



Specialised Healthcare Alliance

Responding to the Consultation

When you should submit your contributions by?

Comments and other responses should reach the Standards Consultation Mailbox at the latest by **Tuesday 4 May 2004**.

Where should you submit your contribution?

By email to: standards.consultation@doh.gsi.gov.uk

By post to:

Standards Consultation
Room 531B
Department of Health
Skipton House
80 London Road
London SE1 6LH

What should you submit?

Please submit your views using the questions set out on the following pages. These includes details about yourself, general questions on the standards overall and an opportunity for you to comment on each of the 10 individual developmental standards and the 24 individual core standards.

The information you send to us may need to be passed to colleagues within the Department of Health and/or published in a summary of responses to this consultation. We will assume that you are content for us to do this and if you are replying by e-mail, that your consent overrides any confidentiality disclaimer that is generated by your organisation's IT system, unless you specifically include a request to the contrary in the main text of your submission to us.

PERSONAL DETAILS

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IF YOU ARE REPLYING ON BEHALF OF A GROUP OR ORGANISATION:

Name of organisation	Specialised Healthcare Alliance (SHCA)
Address (if different from above)	
Post Code	
Email address	

QUESTIONS.

The Specialised Healthcare Alliance is a coalition of twenty six patient groups supported by five corporate members. It has been set up to campaign on behalf of people with conditions which require specialised medical care. These conditions tend to be rarer and both complex and expensive to treat but cumulatively affect a large population. For example, it is estimated that there are 200,000 people with chronic liver disease, 85,000 with multiple sclerosis, 50,000 with HIV and 37,500 with end stage renal failure. In addition, conditions such as diabetes and rheumatoid arthritis can trigger the need for specialised treatment.

Specialised services commissioning is highly complex, involving collaboration between significant numbers of PCTs and across StHA boundaries with a view to maintaining specialist centres and the skills and expertise to run them. Although it accounts for about 10% of overall commissioning budgets, it relates to few performance indicators and can be something of an afterthought in the development of policy. The SHCA therefore welcomes this opportunity to respond at an early stage to the consultation, in the hope that standards can be formulated which will encourage health organisations to place a higher priority on the provision of specialised services.

1. Do the standards cover all key areas of health provision?

~~Yes – these standards cover the key areas of health provision.~~

No - if so, what additional key areas need to be covered?

i. Commissioning

The SHCA considers that the standards place insufficient emphasis on the commissioning process, which substantially affects the quality of services and the patient experience. This includes commissioning of specialised services which was also devolved to PCTs in 2002.

A recent survey commissioned by the SHCA revealed that Strategic Health Authorities were not fulfilling their assigned monitoring role in relation to the commissioning of specialised services. Given this lack of oversight in this area, the SHCA would recommend strengthening the second domain of clinical and cost effectiveness to include a standard which states:

“Health care organisations should ensure they have systems in place to plan, procure and monitor commissioning of general and specialised services effectively.”

ii. Data

The availability of accurate and relevant data is essential to the good planning, procurement and monitoring of services upon which effective health organisations depend. Evidence gained by the SHCA suggests that collective data is not accessible to those commissioning specialised services.

In rare cases where a commissioning group holds a pooled budget and procures services on behalf of PCTs it will have some contract information. More usually, the commissioning group plans and negotiates with providers, leaving contracts and associated data with individual PCTs.

The lack of appropriately aggregated data eg from the NHS-Wide Clearing Service constitutes a vital gap in knowledge which the SHCA considers should be addressed through the introduction of a developmental standard establishing the importance of access to appropriate data. The SHCA recommends that a new developmental standard be added to the second domain of clinical and cost effectiveness which states:

“Healthcare organisations should ensure they have agreed individual and, where appropriate, collective datasets and a process for monitoring activity, clinical practice and outcomes”

2. Is there sufficient distinction between the core and developmental standards?

Yes.

No - if so, how should their distinction be increased?

The SHCA is in general agreement with the distinction between the standards, with the exception of developmental standard 2:

“Patients receive effective treatment and care that:

a) conform to nationally agreed best practice, particularly as defined in National Service Frameworks, NICE guidance, national plans and agreed national guidance on service delivery; b) meet their physical, social and psychological needs and preferences; and c) are well co-ordinated to provide a seamless service across all healthcare and other organisations that need to be involved.”

Developmental standards are designed to enable the overall quality of healthcare to rise as the additional resources being invested in the NHS take effect. Standard D2 would sit more appropriately as a core standard which outlines “a level of quality of care which can be expected by all NHS patients, regardless of where they are treated.”

3. Are there any standards in this consultation document which you feel should be removed? If so, which ones? Please give reasons.

4. How challenging is it to expect that the NHS will meet the core standards?

5. We would welcome your comments on the proposal to converge the National Minimum Standards for Independent Healthcare with these standards for the NHS.

6. Please give any further comments about the standards.

The SHCA believes it would be appropriate to include some reference to the National Definition Set for specialised services within the standards given the inclusion of other major guidance and the relevance of the National Definition Set to the overall performance of the NHS.

Whilst specialised services are, broadly, those with low patient numbers, when taken as a whole they affect tens of thousands of patients. The standard and availability of specialised services is fundamental to a continuum of care within a properly functioning National Health Service. Research commissioned by the SHCA indicates that specialised services account, on average, for 10 per cent of the acute budget of PCTs.

The SHCA therefore proposes an amendment to developmental standard 2 (preferably redesignated a core standard – see point 2) to include specific reference to the National Definition set for Specialised Services: “Patients receive effective treatment and care that conform to nationally agreed best practice, particularly as defined in National Service Frameworks, NICE guidance, **the Specialised Services National Definition Set**, national plans and agreed national guidance on service delivery.”

Alternatively core standard 6 could be amended as follows:

“Health care organisations have systems in place to ensure that treatment and care are based upon nationally agreed best practice or nationally agreed guidance, including NICE technology appraisals **and the Specialised Services National Definition Set.**”

Thank You

Please indicate whether you are happy with the current wording of each individual standard.

Standard (please refer to main text)	Yes	No	Comments
	Please tick		
C1	✓		
C2	✓		
C3	✓		
C4	✓		
C5	✓		
C6		✓	Amend to include reference to the Specialised Services National Definition Set, ““Health care organisations have systems in place to ensure that treatment and care are based upon nationally agreed best practice or nationally agreed guidance, including NICE technology appraisals and the Specialised Services National Definition Set. ”
C7	✓		
C8	✓		
C9	✓		
C10	✓		
C11	✓		
C12	✓		
C13	✓		
C14	✓		
C15	✓		
C16	✓		
C17	✓		
C18	✓		
C17	✓		
C18	✓		
C19	✓		
C20	✓		
C21	✓		
C22	✓		
C23	✓		
C24	✓		

Standard (please refer to main text)	Yes	No	Comments
	Please tick		
D1	✓		
D2		✓	<p>This standard would be more appropriate as a core standard within the clinical and cost effectiveness domain.</p> <p>In addition it should be amended to include a reference to the Specialised Services National Definition Set, “Patients receive effective treatment and care that conform to nationally agreed best practice, particularly as defined in National Service Frameworks, NICE guidance, the Specialised Services National Definition Set, national plans and agreed national guidance on service delivery.”</p>
D3	✓		
D4	✓		
D5	✓		
D6	✓		
D7	✓		
D8	✓		
D9	✓		
D10	✓		

i Specialised Health Services in England, The Policy Analysis Centre, January 2004

ii Outlined in the DH Guidance on Commissioning Arrangements for Specialised Services, March 2003

iii Specialised Health Services in England, The Policy Analysis Centre, January 2004