Appraisal of Carmustine implants and temezolomide for the treatment of newly diagnosed high grade glioma

Comments on the ACD – Jane Redman, patient expert

Having approached this appraisal with an open mind and with no particular axe to grind on behalf of these treatments, I find that the experience has helped form my opinions.

I am disappointed with the committee's recommendations as I felt there was clear evidence from clinical trials that these treatments prolonged life with few side effects. They clearly represent the best treatment currently available for patients suffering from high grade glioma, and as such, I believe they should be made available as first line treatment.

If these treatments were approved, the number of patients for whom they would be suitable would be very small and the cost to the NHS overall would therefore be relatively small. By comparison, for example, with Herceptin, which is applicable to far more people and which leapfrogged the system owing to public pressure and political intervention, the cost would be tiny. The committee's recommendation not to approve these treatments takes no account of the fact that they only apply to a small minority of extremely disadvantaged patients.

Unfortunately for those with glioma, the disease itself is so devastating that neither patients nor families are likely to be in a position to engineer the kind of public outcry that accompanied Herceptin and has recently accompanied treatments for Alzheimers. If sheer force of numbers is allowed to determine what treatments are approved then minority groups will inevitably be discriminated against.

The committee's criticisms of some of the data in the clinical trials seemed at odds with its apparent willingness to be overwhelmingly influenced by an economic model that is itself deeply flawed. Patient groups' and clinicians' criticisms of the economic model appear to have been largely ignored, and the rigour rightly demanded of the clinical trials does not seem to have been demanded of the bizarre and rigid system used to assess the cost effectiveness of the treatments in question.

I am fully appreciative of the hard decisions that have to be made and of the need to balance cost with benefits, and of the role of the QALY. I believe that quality of life is paramount in establishing the value of a treatment. However, I do not believe the following factors were taken into account when establishing cost effectiveness:

a) There was only a token acknowledgement of the discrepancy between patients' own view of their quality of life and the view of clinicians/relatives.
b) There was a blanket assumption that the value of life went down correspondingly the closer the patient got to death. In fact, anyone will tell you that life increases dramatically in value when it is about

to end. To a condemned person, (particularly a relatively young person as many glioma sufferers are) an extra two months with loved ones may be worth far more than the two months of ‘normal’ life.

c) Although the increase in survival was small, this represents a considerable improvement in outcome for patients suffering from this type of brain tumour. There was no acknowledgement of the fact that, for glioma sufferers, the benefits of these treatments represent a huge step forward.
d) No differentiation was made regarding the age of the patient, even though younger people were shown to respond better to the treatment and, as a percentage of overall lifespan, the improvement in survival means much more to a younger patient.

The committee is calling for more and better clinical trials to prove the effectiveness of these drugs, even though it heard expert evidence about the difficulties of conducting clinical trials in this area. This demand for further proof effectively condemns patients suffering from high grade glioma to many more years in the wilderness. Again, this is a form of discrimination against minority groups with intractable diseases. Wonder drugs don’t spring out of nowhere overnight, and if these small steps forward cannot be acted upon, and built upon, no progress will be made.

Lastly, this decision will put Britain out of step with the rest of Europe, where Temezolomide, in particular, is widely used in first line treatment.