North of England
Specialised Commissioning Group

26 September 2012

Statement from North of England SCG on behalf of the four Specialised Commissioning Groups in England

Ivacaftor (brand name Kalydeco) for cystic fibrosis

The four Specialised Commissioning Groups (SCGs) in England are committed to commissioning innovative and cutting edge medical healthcare and ensuring that all new treatments that may benefit our patients are assessed in a timely and consistent way.

The Clinical Priorities Advisory Group (CPAG) has been established to provide the four SCGs in England with a single point of national advice on the clinical and cost effectiveness of Ivacaftor (Kalydeco). They will be making their recommendations to the four SCGs based on a robust clinical and economic evaluation (Health Technology Appraisal) carried out by the NHS Institute for Health and a report from the national Cystic Fibrosis Clinical Reference Group.

On 25 September 2012 the CPAG met for the first time to start the first stage of deliberations on their recommendations on the commissioning of Ivacaftor to the four SCGs in England.

Yesterday's meeting focused on the clinical effectiveness and appropriateness of Ivacaftor for patients. All members agreed that the drug does provide clinical benefits and is appropriate for patients with the G551D gene mutation. Representatives of the Cystic Fibrosis Trust and the manufacturers of Ivacaftor (Vertex Pharmaceuticals) were present alongside members at the meeting.

The economic and cost effectiveness of Ivacaftor was not considered at yesterday's meeting as this will require further in depth detailed examination. Therefore a second meeting will take place in approximately four weeks' time to consider this.

A single report containing the CPAGs recommendations will be taken to the relevant SCG Boards in time for their December meetings. The four SCGs will then be responsible for co-ordinating a single commissioning decision for England via their local governance arrangements.

We recognise that the unique nature of this new treatment has generated significant interest within the Cystic Fibrosis community and we are working hard to keep to a minimum, any delays to a commissioning decision.

Ends

For media enquiries please contact 01279 666969 or email communications@eoescg.nhs.uk

Notes to editors

- The four Specialised Commissioning Groups in England are, North of England, South of England, Midlands and East and London.
- The Yorkshire and the Humber office of the North of England Specialised Commissioning Group, is the national commissioning lead for cystic fibrosis and is working on behalf of the four Specialised Commissioning Groups in England.
- The Yorkshire and the Humber office of the North of England Specialised Commissioning Group (SCG) commissioned a Health Technology Appraisal (HTA) of Ivacaftor to provide a robust clinical and economic evaluation for the treatment. The final HTA report was received in August.
- The draft minutes of CPAG will be published on the North of England SCG (Yorkshire and the Humber Office) website (www.yhscg.nhs.uk) and the CF Trust website (www.cftrust.org.uk) as soon as they become available. This is expected to be in early October.
- The CPAG adopted the decision making framework currently used by the Advisory Group for National Specialised Services (AGNSS) for the national commissioning of highly specialised services to ensure a fair and consistent approach
- The role of the CPAG is to advise the four SCGs on the clinical and cost effectiveness of Ivacaftor and they will make a final recommendation to the SCGs
- The membership of the national Cystic Fibrosis Clinical Reference Group includes clinicians, patient representatives, and representatives from the Cystic Fibrosis Trust and NHS commissioners.
- Ivacaftor has orphan drug status which means it is only effective for a small population size. As it will only benefit a small number of people it will not be evaluated by the National Institute of Clinical Excellence (NICE) as the population size is too small to publish guidance.
- CPAG has been established by the NHS in the absence of an evaluation by NICE due to Ivacaftor's orphan drug status