

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

## **NICE guidance**

**Draft for consultation, June 2011**

If you wish to comment on this version of the guidance, please be aware that all the supporting information and evidence is contained in the full version.

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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) 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.

National initiatives aimed at improving patients' experience of healthcare include NHS Choices, a comprehensive information service that helps people to manage their healthcare and provides patients and carers with information and choice about their care. Local initiatives, such as patient advice and liaison services (PALS), have also been introduced.

Despite these 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' (July 2010) that more emphasis needs to be placed on improving patients' experience of NHS care. This guidance on patient experience in adult NHS services is a direct referral from the National Quality Board.

This guidance 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.

NICE clinical guidelines are usually shaped around both clinical and economic evidence. These guidelines also 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 this 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 patient experience. The guidance draws on multiple evidence and data sources in developing the recommendations, which are further distilled into commissioning guidance in the quality standard.

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.

## **Patient-centred care**

This guidance offers best practice advice on improving the experience of people who use adult NHS services.

Patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. If patients do not have the capacity to make decisions, healthcare professionals should follow the Department of Health's advice on consent (available from [www.dh.gov.uk/consent](http://www.dh.gov.uk/consent)) and the code of practice that accompanies the Mental Capacity Act (summary available from [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)). In Wales, healthcare professionals should follow advice on consent from the Welsh Assembly Government (available from [www.wales.nhs.uk/consent](http://www.wales.nhs.uk/consent)).

## Draft quality statements

No.	Draft quality statements
1.	Healthcare professionals and all other staff who interact directly with patients are, as part of their annual performance assessment, evaluated and mentored for compliance with the NICE guidance on patient experience in adult NHS services.
2.	Patients are asked about any physical or learning disabilities, sight or hearing problems, and difficulties with reading, understanding or speaking English, in order to help maximise their participation in consultations and care.
3.	Patients are given the opportunity to discuss their health beliefs, concerns and preferences in order to individualise their care.
4.	Patients are treated with dignity and experience a culture of kindness, compassion, courtesy, respect, understanding and honesty.
5.	Patients regularly have their physical needs (such as nutrition, hydration and personal hygiene) and psychological concerns (such as fear and anxiety) assessed in an environment that maintains their dignity and confidentiality.
6.	Patients are introduced to all members of the healthcare team and given a clear explanation of each member's roles and responsibilities.
7.	Patients' preferences for involving and sharing information with partners, families and carers are established at the first point of contact and continuously respected throughout their care.
8.	Patients' rights to choose, accept or decline treatment are respected and supported.
9.	Patients receive care that is tailored to their needs and circumstances (which are reviewed regularly), taking into account locality, access, personal preferences and coexisting conditions.
10.	Information about patient care is exchanged in a timely, appropriate, clear and accurate manner between relevant healthcare professionals to ensure effective coordination and prioritisation of care.
11.	Patients are given clear advice about who to contact, how to contact them and when to make contact about their ongoing healthcare needs.
12.	Patients have their requirements for continuity of care considered – this may involve seeing the same healthcare professional or healthcare team to promote and maintain continuity of care.
13.	Patients are cared for by healthcare professionals who have a demonstrated competency in communication skills.
14.	Healthcare professionals establish and use the most suitable way of communicating with each patient and confirm the patient's understanding.

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15.	Patients, when making decisions about screening, investigation, treatment and care, are supported to be involved in shared decision-making to ensure that they are informed of and understand all relevant options, outcomes and implications consistent with what is important to them.
16.	Patients are provided with evidence-based information that is understandable, personalised and clearly communicated.
17.	Where available, patients have access to high-quality decision support tools such as patient decision aids.

## Guidance

The following guidance is based on the best available evidence. The full guidance ([\[hyperlink to be added for final publication\]](#)) gives details of the methods and the evidence used to develop the guidance.

### **1.1      *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 individuals 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      See the patient as an individual, and develop an understanding of how the condition affects the person, and the person's circumstances and experiences affect their condition and treatment.
- 1.1.2      Consider the extent to which factors such as physical or learning disabilities, sight or hearing problems and difficulties with reading, understanding or speaking English may affect the patient's ability to participate in consultations and care.\* **[QS2]**
- 1.1.3      Consider factors, such as the patient's 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.

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\* This recommendation is adapted from a previously published NICE clinical guideline – see appendix B for details.

- 1.1.4 Be aware that a patient's beliefs and concerns affect how and whether they engage with treatment, and so may affect their care.\*  
**[QS3]**
- 1.1.5 Listen to and address any health beliefs, concerns and preferences that the patient has. Respect their views and offer support if needed to help them engage effectively with healthcare services.\*  
**[QS3]**
- 1.1.6 Avoid making assumptions about the patient based their:
- culture, ethnic origin or religious beliefs
  - age, gender, educational level or socioeconomic status
  - disability or health status.\*
- 1.1.7 Assess and discuss the patient's physical, psychological, domestic, social, spiritual and financial circumstances on a regular basis and at key points in their care. Offer support where appropriate and review regularly their circumstances and need for support.\*

## **1.2 *Essential requirements of care***

Patients have needs other than treatment of their physical symptoms. 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, safety and pain management. Attention to these fundamental needs applies particularly to inpatient settings, but they should also be addressed in other healthcare settings if relevant.

- 1.2.1 Treat all patients with respect, kindness, dignity, compassion, understanding and honesty. **[QS4]**
- 1.2.2 Respect the patient's right to confidentiality.\* **[QS5]**
- 1.2.3 Do not discuss the patient in their presence without addressing them directly.

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\* This recommendation is adapted from a previously published NICE clinical guideline – see appendix B for details.

- 1.2.4 Be prepared to broach sensitive issues, such as sexual activity, as these are unlikely to be raised by some patients.\*
- 1.2.5 Discuss any fears or concerns the patient has in a non-judgemental and sensitive manner.\* **[QS5]**
- 1.2.6 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).\*
- 1.2.7 All healthcare professionals who are directly involved in patient care should receive education and training, relevant to their post, on the importance of providing adequate nutrition.\*
- 1.2.8 Ensure that the patient’s nutrition and hydration are adequate, when 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 aids.\*
- [QS5]**
- 1.2.9 When patients in hospital are taking medicines for long-term conditions, consider and discuss with them whether they are able to, and would prefer to, manage these medicines themselves.

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\* This recommendation is adapted from a previously published NICE clinical guideline – see appendix B for details.

- 1.2.10 Do not assume that pain relief is adequate. Ask the patient regularly about levels of pain. Provide pain relief on time and adjust as necessary. **[QS5]**
- 1.2.11 Address the patient's personal needs (for example, relating to continence and personal hygiene) promptly, and ensure maximum privacy. **[QS5]**
- 1.2.12 Ensure that the patient is given regular, accurate information about any delays during episodes of care.

### **1.3 *Tailoring healthcare services to the individual***

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.

- 1.3.1 Adopt an individualised approach to healthcare services that is tailored to the patient's needs and circumstances, taking into account locality, access, personal preferences and coexisting conditions. Review the patient's needs and circumstances regularly. **[QS9]**
- 1.3.2 Give the patient information about relevant and available treatment options, even if these are not provided locally.
- 1.3.3 Tell the patient about health and social services that are available (for example, smoking cessation services) and encourage them to access these according to their individual needs.\*
- 1.3.4 Introduce all healthcare professionals involved in the patient's care and explain their roles. Introduce students and anyone else present

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\* This recommendation is adapted from a previously published NICE clinical guideline – see appendix B for details.

at consultations, and allow the patient to decide if they want them to stay. **[QS6]**

- 1.3.5 Clarify with the patient at the outset 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. **[QS7]**
- 1.3.6 If the patient agrees, share information with their partner, family members and/or carers. If the patient cannot indicate their agreement, share the information that those close to the patient need, unless there is reason to believe that the patient would object. **[QS7]**
- 1.3.7 Ensure that discussions are held using a style that allows the patient to express their personal needs and preferences for care, treatment and management.
- 1.3.8 Review the patient's knowledge, understanding and concerns about their condition and treatments, and their view of their need for treatment, at intervals agreed with them, because these may change over time. Offer repeat information and review to the patient, especially when treating a long-term condition.\*
- 1.3.9 Accept that the patient may have different views from healthcare professionals about the balance of risks, benefits and consequences of treatments.\* **[QS8]**
- 1.3.10 Accept that the patient has the right to decide not to have a treatment, even if you do not agree with the decision, as long as the patient has the capacity to make an informed decision and has been given the information needed to do this.\* **[QS8]**
- 1.3.11 Respect and support the patient in their choice of treatment, or if they decide to decline treatment. **[QS8]**

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\* This recommendation is adapted from a previously published NICE clinical guideline – see appendix B for details.

- 1.3.12 Give the patient opportunities to give feedback about their care, using different formats, and respond to any feedback given.

#### **1.4 *Continuity of care and relationships***

Continuity and consistency of care and establishing trusting, empathetic and reliable relationships with competent and insightful health care professionals is key to patients receiving effective, appropriate care. Relevant information should move seamlessly between professionals and across healthcare boundaries to support high-quality care.

- 1.4.1 Consider 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. **[QS12]**

- 1.4.2 Inform the patient about:

- who is responsible for their care and treatment
- the roles and responsibilities of the different members of the healthcare team
- the communication that takes place between members of the healthcare team. **[QS11]**

1.4.3 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.

**[QS11]**

1.4.4 For patients who require a number of different services (for example, services in both primary and secondary care, or attending different clinics within a hospital), ensure effective coordination and prioritisation of care to minimise the impact on the patient. **[QS10]**

1.4.5 Ensure clear and timely exchange of patient information between healthcare professionals. **[QS10]**

## **1.5 *Enabling patients to actively participate in their care***

Patients wish to be considered as active participants in their own health care, and to be involved in the creation and management of their health strategy and use of services.

### **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
- positioning yourself at the same level as the patient
- ensuring that the patient is appropriately covered.

1.5.3 Establish how the patient wants 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 consider ways of improving communication. Examples

include using pictures, symbols, large print, Braille, different languages, an interpreter or a patient advocate.\* **[QS14]**

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. Use interpreters if necessary. **[QS14]**

1.5.6 Use words the patient will understand, define unfamiliar words and confirm understanding by asking questions. Avoid using jargon.\* **[QS14]**

1.5.7 Use open-ended questions to encourage discussion.\*

1.5.8 Summarise information at the end of a consultation and check that the patient has understood the most important information. **[QS14]**

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 use language that they will understand.

1.5.10 All members of the healthcare team should have a demonstrated competency in relevant communication skills.\* **[QS13]**

1.5.11 Be aware that the consultation skills needed for increasing patient involvement can be improved.\*

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\* This recommendation is adapted from a previously published NICE clinical guideline – see appendix B for details.

## Information

- 1.5.12 Give the patient information in order to promote active participation in their care and self-management of their condition. \*
- 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.\* **[QS14]**
- 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, contextualised, tailored information throughout all stages of their care. Include information about:
- their condition, proposed care and any treatment options
  - where they will be seen
  - who will undertake their care
  - expected waiting times for consultations, investigations and treatments.\* **[QS14, QS16]**
- 1.5.15 Ensure that mechanisms are in place to provide information about appointments to patients who require information in non-standard formats.
- 1.5.16 Give the patient both verbal and written information.\* **[QS14]**
- 1.5.17 Explore with the patient whether they want to be accompanied by a friend, relative or advocate, and whether they would like to take notes and/or an audio recording of the consultation.
- 1.5.18 Give the patient (and/or their carers) information to enable them to use any medicines and equipment correctly. Ensure that the patient

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\* This recommendation is adapted from a previously published NICE clinical guideline – see appendix B for details.

and their carers feel adequately informed, prepared and supported to carry out care.\*

1.5.19 Tell the patient where they might find reliable high quality information and support after consultations, from sources such as:

- local support groups and networks
- local and national information services.\*

### **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.

1.5.21 Give the patient the opportunity to discuss their diagnosis, prognosis and treatment.\* **[QS15]**

1.5.22 Before starting any screening, investigations or treatment:

- 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 (taking into account factors such as coexisting conditions and the patient's preferences)
- set aside adequate time to allow any questions to be answered, and arrange further consultation if required.

Discussion should be at the level preferred by the patient.\* **[QS15]**

1.5.23 Clarify what the patient hopes the treatment will achieve and address any misconceptions.\* **[QS15]**

1.5.24 Give the patient, and their family members and/or carers if appropriate, adequate time to decide whether or not they wish to undergo investigations and/or treatment.\* **[QS15]**

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\* This recommendation is adapted from a previously published NICE clinical guideline – see appendix B for details.

1.5.25 Accept and acknowledge that patients may vary in their views about the balance of risks, benefits and side effects of treatments.\*

1.5.26 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
- consider using a mixture of numerical and pictorial formats (for example, numerical rates and pictograms).\* **[QS16]**

1.5.27 Be aware of the value and availability of patient decision aids. If suitable high quality decision aids are available, offer the most appropriate one to the patient.\* **[QS17]**

1.5.28 Offer support to the patient when they are making and reviewing decisions. If a patient decision aid or other decision support tool is

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\* This recommendation is adapted from a previously published NICE clinical guideline – see appendix B for details.

not available, the principles of shared decision making should be used:

- 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 decision is consistent with this. **[QS15]**

### **Education programmes**

1.5.29 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).\* **[QS16]**

1.5.30 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 1.5.29.\*

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\* This recommendation is adapted from a previously published NICE clinical guideline – see appendix B for details.

## 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. The scope of this guidance and the accompanying quality standard is available from [www.nice.org.uk/guidance/index.jsp?action=folder&o=54592](http://www.nice.org.uk/guidance/index.jsp?action=folder&o=54592)

### How this guidance was developed

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

There is more information about how NICE clinical guidelines are developed on the NICE website ([www.nice.org.uk/HowWeWork](http://www.nice.org.uk/HowWeWork)). A booklet, 'How NICE clinical guidelines are developed: an overview for stakeholders, the public and the NHS' (fourth edition, published 2009), is available from NICE publications (phone 0845 003 7783 or email [publications@nice.org.uk](mailto:publications@nice.org.uk) and quote reference N1739).

## 3 Implementation

NICE has developed tools to help organisations implement this guidance (see [www.nice.org.uk/guidance/CG\[XX\]](http://www.nice.org.uk/guidance/CG[XX])).

## 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 guideline. It is published by the National Clinical Guideline Centre, and is available from our website ([www.nice.org.uk/guidance/CG\[XX\]/Guidance](http://www.nice.org.uk/guidance/CG[XX]/Guidance)). **Note: these details will apply to the published full guidance.**

## 4.2 *NICE pathway*

The recommendations from this guidance have been incorporated into a NICE pathway, which is available from [http://pathways.nice.org.uk/pathways/\[xxx\]](http://pathways.nice.org.uk/pathways/[xxx])

**Note: these details will apply when the guidance is published.**

## 4.3 *'Understanding NICE guidance'*

A summary for patients and carers ('Understanding NICE guidance') is available from [www.nice.org.uk/guidance/CG\[XX\]/PublicInfo](http://www.nice.org.uk/guidance/CG[XX]/PublicInfo)

For printed copies, phone NICE publications on 0845 003 7783 or email [publications@nice.org.uk](mailto:publications@nice.org.uk) (quote reference number N[XXXX]). **Note: these details will apply when the guidance is published.**

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

## 5 Related NICE guidance

### Under development

NICE is developing the following guidance (details available from [www.nice.org.uk](http://www.nice.org.uk)):

- Service user experience in adult mental health. NICE guidance and quality standard. Publication expected October 2011

## **Appendix A: The Guideline Development Group, National Collaborating Centre and NICE project team**

### ***Guideline Development Group***

#### **Sophie Staniszewska (GDG Chair)**

Senior Research Fellow, Lead for Patient Experiences and Patient and Public Involvement Programme, Royal College of Nursing Research Institute, University of Warwick

#### **Jo Adams**

Senior Lecturer, Professional Lead for Occupational Therapy, University of Southampton

#### **Eloise Carr**

Deputy Dean Research and Enterprise, Bournemouth University

#### **Miranda Dodwell**

Patient and carer member

#### **Christianne Forrest**

Patient and carer member

#### **Melanie Gager**

Follow Up Sister, Royal Berkshire NHS Foundation Trust

#### **Annette Gibb**

Nurse Consultant in Pain Management, Royal Berkshire NHS Trust

#### **Poonam Jain**

Patient and carer member

#### **David Martin**

Patient and carer member

#### **Tom McLoughlin-Yip**

Patient and carer member

**Alan Nye**

Principal General Practice, Associate Medical Director NHS Direct, and  
Director of Pennine MSK Partnership Ltd

**Suzannah Power**

Patient and carer member

**Amanda Smith**

Executive Director of Therapies and Health Sciences, Powys Teaching Health  
Board

**Richard Thomson**

Professor of Epidemiology and Public Health, Institute of Health and Society,  
Newcastle University

**Chandi Vellodi**

Consultant Physician in Acute Medicine and Medicine for the Elderly, Barnet  
and Chase Farm Hospitals NHS Trust

**Barrie White**

Neurosurgeon, Nottingham University Hospitals NHS Trust

***National Clinical Guideline Centre***

**Joanna Ashe**

Senior information scientist

**Liz Avital**

Guideline manager

**Ian Bullock**

Chief operating officer

**Taryn Krause**

Senior project manager and research fellow

**Kate Lovibond**

Senior health economist

DRAFT FOR CONSULTATION

**Norma O'Flynn**

Clinical director

**Silvia Rabar**

Senior project manager and research fellow

***NICE project team***

**Fergus Macbeth**

Associate Director/Programme Director/Centre for Clinical Practice Director

**Rachel Ryle**

Guideline Commissioning Manager

**Nick Staples**

Guideline Coordinator

**Ruaraidh Hill**

Technical Lead

**Prashanth Kandaswamy**

Health Economist

**Lyn Knott, Katie Prickett**

Editors

## Appendix B: Recommendations from previous clinical guidelines

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

<b>Recommendation number in current guidance</b>	<b>Published clinical guideline</b>
1.1.2	Medicines adherence (CG76)
1.1.4	Chronic heart failure (CG108); Medicines adherence (CG76)
1.1.5	Medicines adherence (CG76)
1.1.6	Pregnancy and complex social factors (CG110)
1.1.7	Advanced breast cancer (CG81)
1.2.2	Pregnancy and complex social factors (CG110)
1.2.4	Chronic heart failure (CG108)
1.2.5	Pregnancy and complex social factors (CG110)
1.2.6	Critical illness rehabilitation (CG83)
1.2.7	Nutrition support in adults (CG32)
1.2.8	Nutrition support in adults (CG32)
1.3.3	Pregnancy and complex social factors (CG110)
1.3.8	Medicines adherence (CG76)
1.3.9	Medicines adherence (CG76)
1.3.10	Medicines adherence (CG76)
1.5.4	Medicines adherence (CG76)
1.5.6	Chronic heart failure (CG108)
1.5.7	Medicines adherence (CG76)
1.5.10	Breast cancer: early and locally advanced (CG80)
1.5.11	Medicines adherence (CG76)
1.5.12	Low back pain (CG88)
1.5.13	Glaucoma (CG85); Barrett's oesophagus – ablative therapy (CG106)
1.5.14	Surgical site infection (CG74); Antenatal care (CG62); Chronic kidney disease (CG73); Barrett's oesophagus – ablative therapy (CG106)
1.5.16	Barrett's oesophagus – ablative therapy (CG106)
1.5.18	Chronic obstructive pulmonary disease (updated) (CG101)
1.5.19	Chronic heart failure (CG108); Prostate cancer (CG58); Medicines adherence (CG76)
1.5.21	Glaucoma (CG85)

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1.5.22	Medicines adherence (CG76); Lipid modification (CG67)
1.5.23	Medicines adherence (CG76)
1.5.24	Prostate cancer (CG58)
1.5.25	Medicines adherence (CG76)
1.5.26	Lipid modification (CG67)
1.5.27	Breast cancer (advanced) (CG81)
1.5.29	Type 2 diabetes (CG66)
1.5.30	Rheumatoid arthritis (CG79)