

Bevacizumab, sorafenib, sunitinib and temsirolimus for renal cell carcinoma

Appraisal Consultation Document

Comments from *Patient expert*, Patient Expert, [REDACTED]

I am extremely concerned at the decision reached by the panel. I fear the panel failed on many fronts to address the appraisal in a fair, patient centred manner and showed a real lack of understanding of the current options for kidney cancer patients and the potential significant benefits of the new treatments.

This decision also contradicts the positive commissioning of these treatments in the rest of the western world. This includes both Canada and Sweden where the commissioning structure is comparable. One has to question why you are completely at odds with them.

i) Do you consider that all of the relevant evidence has been taken into account?

No, all the relevant evidence has not been taken into account. This includes evidence from the leading clinicians worldwide who are extremely committed to these treatments for rcc patient. They have explained clearly that without these treatments patients are condemned to a premature death. The panel failed to comprehend the current system whereby many oncologists are refusing to prescribe the only available treatment "Interferon" due to its lack of efficacy and appalling side effects. I am also extremely concerned by comments from employees of NICE made to the press that these drugs offer "just a few weeks" of extra life. This is misleading and incorrect. You were all supplied with the Pfizer data which cites 28 months pfs in the latest clinical trial updates. The "real world" data also suggests that a significant number of patients are living far longer than weeks with a far better quality of life on treatment.

The panel also failed to acknowledge and request the views of the patient experts at the meeting and by doing so failed to consider the damage both physically and psychologically by failing to treat rcc patients with these treatments.

ii) Do you consider that the summaries of clinical and cost effectiveness are reasonable interpretations of the evidence and that

the preliminary views on the resource impact and implications for the NHS are appropriate?

The panel has failed to take into account the vast resources spent on supportive care once no further treatment is available to rcc patients. PenTag came up with a totally inaccurate costing for best supportive care factoring it as approximately £85 – a cost for a visit from the community nurse. Many rcc patients will have bone metastases without active treatment. This will be treated with surgical intervention and intensive physiotherapy. This is hugely costly to the NHS and the figures in the appraisal should reflect interventions needed due to the spread of disease such as this.

Without the benefit of a qualification in health economics it is extremely difficult to assess the QALY figure put forward by NICE. However, for these figures to differ so widely from those put forward by health economists from the companies, one has to question the accuracy of the formulas used by PenTag. From the numerous health economists I have consulted with since the ACD it would seem that the argument is based on a failure by NICE to take into account the orphan status of these treatments and thus the fewer beneficiaries. NICE should use a different formula when cost appraising treatments of this nature.

iii) Do you consider that the provisional recommendations of the Appraisal Committee are sound and constitute a suitable basis for the preparation of guidance to the NHS?

These recommendations are unsound due to the failures discussed above.

iv) Are there any equality related issues that may need special consideration?

Special consideration needs to be given to patients with an uncommon cancer, as in kidney cancer.

Consideration also needs to be given due to the lack of alternatives for these patients.

It is the role of NICE to look at equality for all patients including those disadvantaged with a terminal illness. This decision punishes them for this very reason.