

7th July 2000

Anne-Toni Rodgers  
NICE  
90 Long Acre  
Covent Garden  
London WC2E 9RZ

Dear Ms Rodgers

**Re: "Have Your Say" Consultation Document**

Thank you for sending a copy of this consultation document to the Genetic Interest Group. As the UK alliance of support groups for all those affected by or at risk from disorders caused by or to which patients are pre-disposed as a result of genetic factors we welcome the opportunity to participate in this consultation exercise.

GIG believes in the importance of taking the views of patients, carers and because of the inherent nature of genetic disorders, the wider family into proper consideration when evaluating the impact of a particular clinical intervention. We welcome the commitment from NICE to including these views as a central strand of the Institute's decision making process.

Clearly, any appraisal process must not be prolonged beyond that which is absolutely necessary to reach a decision if patients are not to be denied access to beneficial technologies. The clear timetable outlined in the consultation document and the guidance as to the information that NICE would find helpful is very welcome. In particular, the proposal to include examples of good practice in the final document is very useful and we hope that organisations will be prepared to give their consent for this to happen. Such examples should not concentrate on one particular aspect of NICE's interest, but should span the spectrum of its concerns, taking in pharmaceuticals, devices, diagnostics and other types of inventions.

For large well established patient groups generating a response to a request from NICE in respect of a particular intervention will require a substantial effort, possibly involving internal consultation with "in-house" experts and the gathering of information from affected individuals and families relevant to the technology being evaluated.

The vast majority of patient support groups are small. They do not have staff or other resources charged with specific responsibilities that relate to the questions on which NICE is likely to be seeking an intervention and any request is likely to require the development of an ad-hoc mechanism. This will take time and command scarce resources. Of the groups in membership of GIG, the majority only have a small staff or rely entirely on volunteers (who may themselves be

affected by chronic health problems). Yet the views of small organisations and of patients affected by relatively uncommon conditions should be recognised as important by NICE and taken into account - particularly when the technology under appraisal is one which is not condition specific in its application.

Patient groups are a vast repository of practical expertise on the consequences of complex disorders and the strategies for coping with them. In this respect they are as skilled as many more obviously professional groups. Tapping into this knowledge will add significantly to the impact and value of NICE's deliberative processes. In seeking to generate this input the fact that membership of a patient support group comes about as a consequence of a disease or a disorder in the family, rather than as an expression of a voluntary commitment to an issue of interest to the members must not be forgotten. The disease itself imposes constraints on the affected person and their family, reducing time and energy available to involve oneself in activities like responding to consultation processes. Any system genuinely seeking user views must be user friendly. Too overt an emphasis on particular types of input (reflecting, for example scientific or clinical terminology) will serve to dissuade rather than encourage patient groups from responding.

Consultation procedures raise the question of confidentiality as to the information divulged on which views of patients and patient groups such as GIG are to be sought. It is not clear from the consultation document how this will be addressed in practice and we would welcome further indications as to NICE's thinking in this area.

Finally, the NHS is committed to equity - to responding to patients on the basis of their clinical need. An important manifestation of the reality of this commitment is the extent to which the needs of those with rare disorders are recognised and responded to by the NHS in general and by NICE in particular. Whether the condition that affects you is rare or common is irrelevant, if you have it, you have it 100% and you need to feel that the health service recognises the validity of your experience and of your needs and hopes for treatment that reflects scientific knowledge and clinical possibility. Given this, it is important that, if NICE's commitment to consultation with patients is to be genuinely open, that it takes steps to ensure that there is a genuine opportunity for the Institute to hear and respond to the real experience of patients and their families - even if the diversity of this experience makes standardising a response and drawing general conclusions on which advice can be given to the NHS and the DoH a complex process. Failure to do this will undermine public confidence in the decisions made by NICE, politicising its role to a greater extent than need be the case, with consequently greater scope for schism rather than consensus about the proper application of health technologies in the NHS.

The Genetic Interest Group looks forward to a continuing dialogue with NICE and would be keen to assist with developing mechanisms whereby technologies under evaluation can benefit user input to the appraisal process. We would be happy to meet with the Institute to expand on these comments or otherwise develop links if this would be helpful to you.

I look forward to hearing from you.

Yours Sincerely

**Alastair Kent**  
**Director**