



National Voices

People shaping health
and social care

National Voices

Response to the Consultation: Introducing Fundamental Standards

April 2014

Summary

National Voices intends only to answer one question in the consultation, namely:

vii. Do you think any changes are needed to the draft regulations to ensure they reflect the policy aims we have set out in chapter 4?

The purpose of regulation is to ensure high quality care, treatment and support for people who use services. These draft regulations muddle the legal definition of quality in a way that is not helpful.

There must be clear reference to the involvement of, and respect for, people who are carers, family members and/or representatives of the person who uses the service.

Despite the government's intentions, outcomes relating to the full involvement of people who use services are not adequately reflected in the draft regulations.

Now that the government has taken the decision not to proceed with a 'two tier' approach to standards, and only to legislate for the Fundamental Standards, it is even more important that the regulations reflect these outcomes.

In particular we are concerned about, and will provide detailed comment on what we consider to be the following significant omissions:

- The omission of carers, family members and/or representatives of the person
- The omission of the outcome that people have choice and control
- The omission of people's right to full information with which to make decisions
- The omission of the outcome that people are supported to manage their health, care and support
- The omission of any reference to people being involved in planning their care, support and treatment

Finally, we believe that outcome-focused regulations should reflect that the primary purpose of hearing both complaints and the views and experiences of service users, their carers and families should be for the improvement of the quality of the service, not as an outcome in itself or for the completion of good governance.

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About National Voices

National Voices is the national coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them.

National Voices previously responded to the CQC consultation, A New Start, in 2013. A copy of this response can be seen [here](#).

Our principal concern in that response was to highlight the risk of providers being caught between two approaches: on the one hand, an emphasis from social care and from NHS commissioners on personalised, or person centred approaches and the full involvement of service users; on the other, a reductive, back to basics regulatory system that did not promote those approaches.

While we recognise the government has made some effort to respond to this concern in the new draft fundamental standards regulations, we believe the risk remains and that further revisions are required.

Response to questions in the consultation

National Voices intends only to answer one question in the consultation, namely:

vii. Do you think any changes are needed to the draft regulations to ensure they reflect the policy aims we have set out in chapter 4?

Quality definition

Part 2 of the draft regulations is titled 'Quality and Safety of Service Provision'. This confuses the legal definition of quality in a way that is not helpful.

For the NHS, 'quality' is now legally defined in the Health and Social Care Act 2012 as including three domains of 'safety, effectiveness and patient experience'. Thus the phrase 'quality and safety' repeats one of these domains and raises questions about what is meant by 'quality' in these regulations. This includes a question about whether patient experience is seen as part of quality here.

For the benefit of providers we suggest that this Part should align with the 2012 Act definition.

Carers, family and representatives

It is a significant and potentially damaging omission that, throughout these draft regulations, there is no reference to the family, carer(s) or other representatives of the person using services.

The current regulations for registered providers include family, carers and representatives throughout, so this represents a major loss in regulatory provision for their needs and involvement.

Carers also have rights to have their needs assessed and to be supported (see the provisions of the Care Bill 2013) and this is frequently part of NICE Quality Standards for various aspects of care and treatment.

Carers often provide the bulk of personal care for someone with needs and are an important source of continuity, as well as a resource with knowledge of the person's needs, wishes, values and preferences. This is especially important in relation to living wills and advance decisions.

Good practice in high quality care is to involve the person's family and carers as much as the person wishes, and to make them feel part of the 'team around the person'.

We note that, through the NHS Constitution, the NHS pledges: "to put you, your family and carers at the centre of decisions that affect you or them" and "to work in partnership with you, your family, carers and representatives".

The Constitution further recognises that carers and family share people's right to decision making:

"You have the right to be involved in discussions and decisions about your health and care, including your end of life care, and to be given information to enable you to do this. Where appropriate this right includes your family and carers."

'Representatives' may include advocates for people with disabilities or reduced capacity; or people who have been given lasting power of attorney to make decisions about health and welfare, and' or property and finances, for a person who has lost capacity.

The omission is particularly dangerous in relation to section 4(3)(d) – the case of someone who does not have capacity to express preferences. This draft regulation makes the paternalist assumption that in such cases it shall be the provider alone who is responsible for "determining and acting in accordance with the best interests of the service user".

Families, carers and/or representatives must have a right to be involved and consulted in such circumstances, or there is a very high risk that the known preferences, values and wishes (and the advance decisions) of the service user will be disregarded.

It is therefore vital that, when inspecting, monitoring and regulating for quality against the fundamental standards, the CQC is able to assess the degree to which carers, family members and representatives are or have been included and involved in the processes and decisions relating to people's care.

We suggest that the government should consider either a) including an overarching section that describes the role of carers, family members and representatives and clarifies that this applies under every fundamental standard, or b) inserts wording relating to carers, family members and representatives under each relevant standard as appropriate.

Person centred care standard Part 2, Section 2, 4

We recognise that this standard has been prepared in response to concerns raised by various stakeholders, including National Voices, that person centred care was not adequately emphasised in the CQC consultation in 2013. We value its prominence as the first of the fundamental standards.

However we believe the drafting needs revision to ensure that policy aims are fully reflected here.

There are various definitions of ‘person centred care’ available internationally, the common elements of which have recently been summarised by the Health Foundation¹:

“Person-centred care is a philosophy that sees patients as equal partners in planning, developing and assessing care to make sure it is most appropriate for their needs. This involves patients and their families being at the heart of all decisions. Services are reorientated to be user-focused, to promote control, independence and autonomy...”

The draft fundamental standard does not take this approach. It does not reflect these central tenets of person centred care.

The simple standard says that ‘The care and treatment of service users must reflect their needs and preferences’. This is well short of an equal partnership and the promotion of control, independence and autonomy.

We recognise that ‘autonomy’ and ‘independence’ are referenced under the draft fundamental standard on Dignity and respect. **We suggest that the words ‘choice’ and ‘control’ should also be included in that standard.**

If that were done, then the remaining issue with the draft standard on person centred care would be with the ‘equal partnership’ approach.

We note here that the health and social care systems nationally are currently united around a drive for ‘integration’, where that is defined as ‘person centred coordinated care’ in the Narrative produced by National Voices and Think Local Act Personal. This definition has already been widely adopted by local areas including all those that applied to be integration ‘pioneers’ (around 100 local areas). It is used as a

¹ ‘Helping measure person-centred care: Evidence review’, The Health Foundation, 2014

basis for the guidance for all local areas making proposals under the Better Care Fund.

The definition emphasises that the person with needs should be enabled to plan their care, to be involved in all discussions and decisions about their care, support and treatment, and to remain in control as much as possible at all times. Again, this goes far beyond 'needs and preferences'.

More recently NHS England has issued a new strategic approach for transformation in the NHS in the next five years, to achieve a system with six characteristics². The first of these is:

“a completely new approach to ensuring that citizens are fully included in all aspects of service design and change, and that patients are fully empowered in their own care”.

NHS England and all clinical commissioning groups are under a legal duty in the Health and Social Care Act 2014 to 'promote the involvement of each patient in decisions relating to prevention, diagnosis, care or treatment'.

The draft fundamental standard is not adequate to reflect these legal duties and strategic intentions. Nor is it adequate to reflect the strategic intentions of the social care system to deliver personalised care and support.

The word 'preferences' in the standard itself is too weak to encompass these approaches.

Within the subsequent text, clause 4(3)(c) on service users being able to make, or participate in making, decisions in relation to their care or treatment', effectively carries over sections of the text from the current regulation 17, with which we are content.

However, what is now omitted are a) the additional provisions from the current regulations which, in line with the NHS Constitution, make shared decisions possible and more likely to happen, and b) additional matters which have come into policy, and the NHS Constitution, since the current regulations were framed.

First, people cannot have meaningful participation in decisions unless they have the information to do so. The NHS Constitution provides a right for people “to be given information about the test and treatment options available to you, what they involve and their risks and benefits.”

Current regulation 17(2)(b) goes some way to reflecting this: “provide service users with appropriate information and support in relation to their care or treatment”.

We suggest the government should insert wording in this fundamental standard to require the provision of comprehensive information about tests and treatments, and their risks and benefits.

² 'Everyone Counts: planning for patients 2014-15', NHS England

Second, while ‘decisions’ may include specific preference-sensitive treatment decisions, that is not the only type of decision that people need to make. People with existing mental or physical health conditions or disabilities need to make daily decisions about how to live their lives while managing their conditions. Thus a key aspect of person centred care is to support and enable people to ‘self manage’.

This is recognised in the current Mandate to NHS England, where there is an objective for it to increase people’s ‘skills, knowledge and confidence’ to self manage; in NHSE’s statutory ‘participation guidance’ to CCGs on their duty to promote involvement, which emphasises support for self management; and in the new strategic objective of NHSE to achieve ‘patients fully empowered in their own care’.

Without a reference to supporting self management in the fundamental standards, providers will be caught between commissioners driving one approach, and regulation that does not actively support that approach.

We suggest the government should re-instate the wording from current regulation 17(2)(e): “where appropriate, provide opportunities for service users to manage their own care or treatment”.

Third, an important set of decisions for any service user is how to plan their care, support and treatment in advance. Although care and support planning does not feature in the current regulations, since their drafting it has risen up the agenda in various ways:

- the NHS Constitution has been amended so that the NHS pledges: “to involve you in discussions about planning your care and to offer you a written record of what is agreed if you want one”
- the Care Bill 2013 creates a statutory entitlement for a person with assessed needs to have a care plan
- the Children and Families Bill replaces statements of special educational needs with the right to an education, health and care plan
- the Liverpool Care Pathway for end of life care is being replaced by an emphasis on care planning
- government policy remains that every person with a long term condition should have a care plan, and this responsibility has been assumed under the Mandate by NHS England
- the Narrative for person centred coordinated care, adopted as the national system definition for integration, puts care planning at its centre and outlines what it involves from the service user’s perspective

Care and support planning can play a crucial role in helping people to coordinate their care and support, to achieve choice and control, to anticipate and plan for changing circumstances, and to anticipate, prevent or mitigate crises. It is also, therefore, vital for the objectives of the health and care systems to achieve sustainability by improving prevention and reducing unwarranted use of emergency and inpatient care.

Care and support planning is, on the whole, not happening now. Only 3% of people who identify themselves as having a long term condition say they have a care plan³.

It will not happen unless providers are very clear that it is an integral part of the fundamental standard on person centred care.

We suggest that the government should insert new text in this draft regulation, relating to providing service users with the opportunity to plan their care, support and treatment with their service providers.

Dignity and respect Part 2, Section 2, (5)

We are broadly content with this standard but, for the reasons outlined above, **we suggest inserting the words ‘choice’ and ‘control’ into clause (5)(2)(a).**

Receiving and acting on complaints, and Good governance Sections 11 and 12

Current regulations make it clear that the purpose of listening to people who sue services, and their families, carers and representatives, is to improve the quality of the service.

By contrast the new draft regulations emphasise the establishment of systems and the keeping of records.

This is surely not the right direction of policy given the focus of the Francis report and other inquiries on the need to move away from ‘tick box’ approaches to regulation, and to create effective, action-oriented complaints and feedback mechanisms.

On complaints, current regulation 10 requires providers to:

“have regard to (i) the complaints and comments made, and views (including the descriptions of their experiences of care and treatment) expressed, by service users, and those acting on their behalf”

The new draft fundamental standard on complaints, though its top line emphasises acting on complaints, merely requires providers to “establish and operate effectively a system for identifying, receiving, recording, handling and responding appropriately to complaints”, and to be able to give the CQC written information on these.

We are concerned that the new draft will encourage providers to establish systems but not to use these for the purpose of improving the quality of the service. All they will have to show is that they recorded the complaint and conducted relevant correspondence.

³ Figure from responses to the most recent General Practice Patient Survey

We prefer current regulation 10 in that it references not just formal complaints made through such an audited system, but all comments made, views expressed and experiences described by those who use the service.

In the new draft, these other views and experiences are managed instead under the fundamental standard on good governance. This says the provider must have a system to “assess, monitor and improve the quality of the services provided (including the quality of the experience of service users in receiving those services)”.

This usefully provides some reference to quality improvement; but we believe the emphasis on improvement is not sufficient, bearing in mind that this is only one part of a section that is essentially about record keeping, and that the overall fundamental standard here is that:

“Systems or processes must be established and operated effectively to ensure compliance with the requirements in this Part.”

We believe this really says nothing, and is not a fundamental standard of care in the sense that Francis was recommending.

We would strongly encourage the government to look again at these two standards together, with a view to revision so that:

- there is a fundamental standard that gives service users the right to a voice within the service, and to have that voice recognised, taken seriously and acted upon;
- that such a standard brings together not only complaint, but also comments, descriptions of experiences, and formal experience measurement; and
- that a clear purpose is described, which is to use these complaints, comments and experiences for the purpose of improving the quality of the service for all who use it.

In making such revisions we suggest the government draws upon current regulations 10 and 17, where providers are variously required to:

- “regularly seek the views (including the descriptions of their experiences of care and treatment) of service users”;
- “encourage service users, or those acting on their behalf, to... express their views as to what is important to them in relation to the care or treatment”; and
- “where necessary, assist service users, or those acting on their behalf, to express the views referred to [above] and, so far as appropriate and reasonably practicable, accommodate those views”;

We would like to see this focus on a planned, proactive and regular collection of service user feedback (including, but not only, complaints) brought into a new fundamental standard.

For queries or information

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