

National Institute for Health and Clinical Excellence

**Patient experience in generic terms**

**Stakeholder Comments**

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<b>Stakeholder Organisation:</b>	National Voices
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<b>Name of commentator:</b>	Don Redding, Director of Policy
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Order number <i>(For internal use only)</i>	Document	Section Number	Page Number	Comments
	Indicate if you are referring to the <b>Full version NICE version Appendices</b> Or <b>QS (Quality Standard)</b>	Indicate <b>number</b> or <b>'general'</b> if your comment relates to the whole document	Indicate <b>number</b> or <b>'general'</b> if your comment relates to the whole document	<p><b>Please insert each new comment in a new row.</b></p> <p><b>Please do not paste other tables into this table, as your comments could get lost – type directly into this table.</b></p>

Example	Full	3.4.6	45	Our comments are as follows .....
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Example	NICE	1.1.2	12	Our comments are as follows .....
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Example	QS	6	15	Our comments are as follows .....
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**PROFORMAS THAT ARE NOT CORRECTLY SUBMITTED AS DETAILED ABOVE MAY BE RETURNED TO YOU**

1	Full/QS	General		<p>The guideline discussion and recommendations, and the subsequent Quality Statements, appear to the lay reader to be tilted towards hospital care settings rather than primary or community healthcare.</p> <p>For example, recommendation 16 says that ‘when patients in hospital are taking medicines for long term conditions’ there should be a discussion about self-management. But patients with long term conditions need such opportunities whether they are in hospital or in the community.</p> <p>This hospital bias may be a natural consequence of the fact that much of the evidence around patient experience, and many of the tools for measurement, have been developed in relation to hospital inpatients in particular. It may also be influenced by the fact that the approved Indicators for Quality Improvement are primarily drawn from the national inpatient survey.</p> <p>However, there is a substantial literature on patient experience in primary care, and a range of instruments that have been developed to measure patient experience generally, and experience of the consultation in particular. Until 2008, the regulator commissioned annual surveys of people’s experience of primary care as part of the national patient survey programme. These were superseded by the DH-commissioned General Practice Patient Survey. To date there has been little analysis of the GPPS data for purposes other than monitoring the performance of GP</p>
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practices. These, and other tools for measuring patient experience in primary care, are discussed in 'The quality of patient engagement and involvement in primary care', Parsons, S et al, Kings Fund, 2010, a report commissioned as part of the Kings Fund Inquiry into the quality of primary care.

That report concluded, on the basis of a literature review and a review of measurement tools, that the 'key domains' of engagement in primary care consultations are as follows:

- listening
- involvement in decisions
- information, explanation, questions being answered
- consultation length
- empathy

We also note that there have been national surveys of the experience of maternity service users. Although these in part reflect hospital experiences (since the majority of women gave birth in hospital), they also track experience in relation to services provided in the community and in primary care both before and after the birth.

This general reflection is relevant because the factors that contribute to overall experience of care in primary and community settings may differ in some respects to those that contribute to experience of hospital care and treatment. For example, they are likely to be less focused on specific single treatment interventions and more focused on maintenance of quality of life in the face of one or more continuing health conditions.

In this context, more emphasis may need to be placed on consultations and discussions that help people to manage their health in the context of their general life circumstances. The importance of the 'consultation length' factor in the above list indicates that such discussions can either be enabled by (longer) consultations or limited by (shorter) consultations.

If these hypotheses are correct, then the guideline recommendations and quality statements should be reviewed to ensure that they properly reflect the importance of techniques and interventions that enable patients actively to manage their situation. These might include, for example:

- longer consultations/changed consultation styles
- opportunities to learn about, and be supported in, managing one's own condition(s)
- use of opportunities to review management, including helping patients to prepare and make use of reviews
- participative care planning

This general comment leads to our suggestions in comments 2-5 in relation to education for self-management; and to our further comments in relation to revising the recommendations on information provision and decision making in the full guideline.

				<p>We are aware that the Health Foundation is preparing a submission, drawing on a community of expertise, and considerable research literature in relation to these matters. National Voices also supports that submission and asks the GDG to give its full consideration to the evidence and arguments therein.</p>
2	Full	10.5	108-112	<p>National Voices was surprised that in the section on 'education programmes' the literature search identified only one systematic review and no other high level studies on the effectiveness of education for self-management.</p> <p>We would ask the GDG to reconsider the evidence relating to this section. As part of this we suggest liaising with other experts familiar with this literature. We would also ask the GDG to review the evidence listed at <a href="http://www.investinengagement.info/Self-managementOutcomes">http://www.investinengagement.info/Self-managementOutcomes</a> This is a Department of Health-funded website researched and published by Picker Institute Europe, which identified, reviewed and summarised evidence (systematic and other high level research reviews) for the effectiveness of patient-focused interventions.</p> <p>The evidence listed here does, in part, support the GDG's view that education programmes fit into disease- or condition-specific guidance – in that it indicates that condition-specific education is more useful to patients than generic self-management courses for long term conditions.</p> <p>However, our assessment of this evidence is that it also shows strong enough benefits across a range of conditions for the GDG to strengthen its support to education interventions; to strengthen the wording of Recommendation 66; to improve the wording of Recommendation 65; and, in the Quality Standard, to include an additional item on education. We make suggestions for these in subsequent lines of this consultation response.</p> <p>According to this evidence review, numerous studies show that self-management education has a positive impact on patients' experience of using health services, including by:</p> <ul style="list-style-type: none"> <li>• increasing patients' knowledge and recall of relevant information;</li> <li>• improving their satisfaction with services;</li> <li>• improving their coping skills;</li> <li>• increasing their confidence to manage their condition; and</li> <li>• increasing their perception of being socially supported.</li> </ul> <p>Like the GDG, we acknowledge some limitations to these studies, particularly in that they often studied outcomes only in the relative short term (for example, up to six months after participating in education).</p> <p>However, from this review it does seem there is more evidence, albeit patchy, for the cost-effectiveness of education interventions in relation to, for example, diabetes, COPD and asthma.</p>

3	Full	4.1	27	<p>Evidence from the 'invest in engagement' website reviewing the effectiveness of self-management education suggests that these are most effective when they are a) condition-specific, and b) linked back in to their continuing care under the main professionals involved with them. Linking the patient's learning from self-management education to their goal-setting with clinicians is more likely to enable sustained changes in behaviour, and to improve experience.</p> <p>National Voices would suggest the following amendments to recommendation 65 on education programmes:</p> <p>In line 41, after 'taking into account', insert 'their specific condition as well as'...</p> <p>In line 40, after 'objectives', insert ', which are discussed and reviewed with their primary healthcare professional'.</p>
4	Full	4.1	28	<p>In accordance with our comments above, National Voices would suggest strengthening the wording of Recommendation 66. The words 'that are available and meet' should be deleted, and replaced with, 'by providing these in accordance with the criteria listed in recommendation 65'.</p>
5	QS	16	4	<p>In accordance with our comments 2-4 above, National Voices suggests extending QS 16 to include the provision of education as well as information. An additional paragraph could be added which states:</p> <p>'Patients with an identified long term condition are provided with the opportunity to participate in evidence-based education on how to manage that condition, which takes into account their particular condition and needs, and helps them to set aims and objectives in partnership with their primary healthcare professional'.</p>
6	Full/QS	General		<p>National Voices welcomes many of the recommendations and quality statements around the themes of informing patients and engaging them in decisions. In these statements the word 'treatment' is used to cover all treatment interventions. We would ask the GDG to consider whether there should be a specific QS on medicines.</p> <p>This is because the decision to prescribe a new medicine is, in many settings, the most frequent treatment decision taken, and yet there is evidence that clinicians may not see medicine prescription as a significant locus for involving patients in the decision.</p> <p>Data from national patient surveys indicates that around 80% of inpatients and 54% of primary care patients say they received a new medicine during the most recent episode of healthcare.</p> <p>However, in 2010 only 37% of inpatients said they were told 'completely' about possible side effects to watch out for; and 44% said they were not told. One quarter of inpatients said they were not told fully told about the purpose of their medicine, or how to take it,</p>

				<p>in a way they could understand. One third said they were not given full written information about their medicines. (National inpatient survey, Care Quality Commission, 2010)</p> <p>The General Practice Patient Survey does not include questions on medicines. Its predecessor, the healthcare regulator's primary care survey, found that, while 70% of patients said they were as involved as they wanted to be in decisions overall, this fell to 60% when those prescribed a new medicine were asked whether they were as involved in that specific decision as they wanted to be. 41% of these patients said they did not have enough information about potential side effects and 20% wanted more information about the purpose of the medicine. (National survey of local health services, Healthcare Commission, 2008)</p> <p>In NICE guideline 76 on medicines adherence, the alarming estimate that one third of medicines for people with long term conditions are not taken correctly is linked to the systemic failure of healthcare delivery to involve patients in these discussions and decisions. The guideline recommends that, in order to improve adherence, clinicians should prescribe new medicines in the context of a shared decision making approach.</p> <p>The purpose of a specific quality statement on this issue would be to highlight the need specifically to measure this aspect of patient experience, including the effective provision of information and the extent to which prescribing decisions are made in partnership with patients.</p> <p>Existing indicators that could be used for this purpose include the following questions taken from the inpatient survey 2010 and the regulator's primary care survey 2008:</p> <ul style="list-style-type: none"> <li>• Were you involved as much as you wanted to be in decisions about the best medicine for you? (2008)</li> <li>• Were you given enough information about the purpose of the medicine? (2008) <i>or</i> Did a member of staff explain the purpose of the medicines in a way you could understand? (2010)</li> <li>• Were you told how to take your medication in a way you could understand? (2010) <i>or</i> Were you given enough information about how to use the medicine (e.g. when to take it, how long you should take it for, whether it should be taken with food)?</li> <li>• Were you given enough information about any side-effects the medicine might have? (2008) <i>or</i> Did a member of staff tell you about medication side effects to watch for when you went home?</li> </ul>
7	QS	15	22	<p>National Voices strongly welcomes the formulation of the 'shared decision making' quality statement. With its emphasis on <i>support to the patient</i> to participate in decisions, this formulation should be reflected back into the recommendations in the full guideline.</p>

				<p>We further suggest that after the word 'involved' the following text is inserted: 'as much as they wish to be'.</p> <p>The justifications are that:</p> <ol style="list-style-type: none"> <li>a. Not all patients wish to take an active role in sharing decisions. Around 25% of patients may wish to let health professionals decide for them.</li> <li>b. This additional wording reinforces the thrust of the quality statements generally in requiring that healthcare staff make efforts to <i>elicit</i> from the patient the degree to which they desire and feel confident to take part in decisions.</li> <li>c. The additional wording also reflects the formulation of the tested question on this issue from the national surveys (referred to in the 'relevant existing indicators' box) which asks: 'Were you as involved <i>as you wanted to be</i> in decisions about your care and treatment?'</li> </ol>
8	Full	4.1	26-27	<p>National Voices is concerned about the form of recommendation 58, as part of the section on decision making. This text makes the assumption that the clinician has already made a decision on the most appropriate course of action, and that the patient's role is 'merely' to listen passively to information and explanations. It might belong in the context of trauma or other emergency care where there is self-evidently one single course of action that is appropriate. It does not belong in the realm of patient experience generically of healthcare services.</p> <p>For patient experience generically of healthcare services, the overall approach should be one of shared decision making. This is clearly indicated by the professional codes for all doctors and all nurses and midwives (General Medical Practice 2006, Nursing and Midwifery Code 2008) which place duties on these professionals to work in partnership with their patients; by the regulations for all registered healthcare providers under the Health and Social Care Act 2008, which include requirements to involve people wherever appropriate in discussions and decisions about their care; and by the policy intentions of the current government in its White Paper 'Liberating the NHS' and the subsequent Health and Social Care Bill 2011, which places duties on healthcare commissioners to ensure 'patient involvement'.</p> <p>By contrast to recommendation 58, shared decision making relates to the common situation where there is <i>no</i> single self-evidently 'correct' course of action, and therefore the values and preferences of the patient are an important factor bearing on the choice of the most appropriate course of action <i>for them</i>. A much better formulation is in recommendation 64 – the principles of shared decision making.</p> <p>It is unfortunate that recommendation 64 comes after the recommendation 63 on the use of patient decision aids, and appears to recommend the <i>approach</i> of shared decision making only where there is no available decision aid. This is mistaken – shared</p>

				<p>decision making is the overarching approach, within which evidence-based patient decision aids may be an enhancement.</p> <p>(We would, in passing, ask the GDG to note that the strong evidence base for the effectiveness of patient decision aids is overwhelmingly from North America, where hundreds of such aids have been developed. Pilots in the UK have found that imported American content is alienating to UK patients, and that there is therefore a need to develop culturally specific aids for patients in this country. See, for example, 'Implementing patient decision aids in urology', Wirmann E and Ashkam J, Picker Institute Europe, 2006. So far only a very small number of UK-specific decision aids is in development, and therefore the recommendation to use decision aids 'where available' may, at this stage, have little operational relevance.)</p> <p>This section of the recommendations in the guideline is therefore somewhat confused in terms of content and ordering. National Voices would prefer to see a section of recommendations on 'shared decision making' clearly separated out from other types of decisions. In such a section:</p> <ul style="list-style-type: none"> <li>• Recommendation 58 would be excluded (or deleted)</li> <li>• The recommendations would be re-ordered to establish the principle of shared decision making at the start</li> <li>• The formulation used in Quality Statement 15 (with the amendment we suggest in comment 7, above) should be used</li> <li>• Recommendation 64 would precede recommendation 63, and would be amended to reflect the text on p.100 of the guideline which states that 'Patient decision aids... may act as an adjunct to good clinical practice... [but] are not necessary to deliver good decision making'</li> </ul>
9	Full	4.1	26	<p>National Voices welcomes the range of recommendations on the provision of information to patients, and particularly the emphasis on information that is in formats appropriate to each patient.</p> <p>However, we would like to raise two issues regarding these recommendations.</p> <p>First, we would ask the GDG to recognise that the sheer provision of information, while crucial, is not on its own sufficient to change behaviour or to help patients to be active in their own care and treatment, or to participate in decisions.</p> <p>One way to illustrate this is that, while patients report that the provision of information and explanations by healthcare professionals has improved, there has been no corresponding improvement in the involvement of patients in decisions – see 'Is the NHS becoming more patient-centred? Trends from the national surveys of NHS patients in England 2002-07', Richards N and Coulter A, Picker Institute Europe 2007.</p>

				<p>Research evidence shows that, contrary to the apparent assumption in recommendation 48, many patients experience difficulty in making active use of the information with which they are provided. It is the patients who most need to improve their health status who also most need help to make use of information with which to do so: people with low health literacy have poorer health status, undergo more hospital admissions, are less likely to adhere to treatment recommendations, experience more drug and treatment errors, and make less use of preventive services (Institute of Medicine. 'Health Literacy: a prescription to end confusion'. Washington DC: The National Academies Press, 2004).</p> <p>For this reason, it has been recommended elsewhere that all strategies to strengthen patient engagement should aim to improve health literacy: see Coulter A and Ellins J. 'Effectiveness of strategies for informing, educating and involving patients'. British Medical Journal 2007;335:24-7</p> <p>However, information that is delivered by a health professional, with both written and verbal explanations, and tailored to the individual patient, can be much more effective (Haywood K, Marshall S, Fitzpatrick R. 'Patient participation in the consultation process: A structured review of intervention strategies.' PATIENT-EDUC-COUNS 2006;63:12-23).</p> <p>Accordingly recommendation 50 gives a much better account of the role of the healthcare practitioner in providing information, and in this context, recommendation 48 is either superfluous, or should be amended, for example by inserting the words 'consistent support to make use of' before the word 'information'.</p> <p>Second, there is no single recommendation that states explicitly the need to provide patients with information which covers all their holistic needs, and not just clinical. Patients also require information on practical, emotional, social, spiritual and financial matters. Research has shown that it is on these issues where patients experience the greatest information deficits ('Assessing the quality of information to support people in making decisions about their health and healthcare', Coulter A et al, Picker Institute Europe, 2006).</p> <p>The importance of these non-clinical factors is recognised in recommendations 1 (see the patient as an individual), 3 (consider all factors affecting the patient's condition) and 7 (assess and discuss the patient's physical, psychological, domestic, social, spiritual and financial circumstances on a regular basis), yet there is no corresponding encouragement to help them through the provision of tailored information.</p>
10	QS	5	3	<p>The quality standard currently does not refer to pain control or relief. As noted in 'Core domains for measuring inpatients' experience of care', Sizmur S and Redding D, Picker Institute Europe 2009, pain control stands out as a single important factor bearing on respondents' satisfaction with the service.</p>

				<p>Recommendation 17 in the full guideline is "do not assume that pain relief is adequate, ask regularly, provide on time and adjust as necessary". National Voices suggests that 'pain control' should be inserted in QS 5 alongside 'nutrition, hydration and personal hygiene'.</p>
11	Full	4.1	25	<p>The recommendations on continuity of care are welcome. We would ask the GDG to consider whether to add an additional point to these, perhaps in recommendation 32.</p> <p>This would be to ensure that the definition of 'healthcare team' includes at least one person specialising in any long term condition the patient may have – irrespective of the reason for any current episode of care and treatment. Thus, for example, a diabetes patient who is hospitalised with a related or unrelated illness should have ready access to a diabetes specialist nurse or doctor.</p>
12	QS	General		<p>National Voices is concerned that, while NICE standards are expected to play a key role in helping commissioners and providers across a more decentralised system to maintain best practice, this draft standard contains a number of quality statements for which the GDG have been unable to identify relevant indicators.</p> <p>Commissioners will, under the Health and Social Care Bill 2011, have a duty to ensure the involvement of 'each patient' in their own care and treatment, and will be expected to fulfil this duty 'in the exercise of [their] functions' – meaning in everything they do. Commissioners will also have a duty to work for continuous quality improvement, with the definition of 'quality' including the domain of patient experience. Finally the NHS as a whole will be required through 'mandates' from the Secretary of State to achieve objectives in relation to the five domains of the NHS Outcomes Framework, which includes the domain of patient experience (and the domain of long term conditions, which is relevant to many of our comments above).</p> <p>The NICE Quality Standard on patient experience of generic services will provide the basis for these commissioning activities. It is therefore essential that it supports commissioners with the fullest possible information about how to measure and assess the experience of patients for whom they are responsible. As noted in our first comment, the Quality Statements are currently overly biased towards hospital settings and towards indicators that have been through the approval of the National Quality Board. The latter process has been extremely slow, and it is regrettable that indicators for primary care are in particular have not been assessed and approved, when national survey instruments are available.</p> <p>We would request the GDG to consider the inclusion of indicators for primary care drawn from:</p> <ul style="list-style-type: none"> <li>the Healthcare Commission's survey of patients using local health services (2008)</li> </ul>

				<ul style="list-style-type: none"> <li>• the General Practice Patient Survey (current)</li> <li>• other validated survey tools such as the CARE (Consultation and Relational Empathy) Measure</li> </ul> <p>We would also direct the GDG's attention to the fact that the co-ordination centre for the national patient survey programme has provided, for local use, a set of common questions and tools with which commissioners and providers locally could construct their own patient experience surveys. These are at: <a href="http://www.nhssurveys.org/localsurveys">http://www.nhssurveys.org/localsurveys</a></p> <p>The GDG will need positively to consider the viability and appropriateness of enabling commissioners and providers to select from tested indicator sets, where these may not yet have been through NQB or similar approval.</p> <p>Further, we suggest that there are some cases in which the quality statements overlook questions from national patient surveys that are relevant. For example, QS 16 on the provision of evidence-based information could recommend the questions on medicines information suggested in our comment above, knowing that these would be relevant for around 80% of inpatients and 54% of primary care patients (as well as around one quarter of outpatients). We would therefore request a further review of the available survey questions to populate the quality statements.</p>
13	Full	4.1	26	National Voices notes, with regard to recommendation 50, that it may be useful to reference sources of evidence-based information, including NHS Evidence, and patient information that is produced by organisations accredited with the Information Standard.
14	QS	Appendix 1	25	National Voices considers it important that the list of policy sources should include the NHS Constitution.
15	Full	4.1	26	National Voices welcomes recommendation 55 which recognises the value to patient experience of being sign-posted by professionals to extended sources of support. We would wish to see this reflected in the Quality Standard. Patients very often experience gaps in care which these support services can help to close. Moreover, these sources are often the best placed to provide the types of patient information that the NHS itself may not adequately provide, including relevant social, emotional and financial information.
16	Full	General		Accountability for care and treatment may be a relevant factor to patients, especially where they are seeking to rectify deficits in their experience of services. National Voices asks the GDG to consider where, within the draft documents, it may be possible to insert guidance that patients should be informed who is responsible for their current care and treatment. This may sit with other general provisions on information, or with the recommendation on enabling patient feedback, for example.
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Please add extra rows as needed

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**Closing date: 19<sup>th</sup> July 2011 at 5pm**

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