NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Axitinib for the treatment of advanced renal cell carcinoma after failure of prior systemic treatment

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: Pat Hanlon

Name of your organisation: Kidney Cancer UK

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,)

X a patient with transitional cell carcinoma (TCC)

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Single Technology Appraisal (STA)

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.

Metastatic renal cell carcinoma (mRCC) is very largely resistant to radiotherapy, chemotherapy and hormone therapy. Consequently, in treating it, a lot of reliance has to be placed upon new classes of targeted drugs, such as TKIs, of which axitinib is one. Axitinib aims to slow down, halt or even reverse tumour growth; and it has been shown to lead to significant increase in progression-free survival as compared with other targeted drugs.

(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.

In second –line treatment axitinb has the potential to extend progression-free survival by several months and thus delay the need for best supportive palliative care. In this way the drug produces some important psychological benefits for patients in giving them more time with their families at the end of their lives, something that is very highly valued by both patients and their carers.

In addition to greater potency in slowing tumour growth, axitinib appears to be more easily tolerated than other drugs. Its side effects are less severe, being classified as ‘mild’ to ‘moderate’. And some side effects which patients find especially difficult to

cope with (eg blisters on hands and feet) are much less pronounced with axitinib than with other TKI drugs.

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).

Axitinb does not lead to a curative outcome. It can only delay the advance of tumours. And some patients may find the anxiety engendered by this difficult to come to terms with.

Not all patients respond equally well; and axitinib still has some serious side effects, like diarrhoea, fatigue nausea and vomiting. Although most side effects can be controlled by appropriate medication and life-style changes, it may take some time before the correct medication and dose is found.

There are a few potentially serious adverse events (SAEs). These are more likely to pose problems to patients with the conditions of hypothyroidism and hypertension.

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Single Technology Appraisal (STA)

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

It's often a matter of personal choice. Some patients look upon the use of the technology of axitinib as 'putting off the inevitable' and manage their disease in other ways. But the vast majority welcome this development in the treatment of mRCC.

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?

As with many conditions, younger and fitter patients may benefit more than older patients presenting with a multiplicity of other health issues. The latter might be expected to find the side effects more difficult to deal with

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Single Technology Appraisal (STA)

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.

There is currently no drug approved by NICE for second-line treatment of mRCC. Everolimus has been quite widely used, but was not recommended on the ground that it is not considered cost-effective. Both everolimus and axitinib are included on the list of drugs eligible for support from the Cancer Drugs Fund. But this only applies in England. The recent decision of the Scottish Medicines Consortium to approve axitininb for funding by NHS Scotland is most warmly welcomed. But patients in Wales and Northern Ireland currently have access to no publicly funded drug for second-line treatment of mRCC

(ii)

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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.)

The main advantages of axitinib over current standard practice are greater potency (leading to longer patient survival) and fewer and less severe side effects.

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Single Technology Appraisal (STA)

(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 disadvantages of axitinib are no more than the disadvantages associated with drugs in current standard use

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

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

We have no particular reasons to suggest that the axitinib technology would do anything to impair equality and diversity

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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.

Not known

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

None that we are aware of

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Single Technology Appraisal (STA)

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

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Single Technology Appraisal (STA)

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?

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

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Single Technology Appraisal (STA)

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