

Dear Dr Wollaston

23 May 2019

As requested, I am writing to update you on the discussions that have taken place with Vertex Pharmaceuticals to secure access for patients to their portfolio of cystic fibrosis medicines at fair and affordable prices.

Five meetings have now been held with Vertex since you wrote to the Secretary of State for Health & Social Care on 8th March setting out the Committee's findings and recommendations. We have not received any specific or formal proposals from Vertex during this period. However, NHS England has formally made a revised and improved offer to Vertex, building upon the helpful recommendations made by the Committee.

The detail of this offer, including pricing information, is commercially sensitive and confidential. However, it is appropriate to describe some of the key features.

Most importantly, we have proposed a two-year managed access arrangement for Orkambi and Symekvi, providing full access for all eligible patients. This would allow for the collection of real-world data on patient outcomes that could then inform the appraisal of both products by NICE, alongside any other newly available evidence, at the end of the managed access period.

During this interim funding period, we have proposed a significant increase in the per patient per year price for each medicine compared to our July 18 offer. At the end of the managed access period, prices could then either be adjusted upwards further or downwards depending on the NICE Committee's

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conclusions. In order to safeguard taxpayers' interests, should NICE conclude that the interim price had been set too high then the NHS would receive a rebate for the difference.

We have also made further proposals on Kalydeco, which is already reimbursed by the NHS for some patients, but would now extend access to all licensed indications. At Dr Leiden's request, the triple therapy has been taken off the table for now.

In recent days we have announced that a number of deals for innovative drugs have been reached with pharmaceutical companies, as part of the NICE appraisal process, including Ocrelizumab (Ocrevus) for the treatment of Primary Progressive Multiple Sclerosis and Nusinersen (Spinraza) for the treatment of Spinal Muscular Atrophy. This illustrates that where companies are willing to engage with NICE and price responsibly then deals can be reached that are of benefit to patients, taxpayers and industry.

We hope Vertex will now take a similarly responsible approach.

Yours sincerely



John Stewart

National Director, Specialised Commissioning

NHS England