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:

Judy Birch

Name of your organisation:

Pelvic Pain Support network

Are you (tick all that apply):

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

- 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)

Volunteer Chief Executive

- 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.

Neuropathic pain – a reduction in the severity of pain enabling increased function and mobility.
It is reversible when a trial is carried out first. A trial should be standard practice.

(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.

This technology has the potential to prevent and improve a downward spiral of increasing pain, disability and depression. It can help people to maintain or increase their work and or family commitments and enable them to participate in a more normal social capacity. Family, friends and employers benefit from the increased independence of the patient enabling them to fulfil their own roles.

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).

Patients need to understand what the technology and the procedure entails. They also need to be informed about the potential complications , minor and severe. Without this information patients are unable to make an informed decision regarding treatment. Some patients may not be willing to undergo subsequent additional procedures which may be considered minor to a clinician ie, to replace leads, batteries, devices etc. Similarly patients would not tolerate an increase in pain. Some may even prefer to live with their disability and severe pain rather than accept the risk of a major complication however small or unlikely it is. Family and friends also need to be aware of the above and have an opportunity to discuss how they feel about it. Patients and their carers should have the opportunity to discuss the technology with others who have personal experience of it, both positive and negative as part of the decision making process. It should not be a compulsory requirement to undergo a pain management programme prior to SCS. There will be cases where a patient has tried all of the available options, medical, physical and psychological and tried all coping strategies. In such cases a PMP is not going to add anything other than cost. In addition psychological assessment has not demonstrated an impact on long term outcome of SCS.

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

The patient experience is very individual and what is acceptable to one individual may not be acceptable to another. Some patients may prefer to continue exploring other medical and /or self-help strategies.

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?

The technology has advanced and is continuing to do so but there is limited data available due to difficulties in carrying out trials, the number of conditions, variables, presenting symptoms. Patients whom it is thought may benefit from such a therapy should know about it and be allowed to consider it. It is important to establish a registry of all patients receiving SCS and the indications. This should go beyond the UK. SCS is being carried out for a wider range of indications in some countries.

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.

There may be treatments which have not been tried by patients due to regional differences in prescribing and lack of knowledge around pain. Physiotherapy and some other manual therapies that may be useful are difficult or impossible for

patients to access for some indications where quality of life is severely affected. Similarly patients may not be given the opportunity to try opioids or they may try one kind that may not help whereas another may have some benefit. There are unacceptable variations in practice around the country.

(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.)

(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).

Many patients do not like taking medication which can have significant side effects. There may also be side effects from SCS. This should be down to patient preference and what works best for them. Where the patient has a preference for a technology that could enable them to reduce medication, improve their quality of life and where the patient understands the risks, has explored the advantages and disadvantages and would be able to cope with recharging the battery, adjusting settings etc, they should be allowed the opportunity to access the technology.

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.

I think there may be some differences in the reported outcomes in some establishments and the patient experience. Clinicians may prevent patients from hearing any negative experiences. This can give a distorted view or impression which can lead to further disappointment.

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

Severe adverse effects appear not to have been published.

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.

Some patients have been asked about their experiences but it seems these were selected patients who had had a positive experience with SCS. I have spoken to patients who had had a range of experiences with the technology and feel that this lends itself to further exploration.

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?

This could enable patients who are currently unable to cope with their pain level and disability, increasing their independence. This would have a knock on benefit to carers giving them increased independence and enabling greater participation all round by those affected in contributing to society.

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

Continuing misery, lack of hope, further downward spiral

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

Possibly some mental health patients

Other Issues

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

Patients should have a say in the choice of device which should be based on the patient's needs. They should know the extent of the experience of the clinician who is to perform the procedure in carrying out the procedures for similar indications and the outcomes for that clinician. In order to expand expertise, it should be a requirement for a clinician to perform more than ten procedures per year. A patient is entitled to know if a clinician has not performed a procedure before and if it is being carried out for the first time.

There are areas of the country where there is no expertise in this field. This should not be a barrier to patients accessing such a therapy if they are suitable and if it is their wish based on objective information.

If a patient regards less than 50% improvement as a significant improvement in pain , this should not be a hindrance to continuing with permanent implantation. Even 30% improvement can make a world of difference to someone with such pain. It could be the difference between being able to cope and not coping at all.