NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Patient/carer expert statement (STA)

Everolimus for preventing organ rejection in liver transplantation [ID559]

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: Liver4Life
Do you know if your nominating organisation has submitted a statement?

No

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

No

(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?

No

- a carer of a patient with the condition?

No

- a patient organisation employee or volunteer?
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Yes

Do you have experience of the treatment being appraised?

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 am neither a patient nor carer, however I support a large number of patient groups who help people who are either waiting for a transplant, or have had one or more liver transplants.

The 'condition' will vary between transplant recipients, as the reason for transplant can vary according to disease type, including cancer, alcohol, viral hepatitis, fatty liver (obesity), auto-immune diseases and acute liver failure.

However, for all people that receive a liver transplant they have a lifelong commitment to taking a daily regimen of pills, while dealing with the fact that they are grateful to be alive, and have received a liver transplant.

3. 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.

Treatment outcomes that are most important to people who have had a transplant are that they can regain the standard of living they had before their liver transplant, and the chance of organ rejection is minimised as far as possible.

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

Transplantees tend not to have a preference regarding the immune-suppressants they take, and rely on clinicians to decide the most appropriate medicine for them.

4. 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.

For certain groups of transplant recipients (people with Hepatitis C and cancer), Everolimus will be beneficial. It is also important that clinicians have a wide range of options when deciding which is the most appropriate treatment to start a transplant recipient on after the procedure.

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

See above

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.

None

5. 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.

None

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

None

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.

No

6. Patient population

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

For certain groups of transplant recipients (people with Hepatitis C and cancer), Everolimus will be beneficial. It may also reduce renal impairment, and slow the onset of cancer

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

No

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

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

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.

8. 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.

None

9. Other issues

Do you consider the treatment to be innovative?

Yes

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

For certain populations (HCV and HCC) this treatment appears to benefit transplant recipients more than other current treatments.

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

10. Key messages

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

- More options for people with HCV and HCC who have ben transplanted
- Reduction in renal impairment
- More options for clinicians when deciding on most appropriate care package
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