

BMJ

Thorax Roundtable Meeting on
Idiopathic Pulmonary Fibrosis

June 2014

Summary

1. 60% of respondents work in a General respiratory unit, 11% in a Specialist ILD centre, 10% in a General medical unit.
2. 61% of respondents from Primary Care Practices had diagnosed IPF in their lifetime, the remaining primary care respondents were excluded from further questions.
3. 93% of respondents have direct access to HRCT Scanning and Reports in their hospital, 1% outside their hospital, and 2% have Direct GP access.
4. On diagnosing patients with IPF, 34% of respondents provide them with written information about their condition, 39% sometimes provide written information, and 27% do not provide written information.



Summary

5. 81% of respondents consider pulmonary rehabilitation to be beneficial for patients with IPF
6. Pulmonary rehabilitation was considered beneficial for patients with IPF: “At diagnosis” (42%); “When disability has already set in” (37%); and “After a trial of drug treatment” (6%)
7. 82% of respondents think oxygen should be used for “Improving exercise capacity”, 72% for “Long term oxygen therapy”, and 53% for “Palliation of symptoms only”.
8. 73% of respondents refer IPF patients to their regional centre for consideration for pirfenidone when appropriate, 15% never refer, and 12% always refer.

Summary

9. Respondents consider end of life discussions with IPF patients “When disability has already set in” (48%); “During management” (36%); “At diagnosis” (6%); or at “Other times” (9%).
10. 56% of respondents felt that specialised commissioning and the designation of specialised regional centres for ILD will improve care for IPF patients, 31% were unsure, and 14% did not think that these centres would improve care.
11. See free text comments for clarification of the answers above.
12. On average, 44% of respondents’ total (definite, probable or possible) IPF cases are discussed at a specialist ILD centre MDT for advice re diagnosis and management

Introduction

- 2013 marked an important year for patients with idiopathic pulmonary fibrosis in the UK. NICE published its guidance on diagnosis and management of this devastating and lethal interstitial lung disease and approved a first drug treatment for affected patients – pirfenidone. The British Lung foundation has selected IPF as one of its key strategic activities for 2014.
- To stimulate debate about the poor awareness, the NICE recommendations and next steps in improving outcomes for patients with IPF, Thorax will host a multi-disciplinary round-table discussion on 20 June. The meeting will address questions on best ways to implement recent evidence and recommendations to improve care of patients with idiopathic pulmonary fibrosis including increasing access to specialist centres.
- The event will be chaired by Professor Ann Millar, Consultant in Respiratory Medicine, North Bristol Trust. A summary of the discussion will be published in *Thorax* in October 2014.
- In anticipation of the event, *Thorax* has conducted a short online survey to gather the views of respiratory physicians and GPs on this subject.

Methodology

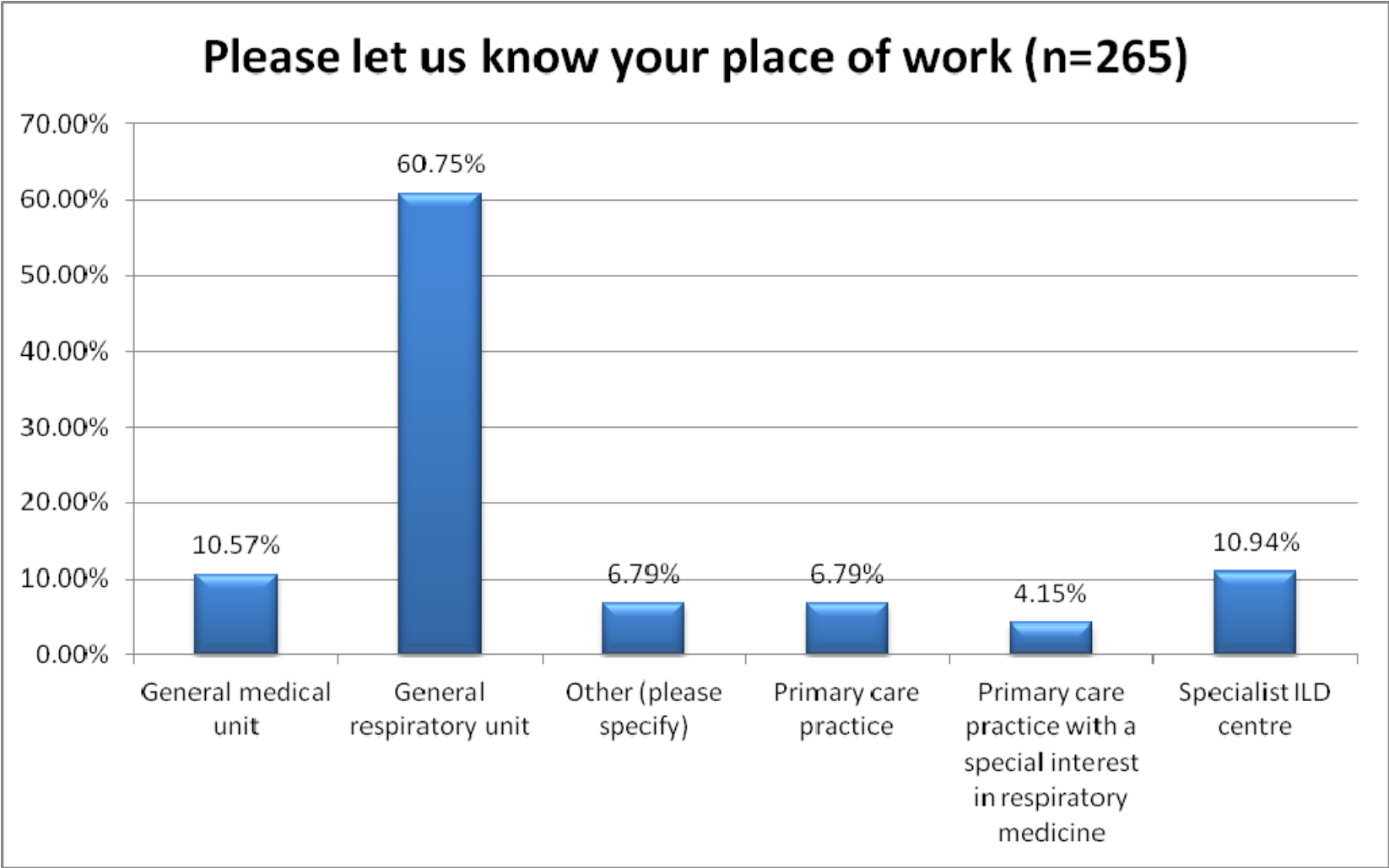


- Quantitative research
- Self-completion online survey
- Sample:
 - UK respiratory physicians
 - UK GPs with an interest in respiratory medicine
- Sample drawn from *BMJ Mastervision* database
- Participants sent a covering email explaining the purposes of the study and inviting them to click on a link to the questionnaire.
- To engage participants kept the questionnaire short and offered to share the results of the meeting with them.
- 5,638 invitations were sent, and 265 people completed the survey, a response rate of 4.7%.

Results

Results

1. Please let us know your place of work

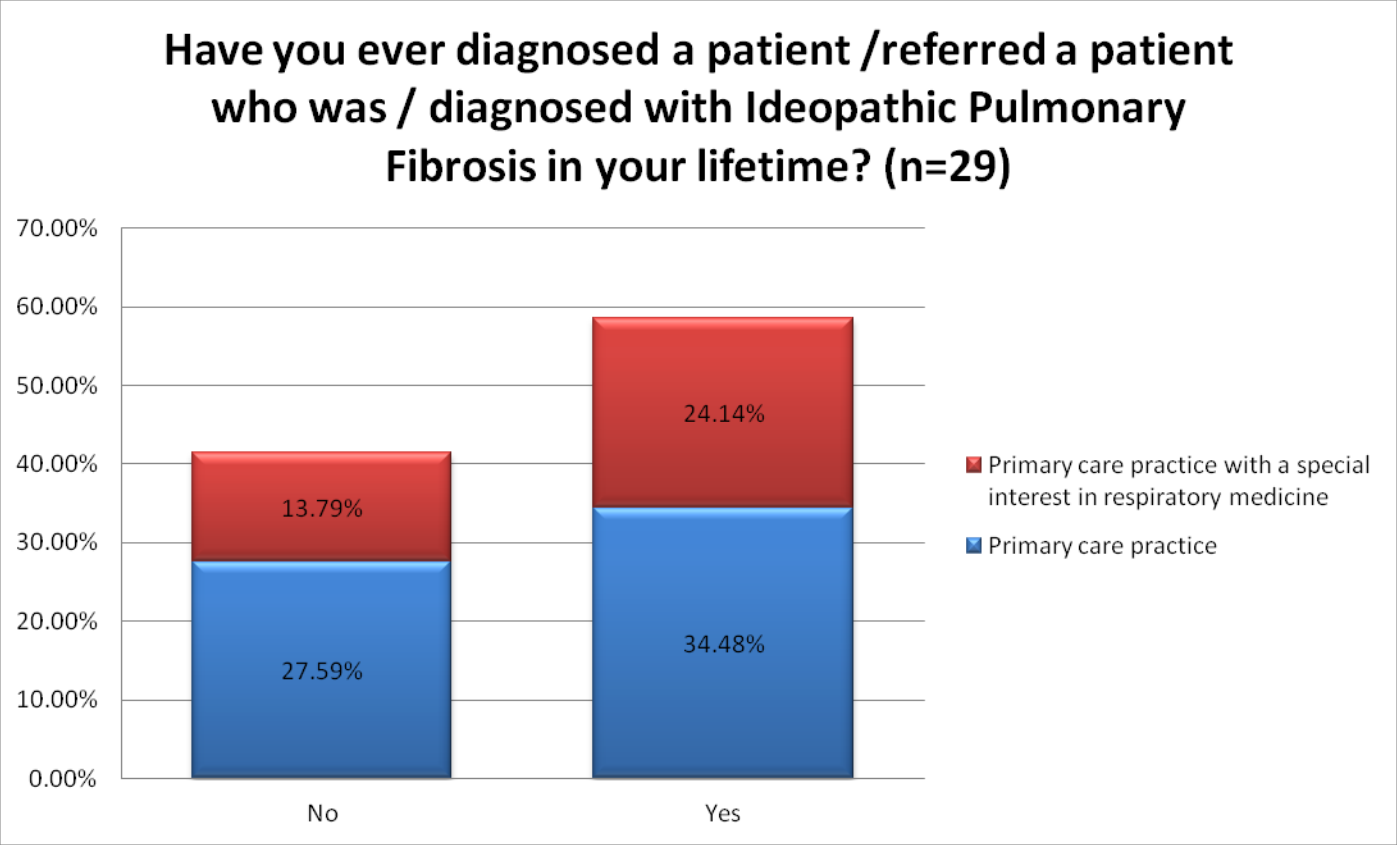


Diagnosis of Ideopathic Pulmonary Fibrosis (IPF)

Diagnosis

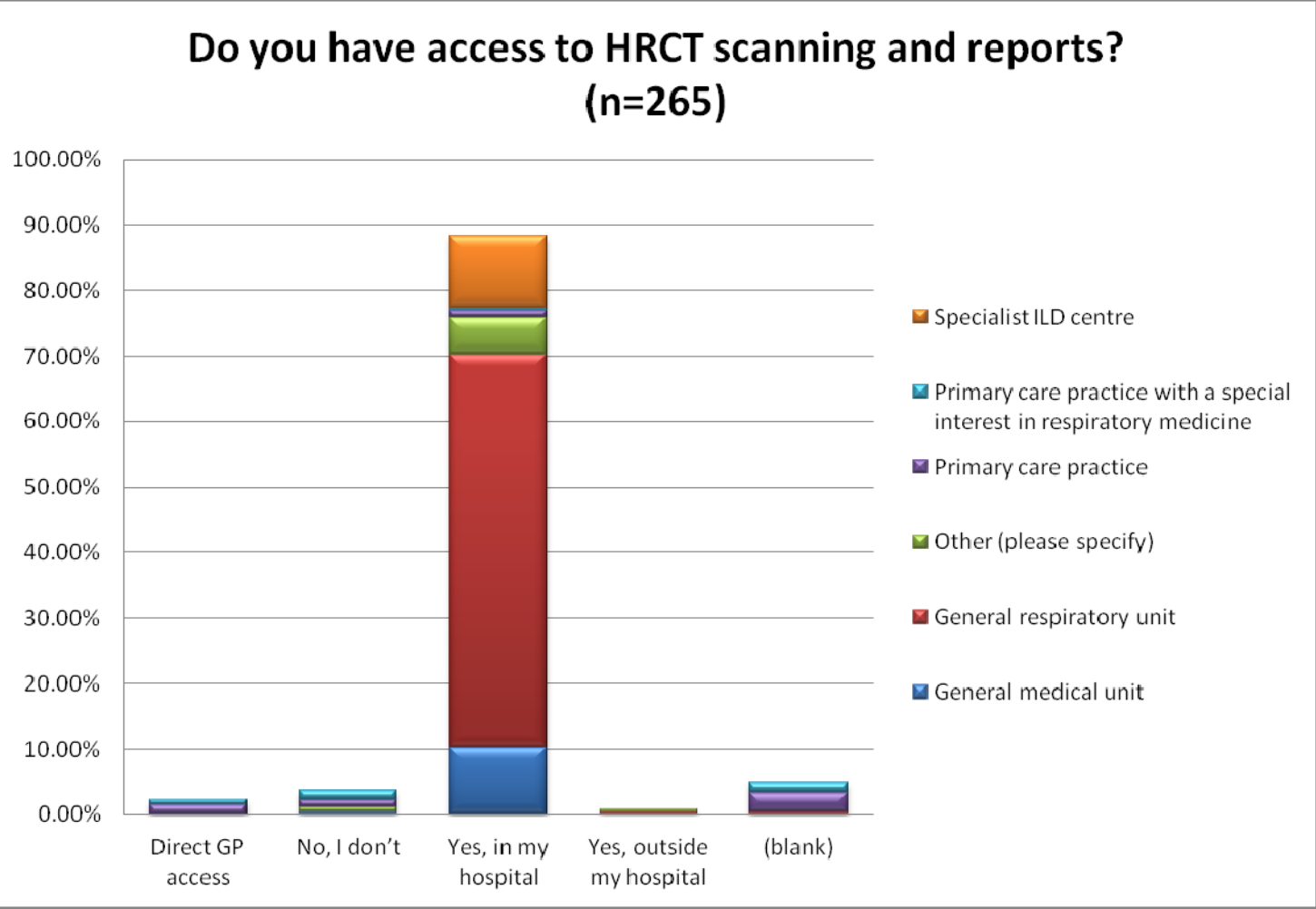
2. Have you ever diagnosed a patient /referred a patient who was diagnosed with Ideopathic Pulmonary Fibrosis in your lifetime?

Primary Care Practices only, those replying “No” excluded from further questions



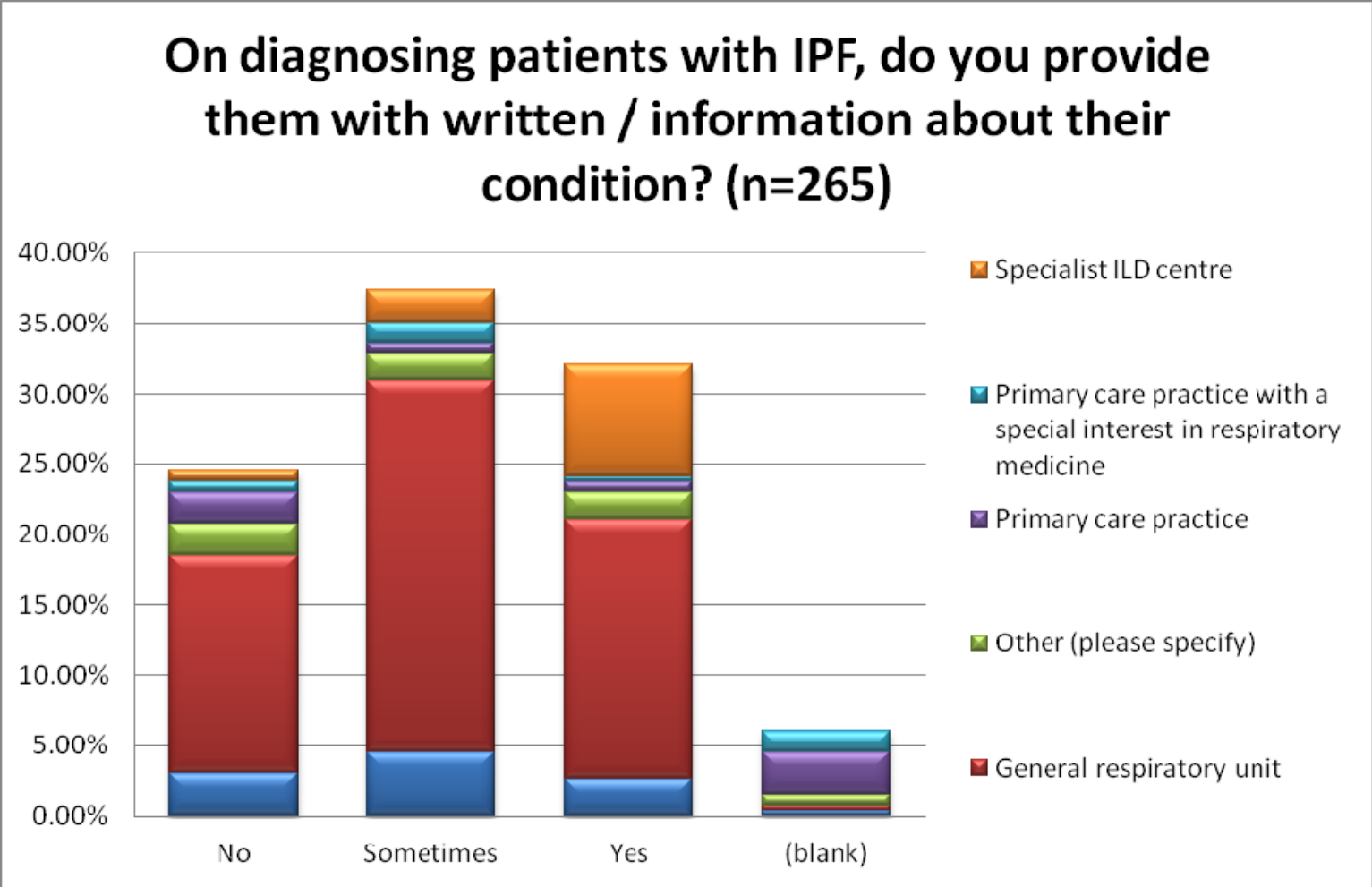
Diagnosis

3. Do you have access to HRCT scanning and reports?



Diagnosis

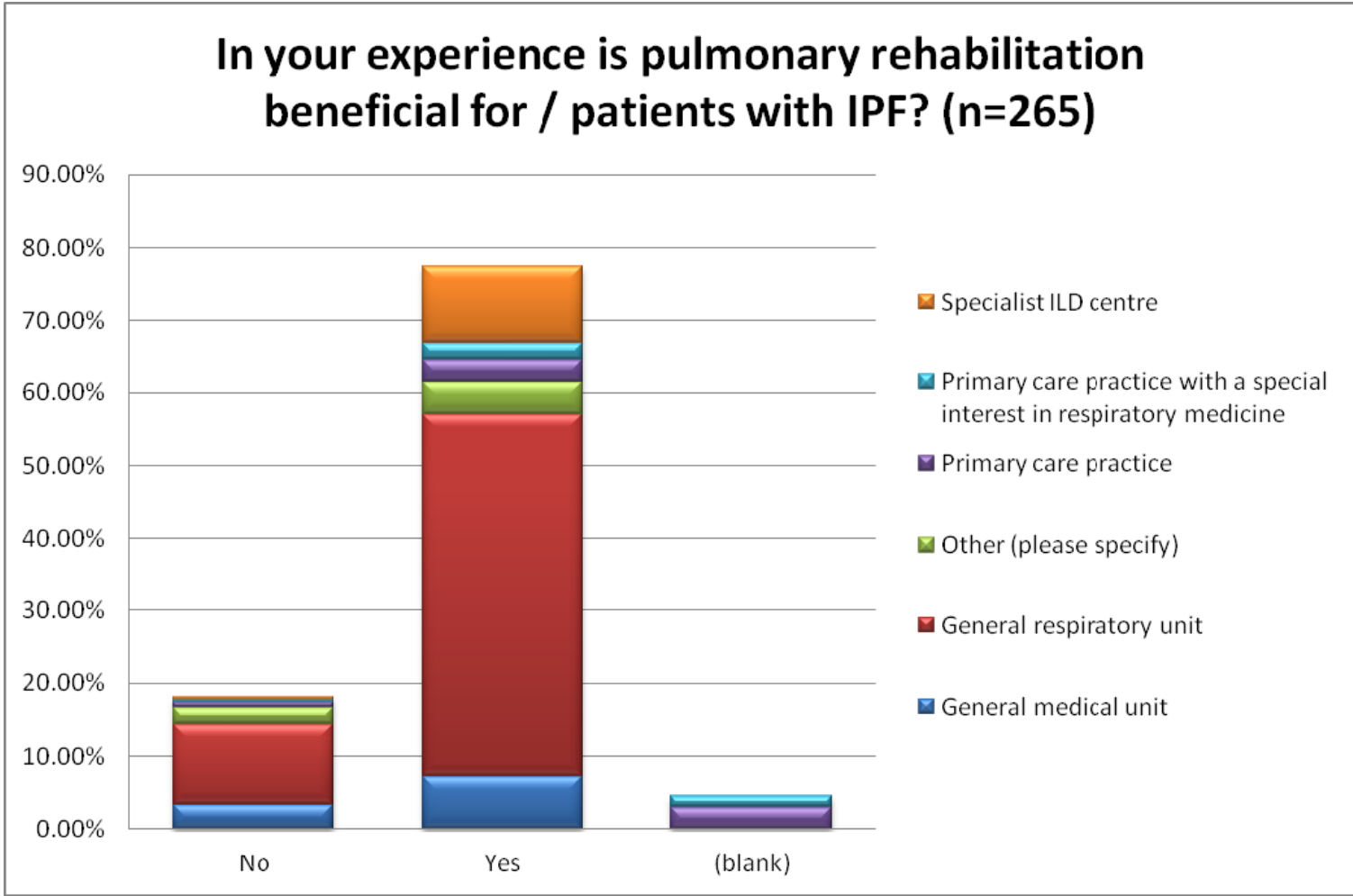
4. On diagnosing patients with IPF, do you provide them with written information about their condition?



Management of Ideopathic Pulmonary Fibrosis

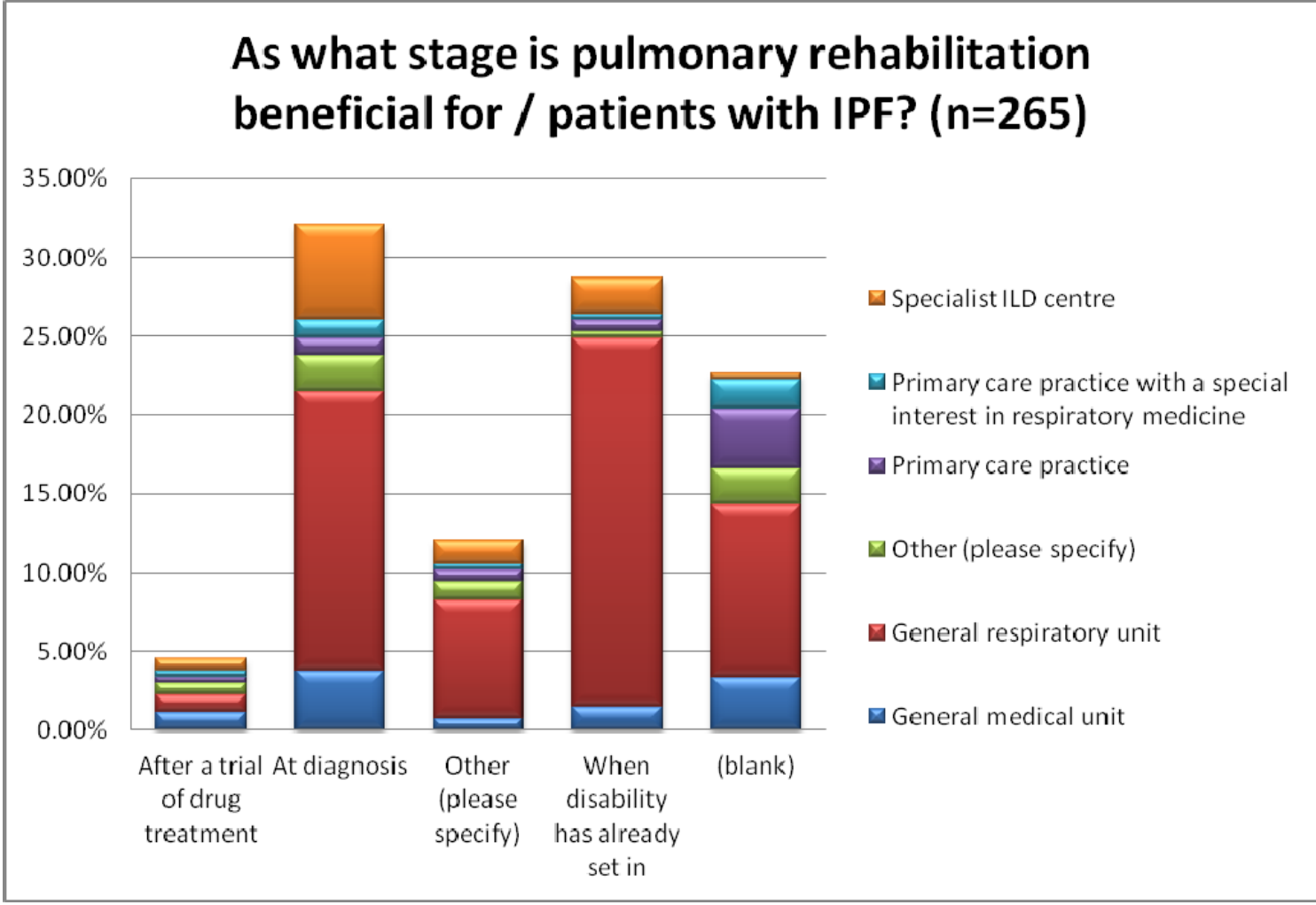
Management

5. In your experience is pulmonary rehabilitation beneficial for patients with IPF?



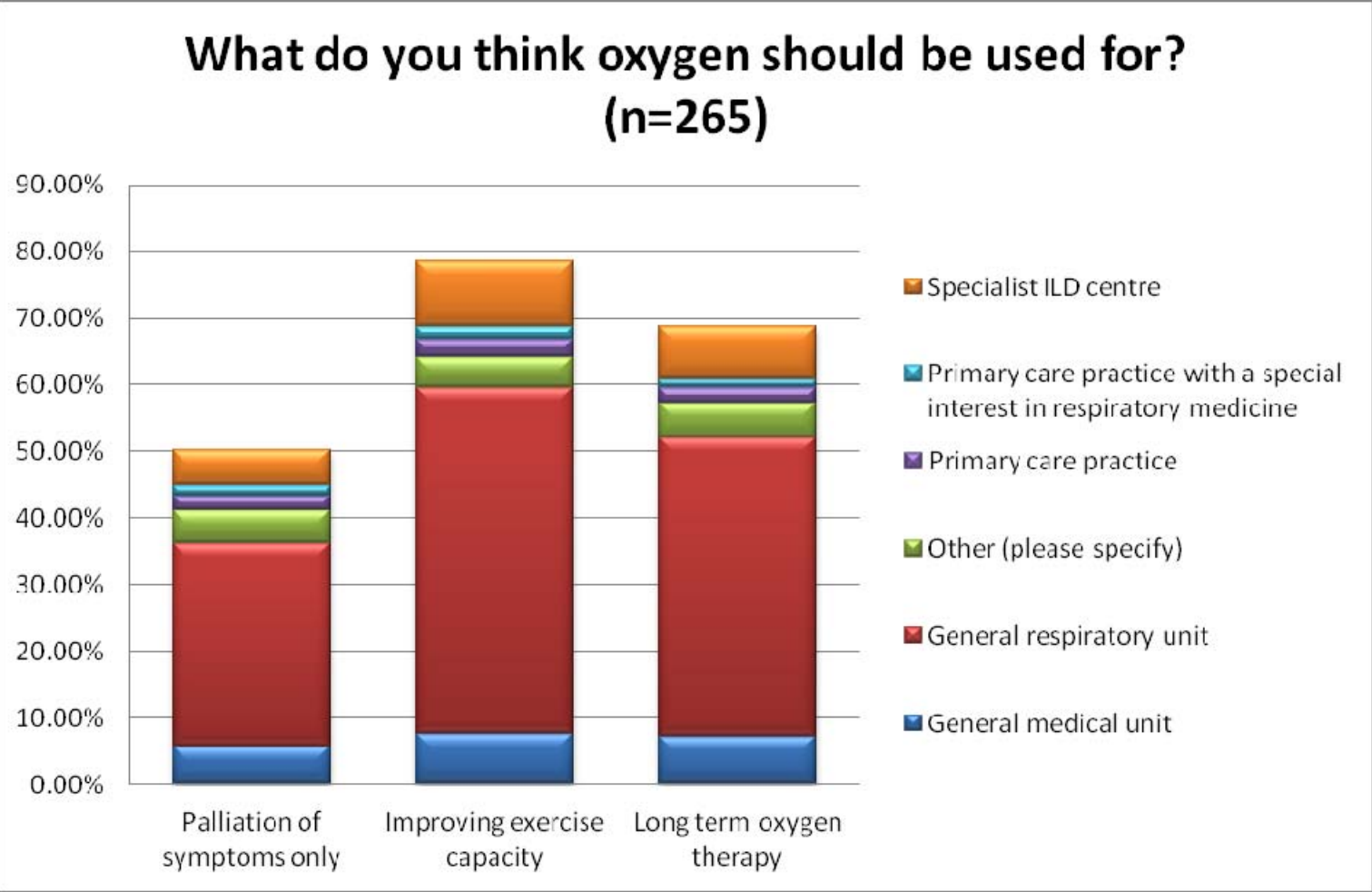
Management

6. As what stage is pulmonary rehabilitation beneficial for patients with IPF?



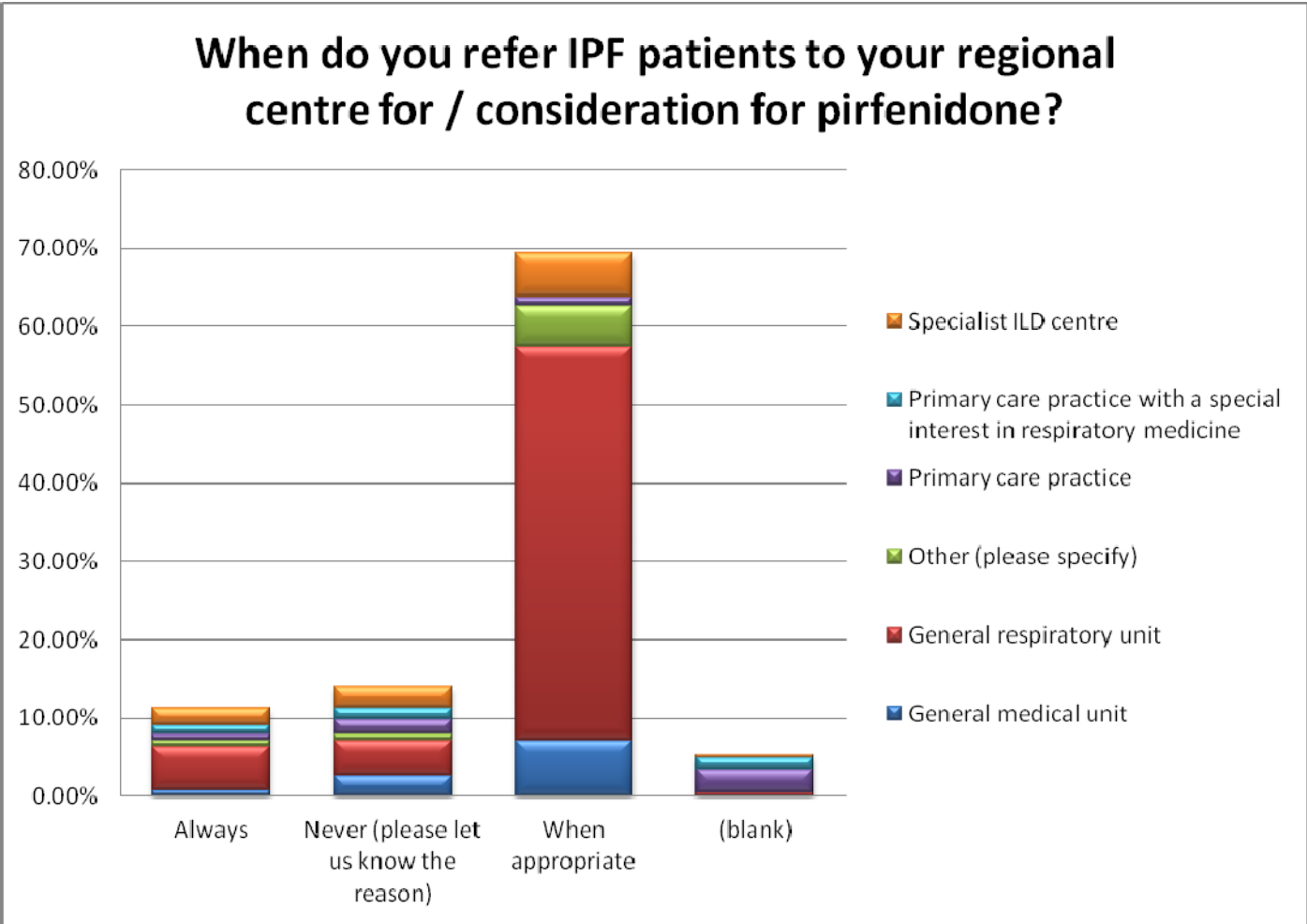
Management

7. What do you think oxygen should be used for? Please select all that apply



Management

8. When do you refer IPF patients to your regional centre for consideration for pirfenidone?

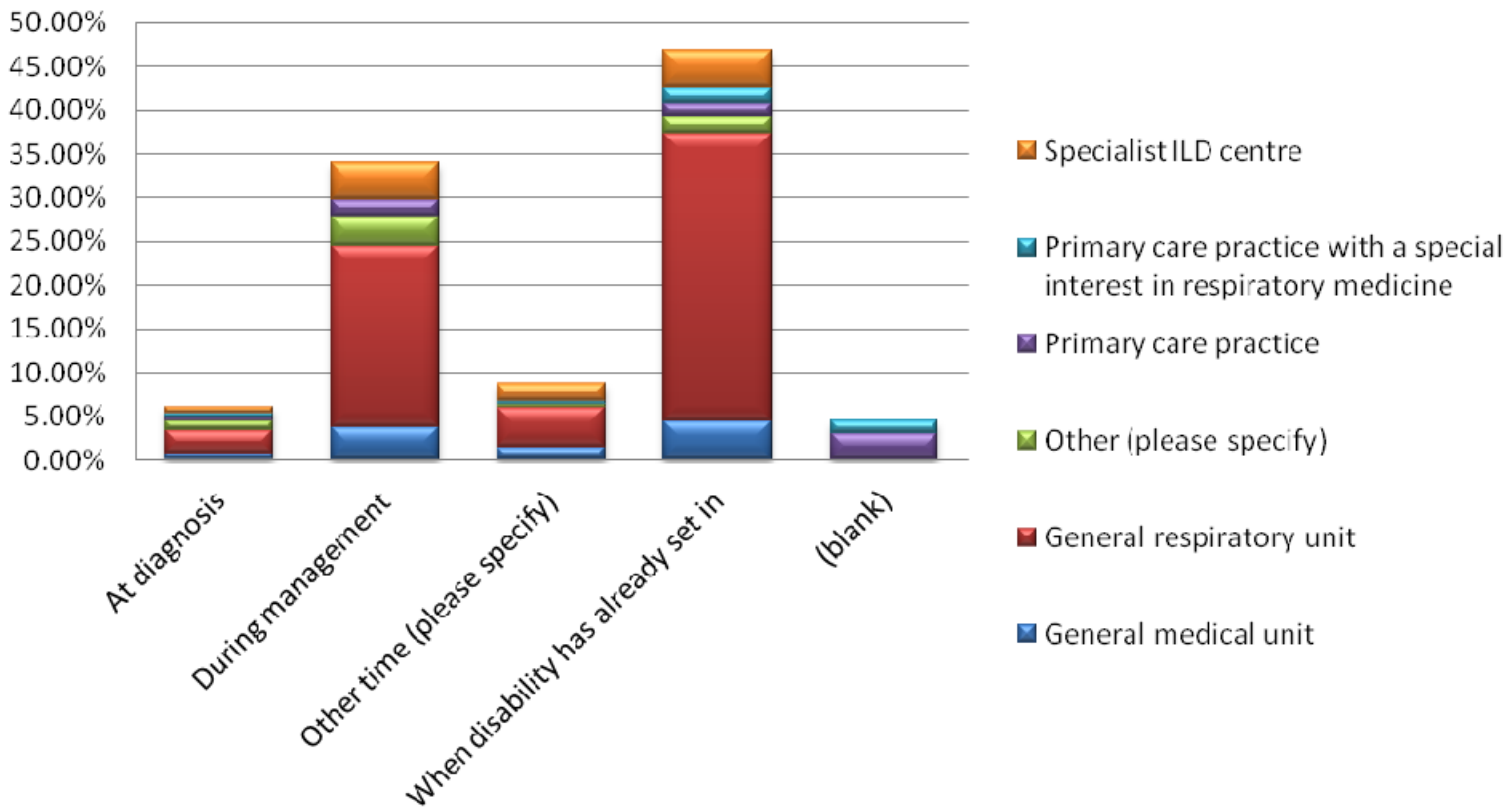


Other issues

Other issues

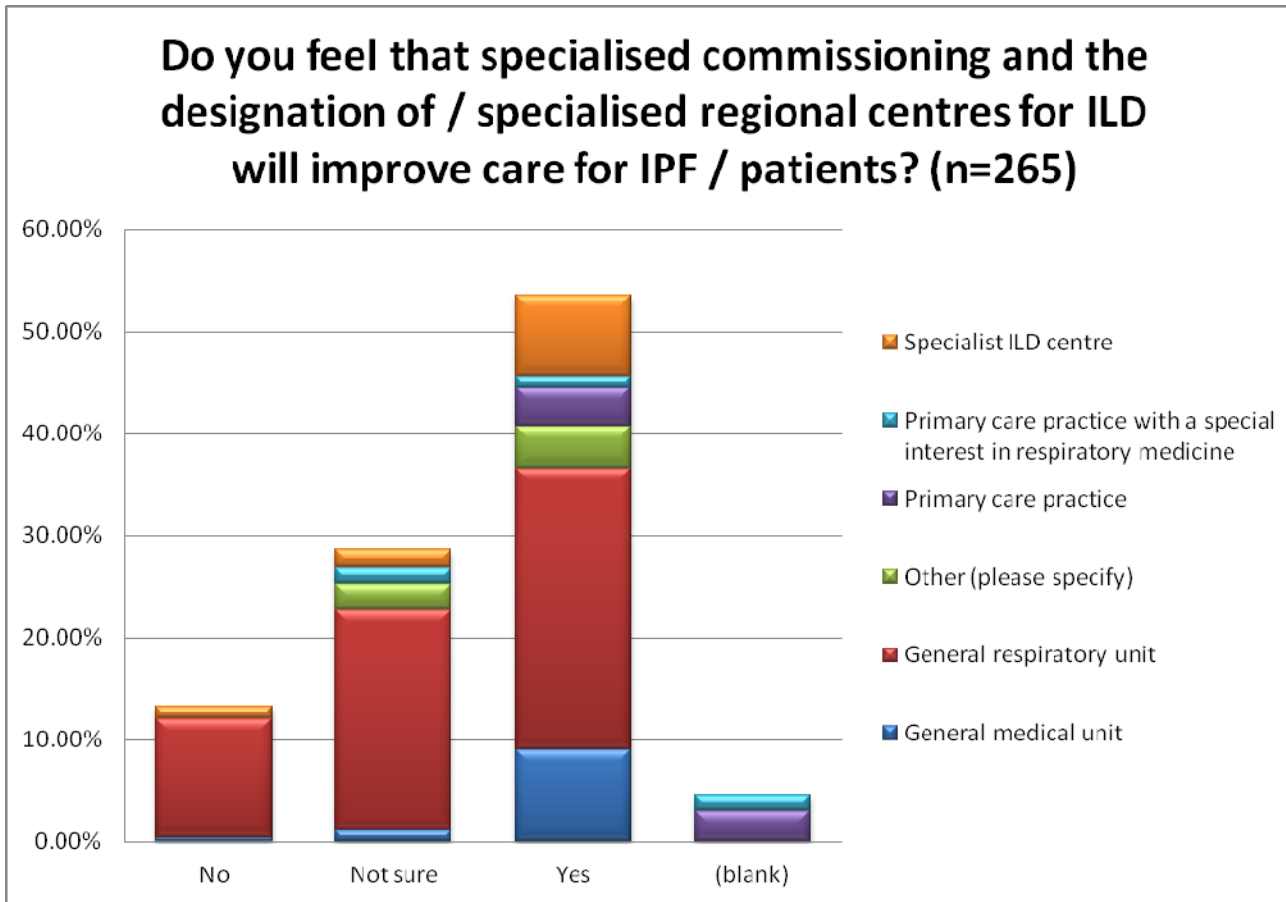
9. When would you consider end of life discussions with your IPF patients?

When would you consider end of life discussions with your IPF / patients? (n=265)



Other issues

10. Do you feel that specialised commissioning and the designation of specialised regional centres for ILD will improve care for IPF patients?



Other issues

11. Please add some comments to clarify your answer above (n=140)

See Word document for free text replies

I find it frustrating I have to refer patients for pirfenidone when there is clear guidance as to who should have it. Patients often have to wait some weeks or months before being seen and have to travel far and find that process frustrating

Fewer people seeing more patients gives greater depth of experience

Improved understanding of current management guidelines by Respiratory physicians will improve care. At the moment for example, it is still not clear what to use for treatment following the PANTHER study outcome in places without access to Pirfenidone

Other issues

12. What percentage of your total (definite, probable or possible) IPF cases are discussed at a specialist ILD centre MDT for advice re-diagnosis and management?

Percentage of IPF cases discussed at a specialist ILD	Percentage of respondents
0-25%	35.85%
26-50%	14.72%
51-75%	11.70%
76-100%	21.51%
Blank	16.23%
Total	100.00%

Other issues

13. Please explain the reasons for your answer above (n=162)

See Word document for free text replies

Aim to refer all patients. However, some patients do not want to have yet another hospital team involved especially if they are disabled or the benefits may be modest. The key should be for the initial referral to be to the most appropriate specialist

If patient remains stable and does not need prifenidone, they are not referred to specialist centre.

I work in a centre with a dedicated ILD specialist and so virtually all patients are discussed with her or more often in MDT

Other issues

14. Please let us know if there is anything else that you would like to add about the diagnosis and management of patients with IPF (n=80)

See Word document for free text replies

In my view, IPF is one of the most terrible ways to die. The breathlessness at the end stage is unlike anything we see in palliative care in any other illness. We must make sure that palliative care is an integral part of the care of these people and this must be available locally to the patient

I am still very pessimistic about this condition and do not feel comfortable consenting my patients for a drug that will slow the decline of their FVC/VC by a small margin. I still think more work needs to be done and I hope there will be a breakthrough in the near future from research.

Delighted to see that there is more focus on IPF. Would welcome a national database approach.