Appendix D – Patient/carer expert statement template

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single technology appraisal (STA)

Ivabradine for the treatment of chronic heart failure

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: Elizabeth Clark

Name of your organisation: Peninsula Heart & Stroke Network Representing the NHS Devon

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) Patient Representative
- other? (please specify)
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.

   My understanding is that it would be particularly appropriate for patients who cannot tolerate Beta Blockers

   (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.

   The benefit would be that the patient could be medicated with a drug they could tolerate.
### 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 needed to access the technology, or the cost of paying a carer).

I understand that some patients suffer from visual side effects. In discussion with two Cardiologists, who prescribe Ivaradine for a small number of patents suffering from angina who cannot tolerate Beta Blockers, I was assured that none of their patients had stopped taking the drug for this reason.

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

I am not aware of any
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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?

I only know about those I can read about on the Boots website

Comparing the technology with alternative available treatments or technologies

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

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

Beta Blockers are one of the drugs used

(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, duration, severity etc.)

It has advantages for those unable to tolerate Beta Blockers

(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).

Not aware of any
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<table>
<thead>
<tr>
<th>Research evidence on patient or carer views of the technology</th>
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<tbody>
<tr>
<td>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.</td>
</tr>
<tr>
<td>Not aware of any</td>
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<tr>
<th>Are there any adverse effects that were not apparent in the clinical trials but have come to light since, during routine NHS care?</th>
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<tbody>
<tr>
<td>Not aware of any</td>
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<tr>
<th>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.</th>
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<tr>
<td>No</td>
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National Institute for Health and Clinical Excellence
Patient/carer organisation statement template
Single Technology Appraisal of Ivabradine for the treatment of chronic heart failure
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Single Technology Appraisal of Ivabradine for the treatment of chronic heart failure
### 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?

It would be the small group of patients who cannot tolerate Beta Blockers but I am not aware of other benefits

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

Those intolerant of Beta Blockers not benefiting from the most appropriate treatment

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

Not aware of any
Other Issues

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

I feel that I have very little knowledge of the drug because it appears that it is only used for a small number of patients suffering from Angina. I have asked the patients in the Peninsula Heart & Stroke Network Patient group and members of the Heart Care Partnership and I cannot find one person who has been prescribed this drug. I have spoken to two Clinical Cardiologists who have prescribed Ivabradine to a limited number of patients and they have all coped well with only minor visual side effects. I would be happy to discuss my views with the Lay Patient on this group if you think it would be more cost effective than attending the meeting.

Liz Clark
Patient Representative
Peninsula Heart & Stroke Network
Tel: 01392 873912