

Cystic Fibrosis Trust Statement: Response to Welsh Government announcement regarding access to cystic fibrosis medicines.

David Ramsden, Chief Executive at the Cystic Fibrosis Trust said: "It is great news that Welsh people with cystic fibrosis will soon have access to the life-saving CF drugs Orkambi and Symkevi.

"This has been a hard-fought four-year battle, which has caused real damage and pain and I want to thank everyone, including the Petitions Committee and Assembly Members from all parties, who have contributed to this campaign, for their persistence and determination.

"We must now work with Welsh health authorities to ensure that future cystic fibrosis therapies, including those that will have greater health benefit for a larger number of people with CF in Wales, are not subject to the same damaging delay and are available at the earliest opportunity."

There are 402 people with CF living in Wales according to the 2018 [Registry report](#), and approximately 190 could stand to benefit from these drugs.

The Cystic Fibrosis Trust (as host and sponsor of the [UK CF Registry](#)) has co-signed a data collection agreement with NHS England, NICE and the company, Vertex Pharmaceuticals. The purpose of this agreement is to support evidence-gathering that may address uncertainties identified by NICE's technology appraisal committee.

This is a similar arrangement in place with the Scottish Government, following their separate agreement to provide interim reimbursement of these therapies, in advance of a formal HTA by the Scottish Medicines Consortium.

The UK CF Registry is a secure centralised database, which records health data on consenting people with cystic fibrosis. CF care teams enter data at every specialist centre and clinic across the UK, with over 99% of people with CF consenting to their data being submitted.

These agreements in England and Scotland have been a product of close collaboration with national authorities, and address relevant requirements identified in those geographies. We have offered the same opportunity to Welsh health authorities.