

<b>Date and Time:</b>	<b>7th September 2012, 10.00 – 16.00 hrs</b>
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<b>Minutes:</b>	
<b>10th Guideline Development Group Meeting</b>	
<b>Place:</b>	National Clinical Guidelines Centre, 180 Great Portland Street, Boardroom
<b>Present:</b>	<p>Nik Hirani (<b>Chair</b>)  Ann Millar  Angela Key  Annette Duck  Geraldine Burge  Malcolm Weallans  Melissa Hippard  Nicholas Kim Harrison  Nick Screatton  Patrick Wilson  Sue Copley (am only)  Tessa Lewis</p> <p>Izaba Younis, Research Fellow  Vicki Pollit, Acting Senior Health Economist  Nina Balachander, Senior Research Fellow and Project Manager  Vanessa Delgado Nunes, Guideline Lead</p>
<b>In attendance:</b>	
Jaimella Espley, NICE Editor Stephen Clark, Consultant Cardiothoracic Surgeon	
<b>Apologies:</b>	
Richard Hubbard Clifford Middleton, NICE Guidelines Commissioning Manager	

## Notes

1. Nik Hirani welcomed the group to the tenth GDG meeting. Apologies were received from Richard Hubbard and Clifford Middleton. The Chair asked all GDG members to declare any relevant conflicts of interest.

NH declared personal non-pecuniary interests. NH is a member of the BTS steering group developing an IPF National Registry for which he receives no funding. A student which NH supervises received funding from Boehringer Ingelheim to attend the ERS conference. Funding was within reasonable limits for conference attendance. NH also endorsed an article in Thorax, which discussed what outcomes should be used as end points in trials in lung fibrosis. NH did not receive any funding for this endorsement.

AD declared a personal non-pecuniary interest. AD attended a study day organised by Intermune on 28th June. She received no financial remuneration for attendance. AD also declared a personal pecuniary interest, as she presented a research poster at the ERS on 4th September on 'Perceptions, experiences and information needs of patients with IPF'. Her

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hotel accommodation at the ERS was sponsored by Intermune and flight expenses were covered by her institution. All expenses were within reasonable limits. AD also declared a non-personal non-pecuniary interest. The department in which AD works is taking part in the Pirfenidone Named Patient Programme, which commenced in September 2011 and for which she receives no funding.

AM declared a personal non-pecuniary interest. AM is a member of the BTS steering group developing an IPF National Registry, for which she receives no funding.

GB declared personal non-pecuniary interests. GB attended an IPF update in June, for which she received no funding and has also been involved with an IPF patient self help group (query funding). She also attended an ERS conference, for which travel and accommodation was funded for by Intermune. All expenses were within reasonable limits.

MH declared a personal non-pecuniary interest. MH volunteered to be a patient advisor on the NICE Pirfenidone Technology Appraisal, for which she receives no funding.

NKH declared a personal non-pecuniary interest as he has endorsed an article in Thorax, which discussed what outcomes should be used as end points in trials in lung fibrosis. NKH did not receive any funding for this endorsement.

NS declared a non-personal non-pecuniary interest. His department has received funding from Glaxo Smith Klein for one radiologist and one physicist positions.

PW declared a non-personal non-pecuniary interest. PW's dept. has received a Gilead fellowship research grants for investigating antibiotic therapy in cystic fibrosis.

SC declared personal non-pecuniary interests. SC is a member of the BTS steering group developing an IPF National Registry, for which no funding is received, and is also a co-organizer of an ILD Educational Course, NHLI, which commenced in March 2013 and the funding goes to her department.

There were no changes in any of the other GDG members' or NCGC staff's DOIs since the last meeting.

No actions were taken following these declarations and none of the GDG members withdrew as none of the declarations conflicted with clinical areas to be discussed during the GDG meeting.

### **Presentations:**

Each of the following presentations were given:

1. Introduction to ventilation and lung transplantation – Stephen Clarke
2. Clinical and cost effectiveness evidence review for ventilation – IY and VP
3. Clinical and cost effectiveness evidence review for the optimal timing of referral for lung transplantation – IY and VP
4. Health economic model for pulmonary rehabilitation - VP
5. Re-cap of recommendations – NB
6. Revisiting previous recommendations and research recommendations - NB
7. Workplan - NB

1. Stephen Clarke presented an overview on ventilation and lung transplantation in people with IPF.

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2. IY presented the clinical evidence from six papers for invasive versus non-invasive ventilation in people with IPF. VP presented the costs incurred when a patient is ventilated.
3. IY presented an update on the clinical evidence for timing of referral for lung transplantation for people with IPF. No evidence was retrieved for timing of referral for lung transplantation, but indirect evidence was presented to the GDG on lung allocation scoring used and waiting list mortality in people with IPF. VP presented the costs incurred when a patient undergoes lung transplantation.
4. VP presented the sensitivity analysis for the health economic model according assumptions agreed for pulmonary rehabilitation.
5. The GDG discussed the clinical and economic considerations when drafting recommendations for ventilation and lung transplantation.
6. The GDG revised previous recommendations developed so far taking into account suggestions by the NICE Editor.

The session on decision making for ventilation and optimal timing of referral for lung transplantation overran, so it was decided that the research recommendations and workplan would be discussed via email in between GDG meetings.

### **Any other business:**

NB reminded the GDG of key upcoming dates in the IPF guideline and ongoing work required from the GDG.

### **Date, time and venue of the next meeting:**

**GDG 11:** Friday 5<sup>th</sup> October, NCGC Boardroom, 180 Great Portland Street.