Emily,

Please find below Bowel Cancer UK's formal comments on the ACD and evaluation report for the Health Technology Appraisal of Bevacizumab (Avastin) and Cetuximab (Erbitux). I have used the format of your general headings as requested as follows:

i. Whether you consider that all the relevant evidence has been taken into account

Bowel Cancer UK has submitted comprehensive evidence of the efficacy of both these treatments, from the charity, clinical and patient perspectives. We hope that this and other evidence has been taken fully into account in NICE's appraisals of these drugs.

ii. Whether 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

Bowel Cancer UK believes, from the evidence that we have gathered and submitted, that both these treatments are extremely effective and should be made available to all patients that will benefit from them. Furthermore, we believe that the treatments should be made available on the basis of their efficacy and not be denied to patients on the grounds of cost - which seems, sadly, to be the sole criteria for the provisional negative guidance that NICE has made relating to them.

In the case of Erbitux, it is clear that NICE's guidance is inconsistent on clinical grounds, as your equivalent organisation in Wales, the All Wales Medicines Strategy Group (AWMSG), has approved the treatment's use to bowel cancer patients on the NHS in Wales. While we are glad that Welsh patients will benefit from the drug, it is galling for patients in England and Scotland to know they can't receive it - a situation that is not just grossly unfair but also takes postcode or in this case country prescribing to new extremes.

iii. Whether 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

Bowel Cancer UK is very disappointed with the provisional guidance, because it indicates that these two biological agents will not be made available on the NHS, despite their proven efficacy and potential benefit to many bowel cancer patients.
It is ironic that while the UK has been in the forefront of developing both these drugs, including in clinical trials, it looks as if we shall, once again, be at the very back of the queue when it comes to being able to make them available to patients. It is also very hard not to become angry and cynical when NICE appears to be making decisions on the basis of financial expediency rather than clinical efficacy. We shall continue to campaign for increased access to these valuable treatments and call on NICE to reconsider its decision and make these drugs available to patients that need them.

Additional Comments

As you know, Bowel Cancer UK has invested considerable time and effort in preparing our submission to NICE with regard to these treatments: our submission included a comprehensive summary of the evidence of the treatments' efficacy from three leading clinicians; a dozen case studies of patients who have benefited from them; and our own considered appraisal of both drugs.

We have made these efforts, not just because we are stakeholders in this appraisal, but also because we and the clinicians we work with believe in these treatments; because we know patients who have benefited from them - in terms of improved quality of life and increased length of life; and because both drugs represent a new era in the treatment of colorectal cancer: the era of targeted therapies that will, one day, enable each individual patient to have a tailored treatment for the disease.

As NICE will be aware, things have moved on somewhat since we prepared our submission last year, particularly as a result of the significant growth in the profile of targeted therapies - including these treatments - including in the media. Much of this publicity has been generated as a result of individual patients' high profile campaigns to gain access to these treatments and/or raise the funds to pay for them privately through donations.

Bowel Cancer UK has been privileged to get to know and work with some of these patients and we have been deeply moved by their heroic efforts to fight for what they believe in and in circumstances that would deter many people, i.e. when they were in the advanced stages of the disease and had only weeks to live. It is, frankly, tragic that these patients were forced to fight bureaucracy when they should have been focussing all their efforts on fighting bowel cancer; and that the system that they helped to support throughout their lives - through taxes and other contributions - failed them when they needed it most.

No decision, even one made by NICE, is made in a vacuum and NICE's negative guidance has to be put into the wider context of CRC patients being more willing to campaign for treatments and for the media more willing to help them publicise them. There's no doubt that these campaigns will grow in number and volume if these treatments remain unavailable to those who can and should benefit from them.

It will come as no surprise to NICE to know that Bowel Cancer UK is also going to continue to campaign for access to these treatments, including in support of individual patients who have been recommended them and yet cannot receive them on the NHS.
We have been encouraged by and have publicly welcomed NICE's positive guidance regarding a number of CRC treatments, including oxaliplatin and capecitabine in the adjuvant setting. We hope that NICE will follow its conscience and reconsider its decision with regard to bevacizumab and cetuximab, making these revolutionary and invaluable treatments available to the patients who will benefit from them.

Best wishes.

Ian

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Bowel cancer is the second most common cause of cancer death in the UK.

We are a voluntary organisation relying on donations to fund our work. Visit the website for further information.

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