NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Sofosbuvir for treating chronic hepatitis C

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: Charles Gore

Name of your organisation: The Hepatitis C Trust

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) ✓ **CEO**
- 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.

Please see The Hepatitis C Trust's submission

(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.

Infection with the hepatitis C virus (HCV) affects people differently. Some are largely asymptomatic for many years (although after being cured they often then realise they were not in fact asymptomatic but had merely adjusted, for example to having limited energy); others are hugely impacted. We still encounter people at our support groups who say that they have never before disclosed their infection to anyone, including family. This clearly has the potential for enormous psychological damage. There remains very considerable stigma and discrimination around HCV, much of it connected to its image as a drug users' illness (even though globally it is in fact overwhelmingly a healthcare-acquired infection). My personal experience of having HCV and, in the last 12 years, of working with people living with HCV is that some of the worst discrimination takes place within the NHS. Just a month ago an extremely knowledgeable and successful professional woman reported to me that, while in an NHS hospital having her first child, she was treated both as if she had a highly contagious disease and as if she was completely untruthful, simply because of her HCV status.

People who inject drugs (PWID) have been so routinely refused treatment for HCV (despite NICE making it clear in TA106 that there is no reason not to treat PWID) that the PWID community now believe they have no right to treatment, a disastrous situation since treating those where transmission is occurring is a prerequisite of effective public health.

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We know of a number of cases of people who have lost their jobs within a few months of disclosing their infection – but always for 'other reasons'. We know someone well who has refused to do treatment so far because he is worried that the side effects of 48 weeks of interferon will force him to disclose his infection to his employers. Equally some people find that working full-time with HCV is impossible and acceptance of this is one of the reasons the 4 devolved nations of the UK agreed ex-gratia payments to those infected with HCV through the NHS.

Aside from stigma, discrimination and work, living with HCV can have many other psychosocial effects. For example, it can have an important negative impact on libido with potentially damaging consequences on relationships. A widespread belief that it is sexually transmissible can also be damaging to relationships (someone in touch with the Trust informed us just before Christmas that when she told the person she was dating that she had HCV he broke off the relationship).

HCV is now known to cross the blood/brain barrier and there is a clear link with depression. As well as causing its own problems, depression can exacerbate those discussed above.

Aside from being potentially life-threatening, HCV infection can therefore cause enormous psycho-social problems and significantly lower quality of life. This makes a cure hugely important. However, current standard of care is hard to tolerate for most people, much of which is due to the side effects of interferon. As is well-known, this can make treatment adherence hard with consequently lowered likelihood of a cure. Less well-known is what long term effects interferon may have. In my own case it prompted an immune response to my pancreas after 8 months of taking it which caused enough damage to make me insulin-dependent for the rest of my life. A survey we carried out online, which was consequently biased and was also retrospective, nevertheless strongly suggested that for some people there is ongoing morbidity, generally of an autoimmune type, irrespective of SVR.

The difficulty of doing treatment and in some cases the ongoing problems then creates fear amongst those waiting to do it. This is undoubtedly one of the causes of the low uptake of treatment, which amounts to only about 3% of the prevalent pool each year, not even enough to keep pace with new infections. Some research due to be published later this year with which I have been involved has supported this, suggesting in fact that fear of treatment is worse than its reality.

This new treatment, with no interferon for some genotypes and only 12 weeks of it for the others, will be a huge advance. The absence or limited amount of interferon is likely to remove much of the fear of treatment as well as the difficulty of actually doing it. It may also be that just 12 weeks of interferon is less likely to cause any long-term effects.

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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).

Please see The Hepatitis C Trust's submission

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

Please see The Hepatitis C Trust's submission

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?

Please see The Hepatitis C Trust's submission

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.

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(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.)

Please see The Hepatitis C Trust's submission

(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).

Please see The Hepatitis C Trust's submission

Equality and Diversity

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

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

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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.

Please see The Hepatitis C Trust's submission

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

Please see The Hepatitis C Trust's submission

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.

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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? **Please see The Hepatitis C Trust's submission** What implications would it have for patients and/or carers if the technology was **not** made available to patients on the NHS? **Please see The Hepatitis C Trust's submission** Are there groups of patients that have difficulties using the technology? **Please see The Hepatitis C Trust's submission**

Other Issues
Please include here any other issues you would like the Appraisal Committee to consider when appraising this technology.
Please see The Hepatitis C Trust's submission