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We are an alliance of brain tumour support, advocacy and information groups around the world, including brain tumour patients and caregivers, researchers, scientists, clinicians and allied health professionals who work in the field.

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6<sup>th</sup> March 2008

Mr Clifford Middleton  
National Institute for Health and Clinical Excellence  
MidCity Place  
71 High Holborn  
London  
WC1V 6NA

Dear Mr Middleton,

**Re: Social Value Judgements – Principles for the Development of NICE Guidance (Public Consultation on Second Edition Draft)**

The International Brain Tumour Alliance (IBTA) would like to submit the following comments.

The IBTA notes with concern that in the current second edition of the Social Value Judgements (currently in the process of public consultation) NICE has rejected the suggestion of including the Rule of Rescue (as re-defined by its own Citizens Council in its final report on social values) viz:

**"NICE recognises that when it is making its decisions it should consider the needs of present and future patients of the NHS who are anonymous and who do not have people to argue their case. NICE considers that the principles provided in this document are appropriate to resolve the tension between the needs of an individual patient and the needs of other users of the NHS, present and future. Therefore, the Institute has not adopted an additional rule of rescue."**

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The IBTA is a not-for-profit, limited liability company incorporated in England and Wales, Company Number: 6031485. Registered address: c/o Roxburghe House, 273-287 Regent Street, London W1B 2AD, UK. Address for correspondence: The Secretary, IBTA, PO Box 244, Tadworth, Surrey, KT20 5WQ, United Kingdom.

We further note that a majority of the members of the Citizens Council and a clear majority of respondents in the public consultation for the Rule of Rescue Report opposed rejection of the Rule of Rescue. An overwhelming majority (over 90%) believed that NICE should consider “if the intervention was required to avoid immediate loss of life, *or if there was a good chance of an increased life expectancy, or whether the intervention will result in a significant improvement in quality of life*”. (Page 3, Nice Citizens Council, Rule of Rescue Report, Patient and Public Comments, June 2006.)

We believe that rejecting the Rule of Rescue will negatively impact on patients who suffer from a rare or less common cancer, such as a brain tumour.

The Citizen's Council in fact expanded the term “Rule of Rescue” by adding “exceptional case” because the first term really referred to people in *imminent danger of dying*, whereas the second description also incorporated those who were in a palliative care situation of varying degrees. This expanded definition of Rule of Rescue is not taken into account in section 4.5 of the Social Value Judgements.

We strongly urge NICE not to reject outright the Rule of Rescue - particularly in light of its overwhelming approval by both the Citizens Council and the subsequent public consultation.

We ask that the Rule of Rescue (incorporating the concept of "exceptional case") instead be included in NICE's final edition of Social Value Judgements so that patients in a life threatening or palliative care situation do not feel devalued because of their misfortune.

Yours sincerely,

Kathy Oliver  
Co-Director, International Brain Tumour Alliance (IBTA)