Rheumatology in Wales
The State of Play
Foreword from the BSR

We are pleased to be publishing *Rheumatology in Wales: The State of Play*, an inaugural report exploring Welsh rheumatology services, directly based on the feedback we received from our members based in Wales. We are also delighted that NRAS’s input into the report has allowed the document to provide a complementary, and comparative, narrative of patients’ experience. The report’s wide scope reflects the experiences of the broad range of BSR members, healthcare professionals working across many settings along the care pathway to provide care and support to patients. The report highlights the work the BSR’s membership has undertaken in Wales, such as the Healthcare Quality Improvement Partnership (HQIP) National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis (EIA), and has provided an opportunity to showcase the excellent work conducted by third sector partners in the region. The series of State of Play reports is reflective of the Society’s commitment to supporting our members in Wales and across the four nations. As an organisation, we aim to actively promote report’s recommendations to stakeholders, on a national and local level, to ultimately support and improve Wales’ rheumatology services, particularly in the context NHS Wales’ financial pressures.

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Foreword from the NRAS

We are delighted to be partnering with the BSR in respect of this joint report on services related to Rheumatic and Musculoskeletal Diseases across Wales. The BSR brings the clinical/medical perspective through a survey of its members and NRAS has contributed the patient perspective from a survey conducted in Spring 2016 to members and non-members alike to gauge how people with rheumatoid arthritis (RA) feel about access to care and treatment in their local Health Board area. Both of our organisations have additionally been able to draw on other sources of information, with the BSR able to refer to data from the National Audit for EIA for example and we on feedback in recent times from our Welsh Campaigns Network, our NRAS groups in Wales, the health professionals we interact with and people with RA who engage with us through social media. All of these sources of data indicate that, whilst there are areas where access to care is undoubtedly good, there is significant variation across Wales in access to high standards of care as recommended in NICE guidance. I very much hope that this report will be a useful additional resource to provide further evidence for health professionals and people with RMDs to engage with Health Boards and Assembly Members with the joint aim of improving patient care and outcomes.

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Chief Executive  
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Summary of BSR and NRAS Recommendations

1. NHS Wales and Local Health Boards (LHBs) should support rheumatology services to meet quality standards for the treatment of all RMDs, with a particular emphasis on Rheumatoid Arthritis given the findings of the recent national clinical audit. This should include the allocation of additional resources, providing services with the support and flexibility to redesign pathways and introduce Clinical Musculoskeletal Assessment and Treatment Service (CMATS) and Early Inflammatory Arthritis Clinics. This would be facilitated by the introduction of an appropriate Key Performance Indicator (KPI) and/or for a national delivery plan to be developed specifically for RMDs.

2. Welsh Health Specialised Services Committee (WHSSC) should collaborate with rheumatology services to formalise pathways and networks for each geographical area. Options explored should include hub and spoke models in addition to the development of specialist centres, such as Cardiff Children’s Hospital becoming designated and resourced as a tertiary centre for paediatric rheumatology.

3. The Welsh Government should undertake a review of existing workforce planning arrangements across LHBs ensuring services reflect local needs with an agreed improved workforce strategy in moving forward. Similarly we endorse RCP’s recommendation to develop a Wales training strategy, and support the Welsh Government taking forward the Health Professional Education Investment Review.

4. Rheumatology services should review how their service provides person centred care. This should include assessing the degree services have embedded shared decision making, self-management support and personalised care planning. LHBs should support the required training and service redesign to ensure these services are compliant. Services should work collaboratively with local patient organisations representing each condition, for example by utilising their patient information and referring patients to the relevant patient support groups.
Introduction

This report is a collaboration between the British Society for Rheumatology (BSR), the professional organisation for healthcare professionals working in rheumatology across the NHS, and the National Rheumatoid Arthritis Society (NRAS), the only national patient organisation focussing specifically on rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA). We seek to present a picture of rheumatology services in Wales from both clinical and patient perspectives across all rheumatic and musculoskeletal disorders (RMDs). The clinical perspective is informed by a survey of BSR members in Wales and a scoping exercise with the Cymdeithas Rheumatoleg Cymru (Welsh Rheumatology Society) held in May 2016. The patient perspective is primarily informed by a national survey of people living with RA in Wales, conducted by NRAS in April 2016. As the research content and timeframe overlapped, we have presented the findings into a single report to present a dual perspective.

For clarification this document is applicable to all RMDs, however focuses on RA due to the NRAS survey being specific to this condition and the BSR has also has a significant amount of data on RA and early inflammatory arthritis from the National Audit for EIA which measured services’ performance based on the National Institute for Health and Care Excellence (NICE) Quality Standards for RA in over 16s [1].

Feedback from the health professionals and people with RA in Wales indicated that, whilst there are areas where care and treatment is excellent, there is significant variation in terms of meeting the standards of care developed by the BSR, the NICE and the Welsh Government.

BSR and NRAS hope this joint report will become a resource for healthcare professionals and people with RMDs in Wales and act as a driver for the Welsh Government, NHS Wales, Local Health Boards (LHB) and other stakeholders, to ensure timely and effective care for patients with RMDs, whilst supporting the rheumatology multidisciplinary team (MDT) delivering such care. We hope this document will empower people with RA to engage with their local Assembly Members and other key decision makers in Wales on issues which matter to them and their families.

This report forms part of a series the BSR has produced starting with The State of Play in Rheumatology: Insights into service pressures and solutions in 2015, which highlighted the status of rheumatology services throughout the UK, followed by Rheumatology in Scotland: The State of Play, launched at a meeting of the Scottish Parliament’s Cross Party Group for on Arthritis and Musculoskeletal Conditions in 2016. The fourth report in this series, planned for 2017, focuses on services in Northern Ireland and will enable us to explore similarities and differences in provision of care across the UK. The NRAS survey also builds on similar surveys they have undertaken in England and Scotland.
Prevalence of RMDs in Wales

RMDs, which are treated by the rheumatology MDT, encompass over 200 conditions. These conditions are the biggest cause of the growing burden of disability in the UK, affecting over 10 million adults and 12,000 children [2]. Musculoskeletal conditions are the most common type of self-reported illness [3], accounting for 20% of GP consultations [4]. The Welsh Health Survey 2015 found that 12% of the population aged 16 upwards, reported being treated for arthritis [5]. This is almost the same level as mental illness (13%) and significantly higher than diabetes, which was reported at 7% [5].

Such conditions, and consequently their treatment, have the potential to have a huge impact on individuals and the economy. A National Audit Office study in England found that earlier treatment for rheumatoid arthritis could gain the economy £31 million due to preventing sick leave and unemployment [6].

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Rheumatology Services

There are 18 rheumatology services in Wales. These are located across all LHBs, with the exception of Powys, where outpatient clinics are provided by rheumatologists in neighbouring LHBs. In May 2016, the number of referrals in one month surpassed three thousand across all services in Wales (3,021), a significant increase by comparison to April 2012 when this figure stood at 1,810 [7]. In 2015/16 there were 24,804 new attendances to rheumatology, in comparison to 23,964 in 2011/12 [8]. Such statistics highlight the increased pressure on rheumatology services. Yet the dramatic increase of total referrals and new attendances is unlikely to be reflective of prevalence, anecdotal evidence has indicated that non-inflammatory musculoskeletal (MSK) referrals to rheumatology, which are not traditionally seen by the speciality, have grown due to constraints on other services in the MSK pathway, such as orthopaedics. This increased number of unsuitable referrals has impacted on the treatment received by patients who require direct care from a rheumatologist, who have conditions such as RA or ankylosing spondylitis (AS). The National Ankylosing Spondylitis Society (NASS) found, for example, that 24% of the patients they surveyed in Wales were not under the care of a rheumatologist [9].
Referral to treatment is the time taken from when a GP refers a patient to hospital to when the patient receives treatment, and includes time spent waiting for any hospital appointments and diagnostics needed before being treated. More broadly, there have been slight improvements, with a fall recorded in the number of patients waiting over 26 weeks, from 6% in June 2015 to 5% in June 2016 [12].

Specifically looking at RA, the first annual report of the National Audit for EIA reflected these poor waiting times with only 28% of patients in Wales being seen within 3 weeks of referral, compared to the UK average of 38% [13]. This figure of 28% had fallen to 22% by the second annual report, despite the national average remaining consistent [14]. The National Audit for EIA demonstrated delays in starting treatment with only 48% of patients commencing disease-modifying anti-rheumatic drugs (DMARDs) within 6 weeks compared to the UK average 53% [13], though the second annual report found 75% of patients in Wales were starting DMARDs within 6 weeks [14]. Patients ideally need to be treated within the 12-week window of opportunity to stand the best chance of achieving remission or a low disease activity state [15]. Additionally, early intervention is associated with a reduced need for expensive biologic drugs or joint replacement surgery and increases the chances that the patient will remain in employment, thus improving quality of life whilst saving money for the NHS.

These statistics should be read in conjunction with the findings of the NRAS patient survey, which reported that the median time it took patients was 6-7 weeks from first experiencing RA symptoms to beginning treatment with an RA specialist. However, a worrying minority (20%) of respondents reported waiting over two years to begin treatment, with the delay being primarily attributed to the waiting time between GP referral and first seeing a consultant rheumatologist. There were also a significant proportion of participants who had to fund at least a first visit to see a consultant in order to seek a diagnosis because they felt that the waiting times in the NHS were too long. Recent calls to the NRAS Helpline provide further anecdotal evidence that in many areas of Wales waiting times to first see a consultant rheumatologist are unacceptably high.

In June 2016, 39% of all patients referred to rheumatology (3,114 out of 7,953) were treated within 6 weeks, in comparison to June 2015 when 45% (3,035 out of 6,766) were treated within this period [11].
In terms of follow-up, in 2015/16 there were 93,959 total attendances, with a 2.8 new to follow-up ratio, compared with 2011/12 when there were 94,854 with a ratio of follow up to new attendances of 3.0 [8]. Though this highlights the slow reprioritisation of existing patients, the dissatisfaction of follow up patients is reflected in NRAS’s survey which asked patients about their experiences of care after their first appointment. The survey found that:

- Four in ten patients did not feel that the intervals between appointments with either their rheumatology consultant or specialist nurse were sufficient to keep their RA under control.
- 60% of patients surveyed could self-refer to a rheumatology nurse specialist.
- Eight in ten patients knew who to contact in case of a flare up or change in condition which is promising, though remains an essential area for improvement.
- Only one in ten patients reported having a formal care plan, and a quarter reported that they did not have one but would like to have one. A plan would facilitate care planning and shared decision making, and the Welsh Government has commitment to providing care plans to all people with chronic conditions [16].
- 30% of patients reported having an annual review whilst 25% said they did not have one but would like to, this is at odds with the clinician reported statistic in the National Audit for EIA claiming that 100% of units were delivering annual reviews, however these included informal and formal reviews.
- 85% of patients saw the same professionals during routine care ‘always’, ‘quite often’ or an ‘average’ amount, and respondents were most likely to regularly see the same RA consultant (85%) and RA nurse (80%), but were less likely to see the same physiotherapist (15%).

Rural Services

In 2011, 32.8% of Wales’ population lived in rural areas, the highest percentage in the UK [17], therefore providing healthcare within this setting is vitally important. Powys Teaching Health Board has a rural population therefore patients are referred to other LHBs. Examples of best practice are the Mid-Wales Health Collaborative and the CARTREF Future Hospital development project at Betsi Cadwaladr University Health Board, where secondary care is provided to the rural elderly via telemedicine [18]. However the appropriateness of utilising telemedicine for rheumatology is questionable due to the physical nature of patient assessment required. Additionally innovative technologies requiring the internet are unable to be used due to unreliability of internet connection throughout Wales. The BSR endorses the RCP’s recommendation that there should be a commitment to investing in rural and remote healthcare services in Wales [19], whilst also looking at the needs of the individual specialties. Collaboration with Primary Care via providing shared care is vital in these rural settings.
Implementing an effective triage system, such as the one in place at Princess of Wales Hospital, Bridgend can streamline referrals to alternative MSK services more appropriate to the patient’s condition, resulting in shorter waiting times and be a more prudent use of specialist time. Early Inflammatory Arthritis Clinics can be one method of improving access to treatment [13]. Yet the first and second annual report of the National Audit for EIA found that Wales had the lowest proportion of Boards with early inflammatory arthritis clinics, at 33% [13] [14]. BSR members based in Wales said the creation of these clinics were dependent on the initiative of individual consultants, with no support from management and at the expense of other conditions. There is also limited funding for these services, in comparison to England, where the Best Practice Tariff has driven the creation of EIA's clinic. Dedicated condition specific condition clinics, such as for RA or AS, are another method of managing waiting lists however the lack of a dedicated MDT can prevent their maintenance [9].

Developing effective triage: the Bridgend Case Study [19]

At the Abertawe Bro Morgannwg University Health Board, 13% of patients waited over 26 weeks for an outpatient appointment, breaching a Welsh Assembly Government target. This was a consequence of inconsistencies, delays and inappropriate referrals in a referral pathway consisting of numerous clinicians, working without agreed referral criteria.

As a consequence, a referral prioritisation project was initiated. A single designated consultant would review all referrals, with inappropriate referrals for rheumatology being redirected to other services such as chronic plain or returned to the referring physician or GP with management or investigation plans. Letters were sent to patients explaining the decision. As a result of this new system, the waiting times fell to 4–6 weeks across all sites in the Trust by March 2015.

Subsequently new patient clinics were converted for follow up patients to address the significant follow up caseload waiting longer than their due review date, in 2014 there were over one and a half thousand patients waiting longer than their target date for review from 1,624 in March 2014 to 253 in January 2016. This approach challenges referral habits in primary care, reduces inconsistencies in secondary care, ensures that patients at greatest clinical need are prioritised and avoids unnecessary appointments for those who can be managed elsewhere [10].

1) BSR & NRAS Recommendation: NHS Wales and Local Health Boards (LHBs) should should support rheumatology services to meet quality standards for the treatment of all RMDs, with a particular emphasis on Rheumatoid Arthritis given the findings of the recent national clinical audit. This should include the allocation of additional resources, providing services with the support and flexibility to redesign pathways and introduce Clinical Musculoskeletal Assessment and Treatment Service (CMATS) and Early Inflammatory Arthritis Clinics. This would be facilitated by the introduction of an appropriate Key Performance Indicator (KPI) and/or for a national delivery plan to be developed specifically for RMDs.
Across the spectrum of over 200 conditions treated by rheumatology teams, a proportion are classified as rare and can affect a range of systems including joints, bones, soft tissues, lungs, heart, nervous system, kidneys, skin and eyes. Patients living with these conditions therefore require care across a range of specialities. Rare RMDs can be categorised into two distinct groups, rare autoimmune rheumatic diseases which comprise systemic vasculitis, scleroderma, myositis and sjogren’s syndrome, and rare non-autoimmune rheumatic diseases which includes osteogenesis imperfecta and fibrous dysplasia [21].

The Wales Health Specialised Services Committee (WHSSC) was established by the LHBs in 2010 to ensure patients across Wales have equal access to specialised services. The Welsh Implementation Plan for Rare Diseases of the UK Strategy for Rare Diseases, published in 2015, focuses on the co-ordination of care [22]. The implementation plan does not address the need for improved resources. Yet the feedback we received from clinicians highlighted that they would be unable to implement NICE guidance for rare conditions specifically due to lack of resources. Access to key diagnostics, such as PET CT and TA ultrasound was cited by some respondents as being limited. Additionally the acute nature of rare rheumatology conditions means urgent appointments or urgent day unit capacity is vital, yet clinician respondents reported that services were unable to accommodate either. One respondent stated they had no renal or neurology specialists within their LHB, and as a result, such services were provided by a neighbouring Board which restricted the speed of communication between the health professionals. Feedback received from members of Vasculitis UK, who are individuals living with vasculitis, echoed this statement, noting the poor levels of communication between different specialities within one LHB.

Rheumatology in Wales: The State of Play

The Service Development and Commissioning Directives for Arthritis and Chronic Musculoskeletal Conditions recommended that commissioners collaborate with health professionals to evaluate the needs of patients, and if necessary develop regional musculoskeletal networks to support specialised disorders [23]. Patients currently living with rare rheumatological conditions in Wales do have access to specialists in their condition via their local rheumatology service, which may have an in-house specialist or links with other centres in England that provide advice, satellite clinics, or to which the patient can be transferred. Additionally, complex cases are discussed at local and regional meetings. Feedback we received from Vasculitis UK’s members indicated that joint care with a local service combined with treatment from a specialist centre, even outside Wales, was highly valued yet concern was voiced as to how formal and permanent these arrangements were. In terms of ensuring staff are sufficiently trained to support patients with the aforementioned conditions, LUPUS UK has agreed funding for a Specialist Lupus Nurse to work across North Wales, with plans for recruitment well under way.

UK wide recommendations for action to improve care for people with rare rheumatological conditions can be found in BSR’s report A collaborative approach to improving outcomes in rare rheumatic and musculoskeletal diseases: report from a national workshop which are being taken forward by the Rare Auto-Immune Rheumatic Disease Alliance (formed by BSR, Vasculitis UK, Scleroderma & Raynaud UK and Lupus UK) [21].

Paediatric rheumatology is considered a subspecialty within rheumatology with JIA being one of the most common conditions affecting one in a thousand children. NRAS estimates that there are 400 children living with JIA in South Wales, yet 2014, only 202 children were registered as being treated for paediatric rheumatology conditions at Cardiff hospital. It is therefore concerning that there may be children in Wales who are going undiagnosed, untreated, or are receiving inappropriate treatment, potentially causing irreversible damage and a lifetime of disability. Wales does not have a ‘tertiary centre’ for paediatric rheumatology, and each LHB is differently organised to provide this care. The vast majority is managed via a hub and spoke model with Welsh patients having to access some or all of their paediatric rheumatology services in England at either Alder Hey Children’s Hospital in Liverpool or Bristol Royal Hospital for Children. This has accessibility implications which NRAS highlighted in their JIA in Focus report of 2014. The British Society for Paediatric and Adolescent Rheumatology Standards of Care for JIA state that the core team in a fully resourced tertiary centre should include a paediatric rheumatologist, a specialist nurse, an ophthalmologist, a paediatric physiotherapist, a clinical psychologist, an occupational therapist and a podiatrist [24]. Yet in Cardiff there is currently only 0.25 full time equivalent of an adult rheumatologist and 0.5 of a specialist nurse, this translates to a day and a quarter/two and a half days respectively. Furthermore, managing the transition from paediatric services to adult rheumatology during teenage years is crucial, however, these services are incredibly inconsistent, with only Cardiff and Bangor offering a formal transition service.
As the only nation within the UK without a centre for paediatric rheumatology, Cardiff Children’s Hospital should become a designated and resourced as a tertiary centre for paediatric rheumatology. As the infrastructure already exists, the cost of resourcing a specialist paediatric rheumatology service would be primarily related to the appointment of a paediatric consultant led multi-disciplinary team, costing approximately £235,000. NRAS has been campaigning for this for nearly three years and has been in touch with WHSSC on this topic, working more closely with the rheumatologist at Cardiff to pursue this matter this year. Several parents of children living with JIA have raised the matter with their Assembly Members in the next stage of this campaign.

**2) BSR & NRAS Recommendation:** Welsh Health Specialised Services Committee (WHSSC) should collaborate with rheumatology services to formalise pathways and networks for each geographical area. Options explored should include hub and spoke models in addition to the development of specialist centres, such as Cardiff Children’s Hospital becoming designated and resourced as a tertiary centre for paediatric rheumatology.

Waiting times can also be reduced by quick access to diagnostics. The first and second annual report of the National Audit for EIA found that Wales had the lowest access to same day ultrasound at 33% [13]. Additionally, an all Wales Audit from 2015 published as an abstract at Rheumatology 2016 found only two centres in Wales have partial access to a same day ultrasound service, with the mean wait time for patients at other centres of 8 weeks. Respondents also noted that North Wales has poor access to pathologists; with one respondent reporting that positron emission tomography–computed tomography (PET CT) scanning in their hospital was only available for oncology. This is despite Service Development and Commissioning Directives stating that LHBs should ensure ‘effective modern technologies are in place to facilitate early assessment and diagnosis of arthritis and musculoskeletal conditions’ [23].

Though many patients receive their required drug treatment, there were concerns over the equity in access to medicines. Placing certain medicines on shared care protocols can improve access. It is known from discussions with former ministers in the Welsh Government that the soaring drugs bill in rheumatology since the introduction of ‘biologic’ drugs in the late 90s has made ministers far more aware of rheumatology than they previously would have been.

A key issue of concern was with the Independent Patient Funding Requests process (IPFR), which is required when a patient requires services outside the routinely funded range of treatment and medicine available on NHS Wales. A survey of Wales’ rheumatologists, conducted in 2015 by Dr Ceril Rhys-Dillon, found only a minority were ‘very satisfied’ or ‘satisfied’ with the IPFR process [25]. Practical barriers and concerns around IPFR were the lack of accountability of the IPFR panel, the time consuming nature of the IPFR application and the need for an additional application if the patient is treated in both Wales and England; one for funding to get a patient into a specialist service, another for access to a treatment. Furthermore, allowing all Wales Cohort drug policies for indications not considered by NICE to prevent local variation in access should be considered by the Independent Patient Funding Request Review 2016.
Evidence indicates that early assessment by a specialist multidisciplinary team is effective for RMDs [26]. The first annual report of the National Audit for EIA revealed some interesting variation in Wales in relation to workforce numbers. For example, Wales had the highest rates of consultants at 1.2 per 100,000, and 83% of Trusts had access to physiotherapy, occupational therapy and podiatry, respectively this was 75%, 77% and 55% on a national basis [13]. Yet in contrast, the audit found that Wales had the lowest number of specialist nurses of 0.9 per 100,000 population [13]. The second annual report found the numbers had decreased for consultants (1.18), increased for specialist nurses (0.95) and stayed the same for allied health professionals [14]. The BSR’s members expressed concern over the lack of success or workforce planning across all rheumatology professions, leading to positions being vacant for long periods of time. This view was echoed in the NHS Wales Workforce Review [26].

Specialist nursing has been shown to improve patient satisfaction with care, quality of life and fatigue. This role is vital as it provides patient education, advice on self-management, drug counselling and monitoring. Nurses also co-ordinate care, operate telephone helpline services and run nurse-led clinics which can assess the effectiveness of a management plan. With fewer specialist nurses in place, nurse-led helplines suffer reduced hours or being removed, yet a review of the effectiveness of a telephone helpline supporting the treatment of outpatients with RA found that over 95% of surveyed callers were satisfied with all aspects of the helpline service [28]. In addition, 60% of surveyed patients said that had the helpline not been available, they would have made an appointment with their GP [28]. Healthcare professionals were concerned that rheumatology nurse specialists were being placed in general medical wards the BSR considers it unfortunate that the Nursing Staffing Bill’s impact will largely be in acute hospital wards [29].

An additional concern was that rheumatology services had a limited number of administrative and support staff. It is hoped that the NHS Wales Workforce Review will act as a stimulus for change, though we are concerned with its arguments for more generalist doctors rather than specialists within NHS Wales [27]. As articulated by the BMA, specialists can be more efficient, and that training generalists is lengthier as they require training across a wider skill base [27]. Furthermore, all new specialty registrars in Wales now undergo dual accreditation, resulting in the loss of half of the trainee workforce and no new numbers to back-fill rheumatology services. This is compounded by the changes to non-training middle grade roles.

The Welsh Government has placed a significant emphasis on the training of health professionals. In 2015, the Health Professional Education Investment Review was published [30], and in 2016 it announced a significant amount of investment in nurse and physiotherapy training places [31] [32].

3) BSR & NRAS Recommendation: The Welsh Government should undertake a review of existing workforce planning arrangements across LHBs ensuring services reflect local needs with an agreed improved workforce strategy in moving forward. Similarly we endorse RCP’s recommendation to develop a Wales training strategy, and support the Welsh Government taking forward the Health Professional Education Investment Review.

The collection of data, and, importantly, the availability of technology to facilitate this, has implications for service planning as it would provide the rheumatology team with accurate information on the case mix and service demand. Furthermore, the lack of suitable coding in rheumatology has had a significant clinical impact. For example, the lack of outpatient data means it has been difficult to identify urgent follow ups, and manage day unit capacity, resulting in waiting lists for drugs such as rituximab and making adherence to NICE standards impossible.

Data are not routinely collected on patients in Wales, and any information that is collected in rheumatology is mainly achieved via computerised patients’ notes and recording clinical activity. Routine data collection has been hampered by the lack of software to facilitate this process, the incompatibility of such software with hospital computer systems and the fact that data collection is a secondary function. Individual databases have been set up within departments, however one respondent noted this was done outside of clinic time and are done as routine, with time being given and dedicated to them. As articulated by the BMA, hospital IT systems need to improve so they can connect with the superior electronic systems in place in primary care, as failure to do this can have implications to patients’ continuity of care [33]. The BSR hopes the Welsh Government’s £6.7m investment in a new IT system across health and social care will improve this by being developed in collaboration with health professionals to meet their needs [34].
Research should be core to rheumatology services, to facilitate better care and outcomes for patients. To facilitate this both the RCN and the RCP recommended the development of clinical academic careers, the former in *The Future of Nursing Education in Wales* report and the latter in their action plan for the next Welsh government [35] [19]. Additionally initiatives, such as the Chief Nursing Officer for Wales’ pilot programme to develop clinical academic nursing staff in Wales [35], will facilitate such careers to ensure that academic research be considered in Wales when planning and delivering health services.

The Service Development and Commissioning Directives recommended that LHBs should ensure appropriate information is provided on the support and interventions that are available [23]. Welsh BSR members reported that nurse-led clinics facilitated self-care and shared decision making, complemented by the provision of telephone advice lines and patient education. The second report of the National Audit for EIA found 52% of patients received education and self-management within one month of diagnosis, compared to the national average of 67% [14].

The patient perspective was mixed. For example, 86% of respondents to NRAS’s survey reported being provided with further information about their RA, however 35% of this group were not given, 86% of respondents to NRAS’s survey were provided with further information about their RA, but of this group 35% were not given any other information about related issues such as other available services or organisations that could provide further advice and support. However, nearly all (95%) stated that they had found the information helpful. 30% of respondents reported that no-one had spoken to them about the emotional impact of living with RA, with physiotherapists and RA nurses reported as the most likely to bring up the topic which may have long term mental health and employment implications. A NASS survey of Welsh patients living with AS found that only 19% have a written care plan, and only 64% of those under a rheumatologist felt they had received all/most of the information for their condition [9].

Patient organisations are invaluable in providing support to patients and should be utilised by rheumatology services to deliver additional support to patients. NRAS and other patient groups can complement rheumatology services. For instance, NRAS specifically provides educational and self-management activities, a helpline available during weekdays, telephone and on-line peer support. NRAS also provides training for health professionals; this includes Rheum2Talk delivered by a psychotherapeutic counsellor to teach healthcare professionals how to open the door to conversations about sensitive issues such as emotions, relationships and sexuality. NRAS also has a number of community groups in Wales.

### 4) BSR & NRAS Recommendation: Rheumatology services should review how their service provides person centred care. This should include assessing the degree services have embedded shared decision making, self-management support and personalised care planning. LHBs should support the required training and service redesign to ensure these services are compliant. Services should work collaboratively with local patient organisations representing each condition, for example by utilising their patient information and referring patients to the relevant patient support groups.
Secondary care rheumatology and primary care interact mainly through GP referrals into rheumatology services and shared care. There are also a number of rheumatological conditions which ideally managed in primary care. Referrals from primary care to rheumatology have increased. As stated previously, the number of referrals in one month, September 2016, reached 2,659, compared to April 2012 where there were 1,810 [7]. This is complemented by the first annual report of the National Audit for EIA which showed that Wales had the largest proportion (40%) of patients who were referred by their GP within 3 days of first presentation [13]. This increased to 46% in the second annual report with the UK average at 20%. This reflects the increasing number of referrals to rheumatology [14]. Though prompt referrals are vital for effective treatment, these findings might be a result of GPs in Wales having an increasingly lower referral threshold or being less aware of referral criteria, with inappropriate referrals contributing to larger and longer waiting lists. Such inappropriate referrals include conditions such as osteoarthritis and fibromyalgia which after diagnosis has little additional need for treatment in secondary care when they can be primarily treated in primary care. This may also be a result of all MSK presentations being referred rheumatology due to pressures to reduce lengthy orthopaedic waiting times. It is also important to note the lack of implementation or accountability of the 2014 report by the Welsh Government who convened the Task and Finish Group for Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM), demonstrating a failure to encourage certain conditions traditionally referred to rheumatology to be treated in primary care [36].

To overcome this, as recommended in the Service Development and Commissioning Directives [23], some rheumatology services in Wales do provide email and telephone advice as well as education to GPs and other health professionals to ensure they are adequately prepared for the high volume of consultations. For example, in Wrexham, inappropriate rheumatology referrals are being reduced by educating those practices that have a high rate of referrals resulting in discharge at first attendance, through collaborative working with the CMATS and the GP clusters. The introduction of CMATS can improve referral rates to rheumatology. For example, if a GP is uncertain of the nature or the treatment of the musculoskeletal problem the patient is presenting they can refer the patient to a CMATS who will triage the patient and make an appropriate referral to primary, secondary or community care. Though such initiatives occur in most LHBs, CMATS integration within the pathway is variable, limiting its utility. As previously discussed, the introduction and use of triage services can aid the referral process.

Additionally, rheumatology and primary care routinely collaborate after the patient is diagnosed through the shared care of patients, with GPs taking over responsibility for administering drug treatments and monitoring patients. To support this, shared care protocols and pathways have been developed between GPs and rheumatology departments to facilitate such activity. For example, a respondent stated that for DMARDs the first two weeks of the prescription is given by rheumatology with the dose escalation advised and responsibility transferred to GPs for further treatment. In the case of denosumab, for instance, a treatment for osteoporosis, responsibility is passed on to the GP once the first injection has been given in secondary care.
Rheumatology has built relationships with community care via the district nurses who administer medication to RMD patients with some providing RA clinics, in addition to engaging community physiotherapists and occupational therapists. Despite the efforts of NHS Wales and the Welsh Government to promote collaboration between health and social care, the principal emphasis has been on social, primary and community care, rather than secondary care [37]. In rheumatology, collaboration with social care occurs via occupational therapists or the GP and the feedback we received from healthcare professionals indicates that the rheumatology MDT in Wales believes there would be value in the development of direct pathways. Consequently LHBs should explore on how this can be developed.

Both clinician and patient respondents indicated that access to psychological therapies is limited. Rheumatologists are unable to refer directly to clinical psychologists, only via the GP or pain service, despite clinical psychology being considered to be a beneficial addition to the MDT in the NRAS survey. The mental health needs for these patients have been overlooked on a national level. In the Together for Mental Health: Delivery Plan 2012 to 2016 and the Mental Health (Wales) Measure 2010 there is limited mention of the mental health of patients with physical long term conditions [38] [39]. In terms of third sector provision, North Wales has a pan-regional mental health service (Parabi Talking Therapy) which provides short-term therapeutic interventions provided by a consortium of charities. Rheumatology patients can self-refer into the service which provides generic therapies rather than offering tailored interventions for specific physical conditions. Furthermore, there is no collaboration between such services and the rheumatology MDT, preventing the provision of joined up holistic care. Therefore, the future Welsh Mental Health Strategy should support the mental health of patients with long term conditions, recognising and providing interventions that target their individual needs to promote progress in this area.

Wales faces huge public health challenges. In 2015 just under a fifth of Welsh adults reported that they currently smoke, 31% are physically active on five or more days in the previous week, and 32% on no days, and 59% were classified as overweight or obese [40]. Additionally in Wales 680,000 people live in low income households [41]. In terms of employment, 16% of those reporting to be treated for arthritis had either never worked or were in long term unemployment [42]. 30% of the NRAS RA patient survey respondents were in full or part time employment and a further 35% were out of work due to their RA, high by comparison to a UK wide survey on the impact of RA on work which NRAS carried out in 2007. Since 2006, £90 million has been spent a year on incapacity benefits to individuals suffering with back pain in Wales [23]. All of the above have causational links to RMDs, as articulated by one health professional, ‘we are seeing a lots of the conditions which are the consequence of deprivation, no work, obesity’. The Service Development and Commissioning Directives recommended that LHBs collaborate with Public Health Wales to ensure prevention measures were integral to services for RMD patients [23].

To address both the public health and employment challenges, Welsh BSR members felt that having direct access to occupational therapists and physiotherapists as part of the rheumatology MDT, was crucial, in addition to being able to make referrals to the National Exercise Referral Scheme. BSR respondents, the majority of whom were consultants, reported difficulty in having sufficient time to address these areas in clinic; this is compounded by their perceived lack of knowledge in the area. Furthermore, it was felt rheumatology’s access to dietitians needed to be increased.
The survey questionnaire was designed by the NRAS team and an independent statistician. The survey was circulated electronically to those on the National Rheumatoid Arthritis Society’s Welsh contact list which included members of NRAS and non-members, and was also publicised through NRAS’s various social media channels and website. In total there were 257 responses, however a number of these (54) were discounted due to survey submissions being incomplete, duplicated or not meeting the criteria for inclusion (i.e. living in Wales and diagnosed with RA). This survey captured around 0.7% of people with RA in Wales but we cannot be sure how representative this sample is of the overall RA population in Wales. All percentages have been rounded to the nearest 5%, therefore totals will not necessarily sum to 100%.

- Nearly all who responded were female (90%), and the group had an average (median) age of 56. The ratio of women to men with RA is approx. 3:1. This is consistent with the typical profile of someone with RA as common age of onset is between 40-60.
- Nearly all who responded (90%) had been diagnosed with RA for over a year, and more than 60% reported being diagnosed with RA for over 5 years.
- The geographic location of respondents was collected by LHB area. There was a particular concentration of respondents in the Aneurin Bevan (25%) and Betsi Cadwaladr (25%) LHB areas, although there was participation from all LHB areas across Wales. The areas with strongest responses can be attributed to the strength of the NRAS database in these areas.

For a full copy of the NRAS survey, please email campaigns@nras.org.uk
References


20 Usha Srinivasan. Project Form [e-mail]. Message to: Anna Lewis. 2016 Aug 10 [cited 2016 Nov 7].


25 Ceril Rhys-Dillon, C. IFR Survey [e-mail]. Message to: Anna Lewis.2016 Jan 01[cited 2016 Nov 7].

