC DRUGS: COMPARING DIFFERENCES IN CONCORDANCE WITH TREATMENT, PATIENT SATISFACTION, TIME TAKEN AND DRUG SURVIVAL

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Background: Providing information on anti rheumatic drugs usually takes place with the patient and rheumatology nurse. There is no evidence comparing methods of providing drug information which is of importance because the drugs are toxic, require monitoring, and concordance improves outcome. On this background a pragmatic randomised controlled pilot study was conducted to compare drug information provided to individuals versus groups of patients.
Methods: 62 patients with inflammatory arthritis, requiring information on anti-rheumatic drugs received an individual or group drug information session. A rheumatology nurse specialist saw all subjects using the same drug specific leaflet. Outcomes were concordance by patient self report, pill counts and record of attendance for blood tests and follow up appointments for 12 weeks; Satisfaction 3 weeks post intervention using the Satisfaction with Information about Medicines Scale (SIMS) and time taken to deliver drug information and drug survival at 4 months.
Results: The EG subjects were more concordant than the CG, but not significant statistically. There were no differences between the 10 groups.

Concordance Results, by pill count, attendance for follow up and blood monitoring

Concordance outcomes	Group (EG) N=30	Individual (CG) N=32	Probability
Pill counts	90%	71%	p = 0.11
Follow up attendance	97%	81%	p = 0.10
Attend for blood monitoring	83%	75%	p = 0.54

Satisfaction and drug survival was high overall.

Satisfaction, time taken and drug survival

	Group (EG)	Individual (CG)	Probability	Association
Satisfaction (SIMS)	15 (range 7-17)	16 (11-17)	p = 0.3	no association p = 0.07
Time taken	35 minutes (range 25-45)	33 minutes (range 18-51)	p = 0.53	
Drug survival at 4 months	73%	62%	p = 0.42	

Time taken was equivocal but the actual amount of nurse time taken with the EG's was a mean of 11.6 minutes per subject compared to 33 minutes for CG subjects.
Conclusions: This study has practice implications for optimal use of resources and improving patient outcome. It is recommended that a larger study be conducted with an exploration of the qualitative aspects of providing drug information.
This research was supported by an education grant to undertake the post graduate diploma/Msc in rheumatology nursing at Keele University.

428. PARTICIPATING IN CLINICAL TRIALS: PATIENTS' EXPERIENCES OF THE INFORMED CONSENT PROCESS. A LITERATURE REVIEW

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Background: As a rheumatology clinical research nurse, I am aware of the importance of obtaining genuine informed consent. This literature review focuses on three research questions specifically relating to patient understanding, randomisation and voluntariness.
Methods: The literature search was undertaken systematically using well recognised databases, including MEDLINE and CINAHL. Explicit and clearly defined methods[1] were used to achieve a thorough and rigorous appraisal of the best quality evidence. To further promote rigor and validity of the critical appraisal, a research appraisal checklist was used, supporting the strengths and limitations of the research papers. By careful selection of search terms and clear inclusion criteria, the search strategy identified research papers that could be used as best evidence to answer the research questions. Five quantitative and three qualitative studies were selected.
Results: The appraised research showed that even when presented with an easy to read consent form, patients were not identifying risks of participating and there was an unrealistic perception of benefit. The studies illustrated that individuals can find randomisation difficult to understand as it often conflicts with their trial experience and preconceived ideas and beliefs may take precedent. There is evidence of implicit trust in the clinician and difficulty accepting clinical equipoise. The findings identify that both comprehension and patient autonomy increase with the presence of a research nurse or similar health care professional, possibly because the patient sees this person as being distanced from the therapeutic relationship.
Conclusions: Enabling an individual to make a truly informed consent is difficult to achieve in practice. Development of an information leaflet specifically relating to randomisation may facilitate understanding. In practice it would be advantageous for a research nurse to make the initial approach and seek the decision from the patient. This may result in some of the influencing factors relating to the voluntariness of consent, being reduced.
Reference
[1] Hek et al (2004) Making Sense of Research. An Introduction for Health and Social Care Practioners.

429. WALKING THE LINE: EXPECTATIONS AND INTENTIONS IN QUALITATIVE RESEARCH INTERVIEWS IN RHEUMATOLOGY

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Background: Reflexive practice is an important part of the research process, and particularly in qualitative work. Qualitative research interviews are an effective tool for exploring lived experience in the rheumatic diseases. Our intention was to deconstruct the qualitative interview process and examine some of the difficulties encountered during a recent research project.
Methods: Semi-structured interviews were conducted with 14 women aged 26-77 with a range of rheumatic diseases. These were audio-recorded, transcribed verbatim and analysed using Interpretative Phenomenological Analysis.
Results: Qualitative research interviews require not only a structure within which to investigate the topic(s) of interest, but many of the skills and techniques exercised by our colleagues in the counselling therapies in order to facilitate the interview. These include listening skills; empathy; congruence; positive regard; focusing and summarising. The ethical responsibilities of researchers are paramount throughout the research process. Researcher intentions and subsequently participant expectations should be clear from the

beginning of the process, so that boundaries can be drawn and informed consent given. Despite this, during research interviews, the nature of the interview often makes a subtle shift from research interview to therapeutic interview, as participants reveal previously undisclosed issues. However, the research interview should not become a therapeutic counselling session as a) it is unlikely the researcher has those skills b) it violates the boundaries agreed in informed consent c) both researcher and participant may become distressed and unsure how to proceed thereafter, as counselling rarely takes the form of a single session.
Conclusions: We are concerned that there is a fine line to be walked during the qualitative research interview for which qualitative interviewers may be unprepared. Researchers should be aware that participant needs and expectations may shift during the course of the interview as they reveal their narrative. Adopting the skills of the counsellor are entirely ethical and desireable and facilitate the inteview process, to such an extent that the interview can be perceived as therapeutic in itself.

430. PATIENT PERCEPTIONS OF EMPOWERMENT/ SELF ACTUALISATION WHEN TAKING PART IN A PARENTERAL METHOTREXATE SELF-ADMINISTRATION PROGRAMME

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Background: In 2002 a parenteral methotrexate self-administration programme was established in partnership with an external company within the rheumatology department of the Leeds Teaching Hospitals NHS Trust.
The service was set up for the following reasons:
1. Patient/carer dissatisfaction at having to attend the hospital weekly for therapy to be administered by rheumatology clinical nurse specialists.
2. Increasing numbers of patients requiring parenteral methotrexate.
3. Increasing strain on existing nursing and pharmacy resources.
In 2003 a survey was carried out to determine if a homecare methotrexate self-administration programme was a worthwhile service to provide for rheumatology patients. Part of this survey exained the subject of patient empowerment/self-actualisation in detail.
Methods: A questionnaire was designed using five-point Likert Scales to measure patients attitudes towards taking part in a parenteral methotrexate self-administration programme.
The study was approved by the Local Research Ethics Committee (LREC).
A pilot study was carried out to test for reliability and validity of the questionnaire. Entry criteria was all patients who were participating in the homecare programme at the time of the study (n=117). All patients had rheumatoid arthritis.
Results were returned to a third party administrator to ensure patient confidentiality.
Results: Overall response rate 79.5%.
Results were analysed using SPSS.
68.9% agreed that being able to give their own methotrexate made them feel more confident.
64.4% agreed that giving their own methotrexate made them feel more in control of their disease.
75.5% agreed that they felt they had really achieved something by learning how to inject themselves.
91.1% agreed that they had been given a choice whether to administer their own injections or not.
84.4% did not feel they had been left alone to cope.
83.3% did not feel isolated form the department by choosing to give their own injections.
Conclusions: 1. Patients giving their own methorexate felt more confident overall.
2. Giving their own injections made them feel more in control of their disease.
3. Patients felt they had really achieved something by learning to inject themselves.
4.Patients felt they were given a choice whether or not to participate in the homecare programe
5. Self-adminstering at home did not make them feel as if they had been left alone to cope.
6. Self-adminstering at home did not make them feel isolated from he rheumatology department.

431. AN INFORMATION GATEWAY FOR THE FOOT IN RHEUMATIC DISEASES

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Background: Foot involvement in rheumatic disease can result in severe foot pain and reduced mobility. Studies have promoted the value of interventions such as prescribed orthoses and specialist footwear in the management of the rheumatoid foot (Woodburn et al 2002, Hodge 1999).
However, the scale of foot problems presenting for professional foot health assessment and management in patients with rheumatic diseases in the NW region is not known. Underlying this is the lack of an information infrastructure to support large scale audit and research into foot health and foot care.
The development of standardised guidelines for the referral, assessment and management of the foot in rheumatic diseases has been achieved by the North West Clinical Effectiveness group (Foot in Rheumatic Diseases). The group suggest that there are several key elements to the assessment and management of these patients. These elements are supported by evidence where it is available or general consensus where it is not.
Our aim was to put in place the infrastructure to support an information gateway to enable the University of Salford to collate clinical data on foot health and care in patients with rheumatic diseases from remote NHS sites across the North West.
Methods: Existing foot health assessment forms were analysed and a focus group was formed to explore the aspects of foot health assessment and agree the requirements for a standardised self carbonated form. Following a pilot study of the form and some minor alterations, the form was used in 18 trusts in the NW region with the original form being kept in the patients records and the anonymous carbonated copy sent to Salford University.
Results: Five assessment forms have been returned to date from each of the participating NW trusts (total n=60). The forms were analysed for correctness and usability. The data has also been analysed in respect of the types of foot health problems, their management and the clinical outcomes.
Conclusions: The information collected to date has demonstrated that the foot health assessment form provides the practitioner with a standardised and comprehensive approach to assessment of the patient and foot.The University of Salford is at the hub of a continuous information system, which has the potential to greatly advance our understanding of the foot care delivered to patients with rheumatic diseases.
The information system will provide research data for the purposes of clinical trials, health service research and service planning and delivery. There is further work exploring the potential of an electronic version.

432. THE MANAGEMENT OF PATIENTS WITH RHEUMATOID ARTHRITIS: SPLINT AND ORTHOTIC PROVISION – RESULTS OF A SUREY FROM EIGHT PHYSIOTHERAPY DEPARTMENTS

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Background: As a chronic disease patients with rheumatoid arthritis present a challenge to physiotherapists working in the area of rheumatology. The majority of these patients have foot and hand disease and require orthotic and hand splints. A survey of patients with RA will highlight the frequency of splint and orthotic use among this patient group, information which will be of use to physiotherapists working in this area.
Methods: Patients with RA attending eight physiotherapy departments in Ireland over a six month period from April to October 2003 were informed about the survey and invited to participate. Informed consent was obtained from all particiapnts. The survey form recorded details relating to patient management, splint and orthotic use, footwear and the use of aids and appliances. The Health Assessment Questionnaire (HAQ) was recorded for all participants. Ethical approval was required by and granted for six of the participating centres.
Results: 273 patients (n=199) female participated in the survey. The mean HAQ score was 1.61 (sd 0.77), indicating moderate disability. Mean age was 59.8 years while mean disease duration was 13.8 years. Less than 50% (38.6%, n = 105) of participants wore orthotics. Of these, 46.7% were custom made. 50% of participants wore splints of which 16% were resting, 45% were active and 39% of particiapants had both. The majority of splints were provided by an Occupational Therapist (93.5%) with 6.5% provided by a physiotherapist. The results were further examined to investigate the profile of participants with respect to gait aid provision and use of aids and appliances. T -tests were used to analyse differences between participants with and without gait aids and with or without aids and appliances with re-

spect to age, ESR, disease duration and HAQ scores. Participants with gait aids were significantly older (p=0.026), had significantly longer disease duration (p=0.037), higher ESR (p=0.012) and higher HAQ scores (p=0.015). Participants with aids and appliances had a significantly longer disease duration (p=0.05), higher ESR (p=0.002) and higher HAQ scores (p=0.001) than those without. However, a considerable proportion of participants with moderate (43%) or severe (29%) disability had no aid or appliance.

Conclusions: Results indicate that participants using gait aids were significantly older, had longer disease duration, higher ESR levels and higher HAQ scores. Participants with aids and appliances had significantly longer disease duration, higher ESR and HAQ scores than those without. It is noteworthy that the majority of participants with no aids or appliances had moderate or severe disability.