



Our ref: WQ89598

Sarah Murphy MS  
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4 December 2023

Dear Sarah,

Thank you for your recent written question asking me what discussions the Welsh Government has had with National Institute for Health and Care Excellence (NICE) and the All Wales Medicines Strategy Group, to ensure that Kaftrio and similar drugs are available to those with cystic fibrosis on the Welsh NHS.

I'm sure you can understand that neither myself or officials can comment on individual patient cases in regard to eligibility for certain medicines and therefore this letter sets out the general position regarding access to cystic fibrosis medicines in Wales.

NICE is established to provide independent, expert and impartial advice on whether the benefits of new medicines are in sufficient balance with their costs to represent a cost effective use of NHS resources.

We rely on the expert advice of NICE as an internationally renowned health technology appraisal body. As is the case for cystic fibrosis medicines, where NICE are undertaking an appraisal the All Wales Medicines Strategy Group (AWMSG) would not also do so. All medicines that have been recommended by NICE or the AWMSG are routinely available in Wales where clinically appropriate.

The independent role of NICE means it would not be appropriate for the Welsh Government to intervene in its appraisal processes or to comment on its consultations.

On 3 November, NICE published draft guidance on the use of Kaftrio, Symkevi and Orkambi in which they did not recommend the use of these treatments because: *"the price offered by the manufacturer was substantially above the range NICE considers an acceptable use of NHS resources"*.

As I indicated in my letter to the Chair of the Health and Social Care Committee, the draft guidance does not constitute NICE's final position on the availability of Kaftrio, Symkevi and Orkambi and there is scope for Vertex to consider NICE's findings and an opportunity for them to offer a price which represents appropriate value for money to the NHS. NICE will

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

update its guidance and issue a final recommendation only when the appraisal process has concluded.

At the end of the appraisal process, should NICE not recommend the use of these treatments it will not affect anyone currently receiving them or anyone who commences treatment ahead of NICE's final recommendation, this includes children who commence treatment with Kaftrio in accordance with the license changes which came into effect earlier this month allowing eligible children aged as young as 2 years of age to receive treatment.

I anticipate NICE will publish an updated recommendation early in the new year.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'M. E. Morgan'.

**Eluned Morgan AS/MS**

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services