



Dr Sarah Wollaston MP
Chair, Health and Social Care Select Committee
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Dear Sarah,

CYSTIC FIBROSIS DRUGS

On Tuesday I updated your Parliamentary committee on my team's negotiations to secure access for our patients to certain cystic fibrosis drugs.

I am pleased to let you know that since then NHS England has now secured a definitive agreement with Vertex Pharmaceuticals to make available all three of their UK-licensed CF medicines.

This means NHS patients will now have access to Orkambi and Symkevi. Our deal also further extends access to Kalydeco. As a consequence, around 5,000 people may take up these treatments - but there is no cap on patient numbers, and each and every patient in England who might benefit can now get these treatments, free on the NHS.

Given the time it has taken for the company to reach this agreement, there must be no further delay. So I expect NHS clinicians should be able to start offering these treatments within 30 days from today.

Furthermore, access to all three drugs has been agreed not only for all current licensed indications, but for possible future licence extensions too.

I can also confirm that we have only been able to finalise this negotiation because the company has now agreed confidential commercial terms that constitute good value for British taxpayers. As a result, NICE has also been able to support the agreement.

In addition, we have made it a condition of the deal that the company submits its full portfolio - including in due course its new triple therapy - to NICE for comprehensive appraisal. Vertex have now agreed to do so. The NICE appraisal is expected to conclude by September 2021, supported by an 18-month period of prior real-world data collection. The company has also agreed a flexible contractual mechanism which means that in all circumstances these three medicines will continue

High quality care for all, now and for future generations

to be available following completion of the NICE appraisal.

Wales and Northern Ireland have stood alongside NHS England throughout these extended discussions. We have therefore inserted into the legal agreement that NHS England has negotiated, a requirement that the company must make equivalent terms available to the NHS in Wales and Northern Ireland, should those jurisdictions wish to benefit from them.

Unfortunately, we have not been able to extend this option for Scottish patients. That is because six weeks ago a decision was taken there to step away from coordinated UK-wide approach by ignoring the independent expert medical advice of the Scottish Medicines Consortium – their equivalent of NICE. We are however legally able to share with the Scottish Government confidential details of the improved deal we have now negotiated for England.

Finally, I would like to thank the Health and Social Care Committee for your support for our negotiation on behalf of families affected by CF. It has at times been frustrating, and for patients distressing. But I am in no doubt that the independent, fair, flexible, and objective approach we take to drug price appraisal and negotiation in this country – borne out of more than two decades of internationally-respected experience and expertise – is something that we squander at our peril. In the round, both patients and taxpayers benefit. Today's agreement is just further evidence of that.

With best wishes

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Simon Stevens', with a horizontal line underneath.

Simon Stevens
Chief Executive of the NHS