



Rheumatology

GIRFT Programme National Specialty Report

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Foreword from Professor Tim Briggs

I am delighted to recommend this Getting It Right First Time review of rheumatology, led by Dr Lesley Kay and Dr Peter Lanyon, with advice from Professor Alex MacGregor.

This report comes at a time when the NHS has undergone profound changes in response to the COVID-19 pandemic. The unprecedented events of 2020 – and the extraordinary response from everyone working in the NHS – add greater significance to GIRFT's recommendations, giving many of them a new sense of urgency. I have been impressed to see, from the results of a survey of rheumatology services, how they have been dealing with these pressures and continuing to provide care, often in innovative formats. Actions in this report, such as improving referral systems with clearer criteria, switching where appropriate from intravenous to oral or subcutaneous treatments and improving remote monitoring and support for stable patients, can help the NHS as it faces the substantial challenge of recovering services, while remaining ready for any future surges, by operating more effectively and safely than ever before.

Lesley, Peter and Alex have applied the GIRFT approach to their field of rheumatology, a specialty which can provide life-changing treatment to people facing the burdens of disability and pain due to conditions such as arthritis and autoimmune disorders. From my own experience in orthopaedics, I know how transformative the medical interventions for these patients can be to their quality of life.

The recommendations set out in this report are based on the visits they made to 62 trusts across England, in addition to other data and audits. Implementing these recommendations will help to improve the timeliness and quality of care for the most prevalent and high impact conditions. The recommendations include providing services for non-inflammatory painful conditions closer to home, developing reablement and support services in consultation with patients and ensuring that the NHS maximises the value and efficacy of advances in drug therapies.

Lesley and Peter, like other GIRFT clinical leads, have been encouraged by the response they have had from rheumatology colleagues on their deep-dive visits. There were many examples of learning, insights and experience to share. This is a reflection of the dedication of the specialty to driving local improvements.

That dedication is vital to the GIRFT programme, which can only succeed with the backing of clinicians, managers and everyone involved in delivering care.

My greatest hope is that GIRFT will provide support and impetus for all those involved in rheumatology, to work shoulder to shoulder and continue making a real difference to the lives of people with rheumatic and musculoskeletal diseases.



Professor Tim Briggs CBE

GIRFT programme Chair and National Director of Clinical Improvement for the NHS

Professor Tim Briggs is Consultant Orthopaedic Surgeon at the Royal National Orthopaedic Hospital NHS Trust, where he is also Director of Strategy and External Affairs. He led the first review of orthopaedic surgery that became the pilot for the GIRFT programme, which he now chairs. Professor Briggs is also National Director of Clinical Improvement for the NHS.

Introduction from Dr Lesley Kay and Dr Peter Lanyon

Leading this review has been a great opportunity for us to meet with so many of our rheumatology colleagues throughout the country. We've benefited enormously from their insights and experience and shared our analysis with them to help drive local improvements.

We've also consulted closely with the wider community of professional societies, associations and patient groups, and gathered the largest and most comprehensive specialty data set that has ever been assembled for rheumatology. All of this input has helped us gain a more complete picture of rheumatology services across secondary care and the increasingly important interfaces with primary and community care.

With more than 200 rheumatic and musculoskeletal disorders (RMDs), this could have been a very wide-ranging review. However, GIRFT is about focusing on the areas with the greatest scope for improvement and those which can make the biggest difference to efficiency and patient outcomes.

We have therefore narrowed our scope to those conditions that have the greatest risk of avoidable harm if they are not assessed and treated urgently – including inflammatory arthritis, septic arthritis and rare autoimmune diseases such as vasculitis and connective tissue diseases. Our recommendations are focused on strengthening the pathways for these conditions to ensure we meet national standards for early assessment and quality of care.

The GIRFT process has also brought to light the challenges faced by many units, including rising demand for services, limited resources and an overstretched workforce. It's become increasingly apparent to us that there is an imbalance between capacity and demand in many areas, while some units are close to collapse – something that came into stark relief during the COVID-19 first wave, when five units were forced to close their doors. Meanwhile, many patients with painful non-inflammatory musculoskeletal conditions wait a long time for assessment, which in most cases does not materially improve their health or wellbeing.

To address these challenges and improve patient care, we recommend that services for non-inflammatory painful musculoskeletal conditions should be provided in primary or community care, in line with the NHS Long Term Plan ambition to move services closer to home. This should be supported by reablement and support services co-designed with patients to meet their needs. We recognise that this is a large scale change but we think it is in the long-term interests both of the health system and patients who currently spend too much time waiting for and attending hospital appointments.

Rheumatology patients have benefited hugely from advances in drug therapies, particularly biologics and associated biosimilars, so we have also focused our attention on medications, both in terms of maximising value and efficacy and how they are administered in day case units. Finally, as we continue to deal with COVID-19, we have reflected on the lessons learned during the first wave of the pandemic and how they can help us improve as we restore services.

We would like to thank everyone who has contributed to putting this report together and those who have given valuable feedback on it, informing our thinking and recommendations. We hope that it will help to drive improvement and deliver better outcomes for patients in the years ahead.



Dr Lesley Kay

GIRFT Joint Clinical Lead for Rheumatology

Dr Kay is a consultant rheumatologist at the Newcastle upon Tyne Hospitals NHS Foundation Trust and former Chair of the British Society for Rheumatology Clinical Affairs Committee. She trained in rheumatology and public health in the North East and Cambridge and has worked as clinical director for musculoskeletal services and clinical director for patient safety and quality. Dr Kay is deputy medical director of the Healthcare Safety Investigation Branch, vice-chair of the Northern Clinical Senate Council and is a GenerationQ Fellow with the Health Foundation.



Dr Peter Lanyon

GIRFT Joint Clinical Lead for Rheumatology

Dr Lanyon is a consultant rheumatologist at Nottingham University Hospitals NHS Trust and served as president of the British Society for Rheumatology from 2016 to 2019. Having started his career in general practice, he went on to train in rheumatology and was appointed consultant rheumatologist at Nottingham University Hospitals in 1999. Between 2013 and 2016, he chaired the NHS England Specialised Rheumatology Clinical Reference Group. He has a particular interest in complex autoimmune rheumatic disease, integrating clinical research into service delivery.

Statements of support

British Society for Rheumatology (BSR)

We are pleased to welcome the publication of this GIRFT national report, which will be instrumental in shaping the future of the specialty.

We know from projects such as the National Early Inflammatory Arthritis Audit (NEIAA) that there is clear variation in rheumatology services throughout England. To keep pace with rising demand we need to adapt, and this report's recommendations will enable departments to optimise their available capacity and ensure that patients who need the expert assessment of a multidisciplinary rheumatology team can continue to access this.

The case studies highlight the impressive achievements of hardworking rheumatology teams and the innovative ways that services have evolved to meet patients' needs. It is important that departments are supported by their trusts to adopt these more widely.

BSR has already committed to investing significant resources in addressing the many and varied workforce challenges in 2021, sharing best practice and supporting services through the pandemic. This focus will help to address various aspects of this report, but we also look forward to supporting members to embed the other recommendations into everyday practice.

We will do this on a UK-wide basis wherever possible and continue to work closely with the GIRFT team and other national bodies on the longer term ambitions within this report to drive improvements within the specialty.



Ali Rivett

Chief Executive, British Society for Rheumatology

Statements of support

Specialised Rheumatology Clinical Reference Group

The Specialised Rheumatology Clinical Reference Group (CRG) has appreciated the open engagement with GIRFT throughout its rheumatology workstream. This national report reflects the impressive effort of the GIRFT team, led by Drs Lesley Kay and Peter Lanyon, to analyse rheumatology services across England, identify unwarranted variation and propose solutions to address this variation.

We have welcomed the opportunity to contribute to the report's content on specialised rheumatology services in particular. The conditions treated by specialised rheumatology services affect a small number of patients but can be severe and have a higher risk of mortality and morbidity than more common conditions. The recommendations put forth in this report designed to improve treatment of patients with rare rheumatic and musculoskeletal disorders will go some way to address variation in clinical outcomes. They align with the CRG's own ambitions to ensure equitable access to care and we look forward to continuing to work closely with the GIRFT team to implement them.



Dr Bridget Griffiths

Chair, Specialised Rheumatology CRG, NHS England and NHS Improvement

Executive summary

Supporting sustainable and equitable services

While most trusts provide services for inflammatory arthritis and rare and complex diseases, we found variation in other rheumatology clinics and services. For example, in some units, metabolic bone disease services are provided by rheumatology, while in others they are delivered by departments such as endocrinology, or community services, or not provided at all. Many trusts do not provide dedicated services for non-inflammatory painful musculoskeletal (MSK) conditions, such as hypermobility and fibromyalgia. In other areas, we heard from rheumatology departments that these patients account for an estimated one third of new patient appointments.

Impact on waiting times and patient care

Variations in service provision appear to relate to an imbalance between capacity and demand in many trusts, leading to longer waiting times. We found considerable variation in referral to treatment (RTT) times for rheumatology outpatients, from less than five weeks in the best performing trusts to more than 30 weeks in others. This is concerning given that conditions such as early inflammatory arthritis, giant cell arteritis (GCA) and vasculitis require rapid diagnosis and assessment to reduce the risks of long-term morbidity and mortality.

Many trusts are not meeting national quality standards for early assessment and treatment of these conditions – for example, fewer than half of units achieve target times for assessment and treatment of early inflammatory arthritis. Likewise, many people with non-inflammatory painful MSK conditions are waiting for long periods on waiting lists, often in pain.

Our recommendations

Provide care for non-inflammatory painful conditions outside hospital

To reduce the variations and gaps in service described above, we recommend that care for patients with non-inflammatory painful MSK conditions such as back pain, fibromyalgia and hypermobility, as well as gout, polymyalgia rheumatica, osteoarthritis and soft tissue MSK conditions, should be provided in primary and community care settings. This would help to:

- bring care closer to home for these patients, in line with NHS Long Term Plan ambitions;
- reduce waiting times for conditions that need urgent rheumatology assessment;
- ensure that every patient receives the right care in the right setting to meet their needs.

The reorganisation should be co-ordinated at integrated care system (ICS) level. Services should include reablement support and access to allied health professionals (AHPs), such as physiotherapists, podiatrists and orthotists, and psychologists where needed. Where services need to be added or developed, these should be co-designed with patient groups, primary care networks (PCNs), community services, pain management services and charities to ensure that they are appropriate and convenient to meet people's needs.

RTT times should not exceed eight weeks

We recommend that routine referral to treatment (RTT) times for all conditions that require specialist rheumatology care should not exceed eight weeks. We found wide agreement among the trusts we visited that above this level it becomes difficult to ensure a high quality and efficient service for patients, with inefficient use of urgent appointments.

Improving management of referrals

The reorganisation described above should also be supported by an effective referral management system. We found that less than half of trusts (43%) currently use a referral management system and the effectiveness of those in use varies widely. We also found that current referral criteria for RMDs are generally unclear. To address these issues, referral processes should be reviewed to ensure that patients can be prioritised based on risk of harm from delayed treatment. Clear referral criteria should be developed to enable rapid referrals and triage for rare and complex RMDs, balancing routine and urgent appointments appropriately. In addition, wider use of Advice and Guidance, with adequate time in consultants' job plans, may support improved referral management.

Improving management of patients being followed up

The majority of rheumatology clinic appointments are for patients with long-term conditions. Many of them require follow-up for ongoing assessment and supervision of high cost drugs.

We found variation in the number of outpatient appointments each rheumatology patient attended and in the ratio of first to follow-up attendances. The average ratio is 4.2 but some trusts have ratios of up to 10. Commissioners may interpret this to mean that some trusts are not performing well. But it may simply be that these units are seeing higher numbers of patients who need long-term care due to the nature of the rheumatology caseload.

However, we recognise that there are opportunities to reduce the need for face-to-face follow-ups to free up clinic capacity. We have seen virtual consultations very rapidly come into use during the coronavirus pandemic and they are likely to play an important role in service delivery over the longer term.

Ongoing monitoring of disease-modifying anti-rheumatic drugs (DMARD) presents another potential opportunity to reduce outpatient visits. Some of this could be done in shared care arrangements with primary and community care across a geographical area, for example at ICS level. The need for some appointments could also be avoided by switching patients earlier to biologic agents, which require little monitoring.

Our recommendation

Develop alternatives to outpatient attendance

We recommend that trusts should review their management of follow-up appointments and consider alternative models of outpatient care. However, in developing alternative models of outpatient care we need to ensure that new patients can have a face-to-face appointment, support is available for patients who are not confident using virtual technology and safety net protocols are in place to ensure that patients are not lost to follow-up.

A workforce to meet future needs

We found that many rheumatology units are facing significant workforce challenges.

- Trainees are unevenly distributed across the country. Training numbers have not increased in recent years, despite the expansion of rheumatology as a specialty.
- All trainees now take dual accreditation with general internal medicine (GIM) and now spend 15-20% less time in rheumatology.
- In some trusts, trainees spend a lot of their time on tasks perceived to be of low educational value, such as clerking day case patients.
- Many smaller units struggle to attract and retain consultants, for example because people choose to work in larger centres where there may be more opportunities for career development. We found some units operating with only one consultant.

Our recommendations

Consider extended roles across the skills mix

To meet the workforce challenges described above, trusts should consider enhanced and advanced roles for nurses, pharmacists and allied health professionals (AHPs), to meet increasing demand and improve services for patients. For example, pharmacists could take on a greater role in drug prescribing, monitoring and assessment, including medication reviews and post-discharge support for patients on multiple medications or with long-term chronic conditions. There may also be a greater role for nurse prescribers and some pharmacists who have gained prescriber status, including in patient education.

Improve the quality of rheumatology-specific training

Rheumatology training posts should maximise the quality and value of rheumatology-specific training components to ensure competence and meet patient needs.

Supporting smaller rheumatology units

We have found that some smaller rheumatology units do not have the resilience and support they need to guarantee a stable service when key staff leave or are absent for a long period. We saw trusts where this led to the collapse of the service, with serious knock-on impact for all the surrounding units who have had to accommodate their patients.

An average rheumatology department has four consultants, not all of whom work full time. On our deep-dive visits, we heard that many consultants are approaching retirement. Clinics can become very reliant on one individual so that it becomes difficult to operate without them. If they, or other key members of the team, leave or retire early, the whole service can become very fragile.

Our recommendation

Provide sustainable services through regional networks

To support smaller rheumatology units, we recommend that services should be planned across a wider geographical area, such as at ICS level, with network support to ensure equity of access for patients.

Networks could be co-ordinated through regional multidisciplinary team (MDT) meetings, which can happen online using virtual meeting platforms. They should be well-resourced and underpinned by good IT and connectivity. Departments should also devote time and resource to improve their workforce and succession planning and the distribution of staff.

Improving data and coding to support service planning

The data collected for inpatients and day cases is very rich and includes diagnoses and procedures. However, most rheumatology work is in outpatients where diagnoses are not routinely recorded. We need to know about casemix to understand:

- whether multiple follow-ups are necessary because of the nature and complexity of the patient's condition;
- if current condition-specific pathways and patterns of care are appropriate.

Where units collect their own diagnostic data, we found that the information captured is patchy. Only 11.9% of trusts have a diagnostic database within the electronic health record and 18.9% of trusts hold a specialty-specific list of frequently used diagnostic codes.

Our recommendation

Record outpatient diagnoses

To improve the quality of information available for service planning and benchmarking, we recommend that diagnoses should be coded for outpatients as part of routine activity. Wherever possible, this should be part of an electronic record, which, if linked to electronic prescribing for outpatients and day cases, has the potential to create a powerful dataset to drive improvement.

Variations in attribution of specialty

On our deep-dive visits, we heard from trusts that some rheumatology activity is being attributed to other specialties. For example, some rheumatologists also practise in general medicine and this can result in their activity being coded under that specialty.

Our recommendation

Attribute activity to rheumatology Treatment Function Code (TFC)

To get a clearer picture of the work done by rheumatologists, we recommend that all rheumatology activity should be coded using treatment function code 410.

Improving early management of inflammatory arthritis

We found that not all trusts are meeting the National Institute for Health and Care Excellence (NICE) quality standards for early assessment of rheumatoid arthritis, as audited by the National Early Inflammatory Arthritis Audit (NEIAA), which requires referral within three working days of presenting in primary care and assessment by rheumatology within three weeks of referral. The NEIAA report for 2018-19 shows that:

- 41% of patients were referred within three days;
- 38% of patients were assessed by a rheumatology service within three weeks of referral.

Some units may have long referral to treatment (RTT) times and be under pressure to allocate resources to meet this metric rather than the providing rapid appointments for early inflammatory arthritis (EIA) referrals. Some clinicians we spoke to were concerned about prioritising referrals for suspected EIA, particularly when many patients turned out not to have it, because this may cause delays for other patients with other painful conditions. However, the target times exist because patients diagnosed with EIA will sustain lasting avoidable harm if their treatment is delayed.

Our recommendation

Improve EIA referral criteria and triage

To meet the audited NICE quality statements, we recommend referral criteria should be clearer, with effective triage systems and adequate resourcing to meet patient needs.

Participation in the national audit

We found considerable variation in participation in the NEIAA, with some units only enrolling a relatively small proportion of their eligible patients, or not enrolling from all clinic locations. Some units reported that they were struggling to collect and submit comprehensive audit data, often because of a lack of resource. Failure to comply with the audit is often associated with busy, fragile units where fewer staff are available to provide services.

Our recommendation

Integrate NEIAA into routine data collection

To increase participation and reduce the burden of data collection, we recommend that the NEIAA be integrated into routinely collected data for rheumatology services.

Equitable access to specialised care for rare RMDs through regional networks

Patients with rare RMDs, including autoimmune connective tissue diseases, vasculitis and rare inherited metabolic bone diseases, need specialised care, often involving co-ordinated multi-specialty assessment and high-cost drug therapies. These conditions have a much higher risk of mortality and morbidity than more common conditions, and are a source of high value claims against trusts.

Because of their rarity and severity, care for these conditions is commissioned directly by NHS England through specialised centres, which have the highest concentration of clinical expertise and experience. They should support non-specialised trusts in their region and act as hubs for research and innovation. We found significant variations in how this is being implemented across the country.

- In some trusts there are clinicians who sub-specialise in rare RMDs, while in other trusts, care is provided by every rheumatologist with no sub-specialisation.
- Dedicated clinics, which are associated with greater guideline compliance, are not provided consistently across regions.
- Not all specialised centres complete dashboard returns to the Specialised Services Quality Dashboards (SSQD), which is a service requirement for quality assurance.
- In the SSQD data, the average wait time for the first routine appointment in a specialised clinic was 58 days, and 36 days from primary care.
- Some non-specialised centres are providing specialised care.

Variation in specialised clinical networks

Regional specialised rheumatology networks began in 2015-16 with the aim of linking all specialised and non-specialised rheumatology units in the 12 regions of England to ensure equitable access across geographic areas and uniform standards of care.

We have found significant variation in how networks have developed. In our questionnaire, many trusts and some specialised centres told us they are not part of a formal network. Where networks are established, they do not appear to have a consistent structure, with varying levels of engagement and interaction.

Some trusts told us that patients are waiting longer than they should because there is no formal mechanism for cases to be discussed at virtual MDT meetings rather than attending an appointment at the specialised centre. This can lead to delays in initiation of high-cost drug treatments.

We also found gaps in quality assurance, leadership and oversight – for example, policies and procedures not formalised, so there is often no clear expectation of when clinical cases should be discussed in a network and what support other trusts should expect from the specialised centre. In some areas, referral pathways are not clearly defined and data on patient numbers and outcomes is not consistently collected.

Equitable access to specialised drugs for rare diseases

We found wide variation in the uptake of belimumab, a major innovation in treatment of systemic lupus erythematosus (SLE). In the two years to March 2019, the treatment was only used at 27 trusts and given to 143 patients, far short of the 300 expected in this period. In some cases this meant patients having to accept less effective treatments.

We also found broad variation in the estimated use of rituximab between trusts. Many trusts who are on the NHS England specialised commissioning provider eligibility list (PEL) have very low use of rituximab, while some who are not have relatively high use.

Our recommendations

Improve measurement through routine data collection

To improve specialised commissioning quality and benchmarking, we recommend that all rheumatology units providing care for rare RMDs should collect data on care, caseload and outcomes, using routinely collected data where possible to reduce burden of data collection.

Extend networks to cover all regions and patients

People with rare RMDs should have rapid access to specialist expertise and effective treatments to ensure equity of outcomes regardless of geography. The structure, operation and geographic reach of specialised rheumatology networks should be reviewed and improved to ensure this across and between regions.

Optimising diagnosis and treatment of GCA

Suspected giant cell arteritis (GCA) is a medical emergency as, left untreated, it can lead to occlusion of arteries, causing irreversible sight loss or permanent organ damage. We have found considerable variation in the management of GCA, with 33% of trusts in our questionnaire saying they had no formal pathway for the condition. More than half reported taking longer than the maximum three day target to see patients.

Variation in confirmatory diagnostic tests

Patients with suspected GCA should have a confirmatory diagnostic test, either a temporal artery biopsy (TAB) or an ultrasound of the temporal and axillary arteries, or both. We found variation in ease and speed of access to TABs, and which specialty is performing them. In our questionnaire, 44% of trusts said they are performed by vascular surgeons, while 36.4% said ophthalmologists. There is also wide variation in the time taken to deliver biopsy results, ranging from 1 to 77 days.

We found that many trusts are struggling to establish a clear pathway using temporal artery ultrasound for GCA. Our questionnaire data indicates this service is currently being provided in 49% of trusts, leading to geographical variation in access. Ultrasound needs to be done rapidly, shortly after initiating on steroid treatment, to ensure accurate diagnosis. We found variation in speed of access, with patients in some trusts waiting up to 20 days for a scan.

Access to biologic therapy

The biologic drug tocilizumab has been approved by NICE for some GCA patients who do not respond to corticosteroids or who relapse on corticosteroid treatment. We found uptake was relatively low, partly due to a mistaken reading of the guidelines to mean that every case must be discussed by a regional specialised network MDT. In fact, this only requires discussion at trust MDT level where the trust is a specialised centre.

Our recommendation

Implement the BSR guideline

We recommend that all trusts should meet the 2019 British Society for Rheumatology (BSR) guideline for GCA; ensuring referrals are rapidly assessed using the latest techniques and pathways.

Governance of ultrasound for MSK and GCA

In our questionnaire, 87% of units said they had access to ultrasound for early arthritis patients, while 49% had access to ultrasound for GCA investigation. We found variation in how ultrasound services are run, including issues such as how competency is maintained and where ultrasound images and reports are stored. In some cases provision relied on the skills of one individual and so the service was not resilient. We also heard that not all departments securely store their scan images or reports on a picture archiving communication system (PACS).

Our recommendation

Improve governance to make ultrasound sustainable

Trusts should review governance of ultrasound to ensure that the service is sustainable and provide equitable access to ultrasound diagnostic tests for all patients who need them.

Reducing variation in hot joint pathways

Hot joints are painful and swollen joints and can be an indicator of septic arthritis, a serious condition requiring urgent management. We found variation in how the hot joint service is organised.

- In our questionnaire, only 31% of trusts said they had a formal written pathway.
- The majority of trusts (83%) said the hot joint pathway was led by orthopaedics.
- Out of hours, less than 2% of rheumatology units are primarily responsible for the service.
- 4% of trusts said rheumatology led on the management of septic arthritis.

Our recommendation

A clear pathway led by orthopaedics

Given the seriousness of septic arthritis and other potential complications, we recommend that pathways for diagnosis and treatment of hot joints should be consistent and led by orthopaedics to ensure 24/7 access for patients, with support from rheumatology as required.

Optimising day case care

In rheumatology, intravenous infusions are usually delivered as day case procedures. In our questionnaire, only 19% of units said they have their own rheumatology-specific day case unit. The majority of units use day case facilities shared with, or run by, another service. In our questionnaire, we found that:

- 46% of units said patients always receive their treatment in a reasonable timescale;
- 47% said patients sometimes have to wait longer than they would like;
- wait time for rituximab varied from next day up to 90 days;
- some patients requiring non-cancer chemotherapy were waiting over 40 days for treatment;
- 59 trusts reported having two or less day case nurses trained in delivery of non-cancer chemotherapy, while 23 had none.

We found that a significant proportion of day case activity is taken up with procedures that could equally be performed in ambulatory settings without the need for a day case admission. For example, some units are performing large numbers of joint injections, while others perform almost none. In some units, patients were returning weekly for administration of subcutaneous injections because there was no provision for patients to self-inject.

Day case infusions that could be replaced with alternatives

There are some IV drug treatments for which an equally effective subcutaneous or oral alternative exists. We found that take up of these alternatives has been slow over recent years. However, we note that use of subcutaneous alternatives has increased in recent months as a result of COVID-19.

Variation in medical supervision of day case patients

For most IV biologic treatments, medical review of infusions is no longer required after initiation. However, we found that in many trusts all day case patients are still routinely reviewed by medical staff prior to infusion. Evidence from our deep dives would suggest that day case units can be more productive and have lower waiting times when they are led by appropriately skilled nurses, with rapid access to medical supervision if it is needed.

Variation in efficiency of drug administration

We found variations in the use of dose banding, and whether infusions were pre-prepared by pharmacy, to improve day case efficiency. In our questionnaire, less than half of trusts said they used dose banding, while a similar proportion used pre-made bags to save time in the infusion process.

Our recommendation

Improve efficiency and consider alternatives

Trusts should optimise use of day case facilities and consider alternatives to day case admission for some procedures to reduce waiting times for the sickest patients and improve the patient experience overall.

Optimising medicines

The average annual spend per rheumatology department is £2.9 million; approximately 9% of the average trust's total medication spend. While this represents a reduction compared with previous years, the figure remains high. We found wide variation in the total medicines spend between trusts, beyond that which might be expected based on differences in size of unit and caseload. Variation was also high when we looked at average spend per patient. Reasons may include:

- Some prescribing activity is not routinely recorded or is coded to other specialties.
- Some trusts may start treating patients at a lower threshold than others.
- Some trusts may be treating more complex patients.
- Differences in rates of uptakes of biosimilar medications.

Improving data quality

As part of our data analysis, we used the Rx-Info Define dataset to examine how medicines were prescribed by trusts. We found some data quality issues, including medicines being coded to other specialties and inconsistencies between data held on different databases within the same trust. We need better data to get a comprehensive, accurate picture of drug spend and prescribing nationally.

Standardising prescribing practice and governance

Biologics are expensive and represent the largest growth area in the NHS medicines budget. We found variation in how they are used across the country. Some trusts have lower prescription thresholds than others, which will in turn increase these trusts' expenditure. We also found variation in how patients are started on high cost drugs. In some units, everyone starting biologic treatment goes through a thorough MDT virtual review, while in other trusts the process is less formal.

NHS England and NHS Improvement have developed a prior approval electronic system for specialised commissioning called Blueteq to monitor high cost drug use, and to reduce variation. On our deep-dive visits, we heard that Blueteq is working well for some biologics such as tocilizumab for GCA, which have relatively small, defined cohort of patients. However, when used for more commonly-prescribed drugs, it can cause a disproportionate workload for some trusts.

Our recommendation

Use national reporting systems to enable spend comparison

Trusts should use national medicines data reporting systems, together with local benchmarking, published through the NHS Model Hospital and Model Health System, to enable transparent local and regional comparison of medicines spend.

Wherever possible, prescribing should be electronic. If this is linked to coding of outpatients and day cases, there is the potential for a powerful dataset on diagnoses and patient outcomes to drive improvement.

Reducing delays in switching to biosimilars

For many biologic drugs, a cheaper biosimilar alternative is available. The total drugs spend by rheumatology departments fell by more than £93 million between 2017/18 and 2019/20, largely driven by the switch to biosimilars.

We found variation in how trusts were using biosimilar medicines and in the time it took different trusts to switch cohorts of patients over to a biosimilar. This is surprising, given that many trusts will be treating the same conditions, with largely similar proportions of patients. Barriers to switching include:

- Safely switching cohorts of patients takes significant administrative and clinical time.
- Some clinicians and patients still have residual concerns about efficacy or safety.
- Where patients self-administer, they may need training on a new delivery device.

National initiatives and incentives have proved effective in encouraging switching to some biosimilars. NHS England's commissioning framework for biologics supports the use of financial incentives to maximise early adoption. These initiatives should be expanded to encourage switching as more biosimilar alternatives become available.

Our recommendation

Support trusts to make switches

Trusts and departments should continue to be supported to make rapid switches to use of best value biologic medicines, including biosimilars, where clinically appropriate.

Standardising the monitoring of DMARDs

Disease-modifying anti-rheumatic drugs (DMARDs) require regular monitoring to ensure patient safety. This involves regular blood tests, which take up a substantial proportion of rheumatology time and cost. We found significant variations and issues with current practice, including:

- Variation in who prescribes initial and continuing treatment, who monitors the therapy, and how repeat prescriptions are issued.
- Variation in shared care protocols to enable transfer of monitoring to primary or community care following initial treatment in rheumatology. This can cause confusion, for example where GPs manage patients who see consultants at different trusts.
- Variation in guidelines issued by different specialties, such as gastroenterology and dermatology, who also use DMARDs.
- Different monitoring procedures between trusts, primary and community care.
- Blood-taking and prescribing carried out in different settings and by different teams.

Often hospitals are dealing with monitoring information in multiple formats and from multiple systems. Monitoring variation can potentially limit the ability to make good clinical decisions and lead to possible errors and patient safety incidents. These issues are compounded by the current inability to match up secondary care and primary care prescribing records to get a whole picture of the patient.

We found that only 25.2% of trusts used an electronic monitoring programme for DMARDs. This means that, in most trusts, patients' results are being recorded and transferred on paper which increases the risk of error, including lost records.

Our recommendation

Standardise monitoring across areas

To reduce the risks associated with monitoring variations, we recommend that monitoring processes should be standardised across geographic footprints and medical specialties, linked to an interoperable electronic monitoring system.

Research and innovation

Research activity is already generally well-established in rheumatology. Some NHS England specialised commissioning policies for high-cost medicines mandate that patients are enrolled in specific research registries, to generate the evidence to support ongoing commissioning.

However, we found substantial variation between trusts in the number of studies with which they engaged, and the number of patients recruited. This variation could not be explained fully by the size of the trust or whether they were allied to a teaching or research facility. Where participation was lower than expected, clinicians told us that the major barrier to recruitment was a lack of resources, particularly lack of time in job plans and insufficient access to research nurses and administrative staff.

Recruitment to registries

We found high levels of recruitment to registers related to the use of high cost drugs. However, in many cases registration was not completed and a number of units failed to register any patients.

Our recommendation

Allocate resources to support participation

Adequate resource should be allocated to ensure involvement in research and support submission to relevant patient registries. Data collection for studies should not become a burden on clinicians. Wherever possible data collection for rare diseases should be aligned with routinely collected data.

Learnings from COVID-19

In July 2020, after the first wave of the pandemic, we carried out an online survey of rheumatology clinical leads. Responses showed that COVID-19 led to the closure of five rheumatology departments, while 26 were required to relocate. While some services such as day case infusions and ultrasound were either restricted or suspended, rheumatology services showed considerable resilience and kept most core services running to at least a minimum level.

How units adapted to maintain core services

Some innovations were accelerated into large scale application including:

- remote outpatient consultations;
- switching patients from intravenous to oral or subcutaneous alternatives which can be self-administered in the community;
- increasing the role of first contact practitioners (FCPs) in providing rapid care for patients without the need for a referral.

Individual trusts highlighted examples of how they had managed demand and kept services running:

- prioritising face-to-face consultations for urgent referrals of new patients;
- offering a helpline by email as well as a telephone to expand capacity;
- holding daily hot clinics for the most urgent cases;
- developing educational material on management of conditions such as gout and fibromyalgia.

Another key lesson is that all rheumatology units should have business continuity plans that set out how they will continue to deliver priority and core services in the event of severe service disruption, whether it is a further phase of COVID-19 or an unrelated crisis. We think there is a need for national guidelines to support this, setting out what core business continuity looks like for each specialty.

Reducing the impact of litigation

Data from NHS Resolution shows that estimated clinical negligence claim costs in rheumatology ranged between £4.3 million to £15.8 million per year over the five years 2013/14-2017/18. The estimated cost of litigation per rheumatology admission or outpatient appointment was £3, which is low compared to other specialties.

Missed or delayed diagnosis was among the most common cause for claims, with missed or delayed diagnoses in connective tissue disorders and vasculitis accounting for 13 cases of litigation attributed to rheumatology units over the five-year period. These included alleged failure to diagnose vasculitis in patients who went on to suffer strokes, and delays in diagnosis of infection, which resulted in amputations. There were also seven claims for failure to diagnose inflammatory arthritis, four of which related to axial spondyloarthritis.

Our recommendation

Reduce litigation costs by application of the GIRFT Programme's five-point plan.

Procurement

Rheumatology departments procure a range of lower cost equipment in high volumes, such as wrist/hand splints, forearm clasps and orthotics, as well as smaller volumes of high cost equipment such as ultrasound machines.

Our recommendation

We recommend that providers adopt the GIRFT 3-point strategy to improve procurement of devices and consumables.

Recommendations

Supporting sustainable and equitable rheumatology services

Recommendation	Actions	Owners	Timescale
1. Care for patients with non-inflammatory painful musculoskeletal conditions should be provided outside of hospital in primary and community care settings in line with NHS Long Term Plan ambitions to bring care closer to home for patients.	a Co-design community services for patients with non-inflammatory painful musculoskeletal conditions in collaboration with patient groups and third sector organisations as a matter of urgency.	NHSE/I, commissioners working with patient groups	Significant progress within 12 months of publication
	b Review service provision across integrated care system (ICS) footprints with view to releasing capacity to enable rheumatology units to focus on priority specialty activity.	Trusts, ICSs	Significant progress within 12 months of publication
2. Referral to treatment (RTT) waiting times should not exceed eight weeks for all patients who need specialist rheumatology care.	a Review referral management to ensure prioritisation based on risk of harm from delayed treatment.	Trusts, regional networks, ICSs, BSR, GIRFT	Within 6 months of publication
	b Develop clear and consistent referral criteria in partnership with the British Society for Rheumatology (BSR) and primary care providers to enable rapid referrals and triage for rare and complex rheumatic and musculoskeletal disorders (RMDs) – balancing routine and urgent appointments appropriately (see 9a).	Trusts, regional networks, ICSs, BSR, GIRFT	Within 12 months of publication
	c Develop specific referral criteria for vasculitis and connective tissue disease with the Clinical Reference Group.	ICSs, BSR, GIRFT	Within 12 months of publication

Improving management of follow-ups

Recommendation	Actions	Owners	Timescale
3. Trusts should review their management of follow-up appointments and consider alternative models of outpatient care.	a Explore options to increase use of virtual consultations, in line with NHS Long Term Plan and Outpatient Transformation Programme ambitions.	Trusts, ICSs	Within 6 months of publication
	b Consider how to safely reduce the frequency of review for stable patients, for example by: - reducing the need for attendances for escalation and flare with earlier use of definitive treatments; - enabling patients to record outcome measures remotely, with reviews triggered when outcomes exceed thresholds; - implementing National Institute for Health and Care Excellence (NICE) and British Society for Rheumatology (BSR) guidance; - increasing the involvement of multidisciplinary teams (MDTs) in annual reviews.	NHSE/I OTP, GIRFT, trusts, BSR	Within 18 months of publication
	c Review treatment thresholds for biologic agents, including the total costs of service not just drug costs.	NICE	Ongoing
	d Investigate the reasons why outpatient appointments are deferred by rheumatology units to ensure that this does not impact on quality of patient care.	Trusts	Within 12 months of publication

A workforce to meet future needs

Recommendation	Actions	Owners	Timescale
4. Rheumatology medical training posts should maximise the quality and value of rheumatology-specific training components to ensure competence and meet patient needs.	a Reduce variation in training by defining tasks that are of low educational value for trainees and minimise these in each trust.	SAC/BSR, trusts	Within 12 months of publication
	b Reduce variation in clinical supervision by fully implementing the Royal College of Physicians (RCP) training guidance in all trusts.	SAC, training committees, trusts	Within 6 months of publication
	c Carry out a review of rheumatology training to include training needs, curriculum, and service tasks, to establish clear principles for trusts to follow.	SAC	Ongoing
	d Assess the value of trainees being 'on call' for rheumatology and specify the experiences that trainees should acquire during their training period.	SAC	Within 12 months of publication
5. Trusts should make full use of the multidisciplinary skill mix and consider enhanced roles for nurses, pharmacists and allied health professionals, to meet increasing demand and improve services for patients, in line with the NHS Releasing Time to Care ambitions set out in the interim People Plan.	a Ensure that patients have access to specialist nurses and a range of other health professionals, including physiotherapists, occupational therapists, pharmacists, podiatrists, psychologists and radiographers, through a single named co-ordinator.	Trusts	Ongoing
	b Consider how specialist and consultant rheumatology pharmacists could play a greater role in patient care, education, drug management and monitoring, as well as prescribing.	Trusts	Within 18 months of publication
6. Rheumatology services should be planned across a geographic area, with services for some conditions commissioned at integrated care system (ICS)/sustainability and transformation partnership (STP) level to improve efficiency and outcomes overall, with network support for smaller units to make them more sustainable and ensure equity of access for patients.	a Review existing regional network arrangements for specialised services and consider broadening the scope or setting up parallel networks.	NHSE/I CRG, networks, trusts, ICSs	Within 12 months of publication
	b Review local workforce professional skills mix and succession planning and work collaboratively with other trusts to ensure regional services are sustainable in the longer term, reducing reliance on individual clinicians and further promoting the use of the entire multidisciplinary team.	Trusts/ICSs	Within 18 months of publication

Improving data and coding to support service planning

Recommendation	Actions	Owners	Timescale
7. Diagnoses should be coded for outpatients as part of routine activity to enable service planning and benchmarking between trusts.	a Establish specified list of core diagnoses which should be routinely coded from clinic letters and inpatient and day case episodes.	GIRFT, NHS Digital, BSR	Within 12 months of publication
	b Use the specified list of core diagnoses to identify cohorts of patients and enable review of condition-specific pathways to ensure frequency of care is aligned with national guidance.	Trusts	Within 6 months of action A completion
	c Drive routine collection of patient-reported outcome measures (PROMs) to identify variation in outcomes and measure the benefit of services to patients.	GIRFT, NHSE/I, BSR	Within 18 months of publication
	d Implement electronic prescribing for rheumatology outpatients, day cases and inpatients to support accurate clinical coding and provide information for comparison.	Trusts	Within 12 months of publication
8. All rheumatology activity should be coded using treatment function code 410.	a Ensure activity is correctly attributed to the specialty and staff group.	Trusts	Ongoing

Improving early management of inflammatory arthritis

Recommendation	Actions	Owners	Timescale
9. Management of suspected early inflammatory arthritis (EIA) should be improved through clearer referral criteria, effective triage systems and adequate resourcing to meet patient needs and comply with the audited National Institute for Health and Care Excellence (NICE) quality statements.	a Develop standard nationally agreed referral criteria for suspected EIA, to support effective triage and evaluate them over time.	GIRFT, BSR	Within 18 months of publication
	b Liaise with primary care networks to review local referral rates/yield and refine referral processes in line with 9a to ensure patients are assessed within the three week target set by the audited NICE Quality Statement 2.	Trusts, PCNs, BSR audit	Within 6 months of 9a completion
	c Model demand and ensure there is adequate dedicated clinical resource to meet local patient needs, including dedicated EIA clinics where possible.	Trusts	Ongoing
	d Interrogate the audited NICE Quality Statement 3 performance data to assess and address root causes of delays in patients initiating treatment once diagnosed.	Trusts	Ongoing
10. Participation in the National Early Inflammatory Arthritis Audit (NEIAA) should be enhanced by considering how the audit could be integrated into routinely collected data for rheumatology services.	a Improve the quality of the electronic health record to allow for standardised data capture.	NHS Digital	Within 12 months of publication
	b Review administrative and audit resourcing to support full participation in the NEIAA.	Trusts	On publication
	c Review individual consultant recruitment to the NEIAA and discuss identified challenges/solutions.	Trusts	Within 6 months of publication
	d Consider including NEIAA performance metrics in the development of a National Clinical Improvement Programme (NCIP) portal for consultant rheumatologists.	GIRFT	Within 12 months of publication

Equitable and sustainable access to care for rare RMDs through regional networks

Recommendation	Actions	Owners	Timescale
11. All rheumatology units providing care for rare rheumatic and musculoskeletal disorders (RMDs) should collect data on care, caseload and outcomes for people with rare RMDs, using routinely collected data where possible to reduce burden of clinician data collection and submission.	a Reduce the burden of specialised commissioning quality dashboard data collection by aligning metrics to data that is already collected as part of standard practice.	NHSE/I, Spec Comm, GIRFT, Networks, CRG	Within 18 months of publication
	b Ensure that all rare RMDs are included in data collection.	Networks, NHSE/I, Spec Comm, trusts, CRG	On completion of 11a
	c Use audit, and dashboard data where appropriate, to understand how care is being delivered and develop quality improvement tools to improve outcomes.	BSR, NHSE/I, Spec Comm/ specialised centres, CRG	On completion of 11b
	d Promote national rare disease registration with the National Disease Registration Service (NDRS) to facilitate use of routinely collected healthcare data to support high quality care and service planning, and consider adapting the NDRS pathway toolkit for rare RMDs.	NHSE/I, NDRS, Spec Comm, specialised centres, CRG	Within 12 months of publication
12. People with rare RMDs should have rapid access to specialist expertise and effective treatments to ensure equity of outcomes regardless of geography and reduce the risks of morbidity and mortality.	a Identify responsible clinicians and lead nurses/allied health professionals in each trust offering care for rare RMDs, to co-ordinate care for each main category of specialised rheumatology: connective tissue diseases, vasculitis, and rare metabolic bone diseases.	Trusts, networks, NHSE/I, Spec Comm, CRG	Within 6-12 months of publication
	b Ensure effective co-ordination of care across all specialties as required.	Trusts, CRG, NHSE/I, Spec Comm	On publication
	c Develop analytical approaches to identify geographical variation and potential health inequality in the use of high cost drug treatments for rare RMDs and the application of national commissioning policy criteria, including treatment initiation at specialised centres.	NHSE/I, Spec Comm, CRG	Within 12 months of publication
	d Develop a National Institute for Clinical Excellence (NICE) Quality Standard for rare RMDs based on the new NICE-accredited British Society for Rheumatology (BSR) guidelines on care of rare RMDs.	NICE, CRG, NHSE/I, Spec Comm	Within 2 years of publication
	e Investigate apparent differences in diagnostic reporting times, for example related to anti-neutrophil cytoplasmic antibody (ANCA).	Trusts, regional networks	Within 6 months of publication
	f Investigate if care and outcomes for rare diseases differ between specialised and non-specialised centres and consider how to support units with low activity volumes to consolidate services across regions.	GIRFT, NHSE/I, Spec Comm, CRG	Within 12 months of publication
	g Investigate if litigation and claims for rare diseases differ between specialised and non-specialised centres.	NHS Resolution, NHSE/I, Spec Comm, CRG	Within 12 months of publication
	h Continue to implement NHS England and NHS Improvement's COVID-19 prioritisation.	Trusts, NHSE/I, Spec Comm, CRG	Ongoing

Equitable and sustainable access to care for rare RMDs through regional networks

Recommendation	Actions	Owners	Timescale
13. The structure, operation and geographic reach of specialised rheumatology networks should be reviewed and improved to ensure equitable, sustainable provision of specialised care for rare RMDs across and between regions.	a Mandate the delivery of effective specialised networks in each region, including principles, standard operating procedures and memoranda of understanding, building on existing best practice.	NHSE/I, Spec Comm, GIRFT, BSR, CRG	Within 12 months of publication
	b Establish a mechanism to ensure that all trusts with specialised centre status make full dashboard returns and meet the terms of their service specification, and report on progress in achieving these requirements.	NHSE/I, Spec Comm, GIRFT, CRG	Within 12 months of publication
	c Ensure that each specialised network holds regular virtual multidisciplinary team (MDT) meetings, including review of complex cases, to enable timely decision making and ensure patients do not have to travel to the specialised centre unnecessarily.	NHSE/I, Spec Comm, CRG	Within 12 months of publication
	d Review the provider eligibility list (PEL) of specialised centres to ensure it reflects current organisation of specialised services.	Trusts, NHSE/I, Spec Comm, CRG	Within 6 months of publication
	e Consider new models for specialised commissioning of rare RMDs.	NHSE/I, Spec Comm, CRG, BSR	Within 2 years of publication

Optimising diagnosis and treatment of GCA

Recommendation	Actions	Owners	Timescale
14. All trusts should meet the new British Society for Rheumatology guideline for giant cell arteritis (GCA); ensuring referrals are rapidly assessed using the latest techniques and pathways.	a Update or establish trust-wide GCA pathways to meet the new National Institute for Clinical Excellence (NICE)-accredited BSR guideline and achieve the three working day target for initial assessment of referrals.	Trusts	Ongoing / within 3 months of publication
	b Appoint a GCA clinical lead in all trusts, responsible for co-ordinating care with ophthalmology and vascular departments.	Trusts	Within 6 months of publication
	c Ensure rapid access to confirmatory diagnostic tests, either ultrasound or biopsy, for patients with suspected GCA.	Trusts	On publication
	d Co-ordinate multidisciplinary team (MDT) discussions across rheumatology networks to support effective decision-making and prescribing of tocilizumab.	Trusts, networks	On completion of 13a

Governance of ultrasound for MSK and GCA

Recommendation	Actions	Owners	Timescale
15. Trusts should review governance of ultrasound for musculoskeletal (MSK) conditions and giant cell arteritis (GCA) to ensure that the service is sustainable and provide equitable access to ultrasound diagnostic tests for all patients who need them.	a Ensure MSK ultrasound services are not reliant on single-handed practitioners, that competence is maintained through regular practice and continuing professional development and that images and reports are securely stored, linked to the patient record.	Trusts	Within 18 months of publication

Reducing variation in hot joint pathways

Recommendation	Actions	Owners	Timescale
16. Pathways for diagnosis and treatment of 'hot joints' should be consistent and led by orthopaedics to ensure 24/7 access for patients, with support from rheumatology as required.	a Review local provision, liaising with local organisations to align pathways and ensure appropriate involvement of orthopaedics.	Trusts, ICSs	Within 12 months of publication
	b Establish mechanisms to review patient outcomes and variation in length of stay.	Trusts, ICSs	Within 12 months of publication

Optimising day case care

Recommendation	Actions	Owners	Timescale
17. Trusts should optimise use of day case facilities and consider alternatives to day case admission for some procedures to reduce waiting times and improve the patient experience.	a Review current day case activity and remove any that is inappropriate.	Trusts	Within 3 months of publication
	b Review governance of non-cancer chemotherapy including training, competencies, auditing compliance with guidelines, and accessibility for urgent treatment.	Trusts, BSR, SAC, CRG	Within 6 months of publication
	c Ensure day case units are nurse-led with appropriate and proportionate access to medical input for relevant patients/cases.	GIRFT, trusts, CRG	Within 6 months of publication
	d Preferentially use and transition to subcutaneous injection to reduce day case requirements where appropriate.	NHSE/I, trusts	Within 3 months of publication
	e Consider greater use of dose banding where appropriate.	Trusts	Within 6 months of publication

Optimising medicines

Recommendation	Actions	Owners	Timescale
18. Trusts should use national medicines data reporting systems, together with local benchmarking, published through the NHS Model Hospital and Model Health System, to enable transparent local and regional comparison of high-cost medicines usage.	a Ensure appropriate and accurate capture of prescribing spend by rheumatology departments.	Trusts	Ongoing
	b Support and implement patient level electronic systems to report on both hospital and primary care prescribing by indication and patient numbers.	NHSE/I, NHS Digital, NHSX	Within 12 months of publication
	c Develop analytical methodologies to identify opportunities to reduce local, system and regional variations, and improve patient outcomes.	NHSE/I, GIRFT, Model Hospital, Regional Medicines Optimisation Committees (RMOCs)	Within 12 months of publication
	d Review high-cost drug management systems and develop interoperability with electronic prescribing systems to ensure accountability with minimal additional administrative burden.	NHSE/I, CCGs, ICSs	Within 6 months of publication

Reducing delays in switching to biosimilars

Recommendation	Actions	Owners	Timescale
19. Trusts and departments should continue to be supported to make rapid switches to use of best value biologic medicines, including biosimilars, where clinically appropriate.	a Develop national approaches to the choice of best value biologics, similar to the national initiative for switching to biosimilar adalimumab. This should include appropriate commissioning levers including reference pricing to support the costs of clinical changes.	NHSE/I, GIRFT, BSR	Ongoing
	b Continue to use Model Hospital (and future Model Health system) to monitor the uptake of best value biologic medicines.	Trusts, ICSs, NHSE/I	Ongoing
	c Continue to monitor patient safety and optimal clinical outcomes to support future choices around best value biologics.	NHSE/I, RMOCs	Ongoing

Standardising the monitoring of DMARDs

Recommendation	Actions	Owners	Timescale
20. Disease-modifying anti-rheumatic drugs (DMARD) monitoring processes should be standardised across integrated care system (ICS)/sustainability and transformation partnership (STP) footprints and medical specialties, linked to an interoperable electronic monitoring system.	a Standardise DMARD monitoring processes across ICS footprints, possibly co-ordinated by newly appointed clinical pharmacists working in Primary Care Networks (PCNs).	Trusts, ICSs, BSR	Within 18 months of publication
	b Align guidance on DMARD monitoring across all relevant specialties to reduce variation.	BSR, British Association of Dermatologists (BAD), British Society of Gastroenterology (BSG)	Within 12 months of publication
	c Move to electronic monitoring systems – ideally interoperable across ICS footprints.	Trusts, ICSs	Within 18 months of publication (alongside action 20a where possible)

Increasing participation in research

Recommendation	Actions	Owners	Timescale
21. Adequate resource should be allocated to ensure trust involvement in research and to support submission to relevant patient registries..	a Allocate time to lead or contribute to research in consultant job plans.	Trusts	Ongoing
	b Promote clinically-focused research questions from registries and disseminate results to clinical teams as well as via an academic route.	BSR, other registries	Ongoing

Litigation

Recommendation	Actions	Owners	Timescale
22. Reduce litigation costs by application of the GIRFT programme's five-point plan.	a Clinicians and trust management to assess their benchmarked position compared to the national average when reviewing the estimated litigation cost per activity. Trusts would have received this information in the GIRFT 'Litigation data pack'	Trusts	On publication
	b Clinicians and trust management to discuss with the legal department or claims handler the claims submitted to NHS Resolution included in the data set to confirm correct coding to that department. Inform NHS Resolution of any claims which are not coded correctly to the appropriate specialty via CNST.Helpline@resolution.nhs.uk	Trusts	Upon completion of 22a
	c Once claims have been verified clinicians and trust management to further review claims in detail including expert witness statements, panel firm reports and counsel advice as well as medical records to determine where patient care or documentation could be improved. If the legal department or claims handler needs additional assistance with this, each trust's panel firm should be able to provide support	Trusts	Upon completion of 22b
	d Claims should be triangulated with learning themes from complaints, inquests and serious incidents (SI)/Patient Safety Incidents (PSI) and where a claim has not already been reviewed as SI/PSI we would recommend that this is carried out to ensure no opportunity for learning is missed. The findings from this learning should be shared with all front-line clinical staff in a structured format at departmental/directorate meetings (including Multidisciplinary Team meetings, Morbidity and Mortality meetings where appropriate).	Trusts	Upon completion of 22c
	e Where trusts are outside the top quartile of trusts for litigation costs per activity GIRFT we will be asking national clinical leads and regional teams to follow up and support trusts in the steps taken to learn from claims. They will also be able to share with trusts examples of good practice where it would be of benefit.	Trusts	For continual action throughout GIRFT programme.

Procurement

Recommendation	Actions	Owners	Timescale
23. Enable improved procurement of devices and consumables through cost and pricing transparency, aggregation and consolidation, and by sharing best practice.	a Use sources of procurement data, such as the Spend Comparison Service (SCS) and relevant clinical data, to identify optimum value for money procurement choices, considering both outcomes and cost/price.	Trusts	Within 6-12 months of publication
	b Identify opportunities for improved value for money, including the development of benchmarks and specifications. Locate sources of best practice and procurement excellence, identifying factors that lead to the most favourable procurement outcomes	GIRFT	Ongoing
	c Use Category Towers to benchmark and evaluate products and seek to rationalise and aggregate demand with other trusts to secure lower prices and supply chain costs.	Trusts, ICSs/STPs	Within 12 months of publication

What is rheumatology?

Rheumatology is the specialty that covers the investigation, diagnosis and medical management of more than 200 rheumatic and musculoskeletal disorders (RMDs) that primarily affect joints, bones, muscles and tissues, but also encompasses a range of related medical conditions¹. More than 10 million people in the UK are affected by RMDs with a significant burden in terms of disability, quality of life, lost workdays, and cost of treatment.

Rheumatology care in hospitals

The core work of rheumatology teams is the long-term management of complex chronic RMDs, which may largely be controlled with specialist medication regimes. The aim is to improve quality of life, prevent disability and prevent premature death. These include:

- inflammatory arthritis
- autoimmune connective tissue disorders
- metabolic disorders of bone

Areas of practice beyond this vary widely between departments and may include soft tissue disorders, pain and fatigue syndromes. There is also collaboration and overlap with orthopaedic departments and community physiotherapy or podiatry services in the medical management of musculoskeletal (MSK) disorders.

According to the Royal College of Physicians (RCP) latest census², there were 776 consultant rheumatologists and 274 higher specialty trainees in England in 2018-19.

Overview of activity

Rheumatology is mainly an outpatient-based specialty, with more than two million appointments in England every year. A full-time consultant rheumatologist will usually undertake 4–5 outpatient clinics a week.

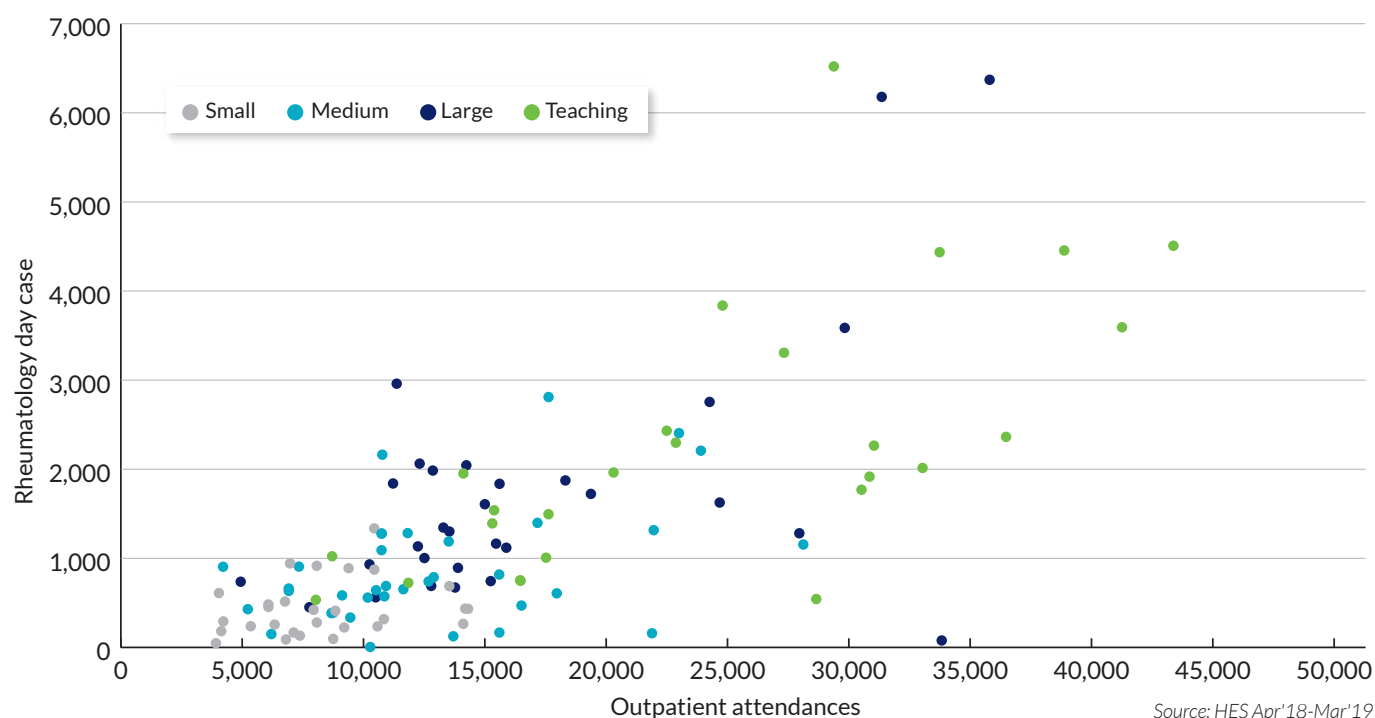
Activity includes new and follow-up appointments, clinics for specific conditions such as autoimmune connective tissue diseases, and combined clinics with departments such as dermatology, renal medicine and respiratory medicine. Most rheumatology departments have a significant day case workload.

Figure 1 shows a broad range in volume of activity across trusts in England by size and type of trust. Many rheumatology departments see fewer than 1,000 admissions for day case treatments each year. However the same units may see large volumes of outpatient appointments. Some larger trusts and teaching hospitals see over 6,000 day case admissions and over 35,000 outpatient attendances in a year. It should be noted that not all large hospitals have large rheumatology departments.

¹ Royal College of Physicians 2016 www.rcplondon.ac.uk/education-practice/advice/specialty-spotlight-rheumatology

² www.rcplondon.ac.uk/projects/outputs/focus-physicians-2018-19-census-uk-consultants-and-higher-specialty-trainees

Figure 1: Day case admissions and outpatient attendances for rheumatology by size and type of trust (Department of Health and Social Care classifications)



Rheumatologists also work outside of hospitals, for example as part of hub and spoke outreach models in community or primary care clinics.

Very few rheumatology patients are admitted to hospital as inpatients. In the last 20 years, both the overall number of rheumatology inpatient beds and the number of trusts that offer them have declined. In answers to our questionnaire, only 41 out of 143 trusts said they had access to dedicated rheumatology inpatient beds.

Multidisciplinary working

People with RMDs require a wide range of specialist skills to help them manage and treat their conditions effectively. Rheumatologists therefore work within multidisciplinary teams (MDTs) including nurses and nurse specialists, physiotherapists – including extended scope practitioners – as well as occupational therapists, pharmacists, psychologists, podiatrists and physician associates.

Patients often have multi-system disorders, so rheumatology teams have close working relationships with other specialists including renal and respiratory physicians, immunologists, dermatologists, neurologists, gastroenterologists, as well as endocrinologists and clinical geneticists for complex metabolic bone disorders.

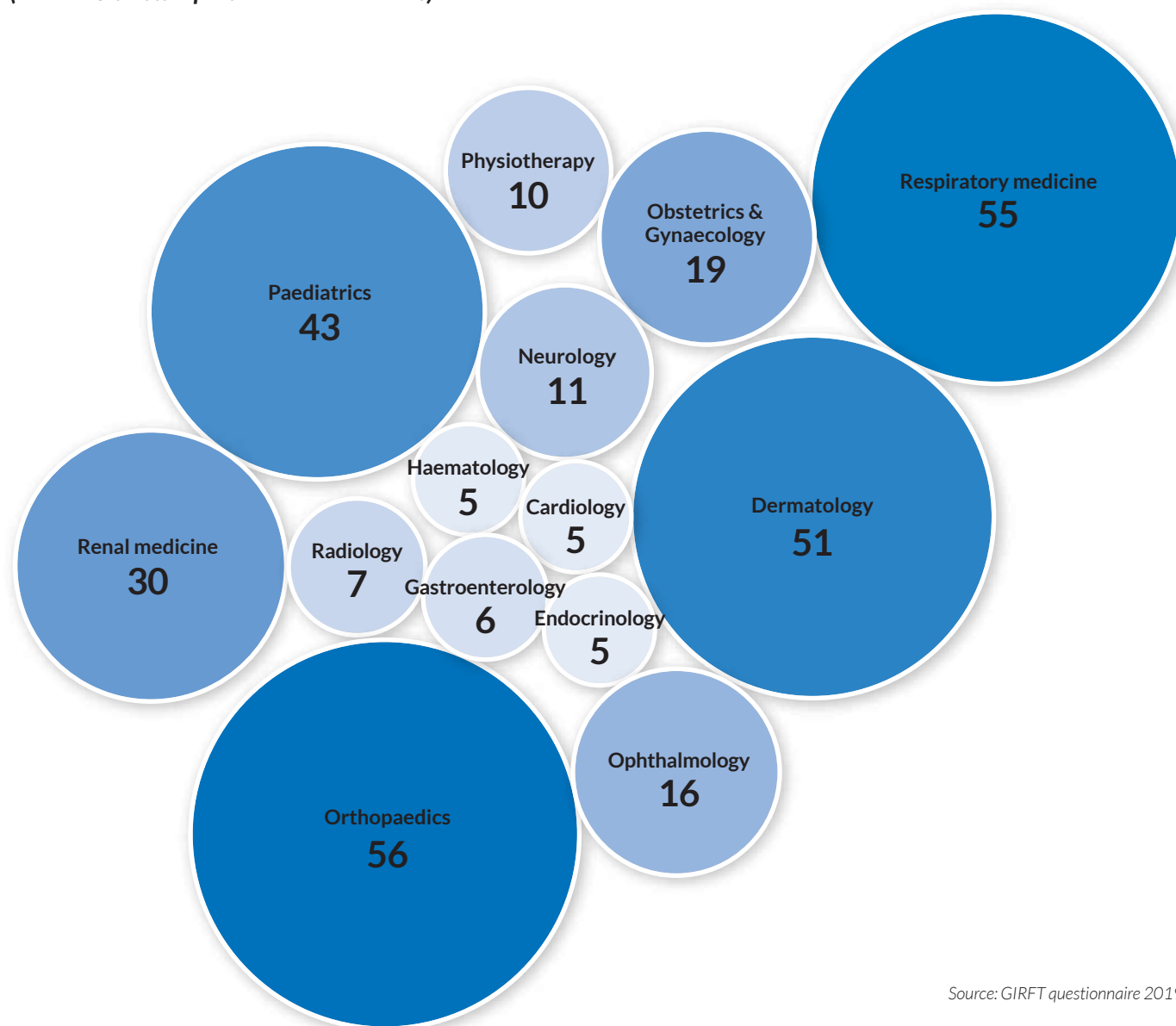
For example, patients with axial spondyloarthritis may have skin, bowel or eye disease, so close relationships with dermatology, gastroenterology and ophthalmology teams are important. Patients with rare connective tissue disorders and vasculitis commonly have kidney, lung or vascular problems so good communication with renal, respiratory and vascular surgery departments is vital.

Traditionally, rheumatologists have worked closely with orthopaedic surgeons. While more successful treatment of RMDs means that fewer RMD patients require orthopaedic intervention, there is still considerable overlap between patients presenting to these services and good working relationships are important. Specialist MSK radiologists contribute significantly to investigation and diagnosis.

Where conditions have a degree of overlap with other specialties, there may be joint working arrangements – for example, rheumatologists in specialised centres will hold combined outpatient clinics for rare RMDs with specialties such as renal medicine, respiratory, dermatology and obstetrics, as shown in **Figure 2**.

For those people whose RMDs begin in childhood, adult rheumatology departments work with paediatricians and paediatric rheumatologists to promote a smooth transition from paediatric care into adult services.

Figure 2: Number of combined clinics run jointly by rheumatology units and other specialties (where >5 trusts reported combined clinics)



Source: GIRFT questionnaire 2019

Working with primary care and community services

Rheumatology also interfaces with primary care and community MSK services. Rheumatology departments receive referrals from primary care and then go on to share management of patients with long-term conditions which require regular follow-up, such as inflammatory arthritis.

Ongoing management of these conditions requires close liaison between all the services involved in the patient's care. This may include shared care arrangements, and co-operation around prescribing for DMARDs and detection and treatment of co-morbidities.

About our analysis

The GIRFT rheumatology workstream has created the largest and most comprehensive specialty data set that has ever been assembled for rheumatology. This includes many national data sources for rheumatology that have never been used before, such as national prescribing and litigation. In some areas our data is particularly strong, for example the rich dataset for day case activity, where diagnoses and treatments are coded, and which is an important area of activity for rheumatology departments.

Data sources

The analysis we carried out in developing this report is based on the Getting It Right First Time (GIRFT) programme model (see page 133).

First, we identified all of the relevant routinely collected healthcare data related to rheumatology, and through data sharing agreements brought this into the GIRFT team for analysis. A main source was Hospital Episode Statistics (HES), which contains every episode of admitted NHS patient care, A&E attendances and outpatient appointments at all NHS hospitals in England.

For inpatient and day case admissions, the information contained within HES is very detailed and includes treating specialty, all prevalent diagnoses coded according to the International Classification of Diseases (ICD-10), as well as procedures, including drug infusions, coded according to OPCS Classification of Interventions and Procedures. We used this to identify all consultant episodes under the rheumatology treatment function code (TFC 410), which records the specialised service within which the patient is treated.

For outpatients, currently fewer than 5% of HES records contain information about diagnoses, as this is not a mandated field in the dataset. There are data about outpatient procedures, for example joint injections, where this information has been collected by the healthcare provider. We pre-selected 20 outpatient procedures, chosen as a representative set of the most frequently used codes likely to cover the largest proportion of rheumatology outpatient activity (see *Gaps in our analysis* below).

Other national sources of trust-specific rheumatology data used as part of the GIRFT rheumatology review included:

- Rx-Info Define, which aggregates prescribing data from participating trusts on a national basis (see *Optimising medicines*, page 95).
- National Early Inflammatory Arthritis Audit (NEIAA) carried out by the British Society for Rheumatology (BSR), commissioned by Health Quality Improvement Partnership (HQIP).
- National Institute for Health Research (NIHR) recruitment data, identifying sentinel trials and registries in rheumatology that could be used as metrics for rheumatology research engagement across all trusts.
- NHS Resolution litigation data, both within the specialty and for some conditions across every specialty.
- NHS England specialised commissioning rheumatology specialised services quality dashboards.
- NHS England Diagnostic Imaging Dataset (DIDS).
- General Medical Council (GMC) national training survey.
- Royal College of Physicians (RCP) Fracture Liaison Service database.

We gained further data and insight from an extensive questionnaire sent to 134 trusts across England requesting further detail on their rheumatology department's services, with a 100% return rate – the first GIRFT workstream to achieve this. We are grateful to rheumatology departments for their generous participation. We feel the completion rate is a great reflection of the commitment of the rheumatology community in every trust to the GIRFT national quality improvement programme and the involvement of the British Society for Rheumatology from the beginning.

Analytical process

We defined the key performance issues we wanted to investigate and looked at how we could best do this using the extensive datasets we had assembled. We prioritised domains for analysis based on their ability to provide a wide-ranging overview of the entire rheumatology activity in NHS hospitals in England. We used these outputs to create a data-driven, clinically led, integrated set of metrics across the whole of rheumatology practice.

This enabled us to benchmark all rheumatology providers on key performance measures which identified variation in practice and outcomes. An extensive data pack specific to each trust was produced, providing insights into the way the department functions.

We then visited trusts to review the data in depth with clinicians, senior management and all those involved in delivering services. These deep-dive visits explored outpatient, day case and inpatient management of rheumatology patients at each trust. During the visits, we discussed any variation in the data and how the trust stands in relation to their peers. These discussions have informed our findings and recommendations.

Specialised commissioning data

Some of the charts in this report show activity carried out in 'specialised' centres. We have defined which centres are specialised using the NHS England provider eligibility list (PEL) for rheumatology. The PEL stipulates which trusts are eligible to receive payments from NHS England for 'specialised' activity. Specialised activity includes services for people with rare conditions or patients with specific common diseases who have complex needs. In rheumatology this includes rare connective tissue diseases, vasculitis and rare metabolic bone diseases. The PEL is compiled with advice from clinical reference groups and is cross-referenced against the self-declarations which trusts make to indicate they meet the core criteria required to provide specialised care, set out in the service specifications available at www.england.nhs.uk/commissioning/spec-services/npc-crg/group-a/a09/.

Data limitations

Because HES does not currently include sufficiently accurate data on outpatient diagnoses, we do not have information about clinical casemix for the majority of rheumatology activity. This limits our ability to assess issues such as appropriate setting of care, whether any patients could be re-directed to another setting, and the appropriateness of referral and long term follow-up for specific conditions. The main source of patient outcome data we have is the NEIAA, which primarily covers rheumatoid arthritis but also includes axial spondyloarthritis in the second phase.

We were unable to identify the contribution that rheumatologists make to inpatient care where they are not the responsible clinician for that patient. Inpatient episodes are coded according to the specialty service within which the patient is treated, and so the significant amount of work incurred by cross-consultations - input into patients for example in intensive care, emergency care and acute ambulatory medicine - cannot be measured.

There are some limitations in our prescribing data. While we had access to Rx-Info Define, in a small number of trusts this did not accurately identify all the rheumatology spend - for example, if biologic medicines had been attributed to a cost code other than rheumatology, such as general medicine or an MSK directorate. We are grateful to the trusts who reviewed their cost-centre coding and identified where the rheumatologists' prescribing had been misattributed. These issues are discussed in more detail in *About our medicines data analysis* on page 96.

We are aware from responses to our questionnaire that there is geographical variation in whether conventional disease-modifying anti-rheumatic drugs (DMARDs), including subcutaneous methotrexate, are prescribed in primary or secondary care, or combinations of the two. However, we could not link primary care prescribing data to the corresponding hospital information, so we were unable to make any detailed comparisons between trusts in the use of these treatments.

Some important areas could not be explored because of a lack of nationally collected data. For example, it was not possible to assess patient experiences of the quality of their care or patient-centred practice such as shared decision-making.

The scope of this report

Our review covers rheumatology services commissioned by Clinical Commissioning Groups and by NHS England and NHS Improvement (specialised commissioning) in relation to the care of adult patients in England. Services for children are provided separately by specialist paediatric rheumatology teams under the umbrella of paediatric services and are therefore outside the scope of this workstream.

Areas of focus

Through the GIRFT process, we have focused our attention where we anticipated there might be the greatest variation in clinical practice at the national level and were most likely to provide the clearest case for clinical improvement, and where clear data were available. These include:

- service organisation: supporting sustainable rheumatology units and ensuring equitable access to services, particularly for rare diseases covered by specialised commissioning;
- service design: meeting demand and ensuring patients get the right care in the right setting;
- optimising patient pathways;
- optimising spend on high-cost medicines and ensuring efficacy;
- enhancing participation in research and innovation.

Conditions and pathways

In reporting on patient pathways, we have chosen to focus on those conditions, such as inflammatory arthritis, giant cell arteritis (GCA) and septic arthritis, where there is the greatest risk of avoidable harm if the right care is not provided promptly, where variation is at its highest and where we felt there was most scope for improvement.

In looking at inflammatory arthritis, we have focused most of our attention on rheumatoid arthritis (RA) as the evidence base for urgent assessment and treatment to ensure good long-term outcomes is greatest for these patients. We also have a rich set of audited data from the NEIAA which enabled us to measure performance against quality standards. We anticipate that service improvements for rheumatoid arthritis would be exemplars for comparable conditions such as psoriatic arthritis and axial spondyloarthritis.

We have not been able to look at pathways for some conditions because we did not have enough coded outpatient data to identify them separately and make a meaningful analysis and/or because care of the condition is shared or led by another specialty in many departments, for example, osteoporosis.

The impact of COVID-19

We have considered our findings and recommendations in the light of COVID-19. In particular, we have looked at how changes resulting from the pandemic, such as greater use of remote consultations and drug monitoring, might continue to shape service delivery in years to come (see *Learnings from COVID-19*, page 120).

Aligning with local and national programmes

In implementing the recommendations and actions in this report, we will consider them alongside all trust-level actions identified on deep-dive visits, as well as any ongoing work by NHS England and NHS Improvement, the Outpatient Transformation Programme, the National Institute for Health and Care Excellence (NICE), the British Society for Rheumatology, HQIP, patient groups and charities, and other bodies designed to improve care for rheumatology patients. We recognise the importance of co-production and believe that in order to support trusts in transforming their care for patients, effective implementation of the recommendations in this report will require collaboration at every level.

Findings and recommendations

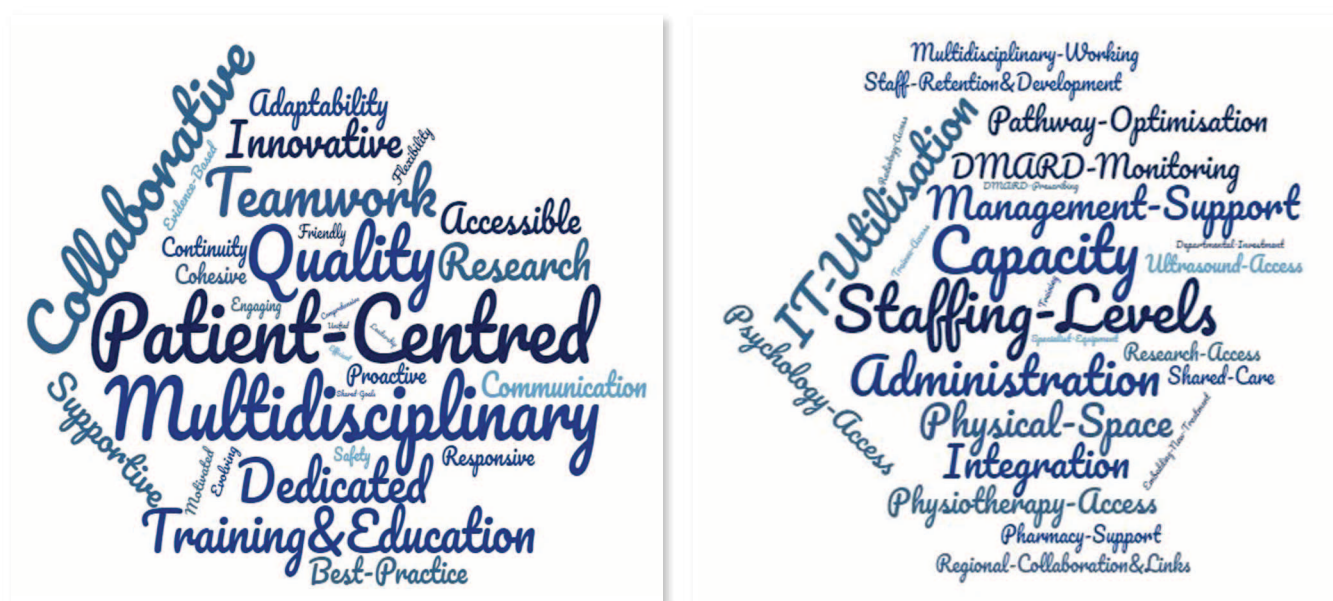
Supporting sustainable and equitable rheumatology services

Rheumatology is a wide-ranging specialty concerned with the treatment of more than 200 rheumatic and musculoskeletal disorders (RMDs). These include complex inflammatory conditions and rare diseases that require early definitive treatment to reduce the risks of long-term morbidity, mortality and social disadvantage.

It is therefore crucial that services are planned and managed effectively across the system to minimise waiting times and meet standards of care for the most serious conditions, and ensure that every person with an RMD gets the right treatment for their needs.

This is particularly important given that many rheumatology departments are small, and as we discuss later, even the largest are under pressure for capacity. Any unplanned variation in referral patterns or change in demand can have an impact on their ability to cope, which can increase waiting times and affect patient care. These pressures were reflected in the responses to our questionnaire. When asked what would make things better in their rheumatology unit, respondents indicated that staffing levels and capacity are the biggest concerns, as shown in **Figure 3**.

Figure 3: Responses from trusts when asked 'What do you feel most proud of in your unit?' (left) and 'What do you feel would make things better?' (right)



Source: GIRFT questionnaire 2019

To address these issues as part of the GIRFT process, we looked at how services are provided across the spectrum of rheumatology RMDs to explore how they might be optimally managed to:

- maximise capacity for the most serious conditions;
- prevent the risk of harm from delayed treatment;
- protect fragile units;
- ensure patients can be seen in the right setting for their needs;
- improve outcomes for all people with RMDs.

Variations in service provision

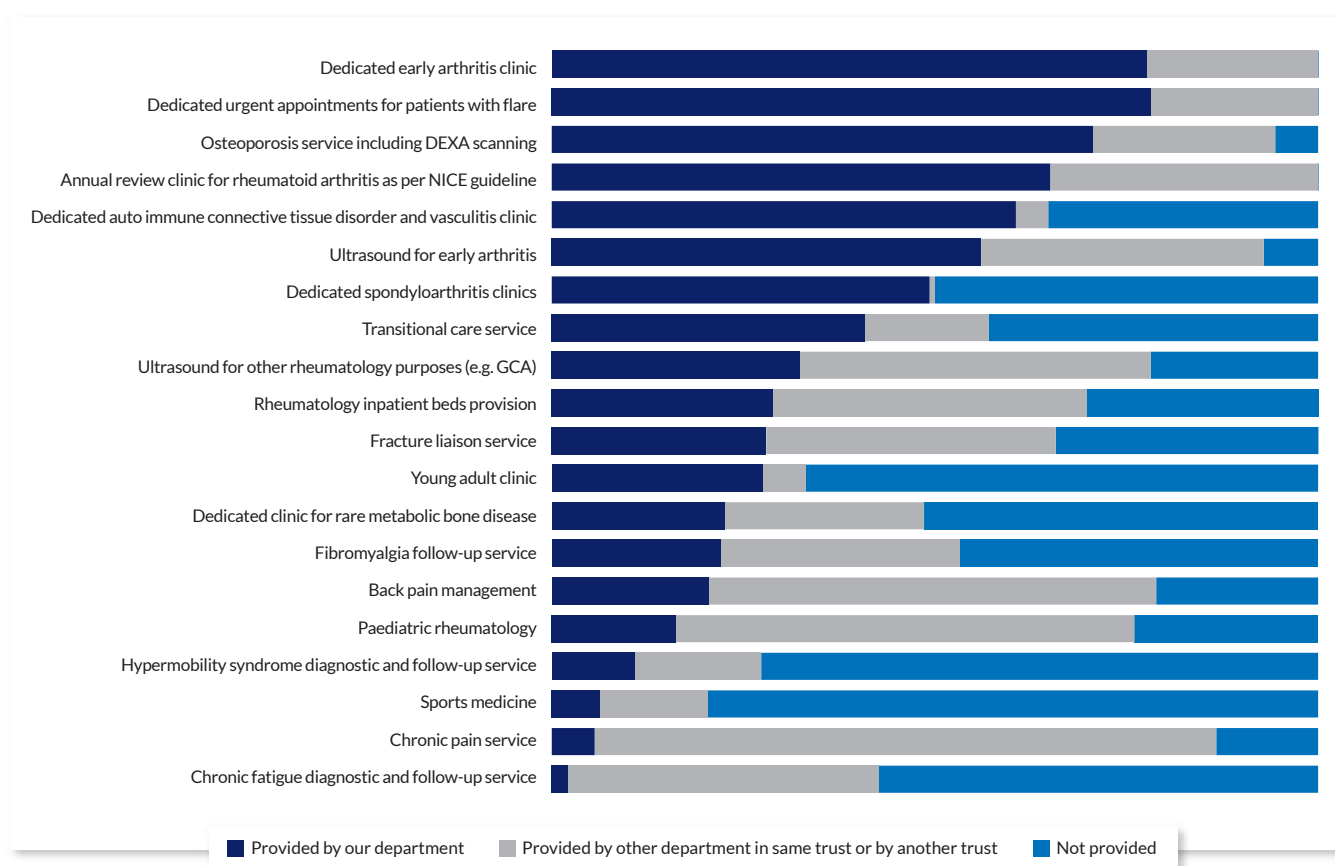
We found wide variation in the clinics and services that rheumatology units offer around the country. As part of our questionnaire, we asked trusts whether a particular clinic, service or facility was provided by their department, provided by another department in the same trust, provided for their patients by another trust, or not provided. Their responses are

captured in **Figure 4**, which shows that the dedicated sub-specialty clinics most commonly provided within rheumatology units were for early inflammatory arthritis, connective tissue disease and vasculitis, spondyloarthritis, osteoporosis and metabolic bone disease. Patients with non-inflammatory painful musculoskeletal (MSK) conditions such as back pain, hypermobility and fibromyalgia are kept under review in a minority of services. We saw that sub-specialty clinics are more common in larger departments and so is follow-up of these non-inflammatory conditions.

In some trusts, metabolic bone disease services are provided by rheumatology, while in others they are delivered by other departments such as endocrinology, geriatric medicine or community services, or they are not provided. Similarly, in some places fracture liaison services are co-ordinated by rheumatology, while in other places these are co-ordinated by other specialties including geriatric medicine, endocrinology, orthopaedics, or they do not exist.

Most departments have access to ultrasound for early arthritis. Many also have access to ultrasound for other purposes including giant cell arteritis (GCA) and MSK, although just under half have provision of ultrasound specifically for GCA (see *Optimising diagnosis and treatment of GCA*, page 76). A majority of trusts said they had access to inpatient beds if needed, although far fewer (41 trusts) have beds specifically reserved for rheumatology.

Figure 4: Proportions of where rheumatology services are provided, by service, for all providers



Source: GIRFT questionnaire 2019

These findings show a significant variation in what rheumatology departments provide and how they organise their services. It is therefore difficult to make direct comparisons between data describing different departments without understanding these differences. The questions also arise, if departments are providing different services, which are core services for rheumatology, which patients might be better served elsewhere, and what are the best indicators to compare one service to another?

Why does service provision vary so widely?

There are many reasons why service models have developed differently from trust to trust:

- Units in some areas are providing high volumes of service for patients with non-inflammatory painful MSK conditions, reducing capacity for other clinics and limiting the time available for rheumatologists to manage those conditions which benefit most from their expertise.
- Units with smaller numbers of patients may not have the critical mass to run dedicated clinics for specific conditions without this being inefficient.
- Services may have developed around the specific interests and expertise of the clinicians and this may have influenced how services are delivered.
- There are few examples of commissioning of specific pathways in rheumatology. It appears that most referral patterns are historic or 'custom and practice', and the benefits and opportunity costs have not been specifically evaluated.
- Evidencing the need for some services has been a challenge historically, especially as most activity is in outpatients which is hard to measure in terms of casemix and evidence of treatment outcomes. For example, fracture liaison services have been shown to be cost-effective, but many trusts told us that clinical commissioning groups (CCGs) have not commissioned them, sometimes citing the difficulty of funding a new service without the ability to recoup the costs by stopping work in another area.

Another factor influencing variation is rheumatology co-dependencies with other medical specialties. Because of the multi-system nature of many RMDs, rheumatologists often work closely with departments such as dermatology, respiratory medicine, renal medicine, ophthalmology, endocrinology and geriatrics, including supporting the use of immunosuppression in those departments. Many units will run combined clinics with other departments, for instance for rare RMDs or conditions which benefit from cross-specialty expertise (see **Figure 2**).

The variation in provision makes it hard to compare units or tell if the current arrangements deliver good care for patients or represent a cost-effective use of limited capacity and resources. This, in turn, makes it difficult to plan how to use the time and expertise of rheumatology teams to the best effect. This is an urgent priority, aligned with recent NHS England and NHS Improvement guidance on prioritisation of rheumatology service provision during the pandemic³.

Imbalance between capacity and demand

Almost all rheumatology departments, including smaller units, are seeing high levels of activity (see **Figure 1**), which includes large volumes of follow-up appointments.

In some cases, these volumes are not matched by adequate resource. As discussed in *A workforce to meet future needs*, page 50, many units struggle to attract and retain consultants and other key members of the multidisciplinary team. On our deep-dive visits, we saw examples of units that are heavily reliant on a small number of clinicians, so departments may become vulnerable and stressed if those members of staff leave (see *Supporting smaller rheumatology units*, page 55).

This is in the context of widespread poor performance against some of the most important metrics related to serious and complex RMDs. Many trusts are not meeting national quality standards – for example less than half of units achieve target times for assessment and treatment of early inflammatory arthritis (see *Improving early management of inflammatory arthritis*, page 60).

Outpatient referral to treatment times

Some rheumatology conditions require rapid assessment. These include early inflammatory arthritis where the National Institute for Health and Care Excellence (NICE) mandates a standard of three weeks (see *Improving early management of inflammatory arthritis*, page 60), giant cell arteritis (GCA) where assessment should be within three days (see *Optimising diagnosis and treatment of GCA*, page 76) and patients with connective tissue disease or vasculitis which can cause damage to organs or be life-threatening if not assessed and treated quickly.

However, almost all patients referred to rheumatology are in pain and should therefore be assessed and treated promptly. We found wide agreement among the trusts we visited that routine referral to treatment (RTT) times for all conditions that require specialist rheumatology care should not exceed eight weeks in any rheumatology department. Above this level it becomes difficult to ensure a high quality and efficient service for patients. Where waiting times are long, this is often

³ www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/clinical-guide-rheumatology-patients-v2-08-april-2020.pdf

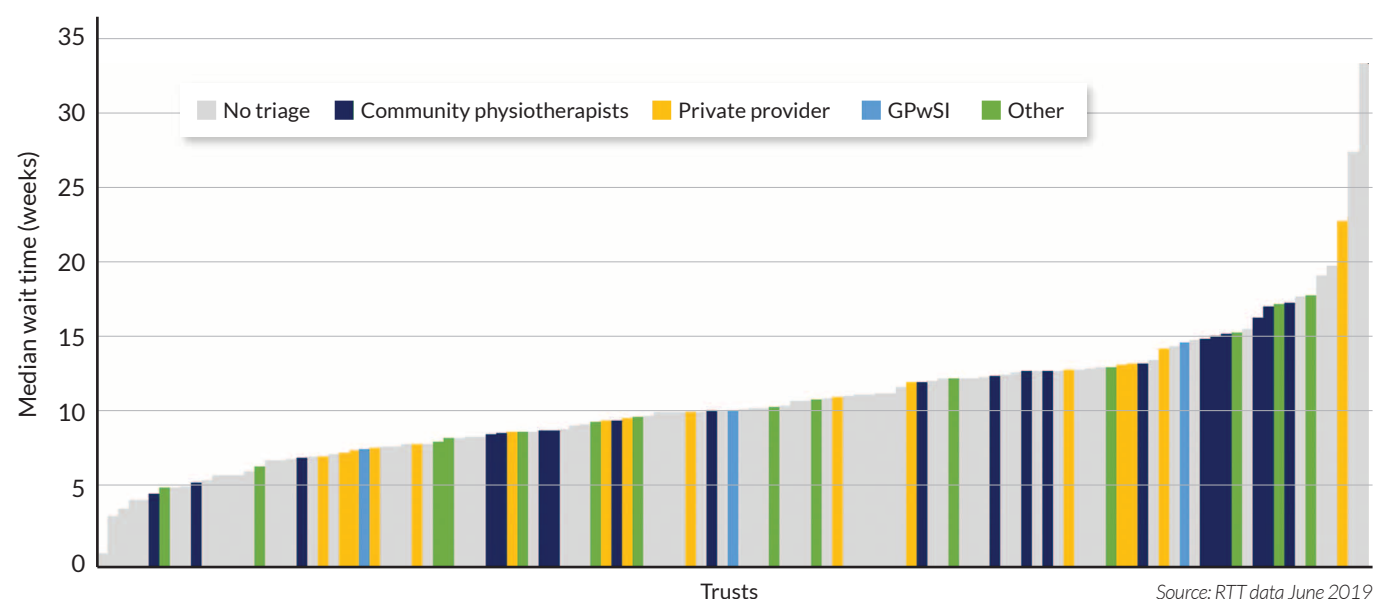
associated with an administrative burden in reprioritising and rebooking referred patients. This makes for inefficient use of time and resources and also creates a burden for referrers who need to communicate more often with rheumatology teams.

Looking at the data, we found considerable variation in RTT times for rheumatology outpatients, from less than five weeks in the best performing trusts to more than 30 weeks, as shown in **Figure 5**.

Longer waiting times are concerning given that early diagnosis and treatment can be critical – for example, inflammatory arthritis may not always be identified by the referrer, and may then be diagnosed too late to prevent serious complications, avoidable disability and potential loss of employment and quality of life. Longer waits can cause significant distress for patients, who are often in considerable pain, and can also have knock-on effects on the system. This, in turn, can lead to higher costs overall because patients need intensive treatment with high-cost drugs for longer periods.

Units that fall behind often spend a lot of administrative time re-prioritising patients and managing lists. This also creates more work for GPs chasing up referrals and arranging appointments for their patients. The coloured bars in **Figure 5** illustrate the presence of a variety of triage services. While we have no measure of the effect of these triage services, we can see that the waiting times for these departments are spread right across the range and show no consistent pattern to suggest any benefit for one type of triage system over another.

Figure 5: Average rheumatology referral to treatment waiting times, categorised by triage provider



Source: RTT data June 2019

Gaps in provision for non-inflammatory RMDs

As we have seen in **Figure 4** above, many trusts do not provide dedicated services for non-inflammatory painful MSK conditions, such as back pain, hypermobility, and fibromyalgia. These conditions carry significant disease burden for individuals but there is little or no evidence that any treatment available in secondary care gives better outcomes than those which can be provided in primary or community care. A minority of areas provide integrated services in primary or community care which include biopsychosocial approaches for holistic care for these conditions.

Defining core services: a proposed service model for rheumatology

It is clear that current models of service provision are failing patients in many areas. Despite best efforts, many patients are waiting too long for treatment; many trusts are not meeting clearly defined quality standards for the most serious and complex RMDs, while some services are fragile and vulnerable when staff leave. On our deep-dive visits, we heard from rheumatology departments that referrals of patients with non-inflammatory painful RMDs account for an estimated one third of new patient appointments. Many of these patients are being referred for a second, third or fourth time.

While changes to training and recruitment could in theory help to address some of these challenges (see *A workforce to meet future needs*, page 50), we heard many examples of posts being unfilled, even where there was funding for expansion or replacement. To address the underlying issues, we need to rethink how and where services are best provided and redesign them where necessary to meet patient needs. Service interruption by the coronavirus pandemic has made these difficulties even more pressing.

With this in mind, we have outlined a proposed new service model below, based on:

- providing care for people in the most appropriate setting, closer to home where possible;
- bringing greater consistency to the way that RMDs are referred to secondary care, and how those cases are triaged;
- enabling rheumatology units in hospitals to focus on the areas where specialist rheumatology care is most needed and where there is an evidence-base that outcomes can be altered by specialist treatment.

This would help to reduce waiting times for patients with inflammatory arthritis and rare and complex RMDs. New patients who could receive more appropriate care in another setting or service would be redirected where possible to increase rheumatology capacity.

Which conditions require rheumatology care?

Some patients should always be under the care of a rheumatologist because the nature and complexity of their conditions means they require specialist care to reduce avoidable disability and morbidity, and they are treated with specialist drugs which require the supervision of experienced consultant rheumatologists. These include:

- rare autoimmune rheumatic diseases, including connective tissue diseases and vasculitis;
- inflammatory arthritis, including rheumatoid arthritis, psoriatic arthritis, enteropathic arthritis, juvenile idiopathic arthritis and axial spondyloarthritis.

These are 'core work' and should be the primary focus of all rheumatology units.

Which services can be provided by rheumatology and/or another specialty?

A second group of services can be provided by rheumatologists but may alternatively be delivered by other specialties. These include services for rare autoinflammatory conditions, metabolic bone diseases, osteoporosis, fracture liaison services and acute vertebral fractures.

Some complex rheumatic diseases, such as systemic vasculitis, may require more than one specialty to be involved. In these cases, there should be clear guidelines that are shared across departments to ensure consistent management.

Which services could be better provided outside hospital?

For a third group of patients, care may be better provided outside of hospital. These include:

- non-inflammatory painful MSK conditions, such as back pain, fibromyalgia and hypermobility;
- gout and polymyalgia rheumatica, with the exception of complex cases and patients who are not responding to treatment;
- soft tissue musculoskeletal conditions and osteoarthritis.

Gout and polymyalgia rheumatica are commonly reasonably straightforward to diagnose, good management guidance exists, and most cases can be appropriately managed in primary care.

Table 1: Indicative view of potential rheumatology service organisation

Should always be under the care of a rheumatology multidisciplinary team	Can be managed by rheumatology or another specialty	Can generally be managed in primary care and community settings
• Inflammatory arthritis (including rheumatoid arthritis, axial spondyloarthritis, psoriatic arthritis, juvenile idiopathic arthritis) • Autoimmune rheumatic diseases (connective tissue disorders and vasculitis – unless by local arrangements managed by other specialties, such as renal medicine) • Complex cases or those which have not responded to primary care management of selected conditions (gout, polymyalgia rheumatica) • Rare autoinflammatory diseases (unless by local arrangements managed by other specialties, such as immunology)	• Metabolic bone diseases • Osteoporosis • Fracture liaison services • Acute vertebral fractures	• Back pain • Upper and lower limb pain • Other non-inflammatory painful MSK conditions • Polymyalgia rheumatica • Fibromyalgia • Hypermobility • Osteoarthritis not requiring surgery • Gout and crystal arthritis

Redesigning services for patients with non-inflammatory painful RMDs

As described above, people with non-inflammatory painful MSK conditions may have significant impairment and disability. Many are waiting for long periods on waiting lists, and may be referred repeatedly back to rheumatology with no significant improvement in outcomes.

Hospital-based services, where they exist, may perform a diagnostic function but are unable to address the social and mental health effects of these conditions any better than other services. Although surgery may be available in a few limited instances, for most patients there is little or no evidence that any effective interventions are available in secondary care which cannot be provided equally well and more promptly in the community, with a potential saving on the cost of hospital care.

We think there is a need for a more holistic patient-centred approach with services designed around patient needs and priorities, in line with NICE guidelines on improving patient experience⁴ and the personalised care agenda set out in the NHS Long Term Plan and NHS England and NHS Improvement guidelines⁵.

An effective approach would be to provide good re-enablement services in the community, commissioned and funded to support people with non-inflammatory painful RMDs. Patients should have access to the right allied health professionals, such as physiotherapists, podiatrists and orthotists, and psychologists where needed. Services should be closer to home and be able to provide prompt assessment and management without the need for onward referral.

Through our visits we have seen examples where service models managed outside of hospital have been implemented and are working well, reducing delays for patients with non-inflammatory painful MSK conditions.

We have discussed this direction of care with the NHS England MSK Clinical Director's leadership team. It is also closely aligned with ambitions laid out in the NHS Long Term Plan to redesign outpatient services to reduce the need for hospital referrals, bring care closer to home and support more productive use of multidisciplinary expertise.

Our recommendations are aligned with the aims of the Outpatient Transformation Programme from NHS England and NHS Improvement, with a focus on the casemix seen in rheumatology as well as making best use of available appointments.

We have also considered our proposals in the light of ongoing changes to services as a result of COVID-19. We believe that they can help departments adapt and prioritise critical services both during and after the pandemic – see *Learnings from COVID-19*, page 120.

⁴ NICE Clinical guideline [CG138] Patient experience in adult NHS services: improving the experience of care for people using adult NHS services www.nice.org.uk/guidance/cg138/chapter/1-Guidance#tailoring-healthcare-services-for-each-patient

⁵ www.england.nhs.uk/publication/universal-personalised-care-implementing-the-comprehensive-model/

Implementing change fairly and equitably

The service reorganisation we propose should be co-ordinated at integrated care system (ICS) level, involving commissioners and primary and secondary care providers. It may involve large scale change in some areas.

We recognise that successful implementation depends to a large extent on commissioning decisions made by local CCGs, good referral systems and the availability of MSK, allied health and other support services locally outside of hospitals to provide appropriate levels of care for people with non-inflammatory RMDs.

This may be a major transformation project in some areas and will need significant planning and resource. Change needs to be communicated well to patients, with clarity on where they should go for treatment and support, especially if their condition deteriorates.

Where services need to be added or developed in primary care and community settings, these should be co-designed with patient groups, primary care networks (PCNs), community services, pain management services and charities to ensure that they are appropriate and convenient to meet people's needs.

This is not about stopping provision of services in one part of the health system and hoping they will be picked up in another. Any changes need to be implemented consistently across ICS footprints to avoid unintended consequences. For example, if one trust stops offering a service for fibromyalgia, there is a risk that those patients will be referred to the nearest available trust offering that service, with no net benefit to the system or to patients.

A networked approach

We think that regional networks, PCNs and MDTs can play a role by establishing clear criteria for referral, discussing cases at clinical meetings with input from rheumatology departments where there is potential benefit from onward referral, and only proceeding to referral where it is agreed to be necessary, with a clear clinical rationale.

Networks can also help by sharing best practice and case studies, recognising that examples of lessons learned from mistakes are as important as those of success in implementing effective systems. The role of networks is discussed further in *Equitable access to specialised care for rare RMDs through regional networks*, page 64.

While accepting that this level of change is challenging, we should start working towards it as a matter of urgency. There is a need to build back services after the interruption caused by COVID-19. We should use this as an opportunity to rethink how rheumatology can be better organised for the future, redesigning services across the system so that they better meet the needs of all patients.

CASE STUDY

Community-based fibromyalgia service improves patient care

Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust

Patients with fibromyalgia are better able to manage their condition and improve their wellbeing, without the need to attend hospital, through a community-based education and therapy service.

Fibromyalgia is a non-inflammatory painful condition which responds best to self-management and therapy rather than medical treatment. The trust had seen a rise in referrals for the condition to around 20% of all new patient referrals and struggled to meet demand, leading to long waiting lists for patients in pain.

To address this, the rheumatology unit joined with local partners including Doncaster IAPT (Improving Access to Psychological Therapies) to design a community-based service, based on education, self-management and access to therapy close to home.

They designed a two-week education group, jointly run by a rheumatology occupational therapist and an IAPT counsellor, covering topics such as pain, fatigue, pacing, physical activity, anxiety, depression, sleep hygiene and diet. On completion, patients can go on to a six-week therapy group, which supports them to develop self-management skills, make positive lifestyle changes and improve their mental resilience and wellbeing.

Results

Since the service began in 2019, more than 600 patients have attended the education group. Patients are seen faster and closer to home and the feedback from those who have attended has been positive.

Improving management of referrals

The reorganisation of services we have proposed above should be supported by an effective referral management system. There should be clear criteria for GPs, first contact practitioners and allied health professionals (AHPs) working in primary care and community settings on when people should be referred to rheumatology or another service, and when cases do not need to be referred.

There is limited evidence for the effectiveness of existing referral management systems in reducing the flow of referrals to rheumatology. Some have shown short-term benefit, and few have longer-term evaluation. In our questionnaire, only 43% of the 142 trusts that answered said their referrals currently go through an external referral management system commissioned by the local clinical commissioning group (CCG) to ensure patients are seen in the right place at the right time, first time.

Where there is a system in place, there is variation in how it is run. Some systems are privately provided, some co-ordinated by primary care, some by secondary care. In some areas, referrals are vetted by an allied health professional. In our questionnaire, of the trusts that said they have a referral management system, more than a third (36%) said the service was run by community physiotherapists (see **Figure 5**).

We understood from deep-dive discussions that these variations can sometimes lead to inconsistency in decision making. We heard that patients are being referred inconsistently and then have to be re-triaged internally, duplicating effort. This highlights the need for consistent and agreed referral criteria, and collaborative working across pathways.

We have also heard of cases where patients who need assessment for suspected early inflammatory arthritis were referred late because they had been delayed in triage services rather than being referred directly for rheumatoid arthritis according to National Institute for Health and Care Excellence (NICE) Quality Standards.

Variation in current referral criteria

While there are clear referral criteria and pathways for presentations such as hip pain and knee pain to orthopaedics for consideration of joint replacement, the criteria for referring RMDs to rheumatology may be less clear. We heard that many rheumatology departments had referral criteria for their early inflammatory arthritis clinics, but there was variation between them, and we did not see evaluations of the performance of these criteria.

In the absence of clear criteria, GPs may understandably err on the side of caution and refer a patient for reassurance, even when there is a very low probability, for example if they are concerned about the possibility of missing a diagnosis for EIA or connective tissue disorders. Likewise, GPs may face pressure from patients to be referred.

Using Advice and Guidance services

Where a GP or allied health professional is unsure about a diagnosis or course of treatment, they may be able to get a second opinion from hospital-based specialists through an Advice and Guidance (A&G) service without the need to make a referral. This can allow the patient's care to be managed in the most appropriate setting and avoid the need for an outpatient visit. Although we understand from our deep-dive discussions that uptake of A&G was slow in rheumatology before COVID-19, we think this has potential to relieve pressure from referral systems and support the service organisation proposed in Recommendation 1. Appropriate time allocation in clinicians' job plans would be required.

Potential solutions: referrals

We think there is a need to develop clearer referral criteria and embed them in everyday practice, aligned with the reorganisation of services proposed in **Table 1**. This should be done in conjunction with the British Society for Rheumatology and primary care. The NHS England Clinical Reference Group for Specialised Rheumatology (CRG) should be also be involved in setting such criteria for connective tissue disease (CTD) and vasculitis.

We also need to ensure that all potential referrers, including community musculoskeletal (MSK) services as well as GPs, are aware of the three-day referral target for suspected early inflammatory arthritis.

Work is already underway to develop clearer referral criteria for some RMDs – for example, the National Axial Spondyloarthritis Society has declared an aspiration to develop 'Gold Standards' for referral to reduce time to diagnosis.

The Choosing Wisely criteria⁶ for diagnostic investigations can also help. These are aimed at improving shared decision making between doctors and patients based on conversations about the benefits, risks and alternatives to potential procedures, treatments, and investigations, and are supported by the British Society for Rheumatology. One good example is the recommendation that testing antinuclear antibodies and extractable nuclear antigens should be done only where there are features of connective tissue disorders, not in the investigation of widespread pain or fatigue.

It would be beneficial to achieve a shared view of referral criteria across the specialty, and particularly in local areas – including common criteria for early inflammatory arthritis and consensus on thresholds for referring suspected connective tissue disorders – and to embed these in local directories of service. This level of consistency could enable evaluation of performance and meaningful comparisons between services.

As discussed above, management of non-inflammatory painful MSK conditions should be supported by the development of community-based enablement services which can help GPs refer more confidently to these settings without needing the 'reassurance' of a specialist opinion.

Changes to referral systems also need to be considered for their impact on hospital support services. For example, virtual clinics have in some cases driven increased demand for imaging services with some patients being referred for scans to confirm a diagnosis in the absence of face-to-face clinical assessment.

⁶ www.choosingwisely.co.uk/i-am-a-clinician/recommendations/#1572879061091-6c332449-706b

CASE STUDY

Pre-appointment questionnaire supports early, effective triage

Guy's and St Thomas' NHS Foundation Trust

People with non-inflammatory painful MSK conditions are identified more easily on referral and triaged to effective services earlier through an online questionnaire completed in advance of their visit.

The rheumatology unit found that referral letters from GPs did not always contain enough information to triage patients effectively at the point of referral. This made it difficult to direct patients who may need therapy or psychological support, rather than specialist rheumatology care, from the first visit.

The team designed an online questionnaire, based on previously validated tools used for assessing inflammatory arthritis, inflammatory back pain, fibromyalgia and depression and anxiety. The answers give clinicians a much clearer idea of which patients had possible inflammatory arthritis and those who were likely to have non-inflammatory painful conditions.

In a 2019 trial, patients who scored highly on criteria for fibromyalgia were directly triaged into a fibromyalgia clinic with multidisciplinary physiotherapist and psychologist support to better address their symptoms on the first visit.

Results

While the trust is continuing to collect and analyse data from the trial, initial indications are that the triage questionnaire supports diagnosis and enables appropriate multidisciplinary interventions earlier in the patient journey.

Recommendations: Supporting sustainable and equitable rheumatology services

Recommendation	Actions	Owners	Timescale
1. Care for patients with non-inflammatory painful musculoskeletal conditions should be provided outside of hospital in primary and community care settings in line with NHS Long Term Plan ambitions to bring care closer to home for patients.	a Co-design community services for patients with non-inflammatory painful musculoskeletal conditions in collaboration with patient groups and third sector organisations as a matter of urgency.	NHSE/I, commissioners working with patient groups	Significant progress within 12 months of publication
	b Review service provision across integrated care system (ICS) footprints with view to releasing capacity to enable rheumatology units to focus on priority specialty activity.	Trusts, ICSs	Significant progress within 12 months of publication
2. Referral to treatment (RTT) waiting times should not exceed eight weeks for all patients who need specialist rheumatology care.	a Review referral management to ensure prioritisation based on risk of harm from delayed treatment.	Trusts, regional networks, ICSs, BSR, GIRFT	Within 6 months of publication
	b Develop clear and consistent referral criteria in partnership with the British Society for Rheumatology (BSR) and primary care providers to enable rapid referrals and triage for rare and complex rheumatic and musculoskeletal disorders (RMDs) – balancing routine and urgent appointments appropriately (see 9a).	Trusts, regional networks, ICSs, BSR, GIRFT	Within 12 months of publication
	c Develop specific referral criteria for vasculitis and connective tissue disease with the Clinical Reference Group.	ICSs, BSR, GIRFT	Within 12 months of publication

Improving management of patients being followed up

The majority of rheumatology clinic appointments are for patients with long-term conditions. Many of them require follow-up for ongoing specialist assessment of their condition and supervision of high cost or 'red' category drugs by a consultant rheumatologist.

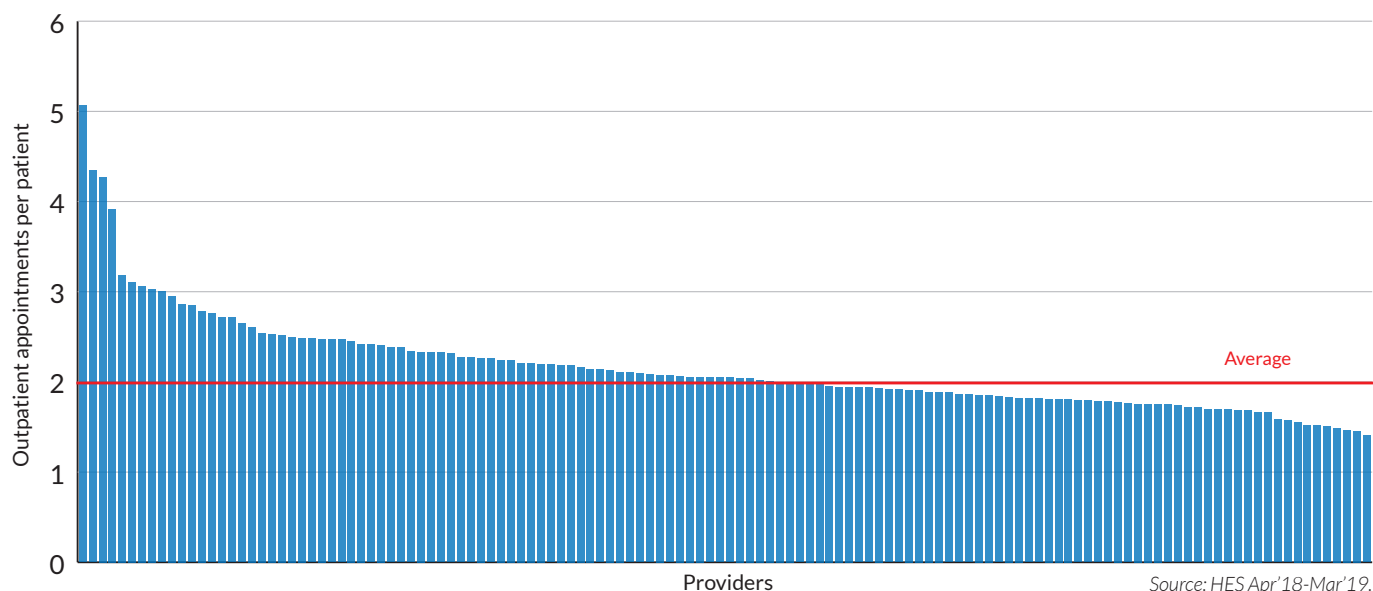
We could not, however, identify what proportion of appointments are follow-ups for these conditions because under current coding arrangements diagnoses are not routinely recorded for outpatients. More information is needed on casemix to enable a better understanding – this could be achieved by coding diagnoses for all outpatient appointments (see Recommendation 7).

Given the capacity challenges identified for rheumatology services, we think that the value of each outpatient appointment should be maximised. On our deep-dive visits, we heard from rheumatology departments about efforts to do this – for example by reducing non-attendance rates, using a range of different staff to deliver appointments, spacing out appointments where appropriate and strategies, such as patient-initiated follow-up, which aim to respond to patients' needs promptly.

Variation in outpatient attendances per patient

Looking at the available data, we found variation in the number of outpatient appointments each rheumatology patient attended. In the year April 2018 to March 2019 the median was 2.2 appointments per patient in a range from 1.5 in some trusts to 5.1 at the top end, as shown in **Figure 6**. Where numbers are high, this may be unwarranted, or it may simply indicate that trusts have higher numbers of patients needing long-term care.

Figure 6: Average number of outpatient appointments per individual patient, per year



Variation in first to follow-up ratios

We also looked at the ratio of first to follow-up attendances (see panel below) in rheumatology units. The average is 4.2 but some trusts have ratios of up to 10⁷. Commissioners may interpret this to mean that some trusts are not performing well. However, it may simply be that these units are seeing higher numbers of patients who need long-term care due to the nature of the rheumatology caseload. Attempts to enforce a specific ratio without understanding casemix can provide perverse incentives and undermine good care.

As an illustration of this, under the service reorganisation we have proposed, we expect that first to follow-up ratios would increase as a narrower range of rare and inflammatory RMDs would be referred, which by their nature require long-term care. So, performance against this target would appear to deteriorate even though a more appropriate service is being provided.

First to follow-up ratios

The first to follow-up ratio is defined as the number of follow-up attendances divided by the number of new (first) attendances over a time period. It is sometimes used as a measure of performance and quality for outpatient activity. A low ratio can be interpreted to mean efficient management with patients being discharged after first appointment. However, it might also indicate that the referral was inappropriate and ongoing hospital-based care isn't needed. The ratio is not always a meaningful measure in rheumatology as many patients attending rheumatology outpatient clinics have rare and complex conditions which, by their nature, require regular follow-up and monitoring, often extending over years.

The impact of target ratios

On our deep-dive visits, some trusts told us that they are not able to offer the intensive early appointment schedule required to adhere to National Institute for Health and Care Excellence (NICE) guidance on the management of rheumatoid arthritis in adults because they are penalised for breaching the first to follow-up target ratio. On the face of it, this is counterproductive as the more frequent early appointments are designed to help the patient achieve disease remission and reduce disability, resulting in fewer appointments in the longer term.

We have also found a problem of hidden waiting lists as people who are overdue follow-up have been deferred in order to achieve other priorities – such as meeting early assessment and treatment targets for inflammatory arthritis. These patients may not have been added to waiting lists so do not appear in any routinely collected data. We heard examples where this had happened when partial booking systems were introduced, but there were not enough available appointments to allocate.

This issue further undermines the accuracy and usefulness of blanket first to follow-up ratios. It may also be a sign that units are over their capacity. Further investigation is needed into the reasons for deferral to ensure it does not impact unduly on patient care and ensure that services are sustainable for the future.

Patient-initiated follow-up

Follow-up appointments which are booked by the patient rather than the hospital are seen as a way to reduce unnecessary outpatient attendances. They can also make services more responsive to patients by seeing them when they need care rather than on a three- or six-monthly schedule.

What is patient-initiated follow-up?

The term patient-initiated follow-up (PIFU) describes when a patient, or their carer, can initiate their follow-up appointments as and when required, for example when symptoms or circumstances change. This helps patients access support when they need it, such as during a flare-up of their symptoms, and avoids unnecessary routine check in appointments. The patient is empowered to manage their own condition and takes responsibility for initiating the appointment. This can be used on its own or in combination with timed appointments if needed.

PIFU has the potential to work well for some rheumatology patients, such as those with stable rheumatoid arthritis or stable mild connective tissue disease, on a case by case basis. We think it is not a safe option for complex early inflammatory arthritis and rare autoimmune diseases as any delay in monitoring these conditions could be dangerous. These patients should have their appointments determined by clinical need as assessed by the rheumatology multidisciplinary team led by a consultant rheumatologist, in agreement with the patient and according to NICE or British Society for Rheumatology (BSR) guidelines.

Patient-initiated follow-up has been shown to reduce attendance rates for patients with stable inflammatory conditions whose disease is well-controlled. These patient can be expected to recognise signs of flare, and should have rapid access to a helpline and to face-to-face or remote review as required.

We have seen interesting pilots where patients can record their disease outcome measures remotely and review can be triggered by pre-agreed thresholds or after review by a treating clinician. Such arrangements must pay attention to the potential for inequity, such as digital inequality.

However, many of these patients are treated with high cost or potentially toxic drugs for which the prescriber will carry responsibility, so there is a balance to be struck between wide interval, perhaps annual appointments and intervening patient-initiated follow-up – for example, some patients with stable rheumatoid arthritis could have an annual review but be able to phone for an earlier appointment if they have symptoms of a flare. There should be a maximum time interval for reviews, no more than two years, even if the patient is stable, regardless of whether they have asked for a follow-up.

Guidance on using patient-initiated follow-up can be found in phase 3 guidance in implementing the NHS response to COVID-19⁸.

Alternative models of outpatient provision

We have seen examples of rheumatology departments developing innovative models to replace the traditional consultation, which could help reduce the need for face-to-face follow-ups. These include the use of remote or digital consultations, by telephone or using online video platforms.

Many stable patients may only require one annual appointment, which can be delivered virtually by a doctor, a specialist nurse, or another health professional, such as a physiotherapist or pharmacist with appropriate experience.

Some departments were already trialling remote consultations, but they have very rapidly come into use during the coronavirus pandemic, in line with the NICE COVID-19 guideline for rheumatology⁹.

We heard that the benefits include convenience and reduced costs for patients, less requirement for outpatient clinic space, and easier access for patients with mobility impairments. In many places telephone advice lines have provided vital support to help patients adapt, especially during lockdown.

However, we note that remote consultations take no less time for rheumatology staff or booking teams, and there are potential disadvantages, in particular the key importance of physical examination for many situations. Staff unused to virtual consultation may also need training to ensure they communicate effectively with patients.

⁸ NHS Implementing phase 3 of the NHS response to the COVID-19 pandemic, section 4
www.england.nhs.uk/wp-content/uploads/2020/08/implementing-phase-3-of-the-nhs-response-to-covid-19.pdf

⁹ NICE COVID-19 rapid guideline [NG167]: rheumatological autoimmune, inflammatory and metabolic bone disorders, recommendation 1.2
www.nice.org.uk/guidance/ng167/chapter/1-Communicating-with-patients-and-minimising-risk

During the coronavirus pandemic the risks of hospital attendance have been higher and so the risk-benefit balance is heavily in favour of remote consultation for most. In developing remote consultation models as we restore services, we need to be aware of:

- The need for careful clinical examination of patients – for example, most new patients who have not yet received a diagnosis will need a face-to-face appointment. Decisions should be based on clinical need and assessment of risk.
- Potential for inequity of access to services, for example for patients who are not confident using virtual technology.
- The prime importance to patients and staff of establishing the therapeutic relationships and trust necessary for shared decision-making and long-term care.
- The need to avoid a two-tier service where some patients continue to be seen in rheumatology due to an absence of viable alternatives while others move to the new model.

A greater focus on patient education, including self-management techniques, may be needed to ensure patients are not disadvantaged by not being seen in person. Online self-management modules could be prescribed and embedded in the treatment pathway to ensure that virtual consultations are as effective as face to face.

Reducing avoidable outpatient appointments

The NHS Long Term Plan sets out an ambition to reduce outpatient visits by 30%, chiefly by making use of digital technology to reduce the need for follow-up appointments.

We have seen good examples of this, with online platforms being used to record outcome measures and completion of exercise programmes. Some departments have used videos to replace or supplement face-to-face education sessions for patients, which have the added benefit that they can be used repeatedly and shared with family and carers.

Monitoring of disease-modifying anti-rheumatic drugs (DMARDs) presents another potential opportunity to free up capacity for priority cases (see *Standardising the monitoring of DMARDs*, page 107). We think it is worth investigating whether better use could be made of shared care or alternative provision of monitoring services shared across a geographical area.

Many outpatient appointments are related to dose escalation and monitoring for inflammatory disease, initiation of additional conventional DMARDs, and responding to patients whose inflammatory disease flares. We think some of these could be avoided if biologic agents, which are some of the most effective drugs for inflammatory arthritis, were introduced earlier in the patient pathway.

For example, biologics can only be initiated for rheumatoid arthritis if at least two conventional DMARDs fail to control disease or are not tolerated, a process that can take 6-12 months with multiple appointments during this time. As biologics require very little monitoring and are very effective, it is likely that introducing them earlier would not only enable more rapid control of disease but also reduce the number of outpatient appointments and blood monitoring required.

We think that this approach could result in savings in the overall cost of treatment over time, as any extra cost from introducing biologics earlier would be balanced by better long-term outcomes and reduced need for outpatient appointments and investigations.

In making any changes to outpatient services, we need to ensure that patients are not lost to follow-up. Safety net protocols need to be in place so that patients who have not attended for their follow-up within a certain period are contacted to return so that their condition can be monitored.

CASE STUDY

Remote monitoring service reduces the need for follow-up visits

Guy's and St Thomas' NHS Foundation Trust, Kings College Hospital NHS Foundation Trust, Lewisham and Greenwich NHS Trust

An award-winning electronic monitoring system has helped patients with rheumatoid arthritis become more engaged with their condition and reduced the need for some follow-up appointments.

Remote monitoring is offered to clinically appropriate patients as part of a digital pathway. The system sends texts prompting them to complete a monthly questionnaire. Based on the Rheumatoid Arthritis Impact of Disease (RAID) tool, the questionnaire evaluates impact on quality of life, including everyday activity, sleep and mental wellbeing on a scale of 1-10.

Patients receive personalised feedback on completion and can communicate directly with clinicians by text to ask questions and get advice. They can also use the app to track their progress and trigger an urgent appointment if they have a flare. The system automatically identifies red flags and triggers a clinical response if scores deteriorate.

Results

The GSTT system gives patients more control and improves their experience while reducing the need for outpatient visits. Data for 2019-20 shows that:

- 86% of patients engaged with the service and completed a questionnaire after their first text
- 72% of patients believe that access to care is easier through remote monitoring
- 22% of patients have maintained low disease activity or a state of remission
- Patient engagement is consistently high, with very high patient satisfaction in surveys

CASE STUDY

Telephone clinics help patients manage flares without attending hospital

Stockport NHS Foundation Trust

Daily nurse-led telephone clinics help patients manage flares and medication issues with access to a weekly face-to-face clinic, supported by consultants, if needed.

This service developed out of the unit's nursing and pharmacy advice lines, which received a growing number of requests for more in-depth consultations from patients and their GPs. Nursing job plans were adjusted to include dedicated telephone clinics, as well as protocols for key issues such as managing patients with flare of inflammatory arthritis.

The clinics have expanded with demand and are now run each working day, morning and afternoon. A nurse-led weekly rapid access clinic has also been established for patients who need face-to-face review following telephone assessment. By ring-fencing the nurse-led telephone clinics, with outcomes recorded electronically, the unit has been able to secure a telephone tariff, ensuring the work is properly reimbursed.

Results

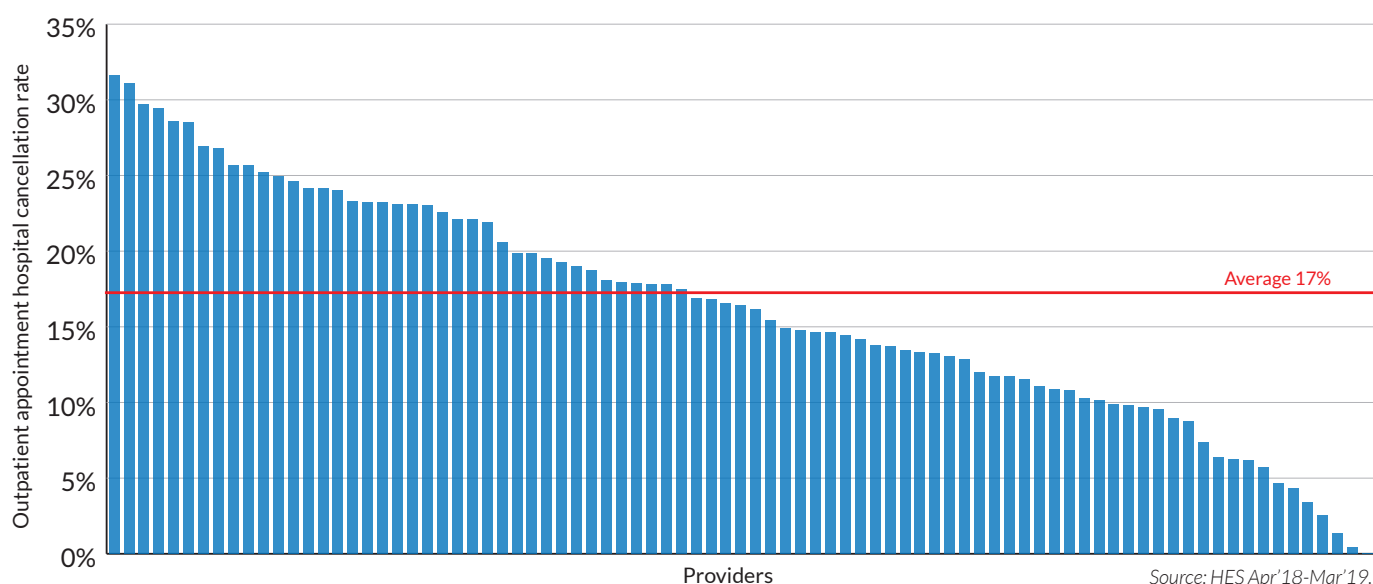
The nurse-led clinics ensure that patients whose disease is flaring are well supported with rapid access to face-to-face review, while relieving pressure on regular outpatient clinics.

Reducing unnecessary cancellations

Figure 7 shows wide variation in outpatient appointments cancelled by rheumatology units among trusts that shared this data across England. In some places almost a third of all appointments are cancelled. This represents considerable inconvenience for patients and workload for booking staff. We don't know the reasons for these cancellations, but the variation warrants further review. High rates of hospital cancellation could reflect overloaded or stressed units, or simply indicate doctors taking leave in a system that doesn't use partial booking.

However, we think it is worth investigating the causes where volumes of cancellations are relatively high to ensure that we are making the best use of appointment slots, optimising capacity for follow-ups prioritising patients who may need early definitive treatment to control their condition or control of disease flares.

Figure 7: Proportion of rheumatology outpatient appointments cancelled by the hospital (among trusts who provided this data)



Potential solutions

We believe that the first to follow-up ratio is not a useful measure in rheumatology. It is too blunt a metric to apply across all patients regardless of their complexity as many patients with rare or inflammatory RMDs will require long-term follow-up by the nature of their conditions or treatment.

However, there are models which are proving useful in reducing the need for follow-up appointments and face-to-face consultations in stable patients, including digital consultations, patient-initiated follow-up, educational videos, and technology that allows patients to record outcome measures with reviews triggered at certain thresholds. We believe that these solutions can help to optimise flow and increase follow-up capacity for patients who need it.

Recommendations: Improving management of follow-ups

Recommendation	Actions	Owners	Timescale
3. Trusts should review their management of follow-up appointments and consider alternative models of outpatient care.	a Explore options to increase use of virtual consultations, in line with NHS Long Term Plan and Outpatient Transformation Programme ambitions.	Trusts, ICSs	Within 6 months of publication
	b Consider how to safely reduce the frequency of review for stable patients, for example by: - reducing the need for attendances for escalation and flare with earlier use of definitive treatments; - enabling patients to record outcome measures remotely, with reviews triggered when outcomes exceed thresholds; - implementing National Institute for Health and Care Excellence (NICE) and British Society for Rheumatology (BSR) guidance; - increasing the involvement of multidisciplinary teams (MDTs) in annual reviews.	NHSE/I OTP, GIRFT, Trusts, BSR	Within 18 months of publication
	c Review treatment thresholds for biologic agents including the total costs of service not just drug costs.	NICE	Ongoing
	d Investigate the reasons why outpatient appointments are deferred by rheumatology units to ensure that this does not impact on quality of patient care.	Trusts	Within 12 months of publication

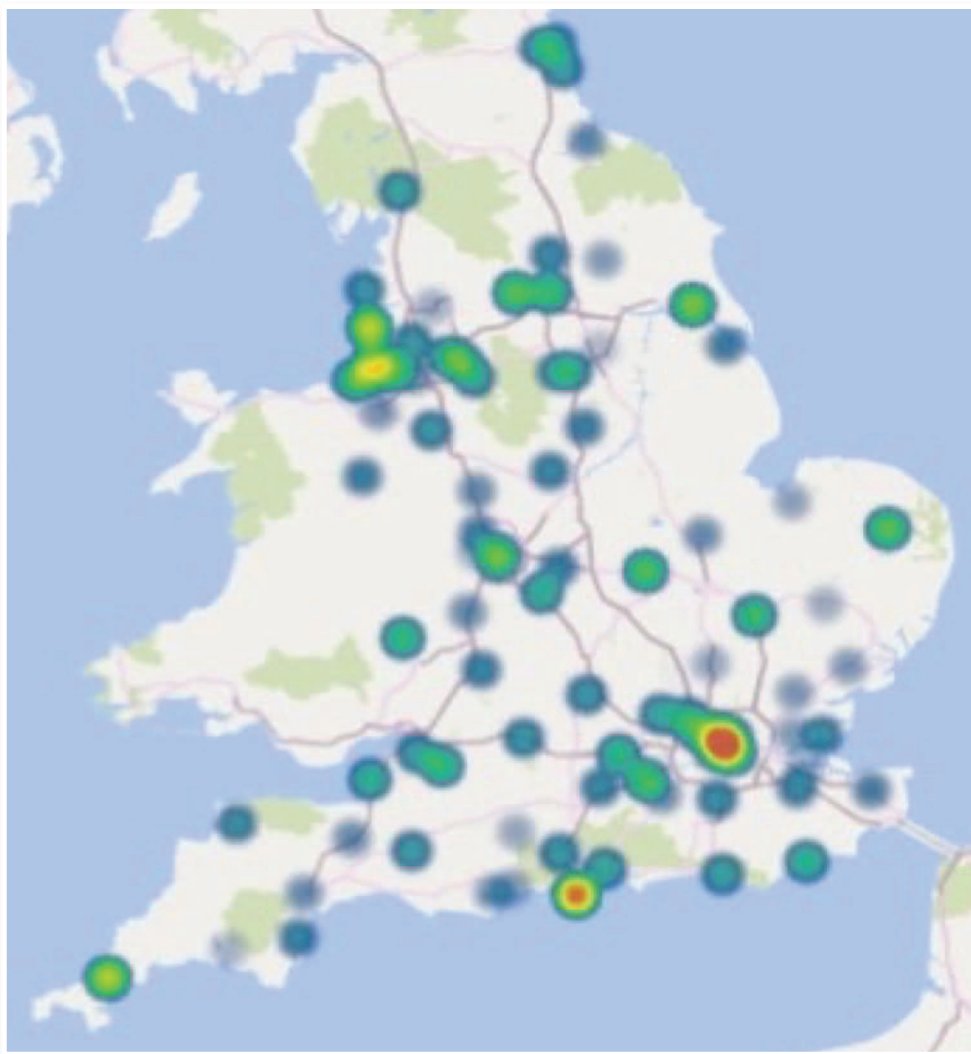
A workforce to meet future needs

Ensuring quality training in rheumatology

There has not been any significant increase in rheumatology training numbers in recent years, despite the expansion of rheumatology as a specialty. The number of trainees is decided at national level by Health Education England (HEE). Within each region, HEE and the Specialty Training Committees allocate trainees to individual trusts based on training needs and where training is best delivered, with larger units generally allocated more trainees.

We have found an uneven distribution of rheumatologists in training across the country, as illustrated in **Figure 8** – the blue spots in the heatmap show the places where there are fewer trainees per consultant, largely in rural and regional centres. The yellow and orange spots indicate the highest concentrations of rheumatologists in training. This distribution appears to follow historical patterns, with little evidence of movement in placement depending on the quality of training or recruitment needs.

Figure 8: Heatmap showing ratio of rheumatologists in training to consultant DCCs



Source: GIRFT questionnaire 2019

Variation in trainee activity and supervision

Following the Shape of Training initiative, which aimed to increase the resources available to manage the acute medical take, all specialty trainees in rheumatology now undertake a five-year programme to achieve dual accreditation with general internal medicine (GIM). As a result, they spend less of their time solely in rheumatology. With the introduction of the Internal Medicine Training (IMT) programme in August 2020, we anticipate that there will be a 15-20% reduction in the amount of rheumatology trainee time in rheumatology nationally.

On our deep-dive visits, we found variation between trusts in the proportion of time that trainees spend in acute GIM training, particularly on call, compared to rheumatology. We also saw variation in the activities that they are undertaking. In some trusts, trainees spend a significant proportion of their time on tasks perceived to be of low educational value, compared to the priority of being trained to deliver high quality ambulatory care.

These tasks included medical review of routine day case infusion patients, routine prescribing of disease-modifying anti-rheumatic drugs (DMARDs) and biologics for the whole department and reviewing all the routine results from patients not under their care. In some rheumatology day case units, all patients are reviewed by a doctor, usually a junior doctor, whereas others are entirely nurse-led. In some trusts, we found that trainees were spending large amounts of time on call for the joint aspiration service across the trust, which prevented them being timetabled to attend outpatient clinics. This was more likely to happen in those trusts where rheumatology led the hot joint pathway (see *Reducing variation in acute hot joint pathways*, page 83).

We suggest that departments review the activities undertaken by their doctors in training and prioritise those which provide good training experience. Trainees should get exposure to a variety of settings, for example through attachments to smaller rheumatology units during their training post. This would not only help trainees to gain a greater diversity of experience, but also help to support smaller rheumatology units – see *Supporting smaller rheumatology units*, page 55.

Trainee supervision

Through our questionnaire, we found variation in how trainee supervision is managed. Only 19% of trusts said they reduce the number of patients attending clinic if they are supervising a junior doctor. Similarly, only 16% of trusts reported that they adjust clinic numbers if they are teaching medical students in clinic.

These responses conflict with Royal College of Physicians (RCP) guidelines¹⁰ for training that patient numbers should be reduced by 25% in clinics where a trainee is being supervised, to enable adequate time for training and patient care. We think that the 25% reduction in patient numbers is a sensible requirement and that the RCP guideline should be implemented consistently across all units to maximise the benefit of training and to ensure appropriate consultant supervision of medical care.

Potential solution: review of training

Given the issues described above, we think a review of rheumatology training would be useful to look at training needs across the specialty, the curriculum and which service tasks are most appropriate, led by the Rheumatology Specialty Advisory Committee (SAC). This would help to establish clear principles for providers to ensure:

- the quality of the clinic outpatient experience for rheumatology trainees at all grades;
- progression in both complexity and volume of patients seen between and within training years;
- provision of consultant supervision in clinics where trainees are present;
- sufficient time allowed in job plans to deliver high quality training.

A review could also consider extending virtual training opportunities, which have proved useful during COVID-19, enabling trainees to access high level regional expertise through webinars and meetings.

¹⁰ RCP Consultant Physicians Working With Patients revised 5th edition 2013, page 239
www.rcplondon.ac.uk/projects/outputs/consultant-physicians-working-patients-revised-5th-edition

Attracting consultants to smaller units

As discussed in *Supporting smaller rheumatology units*, page 55, many smaller units struggle to attract and retain consultants, for example because people choose to work in larger centres where there are more opportunities for career development. Often larger trusts will have more flexibility to create tailored consultant posts that are attractive to their existing trainees and encourage them to stay at that hospital, while smaller trusts may not have the resources or capability to do this.

We saw the impact of this first-hand during our deep dives. Among the trusts we visited, we found some units operating with only one consultant and small district general hospitals (DGHs) struggling to recruit into vacant consultant posts.

We need to find ways to attract and retain staff in areas where there are shortages and consider new ways of working to offer more opportunity for staff based in smaller hospitals. For example, in some places, joint posts have been proposed between teaching hospitals and smaller DGHs.

Making use of the wider skills mix

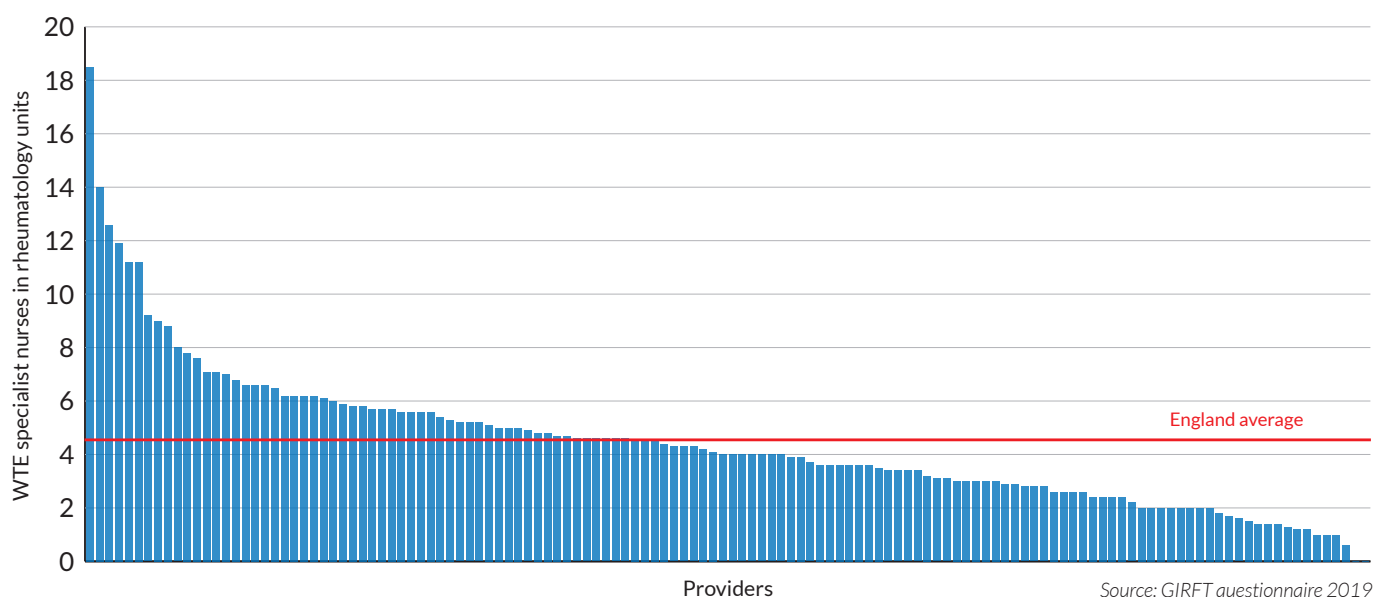
Many rheumatic disorders are complex multi-system conditions that benefit from a multidisciplinary approach involving nurses and specialist allied and other health professionals (AHPs) such as physiotherapists, psychologists, occupational therapists, podiatrists, pharmacists, radiographers and physician associates.

These professionals are central to care provision. We have heard of good examples of advanced practice physiotherapists and physiotherapist independent prescribers supporting patient assessment, disease monitoring and medication management, especially in care of axial spondyloarthritis.

However, during our visits we have found that some units are not making full use of the multidisciplinary skill mix available in order to address capacity challenges, optimise services, and increase their resilience and sustainability.

Specialist nurses play a critical role in rheumatology units - **Figure 9** shows their availability in trusts. Although there is wide variation in numbers, specialist rheumatology nurses are present in even the smallest units. They play a vital role in managing follow-up patients, working to the 'top of their licence' in line with the Royal College of Nursing (RCN) competency framework for rheumatology¹¹ but we heard from trusts about variation in their professional activities and their Agenda for Change banding. When people with rare autoimmune rheumatic diseases were surveyed by the Rare Autoimmune Rheumatic Diseases Alliance (RAIRDA) in 2018, only a third of respondents said their care was supported by a specialist nurse. Nurse-led advice lines are an important service for patients, and we saw several examples of nurse-led day case units.

Figure 9: Number of whole time equivalent specialist nurses in rheumatology units



¹¹ RCN A competency framework for rheumatology nurses <https://www.rcn.org.uk/professional-development/publications/pub-009004>

Figure 10 shows the range of allied healthcare professionals available within rheumatology units across England based on responses to our questionnaire. There is wide variation in the type and number of staff from trust to trust.

On our deep-dive visits we heard of trusts that struggled to attract key staff such as physiotherapists and occupational therapists. However, most units do include a range of specialist allied health professionals (AHPs). In some trusts we visited, these staff may be managed by other departments, but rheumatology patients will have access to them. National Institute for Health and Care Excellence (NICE) guidance says that patients with inflammatory conditions, such as rheumatoid arthritis, should be able to access a range of multidisciplinary skills through a single named co-ordinator¹² and mandates specialist physiotherapy referral for axial spondyloarthritis¹³.

Enhancing skills and extending roles

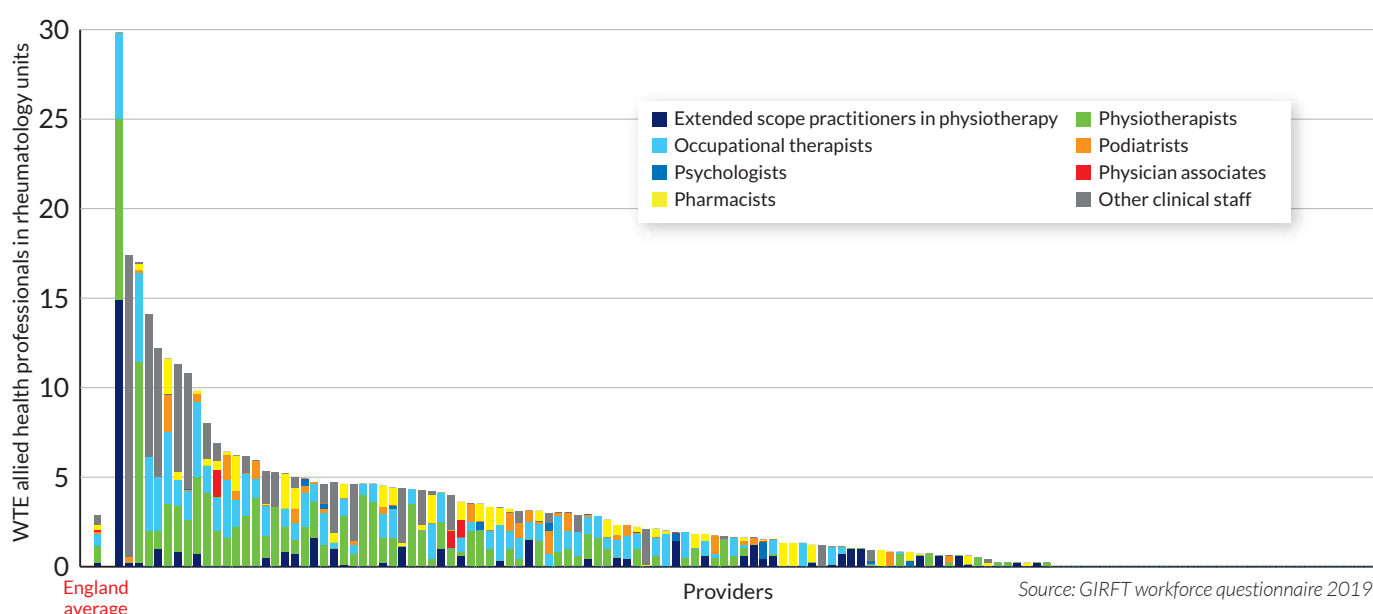
Departments should consider whether they could do more to help their staff to extend and improve their specialist skills and scope of practice. As well as providing greater job satisfaction and opportunities for promotion, this may relieve pressure on busy units and enhance patient care. For example, pharmacists could take on a greater role in drug prescribing, monitoring and assessment, which has already occurred in primary care in many areas. This could include medication reviews and post-discharge support for patients on multiple medications or those with long-term chronic conditions, in line with NICE guidelines on optimising medicines¹⁴.

There may also be a greater role for nurse prescribers and some specialist physiotherapists who have gained prescriber status, with the potential to increase the already important role that AHPs play in patient education.

In the East of England, they have taken a regional approach to reviewing allied healthcare roles, in which consultants, trainees, specialist nurses and other AHPs have collaborated to map a matrix of competencies required for care of connective tissue disease and vasculitis patients and developed training for several of the competencies.

Creating enhanced roles for nurses and AHPs would enable them to use their specialist or advanced skills, as well as supporting consultant colleagues to see patients with more complex needs, in line with the NHS Releasing Time to Care ambitions.

Figure 10: Skill mix of allied health professional staff working in rheumatology units



¹² NICE guideline [NG100] Rheumatoid arthritis in adults: management, recommendation 1.7.2
<https://www.nice.org.uk/guidance/ng100/chapter/Recommendations#the-multidisciplinary-team>

¹³ NICE guideline [NG65] Spondyloarthritis in over 16s: diagnosis and management, recommendation 1.5
www.nice.org.uk/guidance/ng65/resources/spondyloarthritis-in-over-16s-diagnosis-and-management-pdf-1837575441349

¹⁴ NICE guideline [NG5] Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes Recommendations 1.2.6 and 1.4.2
www.nice.org.uk/guidance/ng5/chapter/1-Recommendations#medicines-related-communication-systems-when-patients-move-from-one-care-setting-to-another

CASE STUDY

Physician associate post supports effective workforce planning

York Teaching Hospital NHS Foundation Trust

Adding a physician associate (PA) to the team has helped the York rheumatology unit to meet its workforce challenges and provide reliable outpatient and day case cover.

The PA was one of 13 hired by the trust to address challenges including shortages of junior doctors and clinical nurse specialists, and a reduction in trainee posts. The recruits entered on a two-year preceptorship programme in which they rotated between four departments, supported by an educational supervisor and specialty-specific clinical supervisors, before choosing a specialty to work in full time.

The rheumatology PA is now integrated into the rheumatology multidisciplinary team (MDT) and trained in core tasks including physical examination, joint aspiration and injection, patient assessment and management. The new post has also enabled the delivery of a rapid outpatient clinic for assessment of early inflammatory arthritis (EIA) and provided continuity of care for inpatients with consultant rheumatologist support.

Results

The permanent PA presence means the unit can plan outpatient and day case services with confidence, knowing they have reliable cover. Working within one specialty gives the PA the opportunity to develop additional skills and progress their career.

CASE STUDY

ACP physiotherapist helps develop new services and pathways

East Lancashire Hospitals NHS Trust

A new trainee physiotherapist advanced clinical practitioner is helping develop a new pathway for hypermobility and will support the creation of a therapist-led injection clinic.

The new role was created in response to challenges in recruiting medical staff and the increasing importance of therapy in treatment of rheumatic and musculoskeletal disorders (RMDs).

Following a two-year advance clinical practice Masters, which includes an injection therapy course, the trainee will work independently leading an injection clinic, providing easier access to this treatment option. They have already helped to develop a new pathway for the assessment and management of hypermobility. This enables patients to be referred direct to physiotherapy or occupational therapy, reducing pressure on rheumatology clinics. Other potential support the role will offer includes:

- assessment and diagnosis of inflammatory back pain;
- bloods monitoring as a non-medical prescriber;
- managing orthopaedic and musculoskeletal pathology, considering the need for investigations or onward referral.

Results

The impact of the new hypermobility pathway is being audited but indications are it has reduced the number of new appointments required with a rheumatology consultant.

Supporting smaller rheumatology units

We have found that some smaller rheumatology units do not have the resilience and support they need to guarantee a stable service when key staff leave or are absent for a long period.

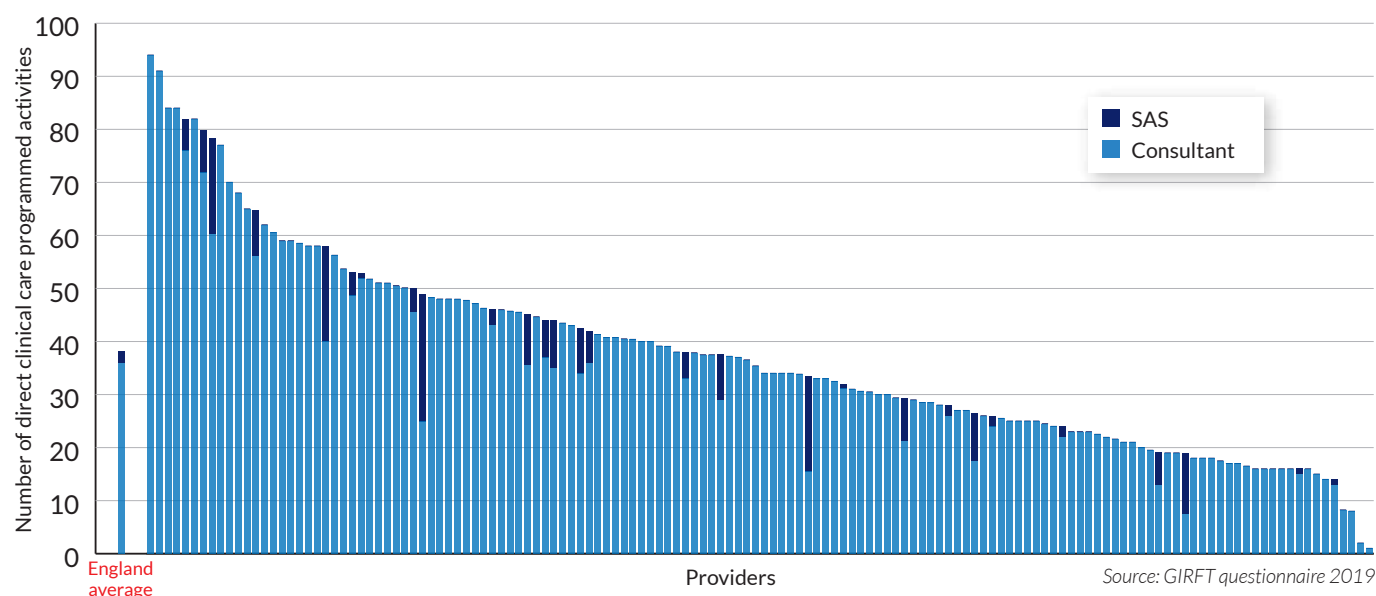
We saw trusts where this led to the collapse of the service, with serious knock-on impact on all the surrounding units who have had to accommodate their patients. A lack of proactive planning and preparedness at a regional level resulted in longer waiting times and travel distances for patients with complex conditions, who often have reduced mobility.

Why are units vulnerable when staff leave?

An average rheumatology department has four consultants, not all of whom work full time. On our deep-dive visits, we heard that many consultants are approaching retirement. Clinics can become very reliant on one individual so that it becomes difficult to operate without them. If they, or other key members of the team, leave or retire early, the whole service can become very fragile.

Figure 11 shows medical time spent by consultants and staff and associate specialist (SAS) doctors in rheumatology as measured by the number of direct clinical care programmed activities (DCC PAs). The chart shows that some units are relying on a small number of DCC PAs to provide a range of rheumatology services.

Figure 11: Number of consultant and SAS doctor direct clinical care programmed activities in rheumatology units



Demand pressures which are felt across the system are likely to have the greatest impact on these smaller units. Some departments may also be seeing large numbers of patients with non-inflammatory painful musculoskeletal (MSK) conditions. The reorganisation of services we propose in Recommendation 1 could help relieve some of this pressure and help make units more resilient.

Problems replacing key staff

We have found that smaller units may struggle to attract consultants and nurses. On our deep-dive visits, we heard of units holding a vacant position for up to a year waiting for trainees to be eligible to apply after failing to recruit in an open process. This is due to a variety of factors, including skill shortages and people choosing to work in larger centres where there may be perceived to be more opportunities for career development and specialisation.

Historically nurses gained an interest in rheumatology through treating inpatients on wards, but this does not happen as frequently now as advances in treatment mean most rheumatology care is provided in outpatients or on day case units where fewer nurses are exposed to the specialty.

Trusts also experience problems finding and retaining experienced AHPs, including physiotherapists and occupational therapists, due to issues such as poor succession planning, lack of funding for clinical education, and in some places cost of living pressures.

Potential solutions: providing sustainable services through regional networks

All of these factors are putting some smaller units under stress, which can put the services they provide at risk. We need to think more proactively about how we can put local services on a more sustainable footing and ensure continuity and equitable access for patients regardless of where they live.

This requires a more co-ordinated approach, with some services commissioned at integrated care system (ICS) level rather than at trust level. This would enable units in the same geographical footprint to support each other and make sure that all services are sustainable overall, through greater flexibility and joint working based on a networked approach.

Networks could be co-ordinated through regional multidisciplinary team (MDT) meetings, which can happen online using virtual meeting platforms. They should be well-resourced and underpinned by good IT and connectivity to support good communication and information sharing. These networks can also link with other emerging networks, such as the imaging regional networks, to plan capacity and ensure continuity of services across a geographic footprint.

We have seen some examples where regional networked approaches are already working well, for example co-operating across a region on aspects of care such as prescribing. These models could be extended so that forward planning is done regionally, taking account of smaller units that may be vulnerable and the potential impact on surrounding units if they are unable to continue with specific services.

The need for closer co-operation between neighbouring trusts is also discussed in detail in *Equitable access to specialised care for rare RMDs through regional networks*, page 64.

Potential solutions: workforce planning, skills mix and training

As discussed in *A workforce to meet future needs*, page 50, we think there is potential for units to make greater use of the skill mix available, including extending the roles and scope of practice of allied health professionals and enabling all staff to work at the 'top of their licence'. This would strengthen the resilience of units, which would no longer be so reliant on individual staff to provide a service.

Departments should also devote time and resource to improve their workforce and succession planning and the distribution of staff in conjunction with local clinical commissioning groups (CCGs) and the integrated care system (ICS) where possible. This should focus on anticipating foreseeable risks and taking proactive measures to ensure continuity and prevent the service suffering when staff leave, with good patient care as the ultimate goal.

As mentioned in our discussion of training requirements, above, shared training posts between teaching hospitals and DGHs could also help to support smaller units, while increasing the breadth of trainees' experience.

Recommendations: A workforce to meet future needs

Recommendation	Actions	Owners	Timescale
4. Rheumatology medical training posts should maximise the quality and value of rheumatology-specific training components to ensure competence and meet patient needs.	a Reduce variation in training by defining tasks that are of low educational value for trainees and minimise these in each trust.	SAC/BSR, Trusts	Within 12 months of publication
	b Reduce variation in clinical supervision by fully implementing the Royal College of Physicians (RCP) training guidance in all trusts.	SAC, training committees, Trusts	Within 6 months of publication
	c Carry out a review of rheumatology training to include training needs, curriculum, and service tasks, to establish clear principles for trusts to follow.	SAC	Ongoing
	d Assess the value of trainees being 'on call' for rheumatology and specify the experiences that trainees should acquire during their training period.	SAC	Within 12 months of publication
5. Trusts should make full use of the multidisciplinary skill mix and consider enhanced roles for nurses, pharmacists and allied health professionals, to meet increasing demand and improve services for patients in line with the NHS Releasing Time to Care ambitions set out in the interim People Plan.	a Ensure that patients have access to specialist nurses and a range of other health professionals, including physiotherapists, occupational therapists, pharmacists, podiatrists, psychologists and radiographers, through a single named co-ordinator.	Trusts	Ongoing
	b Consider how specialist and consultant rheumatology pharmacists could play a greater role in patient care, education, drug management and monitoring, as well as prescribing.	Trusts	Within 18 months of publication
6. Rheumatology services should be planned across a geographic area, with services for some conditions commissioned at integrated care system (ICS)/sustainability and transformation partnership (STP) level to improve efficiency and outcomes overall, with network support for smaller units to make them more sustainable and ensure equity of access for patients.	a Review existing regional network arrangements for specialised services and consider broadening the scope or setting up parallel networks.	NHSE/I CRG, Networks, Trusts, ICSs	Within 12 months of publication
	b Review local workforce professional skills mix and succession planning and work collaboratively with other trusts to ensure regional services are sustainable in the longer term, reducing reliance on individual clinicians and further promoting the use of the entire multidisciplinary team.	Trusts/ICSs	Within 18 months of publication

Improving data and coding to support service planning

Coded data on main specialty, treatment function, procedures and diagnoses can be used to measure levels of activity and understand casemix to provide a basis for payment for service, help us review service needs and improve workforce planning.

The data routinely collected for inpatients and day cases is very rich and includes diagnoses and procedures. However, the bulk of the rheumatology workload is in outpatients, accounting for nearly two million attendances in 2018-19. Hospital Episode Statistics (HES) outpatient records have very limited information about diagnoses, which is recorded in less than 5% of attendances, as this is not a mandated field in the dataset collected by trusts. The main information we have is about the number of new and follow-up appointments, and their outpatient procedures.

The need for better outpatient data

The lack of data on outpatient diagnoses limits our ability to form an accurate picture of the casemix being handled by rheumatology units. As discussed in *Improving management of patients being followed up*, page 43, the ratio of first to follow-up appointments is used by some commissioners as a measure of the effectiveness of a service, with low ratios considered good. It would therefore be vital to know more about casemix to understand if multiple follow-up appointments are necessary because the nature and complexity of the patient's condition requires long term care.

Identifying patient cohorts based on diagnoses would also enable review of condition-specific pathways and help us to understand the appropriateness of current patterns of care compared to national guidance.

Data collected within units

Where units collect their own diagnostic data, we found that the information captured is patchy. Only 11.9% of trusts have a diagnostic database within the electronic health record and 18.9% of trusts who responded to our questionnaire hold a specialty-specific list of frequently used diagnostic codes.

We think there is a need for greater co-operation between coders and clinicians to interpret and validate data consistently and accurately, potentially using SNOMED clinical vocabulary definitions – the standard across the NHS as of 2020 – to map International Classification of Diseases (ICD) diagnostic codes. These are important stepping stones for making progress toward outpatient diagnostic coding.

Rheumatology departments should collect other useful data on outpatients, such as tracking the use of some drug therapies and procedures in outpatient settings, to allow comparisons between services and to enable evaluation. For example, this could include consistent recording on outcome forms whether joint and intramuscular injections have been given. It should also include collection of patient-reported outcome measures.

Variation in first to follow-up ratio

As discussed in *Improving management of patients being followed up*, page 43, we found significant variation between units in the number of outpatient appointments per patient and the ratio between first outpatient appointment and follow-up appointments. The absence of casemix information however means that we can't reliably assess whether this has any impact on productivity and patient care. We understand from our discussions with trusts that some of the variation may be related to differences in how units record nurse-led or physiotherapist-led activity.

Attribution of specialty activity

On our deep-dive visits, we heard from trusts that some rheumatology activity is being attributed to other specialties. For example, some rheumatologists also practise in general medicine and this can result in their activity being coded under that specialty.

Similarly ward consultations, which are often demanding in terms of consultant and registrar time resource, are not recorded in the Hospital Episode Statistics (HES) and this work is therefore not readily identifiable. This gap has also been identified in GIRFT national reports for other specialties including Neurology and Hospital Dentistry.

A similar situation occurred when we looked at prescribing activity using the RX-Info Define and Refine software, which is used by trusts to monitor the use of drug therapies and make benchmarking comparisons with other trusts. Using this system, we found that in a minority of cases, medicines which are used by rheumatology consultants to treat rheumatology patients were being attributed to a cost centre code of other specialties.

Potential solutions

To gain a clearer picture of activity, we recommend that diagnoses should be recorded for outpatients and that progress be made nationally to promote and incentivise coding of outpatient diagnoses within routinely collected healthcare activity data.

Wherever possible, this should be part of an electronic record, which, if linked to electronic prescribing for outpatients and day cases, has the potential to create a powerful dataset on diagnoses and patient outcomes to drive improvement. It could also enable automated data collection, reducing the burden of data capture on clinicians.

Rheumatologists can help by adopting and writing clearly defined diagnoses in clinic letters, potentially using SNOMED-CT clinical terminology that map easily onto specific ICD10 codes.

To ensure that rheumatology activity is attributed correctly, we recommend that all activity that is led by rheumatologists should be coded to the rheumatology treatment function code (410).

Recommendations: Improving data and coding to support service planning

Recommendation	Actions	Owners	Timescale
7. Diagnoses should be coded for outpatients as part of routine activity to enable service planning and benchmarking between trusts.	a Establish specified list of core diagnoses which should be routinely coded from clinic letters and inpatient and day case episodes.	GIRFT, NHS Digital, BSR	Within 12 months of publication
	b Use the specified list of core diagnoses to identify cohorts of patients and enable review of condition-specific pathways to ensure frequency of care is aligned with national guidance.	Trusts	Within 6 months of action A completion
	c Drive routine collection of patient-reported outcome measures (PROMs) to identify variation in outcomes and measure the benefit of services to patients.	GIRFT, NHSE/I, BSR	Within 18 months of publication
	d Implement electronic prescribing for rheumatology outpatients, day cases and inpatients to support accurate clinical coding and provide information for comparison.	Trusts	Within 12 months of publication
8. All rheumatology activity should be coded using treatment function code 410.	a Ensure activity is correctly attributed to the specialty and staff group.	Trusts	Ongoing

Improving early management of inflammatory arthritis

Over 20,000 people are seen in rheumatology clinics with suspected early inflammatory arthritis (EIA) every year. This includes people with conditions such as rheumatoid arthritis, psoriatic arthritis and axial spondyloarthritis. Meeting their needs is one of the core functions of a rheumatology service. In the initial phase of peripheral inflammatory arthritis, there is a much greater chance of achieving disease remission the earlier a patient starts treatment with disease-modifying anti-rheumatic drugs (DMARDs). This reduces the risk of joint damage and disability, with short- and long-term benefits for physical health, mental wellbeing and ability to work.

Referral and treatment standards

Performance against target referral and treatment times for rheumatoid arthritis are monitored by the National Early Inflammatory Arthritis Audit (NEIAA), which measures outcomes against National Institute for Health and Care Excellence (NICE) quality standard 33. The audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and carried out by the British Society for Rheumatology (BSR) on behalf of NHS England and the NHS in Wales with the aim of improving the quality of care for people living with inflammatory arthritis. It is the largest outpatient audit undertaken in the NHS with baseline records for more than 20,000 patients.

The audit standards, based on NICE QS33, which have a target of 100% achievement, include:

- Quality statement 1: adults with suspected persistent synovitis (indicating inflammatory arthritis) affecting more than one joint, or the small joints of the hands and feet, should be referred to rheumatology services within three working days of presenting in primary care.
- Quality statement 2: people with suspected persistent synovitis should be assessed in a rheumatology service within three weeks of referral.
- Quality statement 3: adults with active rheumatoid arthritis should start conventional disease-modifying anti-rheumatic drug within six weeks of referral with monthly monitoring until their treatment target is met.

There is a separate NICE quality standard (170) for axial spondyloarthritis¹⁵. Data were not available for us to make a meaningful analysis of performance against it during our review. However, we note that the second phase of the NEIAA now includes patients with axial spondyloarthritis and records delays to referral and diagnosis.

What we found: performance against the standards

Not all trusts are meeting these targets. The audit report¹⁶ for 2018-19 shows that:

- 41% of patients with suspected EIA were referred within three days (QS1);
- 38% of patients were assessed by a rheumatology service within three weeks of referral (QS2);
- 54% of patients with a new diagnosis of EIA started treatment within six weeks (QS3);
- 35% of patients referred with suspected EIA were found to have this diagnosis.

Why are trusts not meeting the standards?

Where performance did not meet target standards, we understand from our deep-dive discussions with clinicians that there are many reasons for this.

For example, referral criteria for EIA and the triage systems used vary from area to area, which may affect performance against audit standards. Units may have long referral to treatment (RTT) times and be under pressure to allocate resources to meet this metric rather than the providing rapid appointments for EIA referrals. Some clinicians we spoke to found it difficult to justify prioritising referrals for suspected inflammatory arthritis, particularly when many patients turned out not to have EIA, because this may cause delays for other patients with other painful conditions. Almost two-thirds (65%) of patients referred as 'possible EIA' instead have other non-inflammatory conditions that may not have required rheumatology care.

¹⁵ NICE Spondyloarthritis Quality Standard [QS 170] www.nice.org.uk/guidance/qs170

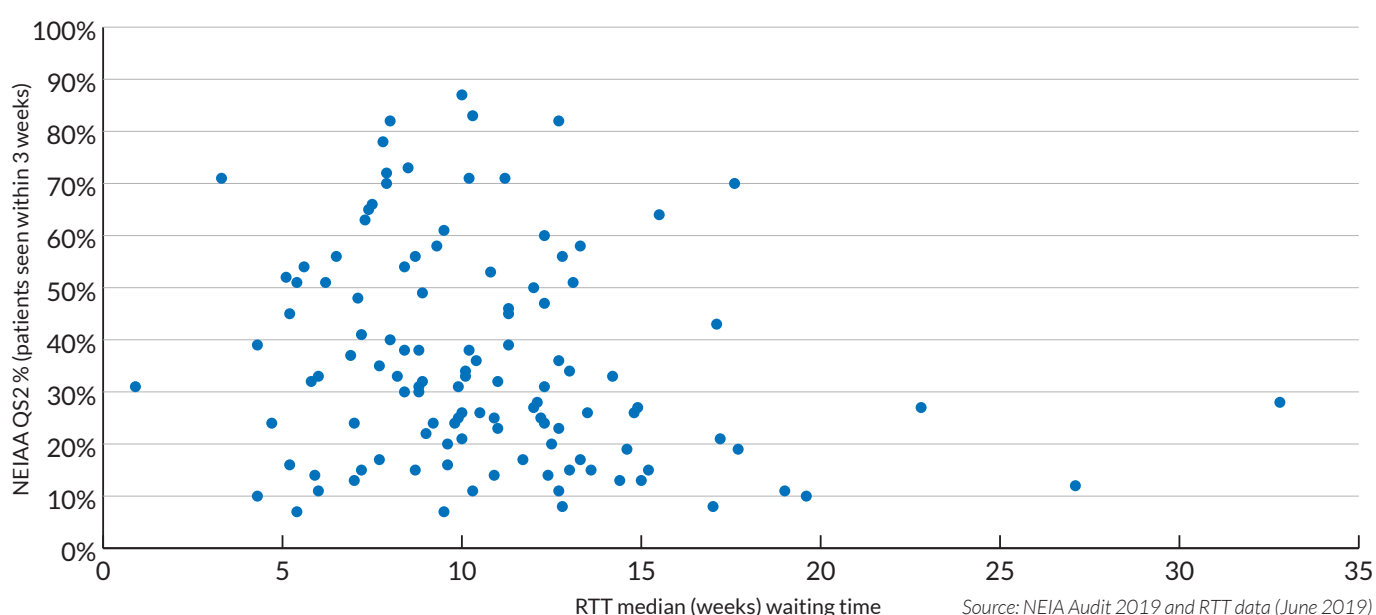
¹⁶ BSR National Early Inflammatory Arthritis Audit Report 2018-19
www.rheumatology.org.uk/Portals/0/Documents/Practice_Quality/Audit/NEIA/2019/NEIA_Audit_report_October_2019.pdf?ver=2019-10-08-103326-710

However, the target times exist because patients diagnosed with EIA will sustain lasting avoidable harm if their treatment is delayed. We do not have such strong evidence for many of the other painful conditions commonly referred to rheumatology.

Units should be aiming to achieve the three-week target for EIA and no more than eight weeks waiting time for all conditions – see Recommendation 2. The service reorganisation we propose in Recommendation 1 would be expected to help achieve these.

As shown in **Figure 12** below, some trusts that perform best on QS2 also have relatively low median RTT waiting times for rheumatology overall and there was no direct relationship between the two. This suggests that there is room for greater prioritisation for patients with EIA, providing they can be reasonably identified from the referral letter.

Figure 12: Relationship between performance against NEIAA quality standard 2 and median referral to treatment waiting times for all rheumatology



Why are GPs referring patients who do not have EIA?

Where referrals for suspected EIA are high, it may be that GPs find it difficult to establish whether a patient is likely to have EIA. They may be uncertain about which patients are most appropriate to refer for assessment and concerned about missing a diagnosis. On our deep-dive visits, we also heard of perceptions that GPs refer patients who are unlikely to have inflammatory arthritis because they will be seen faster if the referral letter mentions suspicion of EIA, and they are concerned that the patient should be seen quickly.

These issues highlight the need for rheumatology units to work more closely with primary care to improve local pathways, break down barriers and support good referral decisions.

Issues around RTT waiting times and triage are discussed further in *Supporting sustainable and equitable rheumatology services*, page 33.

Potential solutions: meeting quality standards

We think prioritisation of EIA could be improved by having clear and consistent referral criteria to support GP referral, or a decision not to refer, as well as working together with primary care to refine referral processes to improve local referral 'yields'.

As mentioned in *Improving management of referrals*, page 40, GPs who are not confident of a diagnosis may be able to get a second opinion from hospital-based specialists through an Advice and Guidance (A&G) service. This would help avoid unnecessary referrals where EIA is unlikely.

There is evidence from the NEIAA report for 2018-19 that units which have dedicated clinics for EIA perform better against the audited NICE quality targets than those which offer dedicated slots to EIA patients as part of larger clinics. The audit found that where dedicated EIA clinics existed, the probability of patients starting DMARDs in a timely manner increased by 12%, an average 18 days sooner compared to patients seen in a general rheumatology clinic. We think that trusts should model demand in their area and consider a dedicated clinic where local need allows.

If more non-inflammatory painful musculoskeletal (MSK) conditions could be redirected to another setting where they could be seen safely and more promptly closer to home, this would also create more capacity and allow faster pathways for the priority of inflammatory arthritis (see *Defining core services: a proposed service model for rheumatology*, page 37).

As discussed in *Improving management of patients being followed up*, page 43, patient education and changes in treatment pathways may also have a role to play in helping those already diagnosed with rheumatoid arthritis to manage their condition to prevent avoidable flares and reduce the need for unplanned outpatient appointments.

Participation in the national audit

As things stand, the NEIAA, which measures performance against referral and treatment targets for rheumatoid arthritis, is the only large scale means to measure the performance of rheumatology departments against quality standards, and to measure patient outcomes.

Until we can develop more routine ways of recording this information, it is vital that all units fully participate in the NEIAA, so we can understand what approaches are working well so we can improve policies and drive up the quality of care. This is particularly important given the lack of recording of diagnoses and outcomes in outpatients.

However, on our deep-dive visits (pre-COVID-19 crisis), we found considerable variation in the degree of participation in the NEIAA, with some units only enrolling a relatively small proportion of their eligible patients, or not enrolling from all clinic locations. We also found variation in the degree of individual clinician engagement with the audit within units.

Some units reported that they were struggling to collect and submit comprehensive audit data, often because of a lack of resource. Failure to comply with the audit is often associated with busy, fragile units where fewer staff are available to provide services. Trusts told us that participating in the audit was generating significant additional work which, in turn, puts added pressure on their departments and may have a knock-on impact on patients with other conditions.

Adequate resource should be provided by trusts to enable clinicians to enrol patients in the audit, to support evidence-based measures to help units meet the NICE standards. NEIAA performance could also be included in individual clinician performance metrics to ensure all clinicians participate, through the National Clinical Improvement Programme (NCIP). It could also be included in annual appraisals for consultants.

Routine use of coded diagnostic data in outpatients with routine recording of patient-related outcome measures could avoid the need for such burdensome separate data collection.

Recommendations: Improving early management of inflammatory arthritis

Recommendation	Actions	Owners	Timescale
9. Management of suspected early inflammatory arthritis (EIA) should be improved through clearer referral criteria, effective triage systems and adequate resourcing to meet patient needs and comply with the audited National Institute for Health and Care Excellence (NICE) quality statements.	a Develop standard nationally agreed referral criteria for suspected EIA, to support effective triage and evaluate them over time.	GIRFT, BSR	Within 18 months of publication
	b Liaise with primary care networks to review local referral rates/yield and refine referral processes in line with 9a to ensure patients are assessed within the three week target set by the audited NICE Quality Statement 2.	Trusts, PCNs, BSR audit	Within 6 months of 9a completion
	c Model demand and ensure there is adequate dedicated clinical resource to meet local patient needs, including dedicated EIA clinics where possible.	Trusts	Ongoing
	d Interrogate the audited NICE Quality Statement 3 performance data to assess and address root causes of delays in patients initiating treatment once diagnosed.	Trusts	Ongoing
10. Participation in the National Early Inflammatory Arthritis Audit (NEIAA) should be enhanced by considering how the audit could be integrated into routinely collected data for rheumatology services.	a Improve the quality of the electronic health record to allow for standardised data capture.	NHS Digital	Within 12 months of publication
	b Review administrative and audit resourcing to support full participation in the NEIAA.	Trusts	On publication
	c Review individual consultant recruitment to the NEIAA and discuss identified challenges/solutions.	Trusts	Within 6 months of publication
	d Consider including NEIAA performance metrics in the development of a National Clinical Improvement Programme (NCIP) portal for consultant rheumatologists.	GIRFT	Within 12 months of publication

Equitable access to specialised care for rare RMDs through regional networks

Patients with rare rheumatic and musculoskeletal disorders (RMDs) need specialised care, often involving co-ordinated multi-specialty assessment and high-cost drug therapies. These include:

- autoimmune connective tissue diseases
- vasculitis
- rare inherited and metabolic bone diseases

These conditions affect a small number of patients but can be very severe, have a much higher risk of mortality and morbidity than more common conditions, and are a source of high value claims against trusts – see *Reducing the impact of litigation*, page 123. Like many rare diseases, they can be difficult to diagnose and can present with non-specific symptoms. This can lead to delays in diagnosis and treatment, and potentially worse clinical outcomes and increased costs to the NHS.

Because of their rarity, it is not feasible for every rheumatologist to have the necessary ongoing clinical caseload experience and continuous specialist education to deliver the best possible care and outcomes for these conditions.

Specialised commissioning for rare RMDs

Since 2013, specialised rheumatology services for rare RMDs have been directly commissioned by NHS England, with the ambition to provide equitable access to specialised care everywhere in the country, based on a service specification which defines the core standards of care.

NHS England's intention is that specialised centres, which have the highest concentration of clinical expertise and experience in these conditions, should provide leadership and clinical advice to all other non-specialised trusts in their region, and act as hubs for research and innovation, as well as providing the specific clinical services outlined in the service specification. A key aim is to ensure equitable access for patients with rare RMDs to expert assessment and specialist treatments, with reduced need to travel to specialised centres.

On our deep-dive visits, we found that specialised commissioning for rare RMDs is working well in some areas. However, we also found significant variations in how it is being implemented across the country, and some areas where there has been no change from pre-existing informal arrangements.

Variation in service provision

There is considerable variation in how services are provided and who provides them. In some trusts there are clinicians who sub-specialise in rare RMDs, providing clinical expertise within their own trust, and sometimes also regionally and nationally, as envisaged in the service specification.

However, in other trusts, care is provided by every rheumatologist with no sub-specialisation. This was reflected in our questionnaire. When asked 'Do you have a lead clinician for connective tissue diseases and vasculitis?' 54% of the 143 trusts that responded said yes.

We also asked 'Do you have a dedicated specialist nurse for connective tissue diseases and vasculitis?' – only 23% of 142 trusts who responded said yes. This finding was reflected in a survey of patients carried out by the Rare Autoimmune Rheumatic Diseases Alliance (RAIRDA) in 2018¹⁷. Only a third of respondents said their care was supported by a specialist nurse.

Dedicated clinics, which are associated with greater guideline compliance¹⁸, and combined clinics with other specialties to improve co-ordination of care, are also not provided consistently across regions. We found that patients in some areas have problems accessing such a clinic.

¹⁷ RAIRDA Reduce, improve, empower: addressing the needs of autoimmune rheumatic diseases
<https://rairdaorg.files.wordpress.com/2019/12/rairda-survey-report-2018.pdf>

¹⁸ Pearce FA, Rutter M, Sandhu R, et al. BSR guideline on the management of adults with systemic lupus erythematosus (SLE) 2018: baseline multi-centre audit in the UK. *Rheumatology* (Oxford). 2020 Dec 8;keaa759. doi: 10.1093/rheumatology/keaa759.

Variation in data collection

Specialised healthcare providers are required to submit data each quarter to the Specialised Services Quality Dashboards (SSQD), whose metrics are designed to provide assurance on the quality of care.

However, we know from our data and our deep-dive visits that this is not happening consistently, with not all specialised centres completing dashboard returns in 2019. The main barriers trusts cited were that data collection is time consuming, requires manual identification of individual patients and outcomes at trust level, and submission of data every quarter.

It is unclear whether the SSQD data has led to improvements in service quality, which may be related to issues around data collection.

This lack of any routinely collected data makes it very difficult to plan how to improve clinical services at local and regional level. Without any process for collecting and comparing clinical and patient-reported outcomes, such as a national audit, we cannot establish whether the care being provided at every trust is equitable.

Variation in waiting times

Within the submitted SSQD data for 2019, we found significant variation in reported waiting times for the first routine appointment in a specialised clinic. There also appeared to be longer waiting times for patients referred from secondary care, averaging 58 days, compared to a 36-day average wait for patients referred from primary care. This is a concern given that these referrals are likely to be from colleagues in non-specialised centres, potentially leading to delays in specialist advice about treatment. Multidisciplinary team meetings, in person or virtual, with properly functioning networks, might reduce the need for such referral and reduce delays to decisions and treatment.

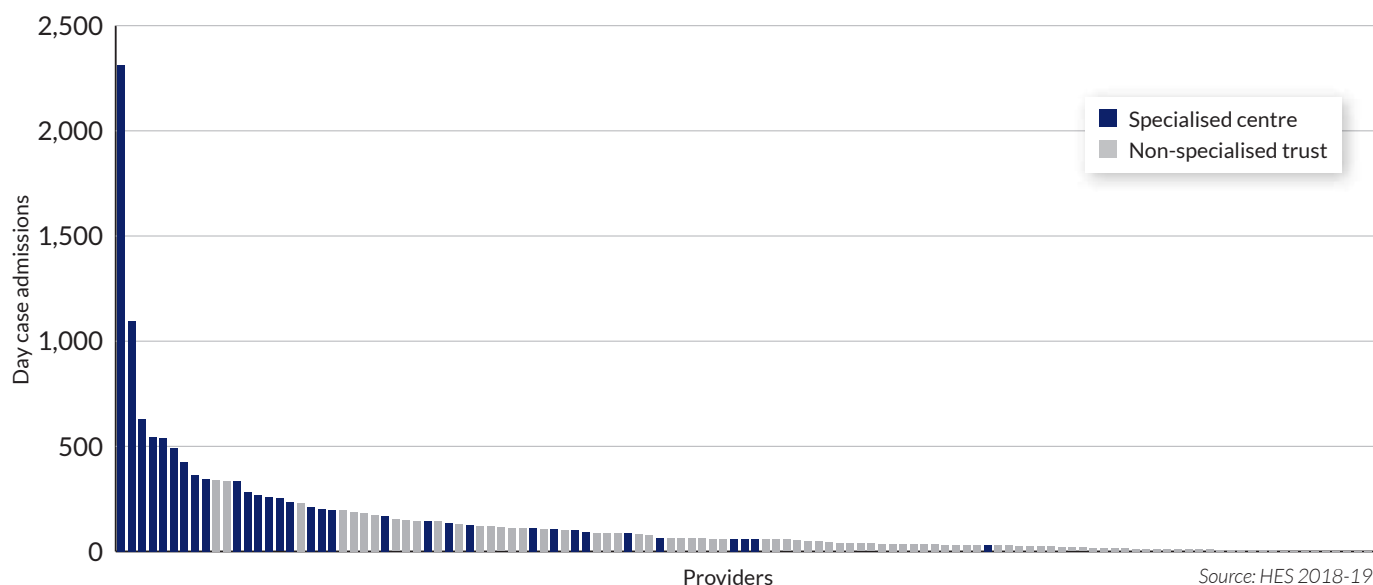
Variation in activity between specialised and non-specialised trusts

We found that, as expected, nine of the top 10 units with the largest volumes of specialised rheumatology day case activity were on the NHS England provider eligibility list (PEL) list of specialised centres. However, as shown in **Figure 13**, 88 non-specialised providers had recorded some specialised rheumatology activity (at least one day case admission), while 72 non-specialised providers had more than 10-day case admissions.

While we recognise that it is appropriate for patients to be treated locally where possible, clinical services which provide larger volumes of care for rare diseases are likely to deliver better outcomes¹⁹ and comply with best practice guidelines, as highlighted in the British Society for Rheumatology lupus audit (2018)¹⁸. Specialised centres would expect to see in the range of 250-500 specialised day case admissions a normal year, though we understand this has not been possible during COVID-19.

We also need to ensure that outcomes are consistently good regardless of where patients are treated. Specialised rheumatology networks are an essential component in ensuring this happens (see below).

Figure 13: Specialised day case admissions²⁰ by type of provider, specialised and non-specialised



¹⁹ NHS England (2013) Service specification for specialised rheumatology services (adult) www.england.nhs.uk/wp-content/uploads/2013/06/a13-spec-rheumatology.pdf

²⁰ Specialised activity data was defined as rheumatology day case care where the primary diagnosis was a condition within the NHS England Specialised Rheumatology Services (Adult) Service Specification.

The role of specialised rheumatology clinical networks

Specialised rheumatology networks were developed as part of an NHS England Quality, Innovation, Productivity and Prevention (QIPP) scheme begun in 2015-16, designed by the Clinical Reference Group (CRG) for specialised rheumatology. This was supported by financial incentives under a Commissioning for Quality and Innovation (CQUIN) framework between 2016-19.

The intention was that each of the 12 previous NHS regions in England would have a network. Each network would ensure equitable access to specialised care for rare RMDs across the geographical area, linking all specialised and non-specialised rheumatology units to bring uniformity in standards of care and outcomes for patients. Networks also have an important role in overseeing the use of high cost treatments, which the commissioning policy requires to be given at, or in discussion with, a specialised centre.

Networks should also link across specialties and externally with primary and community care to ensure that patients are referred appropriately and receive the right care in the right setting as outlined in the NHS England service specification. Integrated care systems (ICS) should help facilitate this way of working.

However, we have found significant variation in how networks have developed and trust engagement with them, both within and between regions, as shown in **Figure 14**. The green dots show specialised centres and the blue dots trusts that are part of a network, indicating an uneven spread of specialised centres and participation in networks across the country. Several specialised centres are not part of a network, as shown by the orange dots on the map. This is at odds with original vision that specialised centres would be at the hub of regional networks. **Table 2** shows a full breakdown of specialised centres and network participation by region.

Variation in network reach, participation and operation

In our questionnaire, a third (33%) of the 139 trusts who answered said they were not part of any formal network for specialised services that meets regularly. There is wide variation. In some regions, participation is high. For example, in the East of England 94% of trusts say they are part of a network. In other regions, participation is low, at 33% in the North West and 26% in London.

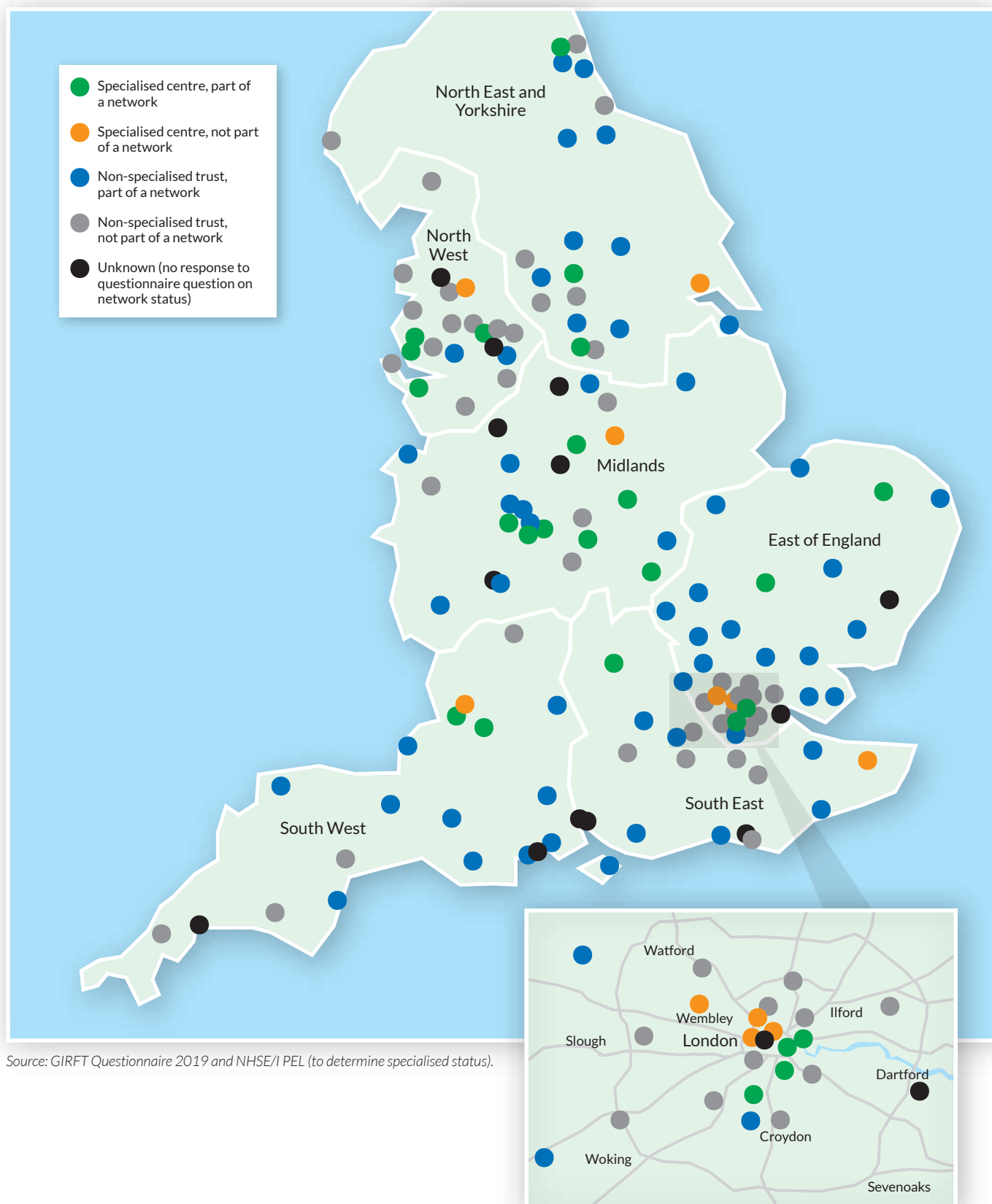
Where networks are established, they do not appear to have a consistent structure, with varying levels of engagement and interaction both within and between regions.

Increasing access through virtual MDTs

Remote meetings can enable joint working across a network. Virtual MDT meetings can be a forum for co-ordinating the delivery of care across a region and making decisions, such as ratifying high cost drugs and considering how to manage highly complex cases. In this way, they can reduce the need for patients to travel to a specialised centre in some cases.

However, some trusts told us that patients are sometimes waiting longer than they should to access specialist advice and treatment because there is no formal mechanism for cases to be discussed at virtual MDT meetings rather than attending an appointment at the specialised centre. This can lead to delays in approval for initiation of high-cost drug treatments locally.

Figure 14: Variation in existing rheumatology networks across England



Source: GIRFT Questionnaire 2019 and NHSE/I PEL (to determine specialised status).

Table 2: Regional variation in organisation of rheumatology networks

NHS region	Trusts in region	Trusts in region with 'specialised' status	Trusts which reported being part of a network	% of trusts in region with 'specialised' status	% of trusts within the region which reported being part of a network
East of England	17	2	16	12%	94%
South West	19	3	12	16%	63%
Midlands	26	8	16	31%	62%
North East & Yorkshire	23	4	14	17%	61%
South East	22	3	11	14%	50%
North West	21	6	7	29%	33%
London	19	8	5	42%	26%

Gaps in quality assurance, leadership and oversight

The sharing of knowledge and guidance needed for networks to work effectively is patchy. In our discussions with trusts, we found that not all specialised centres appear to take leadership responsibility for working collaboratively within the trust and with other acute hospital providers to support best practice for each rare RMD sub-specialty.

We understand from our deep-dive discussions that:

- In some regions, specialised networks have yet to be established.
- In many areas, policies and procedures governing how trusts should work together, including for the care of acutely unwell patients who need specialised centre care, are not formalised; there is often no clear expectation of when clinical cases should be discussed in a network and what support other trusts in the network should expect from the specialised centre.
- Some referral pathways are not clearly defined.
- Some specialised centres are reliant on a single individual, who has expertise in a subset of conditions, with no resilience when they are on leave.
- Information on the number of people with rare diseases treated in each trust is often not available to support service planning.
- Data on clinical outcomes is not being collected, shared or reviewed in a consistent way to enable service improvement.
- In some trusts, patients treated with high-cost drugs are not being enrolled into relevant research registries, which is a requirement of the NHS England clinical commissioning policy. Patients with rare RMDs should also be considered for clinical trials, if appropriate, so they can benefit from the latest treatments early.
- Some patients treated with high-cost drugs at non-specialised centres have not been discussed with a specialised centre, which is a requirement of the commissioning policy.
- In general, the networks that exist are focused on rare autoimmune disease, with no similar structures consistently in place for the rare bone and inherited connective tissue conditions.

These issues make it difficult to measure the effectiveness of the networks and whether patients are getting equitable access to the specialised medical care and expertise that they need. This is needed to assess whether NHS England's specialised services commissioning has led to improvements in clinical care and outcomes for people with rare diseases.

Proposed key principles of an effective network

- clearly identified hub and spoke arrangement including all local departments
- clear links with other relevant specialties
- clear referral pathways (emergency, urgent and non-urgent)
- regular virtual multidisciplinary team meetings
- shared assessment and treatment protocols
- a named network co-ordinator
- a named responsible clinician at each centre that offers care for rare RMDs
- collection of specified data (for the dashboard) with regular local review
- entry of suitable patients into specified trials/registers
- continuous quality improvement
- job planning for network roles
- training opportunities for all disciplines

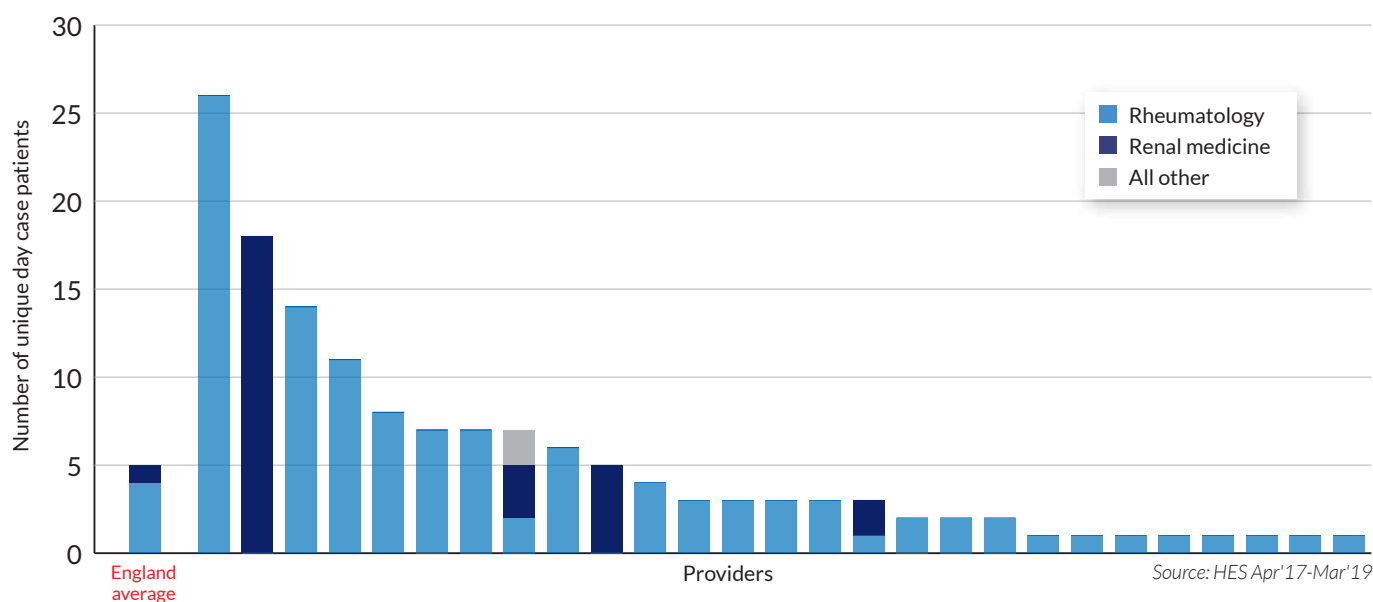
Equitable access to specialised drugs for rare diseases

Variation in uptake of belimumab into NHS practice

Belimumab is a major innovation in the treatment of systemic lupus erythematosus (SLE) and is the first new drug to be licensed for this condition in the past 50 years. After a lengthy technology appraisal process, belimumab was approved by National Institute for Health and Care Excellence (NICE) as a treatment option in 2016. It was anticipated that 300 patients would be treated by 2020. NHS England requires that treatment must be given at a specialised centre.

To estimate belimumab use, we counted the number of patients in HES who had a diagnosis of SLE and an Immune Response Drugs Band 1a procedure code. Of the five drugs within this code, belimumab is the only one administered for SLE. Our analysis shows that in the two years to March 2019, only 143 day case patients had received treatment with belimumab across both rheumatology and renal specialties, as shown in **Figure 15**, much lower than anticipated. We found that the treatment has only been used at 27 trusts. As a result, there are concerns that not all patients eligible for treatment may have received it.

Figure 15: Estimated numbers of unique patients receiving treatment with belimumab at 27 centres with reported activity by treating specialty



In our deep-dive visits we found that the requirement for belimumab to be administered at a specialised centre was a contributory factor leading to geographical inequity, affecting the speed of uptake of this innovation into NHS care. This is because patients eligible for belimumab have very active disease, may be frail, and the travel times to specialised centres, particularly from rural areas, is significant. We were told about examples where this had led to patients who may have been eligible to receive belimumab not accessing this and being treated with other agents instead, which can be delivered locally without the need to travel.

A subcutaneous version of belimumab was introduced for some established patients during COVID-19, which may help avoid the need to travel to a specialised centre if its use is extended in the longer term.

Variation in use of rituximab for lupus and vasculitis in specialised and non-specialised centres

NHS England commissions the use of rituximab for refractory SLE in adults at, or in collaboration with, a specialised centre, and for anti-neutrophil cytoplasmic antibody (ANCA)-associated vasculitis (AAV), which does not require specialised centre involvement for remission induction treatment.

To look at how much of this drug is being administered, we identified in HES any day case or inpatient admission with a diagnosis of either SLE or vasculitis who had a procedure code of an infusion of a cytokine inhibitor drugs Band 1. This code also includes other drugs (infliximab, tocilizumab, abatacept) so while the most likely agent used for these conditions within this code will be rituximab, this is an estimate (see *Coding of diagnoses and casemix*, page 88 for a more detailed analysis). We note that where drug administration is not the primary reason for the inpatient admission it may not be coded, so our data may be an under-representation.

Figure 16a, and **16b** show the variation in rituximab use, comparing specialised centres that are on the NHS England specialised commissioning PEL with non-specialised trusts.

The charts indicate that rituximab is used widely for SLE (86 trusts) and for vasculitis (in 104 trusts). This is a reflection of the NHS England policies enabling treatment to be given locally. As expected, use is concentrated in specialised centres – for example, the ten trusts with the highest rituximab use for SLE account for more than 60% of total volumes.

This is likely to represent use both for their local population and also tertiary referrals from other trusts in the region and beyond. From discussions on our deep-dive visits, we understand that some specialised centres are providing similar regional and supra-regional services for other equally rare diseases, such as myositis, but without any formal designation. This means that trusts aren't always recognised for or aware of the importance of the sustainability of their specialist services as a regional-level resource.

The data shows significant variation in use between specialised and non-specialised trusts. Many non-specialised units use very little rituximab, while some non-specialised centres have larger use than specialised centres. We think that this may be worth review, including a look at into litigation claims, to understand the reasons for the variation and whether all patients are getting appropriate access to the right treatment. This data could also inform discussions about specialised provider eligibility status.

The charts also illustrate that, in some trusts, patients with these conditions are more commonly being treated by renal units. Overall, 22% of the total use of rituximab for SLE and 32% of rituximab use in vasculitis occurs within nephrology. This highlights the multi-system nature of these conditions and the importance of having agreed co-ordinated pathways of care between specialties for these patients to ensure the service is delivered in a timely way and to the same standard. It also illustrates the need and opportunity to share expertise between specialties in the specialised rheumatology networks.

Figure 16a: Estimated use of rituximab for treatment of lupus by treatment specialty, specialised centres on the specialised commissioning PEL vs non-specialised trusts

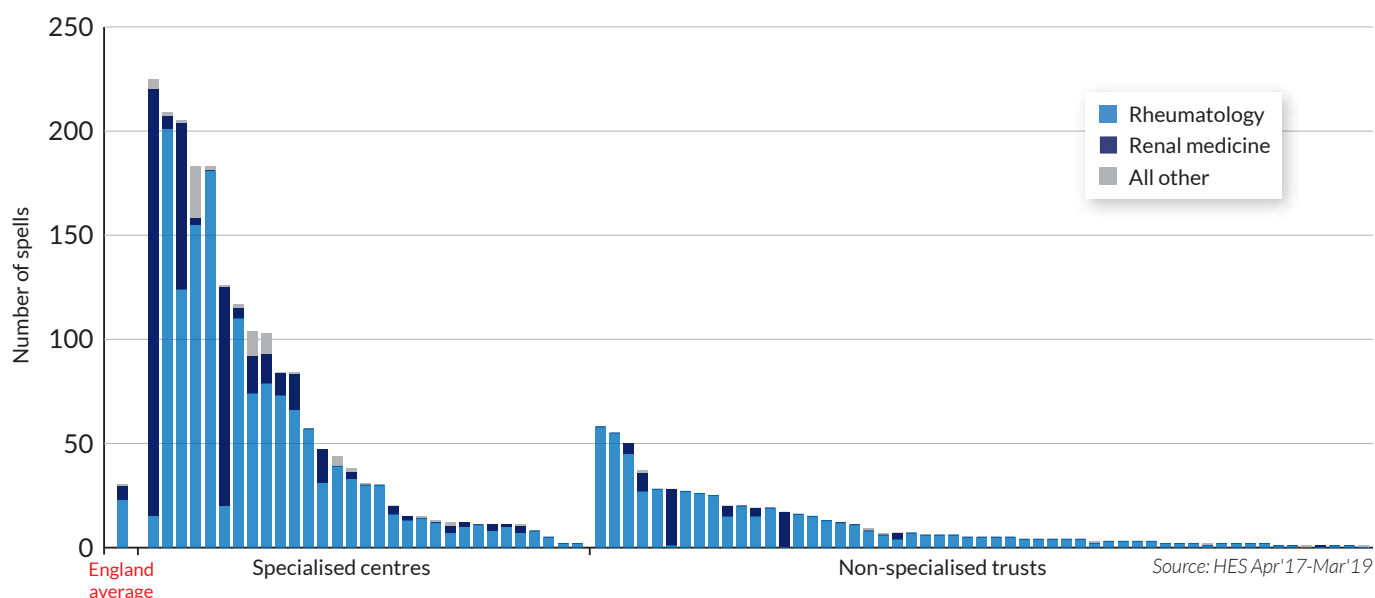
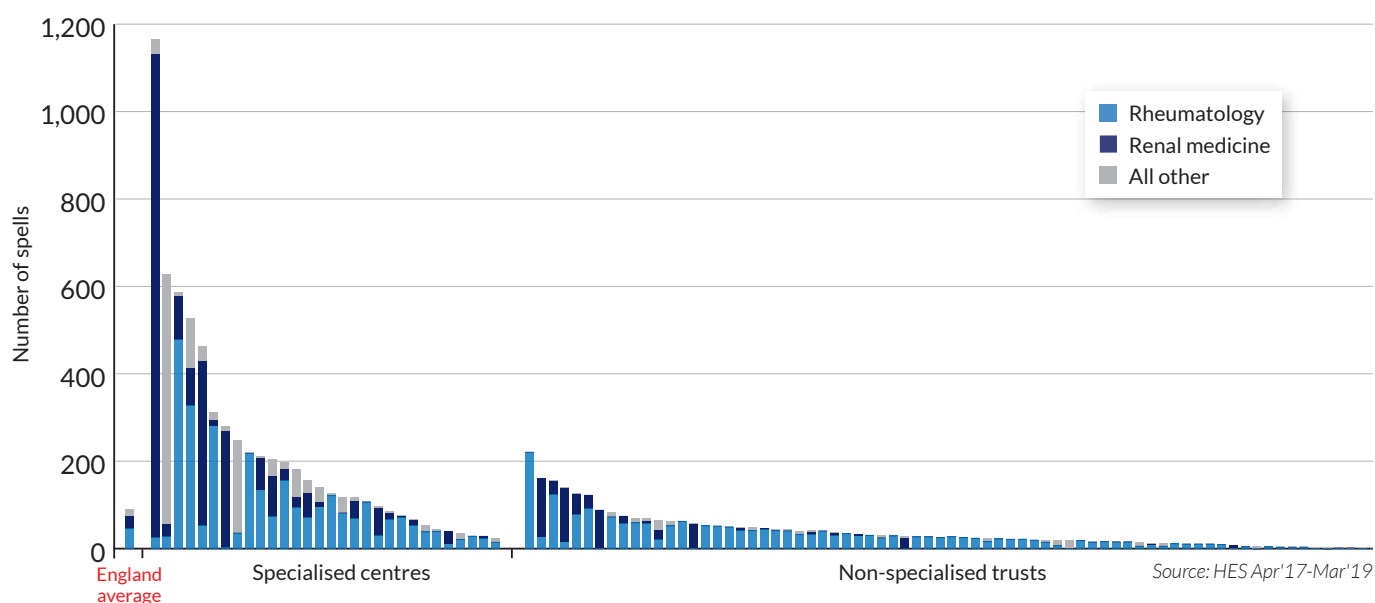


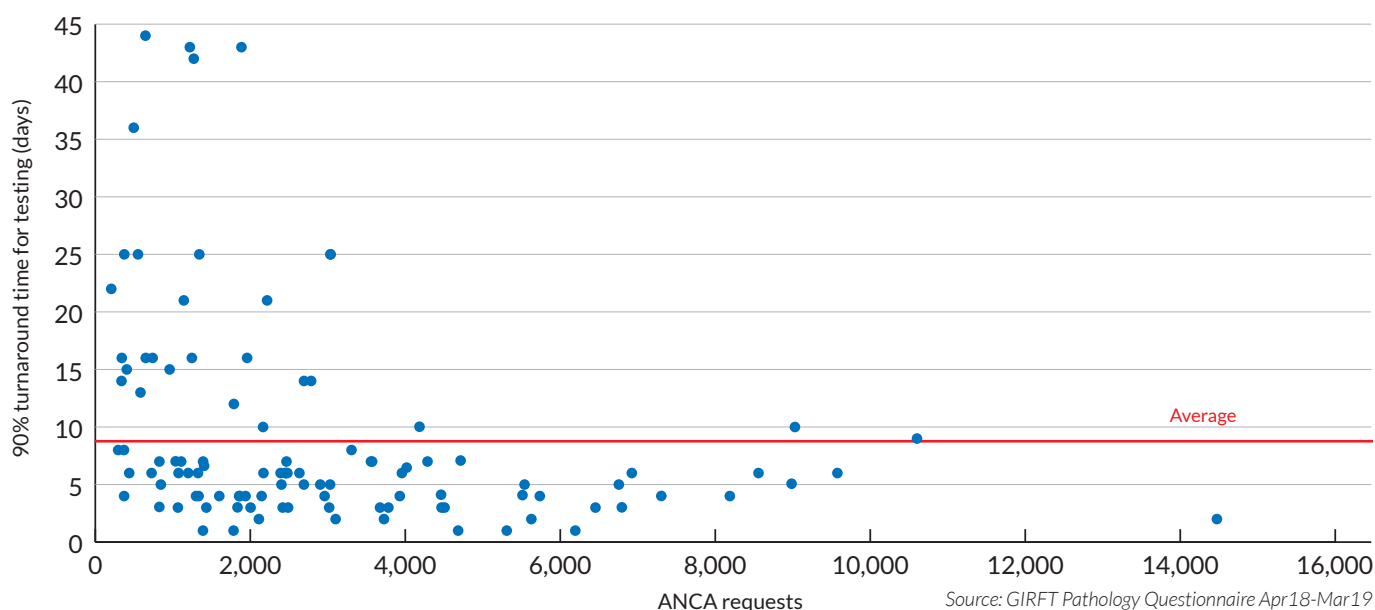
Figure 16b: Estimated use of rituximab for treatment of vasculitis by treatment specialty, specialised centres on the specialised commissioning PEL vs non-specialised trusts



Variation in speed of reporting of diagnostic tests

The GIRFT pathology workstream collected data on the number of anti-neutrophil cytoplasmic antibodies (ANCA) tests carried out to support diagnosis of ANCA-associated vasculitis (AAV). They found that 340,178 ANCA tests are carried out each year. They also found variation in time to reporting. For ANCA, the target in the BSR guidelines is one working day – however, according to the 101 responses to the GIRFT pathology questionnaire only seven trusts are currently achieving this, which is likely to lead to delays in diagnosis and treatment initiation.

Figure 17: 90% ANCA turnaround time against number of tests requested (self-reported)



The need for better management of rare and complex RMDs

The findings outlined above from our questionnaires, activity data, and deep dives, indicate that there is often lack of oversight and responsibility for outcomes for some of the most complex and life-threatening rare RMDs on a regional or national basis. The aims of NHS England's specialised commissioning strategy have not yet been met.

Lack of network development and engagement is limiting the ability to increase skills in case management. There is also insufficient accountability for the administration of high cost drug treatments through virtual regional MDT meetings.

Although most of our data relates to rare autoimmune disease, the principles will also apply to other rare conditions of bone and inherited connective tissue – we were unable to look at this in detail because we were unable to identify the data in HES.

We are aware of at least one litigation claim related to the death of a patient with rare and complex rheumatic conditions in a non-specialised centre. We think it merits further investigation whether better network support and earlier involvement of specialised centre expertise might help to avoid such cases, or might at least provide assurance that all possible opportunities to provide appropriate care have been taken.

Potential solutions: strengthening specialised networks

Trusts need to work more collaboratively to improve access and deliver optimum care to patients with rare and complex conditions, as well as ensuring that rheumatologists working in smaller units are able to seek advice from specialised centres where needed.

To address these issues, we believe that the development of specialised rheumatology networks in each region needs to be accelerated, aligned to existing best practice models. This should be led by specialised centres at the centre that take responsibility for outcomes across the footprint and promote joint working and shared decision making with spoke units in their region.

Robust governance structures with shared standards need to be implemented to help networks operate more effectively, supported by memoranda of understanding between all trusts in each region, to ensure consistency of network operation.

This may require some additional investment in administrative staff and recognition of this important additional clinical activity in consultants' job plans in both specialised and non-specialised units.

Potential solutions: data collection and quality

Data collection required for quality dashboards could be made less burdensome if relevant metrics were fulfilled from existing data, such as the Hospital Episode Statistics database. As discussed in *Improving data and coding to support service planning*, page 58, the quality of this data could be further refined by using clearer terminology, based on SNOMED clinical definitions to map into International Classification of Diseases (ICD10) diagnostic codes. Where bespoke data needs to be collected, this should be incorporated into standard clinical practice.

Data quality could also be improved by collaborating with the National Disease Registration Service (NDRS), which has a data liaison team that could work with trusts and NHS England and NHS Improvement to enable automated reporting to the national rare disease register. This will support improvements in care by enabling identification of geographical variation in high cost drug treatment, care and outcomes as well as auditing of quality standards. NDRS also offers a pathway toolkit²¹, which can track patients from first presentation and diagnosis through to treatment and outcomes irrespective of where they are seen in the NHS. This is currently available for cancer and could be explored for use with rare RMDs.

Potential solutions: remote access and advice

We think there is great potential for virtual meetings to support access to specialised services. As well as enabling regional MDT meetings without the need to travel, online platforms can allow specialised consultants to join local consultations and clinics by video to give opinions and advise clinicians in non-specialised centres.

Given the issues we have identified with access to some services, advice helplines are a vital resource for patients with rare RMDs. No routine data is collected about helpline usage and so we were unable to quantify current provision. We think these should be available to all patients who need them regardless of geography.

Extending the remit of rheumatology networks

Once effectively refreshed or established, we believe the same principles that guide specialised networks should be applied on a whole system basis – so that all patients with conditions that require care from a rheumatologist, not just those that are specially commissioned, can access that care seamlessly regardless of geography. We think these networks should operate on the same regional basis as specialised networks, possibly based on an ICS footprint, to ensure raised standards across the board and greater equity for patients. We recommend that such networks develop and work to shared standards and pathways, for example for early inflammatory arthritis and safety monitoring for disease-modifying anti-rheumatic drugs (DMARDs) and biologics. This is something the GIRFT team will explore in collaboration with the NHS England and NHS Improvement Clinical Reference Group and British Society for Rheumatology.

²¹ <https://healthdatainsight.org.uk/project/pathway-toolkit/>

Recommendations: Equitable and sustainable access to care for rare RMDs through regional networks

Recommendation	Actions	Owners	Timescale
11. All rheumatology units providing care for rare rheumatic and musculoskeletal disorders (RMDs) should collect data on care, caseload and outcomes for people with rare RMDs, using routinely collected data where possible to reduce burden of clinician data collection and submission.	a Reduce the burden of specialised commissioning quality dashboard data collection by aligning metrics to data that is already collected as part of standard practice.	NHSE/I Spec, Comm, GIRFT, networks, CRG	Within 18 months of publication
	b Ensure that all rare RMDs are included in data collection.	Networks, NHSE/I, Spec Comm, Trusts, CRG	On completion of 11a
	c Use audit, and dashboard data where appropriate, to understand how care is being delivered and develop quality improvement tools to improve outcomes.	BSR, NHSE/I, Spec Comm/ specialised centres, CRG	On completion of 11b
	d Promote national rare disease registration with the National Disease Registration Service (NDRS) to facilitate use of routinely collected healthcare data to support high quality care and service planning, and consider adapting the NDRS pathway toolkit for rare RMDs.	NHSE/I, NDRS, NHSE/I, Spec Comm, Specialised centres, CRG	Within 12 months of publication
12. People with rare RMDs should have rapid access to specialist expertise and effective treatments to ensure equity of outcomes regardless of geography and reduce the risks of morbidity and mortality.	a Identify responsible clinicians and lead nurses/allied health professionals in each trust offering care for rare RMDs, to co-ordinate care for each main category of specialised rheumatology: connective tissue diseases, vasculitis, and rare metabolic bone diseases.	Trusts, networks, NHSE/I, Spec Comm, CRG	Within 6-12 months of publication
	b Ensure effective co-ordination of care across all specialties as required.	Trusts, CRG, NHSE/I, Spec Comm	On publication
	c Develop analytical approaches to identify geographical variation and potential health inequality in the use of high cost drug treatments for rare RMDs and the application of national commissioning policy criteria, including treatment initiation at specialised centres.	NHSE/I, Spec Comm, CRG	Within 12 months of publication
	d Develop a National Institute for Clinical Excellence (NICE) Quality Standard for rare RMDs based on the new NICE-accredited British Society for Rheumatology (BSR) guidelines on care of rare RMDs.	NICE, CRG, NHSE/I, Spec Comm	Within 2 years of publication
	e Investigate apparent differences in diagnostic reporting times, for example related to anti-neutrophil cytoplasmic antibody (ANCA).	Trusts, regional networks	Within 6 months of publication
	f Investigate if care and outcomes for rare diseases differ between specialised and non-specialised centres and consider how to support units with low activity volumes to consolidate services across regions.	GIRFT, NHSE/I, Spec Comm, CRG	Within 12 months of publication
	g Investigate if litigation and claims for rare diseases differ between specialised and non-specialised centres.	NHS Resolution, NHSE/I, Spec Comm, CRG	Within 12 months of publication
	h Continue to implement NHS England and NHS Improvement's COVID-19 prioritisation.	Trusts, NHSE/I, Spec Comm, CRG	Ongoing

Recommendations: Equitable and sustainable access to care for rare RMDs through regional networks

Recommendation	Actions	Owners	Timescale
13. The structure, operation and geographic reach of specialised rheumatology networks should be reviewed and improved to ensure equitable, sustainable provision of specialised care for rare RMDs across and between regions.	a Mandate the delivery of effective specialised networks in each region, including principles, standard operating procedures and memoranda of understanding, building on existing best practice.	NHSE/I, Spec Comm, GIRFT, BSR, CRG	Within 12 months of publication
	b Establish a mechanism to ensure that all trusts with specialised centre status make full dashboard returns and meet the terms of their service specification, and report on progress in achieving these requirements.	NHSE/I, Spec Comm, GIRFT, CRG	Within 12 months of publication
	c Ensure that each specialised network holds regular virtual multidisciplinary team (MDT) meetings, including review of complex cases, to enable timely decision making and ensure patients do not have to travel to the specialised centre unnecessarily.	NHSE/I, Spec Comm, CRG	Within 12 months of publication
	d Review the provider eligibility list (PEL) of specialised centres to ensure it reflects current organisation of specialised services.	Trusts, NHSE/I, Spec Comm, CRG	Within 6 months of publication
	e Consider new models for specialised commissioning of rare RMDs.	NHSE/I, Spec Comm, CRG, BSR	Within 2 years of publication

Optimising diagnosis and treatment of GCA

Giant cell arteritis (GCA), also known as temporal arteritis, is a relatively rare condition involving inflammation of arteries, particularly in the scalp, neck and arms. It can be difficult to diagnose as GCA symptoms, such as headache, scalp tenderness, jaw and tongue pain, visual loss and double vision, can mimic other conditions, leading to diagnostic delay. It is a medical emergency because if left untreated GCA can lead to occlusion of arteries, causing irreversible sight loss.

All patients strongly suspected to have GCA should be:

- immediately treated with high-dose glucocorticoids;
- evaluated by a specialist, ideally on the same working day, and in all cases within three working days, according to the National Institute for Health and Care Excellence (NICE)-accredited British Society for Rheumatology Guideline on diagnosis and treatment of GCA²² published in early 2020;
- given a confirmatory diagnostic test, either a biopsy of the temporal artery or an ultrasound of the temporal and axillary arteries, or both.

GCA can present acutely to many different departments within a hospital including rheumatology, ophthalmology, A&E, acute medicine, neurology, geriatrics and stroke medicine. It is therefore essential that each trust has a defined pathway of care to enable all frontline clinicians to initially manage and refer patients with suspected GCA for urgent evaluation by a clinician with appropriate specialist expertise. This will usually be a rheumatologist, although patients with visual symptoms will need same day ophthalmology assessment.

What we found: variation in GCA pathways

We have found considerable variation in the management of GCA. In our questionnaire, although over 80% of the 140 trusts that responded indicated that rheumatology was the primary point of referral for GCA, one third (33.6%) said they had no formal clinical pathway for this condition.

Among the GCA pathways that trusts submitted to GIRFT, we found substantial variation in their content, including when GCA should be suspected, how it should be treated and the timescale for diagnostic tests. This is worrying given the risk of potentially avoidable visual loss if people with suspected GCA are not treated and evaluated rapidly – and also the potential costs. We also found examples of pathway variation when reviewing GCA-related litigation claims (see *Reducing the impact of litigation*, page 123).

Difficulties in establishing a pathway

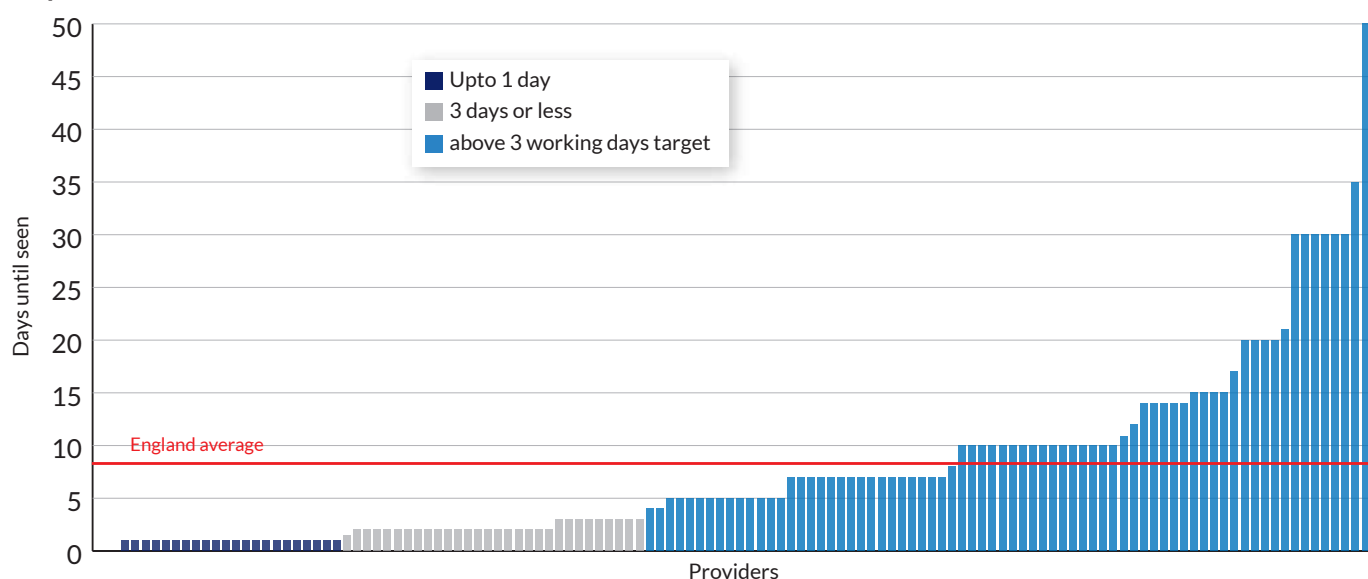
We heard in our deep-dive discussions that establishing an effective pathway for GCA can be challenging. Firstly, the symptoms of headache and facial pain can mimic other conditions, so GCA may not be suspected. Some clinicians also expressed the view that GCA pathways need to avoid becoming a rapid access service for patients with non-GCA related headache, which rheumatologists may not be appropriately equipped to assess.

Other reasons cited were the complexity of creating pathways across departments, for relatively uncommon but urgent events, particularly for rapid delivery of confirmatory diagnostic tests.

We also found variation in how rapidly rheumatology services are seeing patients with suspected GCA. More than half reported taking longer than three days to see patients (the minimum target), as shown in **Figure 18**, with patients waiting more than 30 days in the worst performing trusts.

²² Sarah Mackie, Christian Dejaco, Simone Appenzeller et al British Society for Rheumatology Guideline on diagnosis and treatment of giant cell arteritis *Rheumatology* 2020;59:e1–e23 <https://doi.org/10.1093/rheumatology/kez672>

Figure 18: Proportion of rheumatology units meeting the waiting time target for evaluation by a specialist for suspected GCA



Source: GIRFT questionnaire 2019 responses to 'What is the average delay (in working days) between referral for GCA and the patient being seen in rheumatology?'

Confirmatory diagnostic tests

The BSR guideline states that patients with suspected GCA should have a confirmatory diagnostic test, either a temporal artery biopsy or an ultrasound of the temporal and axillary arteries, or both. This is important to ensure that patients receive the urgent treatment they need, while avoiding the considerable risks of over-treatment with high-dose drug therapies for people who do not turn out to have GCA.

Temporal artery biopsy (TAB)

Each year, approximately 4,300 temporal artery biopsies are performed in England, with numbers consistent over last five years. However, we found variation in ease and speed of access to TABs, and which specialty is performing them. In responses to our questionnaire, 44% of trusts said they are performed by vascular surgeons, while 36.4% said ophthalmologists, with the rest distributed among other specialties. In some instances, trusts reported difficulties in access to biopsy because vascular surgery services had been relocated into regional networks. Timely access to TAB has also been more difficult during COVID-19.

There is also wide variation in the time taken to deliver biopsy results. The questionnaire sent to trusts as part of the GIRFT pathology workstream asked trusts 'what is your turnaround time in days from receipt to final report for 90% of results?' for April 2018 to March 2019. The responses ranged from 1 to 77 days, with an average of 9.2 days and a median of 7 days.

Temporal artery ultrasound

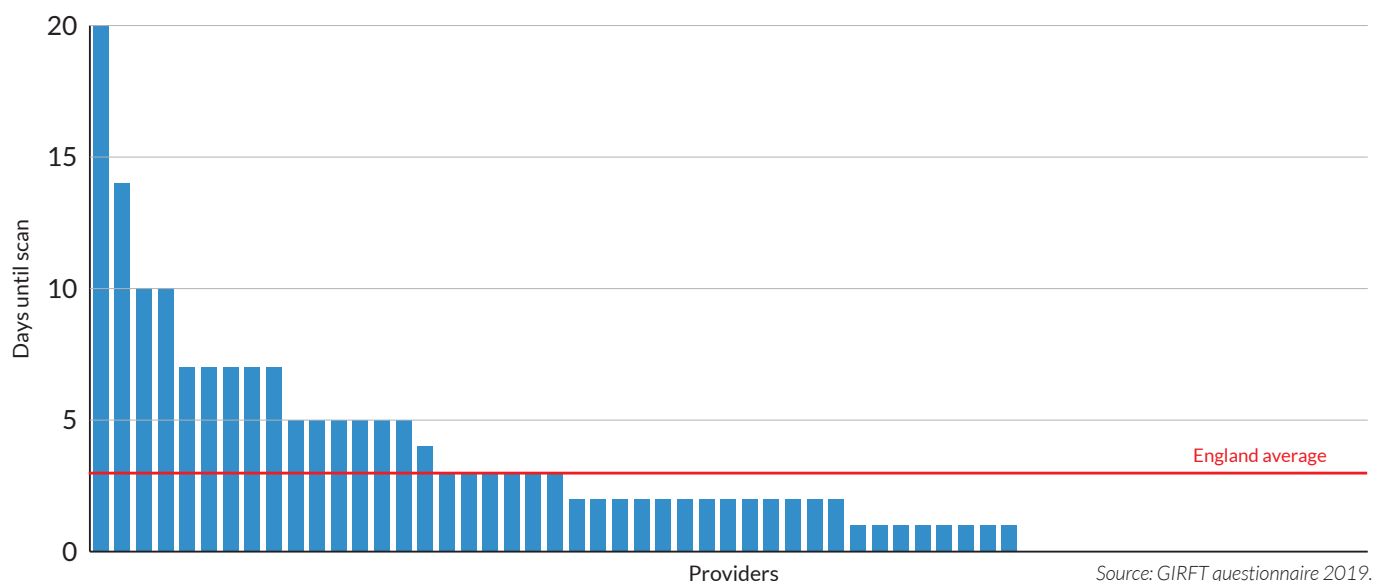
This is a relatively new diagnostic test that can be performed rapidly and is cheaper and less invasive than biopsy. Studies have found that ultrasound, in skilled hands, is more sensitive but less specific than biopsy for diagnosis of GCA. It provides a cost-effective opportunity for reducing the number of patients who need a temporal artery biopsy. Ultrasound is particularly useful for ruling out GCA in low-probability cases or for confirming GCA in high-probability cases. Some patients with suspected GCA will need to proceed to a biopsy, so it does not completely replace this need.

Variation in ultrasound access and pathways

We found that many trusts are struggling to establish a clear pathway using temporal artery ultrasound for GCA. Our questionnaire data indicates this service is currently being provided in 49% of trusts, leading to geographical variation in access.

Where ultrasound is offered, there is variation in speed of access, with patients in some trusts waiting up to 20 days for a scan while other trusts provide access the same day, as shown in **Figure 19**. Ultrasound needs to be done rapidly, shortly after initiating steroid treatment to ensure accurate diagnosis.

Figure 19: Length of delay in days between rheumatology assessment and ultrasound scan for GCA in trusts with reported access to ultrasound (based on the 59 trusts who submitted this data)



We also found variation in which specialty performs the procedure between radiologists, rheumatologists or vascular sonography technicians. There is likely to be variation in training, maintenance of competency and image reporting and storage (see *Governance of ultrasound with MSK and GCA*, page 81).

In some trusts we visited where the service was provided by rheumatology, we found it was reliant on one or two individuals, and did not operate in their absence, causing additional variation and governance concerns.

In other trusts we found rapid and efficient ultrasound access either through well-established vascular sonography pathways that already existed for vascular surgery or transient ischaemic attack (TIA) services, or by having a sufficient critical mass of rheumatologists trained in this technique and performing scans regularly to maintain competence.

We recommend that all trusts seeking to establish an ultrasound service for GCA consider whether this can be incorporated into existing vascular ultrasound services. This may require additional equipment and training over and above the competencies for musculoskeletal (MSK) ultrasound that rheumatologists are more familiar with. The average medium-large trust is likely to need access to no more than 1-2 scans per week but the provision needs to be prompt, reliable, sustainable and robust.

Access to biologic therapy

The biologic drug tocilizumab has been approved by NICE for people with GCA who do not respond to corticosteroids or who relapse on corticosteroid treatment. NHS England commissions this treatment on an individual basis, with each case needing prior approval using the Blueteq system (see *Improving prior approval systems for biologics*, page 100). Cases must also be discussed at a relevant specialised rheumatology or ophthalmology MDT. On our visits we found that some trusts interpreted this to mean that all cases had to be discussed with another specialised centre as part of a regional MDT, rather than within the trust MDT, even if the trust was a specialised centre. This additional bureaucracy, coupled with the fact that only 12 months treatment is allowed, may explain some of the lower than anticipated use of tocilizumab.

Potential solutions: using the guideline to improve services

We recognise the fact that the BSR guideline on GCA is newly-published and trusts have not yet had time to implement it. However, we think that the guideline creates an important opportunity to re-model pathways, particularly at a time when we need to re-think how services will be provided post-COVID-19. This has the potential to help optimise management of GCA, reduce current variations and improve outcomes.

Every trust should have a GCA pathway in place which meets the BSR standards, ensures rapid access to confirmatory diagnostic tests and specialist rheumatology assessment, and is regularly audited. The pathway should be designed collaboratively between rheumatology and other relevant specialties, such as ophthalmology.

This needs to be facilitated by a lead clinician for GCA in each trust, who co-ordinates implementation across all relevant specialties including rheumatology, ophthalmology, vascular services and radiology and is responsible for driving service improvements.

GCA care should be supported by regional MDTs, which can assist with high level decision making and complex case reviews, but this should not delay access to biologic therapies for those who need them.

Work is needed to increase access to ultrasound for suspected GCA and standardise the governance around it (see *Governance of ultrasound for MSK and GCA*, page 81). Where this doesn't already exist, trusts should consider investigating the model for accessing vascular imaging used for TIA and stroke.

CASE STUDY

A reliable pathway for GCA through cross-specialty collaboration

The Newcastle upon Tyne Hospitals NHS Foundation Trust

The rheumatology unit works closely with ophthalmology to ensure that patients with suspected GCA are seen on a fast track pathway within 48 hours of referral with reliable access to diagnostic testing.

The service has a single number for GPs to call for all referrals. Patients are then triaged to either ophthalmology for those with visual symptoms or rheumatology for non-visual symptoms.

Key to the pathway's success is ensuring patients get the appropriate diagnostic tests before or immediately after starting on steroids, as diagnostic effectiveness reduces quickly thereafter. To achieve this, the team ring-fenced daily ultrasound slots for GCA. Four rheumatology consultants were trained to provide scanning, which ensures that the service is resilient and can function even when staff are on leave or during peaks in demand. Administrative support helps co-ordinate appointments and referrals promptly and efficiently.

If patients need further assessment in rheumatology after being seen initially by ophthalmology, or vice versa, strong working relationships mean it can happen quickly, including access to biopsy when required.

Results

Cross-specialty collaboration and service resilience means that the team can confidently meet national guidelines for new referrals, with many patients seen within 24 hours.

CASE STUDY

Simplified pathway standardises care of GCA

Worcestershire Acute Hospitals NHS Trust

Patients with suspected GCA are seen faster and receive more consistent care thanks to a simplified treatment pathway, supported by robust referral procedures and access to a fast track GCA clinic.

Previously, GCA care at the trust was disjointed with patients presenting to several different specialties. Specialist referral was often delayed and diagnosis was dependent on access to temporal artery biopsy.

The rheumatology team developed a simplified pathway based on a decision tree, which gives clear guidance on how to treat and escalate cases depending on symptoms and severity. This is now a single point of guidance for both primary and secondary care.

The pathway incorporates ultrasound, which increases the speed and accuracy of diagnosis. This is provided within the fast track GCA clinic through a shared arrangement with the vascular department. Referrals from primary care are made through the NHS e-referral assessment service (RAS). This enables rheumatology to provide feedback and return referrals back to the referrer with advice where symptoms do not indicate GCA.

Results

The pathway has helped to speed up diagnosis and access to treatment, and reduce the number of referrals. A recent audit showed a quarter (26%) of RAS referrals were redirected, freeing up capacity for urgent treatment of GCA.

Recommendations: Optimising diagnosis and treatment of GCA

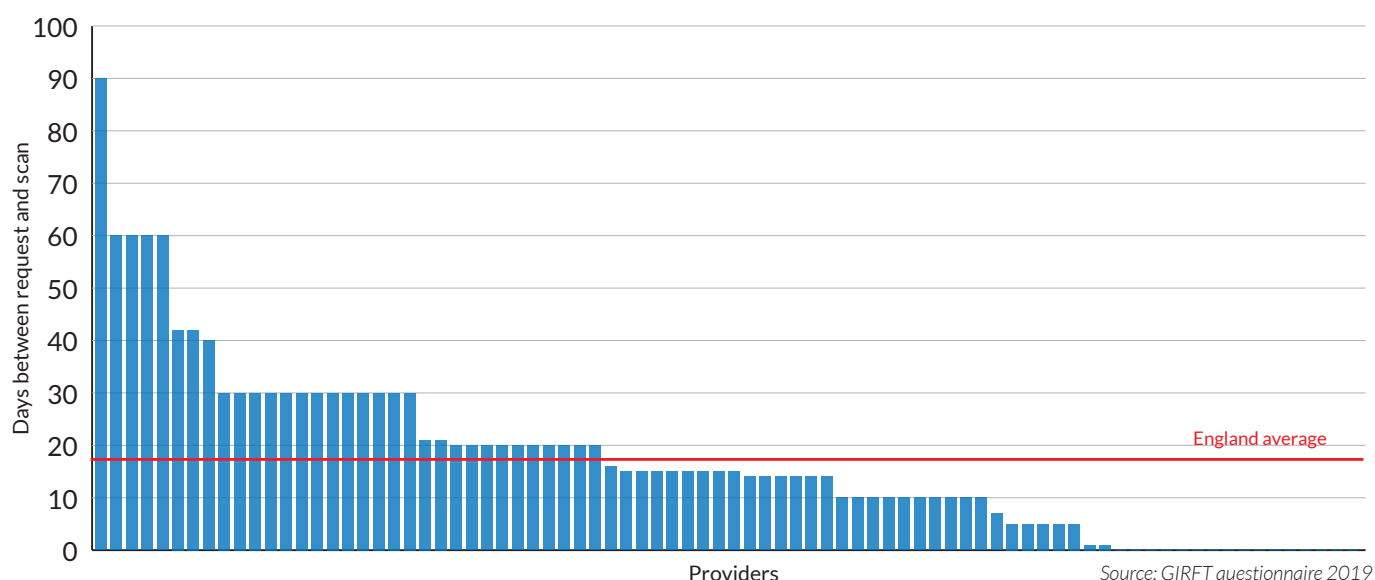
Recommendation	Actions	Owners	Timescale
14. All trusts should meet the new British Society for Rheumatology guideline for giant cell arteritis (GCA); ensuring referrals are rapidly assessed using the latest techniques and pathways.	a Update or establish trust-wide GCA pathways to meet the new National Institute for Clinical Excellence (NICE)-accredited BSR guideline and achieve the three working day target for initial assessment of referrals.	Trusts	Ongoing / within 3 months of publication
	b Appoint a GCA clinical lead in all trusts, responsible for co-ordinating care with ophthalmology and vascular departments.	Trusts	Within 6 months of publication
	c Ensure rapid access to confirmatory diagnostic tests, either ultrasound or biopsy, for patients with suspected GCA.	Trusts	On publication
	d Co-ordinate multidisciplinary team (MDT) discussions across rheumatology networks to support effective decision-making and prescribing of tocilizumab.	Trusts, networks	On completion of 13a

Governance of ultrasound for MSK and GCA

Musculoskeletal (MSK) ultrasound has become an important aspect of practice for many rheumatology departments. In responses to our questionnaire, departments told us that 87% had access to ultrasound for early arthritis patients, while 49% had access to ultrasound for giant cell arteritis (GCA) investigation.

We found variation in how ultrasound services are run, including issues such as how competency is maintained and where ultrasound images and reports are stored. In some cases, provision relied on the skills of one individual and so the service could not be described as resilient. Responses to our questionnaire also showed variation in delays between the request for ultrasound for early arthritis patients and the date of the scan as shown in **Figure 20** below.

Figure 20: Length of delay in days between rheumatology assessment and ultrasound scan for early arthritis in trusts with reported access to ultrasound (based on the 82 trusts who submitted this data)



If treatment decisions are being made for inflammatory arthritis on the basis of these scans then this may cause problems.

We also heard that not all departments have their scan images (40%) or reports (36%) integrated into the trust's picture archiving communication system (PACS), with 43% being able to access reports through the electronic health record. As clinical decisions are made based on these investigations, we recommend that each trust has a robust governance process for availability of images and reports associated with the patient's clinical record.

Potential solution: maintaining competence

As part of improving governance, trusts should ensure that health professionals who deliver ultrasound for MSK and GCA have the training and support they need to maintain competence as part of their continuing professional development. This should be linked to agreed competencies, based on common processes and procedures.

CASE STUDY

Improving processes to deliver an effective ultrasound service

The Mid Yorkshire Hospitals NHS Trust

Robust ultrasound systems and processes have enabled The Mid Yorkshire Hospitals NHS Trust to provide a consistent, convenient diagnostic service for rheumatology patients.

Before the service started, patients needing ultrasound had to travel to Leeds, which was inconvenient with long wait times. Reports were issued by letter only and were sometimes delayed or missing. To address this, the rheumatology unit bought an ultrasound machine from departmental funds and worked with radiology colleagues and service managers to develop an effective service.

The ultrasound is based in radiology and fully integrated with radiology request and reporting systems for full traceability. Images are stored securely on PACS for future review. Three rheumatology consultants have been trained to perform scans, so ultrasound is not heavily reliant on any one individual.

Results

Good governance has made the ultrasound service highly efficient, maximising throughput and capacity. The service has recently expanded from musculoskeletal (MSK) and early inflammatory arthritis (EIA) diagnostics to include tests for GCA.

Recommendation: Governance of ultrasound for MSK and GCA

Recommendation	Actions	Owners	Timescale
15. Trusts should review governance of ultrasound for musculoskeletal (MSK) conditions and giant cell arteritis (GCA) to ensure that the service is sustainable and provide equitable access to ultrasound diagnostic tests for all patients who need them.	a Ensure MSK ultrasound services are not reliant on single-handed practitioners, that competence is maintained through regular practice and continuing professional development and that images and reports are securely stored, linked to the patient record.	Trusts	Within 18 months of publication

Reducing variation in acute hot joint pathways

An 'acute hot joint' generally refers to a single joint which is swollen and inflamed. It could be an indicator of septic arthritis, which can cause damage to the joint and systemic illness such as sepsis and requires urgent treatment to avoid significant morbidity and potential risk to life. Other potential diagnoses include gout and pseudogout.

The majority of these patients require fluid to be drained from the joint, known as joint aspiration, as an emergency. This is vital to obtain fluid for analysis, to exclude sepsis or to identify urate or other crystals. Joint aspiration is a relatively straightforward procedure and can be carried out safely by any clinician who has been trained to do it.

We found variation among trusts in how this service is organised and in which specialty leads on the management of patients admitted with hot joints. In our questionnaire, only 31% of the 139 trusts who answered said they had a formal written pathway for management of the patient presenting with an acute hot joint.

Who should provide the service?

The majority of trusts (83%) said the hot joint pathway is led by orthopaedics. Only a small number (15%) said it was led by rheumatology in office hours. On our visits, we found that in these trusts, rheumatologists in training were spending a significant proportion of their time providing an in-hours joint aspiration service within the hospital. While this may provide useful experience as part of their training, we question whether it should form such a large part of their workload.

Out of hours, less than 2% of rheumatology units are primarily responsible for the on call acute hot joint service. Where this occurs, it is not always a good use of resources, as any out of hours rheumatology resource should be prioritised for patients who require specialised rheumatology skills.

Management of confirmed septic arthritis and variation in length of stay

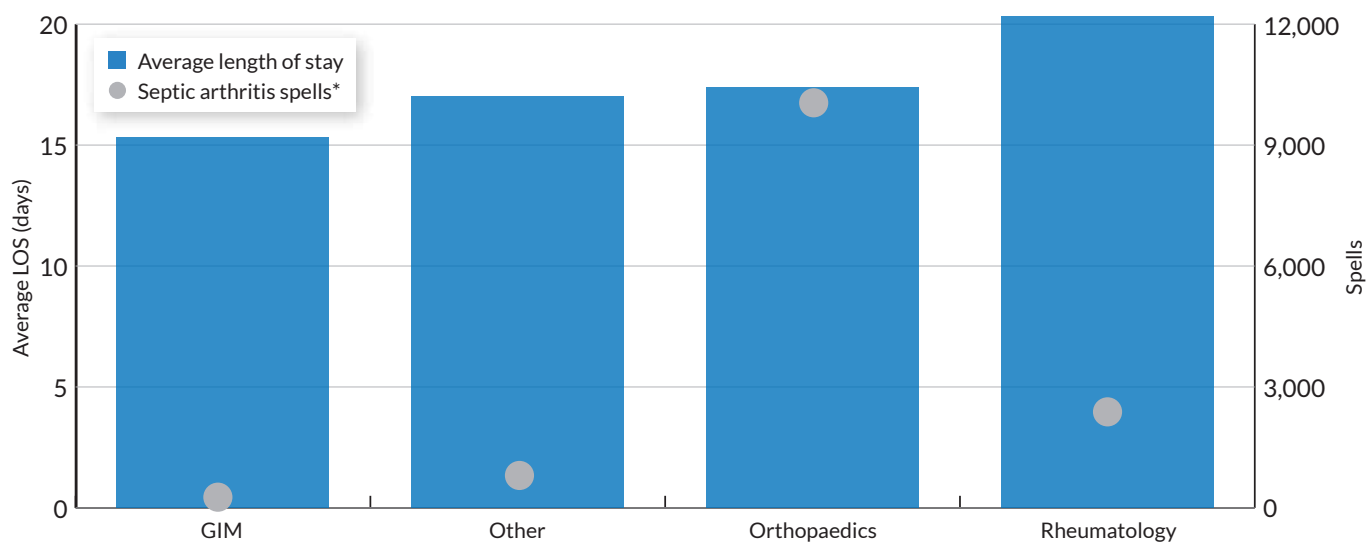
We also found variation in which specialty led on the management of confirmed cases of septic arthritis. This is a serious condition with a 40-42% mortality rate reported in published studies²³, which in addition to joint aspiration may need a formal orthopaedic surgical procedure to 'wash out' affected joints.

These variations may contribute to differences in length of stay from trust to trust, with the average length of stay for each patient with septic arthritis being almost three days longer in trusts where rheumatology primarily leads on management of this condition, compared to orthopaedics, as shown below in **Figure 21**.

A service that is split between departments can also mean that patients find themselves passed between different units, causing confusion and risk of potential errors. Given the seriousness of septic arthritis and the impact if a diagnosis is missed, this is a cause for concern.

²³ Ferrand, J., El Samad, Y., Brunschweiler, B. et al. Morbimortality in adult patients with septic arthritis: a three-year hospital-based study. *BMC Infect Dis* 16, 239 (2016). <https://doi.org/10.1186/s12879-016-1540-0>

Figure 21: Average length of stay for patients with septic arthritis, by specialty leading the pathway



*a spell is a period of healthcare, for example a period spent in hospital or admission to hospital

Source: HES Apr'18-Mar'19

Potential solution

We consider that the management of suspected and confirmed septic arthritis would be improved if all trusts took a more standard approach, with services led by orthopaedics, supported by front-door practitioners who can aspirate joints. Rheumatology should be involved where necessary – for example, where there are confirmed cases of inflammatory arthritis or complex gout, or as part of clinical experience for rheumatologists in training.

Recommendation: Reducing variation in hot joint pathways

Recommendation	Actions	Owners	Timescale
16. Pathways for diagnosis and treatment of 'hot joints' should be consistent and led by orthopaedics to ensure 24/7 access for patients, with support from rheumatology as required.	a Review local provision, liaising with local organisations to align pathways and ensure appropriate involvement of orthopaedics.	Trusts, ICSs	Within 12 months of publication
	b Establish mechanisms to review patient outcomes and variation in length of stay.	Trusts, ICSs	Within 12 months of publication

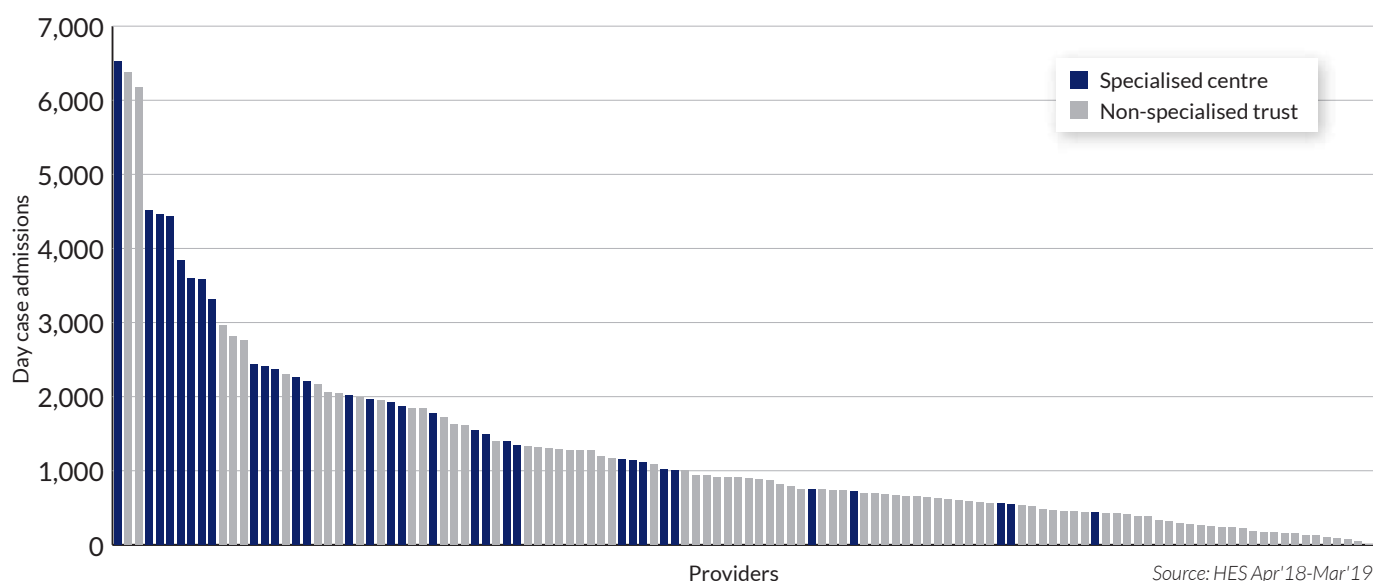
Optimising day case care

Some rheumatology patients require access to day case care, predominately for intravenous (IV) drug treatments. This activity includes:

- new treatments initiated for highly active inflammatory arthritis, such as rituximab and tocilizumab;
- new time-critical remission induction treatments for vasculitis or connective tissue diseases, such as methylprednisolone, cyclophosphamide and rituximab;
- planned regular treatment to maintain remission of inflammatory arthritis or vasculitis with drugs such as infliximab, tocilizumab and rituximab;
- planned or urgent treatment for digital ulceration, for example with iloprost;
- infusions for osteoporosis, such as zoledronate.

This is a significant part of the specialty's activity, as shown in **Figure 22**, which shows an average caseload of more than 1,000 patients a year, with larger trusts seeing up to 6,500. Some units are recording very low levels of day case activity. We don't know if that is accurate or because some activity is being coded to other departments.

Figure 22: Rheumatology day case unit total activity, specialised and non-specialised

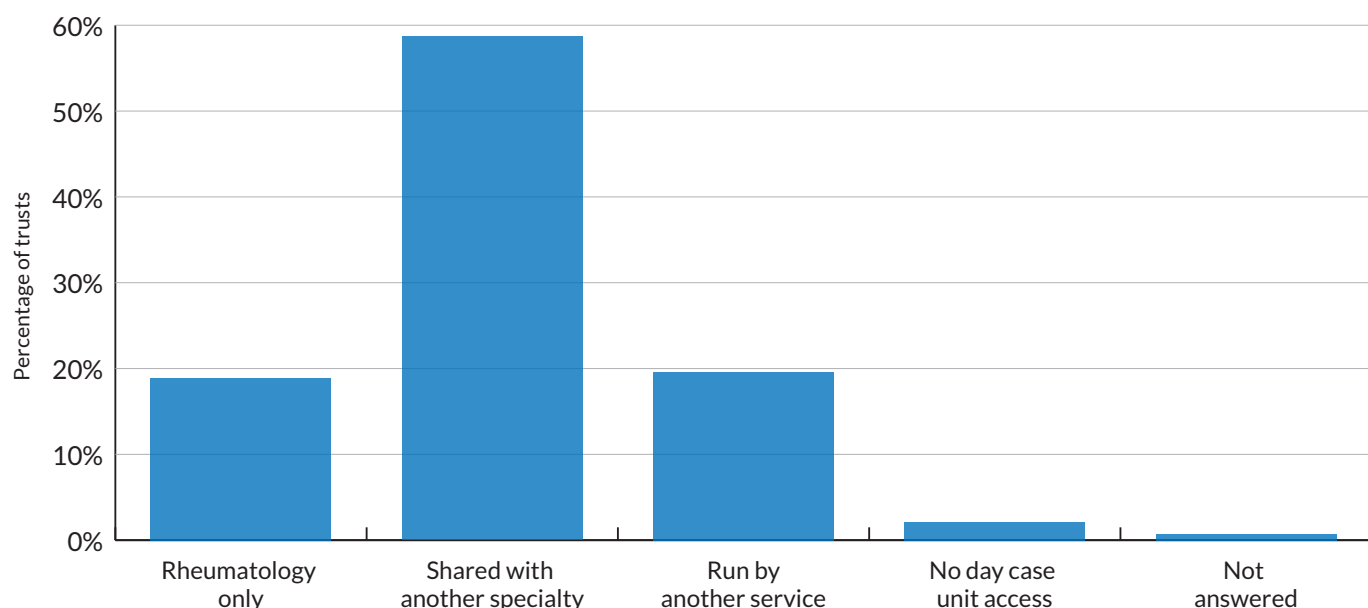


We investigated the variation in the provision and efficiency of rheumatology day case care, including speed of access to treatment, the casemix of diagnoses and procedures being performed and whether the treatment setting was appropriate. It is particularly important to understand these factors if we want to reduce day case activity and move treatment closer to home, as highlighted in NHS England's guidance about rheumatology services during COVID-19.

Provision of day case facilities

In our questionnaire, we asked rheumatology units where their day case facilities are provided. **Figure 23** shows the responses. Only 19% said they have their own rheumatology-specific day case unit. The majority of units use day case facilities shared with, or run by, another service, while 2% of units reported no access to any at all. This variability made it difficult for us to identify and compare the number of day case beds or chairs that are available solely for rheumatology patients in each trust.

Figure 23: Location of day case facilities used by rheumatology



Source: GIRFT questionnaire 2019

Variation in waiting times for treatment

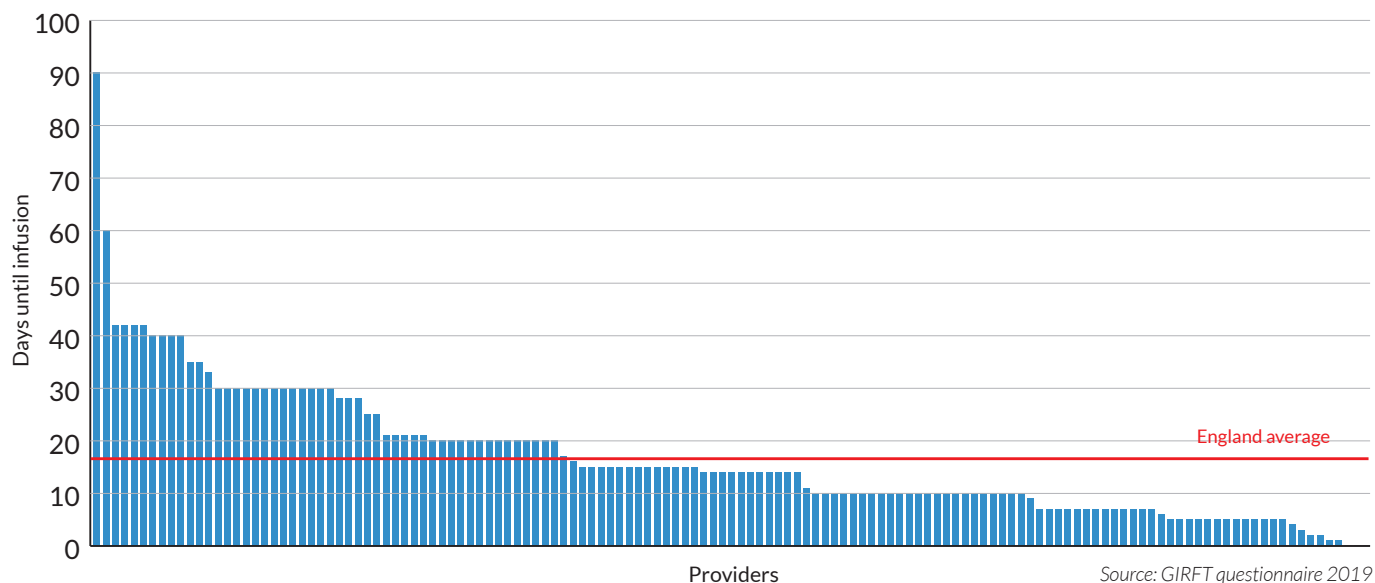
It is very important that patients who require initiation of treatment for active disease receive this rapidly. For some conditions, such as acute vasculitis, treatment delays are also likely to incur an increased risk of irreversible organ damage and mortality.

We found variation in whether units considered they could treat their patients quickly enough. In responses to our questionnaire:

- 46% of units said patients always get their treatment in a reasonable timescale;
- 47% said patients sometimes have to wait longer than they would like;
- 6% said waiting times were unacceptable.

There may be many reasons for this variation, including how day case units are organised, staffing and booking systems. For specific drugs, such as rituximab, there was wide variation in how long patients were waiting for treatment, from next day up to 90 days, as shown in **Figure 24**.

Figure 24: Waiting times from request to treatment for rituximab infusions

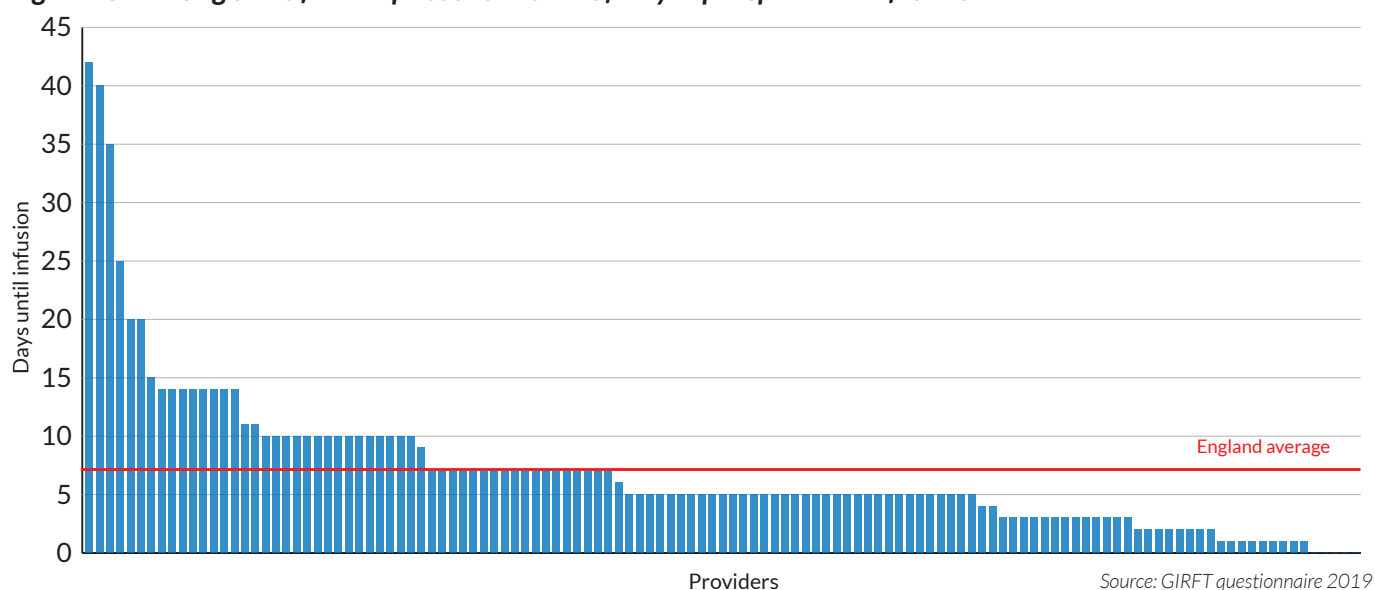


Governance of non-cancer chemotherapy

Some rheumatology patients require treatment with intravenous (IV) cyclophosphamide, a chemotherapy drug, which is used at much lower doses than when used for cancer treatment. The indication for cyclophosphamide is severe internal organ involvement. Treatment usually needs to be given urgently and requires administration by staff trained in the use of chemotherapy.

We found variation in how quickly trusts reported they could deliver this, with some patients waiting over 40 days for routine treatment, as shown in **Figure 25**. We also found variation in the capability of rheumatology day case services to support this treatment, with 59 trusts reporting having two or fewer non-cancer chemotherapy trained nurses and 23 trusts reporting having none.

Figure 25: Waiting times from request to treatment for cyclophosphamide infusions



On our deep-dive visits, we found that some trusts did not have a robust pathway to ensure delivery of urgent cyclophosphamide, relying on making ad hoc arrangements on a case by case basis. In other trusts, we found well established and efficient pathways for cyclophosphamide to be administered within the haematology or oncology day case units.

It is important that every trust has a pathway in place, compliant with best practice (such as NICE guidance) for non-cancer chemotherapy, with enough appropriately-trained nurses to ensure equity of access for patients. This issue has featured in some litigation cases and should be a matter of priority for trusts.

Coding of diagnoses and casemix

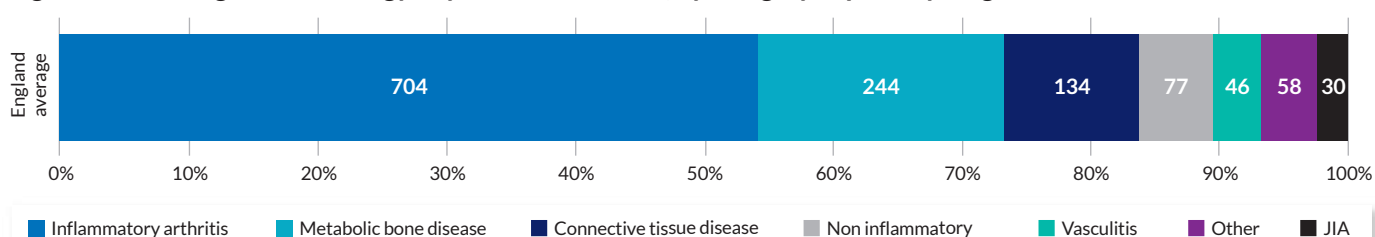
We wanted to look at the casemix within day case units to see which patients are being seen and whether the caseload is appropriate. Casemix data gives us a powerful tool to analyse and review activity in detail and should also be available for outpatients (see *Improving data and coding to support service planning*, page 58).

Within the Hospital Episode Statistics (HES), we identified 157,930 episodes of day case admission attributed to the rheumatology treatment function code in 2017-18. We then reviewed the International Classification of Diseases (ICD) codes of the primary diagnosis in every episode, grouping the individual ICD codes into diagnosis categories: inflammatory arthritis, juvenile idiopathic arthritis (JIA), connective tissue diseases, vasculitis, metabolic bone disease, non-inflammatory painful musculoskeletal (MSK) conditions and other, including non-rheumatological medical conditions, such as anaemia, as shown in **Figures 26a and 26b**.

Surprisingly, given the limited number of rheumatology diagnoses, we found more than 1,600 different ICD codes being used. This suggests that there is considerable variation in how uniformly clinicians are recording diagnoses. For example, within vasculitis, there are a lot of non-specific codes with activity against them, and it is unlikely that vasculitis would have been a non-specific diagnosis. We think this needs further work to ensure that diagnoses are coded accurately.

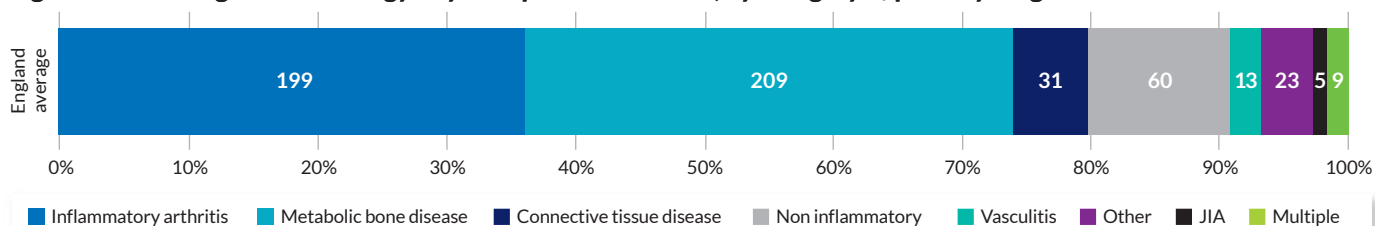
The grey shaded areas indicate a significant amount of activity is for non-inflammatory conditions. We think that some of these are procedures which could be safely performed in outpatients where appropriate (see *Procedures carried out in day case units vs outpatients*, below).

Figure 26a: Average rheumatology day case attendances, by category of primary diagnosis over 12 months



Source: HES 2018-19

Figure 26b: Average rheumatology day case patient numbers, by category of primary diagnosis over 12 months



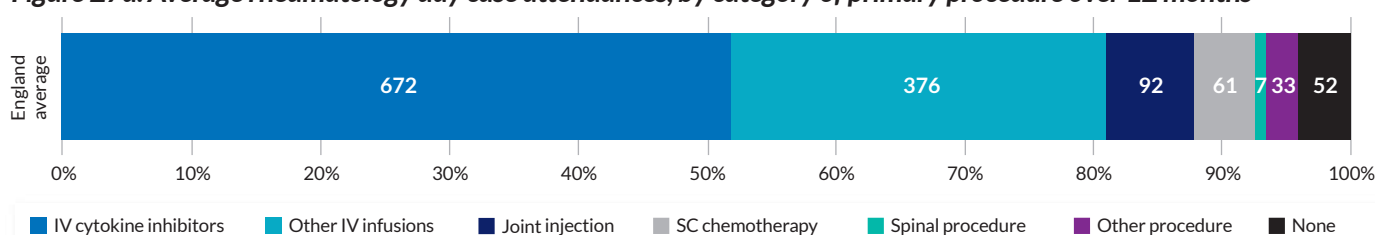
Source: HES 2018-19

Procedures carried out in day case units vs outpatients

We identified 268 OPCS procedure codes used in the primary position of the 157,930 day case admissions and grouped them into clinically meaningful categories of IV cytokine inhibitors, other IV infusions, subcutaneous injections, joint injections, spinal procedures, other procedures and none (where no procedure had been performed), as shown in **Figures 27a and 27b**.

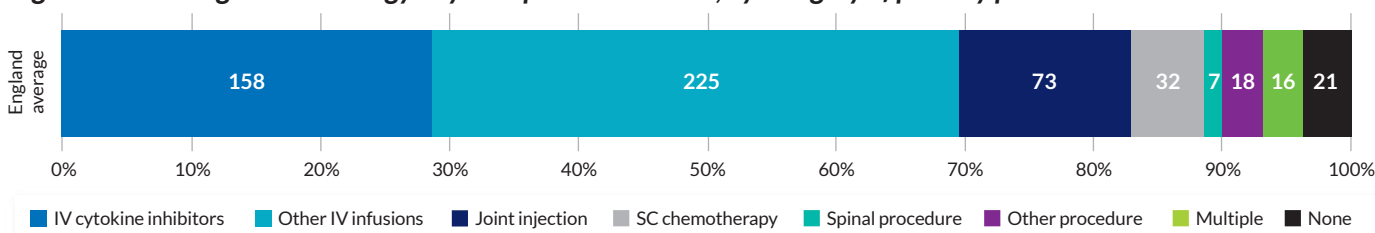
The largest of these categories was administration of cytokine inhibitors drugs band 1 (X92.1), which includes the drugs rituximab, tocilizumab, infliximab and abatacept. The second largest category, within other IV infusions, was continuous intravenous infusion of therapeutic substance (NEC X29.2) which is likely to include methylprednisolone and zoledronate.

Figure 27a: Average rheumatology day case attendances, by category of primary procedure over 12 months



Source: HES 2018-19

Figure 27b: Average rheumatology day case patient numbers, by category of primary procedure over 12 months



Source: HES 2018-19

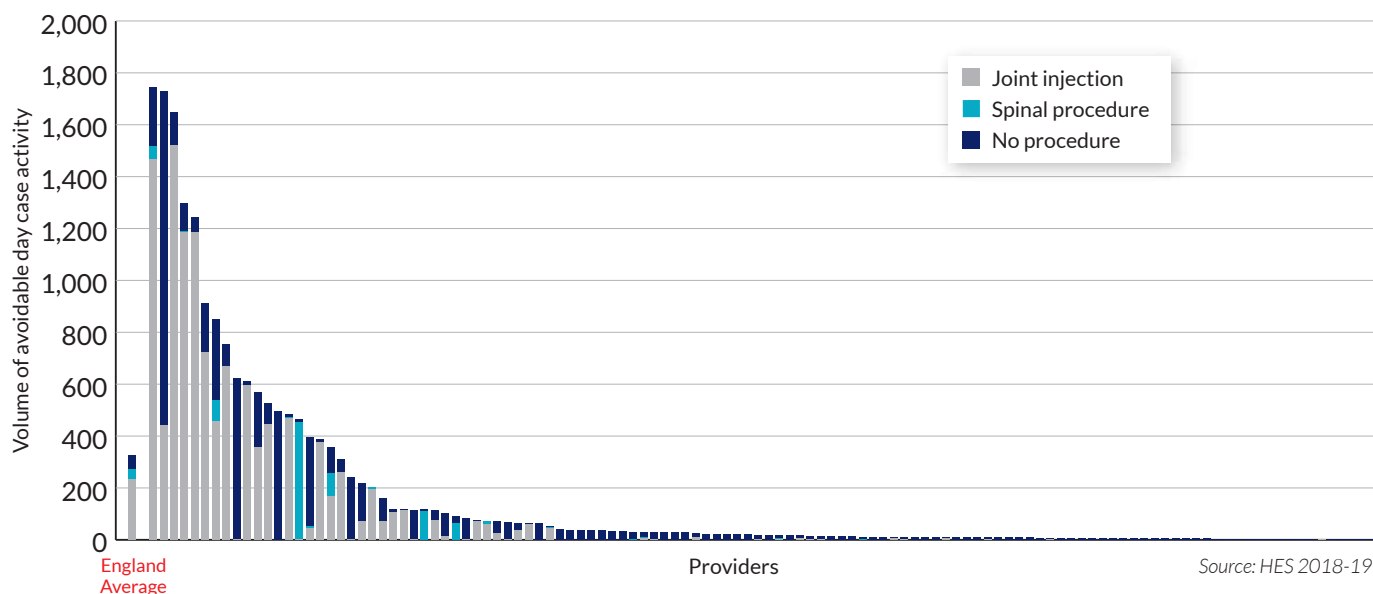
However, we also found that a significant proportion of day case activity is taken up with procedures that could equally be performed in ambulatory settings without the need for a day case admission. For example, some units are performing large numbers of joint injections, and this is correlated with a larger proportion of day case patients having a non-inflammatory MSK diagnosis in these units.

In some units, patients were returning weekly for administration of subcutaneous injections (methotrexate or cytokine inhibitors) because there was no provision for patients to self-inject. In other units there was a high proportion of patients attending who had no procedure performed, and in our deep-dive visits we observed that this was usually due to urgent outpatients being seen in the day case unit because of lack of clinic capacity.

Some of this variation may be related to the fact that there is a higher tariff for day case procedures compared to outpatients under payment by results. However, on our visits we heard that many departments are now working on block contracts - estimated at up to 50% of units when we started our visits and increasing to 100% of units during the COVID-19 pandemic - so tariff issues should be less of a factor in deciding where a patient is seen.

Figure 28 shows the variation, with some trusts performing thousands of joint injections as day cases, while others do almost none. This suggests that in some trusts, significant day case capacity could be created if these were more appropriately performed in outpatient settings.

Figure 28: Total number of day case joint injections, spinal procedures and admissions with no procedure



Source: HES 2018-19

Day case infusions that could be replaced with subcutaneous or oral treatment

There are some drug treatments currently being administered in day case units where an equally effective subcutaneous or oral alternative exists.

For example, iloprost, which is used to treat digital ulcers in systemic sclerosis, is commonly given as an IV infusion in a day case unit. In 2013 NHS England commissioned the use of oral sildenafil (and more recently bosentan) earlier in the pathway with the aim of reducing the cost associated with IV treatment. Despite this, we have found that there has been no overall reduction in IV administration of this drug treatment over the last five years.

However, we note that use of subcutaneous alternatives (particularly for tocilizumab, infliximab and belimumab) has increased in recent months as a result of the COVID-19 pandemic. Subcutaneous and oral alternatives should be considered wherever it is safe to do so, in line with NHS England and NHS Improvement policy.

We understand that the national pharmacy team are also looking to explore out-of-hospital outpatient intravenous therapy (OPIT) and whether it can support increased safe administration in the community. However, we note that this is in the early stage of development and we did not have data to make a meaningful analysis of its potential.

CASE STUDY

Nurse-led booking and prescribing systems maximise DCU efficiency

Sheffield Teaching Hospitals NHS Foundation Trust

A streamlined online booking system and pre-printed prescription forms developed by the nursing team have helped to increase day case unit efficiency and throughput while reducing prescribing time.

The team developed a weekly online booking template for each intravenous (IV) drug treatment, which enabled them to map demand to available capacity and make better use of available slots and day case chairs.

Efficient booking also helps reduce drug wastage – for example, booking all infliximab infusions together makes it possible to share vials across multiple patients. Rapid treatment protocols developed in conjunction with pharmacy also contribute to more efficient drug administration.

The team created pre-printed prescription pro-formas for each IV medication which ensure that all prescribing information is clearly recorded. An administrative staff member works together with the pharmacy team to complete prescribing in advance of the patient's appointment.

Results

The nurse-led service has resulted in fewer delays for IV patients, increased unit capacity and a saving on drug costs. The pre-printed prescription forms have reduced prescribing delays, pharmacy queries and the risk of medication error.

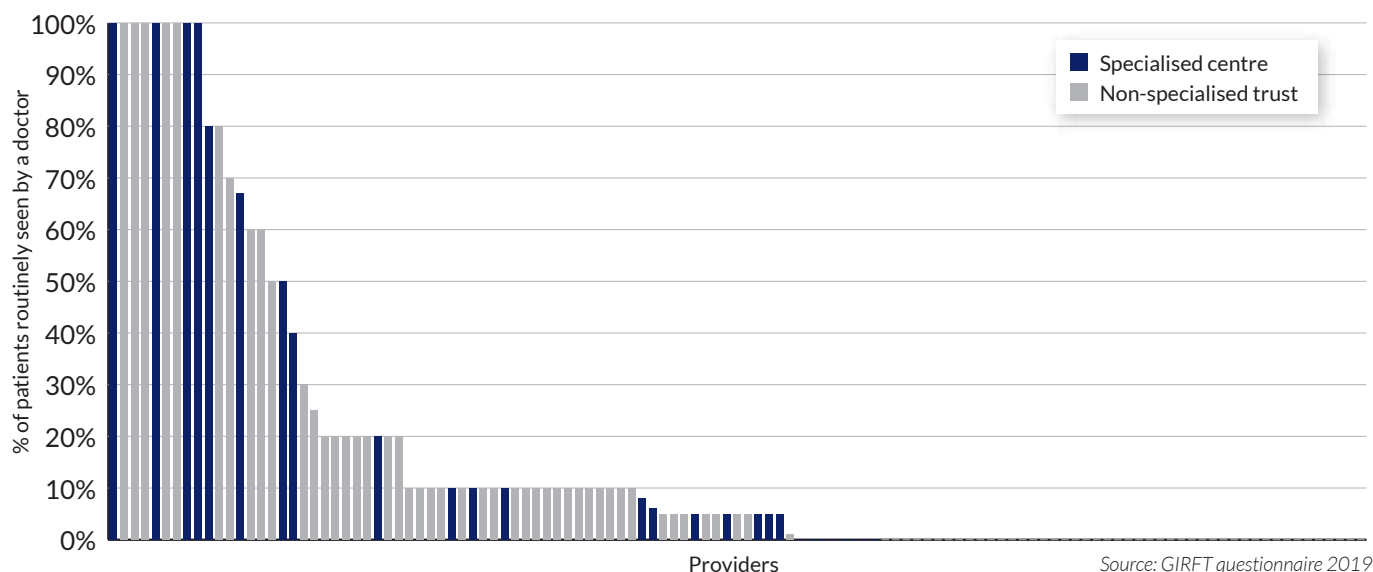
Variation in medical supervision of day case patients

When IV biologic treatments were first introduced into clinical practice, there was a concern about detrimental effects if patients had an infection at the time of infusion. This meant that medical staff review would often take place to ensure the patient was fit to proceed with treatment.

However, with best risk management today, most units have adopted nurse-led pathways, which do not routinely require medical review prior to infusion. However, it is important that medical review is available rapidly for patients who are acutely unwell, such as those who develop infusion reactions or whose day case infusion coincides with clinical review, including those receiving non-cancer chemotherapy and some patients with severe autoimmune disease.

In responses to our questionnaire, there was significant variation between trusts in the proportion of day case patients that are routinely reviewed by medical staff prior to infusion, as shown in **Figure 29**. While several trusts said they medically review 100% of infusions, more than 50, including eight specialised centres and 46 other trusts, said they do not routinely review patients before infusion.

Figure 29: Proportion of patients routinely seen by a doctor before treatment



We investigated whether this might be a reflection of the clinical severity of cases being seen in specialised centres. However, there was no clear pattern of a higher proportion of medical review in specialised centres.

The potential of nurse-led services

As **Figure 29** shows, a significant number of trusts continue to provide medical review of all infusions, even where patients are stable and the procedure is relatively routine as part of their ongoing care. We think this is unnecessary and may be wasteful of rheumatologist time, which could be better spent on other activities.

Anecdotal evidence from our deep dives would suggest that day case units can be more productive and have lower waiting times when they are led by nurses with enhanced and advanced skill sets.

We heard from units who were proud of their efficient, nurse-led services and from some doctors in training who spoke about the routine nature of clerking day case patients, which was not the best use of their time.

We also heard that some units did not have a clear procedure for how medical rheumatology review could be obtained rapidly when it was needed. Trusts should ensure that their day case unit staff have rapid access to the appropriate level of medical support in the event of complications.

Variation in efficiency of drug administration

Relevant to some units reporting longer wait times for infusions, we also explored variation in factors affecting day case unit productivity, such as dose banding, and whether infusions were pre-prepared by pharmacy, reducing the need for day case nurses to do this.

Making better use of dose banding

Dose banding is a system whereby doses for certain medicines are grouped and rounded to a series of pre-defined doses – historically, this was done based on the patient’s height and weight. These are then pre-made. Dose banding can save time in drug administration in day case units, and free up resources for patient care. The practice is standard in some specialties, such as oncology for chemotherapy treatments.

In rheumatology, dose banding is particularly relevant for infliximab and intravenous tocilizumab and occasionally for rituximab use in vasculitis. Many trusts have worked hard to introduce dose banding for infliximab, in particular, in recent years.

In our questionnaire, we asked trusts if they used dose banding. Less than half (49%) said yes. We then asked ‘If you use dose banding, which regimens do you use?’ As shown in **Table 3**, less than half said infliximab and just over a third tocilizumab.

These responses suggest there is scope for expanding use of dose banding to improve day case unit efficiency. However, it’s worth noting that use of these medicines has declined since the introduction of subcutaneous alternatives.

Table 3: Use of dose banding for infusions in rheumatology

	Yes (%)	No (%)	Not answered (%)	Responses
Dose banding regimens	49.0%	46.9%	4.2%	137
If yes, what are they used for:				
Infliximab	47.3%			70
Rituximab	15.3%			62
Tocilizumab	36.6%			20
Not answered	0.8%			

Source: GIRFT questionnaire 2019

Use of pre-made infusion bags

Pre-made bags, often used in conjunction with dose banding, can also save time in the infusion process. In our questionnaire, more than half of trusts said they used pre-made bags for day case administration of rituximab (52%) and cyclophosphamide (55%) but only 34% for infliximab and 29% for tocilizumab, again suggesting scope for greater efficiency. We heard from rheumatology teams that the cost of pre-made bags can vary, and needs to be balanced against the potential for greater throughput of patients on the unit.

Potential solutions

We think there are significant opportunities to improve the use and management of day case facilities and increase the flow of patients to treatment.

Firstly, by looking at the types of condition and procedure currently seen as day cases, giving priority to the sickest patients such as those needing non-cancer chemotherapy, and considering alternatives to intravenous infusions, which are a major driver of demand for day case facilities. And secondly, by measures which can improve efficiency and productivity, such as dose banding, pre-made drugs and reviewing the level of medical supervision needed for day case patients. It may also be worth assessing whether the interval between infusions can be increased for some patients, in line with the National Institute for Health and Care Excellence (NICE) COVID-19 guideline for rheumatology²⁴.

We note that there is an ongoing national programme of work to increase aseptic capacity and uptake of dose banding which was due to report its findings to ministers in autumn 2020. We look forward to its recommendations, which will help drive these developments forward.

²⁴ NICE COVID-19 rapid guideline [NG167]: rheumatological autoimmune, inflammatory and metabolic bone disorders NICE guideline recommendations 4.10 and 4.11 www.nice.org.uk/guidance/ng167/chapter/4-Treatment-considerations

Recommendation: Optimising day case care

Recommendation	Actions	Owners	Timescale
17. Trusts should optimise use of day case facilities and consider alternatives to day case admission for some procedures to reduce waiting times and improve the patient experience.	a Review current day case activity and remove any that is inappropriate.	Trusts	Within 3 months of publication
	b Review governance of non-cancer chemotherapy including training, competencies, auditing compliance with guidelines, and accessibility for urgent treatment.	Trusts, BSR, SAC, CRG	Within 6 months of publication
	c Ensure day case units are nurse-led with appropriate and proportionate access to medical input for relevant patients/cases.	GIRFT, Trusts, CRG	Within 6 months of publication
	d Preferentially use and transition to subcutaneous injection to reduce day case requirements where appropriate.	NHSE/I, Trusts	Within 3 months of publication
	e Consider greater use of dose banding where appropriate.	Trusts	Within 6 months of publication

Optimising medicines

Rheumatology has been transformed over the last two decades, for patients and for health care practitioners, by the earlier and more aggressive use of conventional disease-modifying anti-rheumatic drugs (DMARDs) and by the introduction of biologic agents.

We can now hope to achieve remission for two thirds of patients with newly presenting rheumatoid arthritis and much improved quality of life for patients with many RMDs, such as axial spondyloarthritis. These approaches are life changing and welcome but do carry considerable direct and indirect costs.

Biologic drugs and the newer JAK-kinase inhibitor agents are expensive – costing over £9,000 per patient per year for some. DMARDs are in themselves relatively low-cost agents but require regular blood tests for safety monitoring which generates face-to-face appointments and, from local audits, we understand accounts for up to 5% of blood tests for the whole NHS.

The total rheumatology drug spend for England in 2019-20 was over £416 million, while the average spend per rheumatology department was £2.9 million, approximately 9% of the average trust's total medication spend. This represents a significant reduction on previous years as shown in **Table 4**, largely due to increasing use of best value biosimilar drugs – see *Reducing delays in switching to biosimilars*, page 103.

Table 4: average total medicines spend in rheumatology departments compared to average total spend by trusts, all specialties 2012-20

Financial year	Average rheumatology spend	Average total spend	% rheumatology
2011/12	£1,812,136.50	£14,849,469	12%
2012/13	£2,156,063.99	£16,585,887	13%
2013/14	£2,519,545.90	£19,386,063	13%
2014/15	£2,933,965.74	£22,385,715	13%
2015/16	£3,318,619.39	£25,793,305	13%
2016/17	£3,458,780.39	£27,997,453	12%
2017/18	£3,538,425.02	£30,229,582	12%
2018/19	£3,281,455.34	£31,168,776	11%
2019/20	£2,866,074.46	£32,341,661	9%

Source: RX-Info Define 2020.

However, despite recent reductions, the cost of rheumatology drug therapies remains high. This places a significant responsibility on rheumatology departments to ensure that high cost drugs are prescribed and monitored effectively and to work alongside the pharmacy team and other colleagues at their trust to maximise value for drug spend.

Medicines used in rheumatology: an overview for non-clinicians

DMARDs

DMARDs control rather than cure the disease, improving symptoms and reducing or stopping joint damage. Patients are often prescribed a combination of different DMARDs, according to how their disease responds to treatment. DMARDs include JAK inhibitors, which inhibit the production of enzymes that attack the joints.

Biologics

Biologic (or biological) medicines are made from proteins and other substances that the body produces. They are manufactured using living cells, and work by stopping particular chemicals in blood from activating the immune system and causing inflammation. Biologics are used to treat several RMDs, including rheumatoid arthritis and axial spondyloarthritis, as well as conditions covered by other specialities, such as dermatology or gastroenterology.

Non-specialist medicines: NSAIDs and Cox-2 inhibitors

Non-steroidal anti-inflammatory drugs (NSAIDs) including Cox-2 inhibitors are widely used to relieve pain and reduce inflammation in patients with arthritis and musculoskeletal disorders.

About our medicines data analysis

This report represents the first national review of prescribing practice of rheumatology departments. As part of the process, we used the Rx-Info Define dataset to examine how medicines were prescribed by trusts. This includes information on all drugs prescribed which are attributed to rheumatology, including biologics, DMARDs and others.

Rx-Info Define relies on trusts to upload pharmacy data to its database. Currently more than 90% of acute NHS hospital trusts do so and this has enabled some national benchmarking of drug utilisation based on costs and quantities (defined daily doses). We found some data quality issues, perhaps relating to the relatively recent adoption of this system:

- In a minority of departments, medicines used in rheumatology were coded to other specialities.
- There were some inconsistencies between data held on different databases within the same trust.
- Some trusts did not include medication delivered to people's homes (homecare).

We wanted to look at variation in use of DMARDs prescribed for patients seen in rheumatology. However, DMARD prescribing is commonly split between secondary and primary care. This limited our analysis because primary care prescribing uses a different recording system, which meant we were unable to match data up at patient level between primary and secondary care to get a picture of total prescribing. Our analysis therefore focuses largely on the high-cost drugs which are mainly prescribed in secondary care and have the greatest spending implications.

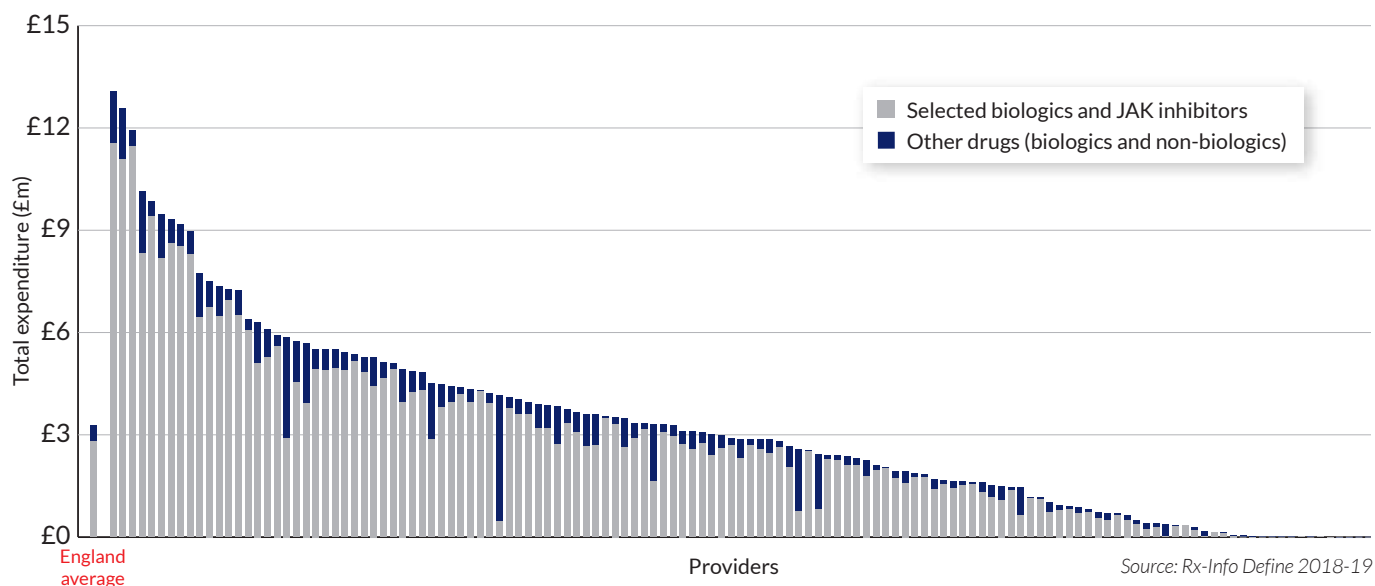
Wherever possible, we have tried to validate findings with the trusts themselves, but this has not been possible in all cases. As a result, some of the outlier data in our charts should be treated with a degree of caution, and figures may under-represent the total prescribing for some trusts. We are grateful to our pharmacy colleagues for helping to identify the causes of data quality issues and to trusts who helped by amending their Rx-Info Define data before we completed our analysis.

Variation in medicines spend and patterns of prescribing

Figure 30 shows the total amount spent by trusts on drugs used. There is wide variation beyond what might be expected based on differences in size of unit and caseload. The colour bar below the chart shows how the average trust spend breaks down between selected biologics and JAK inhibitors:

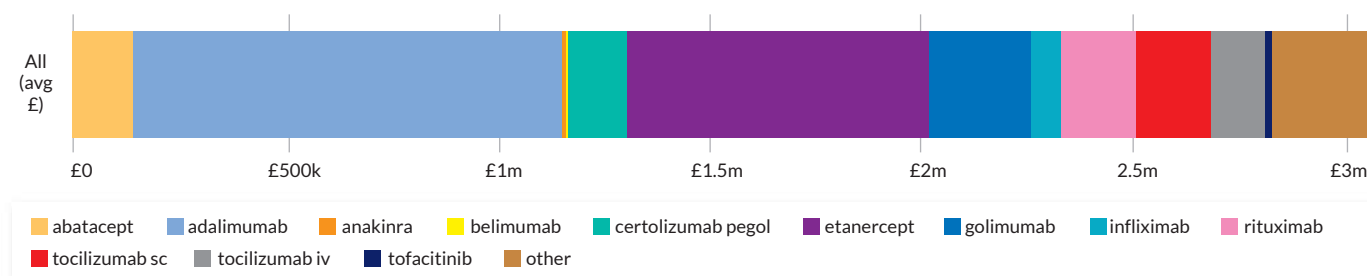
- abatacept
- adalimumab
- anakinra
- belimumab
- certolizumab pegol
- etanercept
- golimumab
- infliximab
- rituximab
- secukinumab
- tocilizumab
- tofacitinib

Figure 30a: Total rheumatology drug spend by category



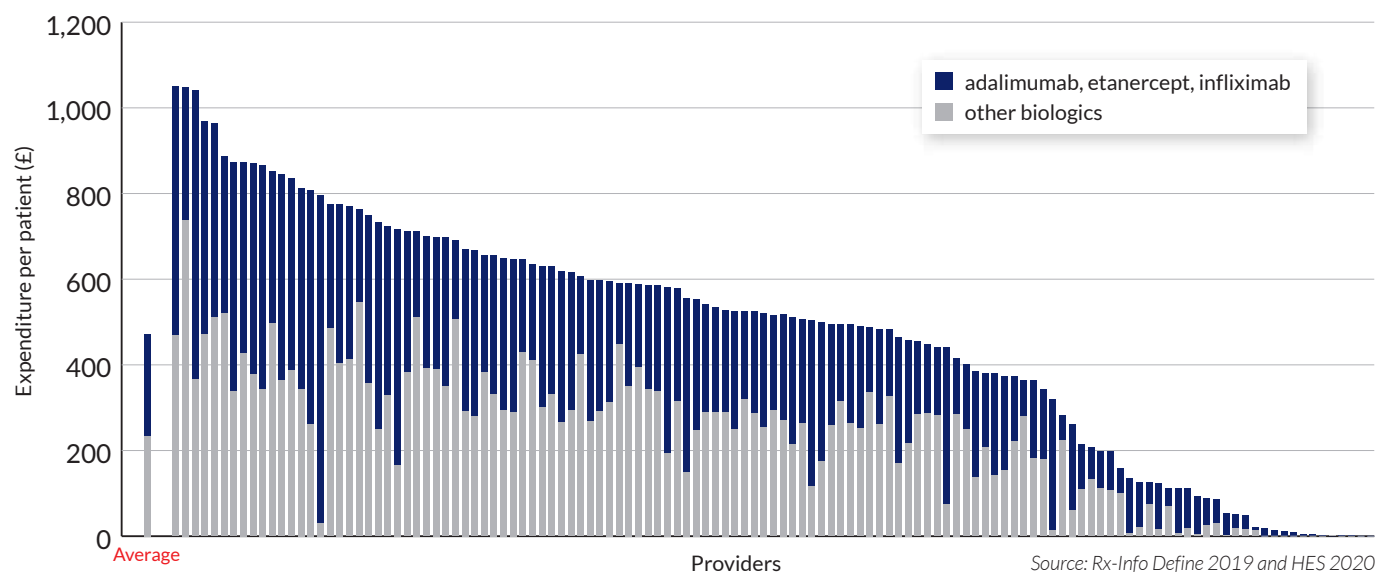
Note: Total expenditure on selected biologics and JAK inhibitors has been deducted from the overall rheumatology drug expenditure to calculate other drugs total. The following biologics and jak inhibitors were selected: abatacept, adalimumab, anakinra, baritinib, belimumab, canakinumab, certolizumab pegol, etanercept, golimumab, infliximab, rituximab, secukinumab, tocilizumab, tofacitinib, ustekinumab.

Figure 30b: Average rheumatology drug spend by category over 12 months



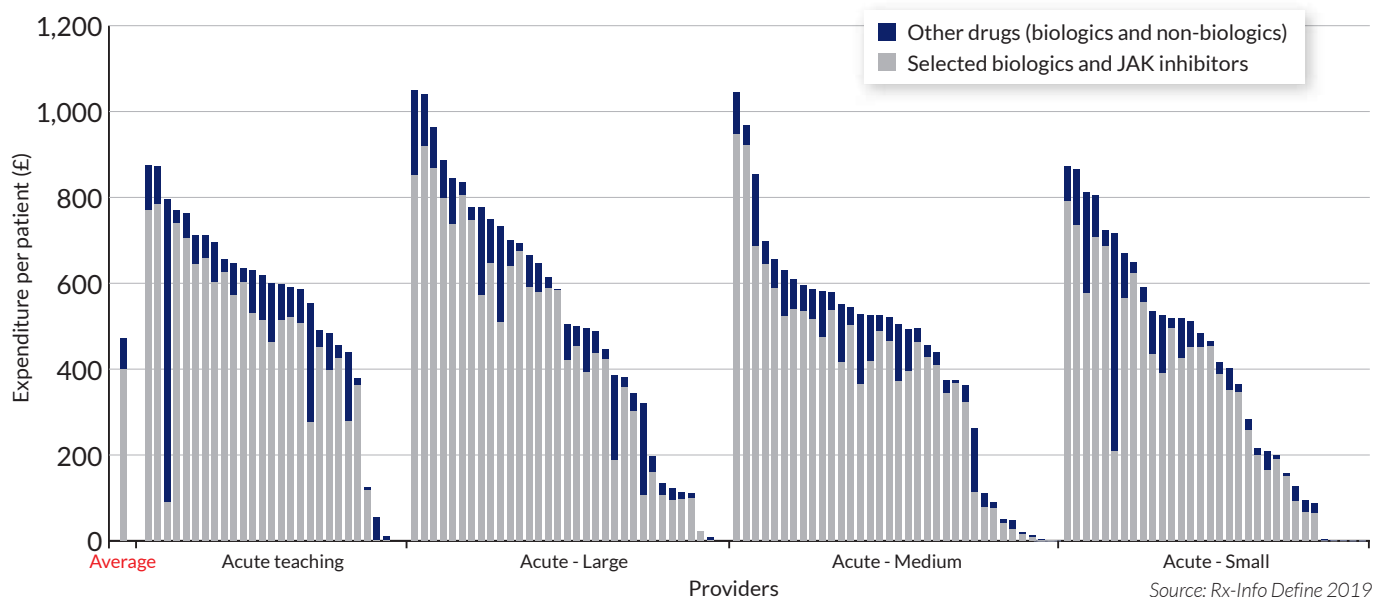
To investigate the variation further, we looked at drug spend per patient, based on identifying the number of individual patients under the care of a rheumatology unit. We would expect this to be broadly similar across rheumatology units given that most will have a similar patient profile, with the exception of specialised centres for rare RMDs or trusts with a high volume of follow-up activity for patients with non-inflammatory painful MSK conditions. However, **Figure 31**, which looks at a selection of key biologics, shows a wide variation.

Figure 31: Average drug spend per patient on adalimumab, etanercept, infliximab and other biologics

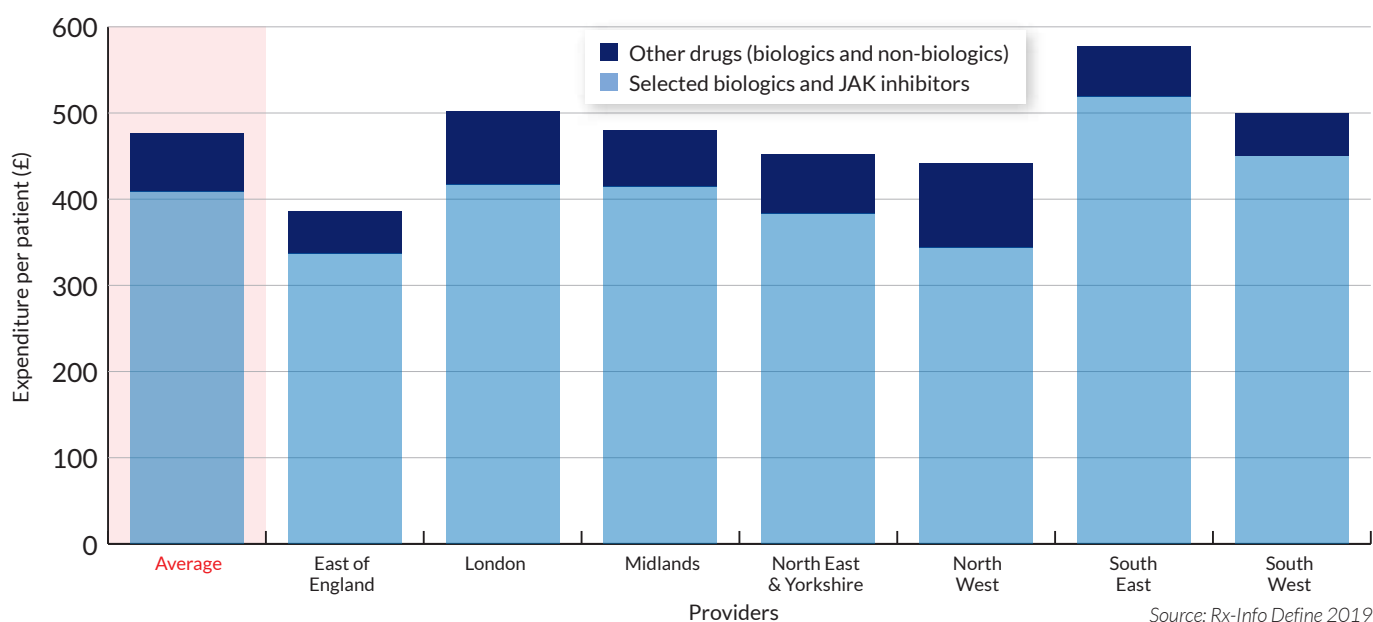


We found similarly high levels of variation when we looked at average spend per patient (biologics and non-biologics) by trust type (small, medium, large, teaching) as shown in **Figure 32**, and also by region as seen in **Figure 33**.

Figure 32: Average rheumatology drug spend per patient by trust type, 2018/19 (including selected biologics, JAK inhibitors and other drugs)



**Figure 33: Average rheumatology medicines spend per patient by region, 2018/19
(including selected biologics, JAK inhibitors and other drugs)**



What lies behind the variation?

The variations shown above are more than can be explained by specialised commissioning, follow-ups or other factors such as tertiary referrals from other trusts. We are not aware of evidence of demographic variations in the prevalence or severity of most RMDs between trusts or regions so we have considered other potential reasons for the variation. These include:

- Data and attribution issues – the data quality issues mentioned in *About our medicines data analysis*, page 96 above may mean that some prescribing activity is not being recorded routinely or is being coded to other specialties.
- Differences in practice – where spend per patient is high, it might indicate that some trusts are treating more patients with a lower threshold.
- Prescribing policy – some trusts and local commissioners may interpret National Institute for Health and Care Excellence (NICE) guidance differently and set lower or higher prescribing thresholds as a result or limit the number of agents an individual patient may receive.
- Casemix and severity – some trusts may be treating more complex patients, for example because they accept referrals of these patients from neighbouring trusts.
- Service provision – trusts may not offer services for some rheumatology conditions, which may be reflected in their drug spend.
- Differences in rates of uptakes of biosimilar medications (see *Reducing delays in switching to biosimilars*, page 103).
- Variation in procurement policies and pricing.

In summary, we have seen wide variation in spend on high cost rheumatology drugs. We have many potential explanations for this variation, but none which we can sufficiently test with available information. We do not know where the ‘right place to be’ in this distribution of spend is, but the degree of variation suggests that there is clear room for improvement. We expect this to be a priority area for further review in rheumatology, especially given the significant financial opportunities associated with improvement, as highlighted in *Notional financial opportunities*, page 129.

Improving data quality

This report is the first attempt to measure the comparative use of biologics and other recent classes of drugs now widely used in rheumatology. However, it is clear from the discussions above that we have more work to do to get a comprehensive, accurate picture of drug spend and how drugs are being prescribed across the country.

To address these issues, we think that prescription data should be collected and collated at a national level through national medicines data reporting systems, and that prescribing data from primary and secondary care should be aligned. This would enable trusts to review their own prescribing behaviour in the context of spend across the system. To enable meaningful comparison the data required would need to include information about:

- the reason for the prescription (prescribing indication) to allow casemix comparison;
- outcome and how it was measured to allow efficacy comparison.

This picture must take account of whether trusts are participating in clinical trials, where they are using more expensive agents, and variation in thresholds for treatment, and enable trusts to compare their own spend with that of other trusts.

Coding of rheumatology diagnoses in outpatients would help improve and clarify medicines data, so long as this includes coding drug prescriptions across the board (see Recommendation 7).

Expanding electronic prescribing

Wherever possible, prescribing should be electronic. As discussed in *Improving data and coding to support service planning*, page 58, if this is linked to coding of outpatients and day cases, there is the potential for a powerful dataset on diagnoses and patient outcomes to drive improvement. Electronic prescribing would provide a comprehensive, accurate picture of drug spend, indication, choice of medicine and outcomes from treatment, as well as costs from the supply systems used.

Standardising prescribing practice and governance

Biologics are expensive and represent the largest growth area in the NHS medicines budget. It is therefore important that they are prescribed and used efficiently and continue to be closely monitored to ensure they provide value and achieve good outcomes. The existing NICE guidance criteria and prior approval systems go a long way towards achieving this, but we still see wide variation in prescription volumes and spend.

On our deep-dive visits, we found variation in how the NICE criteria on how biologics should be used are interpreted across the country. Some trusts have lower prescription thresholds than others, which will in turn increase these trusts' expenditure.

We also found variation in how patients are started on high cost drugs. In some units, everyone starting biologic treatment goes through a thorough multidisciplinary team (MDT) virtual review, or they are checked against a list of criteria, while in other trusts the process is less formal.

Improving prior approval systems for biologics

NHS England and NHS Improvement has developed a prior approval electronic system for specialised commissioning called Blueteq to monitor high cost drug use, and to reduce variation. Some clinical commissioning groups (CCGs) have also commissioned Blueteq locally to manage the forms and approvals for high cost drugs.

On our deep-dive visits, we heard that Blueteq is working well for some biologics such as tocilizumab for giant cell arteritis (GCA). This medication was approved for a relatively small, defined cohort of patients.

However, during our discussions, we found that some commissioners required trusts to use Blueteq for far more commonly-prescribed drugs, causing burdensome and disproportionate workload for some trusts. This is also at odds with the Long Term Plan's aspiration to reduce unnecessary follow-up appointments. For example:

- The system requires staff to input data for each patient at frequent intervals, such as every three months. This can be a burden for follow-up appointments and take up a considerable amount of nurse specialist time.
- If patients need to take a break from their medicines and restart for any reason (such as taking a break for an operation or infection) it can mean that patients have to go back into outpatients for a further assessment.
- In some cases, the patient may lose access to a treatment that is working well for them, through the timing of their assessment.

There are also some issues with how the system operates. For example, we have heard from trusts that prior approval does not always result in a prescription being authorised. The data fed into Blueteq is often unavailable for comparison and analysis.

Blueteq is a useful gateway for prescription of high cost biologics, especially for rarer treatments or conditions and could help to control drug spend, standardise practice and reduce variation between trusts. It has value in assessing the efficacy of new interventions in practice. However, we think it needs to be refined and improved to increase its effectiveness and reduce the administrative burden for more frequently prescribed medications, or alternatives should be found.

It is important to differentiate between the level of approval needed when first starting a treatment and assessing its response, and the lesser amount of information that should be required during long-term follow-up for successful maintenance treatment.

There is a need for accountability for the use of high cost drugs, including understanding the uptake into clinical practice of newly-licensed drugs for rare RMDs. But this must be balanced against the disproportionate workload created by rigid adherence to Blueteq monitoring for common indications for these drugs, particularly where a patient has been shown to have responded well to the drug, qualifying them for maintenance treatment.

Potential solutions

The variations we have found highlight the need for rheumatology units to review their own data to identify any anomalies and improve practice. Rheumatologists should compare with peers both within the trust and with other trusts to understand patterns of prescribing and standardise working, ensuring that:

- each case is properly triaged, and the benefits of treatment are considered before a decision to prescribe, either through an MDT meeting or by a standardised process;
- patients are treated early and aggressively for conditions where the evidence shows they are at risk of long-term avoidable harm if treatment is delayed;
- the lowest cost agents are identified and used where appropriate;
- planning takes account of future pricing including length of patent to optimise value and effectiveness.

We think that there could be a big step towards achieving these aims if we moved to electronic prescribing across the system and collected prescribing data at a national level (see *Improving data quality*, page 100) and published this information on Model Hospital. This solution would allow departments and CCGs to review patterns of prescribing and drug spend and plan future improvements. Linking this to casemix and outcome data would enable further meaningful comparisons.

We think that any extra administrative support needed to enable this change would be countered by a reduced burden in local monitoring of high cost drugs and overall efficiencies that could result from having greater visibility of drug use and spend. We would envisage national collection replacing local data collection over time. We understand that NHS Digital is working with NHSX on a project to support capture of electronic prescribing data with improvements expected during 2021.

Collaborating with other teams within the trust

In some trusts we visited, there were useful examples of rheumatology departments collaborating with their trust's pharmacy team to inform decisions about biologic prescription policies and procedures. We also saw good results where a trust held MDT meetings to discuss new biologics, ratify prescribing practice, and conduct open, honest case reviews to inform future trust prescription policy and individual treatment decisions.

We have found that collaboration between departments and teams, especially where the aim has been to prioritise a longer-term view, can be particularly helpful in encouraging switching from biologic to biosimilar medicines (see *Reducing delays in switching to biosimilars*, page 103).

Working with other trusts across a geographic footprint

Units should also work collaboratively with other trusts across geographic footprints to share data and good practice – for example, holding joint case reviews to review decisions about treatments and using data from Rx-Info Define and Model Hospital to compare performance together. Trusts could also come together to agree shared policies across a region.

Regional Medicines Optimisation Committees (RMOCs) are also well-placed to support trusts in ensuring use of best value biologics, in collaboration with primary care providers and commissioners.

CASE STUDY

Standardising biologics prescribing through a virtual MDT

Sheffield Teaching Hospitals NHS Foundation Trust

A weekly multidisciplinary team (MDT) meeting has standardised decision making on biologics, reducing variations in prescribing practice while increasing cost-effectiveness.

Previously the unit had an informal decision making process, which resulted in variations on issues such as the thresholds for starting patients on biologics and choice of initial medication.

The virtual MDT brought together rheumatology consultants, biologics nurses and pharmacists to agree core principles that everyone could work to. They case review each patient being newly-considered for biologic treatment. After discussing their diagnosis, co-morbidities, treatment so far and disease metrics, they agree and record next treatment options, which are then confirmed when the patient attends their first new start clinic.

The MDT also supports decision making on biosimilars, working on a presumption of lowest cost medication in the absence of a clear clinical reasons to the contrary. Team members share knowledge on new treatments, evidence and guidelines, and support each other in decision making for challenging patients.

Results

The MDT has reviewed more than 900 patients, ensuring compliance with NICE clinical standards and increasing use of lower cost medicines and biosimilars, with significant cost benefits.

CASE STUDY

Whole-system working enables better access to biologic therapies

Pan-Mersey (exemplar shared by St Helens and Knowsley Teaching Hospitals NHS Trust)

A pan-Mersey biologics group of rheumatologists, pharmacists and commissioners agrees evidence-based guidance for extending the use of biologic therapies to patients in need.

The group was set up to look at potential use of existing biologics to help patients whose situations were not specifically covered by any NICE guidelines. It has since expanded its scope to new biologic therapies and cost-effective alternatives, for example subcutaneous versions of intravenous drugs.

Rheumatologists from large acute and smaller general hospitals sit on the group with pharmacy leads from the Cheshire and Merseyside Commissioning Unit and CCG-based pharmacists. They meet every three to four months and agree areas to review.

A sub-group gathers evidence on the efficacy of the drugs in particular situations, then the wider group agrees a business plan, with pathways and guidance, including which drugs may be most appropriate for particular patients. This goes to the Pan-Mersey Area Prescribing Committee for approval. Once approved, the plan is sent to all of the CCGs.

Results

The group has standardised biologics prescribing practice and helped patients who would otherwise have been unable to access biologic therapies. These include people with inflammatory arthritis-related bowel disease and pregnant women for whom some DMARDs are contraindicated.

Recommendations: Optimising medicines

Recommendation	Actions	Owners	Timescale
18. Trusts should use national medicines data reporting systems, together with local benchmarking, published through the NHS Model Hospital and Model Health System, to enable transparent local and regional comparison of high-cost medicines usage.	a Ensure appropriate and accurate capture of prescribing spend by rheumatology departments.	Trusts	Ongoing
	b Support and implement patient level electronic systems to report on both hospital and primary care prescribing by indication and patient numbers.	NHSE/I, NHS Digital, NHSX	Within 12 months of publication
	c Develop analytical methodologies to identify opportunities to reduce local, system and regional variations, and improve patient outcomes.	NHSE/I, GIRFT, Model Hospital, RMOCs	Within 12 months of publication
	d Review high-cost drug management systems and develop interoperability with electronic prescribing systems to ensure accountability with minimal additional administrative burden.	NHSE/I, CCGs, ICSs	Within 6 months of publication

Reducing delays in switching to biosimilars

As we have seen, biologic drugs used in rheumatology are some of the most expensive used in the NHS. Many of these are biologics for which a cheaper biosimilar alternative is available, which has prompted a series of switches to these treatments over the last few years.

What are biosimilars?

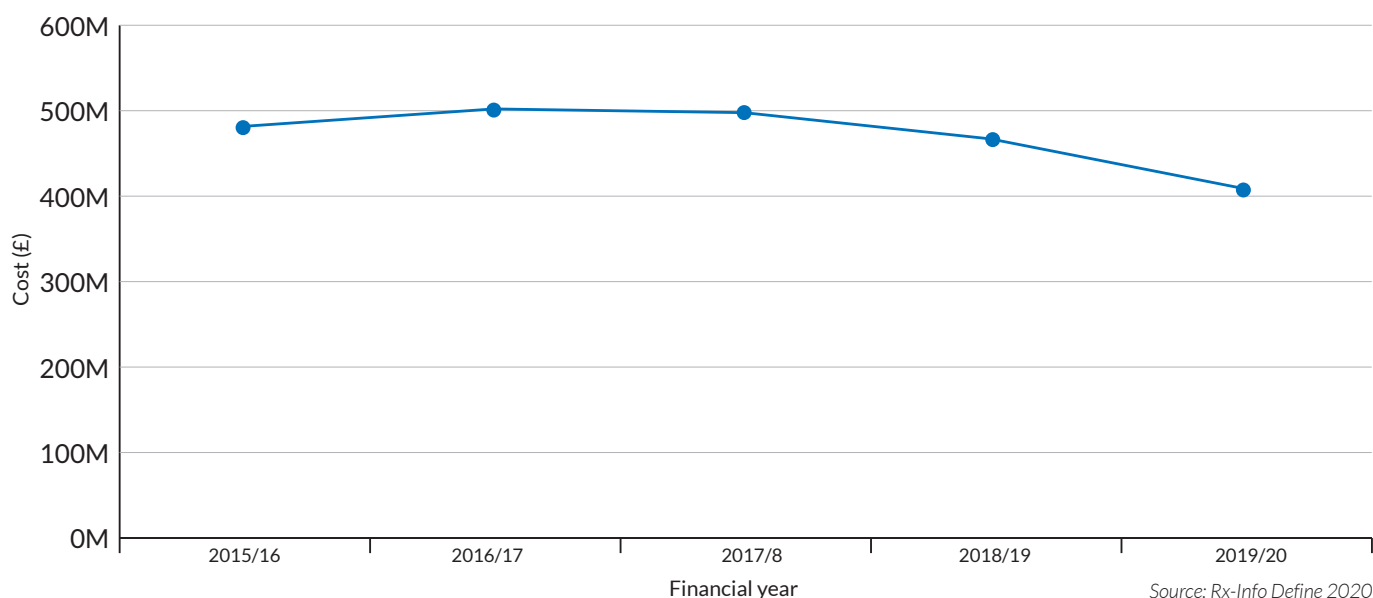
When a patent expires on a licensed biologic medicine, other laboratories may start to make very similar medicines, called biosimilars. Biosimilar medicines cost less than biologic originator medicines but have no clinically meaningful differences from the originator medicine in terms of quality, safety and efficacy. NHS England recommends that trusts move to these treatments wherever appropriate for the patient.

We found variation in how trusts were using biosimilar medicines and in the time it took different trusts to switch cohorts of patients over to a biosimilar. This is surprising, given that many trusts will be treating the same conditions, and will have largely similar proportions of patients who can be switched.

Biosimilar medicines were developed to match the originator biologic in terms of quality, safety and efficacy, but are generally far cheaper. It therefore makes sense for trusts to switch as many eligible patients to biosimilars as possible, while informing patients about proposed switches and involving them in shared decision making. Switching was mandated by NHS England for the most widely-used biosimilar, adalimumab.

Switching to biosimilars is already bringing large savings for clinical commissioning groups (CCGs), NHS England and NHS Improvement, and trusts. As shown in **Figure 34**, total drugs spend by rheumatology departments fell by more than £83 million from over £499m in 2017/18 to around £416m in 2019/20, largely driven by the switch to best value biosimilars, while caring for more patients overall.

Figure 34: Total rheumatology drugs spend in England 2015-20, all prescription types



Understanding barriers for switching

Rheumatology teams in our visits were aware of the safety and efficacy of biosimilars, and happy to switch patients. However, there are barriers to switching that need to be understood, and trusts and commissioners need to manage these appropriately:

- Safely switching cohorts of patients takes significant administrative and clinical time: this may be a barrier for many departments, particularly those that are short of staff. Deciding to switch may also be harder in departments where there is only one rheumatologist who will shoulder all responsibility for the change. In some trusts, extra staff (usually pharmacists) have been allocated to help with the switching process, as there are long-term savings to be made for the CCG, which can also be shared with the trust.
- Some clinicians and patients still have residual concerns about the relative efficacy or safety of biosimilar medicines. However, some biosimilars have been in use for some time, and have been established as safe and effective. This means that sharing experience across teams and recruitment of patients to the British Society for Rheumatology's biologics registers may be useful reassurance.
- Where patients self-administer their therapy, the delivery devices for biosimilars usually differ from the biologic original. This means patients need to be trained in the new delivery device, which can be off-putting for patients and generates additional workload for staff.

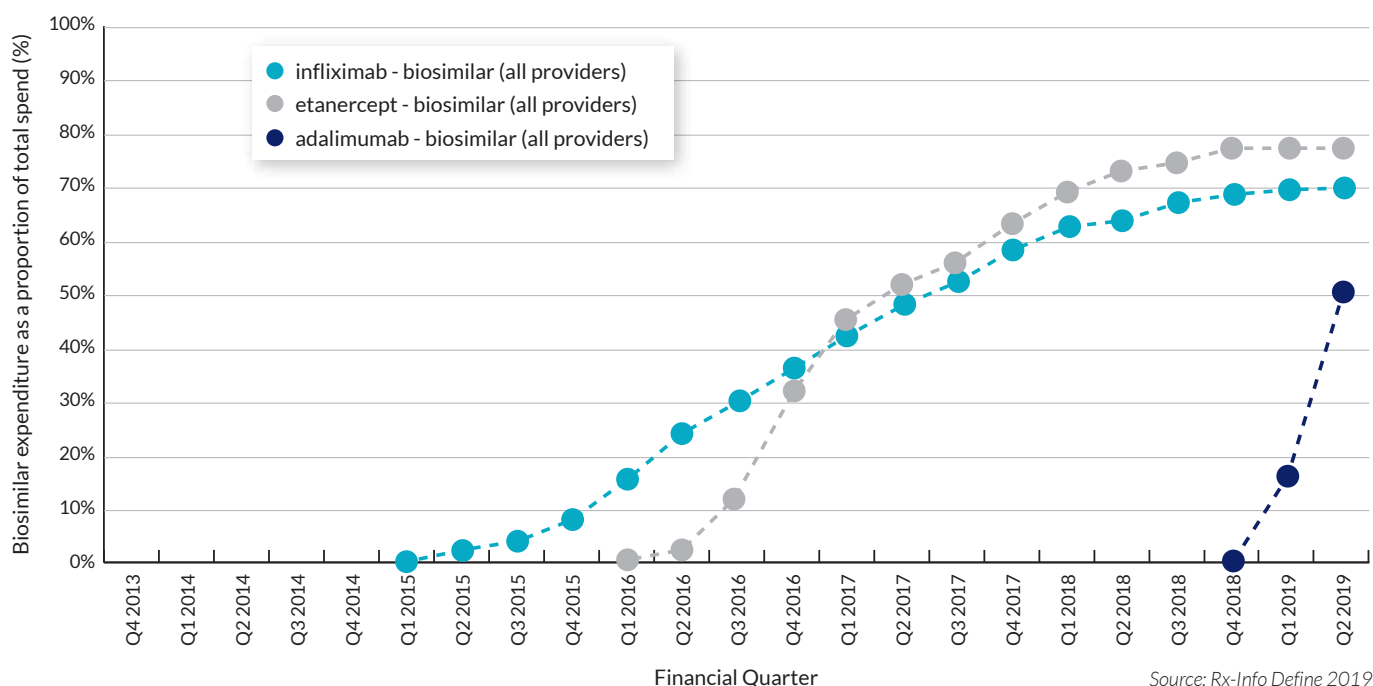
None of these barriers is insuperable, but trusts may need to put in some planning to ensure they do not delay the switching process. It is possible that specialist pharmacists may be able to play a greater role in reducing some of these barriers to switching and allaying any patient concerns. Trusts should follow the briefings on switching developed by NHS England and The Regional Medicines Optimisation Committee (RMOC)²⁵.

The impact of national initiatives

During the GIRFT process, we noted the positive effect that national initiatives have had on the adoption of some biosimilars. When comparing uptake of biosimilars, it is very clear that trusts switched patients from biologic originator Humira® to biosimilar adalimumab products very quickly following a national initiative to encourage this, which started in quarter 4 of 2018. This accelerated adoption is very clear in **Figure 35** below.

²⁵ www.sps.nhs.uk/category/rmoc-recommendation-or-resource/rmoc-medicines-optimisation-recommendation/

Figure 35: Biosimilar expenditure as a proportion of rheumatology spend on selected products 2013 - 2019



The accelerated adoption was driven by NHS England’s new commissioning framework for biological medicines²⁶, published in September 2017. The framework stipulated that eight out of ten existing patients should be switched to the best value biosimilar within 12 months. The framework also supported the use of financial incentives to maximise early adoption, such as a CCG offering to cover the cost of department-level resource required to facilitate switching.

Alongside these local financial incentives, NHS England also established a national reference price to support uptake of the best value adalimumab products, along with an implementation toolkit for trusts²⁷. Commissioners would only pay the reference price for adalimumab, regardless of whether the originator or biosimilars were used. This means that if trusts continued to use original biologic Humira® they needed to bear the substantial difference in cost themselves. This provided a further financial incentive for trusts to switch to the biosimilar.

Potential solution

It is clear from this that national initiatives are a highly effective mechanism in speeding up the adoption of biosimilars. We therefore recommend that similar national initiatives are introduced for other biosimilars, as further biologic medicines come off patent, while adhering to RMOC guidance on sequential use of biologics²⁸.

²⁶ www.england.nhs.uk/publication/commissioning-framework-for-biological-medicines/

²⁷ www.sps.nhs.uk/articles/adalimumab-toolkit-for-commissioners-and-providers/

²⁸ RMOC Advisory statement: Sequential use of biologic medicines www.sps.nhs.uk/wp-content/uploads/2020/01/Sequential-use-of-biologic-medicines-RMOC-1.0.pdf

CASE STUDY

Whole-system working enables safe switch to biosimilars

Kettering General Hospital NHS Foundation Trust

Multidisciplinary collaboration enabled Kettering General Hospital NHS Foundation Trust to switch 280 patients to biosimilar adalimumab swiftly without the need for additional resource, while keeping patients informed and involved.

Most of the patients received the drug at home, so co-ordination with the trust's home care provider and the local clinical commissioning group (CCG) was vital. Sharing resources and infrastructure with the home care provider also helped minimise the cost of switching.

A planned transition process ensured that mass switching was implemented smoothly. A letter went to all patients well in advance advising them of the planned change, with links to information and resources and a contact to discuss the change further if needed. Clinical teams were on hand to take calls and deal with any patient concerns during the transition period.

Once new prescriptions were processed through pharmacy, the home care provider contacted each patient to advise them that their next delivery would be the biosimilar. A nurse visit was arranged for each patient to re-train them on the new self-administration device.

Results

Combined with other biosimilar switches, the trust saved £360,000 from January 2019 to March 2020. The process helped to demonstrate that the trust is a cost-effective prescriber, with capacity to bring new medicines into use quickly and safely.

Reducing delays in switching to biosimilars

Recommendation	Actions	Owners	Timescale
19. Trusts and departments should continue to be supported to make rapid switches to use of best value biologic medicines, including biosimilars, where clinically appropriate.	a Develop national approaches to the choice of best value biologics, similar to the national initiative for switching to biosimilar adalimumab. This should include appropriate commissioning levers including reference pricing to support the costs of clinical changes.	NHSE/I, GIRFT, BSR	Ongoing
	b Continue to use Model Hospital (and future Model Health system) to monitor the uptake of best value biologic medicines.	Trusts, ICSs, NHSE/I	Ongoing
	c Continue to monitor patient safety and optimal clinical outcomes to support future choices around best value biologics.	NHSE/I, RMOCs	Ongoing

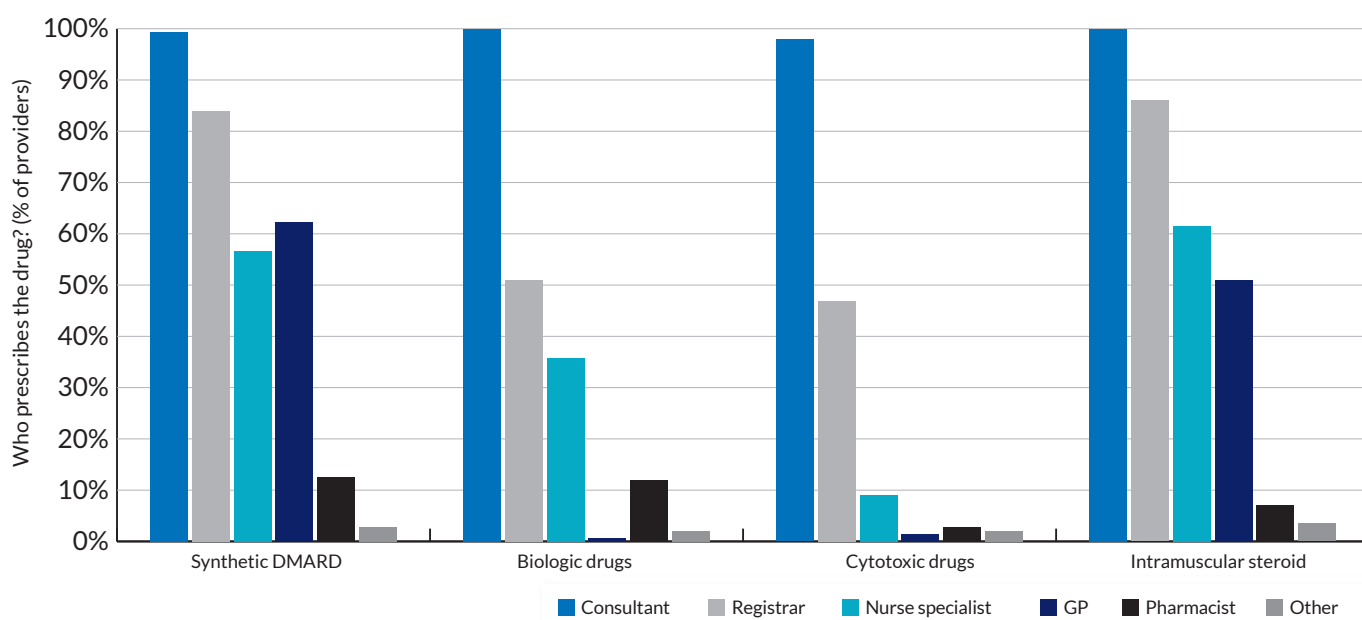
Standardising the monitoring of DMARDs

Disease-modifying anti-rheumatic drugs (DMARDs) are used to control the symptoms of a condition and prevent joint damage and deformity (see *Medicines used in rheumatology*, page 96). These medicines carry a small risk of serious side effects, and so there are corresponding safety issues, with potential for litigation. Regular monitoring is required to ensure patient safety.

Monitoring involves regular blood tests, which take up a substantial proportion of rheumatology teams' time and needs to be managed effectively. This testing also represents a significant cost for the NHS; a local audit carried out in Devon showed that DMARD testing accounts for around 5% of all blood tests carried out (before COVID-19).

Although over 85% of rheumatology departments use the British Society for Rheumatology (BSR) DMARD monitoring guidelines, we found variation in their implementation, including who prescribes initial and continuation treatment, (see **Figure 36** below), who monitors the therapy, and how repeat prescriptions are issued.

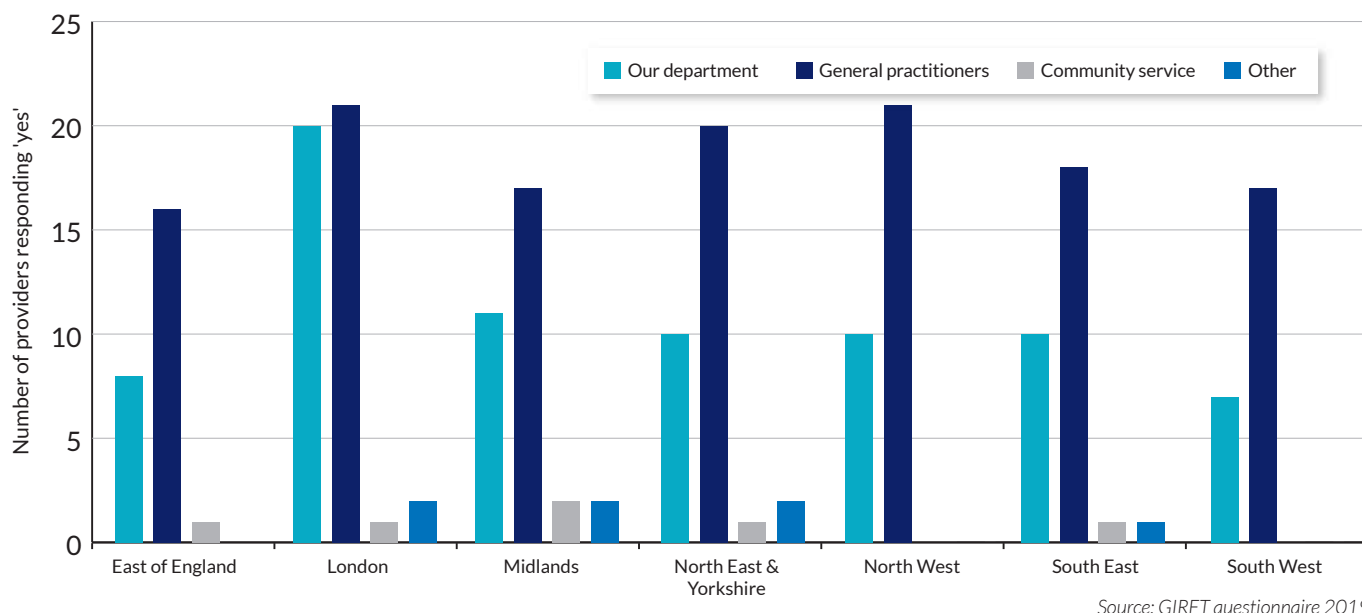
Figure 36: Medicines management: who prescribes the listed treatments? (all providers)



Source: GIRFT questionnaire 2019

We found that the most common pattern was for a patient to receive their treatment from the hospital for the first six months, and then for monitoring to continue closer to home in the community. This allows for initial side effects or queries to be managed by expert specialist nurses, doses to be adjusted and response to be assessed. However, there was considerable variation between regions in which service carries out DMARD monitoring, as shown in **Figure 37**.

Figure 37: Who provides monitoring for stable patients? (by region)



We have also found that there are different prescribing and monitoring shared care protocols between GPs and hospitals, even within the same clinical commissioning group (CCG) area.

These protocols, which include standard dosing and criteria for escalating or stopping medication, need to be standardised. This is especially important where GPs manage patients who see consultants at different trusts, and consultants treat patients from different CCGs. Juggling multiple protocols introduces unnecessary risk and increases administrative burden.

DMARD monitoring in other specialties

Many DMARDs are used by other specialties, including gastroenterology and dermatology, to treat non-rheumatic inflammatory conditions. Different specialist societies have issued their own guidance to specify how frequently monitoring for specific drugs should occur, each of which offers slightly different advice. This can be confusing and potentially lead to patient safety risks. We think that guidance should be aligned across all relevant medical specialties to ensure consistency.

One positive finding from our visits was that the majority (85%) of units said that they follow British Society for Rheumatology (BSR) guidance on monitoring. We have heard feedback that the BSR guidance is practical and easy to follow and we think it could form the basis of common guidelines that could be followed by all specialties.

The stages of monitoring

Monitoring typically involves several stages across both primary and secondary care, as shown in **Table 5**.

Table 5: stages of drug monitoring and the service or clinician responsible

Stage	Who can do this?
Taking blood from the patient	GP surgery, hospital or community phlebotomist
Testing the blood	Hospital laboratory
Presenting normal or abnormal results (electronically or on paper)	Electronic system can flag an abnormal result. Otherwise, a biomedical scientist, GP, consultant, or other clinician can decide
If result is normal: prescriptions continue	GP, consultant, junior doctor, prescribing nurse, pharmacist or other clinician, depending on trust's practice
If result is abnormal: initial steps	Consultant, junior doctor, specialist nurse, pharmacist or GP – to advise on measures to resolve the problem
If the problem doesn't resolve	Usually a consultant or junior doctor will decide on next steps.

Variation in monitoring within an ICS

Sometimes, monitoring varies between different teams within a single integrated care system (ICS) footprint. As an example, within one area:

- In GP surgeries: GPs organise blood test, record this on an electronic system, check the results themselves, and prescribe as appropriate.
- In hospital: hospital staff take blood, which is tested within the hospital; consultants check the results and prescribe as appropriate.
- In the community: phlebotomists visit GP surgeries, take blood and record this on an electronic system; GPs then prescribe if results are normal, but if results are abnormal this is sent as an electronic message to consultants.

We also found some areas where blood-taking and prescribing were carried out in different settings and by different teams: for example, where blood-taking happened in hospital, but primary care providers issued the prescriptions. This carries a higher risk of miscommunication and error.

This variation can mean that every hospital is dealing with monitoring information in multiple formats and from multiple systems. This can cause issues within the trust's area, and if a patient moves between hospitals, these problems can multiply. GPs may also be dealing with different systems for different rheumatology departments, leading to further risk of error.

There is a strong case for aligning monitoring and prescription systems between specialties, not just rheumatology, to reduce these risks.

We also found through deep-dive discussions that while many trusts felt confident in their own monitoring systems, some were less confident in the monitoring of stable patients carried out elsewhere. However, we found that 85% of trusts were already using BSR guidance, meaning we can start from a strong position on standardising monitoring.

The impact of monitoring variation and lack of joined-up care records

The current inability to match up prescription records between community or primary care and secondary care means that it can be hard to gain an overview of the patient's medication.

This is a problem in itself when monitoring patients, but also presents problems in understanding variation in prescribing practice overall.

Monitoring variation has a serious impact on patients and providers alike:

- The most significant impact of this variation is on patient safety and care. DMARDs can provide significant benefits to patients but do have the potential for serious side effects. It is vital that this balance is managed carefully.
- Monitoring variation also affects how effectively results can be shared across organisations within an ICS, which also impacts on how quickly clinical decisions can be made.
- Managing information from multiple systems adds to staff's administrative burden.
- Finally, the lack of monitoring and resulting failure to act on problems, and the lack of a clear view of current medication mean there is more scope for errors, which could lead to patient safety incidents or litigation claims.

How electronic systems can speed up, ease and standardise monitoring

We found that only 25.2% of trusts used an electronic monitoring programme for DMARDs. This means that patients' results are often being recorded and transferred on paper, which is slower and more labour-intensive, draining precious administrative and clinical time and increasing the risk of error, including lost records.

An electronic monitoring system can:

- ensure that results are transferred more quickly;
- enable clinicians to check monitoring results from whichever location they happen to be in – this is particularly relevant for split-site working, and remote working (as has happened during the COVID-19 pandemic);
- flag abnormal results automatically, speeding up decisions on whether a result is normal or abnormal;
- standardise formats so that information can be shared across the ICS (although to do this the systems must be interoperable);
- help to standardise practice;
- free up clinical time, including from nurse specialists, by ensuring monitoring can be achieved as efficiently and as remotely as possible.

Electronic monitoring systems may also allow patients to view their own results, helping them self-manage more effectively.

For these reasons, we feel all trusts should adopt electronic systems for monitoring, and ensure these systems are interoperable across their ICS. We appreciate that this involves an upfront and licensing cost to the trust, but we are confident that the benefits, in terms of freed up staff time, reduced error, and improved patient outcomes, will outweigh this cost (see case studies on page 111).

Identifying patients on particular therapies

Early in the COVID-19 crisis, it became clear that it was difficult to identify all patients receiving particular treatments, to identify those who were in the 'clinically extremely vulnerable' category during the shielding phase of the pandemic – see *Learnings from COVID-19*, page 120.

This problem was due to the use of multiple systems for prescribing, lack of electronic prescribing information and also due to diagnoses not being coded in an outpatient setting. To create a list of vulnerable patients, trusts had to laboriously work through multiple lists, increasing the potential for human error and delay.

Creating unified systems for prescribing and monitoring for patients, and ensuring that diagnoses are coded correctly in outpatients, would mean that in future it would be far simpler to identify all patients taking a particular medicine or living with a particular condition. This could be useful for a variety of reasons – for example if there is a safety concern about a treatment, or a clinical trial involving these patients – as well as creating shielding lists for any future pandemic.

Potential solutions

To summarise the potential solutions for monitoring DMARDs:

- We believe that if DMARD monitoring and prescribing were standardised and managed in a networked way at ICS level, this would improve consistency of practice.
- Using an electronic monitoring system that works across the ICS would maximise the gains in terms of freeing up staff time, speeding up decisions, and making information available in a clear, standard format to staff and patients alike.
- As well as reducing consultants' administrative burden overall by standardising tasks, the approach can also be designed to work with appropriate personnel, including administrative staff, laboratory staff, pharmacists, and nurses.

- A standardised approach could promote better self-management by patients between blood tests through clearer, more uniform information.
- It would make identifying patients on particular treatments, for example for risk stratification of clinical vulnerability during pandemic infection, far easier.

CASE STUDY

Patient-centred DMARD monitoring through shared care protocols

University Hospitals Bristol and Weston NHS Foundation Trust and North Bristol NHS Trust

DMARD monitoring protocols agreed with primary care and the local clinical commissioning group (CCG) have improved continuity of care for patients and reduced risks from polypharmacy.

The shared care protocols standardise ongoing care for patients on DMARDs across the Bristol, North Somerset and South Gloucestershire region. Diagnosis, testing and first month of treatment are all performed by rheumatology, after which prescribing and monitoring transfer to primary care with rheumatology support. Patients receive counselling and information before starting the process.

There are separate protocols for each DMARD, with detailed shared care guidelines covering:

- usual dose and frequency of administration
- frequency of monitoring and when to escalate
- side effects and how to manage them
- significant drug interactions and contra-indications
- when to refer patients back to rheumatology

Education was provided for GPs, who can also contact rheumatology through an advice line for quick response to issues and queries.

Results

GP-led monitoring has reduced pressure on hospital-based services leading to shorter waiting times. Care is closer to home and, because it is more co-ordinated, there are fewer risks from polypharmacy for patients who may have multiple co-morbidities. Feedback from GPs on the shared care guidelines has been very positive.

CASE STUDY

Community-based DMARD monitoring reduces pressure on hospitals

The Newcastle upon Tyne Hospitals NHS Foundation Trust

The trust uses community assessment hubs and electronic systems to improve the efficiency of DMARD monitoring and reduce pressure on busy hospital units.

Patients who require monitoring have their blood tests in community hubs, with results recorded on an automated system, which enables effective joint working between hospital and community teams. The hospital rheumatology unit only becomes involved if the bloods are abnormal. Clinicians at the trust receive an alert through the system. This prompts the creation of a joint management plan including decisions on any further blood tests needed, or whether to temporarily stop or re-start the medication. The plan is then communicated to the patient via nursing staff.

Results

The system enables most monitoring to happen outside of hospital with specialist rheumatology support as needed. This has reduced pressure on waiting lists, while enabling almost 1,000 patients to access services closer to home.

Recommendation: Standardising the monitoring of DMARDs

Recommendation	Actions	Owners	Timescale
20. Disease-modifying anti-rheumatic drugs (DMARD) monitoring processes should be standardised across integrated care system (ICS)/sustainability and transformation partnership (STP) footprints and medical specialties, linked to an interoperable electronic monitoring system.	a Standardise DMARD monitoring processes across ICS footprints, possibly co-ordinated by newly appointed clinical pharmacists working in Primary Care Networks (PCNs).	Trusts, ICSs, BSR	Within 18 months of publication
	b Align guidance on DMARD monitoring across all relevant specialties to reduce variation.	BSR, British Association of Dermatologists (BAD), British Society of Gastroenterology (BSG)	Within 12 months of publication
	c Move to electronic monitoring systems – ideally interoperable across ICS footprints.	Trusts, ICSs	Within 18 months of publication (alongside action 20a where possible)

Research and innovation

Over the last 20 years, rheumatology practice has been transformed, in particular by the advent of new medicines, alongside changes in the use of older medicines. It is a specialty with rapid advances, covering complex, multi-system inflammatory conditions where our knowledge and understanding is evolving at pace. Participation in clinical research helps to build on the latest scientific developments, widen the evidence base and optimise management protocols and treatments to deliver better outcomes for patients.

Rheumatologists have a strong tradition as leaders of clinical research and understand the value of contributing to the full spectrum of research activity ranging from innovations to participation in trials, observational studies and national and local audits. A notable example has been the high level of engagement in the British Society for Rheumatology (BSR) biologics registers which over many years have provided very rich information about real world use of new treatments, and had a significant influence on rheumatology practice in the UK and beyond.

Research is especially important for rare and complex conditions which do not have the same visibility or evidence base for treatment as more common, higher profile conditions. Participation in research provides clear benefits for individual trusts as well as the wider rheumatology community. For example:

- Studies show that research-active trusts are associated with lower mortality rates²⁹.
- Commercial and non-commercial research activity can generate income to support further research and innovation.
- Research supports the life science industry.
- Participating in clinical trials enables patients to benefit from the latest treatments and innovations.

Research can provide experience of new medicines and regimens, and generate confidence in their use. Patients should be considered for clinical trials at relevant points in their therapeutic journey. However, it is important to balance this with the concerns that patients who are prescribed free or discounted new medicines as part of a trial can later find it hard to transition back to less expensive medicines.

Understanding participation in rheumatology research

Research activity is already generally well-established in rheumatology. Some NHS England specialised commissioning policies for high-cost medicines mandate that patients are enrolled in specific research registries, to generate the evidence to support ongoing commissioning (see *Equitable access to specialised care for rare RMDs through regional networks*, page 64). As discussed above, the BSR biologics registers, in particular, are considered to be important national projects that rely on input from the whole of the rheumatology community for their impact.

However, there is no central data register of the number of patients recruited in individual rheumatology departments. To explore this further, we identified all the rheumatology-specific clinical studies in the National Institute for Health Research (NIHR) research portfolio. First, we accessed the written outlines of all NIHR portfolio registered studies and identified those which might reasonably be eligible to recruit patients from rheumatology. To measure rheumatology research activity, we then looked at:

- the total number of these studies that were actively recruiting to each trust;
- the total number of patients recruited in each trust.

We categorised the studies as: commercial or non-commercial; open only to recruitment from a single trust or more widely; national registers or other portfolio-registered projects. The data for this analysis were obtained through a data sharing agreement with NIHR.

Table 6 summarises the median number of studies and median number of patients recruited to rheumatology studies, categorised by trust type.

²⁹ *Research Activity and the Association With Mortality (2015): Baris A Ozdemir, Alan Karthikesalingam, Sidhartha Sinha et al* <https://pubmed.ncbi.nlm.nih.gov/25719608/>

Table 6: Trust participation in rheumatology research studies

	Median number of studies per site (IQR*)	Median number of recruits per site (IQR*)
All rheumatology study types (Source: NIHR FY 2018/19)		
All recruiting sites	8 (3.5, 14)	29.5 (9.5, 107)
Teaching	20 (14, 30)	214 (70, 392)
Large	8 (5, 14)	30 (10, 101)
Medium	6 (3, 11.5)	22.5 (6.5, 70)
Small	5 (4, 7)	21 (10, 55)
All rheumatology studies – commercial and non-commercial (Source: NIHR FY 2018/19)		
Commercial	1 (0, 4)	0 (0, 4.5)
Non-commercial	5.5 (3, 10)	28 (9.5, 103)
National registries – single year (Source: NIHR FY 2018/19)		
All sites	2 (1, 3)	13.5 (5, 27)
Teaching	3 (3, 4)	32 (19, 59)
Large	2 (1, 3)	19.5 (5, 34)
Medium	1 (1.3)	10 (5, 18)
Small	1 (0.2)	7 (0, 15)
National registries – over three years (Source: NIHR FY 16/17-18/19)		
All sites	3 (2, 4)	20 (51, 107)
Teaching	4 (3, 5)	127 (81, 192)
Large	3 (2, 4)	60 (24, 128)
Medium	3 (1, 4)	45 (22, 78)
Small	2 (1, 3)	20 (10, 37)

*The interquartile range (IQR) is the range of values in the central 50% of the dataset.

Source: NIHR

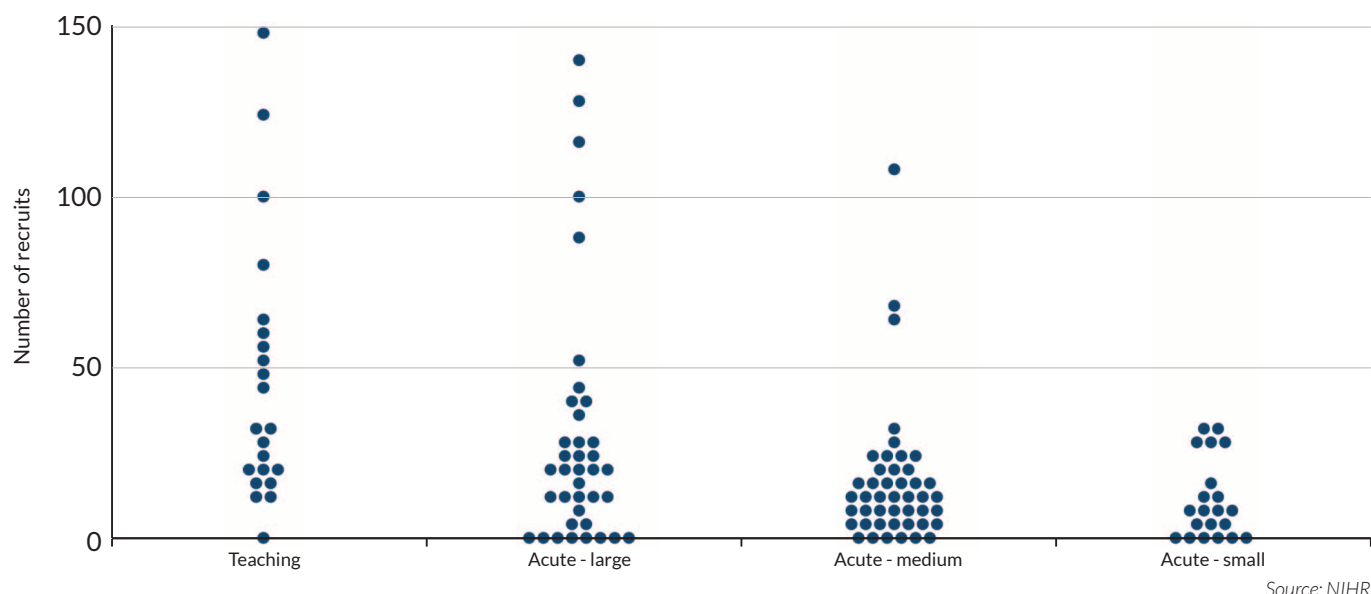
Variation in participation

As shown in **Table 6**, there is substantial variation between trusts in the numbers of studies engaged with and number of patients recruited. To some extent, this related to the size of the trust, and whether or not they were allied to a teaching or research facility, as also illustrated in **Figure 38**. However, these features did not fully explain the variation in participation.

Where participation was lower than expected, clinicians told us on our visits that the major barrier to recruitment was a lack of time in job plans and insufficient access to research nurses and administrative staff, who play an important role leading and supporting research respectively. In some trusts we heard that there had been a decline in research support for non-commercial studies, such as registries, which did not generate income, and difficulties accessing clinical space to undertake research assessments alongside clinical care.

Undertaking research, particularly interventional trials, without appropriate time allocation for medical oversight, is a governance risk to patient safety. In some trusts we heard of successful models where research was integrated into clinical care with specialist nurses undertaking hybrid research nurse roles.

Figure 38: Number of patients recruited to national registers in financial year 2018/2019 categorised by trust type



Recruitment to registries

Table 7 shows participation in key drug and disease registries. The BSR biologics register for rheumatoid arthritis (BSRBR-RA) had the largest number of participating centres, with 62% of trusts involved in recruitment. Continuing recruitment to this register has been driven by the opportunity to study large numbers of patients switching to biosimilar medication.

Registries related to rare RMDs, including BILAG BR (British Isles Lupus Assessment Group Biologics Registry), UKIVAS (UK and Ireland Vasculitis Rare Disease Group), MYOACT/MYOPROP (Myositis Disease Activity/Myositis Prospective Registry) and UK GCA Consortium, are the next most frequent studies, illustrating the role of NHS England commissioning policy to drive the synergy between clinical care and research. However, since these registers are open to all trusts, and have relatively low participation figures, we think there may be an opportunity for greater engagement with these studies.

Table 7: Participation in specific research studies, numbers of trusts and patients

Register studies (England)	NIHR FY 2018/19 (1 year)				NIHR FY 16/17 – 18/19 (3 years)			
	Average patients (all trusts)	Number of participating trusts	Total patients registered	Patients per participating trust	Average patients (all trusts)	Number of participating trusts	Total patients registered	Patients per participating trust
GCA Consortium	1.5	29	229	7.9	5.9	40	904	22.6
BSRBR- RA Toxicity from biologic therapy	8.8	95	1350	14.2	30.5	120	4668	38.9
BILAG Biologics Prospective Cohort	1.4	33	213	6.5	3.7	49	570	11.6
BSRBR-AS	-	-	-	-	6.3	65	962	14.8
UKIVAS	7.0	57	1072	18.8	21.6	64	3300	51.6
MYOPROSP	0.5	20	80	4.0	1.2	24	182	7.6
BSRBR-PsA	0.7	11	101	9.2	-	-	-	-

Source: NIHR

Increasing participation in rare disease registries

As discussed above, the NHS England service specification for specialised rheumatology mandates participation in research, stating that ‘all patients with severe or refractory autoimmune disease should be registered with a specialist centre and entered into a registry to allow systematic analysis of patient outcomes’³⁰. Likewise, the UK Strategy for Rare Diseases³¹ sets out a national priority to create a stronger evidence base for treatment of rare conditions through research.

We therefore looked at whether there might be opportunities to increase the extent of rare disease registry recruitment. We examined trust data returns from the specialised commissioning quality dashboard, focusing on the proportion of their patients each trust estimated had been recruited to specific studies during each quarter of 2018-19. This is shown in **Table 8**. We observed high levels of recruitment to registers related to the use of high cost drugs. However, in many cases registration was not completed and a number of units failed to register any patients in this interval.

The proportion of patients participating in NIHR portfolio studies was also lower than might have been anticipated, which suggests there may be opportunities to develop research for this group of patients. **Figure 39** shows a breakdown of portfolio studies by trust type.

³⁰ NHS standard contract for specialised rheumatology services (adult) www.england.nhs.uk/wp-content/uploads/2013/06/a13-spec-rheumatology.pdf

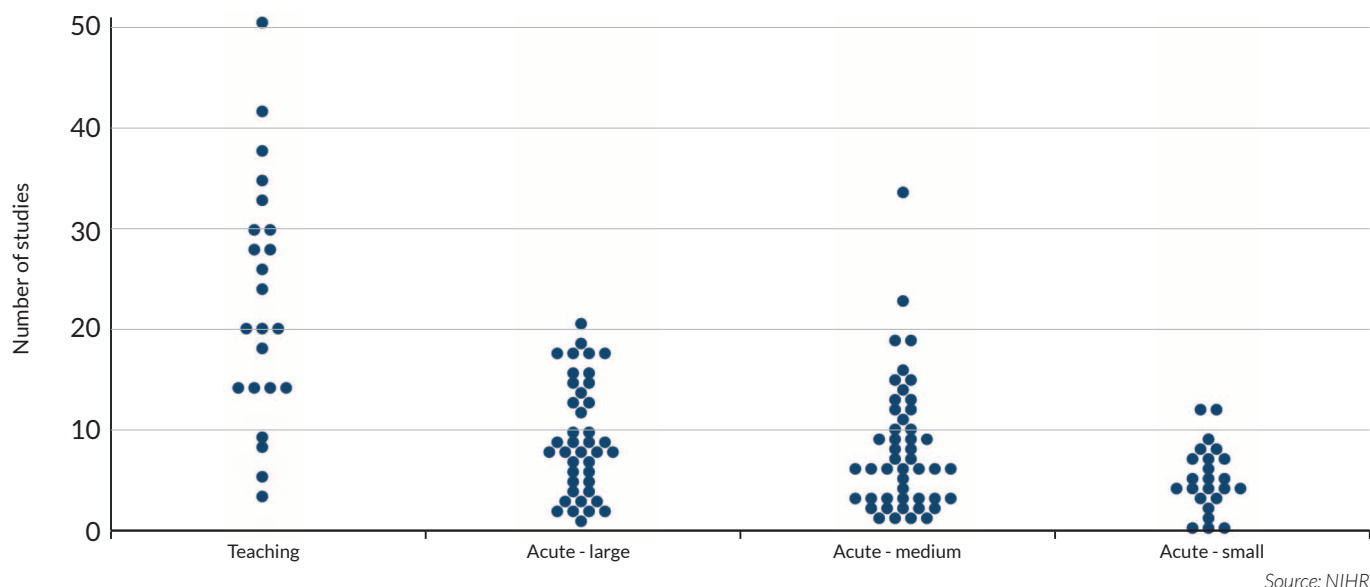
³¹ Department of Health The UK strategy for rare diseases https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/260562/UK_Strategy_for_Rare_Diseases.pdf

Table 8: National averages for recruitment to specialised commissioning registries

Specialised commissioning of systemic autoimmune rheumatic disease and rare disorders 2018/19	National Average Q1	National Average Q2	National Average Q3	National Average Q4
Proportion of patients with lupus who received rituximab and are registered on BILAG BR	72.9%	82.8%	78.5%	87.3%
Proportion of patients with ANCA-associated vasculitis who received rituximab and are registered on UKIVAS	59.6%	60.0%	55.6%	57.0%
Proportion of all specialised rheumatology service patients seen as outpatients who have participated in cross-sectional NIHR Clinical Research Network portfolio studies	4.3%	4.7%	4.3%	6.9%
Proportion of all specialised rheumatology service patients seen as outpatients who have participated in longitudinal NIHR Clinical Research Network portfolio studies (including observational and interventional studies)	3.7%	7.2%	7.6%	9.1%
Proportion of patients with inflammatory myositis who received rituximab and are registered on MYOACT/MYOPROSP	60.0%	38.1%	85.2%	65.4%
Proportion of patients with lupus who received belimumab and are registered on BILAG BR	92.0%	92.5%	94.1%	100.0%

Source: Specialised Commissioning Quality Dashboard 2018-19

Figure 39: Number of portfolio studies recruiting to all trusts in FY 2018/2019 categorised by trust type, based on those studies identified as having potential for recruitment from rheumatology departments



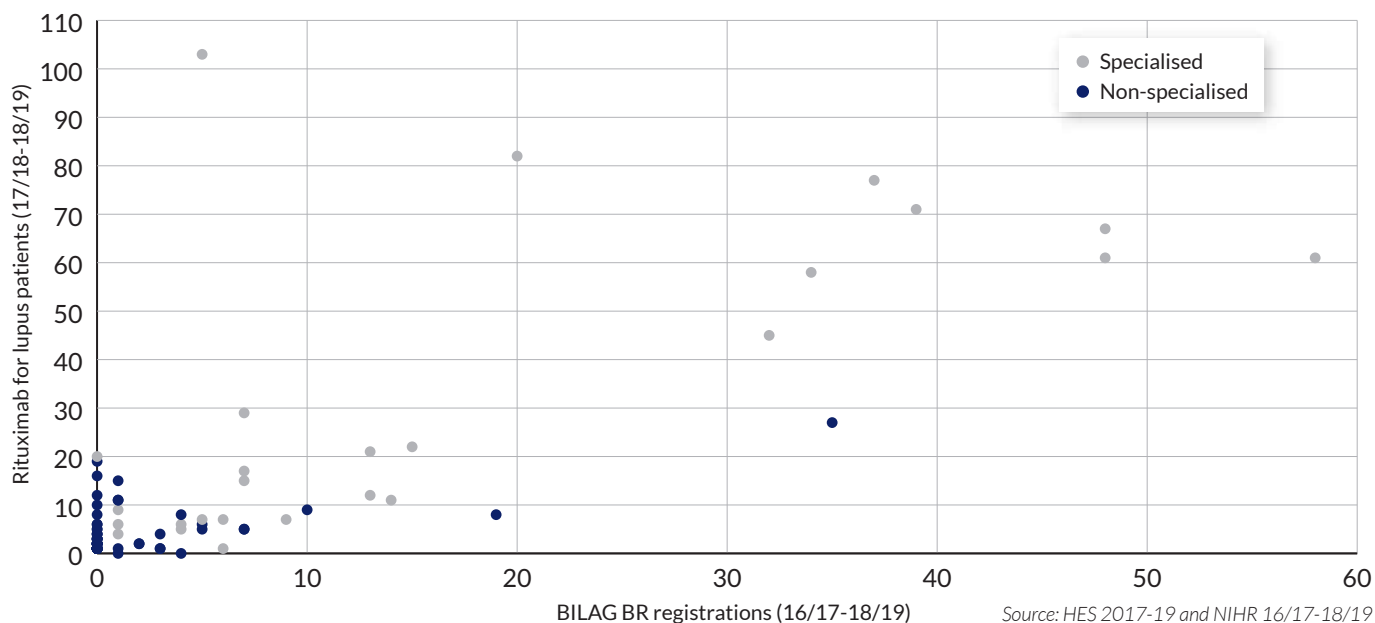
We further investigated participation in BILAG BR by relating the number of patients treated with rituximab for lupus in each unit 2017-19 to the number of new recruits to the BILAG BR 2016-19. This is shown in **Figure 40**, which illustrates that rituximab use and registry recruitment is much higher in specialised centres, indicating compliance with NHS England commissioning policy in the majority of these units. Registry data has provided an evidence base for the successful re-commissioning of this important treatment in 2020³².

However, there are some specialised and non-specialised centres where use of rituximab is associated with either a very low or no recruitment to BILAG BR. We do not know whether this is for a valid reason – for example patients may have been recruited at another specialised centre, or have had re-treatment following recruitment prior to 2016. Improved compliance with BILAG BR, and all of the other specialist disease registries remains an important goal as part of building the case for the use of effective high cost treatments for patients with rare diseases.

³² NHS England Clinical commissioning policy: Rituximab for refractory Systemic Lupus Erythematosus (SLE) in adults and post-pubescent children [200402P]
www.england.nhs.uk/wp-content/uploads/2020/07/Rituximab-for-refractory-Systemic-Lupus-Erythematosus-in-adults-and-post-pubescent-children-2.pdf

Figure 40: Rituximab for lupus patients versus BILAG BR registrations

(accepting that some patients treated with rituximab in 2017-19 may have been initially treated and recruited before 2016 and some recruited to BILAG BR do not receive rituximab)



Potential solutions: removing the barriers to participation

The barriers to research participation in clinical practice are widely recognised, and were also apparent in our discussions with rheumatologists on our deep-dive visits. From our own observations, we have noted that the most effective research-active departments have:

- a clearly defined strategy of how to prioritise the selection of research studies and ensure maximum, safe, recruitment;
- close collaboration with research and innovation departments and NIHR Clinical Research Networks with access to support such as research nurse and administrative/research co-ordinators;
- clinical job plans that allow enough time for the role of a principal investigator, particularly in interventional clinical studies;
- a strong level of patient engagement in designing research studies and registers.

Data collection for studies should not become a burden on clinicians. Wherever possible data collection on treatment and outcomes for rare diseases should be aligned with routinely collected data. We think that expanding rare rheumatology disease registration with the National Disease Registration Service (NDRS) – as proposed in Recommendation 11d (see page 74) – could help achieve this, and potentially enable automated reporting of data to the rare disease register, with appropriate governance and permissions.

The NDRS has existing infrastructure for collecting and processing national data on rare diseases, linking to national datasets such as the Hospital Episode Statistics (HES), Office for National Statistics (ONS) mortality data, and primary dispensing data. It can help co-design data systems to ensure interoperability and non-duplication of effort.

Recommendation: Increasing participation in research

Recommendation	Actions	Owners	Timescale
21. Adequate resource should be allocated to ensure trust involvement in research and to support submission to relevant patient registries.	a Allocate time to lead or contribute to research in consultant job plans.	Trusts	Ongoing
	b Promote clinically-focused research questions from registries and disseminate results to clinical teams as well as via an academic route.	BSR, other registries	Ongoing

Learnings from COVID-19

As part of the ongoing GIRFT process, we have looked at how trusts have adapted their services to cope with COVID-19 while continuing to meet the needs of rheumatology patients, and any lessons that can be learned for the restoration of services.

In July 2020, after the first wave of the pandemic, we carried out an online survey of rheumatology clinical leads in all 134 trusts in the UK and received 109 responses (80%). Unsurprisingly, the results reflected the serious strain that the pandemic placed on departments, services and patients.

The urgent need to prioritise services and beds for COVID-19 patients led to the complete closure of five rheumatology departments, while 26 were required to relocate. In 69 trusts, rheumatology consultants were redeployed to general medical wards. Helplines experienced intense demand in the first few weeks of the pandemic, with patients afraid to attend hospital sites.

However, despite these pressures, rheumatology services showed considerable resilience. Rheumatologists worked hard to keep high quality core services operating for patients with inflammatory rheumatic and musculoskeletal disorders (RMDs).

- 98% kept their helpline running
- 88% retained face to face capability for new patients
- 93% maintained at least minimum levels of urgent and routine services for core inflammatory diseases
- 95% supported day case infusions
- 94% maintained pathways for giant cell arteritis (GCA)

How units adapted to maintain core services

Many of our respondents said they changed their triage procedures – for example, by prioritising face-to-face consultations for urgent referrals of new patients and re-triaging existing referrals, returning some patients who didn't need rheumatology care to the referrer. These practices have the potential to improve referral systems longer term and should be supported by clearer criteria for referrers, as envisaged in Recommendation 2b.

Some innovations which had been in the earlier stages of development were accelerated into large scale application. For example, units were able to limit the number of day case appointments for intravenous infusion by switching patients from intravenous to oral or subcutaneous alternatives which can be administered in the community. This has great potential as an alternative to day case admission, as we propose in Recommendation 17d. Patient contact was also limited by monitoring stable patients less frequently with appropriate support (see Recommendation 3b).

Updated advice issued by NHS England supported these changes, as did the National Institute for Health and Care Excellence (NICE) COVID-19 rapid guideline for rheumatology, which indicates which conditions should be considered for priority treatment³³.

In comments sent with their responses, clinical leads highlighted other examples of how they had managed demand and kept services running:

- offering a helpline by email as well as a telephone to expand capacity;
- holding daily hot clinics for the most urgent cases;
- increasing the capacity of the nurse-led advice line;
- developing educational material on management of conditions such as gout and fibromyalgia with signposting to resources for patients and GPs;
- reducing the frequency of DMARD blood monitoring and offering the option of phlebotomy at home for patients who were shielding;
- encouraging GPs to make greater use of Advice and Guidance (A&G) services;
- developing a virtual pain management programme delivered online;
- nurse-led annual review and escalation clinics.

Signposting to resources from the voluntary sector, such as websites, chatbots and helplines also proved useful in managing demand for help and information.

³³ NICE COVID-19 rapid guideline [NG167]: rheumatological autoimmune, inflammatory and metabolic bone disorders, recommendation 4.9
www.nice.org.uk/guidance/ng167

Issues and limitations

Many rheumatologists expressed anxieties over the limitations of remote consultation and the lack of capacity for face-to-face reviews. These were seen as essential for all new patients, as diagnosis and treatment is so dependent on physical examination and observation of movement. For example, some monitoring of patients with multisystem autoimmune disease, such as muscle strength scoring, can only be done face-to-face, while unpredictable flares, including extension of disease to new organ systems, also require physical examination and urgent follow-up.

Feedback from patients with rare autoimmune RMDs also suggests frustration with remote consultations, which in some cases may be of limited use without the relevant physical monitoring tests³⁴.

Although subcutaneous versions of many drugs were available and integrated into practice, some, such as belimumab, were approved for established patients only during COVID-19, so their use was limited and did not benefit new patients.

Impact on services

While core services were maintained, rheumatologists reported major impacts across their departments. For example:

- 40% of trusts had to restrict day case infusions to selected patients;
- 38% said they had lost access to ultrasound and biopsy services for GCA during the pandemic.

Pain services were discontinued in many units, while treatment for patients with osteoporosis was deferred. Some trusts stopped services for osteoporosis and chronic pain altogether, while physiotherapy, occupational therapy, and psychology services were severely disrupted at many sites.

Care outside of hospital

The closures mentioned above illustrate the fragmented provision of care for non-inflammatory painful conditions in many hospitals. Patients may have suffered less disruption if dedicated services were available in the community – as we propose in Recommendation 1. Patients with long COVID who have prolonged musculoskeletal symptoms would also benefit from access to local reablement services, reinforcing the need to design services around patient needs.

We note that the role of musculoskeletal (MSK) first contact practitioners (FCPs), which had been piloted in some areas, was accelerated during the first wave of the pandemic, supported by Health Education England. These are community-based physiotherapists with extended skills, often based in GP practices, who can provide rapid care for patients without the need for a referral. We support this development and think the FCP role should be developed across England.

Data and coding challenges

One of the greatest challenges faced by rheumatologists was in identifying those patients who needed to shield. Often this required a labour-intensive manual trawl through electronic patient records (EPRs) or spreadsheets of patient medication records. In some instances, different agencies provided conflicting advice, causing confusion, and there were examples of patients who were overlooked. This task would have been much easier if information on outpatients was recorded as part of the coding system, underlining the need for coding of all outpatient diagnoses – see Recommendation 7.

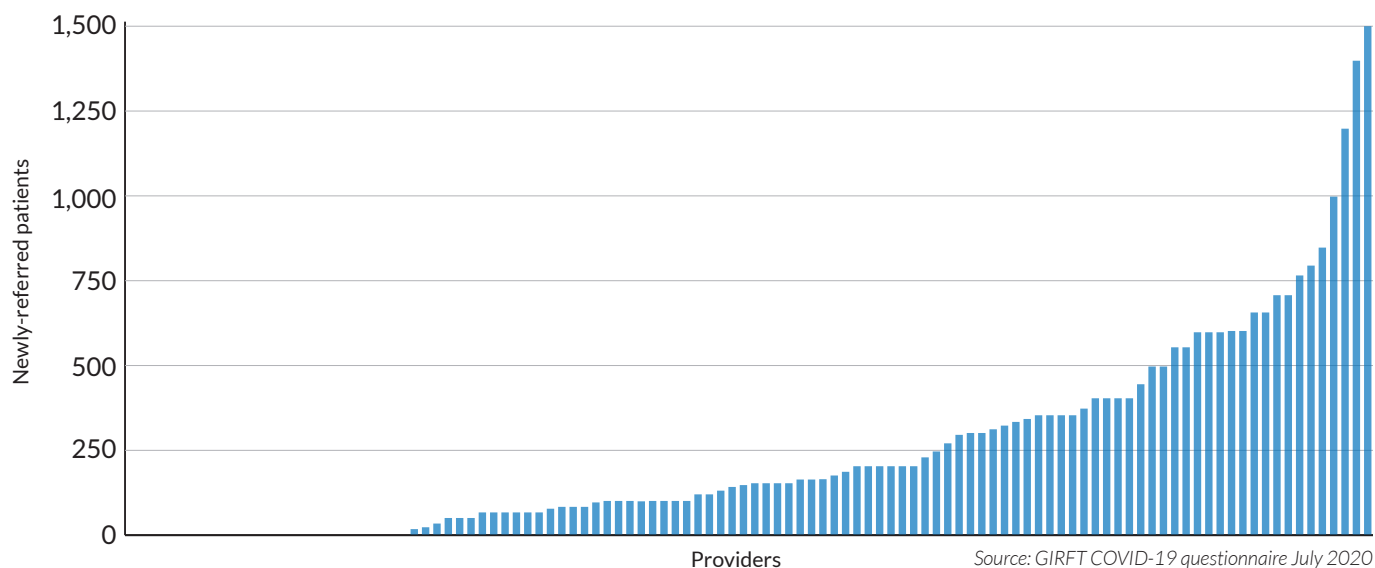
Backlog of new patient referrals

Despite the best efforts of units to keep services running, by July 2020 there was wide variation in the backlog of new referrals to rheumatology. While some trusts managed to keep fully up to date, in most the number of new patients waiting rose dramatically, as shown in **Figure 41**. The median number of new referrals awaiting appointment was 155, with 25% of trusts reporting a backlog of 500 or more. The backlog was generally larger in trusts with greater levels of medical redeployment.

This further highlights the urgent need to agree clear criteria for referral so that GPs and others only refer cases that require urgent rheumatology assessment and care – see *Improving management of referrals*, page 40.

³⁴ RAIRDA Report, *Chronic crisis: the Impact of COVID-19 on people with rare autoimmune rheumatic diseases* www.lupusuk.org.uk/rairda-chronic-crisis-report/

Figure 41: Numbers of newly-referred patients waiting for an appointment by trust



Concerns about the viability of rheumatology services

The short term disruption to services in the first wave of the pandemic risks causing long term harm to patients with rheumatic disease. Many trusts reported that multidisciplinary teams (MDTs) were fragmented limiting the scope for joined-up care.

The upheaval many have experienced made some fear for the future of rheumatology services in their region. Some respondents expressed concerns that they might never be able to provide a high quality service in the future. Urgent co-ordination is needed on a national and regional basis to support rheumatology units that have become more fragile through the pandemic – see *Supporting smaller rheumatology units*, page 55.

Priorities for the future

The pandemic is continuing to disrupt services. While managing demand through any further waves, we must also plan for the restoration of services and use the learnings from COVID-19 to improve them for all patients. Priorities for rheumatology departments in the future should include:

- restoring the best care for core inflammatory RMDs;
- maintaining safe and effective methods of consultation, including face-to-face appointments for those who need them;
- providing effective community rehabilitation for all as close to home as possible;
- achieving digital maturity for diagnostic coding, patient identification and monitoring to support new practices.

Another key lesson is that all rheumatology units should have business continuity plans that set out how they will continue to deliver priority and core services in the event of severe service disruption, whether it is a further phase of COVID-19 or an unrelated crisis. We think there is a need for national guidelines to support this, setting out what core business continuity looks like for each specialty.

Litigation

Reducing the impact of litigation

Each of the GIRFT programme teams has been asked to examine the impact and causes of litigation in their field – with a view to reducing the frequency of litigation and, more importantly, reducing the incidents that lead to it. It is important that clinical staff have the opportunity to learn from claims and complaints, including serious incidents (SIs), Patient Safety Incidents (PSIs) and inquests. This can lead to improved patient care and reduced costs both in terms of litigation itself and the management of the resulting complications of potential incidents.

It was clear during GIRFT visits that many providers had little knowledge of the claims against them. This includes some with high litigation costs per admission as well as those at the low end. As a consequence, there is an opportunity to learn from the claims to inform future practice.

Further work is needed at both a local and national level to analyse claims to maximise this opportunity to improve patient care. This could be done through morbidity and mortality meetings or multidisciplinary team (MDT) meetings, possibly linking with other related specialties, such as ophthalmology, and renal medicine to discuss cases and share learnings from claims.

Variation in average litigation costs

Data obtained from NHS Resolution shows that potential estimated clinical negligence claim costs in rheumatology ranged between £4.3 million and £15.8 million per year over the five years 2013/14-2017/18 (**Table 9**). We found the national average estimated cost of litigation per rheumatology admission or outpatient appointment was £3. There are noticeable differences between providers, as shown in **Figure 42**. The best performing provider is estimated to cost £0, while at the other end of the scale, one provider is expected to generate an average litigation cost of £53 per admission or outpatient appointment. It should be noted that when compared to other medical specialties, and especially to surgical specialties, litigation claims in rheumatology are relatively rare and payments are, in relative terms, generally quite small.

Figure 42: Variation in England between trusts in estimated litigation costs for rheumatology per admission or outpatient appointment notified to NHS Resolution 2013/14 to 2017/18

Includes emergency, elective and day case, excludes all surgical and paediatric specialties, for patients aged 19+

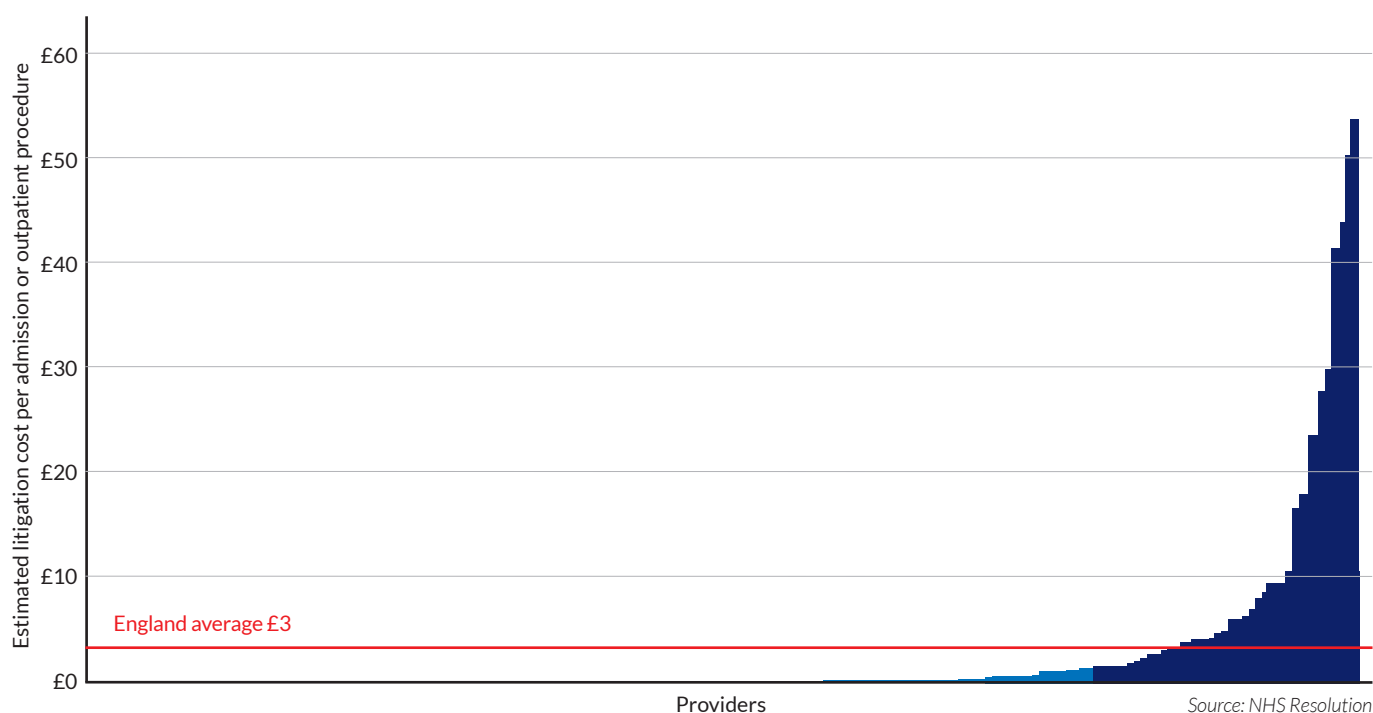


Table 9: Volume and potential estimated cost of medical negligence claims against rheumatology notified to NHS Resolution 2013/14 to 2017/18

Year of notification	No. of claims	% change in no. of claims	Total claim cost (£)	% change in total claim cost
2013/14	26	-	4.3 million	-
2014/15	36	38%	15.8 million	264%
2015/16	46	28%	10.8 million	-31%
2016/17	42	-9%	7.7 million	-28%
2017/18	34	-19%	7.5 million	-3%
Grand Total	184	-	46.1 million	-

Source: NHS Resolution 2013-2018

Claims trends and causes

Trends

Clinical negligence claims do not have as great an impact on rheumatology as they have in surgical or other medical specialties. Rheumatology is the 43rd highest clinical specialty for claims number and is the 35th highest for total claims costs during the financial years 2013/14 – 2017/18. Over the five-year period there was no clear trend in claims activity (**Table 10**). However, as we've seen in **Table 9**, there was a fluctuation in claim costs. This is due to individual high cost claims in some years, especially in 2014/2015.

Table 10: Top four most frequent causes for litigation in rheumatology 2013/14 to 2017/18

Causes	No. of claims
Treatment	85
Diagnosis	77
Medication errors	24
Consent	12

Source: NHS Resolution 2013-2018

Causes

We identified common causes for litigation in rheumatology using NHS Resolution data. It is important to note that more than one cause can be assigned to each claim.

Failure to establish a timely or correct diagnosis was among the most common causes of claims in rheumatology. This is not surprising, as clinical diagnosis and analysis of investigations are the cornerstone of rheumatology. A delayed or missed diagnosis can be compounded by inappropriate treatment and the potential complications that result, potentially leading to claims in the millions.

Missed or delayed diagnoses of connective tissue disorders and vasculitis accounted for thirteen cases of litigation attributed to rheumatology units over the five-year period. These included alleged failure to diagnose vasculitis in patients who went on to suffer strokes, and delays in diagnosis of infection, which resulted in amputations. There were also seven claims for failure to diagnose inflammatory arthritis, four of which related to axial spondyloarthritis.

Medicines monitoring was the primary factor in several medication error claims. Standardising monitoring across geographic footprints as we propose in *Standardising the monitoring of DMARDs*, page 107, could help to reduce these errors.

Damages can reach much higher levels where errors are alleged to cause significant disability to younger patients. The importance of getting their care right first time from diagnosis cannot be overestimated.

Vasculitis including giant cell arteritis (GCA)

We know from our data and discussions with clinicians that some of the most serious patient safety incidents involving patients with RMDs are those associated with vasculitis, including GCA. Of the rare rheumatic and musculoskeletal disorders (RMDs), vasculitis has the highest mortality, with 15-20% of patients dying within their first year, regardless of whether they have been initiated on treatment. It would be useful to understand what proportion of these deaths are preventable by further interrogating incident and litigation data at trust level.

These conditions are not managed solely by rheumatology multidisciplinary teams. Often care is co-ordinated with other specialties (for example ophthalmology for GCA and renal medicine or vascular teams for vasculitis), so patients may present to specialties other than rheumatology.

To further investigate the true picture of litigation associated with GCA and vasculitis, we explored NHS Resolution data for all other specialties relating to these conditions using a text search (**Table 11**). A word search by condition is the most comprehensive method to identify claims from the dataset provided by NHS Resolution. However, we note that it may not identify all claims for a condition since diagnosis is not always provided in the claims description.

Table 11: Litigation claims relating to GCA and vasculitis (2013-2018)

	Adult (18+)
Giant cell arteritis (search terms "GCA" and "giant cell arteritis" in incident details)	
Number of GCA litigation claims (all specialties)	22
Total estimated cost of GCA litigation claims (all specialties)	£6,646,849
Number of GCA litigation claims (rheumatology only)	4
Total estimated cost of GCA litigation claims (rheumatology only)	£397,368
Number of GCA litigation claims (all other specialties)	18
Total estimated cost of GCA litigation claims (all other specialties)	£6,249,481
Vasculitis (search terms "vasculitis" in incident details)	
Number of vasculitis litigation claims (all specialties)	15
Total estimated cost of vasculitis litigation claims (all specialties)	£2,433,326
Number of vasculitis litigation claims (rheumatology only)	3
Total estimated cost of vasculitis litigation claims (rheumatology only)	£194,213
Number of vasculitis litigation claims (all other specialties)	12
Total estimated cost of vasculitis litigation claims (all other specialties)	£2,239,113

Source: NHS Resolution, 2013-2018

As can be seen in **Table 11**, some of the most significant litigation claims associated with these conditions were attributed to other specialties. Rheumatology teams should therefore continue to liaise with ophthalmology, vascular and renal teams to share learning from serious GCA and vasculitis incidents across departments.

We also know from our data and deep-dive discussions that the majority of litigation claims related to GCA and vasculitis come from trusts which are not specialised centres for rheumatology, as shown in **Table 12**.

Table 12: Litigation claims relating to GCA and vasculitis from specialised and non-specialised units

	Count	Sum
Giant cell arteritis (search terms "GCA" and "giant cell arteritis" in incident details)		
GCA litigation claims (specialised trusts)	7	£1,930,350
GCA litigation claims (non-specialised trusts)	16	£2,654,545
Vasculitis (search terms "vasculitis" in incident details)		
Adult vasculitis litigation claims (specialised trusts)	5	£1,369,172
Adult vasculitis litigation claims (non-specialised trusts)	12	£6,608,219

Source: NHS Resolution, 2013-2018

As discussed earlier in this report, we need to address gaps in quality assurance, leadership and oversight in the care of rare and complex RMDs by establishing more effective rheumatology networks (see *Equitable access to specialised care for rare RMDs through regional networks*, page 64). Virtual MDT arrangements should be established within these networks to enable access to specialist advice and support through case discussion. We expect this to reduce the likelihood of serious patient safety incidents and related litigation claims.

We would also expect that fast-track GCA pathways (as described in *Optimising diagnosis and treatment of GCA*, page 76) would help to reduce avoidable blindness.

Recommendation: Litigation

Recommendation	Actions	Owners	Timescale
22. Reduce litigation costs by application of the GIRFT Programme's five-point plan.	a Clinicians and trust management to assess their benchmarked position compared to the national average when reviewing the estimated litigation cost per activity. Trusts would have received this information in the GIRFT 'Litigation data pack'	Trusts	On publication
	b Clinicians and trust management to discuss with the legal department or claims handler the claims submitted to NHS Resolution included in the data set to confirm correct coding to that department. Inform NHS Resolution of any claims which are not coded correctly to the appropriate specialty via CNST.Helpline@resolution.nhs.uk	Trusts	Upon completion of 22a
	c Once claims have been verified clinicians and trust management to further review claims in detail including expert witness statements, panel firm reports and counsel advice as well as medical records to determine where patient care or documentation could be improved. If the legal department or claims handler needs additional assistance with this, each trust's panel firm should be able to provide support	Trusts	Upon completion of 22b
	d Claims should be triangulated with learning themes from complaints, inquests and serious incidents (SI)/Patient Safety Incidents (PSI) and where a claim has not already been reviewed as SI/PSI we would recommend that this is carried out to ensure no opportunity for learning is missed. The findings from this learning should be shared with all front-line clinical staff in a structured format at departmental/directorate meetings (including Multidisciplinary Team meetings, Morbidity and Mortality meetings where appropriate).	Trusts	Upon completion of 22c
	e Where trusts are outside the top quartile of trusts for litigation costs per activity GIRFT we will be asking national clinical leads and regional teams to follow up and support trusts in the steps taken to learn from claims. They will also be able to share with trusts examples of good practice where it would be of benefit.	Trusts	For continual action throughout GIRFT programme

Procurement

Rheumatology departments procure a range of lower cost equipment, such as wrist/hand splints, forearm clasps and orthotics, in high volumes, as well as smaller volumes of high cost equipment such as ultrasound machines.

In 2016 NHS Improvement mandated all trusts to submit their monthly purchase order data to a central database: the NHS Spend Comparison Service (SCS). This is the first time a single national dataset of procurement information has been established for the NHS.

Since that time the GIRFT programme has been analysing this data to better understand the variation in products and brands used, and prices paid across NHS trusts. This analysis has been a feature of previous GIRFT reports with examples of variation in the number of brands used by clinicians.

Variation can lead to compromises in patient safety and can add significant costs to the NHS Supply Chain. Addressing variation therefore would have the potential to improve safety and efficacy and provide a potential opportunity to secure better deals and improved value for money for trusts.

Reducing unwarranted variation and improving value for money

To help, GIRFT has established a programme to root out unwarranted variation, improve the evidence base to enable better decision-making, accelerate adoption of new proven technologies, and improve overall value for money by reducing supply chain costs.

The GIRFT Clinical Technology Optimisation programme has been working with GIRFT clinical leads to examine the data and evidence that support products and, in some cases, national Clinical Technology Advisory Panels (CTAPs) have been established with leading clinicians from the specialty to address safety, efficacy, innovation and value – with the objective of providing better information to clinicians and procurement professionals across the NHS.

GIRFT has also been working with the new NHS operating model for NHS procurement, including the new Category Towers, to develop plans for helping trusts and clinicians to address variation and improve value for money.

Another priority is to understand the clinical impact of different brands. To assess this, NHS England and NHS Improvement has launched 'Scan4Safety³⁵' (2020) in which individual products can be traced to individual clinicians. We are looking at the feasibility of creating links between the National Clinical Improvement Programme (NCIP) and Scan4Safety to assist in identifying the efficacy of different brands and, perhaps most importantly, to allow tracking of new implants or procedures across the NHS.

We recommend that providers adopt the GIRFT 3-point strategy to improve procurement of devices and consumables.

Recommendation: Procurement

Recommendation	Actions	Owners	Timescale
23. Enable improved procurement of devices and consumables through cost and pricing transparency, aggregation and consolidation, and by sharing best practice.	a Use sources of procurement data, such as the Spend Comparison Service (SCS) and relevant clinical data, to identify optimum value for money procurement choices, considering both outcomes and cost/price.	Trusts	Within 6-12 months of publication
	b Identify opportunities for improved value for money, including the development of benchmarks and specifications. Locate sources of best practice and procurement excellence, identifying factors that lead to the most favourable procurement outcomes.	GIRFT	Ongoing
	c Use Category Towers to benchmark and evaluate products and seek to rationalise and aggregate demand with other trusts to secure lower prices and supply chain costs.	Trusts, ICSs/STPs	Within 12 months of publication

Notional financial opportunities

This report sets out a series of recommendations to improve the delivery of rheumatology services. Taken together, the recommendations are designed to optimise capacity, enabling more patients to be seen and treated in a timely way and to reduce the amount of time patients spend in hospital where clinically appropriate. In this busy specialty, where demand for outpatient services is high, progress in these areas would be invaluable to patients and providers alike.

Due to the lack of coding in outpatients highlighted in earlier sections of this report, the specific impact of our recommendations is hard to measure in many areas, but in others, there is a more tangible benefit that could be realised. We have sought to quantify this. GIRFT analysis has calculated there is a notional financial opportunity of between £61.9m and £93.2m a year. The most significant opportunities relate to optimising best-value medicines use.

The notional financial opportunities put an estimated value on the resource associated with variation based on providers achieving average or best performance. The figures are gross sums, based on activity levels. As they rely on process change and productivity improvements, they are not necessarily cash-releasing and do not represent a comprehensive set of all opportunities discussed in the report. Nonetheless, they provide an indication of what may be possible.

Each opportunity would also bring with it benefits to patients. For example through enabling care closer to home and reducing unnecessary visits to hospital.

There are further savings that could be realised through streamlining procurement and reducing costs resulting from litigation. This report identifies a total spend of £46.2m on litigation against rheumatology over a five year period. We expect implementation of the GIRFT programme's five-point plan to improve patient safety and reduce litigation costs trust-wide.

Further opportunities

The opportunity values shown in **Table 13** are for illustration only. Individual providers and clinicians should assess their own services to determine the unwarranted variation that exists and associated opportunities. This assessment will help departments and trusts prioritise service changes. Individual providers may also have other opportunities that are not included here, such as those recommended on deep-dive visits.

'Standard' figures in **Table 13** represent improvements to what is, or could be considered, 'average' performance, while 'Target' figures represent 'best' performance.

Table 13 – Gross notional financial opportunities

Improvement	Standard			Target		
	Activity	Activity opportunity*	Gross notional financial opportunity**	Activity	Activity opportunity*	Gross notional financial opportunity**
Care for patients with non-inflammatory painful conditions provided outside of hospital <i>(Recommendation 1)</i> Opportunity = Reduction in outpatient attendances (through increase in effective community interventions) <i>Base data: April 19 - Mar 20.</i> Cost estimated based on average rheumatology new/follow-up OP attendance (18/19 ref costs uplifted to 20/21 prices)	Clinical view			Clinical view		
New outpatient attendances	2% reduction in hospital new outpatient attendances	7,900 new OPs	£1.8m	5% reduction in hospital new outpatient attendances	19,800 new OPs	£4.51m
Follow-up outpatient attendances	2% reduction in hospital follow-up outpatient attendances	33,100 follow-up OPs	£4.47m	5% reduction in hospital follow-up outpatient attendances	82,700 follow-up OPs	£11.16m
Consider alternative ways to manage follow-up appointments <i>(Recommendation 3)</i> Opportunity = Shift in hospital follow-up face-to-face attendances to non face-to-face <i>Base data: April 19 - Mar 20.</i> Note: impact calculated related to reduction in overall rheum FU OP attendances (above) is offset in the financial opportunity calculated here Cost estimated based on rheumatology follow-up F2F less 1.5 x non F2F OP attendance (18/19 ref costs uplifted to 20/21 prices)	Clinical view			Clinical view		
	25% shift from F2F to non F2F outpatients	380,500 follow-up OPs - move from F2F to non F2F	£8.18m	30% shift from F2F to non F2F outpatients	413,600 follow-up OPs - move from F2F to non F2F	£8.89m

Table 13 – Gross notional financial opportunities

Improvement	Standard			Target		
	Activity	Activity opportunity*	Gross notional financial opportunity**	Activity	Activity opportunity*	Gross notional financial opportunity**
Better screening in primary care for Early Inflammatory Arthritis (EIA) prior to referral <i>(Recommendation 9)</i> Opportunity = Reduce EIA first outpatient attendances <i>Base data: April 19 - Mar 20.</i> <i>Note: impact calculated related to reduction in overall rheum First OP attendances (above) is offset in the financial opportunity calculated here</i> <i>Cost estimated based on average rheumatology first OP attendance (18/19 ref costs uplifted to 20/21 prices)</i>	<i>Clinical view</i> 30% reduction in EIA first outpatient attendances	27,700 EIA new OPs	£6.32m	<i>Clinical view</i> 50% reduction in EIA first outpatient attendances	44,500 EIA new OPs	£10.15m
Consistent specialty leading on the management of confirmed cases of septic arthritis <i>(Recommendation 16)</i> Opportunity = Reduced LOS for septic arthritis <i>Base data: April 19 - Mar 20.</i> <i>Cost estimated based on average HD23 HRGs (inflammatory disorders) - excess bed day (17/18 ref costs uplifted to 20/21 prices)</i>	<i>National average</i> 17.9 days average LOS for septic arthritis admissions	23,700 bed days	£8.98m	<i>Upper quartile</i> 14.7 days average LOS for septic arthritis admissions	48,300 bed days	£18.31m

Table 13 – Gross notional financial opportunities

Improvement	Standard			Target		
	Activity	Activity opportunity*	Gross notional financial opportunity**	Activity	Activity opportunity*	Gross notional financial opportunity**
Consider alternatives to day case admission for some procedures <i>(Recommendation 17)</i> Opportunity = Move day case joint injections and spinal procedures to outpatient setting <i>Base data: April 18 - Mar 19</i> Joint Injections <i>Cost estimated based on HRG AB27/8 (Joint injection) - Day case less outpatient procedure (18/19 ref costs uplifted to 20/21 prices)</i> Spinal Procedures <i>Cost estimated based on HRG AB16 (spinal injection) - Day case (18/19 ref costs uplifted to 20/21 prices)</i>	<i>Clinical view</i> 75% shift from day case to outpatient procedure 95% reduction in day cases	8,500 day cases - moved to outpatient procedures 855 day cases	£2.34m £0.67m	<i>Clinical view</i> 95% shift from day case to outpatient procedure 100% reduction in day cases	10,800 day cases - moved to outpatient procedures 900 day cases	£2.97m £0.7m
Reduce costs related to rheumatology drug use (primarily through speeding up switch to biosimilars) <i>(Recommendations 18 and 19)</i> Opportunity = Reduce rheumatology drugs costs (see note below) <i>Base data: April 19 - Mar 20.</i> <i>Cost estimated based on 20/21 total estimated Trust drug spend (Define 2020)</i>	<i>Clinical view</i> 8% reduction in rheumatology drugs expenditure		£29.16m	<i>Clinical view</i> 10% reduction in rheumatology drugs expenditure		£36.45m
Total			£61.92m			£93.14m

Notes to table:

* Activity opportunities are annual figures, based on one year of activity data unless specified.

** The gross financial opportunity does not take account of additional investment that may be required in primary / community care.

Costing financial opportunity:

Unless otherwise stated, cost estimates are based on national average of 18/19 reference costs, uplifted to 20/21 pay and prices using tariff inflation.

Rheumatology drug use financial opportunity:

The pharmacy workforce together with rheumatology teams across the NHS in England have implemented patient focussed approach and best medicines optimisation practices to:

1. reduce unwarranted variation;
2. prompt switches to 'Best Value Biologics' (BVB) in line with National Institute for Health and Care Excellence (NICE) guidance and Commissioning framework for biological medicines³⁶;
3. optimise use of JAK inhibitors, DMARDs other medicines used in rheumatology.

There remains an opportunity however, to reduce costs further (estimated in the table above) by patient-focussed collaborative work across systems (STP/ICS level) to implement best evidence-based clinical and medicines optimisation practices. Please see *Optimising Medicines*, page 95 which discusses medicines opportunities in more detail.

³⁶ <https://www.england.nhs.uk/wp-content/uploads/2017/09/biosimilar-medicines-commissioning-framework.pdf>

About the GIRFT programme

Getting It Right First Time (GIRFT) is a national programme designed to improve medical care within the NHS.

Funded by the Department of Health and Social Care and jointly overseen by NHS England and NHS Improvement and the Royal National Orthopaedic Hospital NHS Trust, it combines wide-ranging data analysis with the input and professional knowledge of senior clinicians to examine how things are currently being done and how they could be improved.

Working to the principle that a patient should expect to receive equally timely and effective investigations, treatment and outcomes wherever care is delivered, irrespective of who delivers that care, GIRFT aims to identify approaches from across the NHS that improve outcomes and patient experience, without the need for radical change or additional investment. While the gains for each patient or procedure may appear marginal they can, when multiplied across an entire trust – and even more so across the NHS as a whole – deliver substantial cumulative benefits.

The programme was first conceived and developed by Professor Tim Briggs to review elective orthopaedic surgery to address a range of observed and undesirable variations in orthopaedics. In the 12 months after the pilot programme, it delivered an estimated £30m-£50m savings in orthopaedic care – predominantly through changes that reduced average length of stay and improved procurement.

The same model is now being applied to 40+ different areas of clinical practice. It consists of four key strands:

- A broad data gathering and analysis exercise, performed by health data analysts, which generates a detailed picture of current national practice, outcomes and other related factors.
- A series of discussions between clinical specialists and individual hospital trusts, which are based on the data –providing an unprecedented opportunity to examine individual trust behaviour and performance in the relevant area of practice, in the context of the national picture. This then enables the trust to understand where it is performing well and what it could do better – drawing on the input of senior clinicians.
- A national report, that draws on both the data analysis and the discussions with the hospital trusts to identify opportunities for NHS-wide improvement.
- An implementation phase where the GIRFT team supports providers to deliver the improvements recommended.

Implementation

GIRFT works in partnership with NHSE/I regional teams to help trusts and their local partners to implement improvements and address the issues raised in both the trust data packs and the national specialty reports. The GIRFT team provides support at a local level, advising on how to reflect the national recommendations into local practice and supporting efforts to deliver any trust specific recommendations emerging from the GIRFT visits. GIRFT also helps to disseminate best practice across the country, matching up trusts who might benefit from collaborating in selected areas of clinical practice. Through all its efforts, local or national, the GIRFT programme strives to embody the ‘shoulder to shoulder’ ethos that has become GIRFT’s hallmark, supporting clinicians nationwide to deliver continuous quality improvement for the benefit of their patients.

Glossary

Advanced practitioner

Healthcare professionals such as nurses, pharmacists and therapists who have developed skills and knowledge to allow them to take on expanded roles in caring for patients.

Advice and Guidance (A&G) service

A service providing primary care with continued access to specialist clinical advice, enabling a patient's care to be managed in the most appropriate setting, strengthening shared decision making and avoiding unnecessary outpatient activity.

Anti-neutrophil cytoplasmic antibody (ANCA)-associated vasculitis (AAV)

A group of diseases characterised by destruction and inflammation of small vessels.

Axial spondyloarthritis

A painful, chronic arthritis that mainly affects the joints of the spine. It can also affect other joints in the body, as well as tendons and ligaments.

Casemix

The type or mix of patients, categorised by a variety of measures, including: demographics, disease type and severity, and the diagnostic or therapeutic procedures performed.

Clinical Commissioning Groups (CCGs)

Clinically-led statutory NHS bodies responsible for the planning and commissioning of healthcare services for their local area.

Clinical Reference Group

A group of clinicians, commissioners, public health experts, patient and public voice (PPV) representatives and professional associations which offer specific knowledge and expertise to advise NHS England and NHS Improvement on the best ways that specialised services should be provided

Clinical Research Network

A national network set up to provide infrastructure support for the initiation and delivery of high quality research within the NHS. It includes 15 regional Local Clinical Research Networks.

Comorbidity

Presence of one or more additional diseases or disorders co-occurring with a primary disease or disorder.

Connective tissue diseases/autoimmune connective tissue disorders

Diseases that affect the immune system, such as lupus, myositis, scleroderma and Sjogren's syndrome, that cause inflammation in a variety of tissues in the body, for example skin, joints, blood vessels and organs such as the kidneys or lungs

Corticosteroids

Anti-inflammatory medicines prescribed for a wide range of conditions, man-made versions of hormones normally produced by the adrenal glands.

CQUIN

Commissioning for Quality and Innovation (CQUIN) is a commissioning framework that supports improvements in the quality of services and care by setting agreed goals and incentivising best practice.

Cytokine inhibitors

Drugs that inhibit the production of cytokines – proteins released by cells when the immune system is activated, which are linked to autoimmune inflammatory diseases.

Direct clinical care programmed activities (DCC PAs)

Blocks of time that consultants are contracted to spend on providing direct clinical care to patients.

Electronic patient record (EPR)

A digital version of a patient's record that can be integrated across health and care services.

Enteropathic arthritis

A type of arthritis that can develop in people with an inflammatory bowel disease such as ulcerative colitis or Crohn's disease, which usually affects the joints of the lower limbs and the spine.

Fibromyalgia

A long-term condition that causes pain all over the body often accompanied by symptoms such as increased sensitivity to pain, extreme tiredness, muscle stiffness and difficulty sleeping.

First contact practitioners

Community-based physiotherapists with extended skills, often based in GP practices, who can provide rapid care for patients without the need for a referral.

Fracture liaison service

A preventative service which proactively identifies patients with fragility fractures with the aim of reducing their risk of further fractures.

Gout

A type of arthritis where crystals form inside and around joints causing sudden and severe pain. Usually starting in the big toe, it can affect joints in areas such as the ankle, knee and foot.

Healthcare Quality Improvement Partnership (HQIP)

An independent organisation led by the Academy of Medical Royal Colleges, The Royal College of Nursing and National Voices, with the aim of promoting quality in healthcare and increasing the impact that clinical audit has on healthcare quality improvement.

Hospital episode statistics

Data on all admissions, outpatient appointments and A&E attendances at NHS hospitals in England for each 'episode' of admitted patient care.

Hub and spoke

A network arrangement between larger and smaller service providers in a geographic area.

Hypermobility

A group of syndromes characterised by very flexible joints, which may be associated with joint and ligament injuries, pain, fatigue and other symptoms.

Juvenile idiopathic arthritis

The most common type of arthritis in children and teens. It typically causes joint pain and inflammation in the hands, knees, ankles, elbows and/or wrists.

Inflammatory arthritis

A group of autoimmune conditions, including rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis, in which the body's defence system attacks its own tissues causing pain, stiffness and joint damage and systemic symptoms such as fatigue.

Integrated care systems (ICS)

Advanced local partnerships involving primary and secondary care, local councils and others, taking shared responsibility to improve the health and care system for their local population.

ICD codes

International Classification of Diseases are globally-recognised diagnostic codes for a wide range of indications such as diseases, signs and symptoms, abnormal findings and complaints. They form the basis of diagnostic recording in the NHS.

Lupus/systemic lupus erythematosus (SLE)

A long-term autoimmune condition that causes inflammation of different parts of the body including the lungs, heart, liver, joints and kidneys, resulting in symptoms such as joint pain, skin rashes and tiredness.

Main specialty code

A unique code identifying each main specialty designated by Royal Colleges. It identifies the specialty of the health professional delivering the service.

Metabolic disorders of bone

Disorders of bone strength caused by an imbalance of minerals such as calcium or phosphorus, as well as vitamin D, bone mass or bone structure.

Model Hospital

A free digital tool provided by NHS Improvement to enable trusts to compare their productivity and identify opportunities to improve. The tool is designed to support NHS provider trusts to deliver the best patient care in the most efficient way.

Multimorbidity

The presence of two or more long-term health conditions.

National Clinical Improvement Programme (NCIP)

A GIRFT programme that aims to support NHS clinicians with learning and continuous self-development in their specialty.

National Disease Registration Service (NDRS)

The National Disease Registration Service collects, quality assures and analyses data from the NHS about cancer, rare diseases and congenital anomalies to detect changes in the health of the population and help the NHS improve the diagnosis and treatment of these diseases.

National Early Inflammatory Arthritis Audit (NEIAA)

An audit, commissioned by HQIP and delivered by the British Society for Rheumatology, which collects information on all new patients over the age of 16 seen in specialist rheumatology departments with suspected inflammatory arthritis in England and Wales with the aim of improving quality of care.

National Institute for Health and Care Excellence (NICE)

Provides evidence-based guidance, advice, quality standards, performance metrics and information services for health, public health and social care.

NHS England provider eligibility list (PEL)

A list of providers eligible to receive payment for specialised commissioning activity.

NHS Resolution (formerly the NHS Litigation Authority)

An arm's length body of the Department of Health that provides expertise to the NHS to resolve negligence concerns, share learning for improvement and preserve resources for patient care.

Non-inflammatory painful musculoskeletal (MSK) conditions

Conditions such as fibromyalgia, hypermobility, osteoarthritis and back pain, which are not caused by inflammation and which are defined by the pain they cause rather than the level of stiffness or immobility.

OPCS codes

Also known as procedure codes, the OPCS Classification of Interventions and Procedures is a statistical classification used by health care providers and national and regional organisations to report/summarise episodes of care.

Osteoarthritis

A disorder caused by thinning cartilage which causes joints to become painful and stiff.

Pathway

An agreed set of evidence-based practices and interventions for a specific patient group.

Patient-related outcome measures (PROMs)

Measures derived from survey scores that assess the quality of care delivered to NHS patients from the patient perspective.

Physician associate

Medically-trained generalist healthcare professionals, who work alongside doctors and provide medical care as an integral part of the multidisciplinary team.

Polymyalgia rheumatica

A condition that causes pain, stiffness and inflammation in the muscles around the shoulders, neck and hips, usually affecting older people.

Polypharmacy

Concurrent use of multiple medications.

Primary Care Network (PCN)

A network of GP practices covering a population that develops services across a geographic area of between 30-50,000 people.

Psoriatic arthritis

A type of arthritis that affects some people with the skin condition psoriasis. It typically causes affected joints to become swollen, stiff and painful.

Research registry

A database that collects information about patients who are affected by a particular condition on an ongoing basis with the aim of improving treatment pathways.

Rheumatic and musculoskeletal disorders (RMDs)

A diverse group of diseases that commonly affect the joints, but can affect any organ of the body. There are more than 200 different RMDs, affecting both children and adults.

Rheumatoid arthritis

See inflammatory arthritis.

Rheumatology Specialty Advisory Committee (SAC)

A body that contributes to the development of specialist rheumatology training policy and supervises the delivery of training to meet quality standards.

RX-Info Define

A software package that helps healthcare organisations analyse their medicines spend.

Septic arthritis

A serious bacterial joint infection which typically occurs in the hip, knee or shoulder.

SNOMED CT

The clinical vocabulary which is used to record consistent, reliable and comprehensive patient information as an integral part of an electronic patient record, facilitating a number of processes such as decision support, care pathway management and drug alerts.

Specialised commissioning

Services for certain diseases and conditions which are not offered in all hospitals and are commissioned nationally by NHS England and NHS Improvement rather than local CCGs.

Specialised Services Quality Dashboards (SSQD)

Data on patient outcomes against an agreed list of measures for each condition under specialised commissioning. SSQDs are designed to enable comparison between providers, provide quality assurance and support improvements over time.

Spend Comparison Service (SCS)

Provides benchmarking and spend analytics on purchase order data from across all of NHS England's providers including acute hospital, ambulance and mental health trusts.

Sustainability and transformation partnerships (STPs)

Partnerships between NHS providers, CCGs, local authorities and other health and care services to develop proposals for how local areas will work together to improve health and care for their local population.

Temporal artery biopsy

A biopsy under local anaesthetic, where a small piece of the temporal artery is removed and checked for signs of giant cell arteritis (GCA).

Temporal artery ultrasound

An ultrasound scan of the temporal artery used in diagnosis of GCA.

Treatment function code

A unique code that is recorded to report the service/specialty within which the patient is treated.

Vasculitis

A group of conditions characterised by inflammation of the blood vessels, which can range from minor problems of the skin to more serious illness affecting organs like the heart or kidneys.

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Lesley Kay, Peter Lanyon and Alex MacGregor

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The full report and executive summary are also available to download as
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