

## **NHS Norfolk and Waveney ICB Board Meeting Questions - 25 September 2024**

The following questions were received from members of the public. Given both questions did not relate to agenda items of the meeting, a written response was provided, in line with the ICB's protocol.

**Question 1: I would like to ask about funding levels provided for treatments for neurological conditions such as Migraines. Treatment options such as Agovy, Aimovig, Emgality & Vyepti. All of these are "supposed" to be available on the NHS to patients that meet the migraine condition criteria but gaining access to these medications is a Post Code lottery. The Norfolk & Waveney Trust currently isn't providing funding for new patients to access these medications therefore in a lot of cases directly restricting access to an even remotely basic quality of life. I want to question the board on a) how this decision is justifiable? b) how we go about changing this misguided funding policy? and c) how we shift the focus from short term funding decisions to longer term patient driven decisions which also deliver financial gains as well.**

Answer 1: For the prevention of Migraine, NHS Norfolk and Waveney Integrated Care Board (ICB) has commissioned the use of Botulinum toxin type A (Botox), Galcanezumab (Emgality®), Erenumab (Aimovig®), Fremanezumab (Ajovy®), Eptinezumab (Vyepti®), Rimegepant (Vydura®) and Atogepant (Aquipta®). Due to procurement agreements, most of these products must be provided by secondary care or via a homecare provider. In July 2024, the provision of Rimegepant & Atogepant was also commissioned as an option for prescribing in primary care after initiation and review by a Migraine specialist.

These options have been approved by the ICB, in line with positive NICE technology appraisals, and are supported with an agreed local pathway with input from specialists across the area. This was agreed by the ICB therapeutics advisory group and was published July 2024. The Norfolk and Norwich University Hospital (NNUH) is currently going through its own internal processes to ensure compliance with this. Trusts do have to follow due processes within their own organisation. The ICB does not have control over the internal processes at the acute trusts, but we provide support around the process for commissioning new medicines and the production of clinical pathways.

The above treatments are not licenced or recommended for treatment of cluster headache. There is no formal position for most of the products used in cluster headaches, however this is not unusual when treatment is in line with recommended NICE guidelines. The only product which the ICB has taken steps to prevent use of, relates to Imigran RADIS®, due to this being significantly more expensive than equivalent products with the same active ingredient.

**Question 2: There is a big gap in provisioning for more severe ME/CFS patients and what exists (4 group sessions) is not NICE compliant, causing delayed diagnosis, no clinical monitoring or treatment and poor patient outcomes. There's no provision at all for severe (housebound) and very severe (bedbound) patients. Given the Maeve Boothby inquest (died due to lack of**

**commissioning) and this has been acknowledged by Minister Andrew Gwynn, what is the ICB doing to resolve the issue?**

**In addition, please can Norfolk keep step with Suffolk and Essex in implementing their newly developed, cost neutral, clinical ME/CFS service pathway design? Failing to do so is turning ME/CFS healthcare into a postcode lottery and creating health inequality in East Anglia, which you are supposed to be fighting as part of your mission.**

Answer 2: The ICB currently commissions a service from East Coast Community Health (ECCH). This is a specialist service that provides expertise in assessing, diagnosing and advising on the clinical management of ME/CFS, including symptom control, and provides a range of therapeutic and rehabilitative interventions. It raises awareness and improves the diagnosis, treatment and quality of life of patients with ME/CFS, and their carers. The service offers face to face clinic appointments, and well as video and telephone appointments for those unable to attend in person. They are unfortunately unable to routinely offer home visits due to resource constraints, however they do undertake them where they have identified a clinical need, which is assessed on a case-by-case basis. The service is responding to NICE guideline [NG206] Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management.

The ICB is actively working with ECCH to redesign the service to respond to NICE guideline NG206 and to ensure an optimum pathway for our patients within the available resources. As part of this redesign, contact will be made with NHS Suffolk and North East Essex ICB to ensure we learn from their experience, and understand and take into account the services recently redesigned and being implemented there to improve outcomes and reduce inequalities for our population.