NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single technology appraisal (STA)

Rifaximin for maintaining remission from episodes of hepatic encephalopathy

Thank you for agreeing to give us your views on the technology and the way it should be used in the NHS.

Patients and patient advocates can provide a unique perspective on the technology, which is not typically available from the published literature.

To help you give your views, we have provided a template. The questions are there as prompts to guide you. You do not have to answer every question. Please do not exceed the 8-page limit.

About you

Your name: ANDREW LANGFORD

Name of your organisation: BRITISH LIVER TRUST

Are you (tick all that apply):

- a patient with the condition for which NICE is considering this technology?
- a carer of a patient with the condition for which NICE is considering this technology?

√ an employee of a patient organisation that represents patients with the condition for which NICE is considering the technology? If so, give your position in the organisation where appropriate (e.g. policy officer, trustee, member, etc)

- other? (please specify)

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What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition?

1. **Advantages**
(a) Please list the specific aspect(s) of the condition that you expect the technology to help with. For each aspect you list please describe, if possible, what difference you expect the technology to make.

● this would potentially improve the quality of live for both patient and carers significantly

● the treatment would offer more dignified and less traumatic treatment than what is currently available

(b) Please list any short-term and/or long-term benefits that patients expect to gain from using the technology. These might include the effect of the technology on:

- the course and/or outcome of the condition
- physical symptoms
- pain
- level of disability
- mental health
- quality of life (lifestyle, work, social functioning etc.)
- other quality of life issues not listed above
- other people (for example family, friends, employers)
- other issues not listed above.

● an alleviation of the affects of encephalopathy

● an increased sense of well-being

● less traumatic for those affected

What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition? (continued)

2. **Disadvantages**
Please list any problems with or concerns you have about the technology. Disadvantages might include:

- aspects of the condition that the technology cannot help with or might make worse.
- difficulties in taking or using the technology
- side effects (please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate)
- impact on others (for example family, friends, employers)
- financial impact on the patient and/or their family (for example cost of travel

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needed to access the technology, or the cost of paying a carer).

● whilst there is an awareness of the risk of health related side effects – the benefits out-weigh these

● with good symptom control any side effects could soon be alleviated

● the side effects of current treatment, especially diarrhoea, are considered far worse for most patients and carers

3. Are there differences in opinion between patients about the usefulness or otherwise of this technology? If so, please describe them.

Not that we are aware of – more importantly there is an enthusiasm to have this as part of ant treatment plan asap

4. Are there any groups of patients who might benefit **more** from the technology than others? Are there any groups of patients who might benefit **less** from the technology than others?

No

Comparing the technology with alternative available treatments or technologies

NICE is interested in your views on how the technology compares with with existing treatments for this condition in the UK.

(i) Please list any current standard practice (alternatives if any) used in the UK.

Current treatment is extremely high doses of laxatives, especially lactulose

(ii) If you think that the new technology has any **advantages** for patients over other current standard practice, please describe them. Advantages might include:

- improvement in the condition overall
- improvement in certain aspects of the condition
- ease of use (for example tablets rather than injection)
- where the technology has to be used (for example at home rather than in hospital)
- side effects (please describe nature and number of problems, frequency,

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duration, severity etc.)

as described above – the physical and psychological side effects of current treatment have a devastating effect on quality of life for both patient and carer

(iii) If you think that the new technology has any **disadvantages** for patients compared with current standard practice, please describe them. Disadvantages might include:

- worsening of the condition overall
- worsening of specific aspects of the condition
- difficulty in use (for example injection rather than tablets)
- where the technology has to be used (for example in hospital rather than at home)
- side effects (for example nature or number of problems, how often, for how long, how severe).

we don't

Research evidence on patient or carer views of the technology

If you are familiar with the evidence base for the technology, please comment on whether patients' experience of using the technology as part of their routine NHS care reflects that observed under clinical trial conditions.

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Are there any adverse effects that were not apparent in the clinical trials but have come to light since, during routine NHS care?

no

Are you aware of any research carried out on patient or carer views of the condition or existing treatments that is relevant to an appraisal of this technology? If yes, please provide references to the relevant studies.

Only the trails that will have been submitted by Norgine

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Availability of this technology to patients in the NHS

What key differences, if any, would it make to patients and/or carers if this technology was made available on the NHS?

Improved quality of life for the patient

Improved quality of life for carers / families etc

Reduced overall costs

What implications would it have for patients and/or carers if the technology was **not** made available to patients on the NHS?

The continuation of only one mode of treatment that has a huge negative effect on quality of life

Are there groups of patients that have difficulties using the technology?

No

Other Issues

Please include here any other issues you would like the Appraisal Committee to consider when appraising this technology.

The trauma of someone with encephalopathy – especially the confusion - with the effect of current treatment of purulent diarrhoea is a devastating state for all involved. Use of this less undignified treatment must be considered.