

National Care Standards Review Public Consultation

RESPONDENT INFORMATION FORM

Please Note this form **must** be returned with your response to ensure that we handle your response appropriately



1. Name/Organisation

Organisation Name

The Neurological Alliance of Scotland

Title Mr Ms Mrs Miss Dr **Please tick as appropriate**

Surname

Dillen

Forename

Candice

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3. Permissions - I am responding as...

Individual / **Group/Organisation**

Please tick as appropriate

- (a) Do you agree to your response being made available to the public (in Scottish Government library and/or on the Scottish Government web site)?

Please tick as appropriate

Yes **No**

- (b) Where confidentiality is not requested, we will make your responses available to the public on the following basis

Please tick ONE of the following boxes

Yes, make my response, name and address all

- (c) The name and address of your organisation **will be** made available to the public (in the Scottish Government library and/or on the Scottish Government web site).

Are you content for your **response** to be made available?

Please tick as appropriate

Yes **No**

available

or

Yes, make my response available, but not my name and address

or

Yes, make my response and name available, but not my address

(d) We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Please tick as appropriate

Yes

No

CONSULTATION QUESTIONS

Question 1

Do you think that the new National Care Standards should be grounded in human rights?

The Neurological Alliance of Scotland (NAoS) welcomes this proposal and agrees that the new National Care Standards should be grounded in human rights.

As the standards will apply across a variety of settings we believe that there is a need for common understanding between disciplines around the approach to promotion and respect for human rights. We would advocate that the revised standards be supported by clear information to ensure collective understanding of what human rights are and their relevance to the development and delivery of services. Education and support for staff will also be necessary to ensure they are able to understand and properly implement a human rights based approach.

Services should be consistent ensuring the position they take is one of active consideration where human rights are at the centre of decision making whether at an individual or service level rather than simply a position of not breaching an individual's rights.

It will also be important to help enable care users to understand what their rights are, and what they can expect from the Standards.

Question 2

a. Do you agree that overarching quality standards should be developed for all health and social care in Scotland?

We support the premise that the remit of the standards should encompass all health and social care services for all age groups. This should include all care at home services.

b. Do you agree that the overarching quality standards should set out essential requirements based on human rights?

We agree that the overarching quality standards should set out the essential requirements but reiterate the importance of ensuring a collective understanding of these.

c. Do you agree that the current National Care Standards should be streamlined and a set of general standards developed that would sit below the overarching standards and apply to all services?

We are broadly in favour of streamlining the standards which we believe could support cohesion in practice across different settings. However a move to a more generalised approach may run the risk of providers not being clear on how to ensure they meet their responsibilities and fail to provide robust measures of accountability. There needs to be a clear process that those using services, their carers and families can follow if they feel that services are not meeting the standards. Therefore, it is important that, whilst streamlined and generic, the standards have tangible meaning for peoples' care. This will also help to make them more measurable for scrutiny purposes.

We believe it is also important that both the general standards and service-specific standards make reference to the training required to help fulfil them.

d. Do you think general standards should set out essential requirements and aspirational elements?

Aspirational elements are useful as a means of driving ongoing improvement and will help to avoid services aiming to fulfil only the basic requirements. We would not want there to be too much emphasis on aspirational elements as standards, unlike guidelines, are meant to be enforceable and aspirational elements are clearly not.

We also have some concerns regarding the risk of aspirational elements being open to interpretation. This may result in some ambiguity amongst providers about how to prioritise meeting these which could lead to inconsistencies in provision, contrary to the purpose of the standards. It will therefore be important that any aspirational elements are clearly defined and it should also be recognised that in order to meet more aspirational targets, service providers may require greater resources.

e. Do you agree that a suite of specific standards are developed for particular aspects of care, circumstances or need?

We accept that a suite of specific standards for particular aspects of care, circumstances or need would be helpful but are unsure on what basis these will be agreed and how many there would be. We believe the views of people using services, their carers and families should be engaged in agreeing this suite of specific standards to ensure they encompass all aspects of care circumstance and need. We would like to see young people with complex and long term neurological conditions also involved in developing any specific standards. The transition period is very important to many young people with a neurological condition (epilepsy, spina bifida, cerebral palsy etc.) where quality of care may differ between child and adult services.

We also feel that specific standards should link to existing documents such as clinical standards, evidence-based statutory guidance and legislation, but should also be informed by best practice within the respective fields.

Having prescribed guidelines will not in itself lead to optimal care, we feel it is important that individual care plans are carefully tailored to reflect the needs of each person and that the relevant standards are worked into these.

Question 3

a. What are your views on how standards should be written?

We believe that the standards must be clear and free from jargon so that they are easy to understand from the perspectives of:

- Service providers.
- People using services, their families and carers who may need to use to the standards to assess the quality of the care they or their loved ones are receiving.

It will be particularly important to ensure that the needs of all people are met, for example, taking account of communication support needs which many people with neurological conditions may have. We therefore feel they should be written clearly in plain English, with various different formats available according to language requirements, visual impairment and learning disability. It would also be helpful to colour code sets of standards and to use clear visual imagery and a glossary. The Standards should be accessible online, however to ensure equality of access hard copies should be produced.

We understand that there is a balance to ensuring the standards are both easy to understand and yet comprehensive and believe that the best way to achieve

this balance is to ensure people who use services and their carers are at the heart of developing the Care Standards. They should be involved in large numbers, across a broad spectrum of illnesses (including neurological) and there should be a wide geographical spread.

b. What are your views on the example of how the rights and entitlements of people using services and the responsibilities of service providers could be set out?

Whilst we are broadly supportive of setting out the rights and entitlements of people and the responsibilities of services, we believe it will be crucial to ensure that having different definitions does not lead to disparate expectations of service delivery. For example, expectations of meaningful participation may be different from and between those using the service and service providers. We believe it will be important to also ensure that legal rights are distinguishable.

A clear process should be included within the standards for people using services to undertake should they feel services are not being met. It would also be helpful for the standards to demonstrate how to put principles into practice. Some case studies or practical examples of respecting and ensuring service users' rights would be helpful in showing how these rights relate to the Standards in real terms.

Question 4

a. Do you think the Care Inspectorate and Healthcare Improvement Scotland should hold services they regulate to account for meeting the proposed overarching standards, the general standards and the suite of specific standards?

NAoS supports the role of the Care Inspectorate and Healthcare Improvement Scotland in holding services they regulate to account for meeting the standards. It will be important however that progress in improvement as well as outcomes are recognised and appropriate support is available to assist service providers. If standards are to be aspirational, it is important to have an ongoing dialogue and understanding of how services are developing and working rather than simply increasing unannounced inspections and/or inspections which focus entirely on a day's snapshot of the service. It is also important that inspection is not obtrusive to care users and that users

understand how to make a complaint about the service they receive and feel enabled to do so.

b. How should we ensure that services not regulated by the Care Inspectorate and Health Improvement Scotland comply with the new standards?

We are unclear as to the range of these services, particularly as the implementation of self directed support will widen the range of services a person may choose to purchase.

It is important that responsibility is articulated in the standards so that it is clear that providers are accountable.

Whilst we would expect Local Authorities and those commissioning services to be involved in the monitoring of those services, including where clients are in receipt of Self-Directed Support, we would also expect that services' adherence to the standards be taken into account during procurement processes and when services are being commissioned.

Ideally, however, we would favour an independent and external scrutiny body to oversee adherence. We are not convinced that local commissioners alone having a scrutiny role provides a robust enough approach to ensuring services are complying with the standards. We would favour independent external scrutiny which we believe necessary to ensure transparency.

We are also unsure as to what impact health and social care integration will have on the implementation of the new standards. For example will primary care services such as GP practices be regulated as part of the new partnerships? We would welcome clarity regarding this.

c. We suggest that the Care Inspectorate and Healthcare Improvement Scotland, consulting with others, should develop the suite of specific standards. Do you agree with this?

We are in support of the Care inspectorate and Healthcare Improvement Scotland developing the suite of specific standards as we believe they are well placed to ensure wide engagement with relevant stakeholders. We would stress the importance of ensuring there is meaningful involvement of people who use services, their carers and families. It is also important to involve

professionals currently working within the sector with a track record of delivering consistently high quality care.

Question 5

a. Please tell us about any potential impacts, either positive or negative, you feel any of the proposals set out in this consultation paper may have on particular groups of people, with reference to the 'protected characteristics' listed above.

b. Please tell us about any potential costs or savings that may occur as a result of the proposals set out in this consultation paper and any increase or reduction in the burden of regulation for any sector. Please be as specific as possible.

We would expect that there may be costs incurred by the potential increase in staffing and training levels required to comply with new standards. Also, it is likely that the better staff pay and conditions are for those in the social care sector, the better staff retention and performance would be, which would more successfully support the longer term implementation and achievement of the standards.

There may be costs incurred by more frequent or fulsome monitoring of services concerning their performance against the standards. There will also be costs associated with producing and raising awareness of the new standards.

Question 6

Please tell us if there is anything else you wish us to consider in the review of the National Care Standards that is not covered elsewhere in the consultation paper.

It would be helpful to link the new National Care Standards to social care qualifications and staff induction.

It would be helpful to have a single or unified complaints procedure which is as accessible as possible.

There needs to be more thought around how the standards can be applied to Self-Directed Support carers and how this can be regulated.

The voluntary sector has a part to play in delivering the standards and in preventative and anticipatory care, so the NHS should be ready to work in partnership to adequately fund this.

The standards should be reviewed on a regular basis as the integration of health and social care develops over time, to ensure that they link in with integrated outcomes.

How to respond

We are inviting responses to this consultation paper by 17th September 2014. Please send your response with the completed Respondent Information Form to nationalcarestandardsreview@scotland.gsi.gov.uk

or to:

Carly Nimmo
Mental Health and Protection of Rights Division
The Scottish Government
Area 3ER, St Andrews House
Edinburgh
EH1 3DG

We would be grateful if you would **use the consultation questionnaire provided in the consultation document or clearly indicate in your response which questions or parts of the consultation paper you are responding to** as this will aid analysis of the responses received.

This consultation, and all other Scottish Government consultation exercises, can be viewed online on the consultation web pages of the Scottish Government website at <http://www.scotland.gov.uk/consultations>

Handling your response

We need to know how you wish your response to be handled and, in particular, whether you are happy for your response to be made public. Please complete and return the Respondent Information Form as this will ensure that we treat your response appropriately. If you ask for your response not to be published we will regard it as confidential, and we will treat it accordingly.

All respondents should be aware that the Scottish Government are subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

Alternative formats and languages

If you require a copy of this paper in an alternative format or different language please contact us at the address above.

Next steps in the process

If you tell us we can make your response public we will put it in the Scottish Government Library and on the Scottish Government consultation web pages. We will check all responses where agreement to publish has been given for any wording that might be harmful to others before putting them in the library or on the website. If you would like to see the responses please contact the Scottish Government Library on 0131 244 4565. Responses can be copied and sent to you, but a charge may be made for this service.

What happens next?

Following the closing date, all responses will be analysed and considered along with any other available evidence to help us reach a decision about how to proceed with the review of National Care Standards. We will issue a report on this consultation process which will be published on the Scottish Government's website at:

<http://www.scotland.gov.uk/Publications/Recent>

Further consultation on the detailed content of the new standards will take place during 2014-15.

Comments and complaints

If you have any comments about how this consultation exercise has been conducted, please send them to:

Lindsay Liddle
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The Scottish Government
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