NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Patient/carer expert statement (STA)

Nintedanib for treating idiopathic pulmonary fibrosis [ID752]

Thank you for agreeing to give us your views on this treatment that is being appraised by NICE and how it could be used in the NHS. Patients, carers and patient organisations can provide a unique perspective on conditions and their treatment that is not typically available from other sources. We are interested in hearing about:

- the experience of having the condition or caring for someone with the condition
- the experience of receiving NHS care for the condition
- the experience of having specific treatments for the condition
- the outcomes of treatment that are important to patients or carers (which might differ from those measured in clinical studies, including health-related quality of life)
- preferences for different treatments and how they are given
- expectations about the risks and benefits of the treatment.

We have already asked your nominating organisation to provide an organisation's view. We are asking you to give your views as an individual whether you are:

- a patient
- a carer (who may be voicing views for a patient who is unable to) or
- somebody who works or volunteers for a patient organisation.

To help you give your views, we have provided a questionnaire. You do not have to answer every question — the questions are there as prompts to guide you. The response area will expand as you type. The length of your response should not normally exceed 10 pages.

1. About you

Your name: [redacted]
Name of your nominating organisation: ACTION FOR PULMONARY FIBROSIS
Do you know if your nominating organisation has submitted a statement?

APF have not submitted a statement

Do you wish to agree with your nominating organisation's statement?

Not Applicable.

(We would encourage you to complete this form even if you agree with your nominating organisation's statement.)

Are you:

- a patient with the condition?

X Yes ☐ No

- a carer of a patient with the condition?

☐ Yes X No

- a patient organisation employee or volunteer?
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☐ Yes X No

Do you have experience of the treatment being appraised?

X Yes ☐ No

If you wrote the organisation submission and do not have anything to add, tick here ☐ (If you tick this box, the rest of this form will be deleted after submission.)

2. Living with the condition

What is your experience of living with the condition as a patient or carer?

I was diagnosed with IPF in April 2013 when I was an active sportsman and regular marathon runner. I had experienced a marked deterioration in my ability to run and can now no longer engage actively in sport. This has changed my life enormously both from having to find other outlets for my energies and having to create an entirely new social life. I no longer meet many of the people that I engaged with previously when I travelled nationwide weekly to compete in events. Also, most of my local friends are either members of my running club or active sports people and it can be frustrating having to listen to conversation relating to their current exploits knowing that I can no longer participate. This is all the more frustrating as many of these friends are much older than myself. Thankfully, my routine has not been curtailed significantly in any other way. I am still able to walk quite long distances, which enables me to join in some of my club's activity. I am, however, conscious that I have to restrain my competitive streak and not try to overtake slow runners at the back of the field! I constantly appraise myself on distances covered and time taken. I also measure my oxygen saturation levels, blood pressure and pulse for signs of whether my condition is worsening. But none of these has given any indication of the actual deterioration in lung function. On a day to day basis, in the absence of definitive test results, how I feel after climbing a flight of stairs is the most effective gauge of my state. I still feel well in spite of a quite significant loss of lung function (over 30% in the 18 months since I became a patient at Papworth Hospital). I am quite apprehensive about having to go onto oxygen. I sometimes feel my mental state is more debilitating than my physical condition.

Current practice in treating the condition

Which treatment outcomes are important to you? (That is, what would you like treatment to achieve?) Which of these are most important? If possible, please explain why.

I have IPF, an incurable and progressive lung condition. I am anxious to ensure that I have access to any medicine that is able to halt or slow the progress of fibrosis in my lungs. Medicines so far prescribed for me, based on lung function test results, appear not to have had that effect. I was initially prescribed Prednisolone (steroid) and, for 9 months up to March 2015, I was taking Pirfenidone. I started taking Nintedanib in April 2015. Since then, I have had only one lung function test - 6 weeks after starting to take Nintedanib. The result of that, in June 2015, showed there had been no further loss of lung capacity since my previous test in February 2015. While it is too soon to

say whether my condition has stabilised this initial finding is encouraging and gives me great hope.

What is your experience of currently available NHS care and of specific treatments? How acceptable are these treatments – which did you prefer and why?

I believe I have had the best of treatment from Papworth Hospital – with help and advice always on hand - and it is a great comfort to know that I am in a place that gives me access to new medicinal treatments for IPF. I was emotionally buoyed up when I was prescribed Pirfenidone, that has been so successful in slowing the fibrotic process in so many IPF patients. My deflation was no less significant when it was decided I should be taken off Pirfenidone as it appeared not to be working in my particular case. Nintedanib restores my hope and enthusiasm that there might be a medicine that works for me. While it was a small inconvenience, I did find the inability to go out in the sun a very limiting feature of Pirfenidone. In that respect,Nintedanib does not interfere with my ability to go out in the country on a warm day; one of the delights of my life.

3. What do you consider to be the advantages of the treatment being appraised?

Benefits of a treatment might include its effect on:

- the course and/or outcome of the condition
- physical symptoms
- pain
- level of disability
- mental health
- quality of life (such as lifestyle and work)
- other people (for example, family, friends and employers)
- ease of use (for example, tablets rather than injection)
- where the treatment has to be used (for example, at home rather than in hospital)
- any other issues not listed above

Please list the benefits that you expect to gain from using the treatment being appraised.

Effective slowing of the fibrotic degeneration in my lungs.

Enables me to maintain a high level of mobility. I feel less breathless going upstairs since I started taking Nintedanib.

My mental state definitely improves when I can feel that medication is having a positive effect.

Please explain any advantages that you think this treatment has over other NHS treatments in England.

In my particular case all other currently available medications have failed to slow the deterioration in my lung function. Nintedanib gives me hope that there is still a solution available.

If you know of any differences in opinion between you and other patients or carers about the benefits of the treatment being appraised, please tell us about them.

I know of none.

4. What do you consider to be the disadvantages of the treatment being appraised?

Disadvantages of a treatment might include:

- aspects of the condition that the treatment cannot help with or might make worse
- difficulties in taking or using the treatment (for example, injection rather than tablets)
- side effects (for example, type or number of problems, how often, for how long, how severe. Please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate)
- where the treatment has to be used (for example, in hospital rather than at home)
- impact on others (for example, family, friends and employers)
- financial impact on the patient and/or their family (for example, the cost of travel to hospital or paying a carer)

- any other issues not listed above

Please list any concerns you have about current NHS treatments in England.

Pirfenidone has been of benefit to a great number of IPF patients but is either not tolerated by some or, as in my case, has not proved successful. Nintedanib gives hope to those patients for whom Pirfenidone has for one reason or another, not worked.

Please list any concerns you have about the treatment being appraised.

None. Although I was warned of a long list of side effects that might result from being prescribed Nintedanib, none of these has materialised.

If you know of any differences in opinion between you and other patients or carers about the disadvantages of the treatment being appraised, please tell us about them.

I know of none.

5. Patient population

Do you think some patients might benefit more from the treatment than others? If so, please describe them and explain why.

I do not know the differences between Pirfenidone and Nintedanib – although I understand they work in different ways - but based on my own experience so far, it may be that patients react more positively to one medicine rather than the other.

Do you think some patients might benefit less from the treatment than others? If so, please describe them and explain why.

Please see my answer above.

6. Research evidence on patient or carer views of the treatment

Are you familiar with the published research literature for the treatment?

☐ Yes X No

If you answered 'no', please skip the rest of section 7 and move on to section 8.

Please comment on whether your experience of using the treatment as part of routine NHS care reflects the experience of patients in the clinical trials.

Do you think the clinical trials have captured outcomes that are important to patients? Are you aware of any limitations in how the treatment has been assessed in clinical trials?

If the treatment being appraised is already available in the NHS, are there any side effects that were not apparent in the clinical trials but have emerged during routine NHS care?

Are you aware of any relevant research on patient or carer views of the condition or existing treatments?

☐ Yes ☐ No

If yes, please provide references to the relevant studies.

7. Equality

NICE is committed to promoting equality of opportunity and eliminating discrimination. Please let us know if you think that recommendations from this appraisal could have an adverse impact on any particular groups of people, who they are and why.

I cannot think of any.

8. Other issues

Do you consider the treatment to be innovative?

☐ Yes ☐ No See below.

If yes, please explain what makes it significantly different from other treatments for the condition.

I do not know. It is the only medicine that has seemed to stabilise my lung function and capacity.

Is there anything else that you would like the Appraisal Committee to

consider?

No

9. Key messages

In no more than 5 bullet points, please summarise the key messages of your submission.

- Nintedanib gives me hope that my condition is treatable.
- Nintedanib increases the range of options for treating IPF.
- Nintedanib appears effective and its potential side effects are overstated.
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