

Subject: Specialised Services Circular (SSC 2412)
Sent on behalf of: Chair of the SW Specialised Service Circular Group



Dear Colleagues,

Please find attached the following Specialised Services Circular(s):

SSC Number	SSC Title	Trusts approved to prescribe in accordance with the SSC, providing appropriate internal governance arrangements are in place
SSC 2412	HST20: Selumetinib for treating symptomatic and inoperable plexiform neurofibromas associated with type 1 neurofibromatosis in children aged 3 and over.	No South West region trusts Shared care being developed nationally, applicable to University Hospitals Bristol & Weston NHS Foundation Trust between the HSS Complex Neurofibromatosis centres at Manchester University NHS Foundation Trust and Guy's and St Thomas' NHS Foundation Trust

Is an implementation plan required from all SW trusts (regardless of commissioned status) for this SSC? No

For all other South West region trusts this is for information only.

Trusts should ensure that use is registered on the Blueteq system (if appropriate).

Treatment will only be funded where the drugs minimum dataset is fully and accurately populated.

Please direct any queries to: england.speccomm-southwest@nhs.net

Specialised Commissioning South West
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BS1 3NX
Email: england.speccomm-southwest@nhs.net

All Chief Executives

All Medical Directors

All Chief Pharmacists

05 August 2022

Dear colleagues,

RE: HST20: Selumetinib for treating symptomatic and inoperable plexiform neurofibromas associated with type 1 neurofibromatosis in children aged 3 and over.

I am writing to advise you regarding the commissioning position on the recently published NICE Highly Specialised Technologies guidance for selumetinib.

The guidance can be found at: <https://www.nice.org.uk/guidance/hst20>

NICE has stated in their guidance, published on 5th May, that:
Selumetinib is recommended, within its marketing authorisation, for treating symptomatic and inoperable plexiform neurofibromas (PN) associated with type 1 neurofibromatosis (NF1) in children aged 3 and over, only if the company provides selumetinib according to the commercial arrangement.

Selumetinib will be commissioned, in line with the HST criteria, from 3rd August 2022.

The HSS Complex Neurofibromatosis centres at Manchester University NHS Foundation Trust and Guy's and St Thomas' NHS Foundation Trust will assess each patient's suitability to receive the product, which will then be prescribed by Paediatric Oncology centres through a shared care agreement. Please see Appendix for the list of commissioned paediatric oncology units which will be prescribing this product.

The Summary of Product Characteristics for selumetinib states that there is limited data in patients older than 18 years of age and that continued treatment into adulthood should be based on benefits and risks to the individual patient as assessed by the physician; and starting treatment with selumetinib in adults is not appropriate. Continuation of selumetinib in adolescents that turn 18 years of age should be considered on a case-by-case basis with the HSS provider and the Paediatric oncology centre.

If your Trust does not meet the definition of a specialised centre for a specific recommendation included in this letter and patients may benefit from the intervention, then you should consider onward referral to a specialist centre.

If a patient is already receiving treatment with selumetinib, meets the NICE criteria and can be safely transferred over to the licensed formulation, the treatment will be routinely commissioned. If the patient is responding to treatment with another MEKi, via a company-led scheme, they should continue on that scheme.

All Trusts will be required to:

- Ensure that they are purchasing selumetinib at the agreed patient access scheme (PAS) discounted price. This discounted price will be applied automatically at point of invoice and applies to all indications.
- Comply with treatment indications as defined in the NICE Appraisal
- Register and comply with data collection required for the prescribing of high cost drugs (Blueteq)
- Report to NHS England in line with the terms and conditions included in the NHS Standard Contract and as per the agreement that Services are commissioned with Trusts, Schedule 6a Reporting Requirements for drugs. Reimbursement to Trusts will be contingent on the completion of the drug minimum data set (drug MDS) record and this information being made available in a timely way.
- Ensure that local governance aspects (e.g. technical issues, education & training, patient information) have been identified and addressed for all staff groups (as appropriate) in order to permit the safe delivery of this therapy.


Providers of services relating to these recommendations should engage with their local specialised commissioning team to consider the implications of implementing this guidance.

I would be grateful if you could cascade this information to relevant clinical teams within your organisation to support the consistent adoption of the policy nationally.

With best wishes,



Dr Peter Wilson
Medical Director (Commissioning)



Tracey Williams
Principal Pharmacist

Appendix A

HSS Complex Neurofibromatosis centres:
Manchester University NHS Foundation Trust
Guy's and St Thomas' NHS Foundation Trust

List of Paediatric oncology units:

1	Great North Children's Hospital, Newcastle Hospitals NHS Foundation Trust
2	Royal Manchester Children's Hospital, Manchester University NHS Foundation Trust
3	Alder Hey Children's Hospital, Alder Hey NHS Foundation Trust
4	Leeds Children's Hospital, Leeds Teaching Hospitals NHS Trust
5	Sheffield Children's Hospital, Sheffield Children's NHS Foundation Trust
6	Nottingham Children's Hospital, Nottingham University Hospitals NHS Trust
7	Leicester Children's Hospital, Leicester University Hospitals NHS Trust
8	Oxford Children's Hospital, Oxford University Hospitals NHS Foundation Trust
9	Birmingham Children's Hospital, Birmingham Women's and Children's NHS Foundation Trust
10	Cambridge Children's Hospital, Cambridge University Hospitals NHS Foundation Trust
11	Great Ormond Street Hospital Children NHS Foundation Trust
12	University College London Hospital Hospitals NHS Foundation Trust
13	The Royal Marsden NHS Foundation Trust
14	Bristol Royal Hospital for Children, University Hospitals Bristol NHS Foundation Trust
15	Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust