Appendix G – patient/carer organisation statement template

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Nalmefene for reducing alcohol consumption in people with alcohol dependence

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: [redacted]

Name of your organisation: Adfam

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)

[redacted]

-
- 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.

Enabling the person with the alcohol problem to become abstinent and thus, potentially cease to cause problems in the family

Enabling a period of respite for the families and the stresses often caused by living with someone with an alcohol problem

(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

Improved mental health and quality of life for the family members living with someone with a dependant drink problem

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 thier family (for example cost of travel needed to access the technology, or the cost of paying a carer

Is this a medication which can be administered at home? If so, then the disadvantage to the carer would be confined to the cost, if not available on NHS
If supervised consumption is necessary, the carer may have additional responsibilities; for example, ensuring the user received the medication and taking him/her to the pharmacy – thus incurring costs

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

We currently are not aware of any documented views of carers of this technology. However, carers living with a heroin user who is prescribed methadone on a long term basis, often describe this as being 'parked' on methadone, thus restricting – in their view- the potential for recovery which – again in their view – they interpret as abstinence.

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?

Patients living in stable accommodation with a caring family and friends are likely to benefit from this technology more than those living chaotic lives.

There may also be improved outcomes for children living with a problem drinker if this technology is used, although this will be difficult to measure. There may also be a reduction in domestic violence.

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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.

Opiate substitution treatment – e.g. methadone and buprenorphine

Please see comment above

(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 of 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)

(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).

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.

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

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.

I am not aware of any, but Adfam could conduct a brief survey to identify views of family members/carers

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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?

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

Cost – and many carers may not be able to afford a treatment which they may well regard as a 'magic bullet' to sort out their loved ones' – and their attendant – problems

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

Equality

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NICE is committed to promoting equality of opportunity, eliminating unlawful discrimination and fostering good relations between people with particular protected characteristics and others. Please let us know if you think that this appraisal:

- could exclude from full consideration any people protected by the equality legislation who fall within the patient population for which [the treatment(s)] is/are/will be licensed;
- could lead to recommendations that have a different impact on people protected by the equality legislation than on the wider population, e.g. by making it more difficult in practice for a specific group to access the technology;
- could lead to recommendations that have any adverse impact on people with a particular disability or disabilities.

Please tell us what evidence should be obtained to enable the Committee to identify and consider such impacts.

There is evidence to support the position that families living with someone with an alcohol problem are stigmatised by society; this should be considered

Other Issues

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