Notes from IPF Stakeholder workshop

16th December 2010

Bollin Room, NICE Manchester Offices

Chair: Nik Hirani

Scribes: Vanessa Delgado Nunes and Grammati Sarri

As there were a relatively small number of Stakeholders attending the meeting, it was decided not to break into small groups. The NICE Associate Director went through the individual sections of the IPF scope and invited stakeholder comments and discussion.

Title

Stakeholders concluded that the wording 'initial assessment' was to be dropped.

Stakeholders discussed whether suspected should be dropped as well, but the decision was to leave it in.

Current Practice section

Stakeholders agreed that the extra word “support” was to be removed.

Population: No changes made to this section

Setting:

Stakeholders argued that the section should read: Primary care and secondary care will be covered.

Diagnosis:

Stakeholders stated that sub-optimal exercise testing should be a bullet point on its own, and that sub-optimal needed to be changed to sub-maximal.

Stakeholders agreed that echocardiography should be listed separately under a new heading for prognosis and they discussed what is the echocardiography’s value on routine basis or selectively.

Finally, Stakeholders discussed quite extensively and agreed on the importance of looking at the multidisciplinary team in the diagnosis process (for example: the physician, pathologist or radiologist).

Management:

Pharmacological treatment

Stakeholders discussed:

- whether oxygen should be listed as a pharmacological option or under supportive care, and that this treatment constituted one of the most significant points of variation in practice in the England.

Stakeholders agreed that:

- Warfarin and Imatinib would be removed as pharmacological options because they are not commonly used and not a priority to review.

- Mycophenolate mofetil would be added to the list

Non-pharmacological treatment

- that lung transplantation would cover issues around timing and selection of patients for the procedure but not the effectiveness of transplantation. That what was included under Best Supportive Care are: opiates and oxygen for symptom relief and breathlessness management and also the use of benzodiazapines. It was also noted that there are guidelines on opiates in palliative care and these should be refered to.

- Pulmonary rehabilitation should include breathlessness management.

- Pharmacological and non-pharmacological treatments were not the most accurate terms for the sub headings. Stakeholders suggested disease modifying management and symptom relief management.

The NICE commissioning manager stated that there was currently a short guideline being developed for opioids in palliative care. Reviewing the literature on the use of opioids in palliative care in the guideline would need to be ascertained.

The NICE PPIP project manager suggested that information support for patients and carers should be included as a scope item. The NICE commissioning manager asked the patient representatives for further input whether there were specific issues regarding provision of information for IPF patients, which could then be brought up in the scope consultation.

Outcomes:

Stakeholders agreed that:

- Scoring of CT scans should not be listed as an outcome
- Acute Exacerbation of IPF could be removed
- Majority of studies in IPF would include some measure of lung capacity and/or gas transfer.
- Six minute walk test should be replaced with incremental walk test
- Breathless score should be included.

Stakeholders also discussed whether oxygen saturation should be included as an outcome, however it was decided that it should not be included.

Stakeholders asked and rated the outcomes according to their importance:

(most important) 1st: Measures of lung capacity (FVC or VC) and measures of gas transfer (TLCO) (➔ both measures reflect symptoms)

2nd: Mortality

3rd: Change in health related quality of life (still to agreed on the validated health related quality of life measures), breathless score, incremental walk test

4th: Hospitalizations for IPF related respiratory events (pneumonia, worst of symptoms)