Patient/carer organisation statement template

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: David Hugh Geldard, President, Heart Care Partnership (UK)

Name of your organisation: Heart Care Partnership (UK), the patient arm of the British Cardiovascular Society

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)# Trustee and President, neither post attracts any remuneration.
- other? (please specify)# I am the Patient Representative on the Greater Manchester and Cheshire Cardiac Board, and the Department of Health's Cardiovascular Disease Programme Board.
- # I am a community member of the NICE Smoking Cessation Programme Development Group

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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.
I feel that the technology tackles an important aspect of tobacco addiction by reducing the craving aspect as against a replacement therapy. Research results are promising but confusing following comment from evidence reviewers, however if it can be proved that Varenicline is more effective, or even as effective, in smoking cessation then it must be must be considered most seriously for approval.

By giving smokers a choice of pharmaceutical options this increases their participation in the process and furthers their personal empowerment to quit.

With a complementary advice and back-up service, and the burden of craving reduced, counselling can help the quitter focus on the immediate benefits as well as the longer term ones.

Like all pharma. treatments, varenicline requires an adherence to medication, but if the effect is relatively immediate this should increase the continuation rate

Smokers who wish to quit are aware that their habit is dangerous, if one could place a magic wand on their shoulder and they could stop they would take it. We have no magic wand, and none of this is cheap, but the evidence is clear that interventions with a cost are still far cheaper than continued smoking.

(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.

There is no need to re-state the absolutely unequivocal evidence that smoking is a major, or the main, contributor to a range of disease and early death. However I do feel that the suggestion that a reduction in life expectancy of smoking men is only about 3 years is very much on the low side and needs re-visiting.

As non-smokers become more aware of the dangers of second hand smoking their tolerance of smokers and of smoke is becoming less and less. Smokers are all smelly, they cough, they snort, they wheeze. To non-smokers they are not nice people to have around. People think," what disease or ailment will they get next?" It is not just intolerance it is concern as well.

Fitness in terms of cardiovascular / skeletal muscle functioning is impaired in smokers. Early quitting will enhance performance and continuation in physical recreation activities.

I do not think it is an under-statement that non-smokers have a deep concern generally for their fellow men who are plagued by the habit. For their relatives and friends and people they know who are smokers it is a much more personal and stressful anxiety. Quitting would remove these concerns.

The disadvantages incurred by smokers are legion. At a stroke these issues start to fade.

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 can think of no aspect of smoking where this technology would not help.

Like all medication there are problems with compliance. Again, back-up counselling support should help.

Compared with what discomforts they have to put up with as smokers, these are a very crisis tolerant group. I feel that, generally, they would tolerate mild discomfort, and if they can't, then that is the beauty of alternative therapies.

The impact would be terrific. It's a "get out of jail" card or "welcome back to the world of the living". Tremendous benefits and relief to all contacts, but especially the smoker.

Financially to quit smoking is a win, win situation. For people on lower income, who are more deeply impoverished by their habit, some financial or practical support would be helpful

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

Not that I am aware of. There seems to be sense in broadening the current limited range of treatment options.

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 cannot speak for the mental health patients, where I have heard it argued that smoking is a support.

For other patients I think we have to look at research results around compliance. Without that evidence, who can say which socio-economic group or any other type of group might benefit more or less from the technology? Apart from mental health patients, where I'm not sure, I am not aware of any one who would benefit less from stopping smoking.

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.

Approved for dispensing through NHS -NRT and Buproprion

There are quite a few, eg, in no significant order of adoption, Hypnotherapy, Acupunture, tobacco alternatives, St John's Wort, other herbal products and behavioural techniques

(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.)

We are back to evidence again. The only advantage for a smoker is to quit. Every thing else flows from there. This technology, like the other two approved by NICE, is easy to use, it is convenient, and the side effects are apparently minimal. The treatment term is acceptable. It seems to have similar advantages and disadvantages to the other standard practices.

(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).

The only area of disadvantage might be in a comparison of side effects. I am not aware of any differences.

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 comment.

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

#No comment

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.

Not aware

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 a proven, authorised and approved method of treatment for smoking cessation.

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

It would remove choice and exclude, on the evidence, an option which is appropriate for smoking cessation practice.

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

Again, those groups of patients who have difficulty complying with prescribed medication generally.

Other Issues

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

I have wanted to present a robust position in regard to smoking cessation. I am an ex-smoker and experience on a daily basis the damage I have done to my career, my daily life, and the adverse consequences I have to bear in my family, recreation and social life. I have been involved as a volunteer cardiovascular patient representative for nearly twelve years and stopped smoking, with the assistance of NRT, fifteen years ago. Similarly I am very much aware of the dangers facing current smokers and the harm they are doing to the rest of us from health, economic and general quality of life perspectives. However I am also aware that we cannot proceed on rhetoric, we have to apply evidence. If the evidence is there then we can proceed briskly.

I have mentioned rhetoric, and am aware in some responses that I have been brief.
Please do not let my brevity, where we were asked for lists of adverse conditions and so on, suggest a lack of understanding or interest. Rather I wished to make an emphatic point. Smoking is a preventable addiction that amazingly has hooked millions. It is crazy, it is madness and we must do all we can to eradicate it. This technology appraisal is another step in that direction.