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Response to 'A New Start', a consultation from the Care Quality Commission

August 2013

Overview

Patients, service users, their carers and families want care services which are safe, which do not breach standards and which are effectively monitored, inspected and regulated.

As Berwick's recent report makes clear, service user involvement is indivisible from and indispensable to patient safety.

Moreover, safety is not the only aspect of care services which is important to service users. There are longstanding demands for better coordinated, more personalised services which support service user involvement, empowerment and control.

The CQC in its initial conception was oriented to promote and encourage these, through the primary and secondary legislation that established it.

Other key parts of the health and social care system are currently aligning towards these patient involvement and empowerment objectives, notably through the statutory duties and Mandate objective for the NHS commissioning system to promote the involvement of each patient; the national integration initiative; the vision and strategy of NHS England for meeting the long term conditions challenge; and the provisions of the Care and Support Bill.

In this response to the CQC consultation, 'A New Start', National Voices expresses a range of significant concerns that the current, necessary focus on implementing learning from the final report of the Francis inquiry risks marginalising service user involvement and empowerment at precisely the time that the rest of the system is beginning to catch up.

We have concerns that the preoccupation of this consultation document with basic safety in NHS acute hospitals, and the associated discussion of 'fundamental standards', put at risk the durability and comprehensiveness of the regulatory regime; and that the proposed approaches have a tendency to be paternalistic and regressive.

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While we welcome and support some of the proposals – the hospital inspection approach, and the incorporation of the duty of candour into regulations, for example – we seek a basic reconsideration and reconceptualisation of approaches to ensure that CQC regulation is capable of:

- covering 'quality' comprehensively
- setting standards that are applicable across care settings, and
- aligning with the movement of the health and social care systems towards 'integration' and sustainability, based on person centred care that supports user empowerment

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.

We have more than 150 members with 130 charity members and 20 professional and associate members. Our broad membership covers a diverse range of health conditions and communities and connects with the experiences of millions of people.

Answers to the consultation questions

1. *What do you think about the overall changes we are making to how we regulate? What do you like about them? Do you have any concerns?*

National Voices has a range of significant concerns about these proposals, and therefore we will provide an extensive answer to this question. In summary these concerns are about:

- **durability** – the proposals are a response to the post-Francis patient safety agenda, rather than a forward-looking approach to regulating a changing system of care
- **comprehensiveness** – the proposals are overwhelmingly focused on the NHS and particularly on acute hospitals, and may not be adequate for what is expected to be an era of greater integration, nor appropriate for environments such as social care support in the home, primary healthcare, and mental

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health services, where the agenda of supporting people to control their care is much more prominent

- **paternalism** – the definitions of the five ‘question’ domains, the descriptions of good and bad practice, and the overall approach to ‘bottom line’ regulation all indicate an approach which sees people as passive recipients of care and treatment
- **regressiveness** – the proposals risk sidelining the agenda of patient and service user involvement and empowerment which was built into the initial design of the CQC via the Health and Social Care Act 2008 and the regulations of 2010, especially regulation 17 – at the very time that this agenda is rising in importance through the national integration initiative and the NHS commissioning system

Introduction: safety in perspective

National Voices understands the need for the Care Quality Commission to revise its approach to regulation, inspection and monitoring, and wishes to be supportive to the new leadership of the Commission in so doing. We also understand and welcome the fact that CQC is responding to the second Francis Inquiry and the recommendations in its report.

All patients and service users want care and treatment which is safe, backed by a system of regulation that is fully adequate to identify failings and correct them. National Voices wishes to see the Francis recommendations implemented, and many of our members welcome the CQC’s intentions to improve the safety regime.

However, we also have an objective approach to the Francis recommendations. In our view these are not always perfect, and we believe the government and regulators should be considered and careful in the way they interpret and implement them.

In particular, while Francis accurately diagnosed the failures of the NHS to incorporate and respond to the voices of patients, service users, their carers and families, his recommendations to correct these failings unconsciously mirrored the NHS itself in being paternalistic, favouring incremental change, and having a weak understanding of the preferences of service users.

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There is logic in Sir Robert Francis' argument for a common set of simple standards, running through care systems and all regulatory mechanisms. We also welcome his focus on making these easily explicable to members of the public and users of services, and therefore we appreciate the CQC's attempt to provide a set of simple questions around which inspections and regulation will in future be based.

However, 'safety' does not stand alone. It is part of the trinity of 'safety, effectiveness and patient experience' which are the definition of quality in the Health and Social Care Act 2012. The CQC's revised regulatory approach needs to be adequate to cover all domains of quality.

The Berwick report, 'A promise to learn – a commitment to act', which was also commissioned by government in the aftermath of mid-Staffordshire, demonstrates that the patient safety agenda cannot be divorced from the agenda of involving people in their health and healthcare. His emphasis throughout is that:

'The goal is not for patients and carers to be the passive recipients of increased engagement, but rather to achieve a pervasive culture that welcomes authentic patient partnership – in their own care and in the processes of designing and delivering care. This should include participation in decision-making, goal-setting, care design, quality improvement, and the measuring and monitoring of patient safety.'

His list of the 'most important recommendations for the way forward' envisions the NHS as a learning organisation, 'fully committed to... Engaging, empowering, and hearing patients and carers throughout the entire system and at all times'.

That patient safety is enhanced by patient involvement is not in doubt. For example, patients who can see and correct their records are less likely to receive inappropriate treatment; empowering patients to ask health professionals if they have washed their hands improves cleanliness and reduces hospital acquired infection; care planning with patients reduces the likelihood of harm or neglect resulting from transitions in care.

But the justification for patient and service user involvement and empowerment is not subordinate to the safety agenda. National Voices will argue that service user involvement is important in its own right as a feature of good quality care. This would be recognised by anyone in social care or mental health care, where user independence, control and decision making are consensual aims and principles.

Moreover, recognition is growing throughout the system that, a) person centred care is at the heart of defining 'integration', and b) patient involvement to achieve successful self management is the key to meeting the long term conditions

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challenge; and for both these reasons, patient involvement is at the centre of the future success and sustainability of care.

The CQC regulatory regime must be capable of:

- covering 'quality' comprehensively
- setting standards that are applicable across care settings, and
- aligning with the movement of the health and social care systems towards 'integration' and sustainability.

More than safety

Although regulation must cover all three domains of care quality, the agenda outlined in 'A New Start' is dominated by an urgent emphasis on safety that springs from the mid Staffordshire and Winterbourne View experiences.

This must not be at the expense of a rounded and person focused approach to all aspects of care that are important to the users of services.

While we understand the desire to find simple questions through which to monitor, inspect and regulate, National Voices is of the firm view that the two questions focusing on patient experience, and the way these aspects of care are defined, are not adequate. They may have been too influenced by the relentless media and policy preoccupation with 'compassionate care' and dignity. While these are extremely important to all service users and their families and carers, they are not the only kind of patient experience that is important.

The introduction to the consultation document contains the welcome statement that "Above all, we will always be on the side of people who use services". However, we do not always find this followed through in the proposals.

There is an emphasis on patients being 'listened to', rather than being supported to take control and decision power over their care and treatment. Like the Francis recommendations, this appears paternalistic.

Patients also have demands for autonomy and independence, and for support for self care, personalised care planning and shared decisions.

National Voices, with a mandate from its 130 members who are health and social care charities, has advocated this agenda through the policy progress of the Health and Social Care Act 2012, the NHS Future Forum, the drafting of the NHS England Mandate, the production of the 'narrative' for person centred coordinated care (which

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redefines 'integration' and has been adopted by the Department of Health, NHS England, ADASS and all system leading organisations in health and social care), and the establishment of NHS England's vision and strategy for domain 2 of the Outcomes Framework (improved quality of life for people with long term conditions).

In its origins, and in parliament's intentions, the CQC had a distinct orientation towards service user involvement and empowerment, which we would urge the current leadership to recall and consider.

In both the primary and secondary legislation there is a strong emphasis on full service user involvement, which initially helped determine some of the CQC's orientation (for example, its derivation of the 'outcomes' for which it regulates, and its choice of service user involvement as the most prominent of these), but which then became increasingly obscured by events and decisions.

Regulations 10 (regular use of service user experience for quality improvement) and 17 (respect and involvement for service users) of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 are extremely important to service users.

Regulation 17 currently includes requirements for providers to:

- ensure the independence of service users (not just their 'dignity') [17,1,a]
- ensure that service users are enabled to make, or participate in making, decisions relating to their care or treatment [17,1,b]
- provide service users with appropriate information and support in relation to their care or treatment [17,2,b]
- help service users understand and discuss the risks and benefits of all care and treatment options, and express their views on these [17,2,c]
- 'where appropriate, provide opportunities for service users to manage their own care or treatment' [17,2,e]
- involve service users in decisions relating to the way in which the regulated activity is carried on in so far as it relates to their care or treatment [17,2,f], and
- help service users to achieve 'autonomy, independence and community involvement' [17,2,g].

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This is excellent wording to promote and support the 'patient involvement' agenda (by which we mean, for example, tailored and comprehensive patient information, education for self management, shared treatment decisions and [personalised care planning]).

Since it was published, additional instruments have appeared which align with it. These include:

- the duties in the Health and Social Care Act 2012 for the NHS commissioning system (NHS England and CCGs) to 'promote the involvement of each patient' in decisions relating to 'prevention, diagnosis, care or treatment';
- the objective in the Mandate for NHS England to achieve a dramatic increase in patient involvement, by building the 'knowledge, skills and confidence' of people to manage their health and care; and
- provisions in the Care and Support Bill currently before parliament, to ensure that everyone eligible for social care is entitled to care planning.

National Voices believes it is very important both now, and as the patterns of care services begin to change in the next few years, for regulations 10 and 17 to remain intact, to continue to be requirements for all registered providers, and in particular to be actively used by CQC within its approaches to monitoring, inspecting and regulating on behalf of service users.

Our view is that the concept of 'fundamental standards' risks marginalising this agenda at the political, regulatory and provider levels, if attention is overwhelmingly focused on minimum safety standards and the need not to breach them.

Or to put it another way, we believe that service user involvement, empowerment and control are themselves fundamental outcomes and belong in the set of fundamental standards.

- 2. Do you agree with our definitions of the five questions we will ask about quality and safety (is the service safe, effective, caring, responsive and well-led)?*

In this answer National Voices will concentrate on the two questions focused on 'patient' experience.

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In the way they are defined, these two questions are not adequate to the regulatory task. They exclude some domains of patient experience – and indeed some of the rights of patients under the NHS Constitution – that are central to patients' experience of and satisfaction with services, and which are being pursued through attempts to change the pattern and design of services by other system players.

'Is it caring?'

The explanation for this reads:

“By caring, we mean that people are treated with compassion, respect and dignity and that care is tailored to their needs. For example, do care home staff understand people's individual needs, spend time talking to them and make sure they have the opportunity to take part in activities that they enjoy?”

This is very paternalistic. The culture of care implied here is one where things are done to and for people, but nicely.

Later in this explanation section there is explicit acknowledgement that this is driven by the Compassion in Practice agenda. We support the intentions of Compassion in Practice, but would note that its full title – ‘Compassion in Practice: Nursing, Midwifery and Care Staff: Our Vision and Strategy’ – demonstrates that this is an NHS organisational strategy targeting staff development rather than service user empowerment.

Even here, however, the need to work towards user empowerment is identified. In the list of ‘messages’ that NHS England heard in its consultation on Compassion in Practice, one was:

“Shared decision making and communications with patients and the people we support

“Patient and service user choice and clear communication with patients and the people we care for is crucial to ensure they are partners in their care and they share decision making with the team providing their care. All the people in our care need to have a voice, choice and control.”

As a result the first ‘action area’ in the strategy is ‘Helping people to stay independent, maximising well-being and improving health outcomes’. This involves ‘support and services which enable people to remain active, connected and independent in their own homes, or another place of their choice, for as long as they are able, and it means joining up health and care services to provide the integrated care that people want’.

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We find no reflection of this emphasis on user empowerment and support in the CQC consultation, nor in the definition of the 'Is it caring?' question.¹

'Is it responsive?'

Here the CQC's definition is:

"By responsive, we mean that people get the treatment and care at the right time, without excessive delay, and that they are listened to in a way that responds to their needs and concerns. For example, is a GP surgery open at times to suit the needs of the local population?"

Again we find this inadequate. It hints at consumer responsiveness, which is no bad thing, but it does not reflect a care service culture of service user involvement in care and treatment.

In fact, the document then goes on to use a 'bad care example' where it is precisely the lack of this involvement that is criticised ('some people were not always involved in making decisions about their own care'), so perhaps there is a failure of communication around this question, and the CQC intends 'responsiveness' to be somewhat more comprehensive and deep-reaching than first appears.

Furthermore, it is confusing that this issue of 'involvement' does not reappear in the suggested indicator set for acute trusts on this question, in the Annex. We do not understand why all of those indicators are drawn from sources that are service-reported rather than patient-reported.

Suggestions for improvement

If the fundamental standards, and the questions against which CQC inspects and regulates, are to be adequate, National Voices believes they must work harder to encompass all that is meant by 'patient involvement' or 'service user empowerment' (there are many interchangeable terms available here).

¹ We do, however, note that an examination of the detail of the Annex to the consultation, which suggests indicators for acute trusts on this question, shows that the CQC is considering using the national patient survey question about involvement in decisions. However, this is all buried away. If CQC intends that 'caring' should include the concept of respecting service users' independence and involving them in their care and treatment, this should be clearly explained at the higher levels. Additional indicators testing service user involvement should also be considered in that case.



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For people to be involved in their care and treatment is:

- a. a right (or group of rights) under the NHS Constitution
- b. a human right (in the WHO's definition)
- c. a legislative duty on NHS commissioners (in the Health and Social Care Act 2012 where both NHSE and CCGs have duties 'to promote the involvement of each patient in prevention, diagnosis, care or treatment')
- d. a duty of every doctor ('Good Medical Practice' duty to work in partnership with patients), and
- e. a clearly identified demand, with many complementary and interlocking aspects, articulated by service users via the National Voices narrative for person centred coordinated care² (which all localities are expected to adopt) and the Think Local Act Personal initiative, 'Making it Real'³

Any of these sources could be referenced in order to find wording to encompass user involvement. But in fact this is not necessary. The regulations governing registered providers who are regulated by the CQC already have excellent provision for the inspection and regulation of providers according to these aspects of care (see above).

These provisions were made by parliament after a campaign by consumer organisations who wanted the CQC to be 'future proof' as the culture of care changed.

We believe that if it wants to demonstrate it is 'on the side of patients and service users', the CQC must keep this emphasis on service user empowerment, involvement in decisions and independence at the front of its regime of regulation, inspection and monitoring.

This may be possible within the fundamental standards and the 'five questions' approach, but both will need to be 'conceptualised' in a new way for that to happen.

4. *Do you think there are additional areas that should be fundamentals of care?*

As previously stated, National Voices believes the initial suggestions for fundamental standards are disproportionately driven by post-Francis concerns for safety, and by preoccupation with hospital care.

² see <http://www.england.nhs.uk/2013/05/14/c-care/>

³ see <http://www.thinklocalactpersonal.org.uk/Browse/ThinkLocalActPersonal/?parent=8463&child=9091>



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Common fundamental standards should be future-proof, applicable across all providers, and more securely based on patient and service user rights and empowerment.

4.i The current wording regarding complaints needs some addition. We agree that people should be 'listened to' and not victimised, but it is also important that something happens as a result of the complaint, ie: 'action is taken to put things right, or an explanation is given of why this is not possible'.

4.ii Given the emphasis of the Francis recommendations on creating a culture of candour, there should be a fundamental standard that embodies openness. Part of the purpose of the standards is to enable clear identification of breaches, and consequent regulatory action, and this will be required for prosecution of any instances of cover-up, alteration or loss of records, etc. A standard along the following lines is required: 'If something goes wrong in the course of my care or treatment, I and my family will be promptly and fully informed of the error and its potential consequences for me. The care provider will take action for redress.'

4.iii Where patients have clear, legally sourced rights under the NHS Constitution, these must be reflected through the fundamental standards (since rights are fundamental). We recommend that the CQC and NICE take full cognisance of the patient rights in the Constitution and incorporate these into the standards.

4.iii We suggest a fundamental standard relating to patient records. This would require service providers to adopt common, consistent record formats that include the recording of service user views and preferences, including any agreed care plan.

Many patient safety incidents, and much of the distress of transitions, are due to inadequate integration of patient information. Moreover, interoperable records to which service users have access will be a major enabler of service user empowerment and shared decisions.

A standard relating to this would help align the regulatory regime with the clear government and NHSE intentions to provide records access to all patients, and for the NHS to 'go digital' by 2018. The Professional Records Standards Body⁴ of which National Voice is a founder member aims to set clear standards for these purposes.

⁴ The Professional Records Standards Body (PRSB) www.theprsb.org.uk or contact mala.bridgelal_ram@aomrc.org.uk



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5. *Do the draft fundamentals of care feel relevant to all groups of people and settings?*

No. They are overly focused on NHS acute trusts. For example, the word 'discharge' is only used for the transition from hospital inpatient to another setting.

In order to reflect generic service user demands and expectations, National Voices recommends that the CQC draws on two existing sources of 'I' statements that have been co-produced with service users:

- the narrative for person centred coordinated care which sets out what service users want from 'integration'
- the 'Making it Real' initiative which describes personalised social care from the perspective of service users

As an example, instead of 'discharge', the 'narrative' states:

"When I move between services or settings, there is a plan in place for what happens next.

"I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact."

7. *Do you agree with the proposals for how we will organise the indicators to inform and direct our regulatory activity?*

The pyramid of standards is a logical approach. Our concern is with the selection of indicators, and we hope this will undergo significant development and improvement in due course.

Under the 'caring' domain, we were pleased to see the indicator for involvement in decisions. This, however, conflicts with the higher level explanation of what the 'caring' question means (see above). If indeed it is the intention to include patient involvement and empowerment in this domain, additional indicators would be required, especially around the provision of full information on options for care and treatment, including their risks and benefits (see the NHS Constitution), and on support to self management and personalised care planning.

We do not understand why, under the 'responsive' domain, all the suggested indicators are from service-reported, rather than patient-reported sources. There are various indicators from the national inpatient survey that could be used to monitor responsiveness: some around care responses, such as answering the call button;



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many around communication, such as the giving of information and explanations, and answering patients' questions in a way they can understand.

National Voices welcomes the spotlight on discharge under this section. Discharge is one of the worst organised hospital processes for patients, and this is reflected in poor scores on some patient survey questions around discharge. We are annually dismayed that little attention or action is focused on this transition.

We would urge the CQC to use indicators from the inpatient survey for this domain, particularly those relating to:

- information about any new medicines the patient is taking away;
- information about what to do and who to contact if things go wrong after discharge;
- the involvement of family/carers in decisions around discharge.

For the future we would like to see additional patient experience questions developed around this transition, drawn from the narrative for person centred coordinated care and relating to the planning of subsequent care or support arrangements.

10. Do you agree with our proposals for inspecting NHS and independent acute hospitals?

National Voices welcomes these proposals as being necessary improvements to the previous CQC inspection regime. In particular, we welcome:

- the emphasis on specialised inspection
- the use of additional expertise from outside, and
- the focus on people's views and experiences of care.

The consultation document predates the publication of the review of 14 acute trusts by Sir Bruce Keogh and colleagues. This review developed an inspection process which National Voices (which was on the review's advisory panel) wishes to see the CQC adopt and build upon.

In particular, the Keogh review made innovative use of patient and public opinion, and of patient representatives on the inspection teams. This again is provided for in

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the primary legislation establishing the CQC which requires it to publish a statement about how it will involve service users, including how “any of its functions [are] to be exercised by, or with the assistance of, service users and carers”.⁵

We suggest that, in light of the proposals in ‘A New Start’, the subsequent consultation responses, and changes to the inspection regimes, the CQC should consider revising that statement and consulting on the revision.

17. Do you agree that a duty of candour should be introduced as a registration requirement, requiring providers to ensure their staff and clinicians are open with people and their families where there are failings in care?

Yes.

National Voices with members and allies campaigned for a statutory duty of candour during the passage of the Health and Social Care Act 2012. We recommended that it could be achieved through insertion in the regulations under the 2008 Act.

18. Do you agree that we should aim to draft a duty of candour sufficiently clearly that prosecution can be brought against a health or care provider that breaches this duty?

Yes. The possibility of prosecution for breaches must be clearly understood by providers of care.

19. Do you have any other comments about the introduction of a statutory duty of candour on providers of services via CQC registration requirements?

The Francis Inquiry final report and the recent Berwick report both place great emphasis on the need to shift from a culture of blame and bullying to one of openness and candour. We believe that this needs to be reflected not just in the regulations but also in the CQC’s new approach to regulation, inspection and monitoring.

National Voices therefore urges the CQC to consider:

- a. how the requirement for candour should be reflected in the fundamental standards of care, and

⁵ Health and Social Care Act 2008, 5(1)(d)



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- b. how 'candour' can be incorporated into the use of the question, 'Is it well-led?'. A well-led service provider should be able to demonstrate a culture of openness, transparency and candour.

Further information about this response

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