NHS England South West

Subject: Specialised Services Circular (SSC)
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
2728	**NICE Technology Appraisal Guidance: Burosumab for treating X-linked hypophosphataemia in adults [TA993]**	University Hospitals Bristol and Weston North Bristol Trust Royal United Hospitals Bath

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

**** 31/01/2025 update: Please note that following the review of implementation plans received, we have expanded access to include NBT and RUH.**

We request a joint response from the three providers (UHBW, NBT, and RUH) detailing how clinical teams will collaborate to ensure regional access and equity in prescribing practices.

Specialised Commissioning South West
NHS England
100 Temple Street
Bristol
BS1 6AG
Email: england.speccomm-southwest@nhs.net

31 January 2025

All Chief Executives

All Medical Directors

All Chief Pharmacists

Dear Colleagues,

Re: NICE Technology Appraisal Guidance: Burosumab for treating X-linked hypophosphataemia in adults [TA993]

I am writing to advise you regarding the funding position on the recently published NICE Technology Appraisal (TA993) for X-linked hypophosphataemia in adults.

The TA can be found at: https://www.nice.org.uk/guidance/ta993

NICE in their TA published on 7 August 2024 has stated that:

Burosumab is recommended, within its marketing authorisation, as an option for treating X-linked hypophosphataemia (XLH) in adults. Burosumab is only recommended if the company provides it according to the commercial arrangement.

Burosumab will be routinely commissioned from 5 November 2024 in line with these recommendations and according to a set of treatment criteria which translates the NICE recommendation into a clinical guide as to use in practice.

In addition:

- Trusts must ensure that they are purchasing burosumab 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.

- The discounted price paid by Trusts, for use in all recommended indications, will reduce from 5 November 2024. Trusts should refer to the CAP portal for further information on the PAS price. The CAP portal is available at https://nhsengland.sharefile.eu/Authentication/Login

- Trusts must ensure that any patients registered on the company led compassionate use programme who meet the clinical criteria for the drug are re-registered via Blueteq in order for NHSE to pick up the costs of their ongoing treatment. Patients who do not meet the clinical criteria should continue to receive drug via the manufacturer. Trusts to ensure that any patients continuing on the company led compassionate use programme are not registered on Blueteq and transferred to NHSE.

- Trusts must ensure that only invoices for the drug procurement costs of burosumab in this indication are invoiced to NHSE and that they are also submitting complete and accurate information via the Drugs minimum dataset (MDS). All other on costs are in block arrangements.

- In line with the terms and conditions included in the NHS Standard Contract, Schedule 6a Reporting Requirements for drugs will apply. Payment of Trust invoices will be contingent on the completion of the MDS record and this information being made available in a timely way.

- Patients must be registered via Blueteq (initiation and continuation forms) and meet the clinical criteria on the registration form. This letter gives the required one month's notice as per Schedule 2 Part G (Other Local Agreements, Policies and Procedures) of your Specialised Services contract for prior approval for this treatment/indication. From one month of the date specified above, NHS England will only reimburse these treatments for patients that have been confirmed as meeting the eligibility criteria via the formal Prior Approval Scheme (i.e. Blueteq). You may wish to use the prior approval mechanism earlier than this to expedite access to this drug.

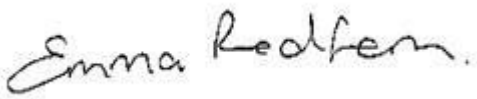
- **Payment of Trust invoices will be contingent on Blueteq registration and the full MDS record applicable to the drug being completed and this information being made available in a timely way.**

- Trusts must 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.

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.

Yours sincerely

With best wishes,



Emma Redfern
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Tracey Williams
Principal Pharmacist