

Cystic Fibrosis Committee meeting 9

Date: 26/04/2016

NICE National Institute for
Health and Care Excellence

Location: Royal College of Obstetricians and Gynaecologists, London.

Minutes: Confirmed

| Committee members present: | |
|-----------------------------------|---------------------------|
| Martin Walshaw | (Present for notes 1 – 6) |
| Mandy Bryon | (Present for notes 1 – 6) |
| Alexander Darlington | (Present for notes 1 – 6) |
| Iolo Doull | (Present for notes 1 – 6) |
| Sarah Collins | (Present for notes 1 – 6) |
| Alexander Darlington | (Present for notes 1 – 6) |
| Zoe Elliot | (Present for notes 1 – 6) |
| Helen McCabe | (Present for notes 1 – 6) |
| Andrew Jones | (Present for notes 1 – 6) |
| Keith Thompson | (Present for notes 1 – 6) |
| Elaine Edwards | (Present for notes 1 – 6) |
| Janis Bloomer | (Present for notes 1 – 6) |
| Sarah Popple | (Present for notes 1 – 6) |

| In attendance: | | |
|-----------------------|--|---------------------------|
| Shona Burman-Roy | Senior Research Fellow | (Present for notes 1 – 6) |
| Annabel Flint | Project Manager | (Present for notes 1 – 6) |
| Gemma Villanueva | Research Fellow | (Present for notes 4 – 6) |
| Hugo Pedder | Statistician | (Present for notes 1 – 6) |
| Gemma Marceniuk | Health Economist | (Present for notes 1 – 6) |
| Rami Cosulich | Research Assistant | (Present for notes 1 – 6) |
| Ferruccio Pelone | Research Assistant | (Present for notes 1 – 6) |
| Katie Perryman-Ford | NICE Guideline Commissioning Manager | (Present for notes 1 – 6) |

Observers:

None.

Apologies:

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| Stephen Murphy | Clinical Director |
| Vanessa Delgado Nunes | Senior Research Fellow and Guideline Lead |
| David Lacy | Committee member |
| Helen Parrott | Committee member |
| Nichola MacDuff | Committee member |
| Stephen Holden | Co-opted member |

1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the ninth guideline committee meeting on Cystic Fibrosis. The Committee members and attendees introduced themselves.

The Chair informed the Committee that apologies had been received and these are noted above.

The Chair outlined the objectives of the meeting, which included: the presentation of the network meta-analysis and health economics for chronic antimicrobial treatment, the evidence review for models of care and multidisciplinary teams.

2. Declarations of interest

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion was the diagnosis and management of Cystic Fibrosis.

The Chair asked everyone to verbally declare any interests that have arisen since the last meeting.

| Name | Job title, organisation | Declarations of Interest, date declared | Type of interest | Decision taken |
|---------------|--|---|---|-------------------------|
| Sarah Collins | CF Specialist Dietician, Nutrition & Dietetic Department, Royal Brompton | Awarded a NIHR/HEE-ICA Clinical Doctoral Research Fellowship, based at Royal Brompton Hospital, | Non-personal financial, non-specific This is non-specific as she | Declare and participate |

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| | Hospital | <p>registration for PhD at King's College, London. Will be undertaking a training and research programme to obtain PhD, in addition to a clinical commitment.</p> <p>26/04/2016</p> | has not started to undertake any research yet and therefore cannot state if the topics will be discussed in this guideline. | |
| Iolo Doull | Consultant Respiratory Paediatrician, Children's Hospital for Wales, Cardiff | <p>Authored a paper that was considered and excluded as part of the Guideline review on models of care in CF - Full, shared and hybrid paediatric care for cystic fibrosis in South and Mid Wales. Doull I, Evans H; South and Mid Wales Paediatric Cystic Fibrosis Network.</p> <p>Arch Dis Child. 2012 Jan;97(1):17-20</p> <p>26/04/2016</p> | Personal non-financial, specific | Declare and participate (This was published in 2012; therefore more than 12 months before he joined the committee) |
| Andrew Jones | Consultant and Honorary Reader in Respiratory Medicine and Cystic Fibrosis, North West Lung Centre, University Hospitals South Manchester NHS Foundation Trust | Invited to be a member of the Study Steering Committee of "The cystic fibrosis (CF) anti-staphylococcal antibiotic prophylaxis trial (CF START); a randomised registry trial to assess the safety and efficacy of flucloxacillin as a long term prophylaxis agent for infants with | Personal non-financial, specific | Declare and participate |

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| | | CF". CF START is a national UK study that has been funded by the HTA. 26/04/2016 | | |
| Nichola MacDuff | Adult Specialist Nurse, Advanced Clinical Nurse Specialist & Lead Nurse, Black Country Adult CF Centre, Royal Wolverhampton NHS Trust | Attended a Chiesi sponsored dinner while at the European CF Conference in Basel, Switzerland. 26/04/2016 | Personal non-financial, non-specific Non-specific as this is a hospitality event and therefore not directly discussed in this guideline | Declare and participate (expenses within NICE policy) |
| Keith Thompson | Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust | As chair of UK CF Pharmacist Group, oversan an update of the CF Trust document 'Pharmacy Standards of Care' for CF centres which is a document referred to in the NHS England Service Specification for CF. 26/04/2016 | Personal non-financial, specific | Declare and participate |
| Keith Thompson | Senior Respiratory Pharmacist, Royal Brompton and Harefield NHS Foundation Trust | Invitation accepted to update a 'tab' entitled 'Approved and Off-Label drugs for the management of CF in the EU' in the Hospital Pharmacy Europe Pocket Guide to CF (the previous edition was published in 2013). This contains information on a number of drugs used in CF which will be discussed in the NICE CF guideline, but is | Personal non-financial, specific | Declare and participate. |

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| | | <p>limited to collation of information on drug doses taken from manufacturers' data or relevant literature, rather than review or recommendation. Support for the editorial development of the project was provided by Vertex, manufacturer of Kalydeco® and Orkambi® which are licensed for the treatment of CF but do not fall within the scope of this guideline.</p> <p>Chapter was published; not referenced in guideline; no personal financial interest (honorarium was not offered or accepted).</p> <p>26/04/2016</p> | | |
| Martin Walshaw | Consultant Physician in General and Chest Medicine at Royal Liverpool and Broadgreen University Hospitals NHS Trust, and The Liverpool Heart and Chest Hospital NHS Foundation Trust | <p>Ongoing role in shaping CF care in England by representing the Mersey Senate area on the Clinical Reference Group. Meeting on – 23/11/15.</p> <p>26/04/2016</p> | Personal non-financial, specific | Declare and participate |
| Martin Walshaw | Consultant Physician in General and Chest Medicine at Royal Liverpool and | Former member of the (now defunct) CF CRG that advised NHSE on CF service specifications | Personal non-financial, specific | Declare and participate |

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| | Broadgreen University Hospitals NHS Trust, and The Liverpool Heart and Chest Hospital NHS Foundation Trust | including those for the formation of clinical services. 26/04/2016 | | |
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The Chair and a senior member of the Developer's team noted that the interests declared did not prevent the attendees from fully participating in the meeting.

3. Minutes of last meeting

The Chair asked the Committee whether any changes were required to the minutes of the last meeting. The Committee agreed that the minutes were a true and accurate account of the meeting.

4. Presentations

The Chair introduced Hugo Pedder, Statistician and Gemma Marceniuk, Health Economist, who gave a presentation on the evidence reviewed for the topic of chronic antimicrobial infection.

The Chair introduced Gemma Villanueva, Senior Research Fellow, and Rami Cosulich, Research Assistant, who gave a presentation on the evidence review for the topic of models of care. The Chair then led the committee through the process of drafting recommendations and LETRs for this topic.

Gemma Marceniuk gave a presentation of the health economic model for service delivery and took questions from the Committee.

Gemma Villanueva and Rami Cosulich then gave a presentation on the evidence review for the topic of multidisciplinary teams and took questions from the Committee. The Chair then led the committee through the process of drafting recommendations and LETRs for this topic.

The Committee thanked everyone for their presentations and contribution to the development of the guideline.

5. Questions and discussion

6. Any other business

There were no other items of business. MW thanked the Committee for attending

and closed the meeting.

Date of next meeting: 15/06/16

Location of next meeting: Royal College of Obstetricians and Gynaecologists,
London.