Health and Social Care Board

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Mr David Ramsden
Chief Executive
Cystic Fibrosis Trust
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London
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6 July 2017

Dear Mr Ramsden

ORKAMBI

Thank you for your letter regarding the availability of lumacaftor–ivacaftor (Orkambi) for people in Northern Ireland

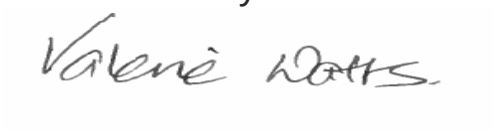
The Health and Social Care Board is committed to making new medicines available to the population of Northern Ireland, subject to the best available evidence on the medicine's clinical and cost effectiveness. In that regard Northern Ireland has a formal arrangement with the National Institute for Health and Care Excellence (NICE) and, consistent with the policy direction set by the Department of Health, the HSC Board adopts NICE technology appraisals and commissions new medicines recommended by NICE.

NICE recently undertook a technology appraisal on lumacaftor–ivacaftor (Orkambi) and published its advice in July 2016. NICE concluded that *lumacaftor–ivacaftor is not recommended, within its marketing authorisation, for treating cystic fibrosis in people 12 years and older who are homozygous for the F508del mutation in the cystic fibrosis transmembrane conductance regulator (CFTR).* The committee which appraised lumacaftor–ivacaftor (Orkambi) concluded that the estimated incremental cost-effectiveness ratios (ICERs) were considerably higher than what is normally considered a cost-effective use of NHS resources.

In this context, the HSC Board does not routinely commission lumacaftor–ivacaftor (Orkambi). For medicines which are not routinely commissioned, a clinician can request a particular medicine for use within its licensed indication, for an individual patient. Such requests can be made to the HSC Board through the Individual Funding Request (IFR) route and funding approval is subject to the clinician being able to demonstrate a patient's clinical exceptionality.

I trust this helps to clarify the current commissioning position in regard to lumacaftor–ivacaftor (Orkambi).

Yours sincerely



Valerie Watts
Chief Executive

CC: Mr Dean Sullivan
Dr Miriam McCarthy
Ms Lynn Keenan