

## Cancer Drugs Fund Consultation

### Reply Form

**Closing date for responses: 19<sup>th</sup> January**

**Please fill in and/or tick the appropriate response.**

#### Response form

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**Before submitting your response to the Department, please make sure that it has been saved in a name that will make it easier for us to track. Many thanks.**

#### **Freedom of Information**

We manage the information you provide in response to this consultation in accordance with the Department of Health's [Information Charter](#).

Information provided in response to this consultation, including personal information, may be published or disclosed in accordance with the access to information regimes. The relevant legislation in this context is the Freedom of Information Act 2000 (FOIA) and the Data Protection Act 1998 (DPA).

If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals amongst other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic

confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.

The Department will process your personal data in accordance with the DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties. However, the information you send us may need to be passed on to colleagues within the UK Health Departments and/or published in a summary of responses to this consultation.

I do not wish my response to be passed to other UK Health Departments

I do not wish my response to be published in a summary of responses

Please indicate all the countries to which your comments relate:

*UK-wide*  *and/or:*  
*England*  *Northern Ireland*   
*Scotland*  *Wales*

Are you responding: - *as a member of the public*  
- *as a health or social care professional*   
- *on behalf of an organisation*

**Country of qualification**

Please indicate as appropriate:

UK  Other EEA  Rest of World

**Area of work:**

NHS	X
Social Care	
Private Health	
Third Sector	
Regulatory Body	
Professional Body	
Education	
Trade Union	
Local Authority	
Trade Body	
Other (Please give details)	
Independent Contractor to NHS	
Manufacturer	
Supplier	
Other (where relevant)	

North East	
North West	
West Midlands	
South East	
London	
Humberside/Yorkshire	
East Midlands	
East of England	
South West	
No answer	X

**If you are responding on behalf of an organisation, please indicate which type of organisation you represent:**

NHS	
Social Care	
Private Health/Independent Sector	
Third Sector	
Regulatory Body	
Professional Body	
Education	
Trade Union	
Local Authority	
Trade Body	
Other (Please give details)	X

BRITISH NEURO-ONCOLOGY SOCIETY

**In which of the following areas do you live:** (please tick one box only)

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**1** What is your sex? \*  
Tick one box only.

Male	<input type="checkbox"/>
Female	<input type="checkbox"/>
Prefer not to say	<input checked="" type="checkbox"/>

**2** Date of Birth \*

e.g.

03	06	1975

**3** Are your day to day activities limited because of any health problem or disability which has lasted, or is expected to last at least 12 months?

The Disability Discrimination Act (DDA) defines a person with a disability as someone who has a physical or mental impairment that

has a substantial and long-term adverse effect on his or her ability to carry out normal day to day activities.

Tick one box only.

I have a longstanding illness	<input type="checkbox"/>
I have a disability	<input type="checkbox"/>
Prefer not to say	<input type="checkbox"/>

**4** Do you look after, or give any help or support to family members, friends, neighbours or others because of either long term physical or mental ill-health/disability or problems related to old age?

Tick one box only.

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Prefer not to say	<input type="checkbox"/>

**5** What is your ethnic group?

Tick one box only.

**A White**

British	<input type="checkbox"/>
Irish	<input type="checkbox"/>
Any other White background, write	<input type="text"/>

**B Mixed**

White and Black	<input type="checkbox"/>
White and Black African	<input type="checkbox"/>
White and Asian	<input type="checkbox"/>
Any other Mixed background, write	<input type="text"/>

**C Asian, or Asian British**

Indian	<input type="checkbox"/>
Pakistani	<input type="checkbox"/>
Bangladeshi	<input type="checkbox"/>
Any other Asian background, write	<input type="text"/>

**D Black, or Black British**

Caribbean	<input type="checkbox"/>
African	<input type="checkbox"/>
Any other Black background, write	<input type="text"/>

**E Chinese, or other ethnic group**

Chinese	<input type="checkbox"/>
Any other, write below	<input type="text"/>

**5** What is your religion or belief?  
Tick one box only.

Christian includes Church of  
Wales, Catholic, Protestant and all  
other Christian denominations.

- |                    |                          |
|--------------------|--------------------------|
| None               | <input type="checkbox"/> |
| Christian          | <input type="checkbox"/> |
| Buddhist           | <input type="checkbox"/> |
| Hindu              | <input type="checkbox"/> |
| Jewish             | <input type="checkbox"/> |
| Muslim             | <input type="checkbox"/> |
| Sikh               | <input type="checkbox"/> |
| Prefer not to say  | <input type="checkbox"/> |
| Other, write below |                          |

**6** Which of the following best  
describes your sexual orientation?  
Tick one box only.

Only answer this question if you  
are aged **16** years or over.

- |                    |                          |
|--------------------|--------------------------|
| Heterosexual       | <input type="checkbox"/> |
| Lesbian / Gay      | <input type="checkbox"/> |
| Gay Man            | <input type="checkbox"/> |
| Bisexual           | <input type="checkbox"/> |
| Prefer not to say  | <input type="checkbox"/> |
| Other, write below |                          |

# Cancer Drugs Fund

## Consultation Questions

- 1. How can clinically-led panels ensure they are able to respond to the changing nature of available technologies and patient demand over the life of the fund?**

The British Neuro-Oncology Society has an expertise (consultant neuro-oncologists; neurosurgeons; neurologists) to respond to the changing nature of available technologies and patient demand as the Society's membership includes all stakeholders, i.e. clinicians, scientists, carers, patients and charities.

- 2. Do you agree that the national weighted capitation formula is the best way of determining each SHA's share of the Fund?**

**Yes**

**No**

The British Neuro-Oncology Society has no particular views on the national weighted capitation formula. The determination of each SHA's share of the Fund, however, is a political not a clinical decision.

- 3. What should the national role be in terms of providing guidance? Are there particular issues that national guidance should address?**

The British Neuro-Oncology Society has expertise in providing national guidance and this is particularly important in relation to rare tumours.

- 4. Do you agree that it would make sense for different regions to take the lead in considering the evidence on drugs for different cancers, to minimise variation, reduce duplication and make the best use of scarce expertise?**

**Yes**

**No**

It is not possible with rare tumours to have expertise on every regional panel and therefore some national guidance will be required.

**5. Is there anything further that could be done to ensure the Fund operates in a way that encourages drug companies to put forward improved value propositions to the NHS?**

The British Neuro-Oncology Society believe that once national guidelines have swiftly accepted the use or non-use of a “new” cancer drug relationships with the pharmaceutical companies should be eased.

**6. How else can we ensure the Fund is focused on providing new drug treatments, and does not subsidise treatments that would otherwise have been funded by PCTs?**

There is some difficulty in defining what is a “new” cancer drug. For example an “old” expensive cancer drug in a common cancer may at a later stage be found to be of use in a rare cancer such as affecting the central nervous system.

**7. Should the NHS have some flexibility in application of the Fund to cover, for example, the funding of radiopharmaceuticals for Cancer?**

**Yes**

**No**

The Fund should cover not only drugs given orally and intravenously but also the added costs of delivery of such drugs. For example in the case of central nervous system the intracavitary drug delivery into the brain requires expensive surgery.

**8. Do you agree that the Fund should be available for use on any cancer drugs that would not otherwise be funded by the NHS, and not be restricted to a national list of eligible drugs?**

**Yes**

**No**

The Fund should only pay for drugs that have been proven at a reasonable level to be clinically affective on evidenced based criteria.

**9. Should guidance be issued on prioritising the Fund application, for example to rarer cancers, or should these be issues left for local resolution within the available funds?**

The Society feels very strongly that rarer cancers should not be ignored and that there should be some kind of central control otherwise postcode prescribing will undoubtedly occur. However, all patients, particularly in small groups or on an individual level, should be referred through the local services with the advice of a properly constituted multidisciplinary team and as prescribed in the Improving Outcomes Guidance (CNS 2006).

**10. What advice can we give the panels on the specific challenge posed by rarity, or single drugs that have the potential to consume a large proportion of the Fund?**

The Society is concerned that a “common cancer” new drug may swallow a substantial proportion of the Fund and therefore rare tumours do need their own location.

**11. Should the Fund be restricted to treatments or should the NHS be able to spend some of the Fund on molecular diagnostic tests to help target the drugs patients are most likely to benefit from?**

The Society believes that molecular diagnostic tests are becoming and have become routine in the treatment of cancer and therefore should be paid for in the same way as normal histopathology through the National Health Service.

**12. Is there a role for NICE, in the context of the Fund, in signalling the technologies that are potentially of significant clinical value (albeit they were unable to recommend them as cost effective)?**

**Yes**

**No**

The British Neuro-Oncology Society is very happy to work with the National Institute for Clinical Excellence. However, this body has shown a certain rigidity in determining approval for drugs in the treatment of rare cancers, where, de facto, evidence base may be not as good as for common cancers. As above, the Society has particular expertise in writing guidelines using the best available evidence.

**13. Do you agree that it would be appropriate for the regional panels to decide not to fund drugs where a manufacturer has refused to cooperate with the NICE appraisal process?**

**Yes**

**No**

The Society has no political views.

**14. What more could be done to deter pharmaceutical companies from charging higher prices for new drugs in expectation these will be met by the Cancer Drugs Fund?**

The Society has no political views.

**15. How can we support patients with appropriate information on the options available to them?**

The British Neuro-Oncology Society always includes patients' representatives in the decision making process and is happy to advise accordingly.

**16. Should there be a national specification or standards for data collection, to promote consistency?**

**Yes**

**No**

The Fund offers a unique opportunity to collect information for the introduction and effectiveness of new cancer drugs and this should be monitored accordingly.

**17. What audit data would it be most valuable to collect and at what level (local or national) should the collection be done?**

The Fund offers a unique opportunity to collect information for the introduction and effectiveness of new cancer drugs and this should be monitored accordingly.

**18. Should the clinical panels be able to decide to use a small proportion of the funding (say 0.5-1%) to audit medicines use at a regional level?**

**Yes**

**No**

The Fund offers a unique opportunity to collect information for the introduction and effectiveness of new cancer drugs and this should be monitored accordingly.

**19. Are there any other comments or information you wish to share?**

**General comments**

Do you have any other comments you would like to make in relation to this consultation?

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