Appendix D – Patient/carer expert statement template

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single technology appraisal (STA)

Ticagrelor for the treatment of acute coronary syndromes

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: JOHN MILLER

Name of your organisation:
Patient representative & patient support visitor
Member of The Ticker Club, UHSM

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)

Quadruple bypass operation Nov 97
Member UHSM cardiac patient support charity The Ticker Club, patient support visitor, formerly officer/committee member over 10 years.
Patient representative at numerous conferences & seminars both within UHSM and organised by bodies such as GM&C Cardiac & Stroke Network.
As former BBC TV factual programmes producer as well as patient have produced a number of patient information films for NHS (2002-2010).
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.

Thus far my knowledge of this drug is limited to information gleaned from:
1. GMMMG New Therapies draft recommendation Jan 11
2. Presentation on Ticagrelor at ‘Cardiology 2011 & Beyond’ 18 Mar 11
   review of guidelines event organised by GM&C Cardiac & Stroke Network

From these I conclude that:
1. I would in general concur with this recommendation
2. There are considerations for and against as touched on below

(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.

Patients can expect to be cured / stabilised, ie given reduced risk of MI
Most patients can expect Ticagrelor to be more effective than clopidogrel
Mortality rates do not differ significantly from eg clopidogrel
For the moment with treatments recommended for max 12 months duration
patients may perceive the benefits as likely to be limited to the short-term rather than long-term
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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).

It would be a serious concern for some patients that side effects are known to be significant
At 19 times the cost of clopidogrel patients will have concerns about PCTs willingness to fund and GPs willingness to prescribe Ticagrelor
Patients will need reassurances about any fears of a high risk of major bleeding they may have in relation to the use of this drug

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

Not to my knowledge. I believe my views expressed here reflect a consensus from (admittedly) limited discussion of these issues with other patient representatives

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 detailed knowledge here
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.

**Clopidogrel (+ aspirin)**

(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.)

Said to be significantly more effective than clopidogrel + aspirin

(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).

Significantly more side effects
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.

**No information**

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

**No information**

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.

**No information**
National Institute for Health and Clinical Excellence
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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?

**An apparently effective treatment for a given group of patients though at a significantly higher cost**

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

**The cost might prove prohibitive to lower income patients thus reducing the options available to cardiologists in treating this group of patients**

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

**No information**

**Other Issues**

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

**Cost effectiveness** of this treatment is a major issue where funding pressures on the NHS make choices inevitable. This treatment can be seen as very expensive for limited results on a limited group of patients. Where cardiologists are constrained to take heed of resources, some may conclude that these are better spent on a wider range of procedures and staff. I believe it is far from clear who takes the real responsibility for cost in such cases where there are allegations of serious wastage elsewhere in the NHS.