

Patient experience in adult NHS services: improving the experience of care for people using adult NHS services

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Introduction

Over the past few years, several documents and initiatives have highlighted the importance of the patient's experience and the need to focus on improving these experiences where possible.

Lord Darzi's report '[High quality care for all](#)' (2008) highlighted the importance of the entire patient experience within the NHS, ensuring people are treated with compassion, dignity and respect within a clean, safe and well-managed environment.

The development of the [NHS Constitution](#) (2009–2010) was one of several recommendations from Lord Darzi's report. The Constitution describes the purpose, principles and values of the NHS and illustrates what staff, patients and the public can expect from the service. Since the Health Act came into force in January 2010, service providers and commissioners of NHS care have had a legal obligation to take the Constitution into account in all their decisions and actions.

The [Equality Act 2010](#) replaces all previous anti-discrimination legislation, and includes a public sector equality duty requiring public bodies to have due regard to the need to eliminate discrimination and to advance equality of opportunity and foster good relations between people who share certain protected characteristics and those who do not. The protected characteristics are age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex and sexual orientation. The Act provides an important legal framework which should improve the experience of all patients using NHS services.

Despite these policy initiatives, there is evidence to suggest that further work is needed to deliver the best possible experience for users of NHS services. The Government signalled in its White Paper '[Equity and excellence: liberating the NHS](#)' (2010) that more emphasis needs to be placed on improving patients' experience of NHS care.

This guidance is a direct referral from the Department of Health. It focuses on generic patient experiences and is relevant for all people who use adult NHS services in England and Wales. The aim of the guidance is to provide the NHS with clear guidance on the components of a good patient experience. This guidance provides the evidence and the direction for creating sustainable change that will result in an 'NHS cultural shift' towards a truly patient-centred service.

A [NICE quality standard](#) for patient experience in adult NHS services has been developed alongside this guidance. NICE quality standards are a set of specific, concise statements and associated measures. They set out aspirational, but achievable, markers of high-quality, cost-effective care. Quality standards are derived from the best available evidence and address three dimensions of quality: clinical effectiveness, patient safety and patient experience. The quality statements for patient experience in adult NHS services are listed in the next section.

NICE clinical guidelines are usually shaped around both clinical and economic evidence, and include recommendations concerned with ensuring a good patient experience, with the recognition that such advice should sit alongside evidence of clinical and cost effectiveness. The recommendations in the current guidance have been informed by research evidence, recommendations in previously published NICE clinical guidelines, national survey data and consensus processes that have identified the key elements that are important to patients and how these can be improved to ensure a good experience of care. The guidance draws on multiple evidence and data sources in developing the recommendations, which are further distilled into commissioning guidance in the quality standard.

The recommendations in this guidance are directed primarily at clinical staff, but patient experience is also significantly affected by contacts with non-clinical staff such as receptionists, clerical staff and domestic staff. Services need to ensure that non-clinical staff are adequately trained and supported to engage with patients in ways that enhance the patient experience.

Taken together, the recommendations in this guidance capture the essence of a good patient experience. Their implementation will help to ensure that healthcare services are acceptable and appropriate, and that all people using the NHS have the best possible experience of care.

Quality statements

These quality statements are from the [NICE quality standard](#) on patient experience in adult NHS services in England, which was developed from the recommendations in this guidance. Recommendations, or parts of recommendations, that underpin the development of the quality statements and associated measures are denoted **[QS]**.

No.	Quality statements
1	Patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty.
2	Patients experience effective interactions with staff who have demonstrated competency in relevant communication skills.
3	Patients are introduced to all healthcare professionals involved in their care, and are made aware of the roles and responsibilities of the members of the healthcare team.
4	Patients have opportunities to discuss their health beliefs, concerns and preferences to inform their individualised care.
5	Patients are supported by healthcare professionals to understand relevant treatment options, including benefits, risks and potential consequences.
6	Patients are actively involved in shared decision making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them.
7	Patients are made aware that they have the right to choose, accept or decline treatment and these decisions are respected and supported.
8	Patients are made aware that they can ask for a second opinion.
9	Patients experience care that is tailored to their needs and personal preferences, taking into account their circumstances, their ability to access services and their coexisting conditions.

10	Patients have their physical and psychological needs regularly assessed and addressed, including nutrition, hydration, pain relief, personal hygiene and anxiety.
11	Patients experience continuity of care delivered, whenever possible, by the same healthcare professional or team throughout a single episode of care.
12	Patients experience coordinated care with clear and accurate information exchange between relevant health and social care professionals.
13	Patients' preferences for sharing information with their partner, family members and/or carers are established, respected and reviewed throughout their care.
14	Patients are made aware of who to contact, how to contact them and when to make contact about their ongoing healthcare needs.

1 Guidance

The following guidance is based on the best available evidence. The [full guidance](#) gives details of the methods and the evidence used to develop the guidance.

1.1 Knowing the patient as an individual

Patients value healthcare professionals acknowledging their individuality and the unique way in which each person experiences a condition and its impact on their life. Patients' values, beliefs and circumstances all influence their expectations of, their needs for and their use of services. It is important to recognise that individual patients are living with their condition, so the ways in which their family and broader life affect their health and care need to be taken into account.

- 1.1.1 Develop an understanding of the patient as an individual, including how the condition affects the person, and how the person's circumstances and experiences affect their condition and treatment.
- 1.1.2 Ensure that factors such as physical or learning disabilities, sight, speech or hearing problems and difficulties with reading, understanding or speaking English are

addressed so that the patient is able to participate as fully as possible in consultations and care.¹ [QS]

- 1.1.3 Ask the patient about and take into account any factors, such as their domestic, social and work situation and their previous experience of healthcare, that may:
- impact on their health condition **and/or**
 - affect their ability or willingness to engage with healthcare services **and/or**
 - affect their ability to manage their own care and make decisions about self-management and lifestyle choices.
- 1.1.4 Listen to and address any health beliefs, concerns and preferences that the patient has, and be aware that these affect how and whether they engage with treatment. Respect their views and offer support if needed to help them engage effectively with healthcare services and participate in self-management as appropriate.¹ [QS]
- 1.1.5 Avoid making assumptions about the patient based on their appearance or other personal characteristics.¹
- 1.1.6 Take into account the requirements of the [Equality Act 2010](#) and make sure services are equally accessible to, and supportive of, all people using adult NHS services.
- 1.1.7 If appropriate, discuss with the patient their need for psychological, social, spiritual and/or financial support. Offer support and information to the patient and/or direct them to sources of support and information. Review their circumstances and need for support regularly.¹

1.2 Essential requirements of care

Patients have needs other than the treatment of their specific health conditions. There should be recognition of the potential need for psychological and emotional support, as well as of the importance of meeting fundamental needs such as nutrition and pain management. Attention to these fundamental needs applies particularly to inpatient settings, but they should also be addressed in other settings where healthcare is provided.

¹ This recommendation is adapted from a previously published NICE clinical guideline – see [appendix B](#) for details.

Respect for the patient

1.2.1 All staff involved in providing NHS services² should:

- treat patients with respect, kindness, dignity, compassion, understanding, courtesy and honesty **[QS]**
- respect the patient's right to confidentiality
- not discuss the patient in their presence without involving them in the discussion.

1.2.2 Introduce students and anyone not directly involved in the delivery of care before consultations or meetings begin, and let the patient decide if they want them to stay.

Patient concerns

1.2.3 Be prepared to raise and discuss sensitive issues (such as sexual activity, continence or end-of-life care), as these are unlikely to be raised by some patients.¹

1.2.4 Listen to and discuss any fears or concerns the patient has in a non-judgemental and sensitive manner.¹ **[QS]**

1.2.5 If anxiety disorder or depression is suspected, follow the appropriate stepped-care model recommended in:

- 'Generalised anxiety disorder and panic disorder (with or without agoraphobia) in adults' (NICE clinical guideline 113) **or**
- 'Depression' (NICE clinical guideline 90) **or**
- 'Depression in adults with a chronic physical health problem' (NICE clinical guideline 91).¹ **[QS]**

Nutrition, pain management and personal needs

1.2.6 All healthcare professionals directly involved in patient care should receive education and training, relevant to their post, on the importance of:

- providing adequate and appropriate nutrition

² This includes people such as chaplains, domestic staff, porters, receptionists and volunteers, as well as healthcare professionals.

- assessing and managing pain.¹ [QS]

1.2.7 Ensure that the patient's nutrition and hydration are adequate at all times, if the patient is unable to manage this themselves, by:

- providing regular food and fluid of adequate quantity and quality in an environment conducive to eating
 - placing food and drink where the patient can reach them easily
 - encouraging and helping the patient to eat and drink if needed
 - providing appropriate support, such as modified eating and/or drinking aids.¹
- [QS]

1.2.8 If a patient is unable to manage their own pain relief:

- do not assume that pain relief is adequate
- ask them regularly about pain
- assess pain using a pain scale if necessary (for example, on a scale of 1 to 10)
- provide pain relief and adjust as needed. [QS]

1.2.9 Ensure that the patient's personal needs (for example, relating to continence, personal hygiene and comfort) are regularly reviewed and addressed. Regularly ask patients who are unable to manage their personal needs what help they need. Address their needs at the time of asking and ensure maximum privacy. [QS]

Patient independence

1.2.10 Give patients using adult NHS services the support they need to maintain their independence as far as possible.

1.2.11 When patients in hospital are taking medicines for long-term conditions, assess and discuss with them whether they are able and would prefer to manage these medicines themselves.

Consent and capacity

1.2.12 Obtain and document informed consent from the patient, in accordance with:

- in England, [Department of Health policy and guidance](#)

- in Wales, [advice from the Welsh Government](#).

1.2.13 Assess the patient's capacity to make each decision using the principles in the [Mental Capacity Act \(2005\)](#).¹

1.3 Tailoring healthcare services for each patient

Patients wish to be seen as an individual within the healthcare system. This requires healthcare professionals to recognise the individual, and for services to be tailored to respond to the needs, preferences and values of the patient. Advice on treatments and care, including risks and benefits, should be individualised as much as possible.

An individualised approach to services

1.3.1 Adopt an individualised approach to healthcare services that is tailored to the patient's needs and circumstances, taking into account their ability to access services, personal preferences and coexisting conditions. Review the patient's needs and circumstances regularly. **[QS]**

1.3.2 Inform the patient about healthcare services and social services (for example, smoking cessation services) that are available locally and nationally. Encourage and support them to access services according to their individual needs and preferences.¹ **[QS]**

1.3.3 Give the patient information about relevant treatment options and services that they are entitled to, even if these are not provided locally. **[QS]**

Patient views and preferences

1.3.4 Hold discussions in a way that encourages the patient to express their personal needs and preferences for care, treatment, management and self-management. Allow adequate time so that discussions do not feel rushed.

1.3.5 Review with the patient at intervals agreed with them:

- their knowledge, understanding and concerns about their condition and treatments
- their view of their need for treatment.¹

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- 1.3.6 Accept that the patient may have different views from healthcare professionals about the balance of risks, benefits and consequences of treatments.¹
 - 1.3.7 Accept that the patient has the right to decide not to have a treatment, even if you do not agree with their decision, as long as they have the capacity to make an informed decision (see recommendation 1.2.13) and have been given and understand the information needed to do this.¹ **[QS]**
 - 1.3.8 Respect and support the patient in their choice of treatment, or if they decide to decline treatment. **[QS]**
 - 1.3.9 Ensure that the patient knows that they can ask for a second opinion from a different healthcare professional, and if necessary how they would go about this. **[QS]**

Involvement of family members and carers

- 1.3.10 Clarify with the patient at the first point of contact whether and how they would like their partner, family members and/or carers to be involved in key decisions about the management of their condition. Review this regularly. If the patient agrees, share information with their partner, family members and/or carers. **[QS]**
- 1.3.11 If the patient cannot indicate their agreement to share information, ensure that family members and/or carers are kept involved and appropriately informed, but be mindful of any potentially sensitive issues and the duty of confidentiality.

Feedback and complaints

- 1.3.12 Encourage the patient to give feedback about their care. Respond to any feedback given.
- 1.3.13 If necessary, provide patients with information about complaints procedures and help them to access these.

1.4 Continuity of care and relationships

Continuity and consistency of care and establishing trusting, empathetic and reliable relationships with competent and insightful healthcare professionals is key to patients receiving

effective, appropriate care. Relevant information should be shared between professionals and across healthcare boundaries to support high-quality care.

1.4.1 Assess each patient's requirement for continuity of care and how that requirement will be met. This may involve the patient seeing the same healthcare professional throughout a single episode of care, or ensuring continuity within a healthcare team.

[QS]

1.4.2 For patients who use a number of different services (for example, services in both primary and secondary care, or attending different clinics in a hospital), ensure effective coordination and prioritisation of care to minimise the impact on the patient.

[QS]

1.4.3 Ensure clear and timely exchange of patient information:

- between healthcare professionals (particularly at the point of any transitions in care)
- between healthcare and social care professionals (with the patient's consent).

[QS]

1.4.4 All healthcare professionals directly involved in a patient's care should introduce themselves to the patient. **[QS]**

1.4.5 Inform the patient about:

- who is responsible for their clinical care and treatment
- the roles and responsibilities of the different members of the healthcare team
- the communication about their care that takes place between members of the healthcare team. **[QS]**

1.4.6 Give the patient (and their family members and/or carers if appropriate) information about what to do and who to contact in different situations, such as 'out of hours' or in an emergency. **[QS]**

1.5 Enabling patients to actively participate in their care

Many patients wish to be active participants in their own healthcare, and to be involved in creating and managing their health strategy and use of services. Self-care and self-management are particularly important for people with long-term conditions.

Communication

- 1.5.1 Ensure that the environment is conducive to discussion and that the patient's privacy is respected, particularly when discussing sensitive, personal issues.
- 1.5.2 Maximise patient participation in communication by, for example:
- maintaining eye contact with the patient (if culturally appropriate)
 - positioning yourself at the same level as the patient
 - ensuring that the patient is appropriately covered (if applicable).
- 1.5.3 Ask the patient how they wish to be addressed and ensure that their choice is respected and used.
- 1.5.4 Establish the most effective way of communicating with each patient and explore ways to improve communication. Examples include using pictures, symbols, large print, Braille, different languages, sign language or communications aids, or involving an interpreter, a patient advocate or family members.¹ **[QS]**
- 1.5.5 Ensure that the accent, use of idiom and dialect of both the patient and the healthcare professionals are taken into account when considering communication needs.
- 1.5.6 Avoid using jargon. Use words the patient will understand, define unfamiliar words and confirm understanding by asking questions.¹
- 1.5.7 Use open-ended questions to encourage discussion.¹
- 1.5.8 Summarise information at the end of a consultation and check that the patient has understood the most important information.

- 1.5.9 Offer the patient copies of letters between healthcare professionals. These should be in a form that is accessible to the patient and if possible use language that they will understand. Answer any questions the patient may have about these.
- 1.5.10 All staff involved in providing NHS services should have demonstrated competency in relevant communication skills.¹ **[QS]**

Information

- 1.5.11 Give the patient information, and the support they need to make use of the information, in order to promote their active participation in care and self-management.¹
- 1.5.12 Give the patient both oral and written information.¹
- 1.5.13 Give the patient information in an accessible format, at the first and subsequent visits. Possible formats include using written information, pictures, symbols, large print, Braille and different languages.¹
- 1.5.14 Explore the patient's preferences about the level and type of information they want. Based on this, give the patient (and their family members and/or carers if appropriate) clear, consistent, evidence-based, tailored information throughout all stages of their care. This should include, but not be limited to, information on:
- their condition and any treatment options
 - where they will be seen
 - who will undertake their care
 - expected waiting times for consultations, investigations and treatments.¹
- 1.5.15 Ensure that mechanisms are in place to:
- provide information about appointments to patients who require information in non-standard formats
 - alert services of any need for interpreters and non-standard formats to be available when patients move between services.

- 1.5.16 Ask the patient whether they want to be accompanied at consultations by a family member, friend or advocate, and whether they would like to take notes and/or an audio recording of the consultation.
- 1.5.17 Give the patient (and/or their family members and carers) information to enable them to use any medicines and equipment correctly. Ensure that the patient and their family members and carers feel adequately informed, prepared and supported to use medicines and equipment and to carry out self-care and self-management.¹
- 1.5.18 Advise the patient where they might find reliable high-quality information and support after consultations, from sources such as national and local support groups, networks and information services.¹
- 1.5.19 Give the patient regular, accurate information about the duration of any delays during episodes of care.

Shared decision making

- 1.5.20 When discussing decisions about investigations and treatment, do so in a style and manner that enables the patient to express their personal needs and preferences.
[QS]
- 1.5.21 Give the patient the opportunity to discuss their diagnosis, prognosis and treatment options.¹ **[QS]**
- 1.5.22 When offering any investigations or treatments:
- explain the medical aims of the proposed care to the patient
 - openly discuss and provide information about the risks, benefits and consequences of the investigation or treatment options (taking into account factors such as coexisting conditions and the patient's preferences)
 - clarify what the patient hopes the treatment will achieve and discuss any misconceptions with them
 - set aside adequate time to allow any questions to be answered, and ask the patient if they would like a further consultation.¹ **[QS]**

- 1.5.23 Accept and acknowledge that patients may vary in their views about the balance of risks, benefits and consequences of treatments.¹ **[QS]**
- 1.5.24 Use the following principles when discussing risks and benefits with a patient:
- personalise risks and benefits as far as possible
 - use absolute risk rather than relative risk (for example, the risk of an event increases from 1 in 1000 to 2 in 1000, rather than the risk of the event doubles)
 - use natural frequency (for example, 10 in 100) rather than a percentage (10%)
 - be consistent in the use of data (for example, use the same denominator when comparing risk: 7 in 100 for one risk and 20 in 100 for another, rather than 1 in 14 and 1 in 5)
 - present a risk over a defined period of time (months or years) if appropriate (for example, if 100 people are treated for 1 year, 10 will experience a given side effect)
 - include both positive and negative framing (for example, treatment will be successful for 97 out of 100 patients and unsuccessful for 3 out of 100 patients)
 - be aware that different people interpret terms such as rare, unusual and common in different ways, and use numerical data if available
 - think about using a mixture of numerical and pictorial formats (for example, numerical rates and pictograms).¹ **[QS]**
- 1.5.25 Offer support to the patient when they are considering options. Use the principles of shared decision making:
- ensure that the patient is aware of the options available and explain the risks, benefits and consequences of these
 - check that the patient understands the information
 - encourage the patient to clarify what is important to them, and check that their choice is consistent with this. **[QS]**
- 1.5.26 Be aware of the value and availability of patient decision aids and other forms of decision support such as counselling or coaching. If suitable high-quality decision aids are available, offer them to the patient.¹ **[QS]**

- 1.5.27 Give the patient (and their family members and/or carers if appropriate) adequate time to make decisions about investigations and treatments.¹ [QS]

Education programmes

- 1.5.28 Ensure that patient-education programmes:

- are evidence-based
- have specific aims and learning objectives
- meet the needs of the patient (taking into account cultural, linguistic, cognitive and literacy considerations)
- promote the patient's ability to manage their own health if appropriate.¹

- 1.5.29 Give the patient the opportunity to take part in evidence-based educational activities, including self-management programmes, that are available and meet the criteria listed in recommendation 1.5.28.¹

2 Notes on the scope of the guidance

NICE guidance is developed in accordance with a scope that defines what the guidance will and will not cover.

How this guidance was developed

NICE commissioned the National Clinical Guideline Centre to develop this guidance. The Centre established a Guidance Development Group (see [appendix A](#)), which reviewed the evidence and developed the recommendations.

3 Implementation

NICE has developed tools to help organisations implement this guidance.

4 Other versions of this guidance

4.1 Full guidance

The full guidance, '[Patient experience in adult NHS services: improving the experience of care for people using adult NHS services](#)', contains details of the methods and evidence used to develop the guidance. It is published by the National Clinical Guideline Centre.

4.2 NICE pathway

The recommendations from this guidance will be incorporated into a [NICE pathway](#).

4.3 'Understanding NICE guidance'

A summary for patients and carers ('[Understanding NICE guidance](#)') is available.

For printed copies, phone NICE publications on 0845 003 7783 or email publications@nice.org.uk (quote reference number N2714).

We encourage NHS and voluntary sector organisations to use text from this booklet in their own information about patient experience.

5 Related NICE guidance

Published

- [Service user experience in adult mental health](#). NICE clinical guidance 136 (2011).

Appendix A: The Guidance Development Group, National Collaborating Centre and NICE project team

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Appendix B: Recommendations from previous clinical guidelines

The following recommendations are adapted from recommendations in the published NICE clinical guidelines listed. See the full guidance for further details, and see the individual guidelines for the original recommendations and for the evidence underpinning them.

Recommendation number in current guidance	Published clinical guideline
1.1.2	Medicines adherence (CG76)
1.1.4	Chronic heart failure (CG108); Medicines adherence (CG76)
1.1.5	Pregnancy and complex social factors (CG110)
1.1.7	Breast cancer: advanced (CG81)
1.2.3	Chronic heart failure (CG108)
1.2.4	Pregnancy and complex social factors (CG110)
1.2.5	Critical illness rehabilitation (CG83)
1.2.6	Nutrition support in adults (CG32)
1.2.7	Nutrition support in adults (CG32)
1.2.13	Medicines adherence (CG76)
1.3.2	Pregnancy and complex social factors (CG110)
1.3.5	Medicines adherence (CG76)
1.3.6	Medicines adherence (CG76)
1.3.7	Medicines adherence (CG76)
1.5.4	Medicines adherence (CG76)

1.5.6	<u>Chronic heart failure</u> (CG108)
1.5.7	<u>Medicines adherence</u> (CG76)
1.5.10	<u>Breast cancer: early and locally advanced</u> (CG80)
1.5.11	<u>Low back pain</u> (CG88)
1.5.12	<u>Barrett's oesophagus – ablative therapy</u> (CG106)
1.5.13	<u>Glaucoma</u> (CG85)
1.5.14	<u>Barrett's oesophagus – ablative therapy</u> (CG106); <u>Surgical site infection</u> (CG74); <u>Chronic kidney disease</u> (CG73); <u>Antenatal care</u> (CG62)
1.5.17	<u>Chronic obstructive pulmonary disease</u> (CG101)
1.5.18	<u>Chronic heart failure</u> (CG108); <u>Medicines adherence</u> (CG76); <u>Prostate cancer</u> (CG58)
1.5.21	<u>Glaucoma</u> (CG85)
1.5.22	<u>Medicines adherence</u> (CG76); <u>Lipid modification</u> (CG67)
1.5.23	<u>Medicines adherence</u> (CG76)
1.5.24	<u>Lipid modification</u> (CG67)
1.5.26	<u>Breast cancer: advanced</u> (CG81)
1.5.27	<u>Prostate cancer</u> (CG58)
1.5.28	<u>Type 2 diabetes</u> (CG66)
1.5.29	<u>Rheumatoid arthritis</u> (CG79)

About this guidance

NICE clinical guidelines are recommendations about the treatment and care of people with specific diseases and conditions in the NHS in England and Wales.

The guidance was developed by the National Clinical Guideline Centre which is based at the Royal College of Physicians. The Centre worked with a group of healthcare professionals (including consultants, GPs and nurses), patients and carers, and technical staff, who reviewed the evidence and drafted the recommendations. The recommendations were finalised after public consultation.

The recommendations from this guidance will be incorporated into a [NICE pathway](#). We have produced a [summary for patients and carers](#). Tools to help you put the guidance into practice and information about the evidence it is based on are also [available](#).

Changes after publication

June 2012: minor maintenance

Your responsibility

This guidance represents the view of NICE, which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summary of product characteristics of any drugs they are considering.

Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.

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