



## Craig Whittaker MP

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### Orkambi Update

Thank you for contacting me about the availability of Orkambi (lumacaftor–ivacaftor). I know many families affected by cystic fibrosis have placed a great deal of hope in this drug and believe particular care should be taken to assess its effectiveness.

I am aware that, following a public consultation, the National Institute for Health and Care Excellence (NICE) published final guidance in July 2016 which did not recommend Orkambi for the treatment of cystic fibrosis. NICE concluded that, compared to the current standard of care, the benefit Orkambi offered did not justify its considerable cost.

I recognise that these are very difficult decisions to make. I can assure you that NICE only publishes final guidance on the use of a drug after very careful consideration of the available evidence and after thorough consultation. I believe, therefore, that it would not be appropriate for Ministers to interfere in its important work.

You may be pleased to know that NICE plans to review its guidance on the prescription of Orkambi in 2019, to ensure that the latest evidence available is always taken into account. I understand that NICE will bring forward a review if significant new evidence comes to light before 2019, but so far NHS England and NICE have not received any fresh proposals from Orkambi's manufacturer.

I know that the Government is determined to make the UK the best place in the world to produce new drugs and other products that can transform the health of patients. I welcome the publication of the final report by the Accelerated Access Review. It provides a strong basis to make the right decisions about how the health system can be adapted to meet future challenges, attract inward investment, encourage growth in the thriving life science industry and use innovation to improve patient outcomes and tackle the financial pressures on the NHS. The Government is carefully considering its recommendations and will respond in due course.

Thank you again for contacting me.

Kind regards,

Craig Whittaker MP