

SHARED CARE PRESCRIBING GUIDELINE

for the prescribing and monitoring of non-biological immunomodulatory drugs in dermatology, gastroenterology and autoimmune hepatitis, neurology, ophthalmology, oral medicine, respiratory and rheumatology in ADULTS

NOTES to the Primary Care Team

The information in the shared care guideline has been developed in consultation with CCGs in South East London and it has been agreed that it is suitable for shared care. **This guideline excludes immunomodulatory drugs that have been prescribed for transplant indications.**

This document should provide sufficient information to enable you to make an informed decision regarding the clinical and legal responsibility for prescribing the non-biological immunomodulator drugs that are included in this guideline.

The questions below will help you confirm this:

- Is the patient's condition predictable or stable?
- Do you have the relevant knowledge, skills and access to equipment to allow you to monitor treatment as indicated in this shared care prescribing guideline?
- Have you been provided with relevant clinical details including monitoring data?

If you can answer YES to all these questions (after reading this shared care guideline), then it is appropriate for you to accept prescribing responsibility.

If the answer is NO to any of these questions you should contact the requesting consultant or your local CCG Medicines Team. There may be implications for the patient where the invitation to share care is declined. For example, the patient may need to be changed to an alternative treatment regimen. It would not normally be expected that shared care prescribing would be declined on the basis of cost.

Sharing of care assumes communication between the secondary care specialist team, primary care team and patient. The intention to share care should be explained to the patient by the clinician initiating treatment. It is important that patients are consulted about treatment and are in agreement with it. The secondary care team, primary care team and patient responsibilities are outlined in Appendix 3.

Prescribing should follow requirements in the [South East London Interface Prescribing Policy](#). **The doctor who prescribes the medication legally assumes clinical responsibility for the drug and the consequences of its use.** The patient's best interests are always paramount.

Once you have read the shared care guideline and considered the information above, please complete the 'Primary Care Decision Form' you have been sent by the secondary care team and email back using the email address provided within 2 weeks of receipt.

Please indicate the decision clearly; if you are not in agreement to participate in shared care please include reasons for this.

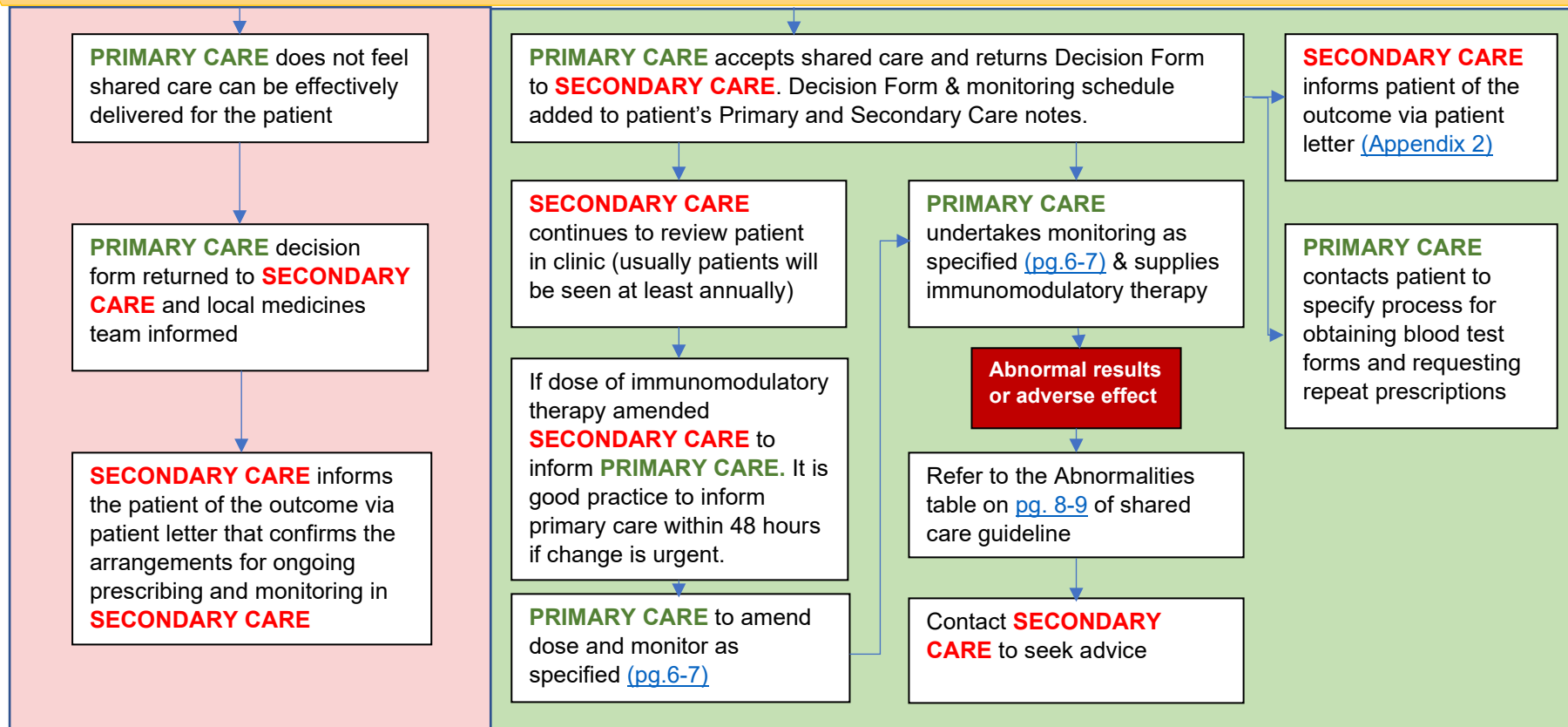
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Flow chart outlining the process for shared care for the prescribing and monitoring of non-biological immunomodulatory drugs in dermatology, gastroenterology and autoimmune hepatitis, neurology, ophthalmology, oral medicine, respiratory and rheumatology in ADULTs

Pre-treatment investigations undertaken in **SECONDARY CARE**. Therapy initiated, supplied and monitored until dose is stable (**at least 3 months**). Shared care discussed with patient, and if in agreement shared care requested from **PRIMARY CARE**. Patient advised that their care remains the responsibility of the **SECONDARY CARE** team until response confirming agreement obtained from **PRIMARY CARE**.

Shared care request letter ([Appendix 1](#)) sent by **SECONDARY CARE** to **PRIMARY CARE** (response within 2 weeks)



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for the prescribing and monitoring of non-biological immunomodulatory
drugs in dermatology, gastroenterology and autoimmune hepatitis,
neurology, ophthalmology, oral medicine, respiratory and rheumatology
in ADULTS

This guideline details the requirements for patient monitoring for immunomodulatory drugs that may be initiated under specialists in secondary care and transferred to primary care.

The information provided in the guideline is not exhaustive. Please also consult the current Summary of Product Characteristics¹ (SPC) or British National Formulary² (BNF) prior to prescribing for up to date information, including detailed information of adverse effects, drug interactions, cautions and contraindications. The interpretation and application of the guideline remains the responsibility of the individual clinician.

Pre-treatment investigations for all non-biological immunomodulatory drugs to be undertaken in secondary care

It is the responsibility of the initiating prescriber in secondary care to undertake pre-treatment investigations.

Prior to initiation the following pre-treatment investigations will be undertaken in secondary care:

- Height & weight
- Full Blood Count
- Renal function
- Liver biochemistry
- TPMT Assay (for azathioprine and 6-MP)

Where indicated, the following investigations may be considered in line with local practice for individual drugs and specialities (this list is not exhaustive and local guidelines should be followed as appropriate):

- Appropriate screening for latent infection e.g. HIV, viral hepatitis
- Urinalysis
- Electrolytes
- Respiratory assessment which may include lung function tests
- Liver fibroscan if available locally
- Blood pressure
- Lipid profile

In addition, the initiating secondary care specialist is responsible for:

- a) Documenting pre-treatment disease status as appropriate by indication
- b) Considering contraindications to treatment, co-morbidities or patient factors that would influence drug choice
- c) Counselling the patient on the risks and benefits of treatment including potential side effects, the need for ongoing monitoring and disease management

Monitoring & follow up arrangements

Secondary care specialists are responsible for the initial prescribing and monitoring of immunomodulatory drugs. The monitoring schedule may vary according to local practice and individual patient factors.

Shared care may be requested after a **minimum of three months** if the patient is considered stable in terms of both disease and drug dose. If therapy is switched to an alternative immunomodulatory drug, or a new immunomodulatory drug is added, secondary care must prescribe and monitor for a **minimum of three months** before shared care can be requested. For patients accepted on to shared care, the monitoring should be undertaken by the primary care team as outlined in the monitoring table on pages 6 and 7. Where monitoring required varies from that outlined, the secondary care specialist must request this in writing in the secondary care letter to request shared care (Appendix 1) on an individual patient basis. Patients should usually be reviewed at least annually by their secondary care specialist team.

It is an NHS improvement requirement that patients taking oral methotrexate are provided with a monitoring record; it is considered good practice for the other immunomodulatory drugs included in this guideline. Patients can register for GP online services which gives them access to their medication record and blood test results; this information can then be shown to the hospital specialist or community pharmacist. Patients who do not wish to register for online access should be issued with a paper monitoring record. Hospital specialists should discuss and agree with the patient which method they would prefer and explain the importance of bringing the record to appointments and when attending the community pharmacy.

Vaccinations

- a) All patients should be up to date with routine schedule as recommended in the Department of Health [Green Book](#) ³
- b) When initiating immunomodulatory drugs, secondary care should obtain pre-treatment immune status, particularly in relation to varicella zoster virus and measles
- c) All patients should be advised to have the pneumococcal and annual influenza vaccine in primary care
- d) All patients should be advised that any additional vaccinations are discussed with their secondary care specialist team to ensure that it is appropriate for this to be administered (as live vaccines may be contraindicated)

Family Planning and Breastfeeding

Family planning should be discussed with all patients at the point of initiation of all drugs included within this guideline, and at regular intervals throughout treatment. Patients should be advised to use reliable contraception. Immunomodulatory drugs can have implications for conception and patients should be advised to contact their secondary care specialist team for advice should they wish to conceive. Where an unplanned pregnancy occurs, treatment should be stopped, and the patient should be discussed with their secondary care specialist team urgently. When prescribing mycophenolate mofetil or mycophenolic acid, the guidance included in the [MHRA alert](#) ⁴ should be followed.

Abbreviations used in this document

ALT	Alanine aminotransferase	GGT	Gamma-glutamyl transpeptidase
AST	Aspartate transaminase	MCV	Mean corpuscular volume
BP	Blood pressure	MMF	Mycophenolate mofetil
Cr	Creatinine	NICE	National Institute for Health & Care Excellence
CRP	C reactive protein	OCT	Optical Coherence Tomography
ESR	Erythrocyte sedimentation rate	6-TGN	6-thioguanine nucleotide
FBC	Full blood count	TPMT	Thiopurine methyltransferase
eGFR	Estimated glomerular flow rate	WBC	White blood cell count

	MONITORING TO BE UNDETAKEN IN PRIMARY CARE ⁵				NOTES
	FBC	Renal Profile ⁺ *	Liver Profile & GGT [#]	ADDITIONAL DRUG SPECIFIC MONITORING	
AZATHIO-PRINE	Within 1 month of accepting shared care agreement, then three monthly *				Therapeutic drug level monitoring, if indicated, will be undertaken in Secondary care
	After dose change ^{**} : Fortnightly for 6 weeks, then three monthly ⁺				
6-MERCAPT OPURINE	Within 1 month of accepting shared care agreement, then three monthly *				Therapeutic drug level monitoring, if indicated, will be undertaken in Secondary care
	After dose change ^{**} : Fortnightly for 6 weeks, then three monthly ⁺				
CICLOSPORIN	Within 1 month of accepting shared care agreement, then three monthly ^{6*}			Three monthly monitoring of: Blood pressure Urine dipstick Electrolytes (K ⁺ & Mg ²⁺)	Secondary care: <ul style="list-style-type: none"> Must specify brand to be continued in primary care Are responsible for therapeutic drug level monitoring and subsequent dose adjustment where applicable Will check non-fasting lipids 1 month after initiation Will monitor HbA1c annually
	After dose change ^{**} : Fortnightly for 6 weeks, then three monthly ⁺				
MMF/ Mycophenolic acid	Within 1 month of accepting shared care agreement, then three monthly *				For mycophenolic acid: refer to the SEL APC recommendation for place in therapy of this agent.
	After dose change ^{**} : Fortnightly for 6 weeks, then three monthly ⁺				
SULFASALAZINE	Within 1 month of accepting shared care agreement, then three monthly *				
	After dose change ^{**} : Fortnightly for 6 weeks, then three monthly ⁺				
	After 1 year, no routine monitoring required if patient on monotherapy ⁵				

*Secondary care clinician may recommend more frequent monitoring for individual patients; this will be communicated to the GP via clinic letter on a case by case basis

** **Secondary care team must inform patients their blood tests will be fortnightly for 6 weeks due to the dose change;** more frequent monitoring after a dose change may be requested by the secondary care specialist team, this will be communicated to the GP via clinic letter on a case by case basis and communicated to the patient

⁺ If any concerns continue fortnightly bloods and contact secondary care to discuss

[#] Liver Profile to include: Albumin, AST or ALT, GGT

⁺Renal Profile to include: eGFR, Cr

	MONITORING TO BE UNDERTAKEN IN PRIMARY CARE ⁵			NOTES	
	FBC	Renal Profile ^{**}	Liver Profile & GGT ^{7#}		ADDITIONAL DRUG SPECIFIC MONITORING
METHOTREXATE	<p>Within 1 month of accepting shared care agreement, then three monthly*</p> <p>For patients co-prescribed leflunomide: Monthly; after 1 year of monthly monitoring specialist may recommend reducing frequency of monitoring</p> <p>After dose change^{**}: Fortnightly for 6 weeks, then three monthly (monthly if co-prescribed leflunomide)⁺</p>				<p>For oral therapy, only prescribe 2.5mg tablets. In the event of methotrexate toxicity/ overdose, folic acid rescue should be considered</p> <p>Concomitant folic acid should be prescribed; dose will vary from 5mg per week to 5mg daily (except day of methotrexate).</p> <p>Mandatory for patient held monitoring record to be in place & up to date; can be electronic or paper</p> <p>Annual fibroscan may be indicated for patients at higher risk of chronic liver disease⁷. This will be responsibility of secondary care.</p> <p>For Dermatology patients: P3NP testing is not available in primary care⁸; where indicated the patient will remain under secondary care for monitoring and prescribing purposes.</p>
LEFLUNOMIDE	<p>Within 1 month of accepting shared care agreement, then three monthly*</p> <p>For patients co-prescribed methotrexate: Monthly; after 1 year of monthly monitoring specialist may recommend reducing frequency of monitoring</p> <p>After dose change^{**}: Fortnightly for 6 weeks, then three monthly (monthly if co-prescribed methotrexate)⁺</p>			<p>Three monthly monitoring of: Blood pressure</p> <p>Weight <i>If greater than 10% weight loss discuss with secondary care specialist team</i></p>	
HYDROXY-CHLOROQUINE	<p>No routine monitoring required⁵</p>			<p>GP should refer to secondary care for advice if patient reports visual symptoms. See RCOPHTH guidelines⁹ for further information.</p>	<p>Secondary care to arrange OCT within 12 months of initiation where locally available. After 5 years of treatment patient will be referred by secondary care for annual OCT screening where locally available.</p>

*Secondary care clinician may recommend more frequent monitoring for individual patients; this will be communicated to the GP via clinic letter on a case by case basis

** **Secondary care team must inform patients their blood tests will be fortnightly for 6 weeks due to the dose change**; more frequent monitoring after a dose change may be requested by the secondary care specialist team, this will be communicated to the GP via clinic letter on a case by case basis and communicated to the patient

⁺ If any concerns continue fortnightly bloods and contact secondary care to discuss

[#] Liver Profile to include: Albumin, AST or ALT, GGT

^{**}Renal Profile to include: eGFR, Cr

Abnormal blood test monitoring or adverse effect - Action required ⁵

It is the primary care prescriber's responsibility to ensure patients adhere to the monitoring schedule. It should be clearly communicated to the patient how often they are required to attend. Concerns that the patient is unable to adhere to the monitoring schedule should be discussed with the secondary care team. Patients must be informed that they will be unable to continue the medication unless they adhere to the monitoring requirements.

The prescriber must respond to abnormal blood test monitoring or adverse effects (see table below). As well as specific values the prescriber must respond to trends in results and act accordingly (e.g. rising AST/ ALT, decreasing WBCs).

Some patients may have more individualised parameters set out by their secondary care specialist which fall outside the normal range; these should be communicated to primary care in writing.

ABNORMALITY	ACTION REQUIRED
WCC < 3.5 x 10 ⁹ /l	If less than the value specified or a significant change from baseline is noted, withhold and discuss with secondary care
Neutrophils < 1.6 x 10 ⁹ /l <i>Reference range may vary between local laboratories (e.g. only results of < 1.5 x 10⁹/l flagged), therefore care needed when interpreting this result.</i>	
Lymphocytes < 0.7 x 10 ⁹ /l	
Unexplained eosinophilia > 0.5 x 10 ⁹ /l	
Platelets < 140 x 10 ⁹ /l	
Unexplained fall in albumin < 30 g/l	
ALT or AST > 100 IU/l	Withhold and discuss with secondary care specialist
GGT > 100 IU/l	Discuss with secondary care specialist ⁷
eGFR < 60ml/min or ≥ 10% decline in eGFR from baseline and/ or , Cr > 30% rise from baseline	Discuss with secondary care specialist; some immunomodulatory drugs may require dose adjustment/ cessation.
MCV > 105 f/l	Check haematinics; treat if abnormal If haematinics normal with raised MCV, discuss with secondary care, continue treatment in the interim.
ESR/ CRP	May be requested by Rheumatology for disease monitoring (no action required from GP). If CRP raised, rule out infection.

ABNORMALITY	ACTION REQUIRED
Signs/ symptoms of infection	Withhold and treat infection; patient can restart therapy when infection resolved. In the case of recurrent or severe infections withhold treatment and discuss with secondary care.
Low magnesium/ High potassium for patients on ciclosporin	Discuss with secondary care
Urine dipstick	If abnormal send MSU and if positive treat according to clinical picture. If sterile proteinuria seek advice from secondary care.
BP > 140/ 90 (if on leflunomide or ciclosporin)	Treat according to NICE guidelines ¹⁰ If on ciclosporin withhold & discuss with secondary care. If on leflunomide discuss with secondary care.
Abnormal bruising/ sore throat	Perform urgent FBC; withhold and discuss with secondary care urgently
Unexplained widespread rash or hair loss	Perform urgent FBC; withhold and discuss with secondary care urgently
Unexplained oral ulceration	Perform urgent FBC; withhold and discuss with secondary care urgently
Unexplained new/ increasing dyspnoea or cough	Withhold and discuss urgently with secondary care
Severe upper abdominal pain (Risk of hepatitis & pancreatitis with 6-MP and azathioprine)	Withhold, check liver biochemistry and amylase and discuss urgently with secondary care

References

1. Electronic Medicines Compendium. *Datapharm Communications Ltd.* www.medicines.org.uk/emc
2. *British National Formulary*. London: British Medical Association and Royal Pharmaceutical Society. <https://www.bnf.org/products/bnf-online/>
3. The Department of Health Green Book, Immunisation against infectious disease. <https://www.gov.uk/government/collections/immunisation-against-infectious-disease-the-green-book>
4. *Mycophenolate mofetil, mycophenolic acid: New pregnancy-prevention advice for women and men.* Medicines & Healthcare products Regulatory Agency (14th December 2015)
5. *BSR and BHPR guideline for the prescription and monitoring of non-biologic disease-modifying anti-rheumatic drugs (2017).* British Society for Rheumatology and British Health Professionals in Rheumatology. www.rheumatology.org.uk/ (All monitoring outlined in this guideline follows this except where individually referenced)
6. *Use of Ciclosporin in Adult Patients in Dermatology.* *Guys and St Thomas' Clinical Guideline* (22 June 2017)
7. *SEL APC Joint Immunomodulators Shared Care Task Group – Sub-Group Acute Specialities meeting minutes (March 2019).*
8. R.B. Warren, S.C. Weatherhead, C.H. Smith and et al. (2016) British Association of Dermatologists' guidelines for the safe and effective prescribing of methotrexate for skin disease. *British Journal of Dermatology*, <https://doi.org/10.1111/bjd.14816>
9. Yusuf, I., Foot, B., Galloway, J. and et al. (2018) *The Royal College of Ophthalmologists recommendations on screening for hydroxychloroquine and chloroquine users in the United Kingdom: executive summary.* *Eye* **32**, 1168-1173
10. National Institute for Health and Care Excellence (Updated November 2016) *Hypertension in adults: diagnosis and management.* ([NICE Guideline CG127](https://www.nice.org.uk/guidance/CG127))

Appendix 1 – Secondary care letter to request shared care from primary care and primary care decision form

Clinic + Hospital Details

GP address
 Patient Details

This letter is to request shared care for our joint patient with the following immunomodulatory drug:

Drug:			
Dose:			
Indication:			
Monitoring Schedule:	As per the monitoring to be undertaken in primary care table in the shared care guideline	<input type="checkbox"/>	
	OR		
	<i>Please specify:</i>	<input type="checkbox"/>	
Additional Monitoring Required:	<input type="checkbox"/> ESR	<input type="checkbox"/> CRP	<input type="checkbox"/> Other, please specify:
	3 monthly		
Date & Quantity of last supply:			
Patient will have been on 3 months treatment by:			
Secondary care team contact details (Direct telephone &/or nhs.net email):			

To be completed by the requesting secondary care team

Treatment initiated is appropriate and baseline monitoring has been undertaken	Check box to confirm
<ul style="list-style-type: none"> ▪ The immunomodulatory drug is being prescribed within local and/or national guidelines and in the remit of this shared care guideline ▪ Where applicable, off-label use has been discussed and agreed with the patient ▪ Baseline investigations have been undertaken as per the baseline investigations section of the shared care guideline and in accordance with local protocol ▪ The patient has been on therapy for at least 3 months and their dose and condition is stable 	<input type="checkbox"/>
Information provided to patient	
<ul style="list-style-type: none"> ▪ The risks and benefits of treatment including potential side effects, the need for ongoing monitoring and disease management have been discussed with the patient ▪ The patient has been provided with written information on the drug (where available) ▪ The decision to request shared care has been agreed with the patient ▪ The patient has been informed of the need for ongoing monitoring ▪ The patient has been advised to sign up to access their GP online services or via a mobile phone app where available; if this is not possible or suitable for the patient then they have been provided with a medicines monitoring record ▪ The patient has been advised what to do if they experience a disease flare & who to contact ▪ The patient has been advised to receive pneumococcal and annual influenza vaccinations in primary care ▪ The patient has been signposted to services that can offer further support (e.g. charities) where available 	<input type="checkbox"/>

Follow up, advice and support to be provided to the primary care team after shared care agreed		<input type="checkbox"/>
<ul style="list-style-type: none"> ▪ Communicate in writing to primary care within 2 weeks if there is a recommendation to amend the dose or if treatment is stopped ▪ Communicate changes to the monitoring schedule to the primary care within 2 weeks, or 48 hours if the change is urgent ▪ Confirm the patient's monitoring schedule at each appointment ▪ Have a mechanism for primary care to contact the secondary care team for advice/ support ▪ Report any suspected adverse events to the MHRA ▪ Arrange ongoing follow up in secondary care 		
Completed by: Job Title:	Date:	

Please find the 'SEL APC Adult Non-Biological Immunomodulatory Drugs Shared Care Guideline' [here](#); please review the request and complete the 'Primary Care Decision Form' within 2 weeks of receiving this request.

Yours Sincerely

Specialist

Primary Care Decision Form for shared care of immunomodulatory drugs

The doctor who prescribes the medication legally assumes clinical responsibility for the drug and the consequences of its use. The information in the shared care guideline has been developed in consultation with CCGs and should provide sufficient information to allow you to prescribe immunomodulatory drugs once you have read the shared care guideline, consider the questions below:

1. Is the patient's condition predictable and stable?
2. Do you have the relevant knowledge, skills and access to equipment to allow you to monitor treatment as per the shared care guideline?
3. Have you been provided with the relevant clinical details including monitoring schedule?

If the answer YES to all of these questions	If the answer is NO to any of the questions
It is appropriate to accept prescribing responsibility. Complete the 'Primary Care Decision Form' below and return to requesting secondary care team.	Contact requesting secondary care team/ local medicines team to discuss. Consider that there may be implications for the patient. It is not normally expected that shared care would be declined due to cost. Complete the 'Primary Care Decision Form' box below & return to requesting secondary care team.

Please complete the below GP decision box and return via email to **secondary care team contact details**** within 2 weeks of receipt of this request for shared care.**

Primary Care Decision Form		
Patient Name	Date of Birth	Address
I agree/ do not agree (delete as appropriate) to participate in shared care for the following immunomodulatory drug(s)		
Azathioprine <input type="checkbox"/>	Ciclosporin <input type="checkbox"/>	Hydroxychloroquine <input type="checkbox"/>
Leflunomide <input type="checkbox"/>	Mercaptopurine <input type="checkbox"/>	Methotrexate <input type="checkbox"/>
Mycophenolic acid <input type="checkbox"/>	Mycophenolate mofetil <input type="checkbox"/>	Sulfasalazine <input type="checkbox"/>
Where shared care is agreed, the primary care team agree to:		
<ul style="list-style-type: none"> ▪ Provide ongoing prescriptions; annotate the prescription 'as per shared care guideline' ▪ Undertake ongoing monitoring as outlined in the shared care guideline ▪ Inform the patient of the specific arrangements for organising and attending for blood tests (and any additional monitoring required) ▪ Adjust the dose as advised by secondary care and undertake additional monitoring as outlined in the shared care guideline ▪ Report any concerns e.g. adverse effects, inefficacy and non-compliance to secondary care for advice ▪ Refer to abnormal blood test monitoring or adverse effect table in the shared care guideline and follow the action specified ▪ Refer the patient back to secondary care if the patient's medical condition deteriorates ▪ Refer the patient back to secondary care if they are planning a family (males and females) or report an unexpected pregnancy ▪ Encourage the patient to sign up to access their GP online services/ via mobile app if available, if not available or if the patient does not wish to have online access then ensure that any changes in treatment and blood test results are documented in the patient's medicine monitoring record ▪ Stop treatment on the advice of the secondary care or immediately if an urgent need arises 		
Where shared care is not agreed, please document reason(s) for declining to participate:		
Completed by: Job Title:	Signature:	Date:

Appendix 2 – Secondary care letter to patient to inform the patient they have been accepted for shared care with ‘What Should You Do Next’ patient information sheet. This letter is for patients prescribed any immunomodulatory drug regimen except hydroxychloroquine monotherapy

Patient details

Specialist Clinic
Details

Date

Dear Patient,

Your GP surgery has agreed to take over the prescribing and monitoring for ****insert drug name****. In order for your GP to safely prescribe ****insert drug name**** your GP surgery will monitor your blood tests. Your GP surgery will arrange for you to have a blood test within the next month and then will continue to monitor your blood tests ****insert monitoring frequency****. It is very important that you attend for your blood tests as if you do not attend then the GP surgery will be unable to issue your prescription.

For patients on ciclosporin or leflunomide: Your GP surgery will also arrange to have your blood pressure/ weight (delete as appropriate) checked when you attend the GP surgery for your appointments.

When you receive this letter we advise that you contact your GP surgery to arrange an appointment so that they can tell you how you can organise blood tests and answer any questions that you may have about arranging prescriptions of ****insert drug name****.

In order to make sure your GP surgery can continue to issue prescriptions for your medication please ensure that you have read and understood the information below. It is important to note that you are still under the care of the hospital specialist for your ****insert condition being treated**** so you should still continue to attend your outpatient clinic appointments in addition to any appointments at your GP surgery.

Attending for blood tests and arranging repeat prescriptions
<ul style="list-style-type: none"> ▪ You must request your blood test form from the GP surgery ▪ You must attend for blood tests (and any additional monitoring required) at least 2 weeks before you need a new prescription ▪ If your results are abnormal your GP surgery will liaise with your hospital specialists and advise you of the outcome ▪ You should request your prescription from your GP at least 1 week in advance
Attending appointments
<ul style="list-style-type: none"> ▪ You must attend scheduled appointments with your GP surgery ▪ You must attend scheduled appointments with your hospital specialist

Medicines monitoring record
<ul style="list-style-type: none">▪ Your hospital specialist may have issued you with a medicines monitoring record, you should bring this to:<ul style="list-style-type: none">➢ Every GP surgery appointment and every time you attend for blood tests➢ Every hospital appointment➢ Every visit to the community pharmacy to collect your medication▪ Alternatively, you can check with your GP surgery if you can sign up to have access to your medication record and blood test results online or via a mobile phone app<ul style="list-style-type: none">➢ You will then be able to print the information and bring it with you, or load the information on your mobile phone to show the community pharmacist or hospital specialist at your appointment
Reporting concerns or side effects
<ul style="list-style-type: none">▪ You can report any concerns about side effects to your GP, practice nurse, pharmacist or hospital specialist▪ If your disease flares or you experience any new or worsening symptoms you should contact your hospital specialist team for advice
Planning a family
<ul style="list-style-type: none">▪ Some medications should be stopped before conceiving a baby. Please inform your hospital specialist or GP if you are planning on becoming a mother or father so you can be offered advice.▪ If you are planning to breastfeed your baby please inform your GP or hospital specialist so you can be offered advice.
Starting new medication
<ul style="list-style-type: none">▪ When purchasing herbal remedies or medications over the counter, check with the pharmacist that there are no interactions with your regular medications
Keeping in touch
<ul style="list-style-type: none">▪ Make sure you let the GP and hospital specialist know if you change your address, telephone number or email address

Please contact the hospital department on ****contact details**** if you have any questions.

Yours sincerely,

Secondary Care Specialist

You, your specialist hospital doctor and your GP have agreed your condition is stable and your care can be shared between your specialist and your GP. Your medicine(s) will now be prescribed by your GP.

What should you do next?

Within the next 2 weeks:

✓ **Make an appointment to see your GP and**

✓ **Obtain a 'Blood Test Form' from your GP Surgery so your monitoring blood tests can be done**

✓ It is always best to try and see or speak to your usual GP, planning ahead will make it possible.

✓ A pharmacist at the GP Surgery can also help with any questions on your medicines.

✓ Consider asking for a batch of blood test forms to cover 6 months or even a year.

✓ Ask at the GP Reception Desk about online services, you could view your blood test results online with any comments from your GP

✓ **Take your Blood Test Form to get your blood tested.**

Get advice from your GP Surgery on where you will go to get your blood tested and when the best time is

✓ **Contact your GP Surgery within 1 week of having your Blood Test to find out the results of your blood test.** Make sure your 'Medicines Monitoring Record' is up-to-date or you have online access to your records.

If your blood tests are normal

✓ **Ask your GP Surgery for a prescription for your medicines.** You may do this through the GP Surgery online services or through the Reception Desk at your GP Surgery.

You can expect your first prescription to last one month and subsequent prescriptions may last two months

✓ Remember to nominate a community pharmacy so your prescription can be sent electronically to your preferred pharmacy and bring your updated 'Medicines Monitoring Record' or have online access to your records.

Your GP Surgery will issue your prescription within 48 hours of your request.

✓ **Take your prescription to your local community pharmacy to get your medicine(s) or go directly to your nominated pharmacy to collect your medicine(s).**

Remember to take your 'Medicines Monitoring Record' or have online access to your records. **Your community pharmacist can only provide your medicine(s) to you when they know your blood test results are acceptable.**

If you feel unwell, contact your GP Surgery immediately and let the GP Receptionist know you are on medicine(s) which affect your immune system.
If you are feeling well, continue to ask for a prescription from your GP Surgery.

Continue to get your blood tested every 3 months or more frequently, if advised by your doctors

✓ Make sure you know when your next blood test is due and that you have a blood test form to get this done

✓ It is best to get your blood tests done at least 10 days before you need your next prescription

Remember your medicines can only be prescribed SAFELY to you if your blood tests are up-to-date

Appendix 2b – Secondary care letter to patient to inform the patient they have been accepted for shared care for hydroxychloroquine monotherapy

Patient details

Specialist Clinic
Details

Date

Dear Patient,

Your GP surgery has agreed to take over the prescribing **hydroxychloroquine**. When you receive this letter we advise that you contact your GP surgery so that they can tell you how you arrange a prescription for **hydroxychloroquine**.

You should still continue to attend your outpatient clinic appointments in addition to any appointments at your GP surgery.

Arranging repeat prescriptions
<ul style="list-style-type: none"> ▪ You should request your prescription from your GP at least 1 week in advance
Attending appointments
<ul style="list-style-type: none"> ▪ You must attend scheduled appointments with your GP surgery ▪ You must attend scheduled appointments with your hospital specialist
Reporting concerns or side effects
<ul style="list-style-type: none"> ▪ You can report any concerns about side effects to your GP, practice nurse, pharmacist or hospital specialist ▪ If your disease flares or you experience any new or worsening symptoms you should contact your hospital specialist team for advice
Planning a family
<ul style="list-style-type: none"> ▪ Some medications should be stopped before conceiving a baby. Please inform your GP or hospital specialist if you are planning on becoming a mother or father so you can be offered advice. ▪ If you are planning to breast-feed your baby please inform your GP or hospital specialist so you can be offered advice.
Starting new medication
<ul style="list-style-type: none"> ▪ When purchasing herbal remedies or medications over the counter, check with the pharmacist that there are no interactions with your regular medications
Keeping in touch
<ul style="list-style-type: none"> ▪ Make sure you let the GP and hospital specialist know if you change your address, telephone number or email address

Please contact the hospital department on ****contact details**** if you have any questions.

Yours sincerely,
 Secondary Care Specialist

Appendix 3 – Summary of secondary care, primary care and patient responsibilities

Secondary Care Responsibilities

- Ensure the immunomodulatory drug is appropriately initiated e.g. no contraindications, cautions, interactions
- Ensure prescribing fits local or national agreement for use of the drug; off-label use of the drug should be discussed with the patient
- Counsel the patient on the risks and benefits of treatment, discuss potential adverse effects and any practical issues related to the use of immunomodulatory therapy
- Provide the patient with written information on the drug where available
- Provide the patient with information on self-management and advise them to contact secondary care specialist if they experience a flare of their disease
- Undertake baseline investigations and initial monitoring according to local protocol
- Advise the patient to sign up to access their GP record online or via a mobile phone app where available; if this is not possible or suitable for the patient then ensure they are provided with a medicines monitoring record and advised of the importance of ongoing monitoring
- Advise the patient to organise pneumococcal and annual influenza vaccinations in primary care
- Signpost the patient to additional support services, such as charities and patient groups, where available and appropriate
- Report any suspected adverse effects to the MHRA: www.yellowcard.mhra.gov.uk
- Discuss shared care with patient and obtain patient agreement to request shared care
- Prescribe treatment for **at least the first 3 months** or until the patient is considered stable and shared care is agreed with GP; if the GP does not agree to shared care continue to prescribe and monitor the immunomodulatory therapy
- When shared care is agreed:
 - Review patient at the request of GP should any problems arise (abnormal blood test monitoring/ side-effects / lack of efficacy/ non-compliance)
 - Arrange routine follow up (usually at least once per year)
 - Communicate (within 2 weeks) with the GP if treatment is changed or stopped; if urgent communicate the change within 48 hours
 - Confirm the patients monitoring schedule at each appointment

Primary Care Responsibilities

- To respond to shared care proposal within 2 weeks of receipt
- Provide ongoing prescriptions and adjust dose as advised by the specialist; annotate the prescription 'as per shared care guideline'
- Inform the patient of the specific arrangement for organising and attending for blood tests (and any additional monitoring required)
- Encourage patient to register to access their record online and ensure this is updated; if the patient does not have online access enter blood results in patient held medicines monitoring record (for replacement or renewal of patient held medicines monitoring records contact the secondary care team)
- Undertake monitoring as outlined in the monitoring table
- Refer to abnormal blood test monitoring or adverse effect table in the shared care guideline and follow the action specified
- Report any concerns e.g. adverse effects, inefficacy and non-compliance to secondary care for advice
- Refer back to secondary care if the patient's condition deteriorates
- Stop treatment on the advice of secondary care or immediately if an urgent need to stop treatment arises
- Report any suspected adverse effects to the MHRA via the Yellow Card scheme: www.yellowcard.mhra.gov.uk
- Refer the patient back to secondary care if they are planning a family (males and females)

Patient Responsibilities

- Read pre-treatment information leaflets when provided by secondary care
- Attend for blood tests as directed by the secondary and primary care team
- Attend scheduled appointments in primary and secondary care
- Bring the medicines monitoring record (booklet or have online access to your records), to all appointments, including appointments for blood tests, and when collecting medication from the community pharmacy
- Contact the secondary or primary care team if unclear on any aspect of the treatment
- Report concerns about side effects to a healthcare professional
- Report any plans to start a family/ breastfeed to primary or secondary care
- Report any new or worsening symptoms to primary or secondary care
- Inform primary or secondary care or community pharmacist of any other medication being taken, including over the counter products or herbal remedies
- Take medicines as agreed and try to ensure no doses are missed
- Keep contact details up to date with both primary and secondary care

Appendix 4 – Contact Details for Secondary Care Teams

King's Denmark Hill Main Switchboard: 020 3299 9000 King's South Sites Main Switchboard: 01689 863 000	
Denmark Hill Rheumatology Consultants Rheumatology Specialist Registrar Rheumatology specialist nurse Department email	Tel: 020 3299 9000 ext 31731 or 31733 (or consultant on call via switchboard) Tel: Via hospital switchboard (Mon – Fri 9am -10pm, Sat – Sun 9am-5pm) Email: kch-tr.arthritis@nhs.net Email: kch-tr.RheumatologySecretariesDH@nhs.net
South Sites - Orpington Rheumatology Consultants Rheumatology specialist nurse	Tel: Via secretary on 01689 865 232 Tel: Via secretary on 01689 865 232
Medication – Prescribing advice, interactions, availability of medicines Specialist Pharmacist – Rheumatology (Both sites)	Tel: 020 3299 9000 ext 37844
Queen Mary's Sidcup Rheumatology Consultants	Tel: 020 3910 7132 or 020 3910 7133

King's Denmark Hill Main Switchboard: 020 3299 9000 King's South Sites Main Switchboard: 01689 863 000	
Consultant team –Denmark Hill Dermatology Specialist Registrar: Dermatology Specialist Pharmacist :	Tel: 020 3299 9000 ext 33258 (or Dermatology consultant on call via switchboard) Tel: Via hospital switchboard (Mon to Fri 09:00 – 17:00), Bleep 214 Tel: 020 3299 9000 extension: 37844 kch-tr.dermatologypharmacist@nhs.net
Consultant team – South Sites Dermatology Specialist Pharmacist:	Tel: 01689 863 000 ext 65260 (or Dermatology consultant on call via switchboard) Tel: 020 3299 9000 extension: 37844 kch-tr.dermatologypharmacist@nhs.net

King's Denmark Hill Main Switchboard: 020 3299 9000 King's South Sites Main Switchboard: 01689 863 000	
Consultant/specialist team – Denmark Hill Neurology Consultants	Secretary via hospital switchboard (or specialist consultant on call via switchboard) or registrar on 020 3299 6534
Consultant/ specialist team – South Sites Neurology Consultants	Secretary via hospital switchboard (or specialist consultant on call via switchboard)
For Myasthenia Gravis and Lambert Eaton Myasthenic Syndrome ONLY	Tel: 020 3299 9000 ext 31552 Email: kch-tr.myasthenia@nhs.net
Medication – Prescribing advice, interactions, availability of medicines Specialist Pharmacist – Neurology	Tel: 020 3299 9000 ext 35717

King's Denmark Hill Main Switchboard: 020 3299 9000	
Consultant/specialist team Hepatology Consultants	Tel: 020 3299 9000 ext 34801 or 33252 (or General Hepatology Registrar on call via switchboard)
Medication – Prescribing advice, interactions, availability of medicines Liver Specialist Pharmacists	Tel: 020 3299 9000 extension 35714 Email: kch-tr.liverpharmacy@nhs.net

King's Denmark Hill Main Switchboard: 020 3299 9000 King's South Sites Main Switchboard: 01689 863 000	
Respiratory Consultants – Denmark Hill	Tel: 020 3299 9000 ext 34630 (Or on-call registrar via switchboard)
Respiratory Consultants – South sites	Tel: 01689 863 000 ext 65877 (Or on-call registrar via switchboard)

King's Denmark Hill Main Switchboard: 020 3299 9000 King's South Sites Main Switchboard: 01689 863 000	
Oral medicine consultants – Denmark Hill	Consultant via switchboard

King's Denmark Hill Main Switchboard: 020 3299 9000 King's South Sites Main Switchboard: 01689 863 000	
Consultant team –Denmark Hill Gastroenterology Specialist Registrar: Gastroenterology Specialist Nurse Helpline: Gastroenterology Specialist Pharmacist : IBD email:	Tel: 020 3299 9000 ext 35844 or 33417 (or gastroenterology consultant on call via switchboard) Tel: Via hospital switchboard (Mon to Fri 09:00 – 17:00) Tel: 020 3299 1606 Tel: 020 3299 9000 extension: 35704 Email: kch-tr.IBDhelpline@nhs.net
Consultant team – South Sites Gastroenterology Specialist Nurse Helpline: Gastroenterology Specialist Pharmacist: IBD email:	Tel: 01689 863 000 ext 63471 or 65860 (or gastroenterology consultant on call via switchboard) Tel: 016 8986 3189 Tel: 016 8986 4012 Email kch-tr.IBDnurse@nhs.net

Guy's and St. Thomas' Hospital switchboard: 0207 188 7188	
<p>Consultant/specialist team Rheumatology Consultants Dr S Agarwal, Dr B Kirkham, Prof A Cope, Dr B Menon, Dr R Byng-Maddick, Dr T Garrod, Dr G Hampson, Dr N Ng, Dr G Sanna, Prof T Spector, Dr F Williams</p> <p>Rheumatology Specialist Registrar</p> <p>Rheumatology specialist nurse helpline:</p> <p>Department email (for return of shared care agreement forms):</p>	<p>Tel: Secretary via hospital switchboard (or rheumatology consultant on call via switchboard)</p> <p>Tel: Via hospital switchboard (Mon to Fri 0900-1700)</p> <p>Book online for helpline call: https://www.zesty.co.uk/practices/gstt-rheumatology-clinic-advice-line</p> <p>Email: gst-tr.rheumandlupus@nhs.net</p>
<p>Medication – Prescribing advice, interactions, availability of medicines</p> <p>Rheumatology Specialist Pharmacists (Andrew Blyth & Karen Topping)</p> <p>Medicines Information (GSTFT)</p>	<p>Tel: 0207 188 5028</p> <p>Tel: 0207 188 8748 Email: medicinesinformation@gstt.nhs.uk</p>

Guy's and St. Thomas' Hospital switchboard: 0207 188 7188	
<p>Consultant/specialist team Dermatology Consultant as per patient clinic letter</p> <p>Dermatology Specialist Registrar</p> <p>Dermatology specialist nurse helpline:</p> <p>Department email (for return of shared care agreement forms):</p>	<p>Tel: Secretary via hospital switchboard (or Dermatology consultant on call via switchboard)</p> <p>Tel: Via hospital switchboard (Mon to Fri 0900-1700)</p> <p>Tel: 0207 188 7847 (Mon to Fri 0900-1700)</p> <p>Email: gst-tr.meddermcns@nhs.net</p>
<p>Medication – Prescribing advice, interactions, availability of medicines</p> <p>Dermatology Specialist Pharmacists (Arlene McGuire, Sarah Guard)</p> <p>Medicines Information (GSTFT)</p>	<p>Tel: 0207 188 5028</p> <p>Tel: 0207 188 8748 Email: medicinesinformation@gstt.nhs.uk</p>

Queen Elizabeth Hospital – Switch Board 0208 836 6000

Guy's and St. Thomas' Hospital switchboard: 0207 188 7188

<p>Medication – Prescribing advice, interactions, availability of medicines Gastroenterology consultant team Gastroenterology specialist registrar Gastroenterology Specialist Pharmacists (for return of shared care agreement forms): Medicines Information (GSTFT)</p>	<p>Tel: Secretary via hospital switchboard (or gastroenterology consultant on call via switchboard) Tel: 07827 949605 (Mon to Fri 09:00 – 17:00) or Via switchboard Tel: 0207 188 5019 Email: gst-tr.gastro-pharmacists@nhs.net Tel: 0207 188 8748 Email: medicinesinformation@gstt.nhs.uk</p>
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Guy's and St. Thomas' Hospital switchboard: 0207 188 7188

<p>Consultant/specialist team ILD Consultants Dr B Lams, Dr S Agarwal, Dr A West, Dr L Pollard, Dr H Cahill, Dr M Kokosi, Dr B Mukherjee, Dr A Patel, Dr P Gordon, Dr A Collett ILD Specialist Registrar ILD helpline: Department email:</p>	<p>Tel: Secretary via hospital switchboard Tel: Via hospital switchboard (Mon to Fri 0900-1700) Tel: 0207 188 8635 (this is an answerphone service. We aim to respond to all calls within 72 hours) Email: gst-tr.khpildservice@nhs.net</p>
<p>Medication – Prescribing advice, interactions, availability of medicines ILD Specialist Pharmacists (Mariam Naqvi & Grainne D'Ancona) Medicines Information (GSTFT)</p>	<p>Tel: 0207 188 8635 (this is an answerphone service. We aim to respond to all calls within 72 hours) Tel: 0207 188 8748 Email: medicinesinformation@gstt.nhs.uk</p>

Guy's and St. Thomas' Hospital switchboard: 0207 188 7188

<p>Consultant/specialist team Neurology, Ophthalmology and Oral medicine (dental) Specialist Registrar</p>	<p>Secretary via hospital switchboard (or specialist consultant on call via switchboard) Tel: Via hospital switchboard (Mon to Fri 0900-1700)</p>
<p>Medication – Prescribing advice, interactions, availability of medicines Medicines Information (GSTFT)</p>	<p>Tel: 0207 188 8748 Email: medicinesinformation@gstt.nhs.uk</p>

Dermatology	
<p><u>Dermatology Consultants:</u> Dr Anna Chapman Dr Rachel Healy Dr Monika Saha Dr Lucia Pozo-Garcia Dr Yana Estfan Dr Alison Shanks Dr Athina Fonia Dr Ljubomir Novakovic</p> <p><u>Dermatology Specialist Nurses</u> Ria Gado Frances Parrish Sushila Karki-Bhudatoke Bernadette Resuello Gloria Osarenkhoe</p>	<p>Dermatology Secretary</p> <p>Contact Details: 0208 836 5260 0208 836 5261</p> <p>Registrars Bleep 540</p> <p>Dermatology CNS Helpline 0208 836 5253 Bleep # 366</p>
Rheumatology	
<p><u>Rheumatology Consultants:</u> Dr Gerald Coakley Dr Louise Dolan Dr Catherine Mathews</p> <p><u>Rheumatology Specialist Nurses</u> Febisola Akinboyewa Kathleen Seggie</p>	<p>Tel: Secretary 0208 836 4923 0208 836 4914 Email Qehrheumatology@nhs.net</p> <p>Rheumatology Reg via hospital switchboard 0208 836 6000 bleep 468</p> <p>Contact Details: 0208 836 6932 Email: qehrheumatologynurses@nhs.net</p>
Gastroenterology	
<p><u>Gastroenterology Consultants:</u> Dr Amit Gera Dr Aathy Loganayagam Dr Alistair McNair Dr Leon Pee Dr Vishal Saxena</p> <p><u>Gastroenterology Specialist Nurse</u> Siet Tye Toyin Obisesan</p>	<p>Tel: Secretary via hospital switchboard 0208 836 5579 Shalane.cross@nhs.net 0208 836 5579 Shalane.cross@nhs.net 0208 836 5580 Elaine.baptiste@nhs.net 0208 836 5579 Shalane.cross@nhs.net 0208 836 5580 Elaine.baptiste@nhs.net</p> <p>IBD Helpline 07770 578387 lg.qe-ibd@nhs.net</p>
Neurology	
<p><u>Neurology Consultants:</u> Dr Eli Silber</p> <p><u>Neurology Specialist Nurse</u> Kitty McCarthy Lisa Perfect 0208 836 4963</p>	<p>Tel: Secretary via hospital switchboard</p> <p>Contact Details: 0208 836 5575</p>
Lewisham Hospital – Switch Board 02083333000	

Dermatology	
<u>Dermatology Consultants:</u> Dr Piu Banerjee Dr Shamali Hoque	Tel: Secretary via hospital switchboard Secretary contact details: 0203 192 6577/ 6181/ 6803
Rheumatology	
<u>Rheumatology Consultants:</u> Dr Ghada Yannì Dr Louise Pollard Dr Pamela Lutalo Rheumatology Registrars	Tel: Secretary via hospital switchboard Tel: via hospital switchboard
<u>Rheumatology Specialist Nurse</u> Leah Irungu	Tel: 0208 333 3000 ext 8356 (this is also the helpline number)
Gastroenterology	
<u>Gastroenterology Consultants:</u> Dr David Dewar, Dr David Reffitt Dr John O'Donohue, Dr Mina Hanna Dr Annika Charlesworth Dr Thawb Al-Chalabi Dr Helen Fidler,	Tel: Secretary via hospital switchboard 020 8333 3000 ask for EXT 6180/6182 Contact Details: LG.GastroSecretaries@nhs.net
<u>Gastroenterology Specialist Nurse</u> Tracy Naughton	Contact Details: LG.ibd@nhs.net Helpline 07500 559478
Neurology	
<u>Neurology Consultants:</u> Nil	
<u>Neurology Specialist Nurse</u> Nil	

Appendix 5 – Indication Tables for Immunomodulators according to speciality

Dermatology conditions and immunomodulating drug licensing

Note some patients may have overlap syndromes with clinical features of multiple diseases

✓ = 'off-label' but considered routine treatment option

X = unlicensed and not currently considered a routine option; these are not covered by this shared care guideline and therefore would not be transferred to primary care.

	Azathioprine	Ciclosporin	Hydroxychloroquine	Leflunomide	Methotrexate	MMF/ Mycophenolic acid	Sulfasalazine
Psoriasis	X	Licensed	X	X	Licensed	X	X
Dermatitis	✓	Licensed (Atopic)	X	X	✓	✓	X
Urticaria (see SEL urticaria treatment pathway)	✓	✓	✓	X	✓	✓	✓
Autoimmune blistering diseases e.g. Bullous pemphigoid Pemphigus foliaceus Pemphigus vulgaris	✓	X	X	X	✓	✓	X
Lichen Planus	✓	X	✓	X	✓	✓ MMF only	X
Connective tissue disorders e.g. Dermatomyositis* Lupus erythematosus(LE)* Scleroderma	Licensed*	X	O/ Licensed* (LE)	✓	✓	✓	X
Vasculitides e.g. Churg-Strauss syndrome Hypocomplementaem ic urticarial vasculitis Microscopic polyangitis Wegener granulomatosis	✓	✓	✓	X	✓	✓ MMF only	X
Cutaneous sarcoidosis	✓	X	✓	X	✓	✓ MMF only	X
Relapsing idiopathic nodular panniculitis	✓	✓	X	X	✓	✓ MMF only	X
Prurigo (nodular, acitinic)	X	X	X	X	✓	X	X
Photodermatoses	X	✓	Licensed	X	✓	X	X

Gastroenterology conditions & Autoimmune hepatitis immunomodulating drug licensing

Note some patients may have overlap syndromes with clinical features of multiple diseases

✓ = 'off-label' but considered routine treatment option

X = unlicensed and not currently considered a routine option; these are not covered by this shared care guideline and therefore would not be transferred to primary care.

	Azathioprine	Ciclosporin	6-Mercaptopurine	Methotrexate	MMF only	Sulfasalazine
Crohn's	✓	X	✓	✓	X	Licensed
Ulcerative colitis	✓	X	✓	✓	X	Licensed
Autoimmune hepatitis	✓	X	✓	X	✓	X

Neurology conditions and immunomodulating drug licensing

Note some patients may have overlap syndromes with clinical features of multiple diseases

✓ = 'off-label' but considered routine treatment option

X = unlicensed and not currently considered a routine option; these are not covered by this shared care guideline and therefore would not be transferred to primary care.

	Azathioprine	Ciclosporin	Hydroxychloroquine	Leflunomide	Methotrexate	MMF only	Sulfasalazine
Neurosarcoidosis	✓	x	x	x	✓	✓	x
CNS Vasculitis or vasculitic neuropathy	✓	x	x	x	✓	✓	x
Progressive MS	x	x	x	x	✓	x	x
Neuromyelitis Optica	✓	x	x	x	✓	✓	x
Idiopathic CNS Inflammation (Including idiopathic optic neuritis, Clippers, Myelitis)	✓	x	x	x	✓	✓	x
Myasthenia Gravis and Lambert Eaton Myasthenic Syndrome	✓	x	x	x	✓	✓	X
Systemic Lupus Erythematosus	Licensed	x	Licensed	x	✓	✓	x
Chronic Inflammatory Demyelinating Polyradiculoneuropathy	✓	✓	x	✓	✓	✓	x
Sensory neuropathy (also known as dorsal root ganglionopathy)	✓	x	x	x	✓	✓	x
Idiopathic inflammatory neuropathy	✓	x	x	x	✓	✓	x
Stiff person syndrome	✓	✓	x	x	x	✓	x
Autoimmune encephalitis	✓	x	x	x	x	✓	x
Paraneoplastic neurological disorders	✓	x	x	x	x	✓	x

Ophthalmology conditions and immunomodulating drug licensing

Note some patients may have overlap syndromes with clinical features of multiple diseases

✓ = 'off-label' but considered routine treatment option

X = unlicensed and not currently considered a routine option; these are not covered by this shared care guideline and therefore would not be transferred to primary care.

	Azathioprine	Ciclosporin	Hydroxychloroquine	Leflunomide	6-Mercaptopurine	Methotrexate	MMF only	Sulfasalazine
Behcets disease	✓	Licensed	X	X	X	X	✓	X
Scleritis	✓	X	X	X	X	✓	✓	X
Sarcoid	✓	X	X	X	X	✓	✓	X
Idiopathic Uveitis	✓	Licensed	X	X	X	✓	✓	X
Post corneal transplant	✓	Licensed	X	X	X	X	✓	X
Optic neuropathy	✓	X	X	X	X	X	✓	X
Juvenile arthritis	✓	✓	X	X	X	✓	✓	X

Oral medicine and immunomodulating drug licensing

Note some patients may have overlap syndromes with clinical features of multiple diseases

✓ = 'off-label' but considered routine treatment option

X = unlicensed and not currently considered a routine option; these are not covered by this shared care guideline and therefore would not be transferred to primary care.

	Azathioprine	Hydroxychloroquine	Leflunomide	Methotrexate	MMF only	Sulfasalazine
Behcet's	✓	X	X	X	✓	X
Sjögren's	X	✓	X	✓	X	X
Mucous membrane Pemphigoid	✓	✓	X	✓	✓	✓
Pemphigus	Licensed	X	X	✓	✓	X
Discoid / Systemic Lupus Erythematosus	Licensed	Licensed	X	✓	✓	X
Recurrent Aphthous Stomatitis	✓	X	X	X	✓	X
Oral Crohn's with / without GIT involvement	✓	X	X	✓	X	✓
Oral Plasmacytosis	✓	X	X	X	✓	X
Churg-Strauss	✓	X	X	✓	X	X
Granulomatosis with polyangitis (GPA)	✓	X	✓	✓	✓	X
Sarcoidosis (oral lesions rarely require DMARDs)	✓	X	X	X	X	X

Respiratory conditions and immunomodulating drug licensing

Note some patients may have overlap syndromes with clinical features of multiple diseases

✓ = 'off-label' but considered routine treatment option

X = unlicensed and not currently considered a routine option; these are not covered by this shared care guideline and therefore would not be transferred to primary care.

	Azathioprine	Ciclosporin	Hydroxychloroquine	Methotrexate	MMF only	Sulfasalazine
Interstitial lung disease	✓	X	✓	✓	✓	X
Connective tissue disease	✓	X	✓	✓	✓	X
Rheumatoid arthritis related interstitial lung disease	✓	X	✓	✓	✓	X
Hypersensitivity pneumonitis	✓	X	✓	✓	✓	X
Vasculitis	✓	X	✓	✓	✓	X
Sarcoidosis	✓	X	✓	✓	✓	X

Rheumatology conditions and immunomodulating drug licensing

Note some patients may have overlap syndromes with clinical features of multiple diseases

✓ = 'off-label' but considered routine treatment option

X = unlicensed and not currently considered a routine option; these are not covered by this shared care guideline and therefore would not be transferred to primary care.

	Azathioprine	Hydroxychloroquine	Leflunomide	Methotrexate	MMF /Mycophenolic acid	Sulfasalazine
Behcets	✓	X	X	X	✓	X
Churg-Strauss	✓	X	X	✓	X	X
Dermatomyositis	Licensed	✓	X	✓	✓	X
Granulomatosis with polyangiitis (GPA)	✓	X	✓	✓	✓	X
Microscopic Polyangiitis (MPA)	✓	X	X	✓	X	X
Polyarteritis nodosa	Licensed	X	✓	✓	X	X
Polymyositis	Licensed	✓	X	✓	X	X
Psoriatic arthritis	X	X	Licensed	✓	X	✓
Relapsing polychondritis	✓	✓	X	X	X	X
Rheumatoid Arthritis	Licensed	Licensed	Licensed	Licensed	X	Licensed
Scleroderma	✓	✓	X	✓	✓	X
Sjogren's	X	✓	X	✓	X	X
Systemic Lupus Erythematosus	Licensed	Licensed	X	✓	✓	X
Takayasu's arteritis	✓	X	✓	✓	✓	X

Appendix 6 – Useful Websites

There are a number of public websites that patients and clinicians may find helpful in understanding their disease and treatment.

Dermatology:	http://www.bad.org.uk/
Gastroenterology & Hepatology:	https://www.bsg.org.uk/ https://www.crohnsandcolitis.org.uk/ https://aihsupport.org.uk/
Oral Medicine:	https://www.bsom.org.uk/patient-information/
Neurology:	https://www.myaware.org/
Respiratory:	https://www.brit-thoracic.org.uk/ https://www.blf.org.uk/ https://www.sarcoidosisuk.org/
Rheumatology:	https://www.versusarthritis.org/ https://www.rheumatology.org.uk/ https://www.sarcoidosisuk.org/