Royal College of Nursing

Biologic Disease Modifying Anti-Rheumatic Drugs (DMARDs) and Targeted-Synthetic DMARDs

CLINICAL PROFESSIONAL RESOURCE

Fifth edition

Acknowledgements

This updated publication has been reviewed by members of the RCN Rheumatology Nursing Forum. We would like to thank the following individuals for their assistance in revising and updating this valuable resource.

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Contents

Foreword

This publication aims to provide a best practice framework for rheumatology specialist practitioners (the term 'practitioner' is used throughout this document and relates to nurses, allied health practitioners and pharmacists) and the wider health care team involved in supporting the administration, monitoring and delivery of care to patients in a variety of settings.

Since the publication of the last edition, developments that have impacted on this sphere of practice include:

- licensing of new complex treatments, including tsDMARDs
- availability of biosimilars and their impact
- updated clinical guidelines, pathways and NICE technology appraisals to improve the management of rheumatological conditions in adults and children issued by each of the devolved nations: lowering of the threshold from severe to moderate RA for some biologic medications ie, a DAS28 >3.1
    - **England**: National Institute for Health and Care Excellence (NICE)
    - **Scotland**: Scottish Intercollegiate Guidelines Network (SIGN)
    - **Wales**: All Wales Medicines Strategy Group (AWMSG)
    - **Northern Ireland**: Department of Health and/or Strategic Planning and Performance Group (SPPG
    - National Institute for Health and Care Excellence (NICE)
    - Updated guidance in the use and administration of biologics in pregnancy and breastfeeding
    - The expansion of the British Society for Rheumatology Biologics Registers (BSRBR-RA, BSRBR-PsA, BSRBR-AS and UK JIA Biologics Register) to monitor the use, progress and long-term outcomes of biosimilars and targeted synthetics, in addition to the biologic originators.

This publication is relevant for rheumatology specialist practitioners, and health professionals who support patients who have been prescribed by their health care team bDMARDs (including biosimilars) and tsDMARDs (eg, JAK inhibitors). This resource does not cover conventional synthetic DMARDs (csDMARDs) such as Methotrexate and Leflunomide.

It is acknowledged that practitioners work in a variety of settings, and this resource that may be useful to patients making decisions about their treatments.

RCN Rheumatology Forum

Introduction

The role of bDMARDs and tsDMARDs in the treatment of rheumatological conditions continues to evolve and is an area that has significant implications for all practitioners and patients. These drugs are effective, well tolerated and safe in most patients; however, they can increase the risk of complications, including infection. As patient safety is paramount, this risk can be reduced by practitioners' careful pre-treatment assessment and monitoring.

This resource has been developed to support practitioners in the safe and effective assessment, screening and management of patients when these drugs are being considered. It can be used in conjunction with the *RCN Competency Framework for Rheumatology Nurses* (2020) available at: **rcn.org.uk/professional-development/publications/pub-009004**

Please refer to **Appendix 4** in Part 1 of this document, which recognises the level of practice a nurse is working towards. It provides practitioners with information to help them care for patients with different rheumatology conditions, in all care settings.

Aim

This publication provides practitioners with an outline of current drugs, both licensed and unlicensed, and signposts the reader to additional key documents and resources. This will support practitioners in the UK to develop a standardised approach to caring for patients receiving bDMARDs and tsDMARDs.

Stop-Think-Reflect notes have been added to help promote learning, best practice, clinical excellence and provision of quality care.

This supports the NMC Code of Conduct (2018) and the NMC revalidation requirements. They support the RCN Advanced level nursing practice competencies (2021) which include clinical practice, leadership and management, education, and research, The Four Pillars are incorporated into the *RCN Competency Framework for Rheumatology Nurses* (2020).

Part 1 of this document focuses on the management of bDMARDs and tsDMARDs in adults for these 3 main treatment indications:

- rheumatoid arthritis (RA)
- psoriatic arthritis (PsA)
- radiographic and non-radiographic axial spondyloarthropathy (AxSpa).

Other long-term conditions treated with these advanced therapies which are not within the remit of this document include:

- systemic lupus erythematosus (SLE)
- skin conditions such as psoriasis
- inflammatory bowel conditions such as Crohn's disease (CD) and ulcerative colitis (UC)
- inflammatory eye condition, uveitis
- giant cell arteritis (GCA).

Part 2 of this document covers specific issues relating to the care of children and young people (CYP) with JIA, including transition of care to adult services.

There is a reference list and suggested further reading at the end of the publication on pages 53-60.

Resources

This document should not be regarded as definitive on all issues related to bDMARDs and tsDMARDs, but should be read alongside the following key texts:

- British Society for Rheumatology (BSR) resources and guidelines
- National Institute for Health and Care Excellence (NICE) technology appraisals and clinical guidelines
- Medicines and Healthcare products Regulatory Agency's (MHRA's) Yellow Card
- Scottish Intercollegiate Guidelines Network (SIGN) guidelines relevant to those working in Scotland
- Nursing and Midwifery Council (NMC) professional regulations or similar bodies for those practitioners where nursing is not their primary professional registration.

The Summary of Product Characteristics (SmPC) for all relevant drugs, including drugs prescribed alongside immunomodulatory anti-rheumatic drugs – found at the online Electronic Medicines Compendium (EMC) (Appendix 4)

- Local protocols, policies and guidelines.
- Local governance arrangements, including home care delivery services policies.

A full and comprehensive listing of these and additional advisory documents, alongside core documents produced by national regulatory bodies, can be found in Part 1, Appendix 1.

Biologic drugs

The term ‘biologic’ describes treatments developed and produced in live cell systems (biologically active systems). There are several drugs for different indications used in rheumatology. Those that are currently licensed target the pro-inflammatory cytokines:

- tumour necrosis factor alpha (anti-TNF alpha)
- interleukins
- B cell depletor
- T-cell co-stimulant inhibitors.

Biosimilars

‘Biosimilar medicines are medicines which have been shown not to have any clinically meaningful differences from the originator medicine in terms of quality, safety and efficacy’ (NHSE, 2023). Where NICE has already recommended the originator biological medicine, the same guidance will normally apply to a biosimilar.

Prescribing biosimilar medicines

Due to regional variation in the availability and prescribing of biologic medicines (including biosimilar medicines), biologic bDMARDs must be prescribed by brand name, specified on the prescription, and should be dispensed as such to avoid inadvertent switching. Automatic substitution of brands at the point of dispensing is not appropriate for biological medicines (BSR, 2017).

Targeted synthetic oral drugs

Targeted synthetic oral drugs are more recent innovations, targeting specific parts of the immune system. They are not made from living cells. The chemicals are smaller than biologic molecules so can usually be taken by mouth. Examples currently licensed include:

- PDE4 inhibitor (eg, apremilast)
- Janus kinase inhibitor (JAKi) (eg, baricitinib, filgotinib, tofacitinib and upadacitinib)

Practitioners should ensure they are familiar with current guidance from the MHRA regarding the JAKi treatments and ongoing updates for cardiovascular system, cancer and VTE risks.

NICE/SIGN and Innovation in Health

NICE/SIGN technology appraisals are recommendations on the use of new and existing medicines and treatments within the NHS, and are based on a review of:

- clinical evidence – how well the medicine or treatment works
- health economic evidence – how well the medicine or treatment works, and if it represents value for money
- drug choice may depend on local funding agreements regarding cost effectiveness.

Practitioners are expected to take these issues into account when exercising their clinical judgement coupled with high-moderate disease activity. However, this guidance does not override the responsibility of individual practitioners to make a shared decision appropriate to the circumstances of the individual patient and/or guardian or carer.

Medicines management

Medicines management is defined by the MHRA as 'the clinical, cost effective and safe use of medicines to ensure patients get the maximum benefit for the medicines they need, while at the same time minimising protentional harm'.

Medicines management includes:

- the processes around the storage
- transportation and disposal of medicines
- administration of medicines
- prescribing of medicines
- supporting people to take their medicines correctly.

Stop-Think-Reflect

Monitoring/safety precautions

- Multidisciplinary team (MDT): Discuss a patient case within the MDT (eg, virtual biologic team) to discuss and decide which best treatment option to offer the patient.
- Refer to monitoring guidelines, eg, BSR, NICE or local pathway.
- Since biosimilars are subject to black triangle (▼), it is important that suspected adverse reactions are reported using the Yellow Card scheme, which is run by the MHRA.
- There is regional variance regarding therapeutic drug level monitoring prior to treatment escalation. What is the practice in your area?

Patient choice and involvement

Shared decision making makes it possible for patients to explore all the treatment options available to them, work through any questions they may have and select a treatment route which best suits their needs and preferences – all in consultation with their practitioner.

Shared decision making ultimately improves treatment adherence rates (NICE, 2021b; NG197). evidence suggests when early treatment with cDMARDs treatments happen, this can support patients' reduction in joint damage, improve quality of life, and help adherence to medications (NICE, 2018; NG100), reducing the need to progress onto advanced therapies.

Stop-Think-Reflect

- How does shared decision making impact the patient?
- What tools are you currently using to aid patient self-management?
- Review NICE guidance NG197 on shared decision making (NICE, 2021b).

Part 1: Adult patients Assessment and monitoring of bDMARDs and tsDMARDs

1 Pre-treatment considerations 'virtual' biologics clinics (VBC)

NICE recommends the Manchester model of 'virtual' biologics clinics (NICE, 2016) to streamline the process of screening and managing referrals within a department.

- MDT approach considers the patient's co-morbidities, while choosing the most clinically effective and cost-effective treatment.
- There is a comprehensive screening document that all practitioners can complete (see Part 1, Appendix 3).
- Treatment should normally be started with the most cost-effective medicine (considering drug administration costs, required dose and product price per dose). This may vary for individual patients because of differences in the method of administration, patient weight and treatment schedules.
- Always refer to local protocol/policy.

When using outcome measures, practitioners should consider any physical, sensory or learning disabilities, or communication difficulties that could affect a person's responses. They should consider appropriate adjustments to the patient's needs and ensure equity of access to treatments.

As well as diagnosis, practitioners should also consider:

- concurrent Methotrexate use is associated with improved disease control and reduced frequency of anti-drug antibody formation
- whether the patient is already prescribed methotrexate (MTX)
- tolerance to MTX, as some bDMARDs are only licenced in combination with MTX – create a support plan for co-prescription if needed
- suitability for self-administration of subcutaneous injection
- patient's choice and understanding of the treatments being offered
- other co-morbidities
- extra-articular manifestations of disease (eg, eye/skin/gut involvement)
- conception, pregnancy and breastfeeding (see: academic.oup.com/rheumatology/article/62/4/1370/6783014?login=false).

If the patient does not fulfil the eligibility criteria or declines treatment you should provide guidance on their treatment options and act as the patient's advocate.

Please see Part 1, Appendix 2 for an example of a pre-screening proforma used in a clinic (this is intended as a guide only and may need to be updated as evidence changes).

Stop-Think-Reflect

- Consider how to deliver patient education post-COVID-19.
- For RA patients the NRAS Self-Management Individualised Learning Environment has a module specifically explaining medications. See: nras.org.uk/smile
- What information and risk assessment should be considered?

2 Vaccinations

The following section is designed as a resource to support the practitioner in providing vaccination advice to the patient or carer – or a health professional providing vaccination (such as a practice nurse). It is not intended to support the process for provision of vaccination itself, as this is outside the remit of rheumatology services and this document.

Practitioners should identify the patient's immune/vaccination status in the screening process.

Unless contraindicated, it is recommended that all patients requiring treatment be up to date with all clinically indicated vaccinations.

- Influenza.
- Pneumococcal.
- COVID-19 vaccine (please refer to national guidelines.)
- Varicella zoster (VZ), noting the now available inactivated (non-live) Shingrix vaccine.
- Hepatitis B.
- Measles, mumps and rubella (MMR).
- Primary Varicella prevention (Live vaccine).

The NRAS' immunisation guide for people with rheumatoid arthritis is a useful reference. See: nras.org.uk/resource/immunisation-for-people-with-rheumatoid-arthritis

2.1 Live vaccines

Live vaccines should not be given to immunocompromised patients or concurrently with b/tsDMARDs (BSR, 2018; individual drug's SmPC) without first seeking the appropriate specialist practitioner's advice. There is no contraindication for the administration of live vaccines to relatives or friends of patients having b/tsDMARDs. Individuals changing the nappies of young children that have received a live vaccine should be advised to wear gloves. Handlers of pets who have received live vaccines should also wear gloves.

Please refer to The Green Book (chapters 6-7) for the latest information on vaccines and vaccination procedures (UK Health Security Agency 2020). See: gov.uk/government/collections/immunisation-against-infectious-disease-the-green-book#the-green-book

Definition of Immunocompromised status

- A patient treated with a single DMARD or combination of azathioprine, ciclosporin, MTX, cyclophosphamide, leflunomide(consider the long half-life of leflunomide) and/or bDMARDs or tsDMARDs and for a period after treatment stops.
- A patient receiving systemic high dose steroids (>40mg/day) for more than one week.
- A patients with immunosuppression due to human immunodeficiency virus (HIV) infection.

If the use of a live vaccine is necessary, it should be administered at least 2 weeks, but preferably 4 weeks, before b/tsDMARDs therapy is commenced (BSR, 2018).

If vaccination is required with a live preparation:

- the appropriate time from discontinuing a b/tsDMARDs before administering a live vaccine is drug specific and is based on at least three cycles of the drug treatment half-life
- this timeframe ensures that the drug has effectively cleared from the body
- the half-life of each drug is documented in its individual drug SmPC
- further advice can be sought from a pharmacist, or local medicines information unit.

3 Pregnancy

3.1 Pregnancy and infant exposure to vaccinations

New guidance relating to pregnancy and breastfeeding has been published by the BSR. See: academic.oup.com/rheumatology/article/62/4/1370/6783014?login=false

Please refer to this and the guidance in the individual drug SmPC where this exists. It is important to note caution regarding vaccination of an infant who may have been exposed to a biologic in utero.

3.2 Pregnancy and conception

For current guidance please refer to: academic.oup.com/rheumatology/article/62/4/1370/6783014?login=false

4 Infection

Patients with inflammatory rheumatology conditions are often immunocompromised, by both the disease itself and by therapies. All b/tsDMARDs should be discontinued in the presence of serious infection and can usually be restarted once the infection has resolved (BSR, 2018). Please refer to the current European Alliance of Associations for Rheumatology (EULAR) 2022 guidance regarding infections and prophylactic treatment.

Patients should be advised to avoid exposure to potential risk factors for infection, given information on the signs and symptoms of infection to watch for, and advised to:

- report symptoms promptly to their GP, so that advice can be given
- STOP any b/tsDMARD if in any doubt (until specialist advice has been obtained)
- complete antibiotics (if prescribed) and to NOT restart therapy until they are free of infection and feel well or appropriately reassessed by the GP and/or specialist practitioner team.

Practitioners should be alert for atypical/opportunistic infections, especially if there is current or recent steroid use and recurrent infections.

Patients should have rapid access to specialist health care for consideration of early treatment (BSR, 2018).

4.1 COVID-19

Patients testing positive for COVID-19 may be eligible for antiviral medication. Please refer to the latest version of local pathways/guidelines.

4.2 Pulmonary disease/interstitial lung disease

RA interstitial lung disease (RA-ILD) is associated with significant morbidity and mortality and cDMARDs and biologic agents have been linked to pulmonary toxicity, albeit rare (Valenzuela et al., 2021). The risks associated with anti-TNF therapy in patients with RA-ILD remain uncertain. However, there is evidence it may cause acceleration of pre-existing interstitial lung disease. Given this uncertainty, patients should be carefully assessed before treatment and strict subsequent monitoring is required (Jani et al., 2014). Current BSR guidelines (2018) suggest rituximab/abatacept should be considered first line choice.

4.3 Tuberculosis (TB)

Appropriate pre-treatment screening for latent TB results significantly reduces the risk of TB (Sellami et al., 2019). Therefore, pre-screening for TB should include checking for previous TB exposure and previous treatment.

Patients with an abnormal chest X-ray (CXR), previous history of TB or TB treatment should be referred to a specialist with an interest in TB prior to commencing a biologic (NICE, 2016; NG33; BTS, 2016).

Chemoprophylaxis can reduce the risk of a first episode of active TB occurring in people with latent TB. Current evidence suggests that decisions about chemoprophylaxis should be based on the results of the Tuberculin Skin Test (TST) and an Interferon Gamma Release Assay (IGRA)/T-SPOT/QuantiFERON. If either test is positive, it would be appropriate to treat with chemoprophylaxis while monitoring carefully for treatment-related side effects (BSR, 2018). Please refer to local guidance.

Current British Thoracic Society guidelines can be accessed at: **thorax.bmj.com/content/60/10/800**

4.4 Venous thromboembolism (VTE)

Despite the positive therapeutic impacts of JAK inhibitors, concerns have been raised regarding the risk of VTE, such as deep vein thrombosis (DVT) and pulmonary embolism (PE). There are several predisposing conditions and risk factors for VTE, including advanced age, obesity, diabetes mellitus, hypertension and hyperlipidemia. Smoking can also contribute to its development.

Greater VTE risk is noted in patients with chronic inflammatory conditions, particularly RA patients with uncontrolled disease activity and any comorbidity. Prior to the initiation of JAK inhibitors, clinicians should consider both the number and strength of VTE risk factors for each patient. In addition, clinicians should advise patients to seek prompt medical help if they develop clinical signs and symptoms that suggest VTE/PE (Mori et al., 2021).

4.5 Varicella/shingles

Please refer to The Green Book, chapter 34, for further information (UK Health Security Agency, 2013).

Definition of VZV contact

Contact is defined as being in the same room as someone with varicella for at least 15 minutes or having face-to-face contact eg, having a conversation. This particularly applies if the person has:

- chickenpox of any distribution (exposure to chickenpox is of greater clinical significance than shingles)

or

- shingles with facial nerve involvement (uncovered lesions eg, facial shingles)

or

- disseminated shingles (< 1 dermatome involved)

or

- if the person is also immunosuppressed.

Source: The Green Book, chapter 34 (UKHS, 2016)

5 Hepatitis B and C

BSR biologic guidelines (2018) recommend screening for Hepatitis B virus (HBV) and Hepatitis C virus (HCV) serology prior to commencing any b/tsDMARDs. Screening for HBV should include testing for Hepatitis B surface antigen (HBsAG) and Hepatitis B total core antibody (HBcAb) in all patients who will receive a b/tsDMARDs.

The reactivation of HBV and worsening HCV have been reported with virtually all the

biologic therapies. Close monitoring of signs and symptoms and of liver function tests should be undertaken for patients receivig b/tsDMARDs (always refer to the SmPC) (ACR, 2021).

For those who are HBsAg positive, advice should be sought from a physician with expertise in Hepatitis B. Ensure you are aware of your local specialist in this area.

For those who are negative for HBsAg, but are positive for HBcAb, then EDTA blood should be sent for HBV PCR. If the HBV PCR shows detection of HBV DNA, then advice should be sought from a physician with expertise in Hepatitis B (NICE, 2017; CG165).

In long-term treatment with bDMARDs, infection risks are posed from both new exposure and from reactivation of latent disease in the context of immunosuppression. Some recent studies suggest a need to repeat testing when switching biologic therapy or, for example, every 5 years (Eden et al., 2022).

6 bDMARDs and malignancy

There is no evidence of an increased risk of solid tumours or lymphoproliferative disease for people with inflammatory arthritis on bDMARDs. There is, however, evidence to suggest that there is an increased risk of some skin cancers as stated in the SmPC, such as melanoma with anti-TNF therapy.

In addition to this risk, patients with psoriasis that have undergone light treatment therapy Psoralen + ultraviolet light A/ultraviolet (PUVA/UVB) may be at further risk of skin malignancy (BSR, 2018). Consequently, ongoing vigilance is required which should include preventative skin care, skin surveillance and early reporting of new skin lesions (BSR, 2018).

Research also suggests that bDMARDs do not increase the risk of recurrent cancer compared to cDMARDs in RA (Wenhui et al., 2020). Of note, most of the evidence is heavily weighted in the RA population and more research is required for people with PsA and AxSpa.

There are no studies looking at outcomes from patients with primary malignant disease from pre-cancerous conditions, but these should be monitored during treatment, including any skin changes (BSR, 2018). In patients with pre-cancerous conditions, eg, Barrett's oesophagus, or in patients with a previous malignancy, b/tsDMARDs and the use of rituximab should be considered as first-line biologic choice (BSR, 2018).

Please refer to SmPCs for individual drugs.

If malignancy occurs while a patient is taking b/tsDMARDs, it may be necessary to stop treatment. This should be discussed, and a shared decision made with the patient and their rheumatologist and oncologist regarding the risks/benefits for the individual patient.

7 Considerations while on treatment

7.1 Tuberculosis (TB)

Patients started on b/tsDMARDs should be closely monitored for TB while on treatment and for at least 6 months after stopping treatment. Patients on biologics who develop symptoms suggestive of TB should receive full anti-TB treatment but may continue with their b/tsDMARDs, if clinically indicated, after risk/benefit analysis and discussion with a TB expert (BSR, 2018; BTS, 2016; ACR, 2021). As the reactivation of TB is a particular concern, patients must report any TB warning signs such as:

- persistent productive cough
- haemoptysis
- weight loss
- fever.

7.2 Uveitis

There have been several case reports of uveitis developing in patients with anti-TNF therapy, reported in the BSR registry data, even though some anti-TNFs have also been reported to successfully treat patients with resistant uveitis.

A meta-analysis comparing incidence of anterior uveitis in both anti-TNF monoclonal antibodies, IL-17A inhibitors and placebo by Roche et al. (2021) found that the incidence of anterior uveitis flares was lower with anti-TNF monoclonal antibodies infliximab, adalimumab, golimumab and certolizumab compared to placebo. There was also a significant difference for a decreased incidence of anterior uveitis with anti-TNF monoclonal antibodies compared to IL-17A inhibitors including secukinumab and ixekizumab.

The other comparison between biologics or between biologics and placebo were not significant. While the results showed that IL-17A inhibitors did not have the same protective effect against anterior uveitis flares as anti-TNF monoclonal antibodies, they are reassuring with regards to a possible deleterious effect of IL-17A inhibitors without significant difference between them and placebo.

7.3 Blood dyscrasias

This is a rare event in patients on a combination of DMARD and biologic therapies. However, practitioners should ensure that patients are encouraged to report signs suggestive of blood dyscrasias, for example, bruising, bleeding, mouth ulcers, shortness of breath and persistent fever, and ensure that vigilance is applied during routine monitoring.

Stop-Think-Reflect

- If a patient has delayed their blood test, what would be your next step?

7.4 Progressive multifocal leukoencephalopathy (PML)

Practitioners should be vigilant for PML, which has been primarily associated with rituximab but has been reported with anti-TNF and some DMARDs, like leflunomide and mycophenolate. PML is often a rare and fatal demyelinating illness with no known treatment. Practitioners need to be mindful of PML (along with other infectious aetiologies) in any patient presenting with new-onset neurological manifestations such as mental state changes, weakness, loss of motor co-ordination, speech, or vision changes (Berger et al., 2018). Biologic DMARDs should be stopped if PML develops, and practitioners should consider the reduction of any concomitant immunosuppressive therapy. Restarting treatment is also not recommended (BSR, 2018).

7.5 Measles

Measles is a serious reportable and notifiable infection. Patients who develop measles should be advised to stop their b/tsDMARDs treatment and report this immediately to their GP and rheumatology team, where further medical advice and treatment can be given. The b/tsDMARDs should not be recommended until the patient has fully recovered and been reassessed by either their GP or rheumatology specialist team. In an outbreak scenario, patients receiving a b/tsDMARD would require immunoglobulin if they were measles IgG negative or equivocal and had been in contact with an individual who had measles. Refer to:

- gov.uk/government/publications/measles-post-exposure-prophylaxis
- gov.uk/government/publications/contraindications-and-special-considerations-the-green-book-chapter-6

7.6 Human anti-chimeric antibodies (HACAs)

Some patients on anti-TNFi are immunogenic, resulting in the formation of antidrug antibodies (ADAs) that can lead to loss of clinical response. In patients treated with anti-TNF therapies, measuring the ADA titre as well as the drug level, can provide an objective view on the patient's clinical response (Rinaudo-Gaujous et al., 2015).

The chimeric biologics for example, infliximab and rituximab, can induce HACAs which can:

- increase the risk of allergic or hypersensitivity reactions and/or
- reduce treatment benefits in therapies used in RA.

Delayed hypersensitivity reactions have also been reported with infliximab when intervals between treatments are increased. Formation of ADAs seems to be reduced when methotrexate is used in combination with biologics. The efficacy of all biologics seems to improve with the co-prescription of methotrexate.

7.7 Cardiac

Please refer to the SmPC in conjunction with the patient's consultant regarding ongoing cardiac events and treatments. These treatments are changing as new evidence emerges. BSR guidelines (2018) state that 'Patients on biologics with cardiac failure: class 111 or 1V should be used with caution and working closely with a cardiologist'.

7.8 Surgery and common practice

Prior to surgery, please refer to the half-life of the drug and type of surgery before pausing treatment. There will be regional variation and close liaison with the individual's surgeon should be sought.

8 Safety monitoring

All medicines are subject to a black triangle status (▼) at the time of initial authorisation. JAKi are currently subject to black triangle status as well as some biosimilars.

8.1 Adverse drug reactions

Adverse drug reactions, or events, are an undesired effect of a medication or medical product. They may occur from an incidental or non-incidental drug overdose, abuse or medication errors because of incorrect prescribing or administration.

The more often that suspected adverse drug reactions are reported, the more information regarding medications or medical products will be available for those prescribing and administering. This will enable prescribers to make a balanced decision based on risk and benefit.

Please see Adverse Drug Reactions in Appendix 4 for information on the most frequently used rheumatology medications and a hyperlink to each of the SmPCs available on the Electronic Medicines Compendium (EMC) website: medicines.org.uk/emc

8.2 Responsibility for reporting possible adverse drug reactions or adverse events

Anyone can report possible undesired effects of a drug or medical products, including members of the public and patients. In the UK, we use the Yellow Card scheme.

Adverse drug reactions can be easily reported online via the website or app.

See: yellowcard.mhra.gov.uk

8.3 Travel advice

Patients should be counselled on the need to avoid live vaccines while on csDMARDs, bDMARDs, tsDMARDs and certain doses of corticosteroid, and the implication that may have for travelling. Travel letters can be provided by the home care companies. Advice regarding cool chain for travel and how long treatment can be left out of the fridge needs to be discussed with the patient. Up-to-date information can be found in the SmPCs.

For information regarding immunisation of patients with underlying conditions, refer to chapter 7 of The Green Book: gov.uk/government/publications/immunisation-of-individuals-with-underlying-medical-conditions-the-green-book-chapter-7

9 Optimisation of therapies

It is recognised that this would be outside of licensed dose recommendations within the SmPCs for these drugs. However, established prescribing practice for DMARDs is

to maintain the patient on the lowest dose and dose tapering that maintains clinical remission. This avoids unnecessary dose-related adverse events while remaining cost effective and preserving excellent clinical outcomes (EULAR, 2019; ACR, 2021; NICE, 2014; Van Herwaarden et al., 2014).

9.1 Switching between therapies

Approximately one-third of patients do not respond to the first therapy (primary failure) and a significant percentage will also lose efficacy later during therapy (secondary failure). For both subgroups different treatment options are available, including switching to an alternative b/tsDMARD therapy or changing to an agent with a different mechanism of action. The case for switching to another agent can be supported based on their different half-lives, which might be translated into a different duration of TNF neutralisation and responses at an individual level (EULAR, 2012, 2019; ACR, 2021).

There is evidence that overlapping therapies, without considering half-life, further increases the risk of infection and adverse effects, and so care should be taken when switching between advanced therapies. It is common practice to rescreen (including for infection), when switching between therapies. Local guidelines should be followed.

Individual risks and benefits must be considered and discussed clearly with patients.

9.2 Administration of therapies: intravenous therapies

There will be regional variations for where treatments are administered (ie, secondary, primary, or home care settings). Robust standard operating procedures need to be in place.

Therapies do not require specialist handling precautions as they are not chemotherapy agents and disposal of equipment and unused medication should be in accordance with local requirements.

For additional detail please refer to the SmPC, discuss with the manufacturer's medical information department, or your pharmacist.

Example questions and actions to consider for an infusion checklist:

- check there are no contra-indications to treatment, including any contra-indicated medication
- check recent blood tests are within satisfactory parameters
- record baseline temperature, pulse, blood pressure and Oxygen(O2) saturation levels if indicated
- check no recent infections or antibiotics – consider a urinalysis/midstream urine (MSU) if symptomatic of a urinary tract infection (UTI)
- if any concerns are raised in the pre-infusion checklist speak to the rheumatology team for assessment.

9.3 Subcutaneous therapies

This section outlines considerations for the therapies currently administered subcutaneously.

This guidance is general only. For additional detail please refer to the SmPC, discuss with the manufacturer's medical information department or your pharmacist.

9.4 Overview of home care

Most people who self-administer b/tsDMARDs will often have their drugs delivered to them at home by a home care delivery service and will receive subsequent training. The service should be well-integrated into the care pathway, provide high quality assurance of safety and quality, and provide evidence of meeting patients' needs.

A campaign by BSR in (2022) highlighted the difficulties with home care services which has led to delay in patients commencing and receiving treatment. Therefore, documentation and audit should be an integral aspect of developing a service for patients receiving subcutaneous biologic therapy.

Stop-Think-Reflect

- Consider all the information required before a repeat prescription for a biologic or targeted-synthetic therapy is completed.
- What information do you need to know about a patient and what assessments are required?

10 Emergency treatment of anaphylactic reactions

Anaphylactic reactions have been reported in all the biologic drugs given by infusion.

The frequency of these reactions is described as uncommon or rare. Evidence suggests this is more likely to occur within 2-4 infusions. Many protocols advise giving pre-medications to reduce risks.

Stop-Think-Reflect

Remember during an anaphylaxis event you don't need a prescription to administer emergency treatment

STOP infusion, check patient, contact rheumatology team if able.

If patient becomes very unwell or unresponsive put out either a peri-arrest call or a cardiac arrest call (2222).

After medical assessment, depending on the type of reaction, you may be asked to re-start the infusion at a lower rate of infusion or give supportive medications.

Appendix 1 Core documents

The first edition of this document was published in 2009. Since then, there have been a number of changes including new publications, advisory documents and updated guidance from professional organisations and regulatory bodies It is vital that practitioners using this document also refer to these core documents, which are listed below:

- BSR (2018) British Society for Rheumatology (2018) The British Society for Rheumatology biologic DMARD safety guidelines in inflammatory arthritis. *Rheumatology*, 58(2), 220-226. **https://doi.org/10.1093/rheumatology/key207**
- BSR (2022a) Guidelines for the treatment of psoriatic arthritis with biologic and targeted synthetic DMARDs. **rheumatology.org.uk**
- BSR (2022b) Guidelines on prescribing drugs in pregnancy and breastfeeding: immunomodulatory anti-rheumatic drugs and corticosteroids. **rheumatology.org.uk**
- NICE guidelines: NG100; NG65; QS33. **nice.org.uk/guidance**
- NRAS: **nras.org.uk**
- EULAR guidelines: **eular.org**
- EULAR (2013) Recommendations for the management of RA with synthetic and biological disease-modifying anti-rheumatic drugs, *Annual of Rheumatic Diseases*, R9, 964-975.
- EULAR (2017) Update of the ASAS/EULAR management recommendations for axial Spondyloarthritis, *Annual of Rheumatic Diseases*, 76, 978-991.
- EULAR (2016) Recommendations for the management of psoriatic arthritis with pharmacological therapies: 2015 update, *Annual of Rheumatic Diseases*, 75, 499-510.

Other guidelines

- ARMA (2006) *Standards of care for people with inflammatory arthritis*. **arma.uk.net**
- BTS (2016) BTS recommendations for assessing risk and for managing mycobacterium tuberculosis infection and disease in patients due to start anti-TNF-alpha treatment. **http://dx.doi.org/10.1136/thx.2005.046797**
- National Axial Spondyloarthritis Society (2019) *Managing My Axial SpA (AS) Flares*. **nass.co.uk/wp-content/uploads/2019/11/Managing-my-axial-SpA-AS-flares.pdf**

Appendix 2 Example of a pre-biologic treatment proforma

Patient information/ID label	**First biologic ☐ / Switch ☐** **Therapy commencing**
Name	
Hospital number	
NHS number	
DOB	
Comments	

Pre-treatment screening questions	**Yes**	**No**
Patient meets NICE criteria (or exceptional request approved)		
Patient has received written and verbal information on proposed treatment		
Patient has understood the side effects and benefits of this treatment		
Patient has been advised to use effective contraception		
Patient advised not to have live vaccines		
Patient advised to have seasonal flu vaccine		
Patient advised to have pneumovax vaccine and keep up to date		
Patient up to date with COVID-19 vaccine (DATE)		
Patient provided with alert card		
Patient is taking methotrexate/other DMARD *unless approved as monotherapy or patient is intolerant of methotrexate		
Tocilizumab only – potential interaction with statins/calcium channel blockers/theophylline/warfarin/phenytoin/cyclosporine/ benzodiazepines		
CXR in last 12 months is normal or with no new changes/unexpected findings		
T-Spot/IGRA/Quantiferon/Mantoux test is non-reactive		
Hepatitis B status +ve/-ve, Hepatitis C status +ve/-ve		
HIV status +ve/-ve		

Varicella status VZIGG immune/not immune		
ANA status +ve/-ve		
FBC, U&E		
Immunoglobulins normal (Rituximab only)		
Baseline ESR/CRP =		
Baseline lipids		
Weight in kgs		
RA DAS 28 CRP/ESR =		
AxSpa BASDAI = VAS =		
PsA DAS 66/68 TJC ( ) SJC ( ) Patient Vas Physicians Vas		
Exclusion criteria	**Yes**	**No**
Active infection		
Severe heart failure (New York criteria)		
Malignancy		
Patient is pregnant or breastfeeding (excluding certolizumab pegol). Discuss other options including other TNF inhibitors that can be administered up to the third trimester.		
Criteria for caution	**Yes**	**No**
History of recurrent/chronic infections		
Septic arthritis of a native joint within the last 12 months		
Chronic leg ulcers		
Multiple sclerosis		
Chronic Hepatitis/HIV		
All IL-6 and JAKi (Tocilizumab) or IBD (Secukinumab and Ixekizumab)		
Hepatic disease		
Renal impairment		
Raised cholesterol in IL-6 and JAKi		

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History or high risk of venous thromboembolism (Baricitinib, Tofacitinib, Filgotinib, Upadacitinib)		
Immunocompromised patients		
Patient advised treatment will be withdrawn in the following circumstances	**Yes**	**No**
Malignancy (excluding non-malignant skin cancer such as basal cell)		
Severe drug related toxicity/unexplained adverse event		
Pregnancy (except in certolizumab pegol and other TNF inhibitors up to third trimester)		
Severe infection (until resolved)		
Patient requires surgery (for a period before and after procedure)		
Patient does not respond to treatment		
Consent	**Yes**	**No**
I have read the written information about this medication		
I have had the opportunity to ask questions regarding the risks and benefits of this treatment		
I understand that I must attend planned appointments to be reviewed		
I understand that the treatment will be discontinued if my condition does not respond or if it is no longer deemed appropriate		
I agree to my details being provided to a nominated home care service who will provide initiation of treatment and the supply of medication		

Script and registration sent to pharmacy/day case	Date:
Signature:	Date:
Practitioner/VBC name:	
Signature:	Date:

Appendix 3 Monitoring efficacy

(NICE guidance at time of production)

	Rheumatoid arthritis	Psoriatic arthritis	Axial spondyloarthritis
Validated assessment tool	DAS28	66/68 tender and swollen joint count	BASDAI and spinal VAS
NICE criteria for access to biologic therapy	Intensive therapy with a combination of cDMARDs (one of which must be MTX unless contraindicated) Moderate disease activity score >3.2 Severe disease activity score >5.1	2 DMARDs (one of which must be MTX unless contraindicated) Tender joint count = 3 or more Swollen joint count = 3 or more Patient GDS _ / 5 Physician GDS _ / 5	Adequate trial of 2 NSAIDs (unless contraindicated) BASDAI >4.0 Spinal VAS >4
Specialist review required following initiation of treatment	12-16 weeks depending on which biologic therapy commenced (See SmPC for individual medication)	12-16 weeks depending on which biologic therapy commenced (See SmPC for individual medication)	12-16 weeks depending on which biologic therapy commenced (See SmPC for individual medication)
Ongoing clinic review	As clinically required due to severity of disease Minimum 6 monthly [4] Local variations may apply	As clinically required due to severity of disease Minimum 6 monthly [4] Local variations may apply	As clinically required due to severity of disease Minimum 6 monthly [4] Local variations may apply
Response criteria	Improvement of DAS28 of >1.2 in severe disease and >0.6 in moderate disease by 6 months	Improvement in at least 2 of the 4 PsARC criteria, (one of which has to be joint tenderness or swelling score) with no worsening in any of the four criteria (People whose disease has a Psoriasis Area and Severity Index (PASI) 75 response at 12 weeks but whose PsARC response does not justify continuation of treatment should be assessed by a dermatologist to determine whether continuing treatment is appropriate on the basis of skin response)	Reduction in BASDAI score to 50% of the pre-treatment value or by 2 or more units And a reduction in the spinal pain visual analogue scale (VAS) by 2cm or more

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Blood monitoring (For further specific guidance check your locally agreed protocols)	Biologic without cDMARD (or with cDMARD that needs no blood monitoring): 3-6 monthly Patient on Biologic + DMARD may need more frequent monitoring IV/SC tocilizumab: Monthly monitoring of neutrophil count and AST/ALT IV rituximab: Requires checking of immunoglobulins before each cycle JAKi: Repeat lipids 8-12 weeks (see SmPC for individual medication)	Biologic without cDMARD (or with cDMARD that needs no blood monitoring): 3-6 monthly Patient on Biologic + DMARD may need more frequent monitoring JAKi: Repeat lipids 8-12 weeks (see SmPC for individual medication)	Biologic without cDMARD (or with cDMARD that needs no blood monitoring): 3-6 monthly Patient on Biologic + DMARD may need more frequent monitoring
Registry	BSRBR-RA (Recruitment until 2026)	BSRBR-PsA (Recruitment until 2026)	BSRBR-AS (Study recruitment ended 2020)

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Appendix 4 Reflection exercise for CPD, NMC revalidation and RCN Competency Framework for Rheumatology Nurses

RCN Competency Framework for Rheumatology Nurses: rcn.org.uk/Professional-Development/publications/pub-009004

Self-reflection exercise: to illustrate understanding behind the changes presented in this update (fifth edition) in line with the NMC (2018).

For revalidation each nurse is required to record a minimum of five written reflections relevant to their experience over three years. This is prior to the renewal of their registration. These reflections can be on a CPD activity or reflection of an event or experience.

The NMC Reflective Accounts Form (at time of publication) can be used to record your thoughts on reading this document, which can then serve as one of the compulsory five written reflections. Any reflective account needs to explain what you have learnt for the CPD activity, how you have changed or improved your work as a result, and how this is relevant to the Code.

Once you have read this document, spend some time considering what you have learnt and how this will inform and change your future practice. Once you have written you can show it to your confirmer and discuss with them what you have written.

Please feel free to develop your questions to assist your reflective learning.

PLEASE NOTE: For revalidation, please ensure you visit the NMC revalidation website for the latest and most up-to-date version of the NMC Reflective Accounts Form: nmc.org.uk/revalidation

This concludes the adult section of the document. Part 2 of the document covers specific issues to the care of children and young people.

Part 2: Children and young people patients

1 Introduction

This document provides guidance for all nurses caring for children and young people (CYP) under the age of 18 with rheumatological conditions requiring DMARDs. These are used to treat the underlying rheumatological condition and reduce inflammation.

There are three main types of DMARDs used in paediatric rheumatology:

- **conventional synthetic DMARDs** (cDMARDs): for example, methotrexate
- **biological DMARDs** (bDMARDs): for example, adalimumab and infliximab
- **targeted synthetic DMARDs** (tsDMARDs): JAK inhibitors, such as baricitinib and tofacitinib.

The role of cDMARDs and bDMARDs is well established. Whereas the use of tsDMARDs continues to evolve in the treatment of paediatric rheumatology conditions, these drugs are effective, well tolerated and safe in the vast majority of patients. However, they can be associated with complications such as neutropenia, infections and, in the long term, may increase the risk of certain types of cancer, for example, skin cancers.

Clinical services for CYP with rheumatological conditions have expanded significantly since 2001. The British Society of Paediatric and Adolescent Rheumatology (BSPAR) originally supported practitioners caring for CYP. BSPAR merged with the British Society for Rheumatology (BSR) in 2016 and BSR is now the parent committee supporting safe practice across the life course in rheumatology.

A multidisciplinary approach is essential to the provision of high-quality care to CYP with rheumatological conditions and this is often co-ordinated by the paediatric rheumatology nurse specialist based in a tertiary centre. Ongoing treatment is commonly given at home by family/carers with the support of children's community nursing (CCN) teams or closer to home in local paediatric units. CYP need developmentally appropriate health care delivered by the appropriate qualified health care professionals.

The clinical assessment of CYP requires specialist knowledge and training. It is not the same as assessing an adult. CYP may not be able to articulate troubling symptoms relating to their disease or their medications and clinicians need to work closely with families or caregivers to understand the health status of the young person. Drug calculations for CYP are based upon body weight or body surface area which can make calculations more complex than for adults. Preparations of these drugs are often only licensed for specific age ranges.

2 Rheumatological conditions

Rheumatological conditions in CYP include Juvenile Idiopathic Arthritis (JIA) and a wide range of connective tissue diseases and vasculitides, for example Juvenile Dermatomyositis (JDM) and Juvenile Systemic Lupus Erythematosus (JSLE). Some paediatric rheumatological conditions are highly specific to the paediatric population (for example JIA), whilst others overlap with adult presentations (for example some of

the vasculitides). Despite these overlaps, paediatric treatment pathways may be quite different to adult pathways with variations in presentation, assessment, management and treatment. An increasingly complex range of auto-inflammatory diseases are also being treated by rheumatology practitioners with bDMARDs and tsDMARDs.

JIA is the most common paediatric rheumatological diagnosis. It is an umbrella term for a collection of subtypes of arthritis. JIA is defined as arthritis in one or more joints lasting for 6 weeks and starting under 16 years of age (see **Part 2, Appendix 1** for Classification of JIA).

A recent study by Costello, McDonagh et al., (2022) showed that over the last 15 years the incidence and prevalence of JIA in the UK has not changed and remains as approximately 6 per 100,000 population and a prevalence of around 1:1000. Diagnosis is based upon clinical findings of persistent arthritis including the medical history, physical examination of all joints and laboratory tests. There is no single test to diagnose JIA. Diagnosis follows process of exclusion of conditions such as infection and leukaemia.

Uveitis can develop in isolation or in association with different inflammatory and rheumatological conditions, in particular JIA. Uveitis is inflammation inside the eye. Many CYP have no obvious symptoms but if left untreated it can result in blindness. Some patients with JIA will go on to develop uveitis in the years following diagnosis so screening of CYP is imperative (see: **engage.england.nhs.uk/consultation/specialised-services-consultation/user_uploads/uveitis-paediatrics-policy.pdf**). Visual symptoms or impairment are often not recognised and therefore not reported by CYP, hence regular screening is important to ensure inflammation is not left untreated. DMARDs are often used in patients with uveitis to try and prevent irreparable visual impairment.

3 Education

Since the paediatric rheumatology clinical nurse specialist community is small, nationally and internationally, seeking credible and accurate educational resources has been problematic. Networks and online communities have been developed to help support colleagues. In 2015, a study identified a gap and lack of educational resources for paediatric nurses caring for CYP with rheumatological conditions (Smith et al., 2015). This led to a collaboration of experts in paediatric rheumatology, nurse education and researchers to develop a free, evidence-based learning resource. Further information can be found at: **www.pmmonline.org/nurse**

There is a national network of paediatric rheumatology clinical nurse specialists caring for CYP with rheumatological conditions. This network facilitates communication, liaises with each other, and provides peer support, education and guidance. This allows for more experienced nurses/teams to share information and expertise (Livermore, 2022).

4 Competency framework

In 2020, a more extensive learning resource was developed by a national group of experts – the *RCN Competency Framework for Rheumatology Nurses* (2020) which is available at: **rcn.org.uk/professional-development/publications/pub-009004**

5 Children and young people are different to adults

Around the UK, tertiary centres with specialist paediatric multi-disciplinary rheumatology teams lead the care of CYP with inflammatory rheumatological conditions. These teams are experienced in the care of a wide range of rheumatological diagnoses

and aim to provide high quality clinical care as close to home as possible to minimise disruption for families/carers. Tertiary centres work closely with local teams, providing specialist education and support as needed, as well as external agencies including schools, social services and the voluntary sector.

Paediatric rheumatology clinical nurse specialists co-ordinate the care of paediatric rheumatology patients, ensuring that CYP and their families and carers are fully informed about the underlying condition and the treatments that may be needed, as well as ensuring families know how and where to access timely and appropriate support and advice

CYP with JIA require prompt diagnosis. Referral to a specialist paediatric rheumatology MDT should be made within six weeks of the onset of symptoms (Davies et al., 2010). Many rheumatology units work with pharmaceutical home care companies and these companies may provide nursing support to train families in the administration of subcutaneous medications. It is essential that such staff are suitably qualified and trained to work with CYP, with regular clinical support and education from the specialist team.

6 Paediatric rheumatology clinical nurse specialist

Each CYP with JIA should be seen within 4 weeks of referral to the paediatric rheumatology team (NHS England Paediatric Medicine Rheumatology Quality Dashboard). The role of the paediatric rheumatology clinical nurse specialist is to guide the CYP and their family through diagnosis and treatment options and provide ongoing support and information. Many tertiary centres offer combined clinics or nurse-led clinics with MDT support for the CYP and family at diagnosis. If this is not possible, a follow-up phone call from the PRCNS to the family should be offered. Having a chronic condition can be devastating for the CYP and their family.

The paediatric rheumatology clinical nurse specialist should have a registered children's nursing qualification and experience within rheumatology (RCN, 2020).

Many families/carers are supported at home by community children's nurses or at their local hospital by ward or day care nurses for the administration of medications and blood monitoring. Community children's nurses require education and ongoing support from the paediatric rheumatology clinical nurse specialists and online resources (PMMonline.org).

The bDMARDs are predominantly prescribed by tertiary centres. Some centres may facilitate shared care arrangements for the local hospital to administer intravenous treatments.

6.1 Supporting CYP

Paediatric rheumatology clinical nurse specialists and registered children's nurses assisting with the administration of DMARDS should be supported by the paediatric rheumatology multidisciplinary team.

They should:

- have expertise in the therapies they are administering and be fully aware of the potential side effects of treatment and monitoring schedules

- be competent in the administration of subcutaneous injections and have the ability to teach and assess the competence of CYP and their families/carers
- be skilled in teaching CYP about their treatment, recognising a patient's level of physical and cognitive abilities
- have expertise and experience to recognise anxiety associated with procedures/needles and support the CYP
- involve other specialists (if available), such as hospital play specialists, youth workers and psychologists, to support CYP who need injections, as required
- involve other agencies in the charity sector to support families and CYP if appropriate. All professionals working with CYP should be able to recognise and know how to act upon concerns when health needs are not being met. This includes when the CYP is not attending regular follow-up appointments or adhering to medication prescribed. All hospitals have designated safeguarding nursing and medical staff with clear policies and information should staff have any concerns about the safety of a CYP or their family. Safeguarding supervision is also advocated so there is a formal process of reviewing staff on a regular basis.

7 DMARDs for rheumatological conditions

The range of immune-modulating treatments licensed and approved for use in the paediatric population has expanded greatly over the last 20 years. As the evidence supporting the use of complex medications expands, the role of these treatments for CYP with inflammatory rheumatological diseases continues to evolve. Treatment choices are informed by a wide range of factors, including the diagnosis, sub-classification, national guidance and local agreements/availability.

Clinical guidance supporting the provision and monitoring of treatment is under constant review. It is, therefore, essential that all CYP receiving treatment have their care managed by a tertiary paediatric rheumatology service, where possible in collaboration with the CYP's local paediatric team.

7.1 Types of DMARD

Corticosteroids were the only effective treatment option for paediatric inflammatory rheumatological conditions until the introduction of cDMARDS in the 1980s.

cDMARDs: These are central to inflammatory rheumatological disease treatment pathways since the 1980s. Due to more established use health professionals are often more familiar with their usage and long-term adverse effects. These medications are usually first line treatment due to the many years' experience and ease of administration. They are much cheaper than many of the newer bDMARDs and tsDMARDs. Examples include methotrexate, leflunamide, sulfasalazine and hydroxychloroquine. These drugs aim to reduce inflammation and are often used in conjunction with bDMARDs or tsDMARDs.

bDMARDs: The term 'biologic' describes treatments developed and produced in live cell systems (biologically active systems). These medications work by targeting parts of the immune system to disrupt the processes that lead to inflammation in the body.

They have a large molecular mass, therefore need to be given by intravenous infusion or subcutaneous injection. They tend to be newer with less long-term safety data. They can be used in combination with some other cDMARDS for an adjunctive effect. Examples include anti-TNFs (etanercept, adalimumab and infliximab), anti-Il6 (tocilizumab), anti Il1 (anakinra and canakinumab), and anti CD20 (rituximab).

tsDMARDs: Targeted synthetic oral drugs are more recent innovations, targeting specific parts of the immune system. They are not made from living cells. The chemicals are smaller than biologic molecules so can usually be taken by mouth (tablet or suspension). Examples include JAK inhibitors such as tofacitinib or baricitinib. Some of these drugs are unlicensed for CYP and are currently in clinical trials. There is currently no long-term data on their use.

7.2 Routes

This guidance is designed to share common principles to be applied, regardless of route of administration.

7.3 Safe administration

Staff should follow local policy and guidance while having the correct knowledge and skills to administer medication safely (Health and Safety Executive, 2002). This will vary according to the DMARD being given.

7.4 What is a biosimilar

Biosimilar drugs have been developed to be close in structure to an original bDMARD. They should provide a similar clinical efficacy, safety and response. Where NICE has already recommended the bDMARD, the same guidance will normally apply to a biosimilar of that originator.

Stop-Think-Reflect

- Spend some time researching the different bDMARDs available to treat paediatric rheumatological guidance. You could use this guidance to help your research: nice.org.uk/guidance/ta373/chapter/1-Guidance
- What medication are you using for your patient group?
- What biosimilar medication is available within your hospital trust?

8 Before treatment starts

CYP and their families/carers should be provided with information (verbal and written) about the treatment. They must demonstrate understanding of the contraindications, the potential risks, and side-effects to enable them to make an informed decision about DMARDs. CYP and families/carers should also be given the opportunity to discuss any concerns.

In addition, CYP and families/carers should have a training plan that provides them with a clear understanding of the process and responsibilities required for either hospital or home administration (see Part 2, Appendix 2). The time it takes to complete the training, together with the number of practice sessions, will vary.

Patient information leaflets on treatment are available from a number of patient organisations, some of which are listed at end of this document. Many manufacturers also produce illustrated patient guides and online videos in addition to their SmPCs and patient information leaflets.

8.1 Informed consent

Complex discussions regarding the risks and benefits of receiving DMARDs may differ from patient to patient. As for all treatments, it is important that the CYP and parents/carers are involved in the discussions regarding treatment options, risks, benefits and precautions. The paediatric rheumatology clinical nurse specialist needs to document exactly what information has been provided.

A small number of treatments may affect fertility or foetal development. These should be identified by the specialist team and the risks versus benefits discussed with the CYP and family/carers.

See guidance relating to pregnancy and breastfeeding, published by the BSR: academic.oup.com/rheumatology/article/62/4/1370/6783014

When prescribing DMARDs, good practice recommends that a named professional is available for CYP and families/carers to contact with any concerns or to seek advice. Many services offer telephone or email advice lines.

Where English is not the first language, or the CYP and family/carer has a hearing or visual deficit, translation facilities must be available to support giving information, answering questions and obtaining consent. It is advised that this should be through a professional translation service, rather than family or friends, other than in exceptional circumstances.

8.2 Shared decision making

When decisions about treatment options are shared, it has been shown to improve engagement and adherence (Bjoness, Viksven et al., 2020). Encouraging CYP and families/carers to ask questions and be involved in making decisions about their treatment supports confidence and the development of self-advocacy (Nagra, McGinnity, Davis et al., 2015).

There are some good resources to support professionals in this process, for example:

- **HEADSSS tool**: (Goldenring, Rosen, 2004) and this online resource: health.nsw.gov.au/kidsfamilies/youth/Pages/heeadsss-videos.aspx
- **Ask 3 Questions posters and resources**: readysteadygo.net/shared-decision-making--ask-three-questions.html

8.3 Funding of DMARDs

High-cost medications are required to be registered on the NHS England database, Bluteq. This allows usage monitoring for expensive treatments, ensuring they are prescribed within nationally agreed policies including NICE guidelines.

If Bluteq agreement is obtained, the drug will be funded by NHS England. Registering such medications is usually performed by the paediatric rheumatology consultant when prescribing the first dose.

It is important to acknowledge that some patients need to be prescribed unlicensed or off label treatment.

The following links will take you to the relevant NICE guidelines:

Abatacept, adalimumab, etanercept and tocilizumab for treating Juvenile Idiopathic Arthritis:

nice.org.uk/guidance/ta373/chapter/1-Guidance

Tocilizumab for the treatment of systemic Juvenile Idiopathic Arthritis:
nice.org.uk/guidance/ta238

Tofacitinib for treating Juvenile Idiopathic Arthritis:
nice.org.uk/guidance/ta735

8.4 Administration of bDMARDs and tsDMARDs

If the prescribed treatment is suitable for home administration, practitioners need to assess the family/carer for their understanding of treatment including their ability to recognise and manage side effects. They also need to be aware of when not to give medication and how to contact the specialist team or out-of-hours services for advice.

CYP and families/carers will need to undertake training to demonstrate the ability to safely administer the medication (either oral or injection). A patient training checklist and competency example can be found in Part 1, Appendix 2.

It is the responsibility of the paediatric rheumatology specialist team to ensure the family/carer has a clear understanding of how to manage the treatment, including correct dose, frequency and waste disposal (if appropriate). Families/carers need to be aware they will need to undertake regular blood monitoring and clinic appointments. All health care staff working with CYP are expected to take appropriate and timely actions when a child is not brought to a pre-arranged appointment by their family/carer.

Stop-Think-Reflect

- What is your hospital policy for following up CYP who aren't brought to hospital for their appointments (eg, clinic, radiology or blood tests)?
- This is sometimes known as a 'was not brought' (WNB) policy and is part of the children's safeguarding procedures.

If the family/carer needs extra support with the administration of injections, they should be referred to the local community children's nursing team. If the prescribed medication is by oral route, and swallowing tablets is difficult for the CYP, there is an interactive training package developed to teach pill swallow (Tse, Vasey et al., 2019) e-lfh.org.uk/programmes/kidzmed.

Nurses administering medications for rheumatological conditions, via an infusion in a clinical environment should have access to the specialist team for support and guidance. Although rare, there is the potential for serious and life-threatening reactions, so CYP should be cared for in a suitable paediatric environment with access to paediatric resuscitation.

The paediatric rheumatology specialist team should provide ongoing support and education for nursing teams managing CYP on complex medications.

8.5 Assessment of a young person

Practitioners should be aware of the need for developmentally appropriate health care and education as children become teenagers and young adults. Key areas for assessment include:

- **home**: who do they live with and who supports them?
- **education**: are they attending regularly and do they have career aspirations?
- **hobbies/interests**: what do they like to do in their own time?
- **risk-taking behaviors**: consider drug or substance misuse and any potential interaction with prescribed medication
- **sexual health**: including partners, contraception, avoidance of sexually transmitted infections, and contraindications with medication
- **mental health**: consider mood, interaction with professionals, self-harm, suicidal feelings, eating problems, gender orientation
- **safeguarding concerns**: any previous or current involvement with social care, exploitation, gangs, neglect, radicalisation.

This is not an exhaustive list and is best encompassed within an assessment tool specifically designed for interaction and engagement with young people, such as HEADSSS (Goldenring, Rosen, 2004) and this online resource: health.nsw.gov.au/kidsfamilies/youth/Pages/heeadsss-videos.aspx

Stop-Think-Reflect

- What tool are you going to use in your service to assess and interact with young people prior to starting treatment?
- Explore useful online websites to support young people and their families including Young Minds and the NSPCC.

8.6 Pre-treatment checklist and baseline investigations

Before starting treatment, baseline investigations will be needed. They may include:

- height and weight (with consideration of BMI calculation)
- blood pressure (if relevant to treatment)
- FBC and differential WBC
- erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP)
- liver function tests
- renal function tests
- urea and electrolytes
- varicella and measles IgG (If these are negative, discuss with lead clinician regarding vaccination)
- TB screening, for example QuantiFERON Gold blood test (QFG)
- Hepatitis b and c
- HIV
- chest X-ray.

9 Live Vaccinations

Vaccination schedules are constantly being adjusted. Up-to-date specific advice is available via The Green Book at: **gov.uk/government/publications/immunisation-of-individuals-with-underlying-medical-conditions-the-green-book-chapter-7**

In general, live vaccines should not be given during treatment and for 12 months following completion (The Green Book, 2013, Chapter 6). However, in individual cases a risk versus benefit analysis may alter this advice. Inactivated vaccines can be given, but the CYP may not build up the appropriate immune response to vaccines.

It is recommended all CYP who have not previously had the pneumococcal vaccine are vaccinated The injectable annual flu vaccines should be given while on treatment. The nasal flu vaccine, once prohibited for CYP on immunosuppression, may now be given in some cases following The Green Book guidance (DH, 2020).

The rapid changes in vaccination schedules during the COVID-19 pandemic illustrate the importance of checking up-to-date guidance.

The Green Book will continue to provide up-to-date information. Nursing staff who are immunising patients should follow the RCN standards (RCN, 2018).

10 Drug reactions

All drugs have the potential to cause allergic/anaphylactic reactions. With the increased use of combination treatments, there is a need for practitioners to be able to recognise and manage potentially fatal reactions to drugs. It is the responsibility of all practitioners to familiarise themselves with management of allergic and hypersensitivity reactions.

Site reactions to subcutaneous injections are usually mild and resolve without treatment. If they persist, over the counter preparations for allergy management can be considered. For example, oral antihistamines and/or topical mild steroid preparations. However, if the reactions do not settle this should be discussed with the specialist team.

Identification of the signs and symptoms of a hypersensitivity reaction relies on practitioners being aware of the potential reactions of the drugs they administer. Reactions vary in severity and progress may be rapid, slow or unusually protracted, or there may be a recurrence of symptoms (biphasic) after they initially seem to settle. Hypersensitivity reactions can be mild, moderate or severe and are more likely to occur during the first or second infusion and sometimes within minutes of commencing the infusion. Practitioners should be aware of Resuscitation Council guidance for emergency treatment of anaphylaxis (Resuscitation Council UK, 2021).

Stop-Think-Reflect

- It is essential that you are fully aware of how to recognise hypersensitivity and anaphylaxis.
- You should be familiar with how patients may present clinically and be able to assess the signs and symptoms. Ensure you read anaphylaxis guidance within your department and have appropriate training.

11 Intercurrent illness or infection

CYP taking any DMARDs are potentially at increased risk of severe infection. Infections are usually viral or bacterial, although fungal infections can occur. CYP may not present with typical features of severe infection as a result of either their underlying disease or the immunosuppression and may become unwell quite rapidly. See SmPCs at: **medicines.org.uk**

High or prolonged doses of steroid and / or combinations of immunosuppressive treatments are associated with increased levels of immunosuppression and therefore increased risk from infection. It is important to remember that immunosuppression can persist for several months after stopping medication and CYP must still be treated accordingly.

Sepsis can occur with any CYP. Sepsis arises when the body responds to an infection. It may lead to shock, multi-organ failure and death – especially if not recognised early and treated promptly.

Your local hospital or tertiary paediatric rheumatology team should have agreed pathways governing the management of intercurrent infections and it is important to familiarise yourself with the advice.

Alert cards/aids may be available from drug companies and some of the condition-related charities. CYP should be advised what to do if they become unwell with a high temperature and should stop their regular DMARDs until they have sought advice from a health care professional.

Stop-Think-Reflect

- Paediatric sepsis is the leading cause of child death. What is your hospital's paediatric sepsis guidance?
- A useful screening and treatment tool for paediatric sepsis is available at the Royal College of Paediatric and Child Health: rcpch.ac.uk/resources/paediatric-sepsis-podcasts

11.1 Varicella and measles infection

Primary or secondary chickenpox and measles is a major concern for patients taking DMARDs. The treatment of a CYP who has been in contact, varies from area to area and local management should be followed.

Prior to starting DMARDs, it's important to take a history of previous exposure to chickenpox, measles and childhood vaccines. Measuring measles and varicella IgG titres in all CYP prior to starting treatment is now standard practice and some even offer the vaccinations to those who have negative titres. These vaccines are live, and this will delay starting treatment. The risks of delaying treatment also need to be considered and should be discussed with the CYP/family/carer. Varicella immunisation is planned to be added to the routine childhood immunisation schedule (2024) gov.uk/government/publications/childhood-varicella-vaccination-programme-jcvi-advice-14-november-2023/jcvi-statement-on-a-childhood-varicella-chickenpox-vaccination-programme

Consideration should be given to providing immunisation to closer relatives who have not previously been infected with chickenpox. It is also vital to note that if chickenpox develops, treatment should be discontinued until the last spot has crusted over and the child is clinically well. Antivira l drugs such as aciclovir should be given as per individual hospital policy. Passive protection against chickenpox (or herpes zoster) with VZIG and/or aciclovir should be given in the event of 'significant contact' in non-immune patients. The Department of Health publication *Immunisation against Infectious Disease* is regularly updated and should be considered as the definitive source of information about vaccinations. It provides an up-to-date definition of 'significant contact' (DH, 2013). Measles is potentially a severe infection for CYP taking DMARDs and advice must be sought from specialist centres. assets.publishing.service.gov.uk/media/6616573be49ee0998d3ea70a/National_measles_guidelines_April2024.pdf

11.2 Opportunist infections

Normal opportunist infections can become more aggressive and difficult to eradicate while taking DMARDs. These include skin infections, for example verruca, molluscum contagiosum, paronychia and impetigo. These conditions may require longer treatment courses via their local health care professional, for example their GP. Occasionally modification of the DMARDs schedule may be needed if the infection persists.

When on these medications, CYP and their family/carers should be counselled about the increased risk of infections associated with body piercings and tattoos.

12 Monitoring

Blood monitoring is central to high quality care for CYP on systemic immunosuppression and, in fact, normal blood monitoring tests are a key prerequisite to provision of repeat prescriptions. The following monitoring regime is recommended for CYP who start treatment, but it may vary according to individual centres, guidance is recommended by Ledingham et al., (2017).

Abnormal blood tests: It is the responsibility of the specialist team to inform families of abnormal results that require withholding the treatment (unless a shared care agreement is in place which delegate's responsibility to a primary care practitioner).

Ongoing regular monitoring

- Bloods: FBC, U&E, LFT, ESR, CRP and renal function should be undertaken at intervals determined by prescribing team.
- Height, weight and blood pressure should be considered.
- If a patient is receiving IV therapies, a blood test should be taken prior to each infusion.
- A medical review should be conducted as agreed by specialist team.
- Any adverse reactions should be reported via the Yellow Card system.
- Ongoing PRCNS support should be made available via an advice line, especially regarding infections eg chickenpox, shingles and measles. However, urgent advice should be made via GP, 111, or in severe cases the emergency department for the management of acute infections.

13 When to stop treatment

As with any medication, the professional, CYP and family/carer need to be aware of the circumstances when they would not administer treatment.

The four most common reasons for temporarily discontinuing treatment include:

- usual childhood coughs, colds or minor infections do not warrant stopping treatment. However, if there is any suspicion that the child is systemically unwell – for example, a high fever or a rash (that is different to any usual fevers or rashes such as those that accompany systemic onset JIA) then expert opinion should be sought
- chickenpox/shingles/measles or any other significant infection. In this situation, the CYP and family/carer should seek medical advice immediately as further treatment will be required
- abnormal blood monitoring
- non-adherence to treatment, including poor attendance to review clinics.

14 Surgery/dental extraction

For CYP who have planned surgery or dental extraction, it is usually recommended that treatment is either stopped or timings adjusted prior to any surgical procedure. Each individual case should be discussed with the specialist team before stopping or restarting treatment.

If emergency surgery is required, patients or their families/carers should be advised to:

- stop treatment
- inform all respective professionals they have been on bDMARDs/tsDMARDs.

Although there is no specific paediatric guidance, it is reasonable to follow recent adult rheumatology safety guidance: academic.oup.com/rheumtology/article/58/2/220/5076445?login=false

15 Travelling

When CYP are travelling away from home, the manufacturer's guidelines/local prescriber should be consulted for advice on medication storage. Families/carers should also seek advice from PRCNS as they may have the option to adjust timings of medication instead of transporting it with them. Families/carers who take medication with them should be advised to carry medication in their hand luggage and ensure the prescription label is visible. Advice is also available from the medication delivery companies who can also provide letters for the airline if carrying medication on a plane.

CYP/families/carers should be advised to:

- arrange any vaccinations they may require well in advance of travel
- inform the vaccination provider that they are receiving regular treatment (to ensure they do not receive any live vaccines)
- use high factor sunscreen as sun sensitivity can be increased while receiving treatment
- ensure they are fully insured in respect of the CYP's condition and its management
- carry enough medication and ancillary supplies for the duration of their holiday and potentially some in reserve in case of travel delays
- seek clarification from the airline if transporting injectable medication.

CYP/families/carers should also be given advice regarding the risks of travelling to areas where there is limited access to specialist paediatric services.

16 Transfer to adult services

Around 50% of CYP with inflammatory rheumatological diagnoses will continue to have active inflammatory disease in their adult life, and up to 60% of all patients continue to have some limitation to daily living activities (Nigrovic and White, 2006). All CYP require varying levels of support through adolescence to prepare for transfer to adult services.

It is known that a poorly planned or ineffective transition is associated with increased morbidity and/or mortality (Nagra et al., 2015). There are already several published documents guiding adolescent or transitional care. The Quality Standard (NICE, 2016) covers transitional care and recommends that adolescents are identified early with developmentally appropriate health care offered from Year 9 and a more recent report is helpful as a guide – **ncepod.org.uk/2023transition/The%20Inbetweeners_summary%20report.pdf**

Developmentally appropriate health care provides the CYP with the knowledge, skills and confidence to manage their own condition as they move into adult services. This model encourages the CYP to build up relationships and to connect with professionals to make decisions about their health and wellbeing while living with a chronic condition. Developmentally appropriate health care is recognised as a more effective approach during transition with the focus being upon the individual young person rather than their age (Dovey-Pearce et al., 2020).

In health care, transition describes the process of preparing, planning and moving from children to adult services. The Ready, Steady, Go, Hello programme is a useful pathway to help CYP and families/carers to prepare for transfer: **readysteadygo.net/rsg-hello-to-adult-services.html**

Transfer to adult care is not always seamless, therefore having a dedicated transitional co-ordinator as part of the MDT is recommended (NICE, 2016). Their role is to link with adult teams and CYP to improve engagement and care prior to and post transfer. Successful transition needs to be planned with established pathways to the most appropriate adult rheumatology team.

Stop-Think-Reflect

Reflect on how you prepare CYP for transfer to adult services.

Are they in an appropriate environment? Do you use the Ready Steady Go Framework for Transfer?

readysteadygo.net/rsg-hello-to-adult-services.html

Appendix 1 Classification of Juvenile Idiopathic Arthritis (JIA)

The classification of JIA is discussed in: **pmmonline.org/nurse/arthritis-conditions/juvenile-idiopathic-arthritis-jia** and also referenced by the International League of Associations for Rheumatology (ILAR) classification criteria (Thomson, Barrett et al., 2002). Available at: **academic.oup.com/rheumatology/article/41/10/1183/1784374**

Classification of JIA	
Oligo articular JIA	Four or less joints affected within 6 months.
Uveitis incidence more common in this type of JIA.	
Extended oligo articular JIA	Oligoarthritis may extend to involve >4 joints after the first six months. It is then known as extended oligoarthritis. This pattern of disease often continues into adult life.
Poly articular JIA	Five or more joints affected within 6 months of disease onset.
Enthesitis-related arthritis (ERA)	Inflammation within the joints and/or tendons often affecting the sacroiliac joints and hips. CYP are often HLA-B27 positive.
Psoriatic arthritis	CYP with arthritis and psoriasis or arthritis and one of the following: • dactylitis (finger swelling) • nail changes • family history of psoriasis.
Systemic onset JIA (SoJIA)	Arthritis associated with recurrent fever and non-contagious rash. Inflammation affects many systems in the body. Associated with SoJIA is a serious, potentially life-threatening condition called macrophage activation syndrome (MAS).
Undifferentiated arthritis	This is where the type of arthritis does not fit neatly into any of the categories above.

Appendix 2 Training checklist

Training checklist for home administration of subcutaneous medication by a CYP or family/carer

Patient name:	
Person taught:	
Assessor:	

Check list	Date completed/ proved competence	CYP's /family/carer's signature	Assessor's signature
CYP/family/carer understands: • verbal and written information given on medication prescribed • reason for giving medication • potential complications/side effects.			
CYP assessment tool used and if appropriate contraception/pregnancy discussed.			
CYP/family/carer understands a normal temperature and has a working thermometer for use at home.			
CYP/family/carer knows and understands where to seek advice if CYP is unwell.			
CYP/family/carer given advice re: chicken pox/ shingles exposure.			
CYP/family/carer given advice re avoidance of live vaccines on treatment.			
Recommendation for seasonal flu, pneumozax and COVID-19 vaccines if eligible.			

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CYP/family/carer knows how to prepare equipment and check the drug.			
CYP/family/carer demonstrates hand washing before administration.			
CYP/family/carer can identify where the injection can be given including the importance of rotating sites.			
CYP/family/carer observed giving the subcutaneous injection using a safe technique.			
CYP/family/carer demonstrates appropriate disposal of sharps.			
CYP/family/carer knows how to deal with a needlestick injury.			
CYP/family/carer understands safe storage requirements for medication.			
CYP/family/carer can discuss instances when not to give the injections.			
CYP/family/carer knows who to contact in case of any problems.			
CYP/family/carer can discuss the rationale and arrangements for blood monitoring while on DMARDs.			
CYP/family/carer knows how to acquire repeat prescription.			
CYP/family/carer knows what to do when travelling with medication.			

One copy for patient and one to be retained in patient's notes.

Certificate of competence for the home administration of subcutaneous medication by patient or patient's carer

Patient name:	
Address:	
Telephone number/email:	

This is to certify that I have received teaching about subcutaneous medication and how to give the injections. I now feel confident and competent in giving the injectable treatment at home. I understand what problems may arise and what to do if they occur.

Patient/family/carer name:	
Signature:	
Date:	
Assessor name:	
Assessor signature:	
Date:	

Appendix 3 Example of specialist practitioner competence checklist

This complements *A Competency Framework for Rheumatology Nurses* (RCN, 2020).

Name of practitioner:	
Name of supervisor:	

Element of competence to be achieved	Date of achievement	Practitioner signature	Supervisor signature
Discuss the rationale for the use of DMARDs in rheumatology conditions.			
Discuss potential issues related to treatment including: • suitability of treatment for individual CYP • benefits of treatment • possible side-effects or adverse events.			
Discuss the process for assessing the patient's suitability for DMARD treatment. For example, medical and social history, concomitant medications, allergies, level of disease activity.			
Demonstrate the ability to check the validity of the current prescription. This includes expiry date, dose, route by which the drug is to be administered and checking patient identification.			
Demonstrate the ability to teach a CYP/family/carer how to administer subcutaneous treatment.			

Describe local health and safety guidelines and risk assessment required for providing a DMARD treatment in hospital and in the CYP home. With particular relevance to: • safe storage and handling • dealing with disposal and rare situation of spillage • preventing unnecessary exposure to other people • travelling and transporting medication.			
Demonstrate the ability to discuss the information/educational needs of the CYP/family/carer in relation to home administration of DMARD treatment.			
Demonstrate the ability to provide the CYP/family/carer with information about the treatment in order that they can give informed consent (written/ verbal – in line with local guidelines).			
Describe sites on the body that would be appropriate for subcutaneous injection.			
Be familiar with local guidelines and policy for administration of intravenous infusions and risk of infusion reactions.			
Demonstrate the ability to maintain concise and accurate CYP documentation and audit.			
Describe the local monitoring requirements and follow-up arrangements for CYP on DMARD treatment and the actions that must be taken in the event of abnormal blood results.			
Describe local policy and actions with a CYP who isn't being brought for clinic or monitoring appointments.			
Identify the ways of maintaining current competency.			

Useful websites

Arthur's Place: **arthursplace.co.uk**

British Society for Rheumatology: **rheumatology.org.uk/guidelines**

Children's Chronic Arthritis Association: **ccaa.org.uk**

JIA@NRAS: **jia.org.uk**

Juvenile Arthritis Research: **jarproject.org**

Lupus UK: **lupusuk.org.uk**

Myositis UK: **myositis.org.uk**

Nursing and Midwifery Council (NMC): **nmc.org.uk**

NSPCC: **nspcc.org.uk**

Olivia's Vision (Uveitis): **oliviasvision.org**

Paediatric Musculoskeletal Matters: **pmmonline.org**

Ready Steady Go: **readysteadygo.net**

Scottish Network for Arthritis in Children: **snac.uk.com**

UK Sepsis Trust: **sepsistrust.org**

Vasculitis UK: **vasculitis.org.uk**

Versus Arthritis: **versusarthritis.org**

What? Why? Children in Hospital: **whatwhychildreninhospital.org.uk**

Young Minds: **youngminds.org.uk**

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Further reading

Patient information leaflets

Information for patients on biologics is provided at the following sites.

Adults and children and young people

British Society for Paediatric and Adolescent Rheumatology: bspar.org.uk

British Society for Rheumatology: rheumatology.org.uk

British Thoracic Society: brit-thoracic.org.uk

Children's Chronic Arthritis Association: ccaa.org.uk

JIA@NRAS: jia.org.uk

Juvenile SLE group: liverpool.ac.uk/life-course-and-medical-sciences/research/groups/ukjsle

Lupus UK: lupusuk.org.uk

Medicines for Children: medicinesforchildren.org.uk

National Axial Spondyloarthropathy Society: nass.co.uk

National Rheumatoid Arthritis Society: nras.org.uk

Paediatric Rheumatology International Trials Organisation: pediatric-rheumatology.printo.it

Patient held records: teens.aboutkidshealth.ca/myhealth-passport

Psoriatic and Psoriatic Arthritis Alliance: papaa.org

Versus Arthritis: versusarthritis.org

Manufacturers' websites

AbbVie: abbvie.co.uk

Biogen: biogen.com

Blueteq Ltd: blueteq.com

Bristol Myers Squibb UK: b-ms.co.uk

Jansen Biotech: stelarainfo.com/about-janssen-biotech-inc#:~:text=About%20Janssen%20Biotech%2C%20Inc.&text=STELARA%C2%AE%20(ustekinumab)

Lilly UK: lilly.co.uk

Novartis UK: novartis.com/uk-en

Pfizer (formerly Wyeth): pfizer.co.uk

Roche UK: roche.co.uk

Schering Plough (MSD): msd-uk.com

UCB UK: ucbpharma.co.uk

Other useful websites

National Electronic Library for Medicines: nlm.nih.gov

NHS Commissioning Board: england.nhs.uk/commissioning

NHS Quality Improvement for Scotland: healthcareimprovementscotland.org

Paediatric Rheumatology European Society (PRES): pres.org.uk

RCN Rheumatology Nursing Forum: rcn.org.uk/Get-Involved/Forums/Rheumatology-Nursing-Forum

You can find full texts of all UK Government legislation at: legislation.gov.uk

Glossary of terms

Abbreviation	Term
ACP	Advanced clinical practitioner
ACR	American College of Rheumatology
ADA	Adverse drug reaction
ADA titre	Anti-drug antibody
ANP	Advanced nurse practitioner
anti-TNF	Anti-tumor necrosis factor
ARMA	The Arthritis and Musculoskeletal Alliance
AS	Axial Spondyloarthropathy (Ankylosing Spondylitis)
ASAS	Assessment of Spondylarthritis International Society
AWMSG	All Wales Medicines Strategy Group
BASDAI	Bath Ankylosing Spondylitis Disease Activity Index
BASFI	Bath Ankylosing Spondylitis Functional Index
BASMI	Bath Ankylosing Spondylitis Metrology Index
bDMARDs	Biological Disease Modifying Anti-Rheumatic Drugs
BMI	Body mass index
BRC	Biomedical Research Centre
BSc	Bachelor of Science
BSR	British Society for Rheumatology
BTS	British Thoracic Society
CD	Crohn's Disease
CD20	B-lymphocyte antigen
cDMARDs	Conventional Disease modifying antirheumatic drugs
COVID-19	Coronavirus disease (2019)
CPD	Continuing professional development
CRP	C-reactive protein
csDMARDs	Conventional synthetic disease modifying anti-rheumatic drugs
CXR	Chest X-ray
CYP	Children and young people
DAS-28	Disease activity score of 28 joints

DipHE	Diploma of Higher Education
DMARDs	Disease modifying anti-rheumatic drugs
EDTA	Ethylenediaminetetraacetic acid
EMC	Electronic medicines compendium
ESR	Erythrocyte sedimentation rate
EULAR	European League Against Rheumatism
FBC	Full blood count
GCA	Giant cell arteritis
GP	General practitioner
HACAs	Human anti-chimeric antibodies
HBcAb	Hepatitis B core antibody
HBsAG	Hepatitis B surface antigen
HBV	Hepatitis B
HBV DNA	Deoxyribonucleic acid (viral load)
HCQ	Hydroxychloroquine
HCV	Hepatitis C
HEADSSS	Home, education/employment, eating, activities, drugs, sexuality, suicidal ideation and safety
HIV	Human Immunodeficiency Virus
IBD	Inflammatory Bowel Disease
IgG	Immunoglobulin G
IGRA	Interferon Gamma Release Assay
IL	Interleukins
ILD	Interstitial lung disease
JAK i	Janus kinase inhibitors
JIA	Juvenile idiopathic arthritis
Lef	Leflunomide
LFT	Liver function test
LLP	Limited liability partnership
MDT	Multidisciplinary team

MHRA	Medicines and Healthcare Products Regulatory Agency
MMF	Mycophenolate mofetil
MMR	Measles, Mumps and Rubella
MSc	Master of Science
MSK	Musculoskeletal
MSU	Mid-stream specimen of urine
MTX	Methotrexate
NG	NICE guideline
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
NMC	Nursing and Midwifery Council
NMP	Non-medical prescriber
nrAxSpa	Non-radiographic Axial Spondyloarthropathy
NSPCC	National Society for the Prevention of Cruelty to Children
o2	Oxygen
PCR	Polymerase chain reaction
PDE4	Phosphodiesterase 4
PML	Progressive Multifocal Leukoencephalopathy
PMM	Paediatric Musculoskeletal Matters International
PsA	Psoriatic Arthritis
PsARC	Psoriatic Arthritis response criteria
QFT	QuantiFERON a blood test to detect infection with tuberculosis
RA	Rheumatoid Arthritis
RA-ILD	Rheumatoid Arthritis - intestinal lung disease
RCN	Royal College of Nursing
RCNRF	Royal College of Nursing Rheumatology Forum
RGN	Registered general nurse
RN	Registered nurse
SARS-CoV-2 Virus	Severe Acute Respiratory Syndrome: Coronavirus
SIGN	Scottish Intercollegiate Guidelines Network

SLE	Systemic Lupus erythematosus
SLEDAI	Systemic Lupus erythematosus disease activity index
SmPC	Summary of product characteristics
SSZ	Sulfasalazine
TB	Tuberculosis
tsDMARDs	Targeted Synthetic Disease Modifying Anti-Rheumatic Drugs
T-SPOT	TB Test for Mycobacterium Tuberculosis Infection and disease
TST	Tuberculin skin test
U&E	Urea and electrolytes (kidney function test)
UC	Ulcerative Colitis
UTI	Urinary tract infection
VBC	Virtual biologics clinic
VTE	Venous Thromboembolism
VZ	Varicella Zoster
VZV	Varicella Zoster Virus
WBC	White blood count

RCN quality assurance

Publication

This is an RCN practice guidance. Practice guidance are evidence-based consensus documents, used to guide decisions about appropriate care of an individual, family or population in a specific context.

Description

The role of bDMARDs and tsDMARDs in the treatment of rheumatological conditions continues to evolve and is an area that has significant implications for all practitioners and patients. This edition has been developed to support practitioners in the safe and effective assessment, screening and management of patients when these drugs are being considered.

It provides a best practice framework for rheumatology specialist practitioners and the wider health care team involved in supporting the administration, monitoring and delivery of care to patients in a variety of settings.

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The Nine Quality Standards

This publication has met the nine quality standards of the quality framework for RCN professional publications. For more information, or to request further details on how the nine quality standards have been met in relation to this particular professional publication, please contact **publications.feedback@rcn.org.uk**

Evaluation

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