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Building national consensus on experiences of care

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Abstract

The NHS in England is measured against specific indicators that focus on ‘ensuring that people have a positive experience of care,’ yet there was a lack of organisational alignment across the new national health and care organisations regarding their understanding of what constitutes a positive experience of care. This represents a major barrier to achieving an aligned and consistent system-wide approach to improving experiences. To address the need to create national alignment in definition and approach, we worked with the Patient Experience Sub-group of the National Quality Board to develop consensus on how national organisations define ‘experience of care’ and what constitutes a good experience of care, drawing on relevant evidence and guidance. Working in collaboration, we developed a ‘Narrative’ to describe this consensus and highlight resources and examples of good practice on improving experiences of care for the wider system, including commissioners and providers, to support broader improvement and implementation efforts.

Keywords

Patient experience, experiences of care, National Health Service; NHS, consensus, definition

Introduction

This short paper describes the process for developing consensus and the key elements of the shared ‘Narrative’ on experiences of care for the major national health and care organisations in England (the organisations are those that are represented on the National Quality Board (NQB)). While the focus is on England, we hope it offers some transferability to other countries faced with the challenge of creating organisational alignment in their approach to ensuring high quality patient experience.

Background

The NQB brings together leaders of the national planning, funding, standard-setting and regulatory organisations across the health and care system (see appendix), alongside expert and lay members,¹ with the ambition of championing quality and ensuring alignment in quality throughout the NHS.² The NQB, and especially its lay members, has consistently championed the importance of patient experience. In addition, in summer 2013 (at the time of this work starting), the National Quality Board had various sub-groups, one of which was a Patient Experience Sub-group. The role of the NQB in the new system has recently been confirmed, as signalled in the Five Year Forward View.³

While there have been important improvements in the experiences that people have of their care in England (for example, there have been consistent improvements across a number of questions in the Cancer Patient Experience Survey⁴), there is still some way to go. We do not yet achieve the standards of consistency that people expect, for example 18% of respondents to the most recent Adult Inpatient Survey rated their experience as poor,⁵ and evidence shows that we have further to go to systematically use the patient feedback we are now collecting to drive improvements.⁶ High-profile instances of a breakdown in people’s experiences, such as at Mid-Staffordshire NHS Foundation Trust⁷ and Winterbourne View,⁸ serve as illustrations that severe breakdown in quality can occur. Work is still required before experience is viewed as equal to the other elements of high-quality care.

Since the passing of the Health and Social Care Act (2012),⁹ the NHS in England has been held to account for the outcomes it achieves for people who use services. This is measured by the three components of high quality care – clinical effectiveness, safety and experience – through the NHS Mandate and the NHS Outcomes Framework. The latter includes specific measures on ‘ensuring that people have a positive experience of care.’ However, from a policy perspective, it was clear there are still variations in organisational approach and, despite many resources and

guidance, there was still a need to develop consensus across organisations, in an attempt to enhance the opportunities for implementing a unified vision of patient experience across the NHS. In this way we were exploring the context into which any intervention to enhance experience would be implemented.

Process

The NQB secretariat, based within NHS England, together with two secondees from Macmillan Cancer Support, worked together with the NQB Patient Experience Sub-group to produce the Narrative. Expert and lay representatives formed an important part of this group.

Rationale

Initially it was important to collect evidence that there was a lack of alignment across the national organisations represented on the NQB regarding their understanding of what ‘patient experience’ means. As a result of new legislation (the Health and Social Care Act 2012), the system and some of the organisations within it were new, meaning that there was no agreed approach. Lacking a foundation of shared understanding serves as an important barrier to aligning work across the system aimed at improving experiences of care and there was a risk of sending mixed and confusing signals to providers if the national planning, funding, standard-setting and regulatory bodies did not have a common approach.

Mapping exercise

A mapping exercise was therefore conducted which involved detailed interviews with representatives from each of the NQB organisations to understand whether each organisation had a recognised definition of ‘patient experience,’ what work it was taking forward to improve people’s experiences and how it was working with other organisations in doing so. A clear finding from the mapping exercise was that, for the majority of organisations, there was no internal agreed understanding of what was meant by ‘patient experience’, and that there was certainly no shared understanding of this across the organisations. While there is a range of published definitions of experience and of a good experience (such as the NICE Quality Standard¹⁰), it is clear that there was no consistent approach to how organisations defined or thought about experience.

Workshop

Using the findings from the mapping exercise, it was possible to gain agreement from the Sub-group that it was important to achieve a shared understanding of what is meant by ‘patient experience’. We therefore held a workshop, facilitated by the King’s Fund, to bring together representatives from all NQB organisations. In order to frame our work at the event, a number of different

definitions of ‘patient experience’ were considered, including The Beryl Institute definition.¹¹ However, it was suggested that the most useful focus for alignment would be an understanding of the different elements of experience, specifically of a good experience of care, particularly relevant for an English context.

At the event we discussed the potential ways in which to frame a good experience. At a later Sub-group meeting it was agreed that the Warwick Patient Experiences Framework represented the best evidence base currently available for defining a good experience.¹² The Warwick Patient Experiences Framework is the first patient experiences framework with an explicit link to an underpinning patient evidence base, linking themes and sub-themes with specific references. National Institute for Health and Care Excellence (NICE) has also used it to underpin both its guidelines¹³ and quality standard¹⁴ on patient experience.

While recognising that the evidence on experiences of social care has not been synthesised to the same extent as the evidence on experiences of health care services, it was agreed at the event that it would be important to make the language used in the Narrative as inclusive of social care as possible. Therefore, it was decided to use ‘experiences of care’ rather than ‘patient experience’ since ‘patient’ is a less helpful term in the context of social care. We also ensured that experts from social care were part of the process of developing the Narrative. Elsewhere in the final Narrative too we have, wherever possible, avoided using the term ‘patient.’ Finally, it was agreed that it would be important to bring clarity to the roles of the different NQB organisations in improving experiences within the broader NHS. This is the first time we have developed such an organic understanding of how the national roles on improving experiences work within the NHS.

Sources of evidence

Following the workshop, the NQB secretariat produced an initial draft of a Narrative, with the aim of achieving organisational-level consensus. This drew on several sources of existing evidence to describe:

- What ‘experience of care’ is (this was not intended to be a formal definition, but to expand on the concept, for example by describing that experience can be divided into ‘functional’ and ‘relational’ aspects, and differs from a number of related terms, such as ‘satisfaction’, ‘engagement and involvement’ and ‘patient-centred care’. It was important to give clarity to this, since it is on experience that the NHS’ performance is measured, not on the other concepts);
- Why experience is important (in particular this draws on evidence that links experience and the other aspects of high-quality care¹⁵ and that links staff engagement and experience of service users¹⁶);

- What a good experience of care is (the elements of experience set out in the Warwick Patient Experiences Framework were drafted as 'I' statements for consideration by the Sub-group. Following feedback from the Sub-group, an element of a good experience on the physical environment was added);
- A shared ambition, towards which all NQB organisations could work, as well as an explanation of the role of each of the national organisations in improving experiences.

Process of synthesis

A key aspect of the process of synthesis of the available evidence was achieving agreement and consensus across the organisations represented on the Sub-group. This involved repeated testing of the draft Narrative with the Sub-group, discussion and amendments made to ensure that consensus was achieved. In effect, therefore, the Narrative drew on existing published evidence, as well as organisational and individual expertise, reflecting the different roles organisations had in relation to experiences of care.

Gaining agreement about what 'experience of care' is and why it is important was vital in framing the 'I' statements that constitute the shared understanding of what a good experience of care is. The Sub-group was keen for the Narrative to have as wide an audience as possible and it was felt that framing the elements of a good experience as 'I' statements would help to make the document as accessible as possible. It also helped to place the person at the centre of the Narrative.

Testing the Narrative

A draft of the Narrative was tested through an online consultation, aimed at individuals within health and care organisations, and service users and the public, but open to anyone to respond. In addition, a key aim of the Narrative was to produce an accessible document that could be used by anyone with an interest in experiences of care, including service users and the public. Therefore, large sections of the Narrative were edited by an organisation specialising in plain English.

Examples of good practice and resources

A significant step in producing the Narrative involved the collection of a large range of examples of good practice and resources for use by the broader system, as well as drawing together the emerging evidence on the organisational-level factors that can impact on whether an organisation is successful in improving quality, including experiences of care. The examples of good practice were collected through a variety of routes, including the online consultation and short-listed entries to the Patient Experience Network National Awards.¹⁷ The use of examples of good practice reflects evidence that suggests that providing examples and story telling about good

practice can often be an effective form of implementation. In addition, a range of patient and staff quotes was collected from online resources such as Patient Opinion¹⁸ and healthtalk.org¹⁹ and through Sub-group members. The intention is therefore that the Narrative, as well as achieving important consensus across the national organisations on the NQB, will also represent a key contribution to supporting the wider system to improve experiences.

Design

Finally, it was agreed that it was important to make the Narrative as interactive and user-friendly as possible. Therefore, we worked with a design agency to produce an interactive PDF version of the final Narrative.

The Narrative

The final Narrative draws together a range of different materials and evidence on experiences of care, including individual and organisational expertise. Most significantly, the Narrative sought to achieve, through on-going dialogue and consensus building, agreement across the major health and care organisations in England regarding experiences of care. This supports a consistent approach to improving experiences from a national perspective and the alignment of efforts. It also highlights the need to discuss the reality of how good practice should be implemented. It was important that we developed a 'Narrative' as opposed to a framework or a set of standards. This was because the Narrative seeks to be part of the grassroots 'movement' in patient experience within quality assurance settings, both in providers and commissioners.

The sections of the Narrative below are those that we think will be of most interest for the purposes of this paper. The full Narrative can be found here: <http://www.england.nhs.uk/wp-content/uploads/2015/01/improving-experiences-of-care.pdf>

Shared understanding

The following elements of a good experience were included in the Narrative (expressed as 'I' statements):

- I am involved as an active partner in my care – this means playing an active role, when I'd like to, in making decisions about my care, treatment and support, and being supported to look after myself day-to-day.
- I am treated as an individual – my needs, values and preferences are respected.
- I am able to access services when I need them, and my care is coordinated so I know where to go next and where to turn if I have a problem.

- The people providing my care recognise that I am the expert on me – this means that my knowledge, skills and expertise as a result of living with my condition, as well as the effect that this has had on my life and on the lives of those who are important to me, are respected.
- I am asked how I would like to be communicated with so that communication is tailored to me and is delivered with care and compassion, and I have the opportunity and time to ask questions and have a conversation about my care, treatment and support.
- I have access to the information I need, which is presented in a way that is right for me, to make sure I understand what is happening and can play a role in making decisions if I'd like to.
- I have access to the support I need and is right for me, including emotional and practical support, and I am able to involve my loved ones in decisions about me.
- The environment in which I receive my care is clean and comfortable and makes me feel dignified.

Organisational-level factors that contribute to improving quality of care, including experiences²⁰

Much of the current evidence is focused on the actions that providers can take to improve experiences, yet many of the factors we identified are applicable to commissioners too:

- Meaningful involvement and engagement with those that use health and care services, their families and the public throughout the process of designing, running, monitoring and reviewing services.
- Strong, committed senior leadership (chief executives, board and senior leaders), including:
 - Setting out a clear strategic vision on quality;
 - Clear and consistent communication of vision and strategy which frame experience as an integral and equal part of the quality framework (alongside clinical effectiveness and safety);
 - Modelling behaviours, including promoting a culture of continual improvement and learning;
 - Empowering people at all levels of the organisation to drive change;
 - Adequately resourcing service redesign that improves experiences.
- An emphasis on data and intelligence on experiences gathered from continual feedback from those who use services, their carers, families and the public to measure and manage performance on experience.
- A focus on the workforce: embedding experiences into HR processes such as induction and appraisal, and prioritising and improving staff engagement, which is strongly linked to improving people's experiences of care.

Discussion

It is recognised that the production of the Narrative is only the first step in truly aligning work at a national level to improve experiences of care. For example, a greater fit between the elements of a good care experience and measures of quality is needed. To this end, it is expected that the Narrative will influence current discussions in England about the insight that is collected nationally on people's experiences and how the payment system could be designed to incentivise improvements in experience. However, gaining agreement at a national level on what we mean by 'experiences of care' is a significant step forward, particularly as we underpinned this with relevant evidence to guide the Narrative. In addition, the direction of travel in England, which sees national organisations coming together to produce policy, guidance and support²¹ is consistent with the way in which the Narrative was produced and what it is seeking to achieve.

The Narrative also provides an example of how other organisations within one country can join together, to draw on key evidence, and develop consensus to guide practice and the delivery of high-quality patient care. This attempt at creating national alignment could be adopted in other country settings to create consistency in understanding and in the implementation of good practice to contribute to high quality care.

The Narrative commits the national organisations to using the document in working together to improve experiences and it is hoped that it will provide a solid base for doing so. Finally, within the context of the NHS Five Year Forward View,²² which recognises the need to focus on systems and not just organisations, the aim of the Narrative is to show what role all parts of the system need to play in setting the climate for consistently good experiences.

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Appendix

The organisations represented on the National Quality Board at the time at which the work was carried out are (please click on each organisation name for more information on its role):

- [Department of Health](#)
- [NHS England](#)
- [Care Quality Commission](#)
- [Monitor](#)
- [NHS Trust Development Authority](#)
- [National Institute for Health and Care Excellence](#)
- [General Medical Council](#)
- [Nursing and Midwifery Council](#)
- [Health Education England](#)
- [Public Health England](#)
- [Social Care Institute for Excellence](#)
- [Healthwatch England](#)
- [Parliamentary and Health Service Ombudsman for England](#).¹

The Narrative was also produced in partnership with:

- [Health and Social Care Information Centre](#)
- [NHS Improving Quality](#).