South East London Integrated Medicines Optimisation Committee
Formulary recommendation

Reference	**170**
Intervention:	**Acetazolamide immediate release tablets and topiramate tablets for the treatment of adult patients with idiopathic intracranial hypertension (IIH)** (acetazolamide and topiramate are carbonic anhydrase inhibitors, reducing the production of cerebrospinal fluid and thereby lowering intracranial pressure)
Date of Decision	**May 2026**
Date of Issue:	**June 2026**
Recommendation:	**Amber 2 – Specialist initiation and minimum first month's prescription from the specialist neuro-ophthalmology team. GP may be requested to prescribe after this period.**
Further Information:	• Idiopathic intracranial hypertension (IIH) is a neurological disorder characterised by raised intracranial pressure causing neuro-ophthalmological symptoms including papilloedema, diplopia, headaches with nausea and vomiting and reduced visual acuity. • Acetazolamide and topiramate are accepted for use in South East London (SEL) for the treatment of adults with a confirmed diagnosis of IIH as follows: – Acetazolamide is the **first line** pharmacological treatment option in patients with a confirmed diagnosis of IIH at an initial dose of between 250mg to 500mg twice daily, titrated according to clinical response and tolerability, up to a maximum of 4g daily. – Topiramate is the **second line** treatment option where acetazolamide is not tolerated, contraindicated, there is an inadequate response or is not clinically appropriate as determined by the specialist team. The proposed topiramate dose is 50mg once daily to 100mg twice daily, with dose titration under the supervision of the specialist team according to response and tolerability. • The use of either acetazolamide or topiramate tablets in this setting is **off-label***. The off-label nature should be explained to the patient/carer and informed consent gained. • In line with consensus guidelines for the management of IIH, pharmacological treatment should be used as part of an overall management plan. Internal Trust treatment guidelines will be used to guide the overall treatment pathway for individual patients. • Periodic renal function, electrolytes and full blood count should be considered with prolonged use of acetazolamide. See the Summary of Product Characteristics (SmPC) for further details. • The use of acetazolamide or topiramate in this setting is expected to improve the following outcomes in people with IIH: – Lower intracranial pressure – Prevention of visual loss – Reduction in headache severity – Improved quality of life These outcomes will be assessed as part of the routine follow up by the specialist team. • Acetazolamide should be avoided in pregnancy. Patients taking acetazolamide should be advised to inform the specialist team promptly if they are pregnant or planning pregnancy. • Topiramate is contraindicated in pregnancy and in women of childbearing potential unless the conditions of the Pregnancy Prevention Programme (PPP) are fulfilled. See the SmPC for further details. • Patients should be adequately counselled on their treatment by the initiating specialist. In line with the MHRA alert on antiepileptic medicines, treatment with acetazolamide or topiramate may be associated with a small risk of suicidal thoughts and behaviour. Patients and carers should be advised to be alert to mood changes, distressing thoughts, or thoughts of self-harm, and to seek medical advice if these occur. • The ongoing need for maintenance treatment with acetazolamide or topiramate for IIH and duration of treatment should be regularly reviewed and guided by the specialist neuro-ophthalmology team.

	• Treatment with acetazolamide or topiramate should be discontinued if the medicine is ineffective, not tolerated, pregnancy-related safety concerns arise, or if the patient achieves remission of IIH through weight loss. **Acetazolamide is licensed for use as a diuretic and for the treatment of glaucoma and epilepsy. Topiramate is licensed for use as an anti-convulsant and for migraine prophylaxis.*
Shared Care/ Transfer of care required:	N/A (Individual Management Plan to be in place for the patient under Amber 2 arrangements)
Cost Impact for agreed patient group	• The formulary applicant estimated approximately 200 patients per annum for acetazolamide and 36 patients per annum for topiramate may be eligible for treatment for the management of IIH in SEL. • Assuming all patients on acetazolamide are titrated up to the maximum 1g four times a day, the estimated cost impact for SEL is £95,703 per annum (£4,785 per 100,000 population). • Assuming all patients on topiramate are titrated up to the maximum 100mg twice a day, the estimated cost impact for SEL is £853 per annum (negligible cost per 100,000).
Usage Monitoring & Impact Assessment	**Acute Trusts:** • Monitor use and submit usage data and audit reports upon request to the Committee.
	SEL Borough Medicines Teams: • Monitor ePACT2 data. • Exception reports from GPs if inappropriate prescribing requests are made to primary care
Evidence reviewed	**References (from evidence evaluation)** 1. Manji, H. et al. 2014. Oxford Handbook of Neurology. Second edition. Oxford University Press. 2. Karissa, N.A and Amaal, J.S. Idiopathic intracranial hypertension. Practical Neurology. 2020. 3. National Library of Medicine, Surgical Idiopathic Intracranial Hypertension Treatment Trial (SIGHT). Last update posted 16/06/2022. Study Details | NCT03501966 | Surgical Idiopathic Intracranial Hypertension Treatment Trial | ClinicalTrials.gov 4. Mollan, S.P. et al. Idiopathic intracranial hypertension: consensus guidelines on management. Journal of Neurology, Neurosurgery and Psychiatry. 2018; 89(10): 1088–1100. 5. Acetazolamide. Summary of Product Characteristics [online] available here [Last accessed 09/05/26]. 6. South East London Adult Joint Medicines Formulary. [online] available at: South East London Adult Joint Medicines Formulary [Last accessed 09/05/26]. 7. Topiramate. Summary of Product Characteristics [online] available here [Last accessed 09/05/26]. 8. Piper, R.J. et al. Interventions for idiopathic intracranial hypertension (review). Cochrane Database of Systematic Reviews. 2015; 8:1-36. 9. Ball, A.K. et al. A randomised controlled trial of treatment for idiopathic intracranial hypertension. Journal of Neurology. 2010; 258:874-881. 10. Wall, M. et al. Quality of life in idiopathic intracranial hypertension at diagnosis: IIH Treatment Trial results. 2015; 84:2449-2456. 11. Friedman, D.I. et al. Headache in Idiopathic Intracranial Hypertension: Findings From the Idiopathic Intracranial Hypertension Treatment Trial. Headache: The Journal of Headache and Face Pain. 2017: 57(8): 1195-1205. 12. Celebisoy, N. et al. Treatment of idiopathic intracranial hypertension: topiramate vs acetazolamide, an open-label study. Acta Neurologica Scandinavica. 2007; 16: 322–327. 13. Shah, V.A., et al. Idiopathic intracranial hypertension. Ophthalmology. 2007: 114(3): 617. 14. Pagan, F.L. et al. A new drug for an old condition? Headache: The Journal of Headache and Face Pain. 2008: 42(7): 695-696. 15. National Health Service England and Wales Electronic Drug Tariff. [online] available here [Last accessed: 09/05/26]

NOTES:

a) SEL IMOC recommendations and minutes are available publicly via the website.

b) This SEL IMOC recommendation has been made on the cost effectiveness, patient outcome and safety data available at the time. The recommendation will be subject to review if new data becomes available, costs are higher than expected or new NICE guidelines or technology appraisals are issued.

c) Not to be used for commercial or marketing purposes. Strictly for use within the NHS