NCGC National Clinical Guideline Centre

Draft for consultation

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

Patient experience in generic terms

Clinical Guideline

Methods, evidence and recommendations

June 2011

Draft for Consultation

Commissioned by the National Institute for Health and Clinical Excellence

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Acronyms and abbreviations

ARR	Absolute Risk Reduction
DH	Department of Health
ED	Emergency Department
FDA	Food and Drug Administration
GDG	Guideline Development Group
GP	General Practitioner
HES	Hospital Episode Statistics
HTA	Health Technology Assessment
ICER	Incremental cost-effectiveness ratio
ITT	Intention To Treat
MD	Mean Difference
NCGC	National Clinical Guideline Centre
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NNT	Number Needed to Treat
NS	Non-significant (not statistically significant)
OR	Odds Ratio
PICO	Framework incorporating Patients, Interventions, Comparison and Outcome
PSA	Probabilistic Sensitivity Analysis
QALY	Quality-Adjusted Life Year
RCT	Randomised Controlled Trial
RR	Relative Risk
RRR	Relative Risk Reduction
SD	Standard Deviation
SMD	Standardised Mean Difference
STD	Sexually Transmitted Disease
WHO	World Health Organization

1 Setting the scene

The NHS Constitution promotes ‘high quality care for all’. In setting out clearly what Professor Darzi (2008)[13] saw as the enduring principles and values of the NHS, the constitution provided clear signposting to the rights and responsibilities for patients, public and staff. Key aspects of this important legislation are:

- Empowering all patients and the public
- Empowering and valuing staff
- Creating shared purpose, values and principles
- Strengthening accountability through national standards for patients.

Quality as understood from a patient’s perspective was highlighted in the follow up report ‘High Quality Care for All – our journey so far’[14]. It defined three aspects that matter to patients; their experience, the effectiveness of care interventions and the safe delivery of healthcare. While significant investment has created new learning in relation to clinical effectiveness and safety, our understanding of what matters to patients in relation to their experience of healthcare and how this can be improved is still developing.

The longest running survey of public satisfaction with the NHS is the British Social Attitudes (BSA) survey, which provides indicative trends from a ‘user of healthcare’ perspective. First conducted in 1983, it captures the public’s attitudes in relation to satisfaction, providing a useful proxy measure of what the general population think and feel about what is undoubtedly our most important public service. The latest BSA survey reported that 64% of the British public are either very or quite satisfied with the NHS, which in fact is the highest level achieved over the last 3 decades and is part of an upward trend since 2002[51]. Appleby (2011)[3] reinforces the value of the NHS to the general public through the work of Ipsos-Mori’s monthly polling, where it is consistently reported that experience of NHS care remains one of the “most important issues facing Britain today.”[38]. The concept of satisfaction has been explored in various formats over the last two decades within the NHS; it is now widely acknowledged that it is a poor indicator for evaluating quality from a patient experience perspective. The NHS survey data[7] aims to capture multiple dimensions of patient experience and has strengthened evaluation of service delivery and experience, providing insight into areas of healthcare which need focussed improvement. The 2010 adult inpatients survey involved 162 acute NHS trusts in England, with responses from over 66,000 patients, achieved a response rate of 50%.

Despite the improvement in services suggested by surveys, variability of patient experience is well reported[33]. Patient experience is complex and multi-factorial and includes factors centred on services and individual healthcare professionals and also factors which are individual to each patient. Examples of service factors include access to healthcare services and the quality of information available, while the ability of healthcare professionals to facilitate joint decision making also influence experience. Each patient also brings individual factors such as previous experience. All impact on the quality of individual experience during each patient’s personal journey.

In trying to estimate policy development impact, independent research has shown[12,45] the NHS has made good progress in improving the overall quality of care for patients. This initially tended to be focussed on waiting times, staffing levels and physical infrastructure. This failed to explore patient experience as individual recipients of healthcare and establish what is important for them. In a King’s Fund Report (2010, p76)[105] reviewing progress made by the NHS over the last decade, in relation to patient experience they establish that there are two particularly weak areas ‘ the need for better information and for more involvement for patients’.

Understanding what provokes individuals to complain and pursue litigation about their experience of healthcare is helpful in informing how we plan and achieve better patient experience. Data relating to this is available through the NHS Information Centre[83] who report that "the highest percentage of written complaints (42.2% or 42,727) concerned the subject area *All aspects of clinical treatment*, a 0.8 percentage point increase from 2008-09. This was followed in turn by *Attitude of staff* (12.2% or 12,331) and *Outpatient Appointments, delay/cancellation* with 10.6% or 10,710 (12.6% or 11,332 and 10.9% or 9,738 respectively in 2008-09). Given that over 50%, as a crude indicator, of all complaints relate to direct patient interaction with healthcare professionals, this data profile supports the NHS Confederation's assumption that improving patient experience requires a culture shift[82].

The NHS Confederation report [82] establishes that patient experience should examine all aspects of care delivery which includes the individual's first point of contact. It goes on to establish that "improving the experiences of all patients starts by treating each of them individually to ensure they receive the right care, at the right time, in the right way for them." The NHS Confederation report explores policy levers that can perhaps bring the intended aim to be realised, by 'including patient experience as a measurable outcome of care in the NHS outcomes framework, providing incentives through the Commissioning for Quality and Innovation (CQUIN) payment framework, and patient reported outcome measures (PROMs) will all play an important role in helping make patient experience a priority. However, national systems alone will not be the answer. For patients' experiences to shape services and become a priority for staff, a big cultural shift at many hospitals is needed.'

As an emerging concept, patient experience is establishing itself as a key determinant in informing commissioning decisions and in shaping healthcare delivery. Whilst this may seem obvious, historically the approach to patient involvement has been limited. Since 2000 NICE has emphasised the importance of patient involvement in all aspects of their work programme. With over 700 pieces of guidance produced over the last decade, patients have routinely been involved in independent advisory groups who clinically interpret evidence with their healthcare professional colleagues to form recommendations for practice. Within the context of this work programme, the emphasis has tended to be on what can be done to improve healthcare outcomes through clinical and cost effectiveness recommendations. More latterly, the importance of asking the question 'how do healthcare interventions and healthcare professionals improve patient experience?' has emerged. This question has been prioritised by the previous and current Coalition governments, and is the focus of a number of current work streams commissioned by the Department of Health[41,81,84,88].

Historically, measures of experience have not been robustly developed or tested, the consequence being potential skewing of data and what should be a cautious approach in responding to this data. Trying to measure quality is by nature complex and multi-factorial (for example: process measures, outcome measures, patient reported outcome measures), but highly relevant when considering how the full impact of this guideline can be realised in time series measurement that will establish sustainable improvement. Inevitably more work is needed in developing more accurate measures that better report patient experience. It is measurement of effect that will lead to sustainable improvement.

This guideline focuses on generic patient experiences and is relevant for all people using adult NHS services (excluding mental health services – see guideline Service user experience in adult mental health). NICE guidance produced particularly over the last five years has been augmented to include recommendations concerned with ensuring a good patient experience. This move reflects the concept of health evaluation first proposed by Professor Sir Richard Doll (1974)[17], who argued that health care needs to be evaluated according to three key criteria – clinical effectiveness, economic efficiency and social acceptability. While social acceptability was not defined in detail, recent work has developed this concept into the idea of patient-based evidence, which should sit alongside clinical and economic forms of evidence (Staniszewska et al 2010)[101]. The value of patients involvement is not a new concept, the revered physician Sir William Osler (1849 – 1919) in a speech marking the opening of an extension to the Boston Medical Library in 1901 said 'to study the phenomenon of disease without book is to sail an uncharted sea, while to study books without patients is not to go to sea at all.'[87]. Such evidence is vital in understanding the acceptability, appropriateness and effectiveness of care from the patient perspective. This guideline benefits from this thinking using multiple evidence and data sources; research evidence, previously published NICE guideline recommendations, national survey data and a consensus processes to develop recommendations. The process has identified key elements of patient experience and resulted in an understanding of how improvements can be made. These recommendations have been further distilled into commissioning guidance in the form of quality standard for patient experience.

The particular journey that the guideline development group embarked upon has been both challenging and rewarding. Developing guidance in a non clinical topic, non setting and non population specific areas have at times been both demanding and stimulating. In order to capture what is important to patients, we have adopted a pragmatic and often rapid evidence synthesis approach and combined multiple evidence sources to ensure that the guidance accurately reflects the current context. The importance of effective patient involvement within the guideline development group cannot be over emphasised. Patient members together with their healthcare professional colleagues have explored key concepts in determining what the national standard should be, consistent with the NHS constitution. This guidance meets all key aspects outlined in the NHS constitution, with particular emphasis on creating a baseline (national standards) from which improvement in the quality of patient experience can be routinely measured. The full implementation of this guidance is possible if local providers exercise the 'local freedoms' that the constitution advocates in pursuit of excellence in the NHS.

Our aim is that this guidance will provide both the evidence for and the direction to create sustainable change that results in a 'NHS cultural shift' that is so clearly required in order to produce care that is effective, acceptable and appropriate for patients. This guidance provides the evidence and expert consensus base to do this and create sustainable change that refocuses commissioning and clinician behaviours to meet this challenge.

In being committed to the central position and importance of the individual experience of healthcare, one might naturally ask, 'what can I do?' Sir William Osler advises.....'live neither in the past nor in the future, but let each day's work absorb your entire energies, and satisfy your widest ambition.'[86]

2 Development of the guideline

2.1 What is a NICE clinical guideline?

NICE clinical guidelines are recommendations for the care of individuals in specific clinical conditions or circumstances within the NHS – from prevention and self-care through primary and secondary care to more specialised services. We base our clinical guidelines on the best available research evidence, with the aim of improving the quality of health care. We use predetermined and systematic methods to identify and evaluate the evidence relating to specific review questions.

NICE clinical guidelines can:

- provide recommendations for the treatment and care of people by health professionals
- be used to develop standards to assess the clinical practice of individual health professionals
- be used in the education and training of health professionals
- help patients to make informed decisions
- improve communication between patient and health professional

While guidelines assist the practice of healthcare professionals, they do not replace their knowledge and skills.

We produce our guidelines using the following steps:

- Guideline topic is referred to NICE from the Department of Health
- Stakeholders register an interest in the guideline and are consulted throughout the development process.
- The scope is prepared by the National Clinical Guideline Centre (NCGC)
- The NCGC establishes a guideline development group
- A draft guideline is produced after the group assesses the available evidence and makes recommendations
- There is a consultation on the draft guideline.
- The final guideline is produced.

The NCGC and NICE produce a number of versions of this guideline:

- the full guideline contains all the recommendations, plus details of the methods used and the underpinning evidence
- the NICE guideline lists the recommendations
- the quick reference guide (QRG) presents recommendations in a suitable format for health professionals
- information for the public (‘understanding NICE guidance’ or UNG) is written using suitable language for people without specialist medical knowledge.

This version is the full version. The other versions can be downloaded from NICE at www.nice.org.uk

2.2 Remit

NICE received the remit for this guideline from the Department of Health. They commissioned the NCGC to produce the guideline.

The remit for this guideline is:

"To produce a quality standard and guidance on patient experience in generic terms."

2.3 Who developed this guideline?

A multidisciplinary Guideline Development Group (GDG) comprising professional group members and consumer representatives of the main stakeholders developed this guideline (see section on Guideline Development Group Membership and acknowledgements).

The National Institute for Health and Clinical Excellence funds the National Clinical Guideline Centre (NCGC) and thus supported the development of this guideline. The GDG was convened by the NCGC and chaired by Sophie Staniszewska in accordance with guidance from the National Institute for Health and Clinical Excellence (NICE).

The group met every four weeks during the development of the guideline. At the start of the guideline development process all GDG members declared interests including consultancies, fee-paid work, share-holdings, fellowships and support from the healthcare industry. At all subsequent GDG meetings, members declared arising conflicts of interest, which were also recorded (Appendix H).

Members were either required to withdraw completely or for part of the discussion if their declared interest made it appropriate. The details of declared interests and the actions taken are shown in Appendix H.

Staff from the NCGC provided methodological support and guidance for the development process. The team working on the guideline included a project manager, systematic reviewer, health economist and information scientist. They undertook systematic searches of the literature, appraised the clinical evidence and cost effectiveness analysis where appropriate and drafted the guideline in collaboration with the GDG.

2.4 What this guideline covers

The guidance and quality standard will outline a level of service that people using adult NHS services (excluding adult mental health services) should expect to receive. For further details please refer to the scope in Appendix A and the review questions in Appendix D.

2.5 What this guideline does not cover

This guideline does not cover:

- People using NHS services for mental health.
- Carers of people using NHS services. The guidance and quality standard will examine the role of carers in the experience of people using NHS services but will not address carers' experiences of services.

It is recognised that some people or groups may have had poor experiences of healthcare and need additional consideration in the delivery of high quality care (for example, because of their age, disability, race, religion or belief). The specific needs of such people or groups will not be addressed within this guidance and quality standard but the principles may be of use in local strategies to narrow inequalities in patient experience.

2.6 Relationships between the guideline and other NICE guidance

NICE Related Guidance currently in development: Service user experience in adult mental health. NICE guidance and quality standard. Publication expected October 2011.

3 Methods

This guidance was developed in accordance with the methods outlined in the NICE Guidelines Manual 2009[77].

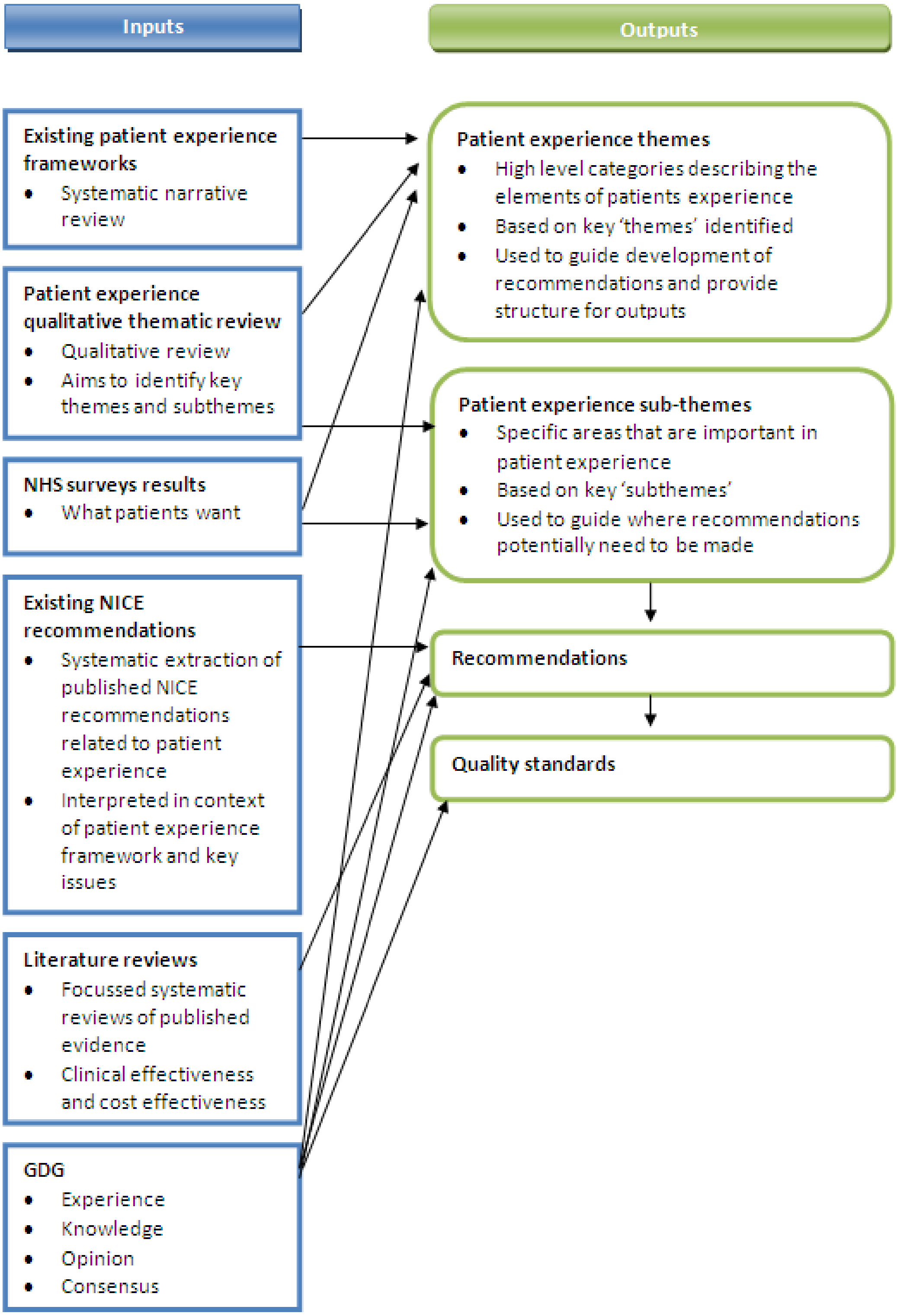
3.1 Overview of approach to guideline development

In developing this guideline, a pragmatic approach was taken to ensure that the guideline development group had multiple sources of evidence/information (see Figure 1 for a graphical representation) in order to establish what is important to patients when considering their experience of healthcare.

- In shaping this work, key sources were:
  - Review of existing patient experience frameworks
  - A Patient Experience Scoping Study –a focused thematic qualitative overview of literature in three disease areas. The aim of the study was to identify key themes/subthemes important to patients in relation to their experience of healthcare
  - Review of NHS survey results
  - Review of existing NICE recommendations related to patient experience
- Drafting of recommendations took into account:
  - Existing NICE recommendations related to patient experience
  - Selected systematic literature reviews for specific interventions that may improve patient experience
  - GDG consensus
- Drafting quality standards
  - The GDG prioritised key areas and drafted quality statements

The methods used to identify the information described above are detailed in the subsequent sections.

Figure 1: Guideline inputs and outputs



3.1.1 Incorporating economic considerations

In NICE guidelines the GDG are asked to take into account both the clinical and cost effectiveness of interventions. Recommendations should be based on the estimated costs of the treatment strategies in relation to their expected health benefits (that is, their 'cost effectiveness'), rather than on the total cost or resource impact of implementing them. Health benefits are usually considered in terms of 'quality-adjusted life years (QALYs)'. The aim of considering cost effectiveness in clinical guidelines is to maximise the health of the population as a whole using available NHS resources.

On the costs side, conventional methods may be applicable to this guideline, since there may be staff time and other costs associated with improving patient experience. However, initial costs may be offset by cost savings, for example if providing patients with appropriate information means that people know to call their assigned nurse when new symptoms emerge rather than attending an accident and emergency unit when symptoms have worsened.

However, in regards to effectiveness there are some additional complexities compared to a standard clinical guideline. While in some cases interventions that improve patient experience may improve 'health' as quantified by QALYs, there is clearly a minimum expectation of what type of patient experience is acceptable, which is not necessarily to do with improving 'health'. For example, a patient and their family have a right to information about their condition and the potential harms and benefits of the treatment they will receive but the aim of this information is not necessarily to improve health. Therefore the quality-adjusted life-year will not capture all the benefits of improved patient experience and it is appropriate to take into account other considerations.

In development of this guideline when quantitative clinical evidence for specific interventions to improve patient experience was identified by a systematic review, evidence of cost effectiveness was also sought (see Section 0). Consideration was given to undertaking a new cost-effectiveness analysis but it was decided that this would not be useful due to the broad range of interventions and populations. For all areas of the guideline, the GDG was asked to consider whether there was a potential cost implication to their recommendations and whether they considered that the benefits to patients would be large enough to justify any additional costs.

3.2 Existing patient experience frameworks

See Chapter 5 for details of how existing patient experience frameworks were identified and used in the guideline.

3.3 Patient experience scoping study - a focused thematic qualitative

A focused thematic qualitative overview of the literature on patient experience was conducted by the University of Warwick. Full methods are described in the full technical report included in Appendix B.

3.4 NHS surveys

See Chapter 5 for details of how NHS survey data fed into the guideline.

3.5 Existing NICE recommendations

NICE guideline recommendations are developed by guideline development groups and subject to public consultation before publication. Recommendations from published guideline considered relevant to patient experience were extracted from existing Clinical and Cancer Care guidelines published between the 1st January 2008 and 26th January 2011. Only recommendations relevant to adults were considered for inclusion. Recommendations from guidance produced by the National Collaborating Centre for Mental Health, Public Health, Technology Appraisals, Interventional Procedures, and Diagnostic programme at NICE were excluded from review.

After each recommendation was identified from the NICE version of the guidance, the full text guideline was reviewed to determine whether the recommendation was derived from an evidence review or guideline development group consensus. Where no details were given it was assumed the recommendation was based on guideline development group consensus[a]. Some recommendations were noted as being 'consensus based on evidence ', meaning there was an issue or barrier identified but no evidence found about how to overcome this. '

As there was considerable overlap in the themes identified in these recommendations, we did not search guidelines published before January 2008 as we believed we had achieved 'saturation' i.e. there were no new themes emerging that could be used to inform new recommendations on patient experience. Recommendations regarded as potentially applicable to the patient experience guideline were then selected by the Patient Experience guideline development group and adapted using consensus or evidence to make them transferable across disease populations and non-setting specific.

3.6 Systematic literature reviews

A limited number of systematic literature reviews were undertaken in areas prioritised by the GDG. Reviews were undertaken in accordance with the methods outlined in the NICE Guidelines Manual 2009[77].

3.6.1 Developing the review questions

Review questions were developed in a PICO framework (patient, intervention, comparison and outcome) for intervention reviews. This was to guide the literature searching process and to facilitate the development of recommendations by the GDG. They were drafted by the NCGC technical team and validated by the GDG.

Table 1: Review questions and outcomes

Chapter	Review questions
10	What is the clinical and cost-effectiveness of decision aids versus no intervention, usual care, alternative interventions, or a combination?
9	What is the effectiveness of interventions to improve the continuity of care of patients in the National Health Service?
10	What methods of presenting information improve a patient's understanding of the risks and benefits associated with their treatment options?
10	What components of patient education programmes improve patient experience?

3.6.2 Searching for evidence

3.6.2.1 Clinical literature search

Systematic literature searches were undertaken to identify evidence within published literature in order to answer the review questions for continuity of care, risk communication and patient education programmes as per The Guidelines Manual 2009[77]. Clinical databases were searched using relevant medical subject headings, free-text terms and study type filters where appropriate. Studies published in languages other than English were not reviewed. Where possible, searches were restricted to articles published in English language. All searches were conducted on core databases, MEDLINE, Embase, Cinahl and The Cochrane Library. The additional subject specific database

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[a] For details about the consensus process used by these groups, please refer to the methodology section of the original full guideline.

PsychInfo was also used. All searches were updated on 9th May 2011. No papers after this date were considered.

Search strategies were checked by looking at reference lists of relevant key papers, checking search strategies in other systematic reviews and asking the GDG for known studies. The questions, the study types applied, the databases searched and the years covered can be found in Appendix E.

3.6.2.2 Health economic literature search

Systematic literature searches were also undertaken to identify health economic evidence within published literature relevant to the identified areas of decision aids and midwife-led care. The evidence was identified by conducting a broad search relating to the topic areas in the NHS economic evaluation database (NHS EED), the Health Economic Evaluations Database (HEED) and health technology assessment (HTA) databases with no date restrictions. Additionally, the search was run on MEDLINE and Embase, with a specific economic filter, from 2010, to ensure recent publications that had not yet been indexed by these databases were identified. Studies published in languages other than English were not reviewed. Where possible, searches were restricted to articles published in English language.

The search strategies for health economics are included in Appendix E. All searches were updated on 10th May 2011. No papers published after this date were considered.

3.6.3 Evidence of effectiveness

The research fellow:

- Identified potentially relevant studies for each review question from the relevant search results by reviewing titles and abstracts – full papers were then obtained.
- Reviewed full papers against pre-specified inclusion / exclusion criteria to identify studies that addressed the review question in the appropriate population and reported on outcomes of interest (review protocols are included in Appendix D).
- Critically appraised relevant studies using the appropriate checklist as specified in The Guidelines Manual[77].
- Extracted key information about the study's methods and results into evidence tables (evidence tables are included in Appendix F).
- Generated summaries of the evidence (included in the relevant chapter write-ups)

3.6.3.1 Inclusion/exclusion

See the review protocols in Appendix D for full details.

3.6.4 Evidence of cost-effectiveness

The health economist:

- Identified potentially relevant studies for each review question from the economic search results by reviewing titles and abstracts – full papers were then obtained.
- Reviewed full papers against pre-specified inclusion / exclusion criteria to identify relevant studies (see below for details).
- Critically appraised relevant studies using the economic evaluations checklist as specified in The Guidelines Manual[77].
- Extracted key information about the study's methods and results into evidence tables (evidence tables are included in Appendix G).

- Generated summaries of the evidence in NICE economic evidence profiles (included in the relevant chapter write-ups) – see below for details.

3.6.4.1 Inclusion/exclusion

Full economic evaluations (studies comparing costs and health consequences of alternative courses of action: cost–utility, cost-effectiveness, cost-benefit and cost-consequence analyses) and comparative costing studies that addressed the review question in the relevant population were considered potentially applicable as economic evidence.

Studies that only reported cost per hospital (not per patient), or only reported average cost effectiveness without disaggregated costs and effects, were excluded. Abstracts, posters, reviews, letters/editorials, foreign language publications and unpublished studies were excluded. Studies judged to had an applicability rating of 'not applicable' were excluded (this included studies that took the perspective of a non-OECD country).

Remaining studies were prioritised for inclusion based on their relative applicability to the development of this guideline and the study limitations. For example, if a high quality, directly applicable UK analysis was available other less relevant studies may not have been included. Where exclusions occurred on this basis, this is noted in the relevant section.

For more details about the assessment of applicability and methodological quality see the economic evaluation checklist (The Guidelines Manual, Appendix H[77] and the health economics research protocol in Appendix D.

3.6.4.2 NICE economic evidence profiles

The NICE economic evidence profile has been used to summarise cost and cost-effectiveness estimates. The economic evidence profile shows, for each economic study, an assessment of applicability and methodological quality, with footnotes indicating the reasons for the assessment. These assessments were made by the health economist using the economic evaluation checklist from The Guidelines Manual, Appendix H[77]. It also shows incremental costs, incremental outcomes (for example, QALYs) and the incremental cost-effectiveness ratio from the primary analysis, as well as information about the assessment of uncertainty in the analysis. See Table 2 for more details.

If a non-UK study was included in the profile, the results were converted into pounds sterling using the appropriate purchasing power parity[85].

Table 2: Content of NICE economic profile

Item	Description
Study	First author name, reference, date of study publication and country perspective.
Limitations	An assessment of methodological quality of the study*: • Minor limitations – the study meets all quality criteria, or the study fails to meet one or more quality criteria, but this is unlikely to change the conclusions about cost effectiveness. • Potentially serious limitations – the study fails to meet one or more quality criteria, and this could change the conclusion about cost effectiveness • Very serious limitations – the study fails to meet one or more quality criteria and this is very likely to change the conclusions about cost effectiveness. Studies with very serious limitations would usually be excluded from the economic profile table.
Applicability	An assessment of applicability of the study to the clinical guideline, the current NHS situation and NICE decision-making*: • Directly applicable – the applicability criteria are met, or one or more criteria are

Item	Description
	not met but this is not likely to change the conclusions about cost effectiveness. • Partially applicable – one or more of the applicability criteria are not met, and this might possibly change the conclusions about cost effectiveness. • Not applicable – one or more of the applicability criteria are not met, and this is likely to change the conclusions about cost effectiveness.
Other comments	Particular issues that should be considered when interpreting the study.
Incremental cost	The mean cost associated with one strategy minus the mean cost of a comparator strategy.
Incremental effects	The mean QALYs (or other selected measure of health outcome) associated with one strategy minus the mean QALYs of a comparator strategy.
ICER	Incremental cost-effectiveness ratio: the incremental cost divided by the respective QALYs gained.
Uncertainty	A summary of the extent of uncertainty about the ICER reflecting the results of deterministic or probabilistic sensitivity analyses, or stochastic analyses of trial data, as appropriate.

*Limitations and applicability were assessed using the economic evaluation checklist from The Guidelines Manual, Appendix H[77]

3.6.4.3 Cost-effectiveness criteria

NICE's report 'Social value judgements: principles for the development of NICE guidance' sets out the principles that GDGs should consider when judging whether an intervention offers good value for money[75].

In general, an intervention was considered to be cost effective if either of the following criteria applied (given that the estimate was considered plausible):

a. The intervention dominated other relevant strategies (that is, it was both less costly in terms of resource use and more clinically effective compared with all the other relevant alternative strategies), or
b. The intervention cost less than £20,000 per quality-adjusted life-year (QALY) gained compared with the next best strategy.

If the GDG recommended an intervention that was estimated to cost more than £20,000 per QALY gained, or did not recommend one that was estimated to cost less than £20,000 per QALY gained, the reasons for this decision are discussed explicitly in the 'from evidence to recommendations' section of the relevant chapter with reference to issues regarding the plausibility of the estimate or to the factors set out in the 'Social value judgements: principles for the development of NICE guidance'[75].

3.7 Developing recommendations

Over the course of the guideline development process, the GDG was presented with:

- The patient experience scoping study – a focused thematic qualitative overview, undertaken by Warwick University.
- A table of existing NICE published recommendations from existing Clinical and Cancer Care guidelines published between the 1st January 2008 and 26th January 2011 (Appendix C).
- Evidence tables of the clinical and economic evidence reviewed from the literature. All evidence tables are in Appendices F and G.
- Summary of clinical and economic evidence and quality (as presented in Chapters 9 and 10).

Recommendations were drafted on the basis of the GDG interpretation of the available evidence, taking into account the balance of benefits, harms and costs. When clinical and economic evidence was of poor quality, conflicting or absent, the GDG drafted recommendations based on their expert opinion. The considerations for making consensus based recommendations include the balance between potential harms and benefits, economic or implications compared to the benefits, current practices, recommendations made in other relevant guidelines, patient preferences and equality issues. The consensus recommendations were done through discussions in the GDG. The main considerations specific to each recommendation are outlined in the evidence to recommendation sections.

3.8 Validation process

The guidance is subject to a four week public consultation and feedback as part of the quality assurance and peer review the document. All comments received from registered stakeholders are responded to in turn and posted on the NICE website.

3.9 Updating the guideline

Following publication, and in accordance with the NICE guidelines manual, NICE will ask a National Collaborating Centre or the National Clinical Guideline Centre to advise NICE's Guidance executive whether the evidence base has progressed significantly to alter the guideline recommendations and warrant an update.

3.10 Disclaimer

Health care providers need to use clinical judgement, knowledge and expertise when deciding whether it is appropriate to apply guidelines. The recommendations cited here are a guide and may not be appropriate for use in all situations. The decision to adopt any of the recommendations cited here must be made by the practitioners in light of individual patient circumstances, the wishes of the patient, clinical expertise and resources.

The National Clinical Guideline Centre disclaims any responsibility for damages arising out of the use or non-use of these guidelines and the literature used in support of these guidelines.

3.11 Funding

The National Clinical Guideline Centre was commissioned by the National Institute for Health and Clinical Excellence to undertake the work on this guideline.

4 Guideline summary

4.1 Full list of recommendations

The patient as an individual

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.
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.
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.
4. Be aware that a patient's beliefs and concerns affect how and whether they engage with treatment, and so may affect their care.
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.
6. Avoid making assumptions about the patient based on their:
    - culture, ethnic origin or religious beliefs
    - age, gender, educational level or socioeconomic status
    - disability or health status.
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.

Essential requirements of care

8. Treat all patients with respect, kindness, dignity, compassion, understanding and honesty.
9. Respect the patient's right to confidentiality.
10. Do not discuss the patient in their presence without addressing them directly.
11. Be prepared to broach sensitive issues, such as sexual activity, as these are unlikely to be raised by some patients.
12. Discuss any fears or concerns the patient has in a non-judgemental and sensitive manner.
13. 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).

14. 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.

15. 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.

16. 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.

17. 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.

18. Address the patient's personal needs (for example, relating to continence and personal hygiene) promptly, and ensure maximum privacy.

19. Ensure that the patient is given regular, accurate information about any delays during episodes of care.

Tailoring healthcare services to the individual

20. 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.

21. Give the patient information about relevant and available treatment options, even if these are not provided locally.

22. 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.

23. Introduce all healthcare professionals involved in the patient's care and explain their roles. Introduce students and anyone else present at consultations, and allow the patient to decide if they want them to stay.

24. 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.

25. 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.

26. Ensure that discussions are held using a style that allows the patient to express their personal needs and preferences for care, treatment and management.

27. 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.

28. Accept that the patient may have different views from healthcare professionals about the balance of risks, benefits and consequences of treatments.

29. 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.

30. Respect and support the patient in their choice of treatment, or if they decide to decline treatment.

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

Continuity of care and relationships

32. 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.

33. 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.

34. 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.

35. 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.

36. Ensure clear and timely exchange of patient information between healthcare professionals.

Enabling patients to actively participate in their care

Communication

37. Ensure that the environment is conducive to discussion and that the patient's privacy is respected, particularly when discussing sensitive, personal issues.

38. 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.

39. Establish how the patient wants to be addressed and ensure that their choice is respected and used.

40. 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.

41. 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.

42. Use words the patient will understand, define unfamiliar words and confirm understanding by asking questions. Avoid using jargon.

43. Use open-ended questions to encourage discussion.

44. Summarise information at the end of a consultation and check that the patient has understood the most important information.

45. 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.

46. All members of the healthcare team should have a demonstrated competency in relevant communication skills.

47. Be aware that the consultation skills needed for increasing patient involvement can be improved.

Information

48. Give the patient information in order to promote active participation in their care and self-management of their condition.

49. 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.

50. 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.

51. Ensure that mechanisms are in place to provide information about appointments to patients who require information in non-standard formats.

52. Give the patient both verbal and written information.

53. 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.

54. Give the patient (and/or their carers) information to enable them to use any medicines and equipment correctly. Ensure that the patient and their carers feel adequately informed, prepared and supported to carry out care.

55. 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

56. 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.

57. Give the patient the opportunity to discuss their diagnosis, prognosis and treatment.

58. 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.

59. Clarify what the patient hopes the treatment will achieve and address any misconceptions

60. 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.

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

62. 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).

63. 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.

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

Education programmes

65. 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).

66. 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 65.

5 Themes for patient experience recommendations and quality standards

5.1 Introduction

Question: What areas are important for delivering a good patient experience?

The GDG wanted to use a framework to develop recommendations and quality standards for improving the patient experience. They recognised that some areas of patient experience are common to all interactions with the NHS, whereas others may be specific to the setting or type of care for example, an emergency episode versus a long-term condition. The GDG considered that this generic guidance is not intended to address aspects of patient experience that are may be particular to specific conditions. Those areas will continue be addressed in NICE guidance and quality standards specific to those conditions.

Three types of evidence were used to inform the GDG discussion and agreement of themes important for patient experience. These were (1) a narrative review of current frameworks of patient experience; (2) a focused thematic qualitative overview of patient experience and (3) results of national surveys of patient experience. Each review is outlined and the GDG discussion and decisions are described below.

5.2 Patient Experience Frameworks

What frameworks of Patient Experience are used in healthcare in the NHS and internationally?

Method of review:

A number of frameworks have been developed to describe the important principles of patient experience and thus potentially provide a structure within which to consider patient experience. A search of the literature was undertaken to identify existing patient experience frameworks. Clinical databases were searched using relevant medical subject headings and free-text terms. Where possible, the search was restricted to articles published in the English language. The search was conducted on core databases, MEDLINE, Embase, Cinahl and The Cochrane Library as well as the additional databases PsychInfo, HMIC Health Management Information Consortium and ASSIA: Applied Social Sciences Index and Abstracts. The search was run up to the 10th February 2011. No papers after this date were considered. The full search strategies can be found in Appendix E. This search did not identify relevant frameworks; these were identified by examining policy documents and following up references. The review is not intended to be definitive or exhaustive but to include frameworks that have been influential. The narrative is confined to an outline of the frameworks and how they were developed.

5.2.1 Gerteis and colleagues – Through the patient's eyes.

Two of the most commonly quoted frameworks; the Institute of Medicine framework and the Picker principles have been developed from the work of Gerteis and colleagues (Gerteis et al)[26].Gerteis et al (1993)[26] and outline seven dimensions considered important for patient-centred care. They defined patient-centred care as an approach that consciously adopts the patient's perspective. The dimensions were developed from three studies of the experience of hospital care by patients and families. The initial US study involved three focus groups of people recently discharged from hospitals in the Boston area and their families. All patients had received medical or surgical treatment. This was followed up with telephone interviews using a questionnaire based on the findings of the focus groups. The telephone interviews were conducted with 50 people from five hospitals across the US and 50 of their family members or friends. Focus groups were also conducted with medical and non-medical hospital staff.

The developers used their framework to design and perform a nationwide survey to assess the quality of care across the US. 6455 patients and 2000 'care partners' were interviewed. High performing centres were visited to learn what these centres were doing that resulted in better patient experiences. Funding for the work by Gerteis and colleagues was provided by the Picker/Commonwealth Program for Patient-Centred Care. The work was published as 'Through the Patient's Eyes' (Gerteis et al) which elaborates on the individual dimensions, quotes from other research to expand on the dimensions and provides examples of good practice from the site visits.

The dimensions developed by Gerteis and colleagues (1993) were as follows:

2. Respect for Patients Values, Preferences and Expressed Needs
3. Co-ordination and integration of care
4. Information, communication and education
5. Physical comfort
6. Emotional support and alleviation of fear and anxiety
7. Involvement of family and friends
8. Transition and continuity

Each dimension was further described as shown in Table 3.

Table 3: Dimensions of Patient Centred Care in Gerteis et al

Dimensions	Attention required to:
1. Respect for patients views, preferences and expressed needs	Quality of life, involvement in decision making, dignity, needs and autonomy
2. Co-ordination and integration of care	Co-ordination and integrations of clinical care; of ancillary and support services; of 'frontline' patient care
3.Information, communication and education	Information, communication and education on clinical status, progress and prognosis; on processes of care; to facilitate autonomy, self-care and health promotion
4. Physical comfort	Pain management; help with activities of daily living; surroundings and hospital environment
5. Emotional support and alleviation of fear and anxiety	Anxiety over clinical status, treatment and prognosis; over impact of the illness on self and family; over the financial impact of the illness
6. Involvement of family and friends	Accommodation of family and friends, Involving family in decision-making, supporting the family as care-giver, recognising needs of the family
7. Transition and continuity	Information on discharge, continuing care organised, continuing support, who to call for help

5.2.2 Institute of Medicine

The Institute of Medicine (IOM) is an independent, not-for-profit US organisation. It was established in 1970 and is the health arm of the National Academy of Sciences. In 2001 the IOM published a report 'Crossing the Quality Chasm: A New Health System for the 21st Century' (Institute of Medicine 2001)[36]. The report outlined 6 major aims for all health care organisations, stating that health care should be; safe, effective, patient-centred, timely, efficient and equitable. Patient-centred care was described as encompassing qualities of compassion, empathy, and responsiveness to the needs, values, and expressed preferences of the individual patient.

The IOM identified six dimensions of patient-centred care. These are the dimensions outlined by Gerteis et al (Gerteis et al)[26] although the IOM list amalgamates dimension 7, Transition and continuity (from Gerteis et al) with dimension 2, Co-ordination and integration of care.

Table 4: Dimensions in IOM framework for patient centred care

Dimension	Description (from Crossing the Quality Chasm)
Respect for patients' values, preferences, and expressed needs.	Responds to each patient's wants, needs, and preferences; gives patients opportunities to be informed and involved in medical decision making; guides and supports those providing care in attending to their patients' physical and emotional needs; care is customised and incorporates cultural competence. Patients' preferences are likely to change over time and to depend on the clinical problems in question.
Coordination and integration of care.	Requirement to ensure that accurate and timely information reaches those who need it at the appropriate time; addresses the need to manage smooth transitions from one setting to another or from a health care to a self-care setting.
Information, communication, and education.	People tend to want to know (1) what is wrong (diagnosis) or how to stay well, (2) what is likely to happen and how it will affect them (prognosis), and (3) what can be done to change or manage their prognosis. They need answers that are accurate and in a language they understand. Common to all such interactions is the desire for trustworthy information (often from an individual clinician) that is attentive, responsive, and tailored to an individual's needs.
Physical comfort	Attention to physical comfort implies timely, tailored, and expert management of symptoms such as pain, shortness of breath or other discomfort.
Emotional support—relieving fear and anxiety.	Suffering is more than just physical pain and other distressing symptoms; it also encompasses significant emotional and spiritual dimensions. Patient centred care attends to the anxiety that accompanies all injury and illness,whether due to uncertainty, fear of pain, disability or disfigurement, loneliness, financial impact, or the effect of illness on one's family.
Involvement of family and friends.	Focuses on accommodating family and friends on whom patients may rely, involving them as appropriate in decision making, supporting them as caregivers, making them welcome and comfortable in the care delivery setting, and recognizing their needs and contributions.

Goodrich and Cornwell (2008)[27] carried out a literature review around patient-centred care as part of the King's Fund Point of care programme. The literature was mapped to the IOM framework. They note that the research is 'uneven and highly specialised and the evidence is full of gaps, in particular, dimensions of involvement of family and friends and physical comfort remain unexplored.

5.2.3 Picker Principles

The Picker Institute was founded in the US in 1986 as a not-for -profit organisation to develop and promote a patient-centred approach to healthcare. The Picker Institute was part of the Picker/Commonwealth Fund patient-centred care program which started in 1986 and funded the work of Gerteis et al (1993)[26]. There are eight Picker Principles of patient-centred care[95]. These are the seven dimensions outlined by Gerteis et al (1993) with an eighth dimension 'access to care' added.

'Access to care' is described as follows:

- Patients need to know they can access care when it is needed
- Attention must also be given to time spent waiting for admission or time between admission and allocation to a bed in a ward.

Specific comment re ambulatory care is made by Picker:

- Access to the location of hospitals, clinics and physician offices
- Availability of transportation
- Ease of scheduling appointments
- Availability of appointments when needed
- Accessibility to specialists or specialty services when a referral is made
- Clear instructions provided on when and how to get referrals

5.2.4 National Health Council (2004)

In a report for the US National Health Council in 2004[11], Cronin identified and analysed the concepts that appeared in nine definitions of patient-centred care. The definitions included by Cronin were described in six reports from organisations and three research reports:

1. Agency for Healthcare Research and Quality (2001),
2. Institute of Medicine (2001)
3. Framework outlined by Gerteis et al in Through the Patients Eyes,
4. Putting patients first (Planetree model) (2003),
5. The Foundation for Accountability (2003) (an Oregon based centre)
6. Integrated Patient-centred care (2002) (a report for the National Health Council)
7. Grin, OW (1994) Patient-centred care: empowering patients to achieve real health care reform Michigan Medicine 93, 25-29
8. Johnson, CL & Cooper PK (1997) Patient-focussed care. What is it? Holistic Nursing Practice 11, 1-7
9. Stewart, M, Brown J, Weston, W, McWhinney, I, McWilliam, C, Freeman, T (1995) Patient-centred Medicine. Thousand Oaks, CA: Sage Publications

Forty-eight concepts were embedded in the nine definitions with six elements appearing in three or more models as follows: Education and shared knowledge; Involvement of family and friends; Collaboration and team management; holistic/sensitivity to non-medical/ spiritual dimensions; respect for patients needs and wants and free flow and accessibility of information. Cronin further analysed the 48 concepts according to their target or focus. She suggested there were two primary targets – the health care system and the health professional-patient relationship. These are outlined in Table 5 in alphabetical order.

Table 5: Patient-centred care properties - by target area. Adapted from Putting Patients First[11]

Health professional-patient relationship (in alphabetical order)	Health care system (in alphabetical order)	Both - Professional-patient relationship and health care system (in alphabetical order)
Alleviation of fear/Anxiety	Collaboration between disciplines towards goal of healing	Clarifies/Standardises terminology to improve communication.
Being Realistic	Continuity over long term	Communication about care
Education/Shared knowledge	Coordinated and integrated care	Culture supporting positive interaction between patients & caregivers
Emotional/Psycho-social support	Creates new standards/evolves	Equitable treatment for all
Enhancing Dr/patient relationship	Effective professional resources for people who can't manage their own health.	Free flow/accessibility of information
Holistic	Focus on expected patient outcomes vs. departmental needs. Incorporate art (music, visual etc.) into patient care	Incorporating prevention/health promotion
Personalization	Incorporate massage/human touch	Involvement of family/friends
Partnership among professionals, patients & families	Infrastructure supports administration, training, information financing & quality improvement	Patients understanding & Participation in goal of healthier society
Patient control	Integrate alternative/complementary practices	Respect for patient needs/customized care
Participate in own care	Patients participation in financing & incentives for healthcare	Respect for patient preferences/wants
Patient responsibility for health	Simplifying care at the bedside	Respect for patient values
Physical comfort	Team management of health professionals	Quality
Reaching agreement about managing illness	Transition planning	Patients' values guide clinical decisions
Self-care	Transparency	
Sensitive to non-	Use architecture/design to promote	

Health professional-patient relationship (in alphabetical order)	Health care system (in alphabetical order)	Both - Professional-patient relationship and health care system (in alphabetical order)
medical/spiritual issues	health	
Shared/supported decision-making	Use nutrition to enhance health	
Understanding patients "illness" experience. (i.e. ideas, feelings etc.)	Use expensive resources appropriately & efficiently	

5.2.5 International Alliance Patients' Organisations (IAPO)

IAPO is a global alliance of Patient Organisations representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world[37]. IAPO's definition of a 'patient' is a person with any chronic disease, illness, syndrome, impairment or disability.

IAPO's vision is that patients throughout the world are at the centre of healthcare. In a survey of membership in 2004, 74% of respondents indicated that defining patient-centred healthcare was very relevant to their organisation. A review of definitions and principles was published in 2005 with a second edition in 2007. The aim of the review was to provide useful reference material on patient-centred healthcare and to assist in identifying and promoting the principles of patient-centred healthcare. The review considered Definitions and Principles of Patient-centred Healthcare, Research on Patient-centred Healthcare and Barriers to the Practice of Patient-Centred Healthcare.

The review of definitions and principles of patient -centred healthcare considered that 'respect for patients' needs and/or wants and/or preferences and/or values' stood out as a commonality explicitly stated in most of the definitions. The review identified four elements that they considered significant omissions from most definitions of patient-centred healthcare. These are (1) Patients' rights; (2) Patients' responsibilities; (3) Evidence based care and (4) Patient safety. The authors accepted that Evidence based care and Patient safety may be omitted because evidence based care is assumed to be common practice and patient safety is accepted to be an essential aim of healthcare but suggested that consideration be given to whether both should be included in definitions of patient-centred healthcare. Other issues that arose from their analyses included: the question of who should define patient-centred healthcare, that definitions identified have originated in North America and Europe, the need to balance public health with individual focused healthcare and that while many principles already laid out focus on the preferred outcome for the patient and can be carried out by individual healthcare professionals, other aspects need to be addressed through the healthcare system to achieve the required outcomes.

IAPO declare that to achieve patient-centred care, healthcare must be based on five principles: (1) Respect; (2) Choice and empowerment; (3) Patient involvement in health policy; (4) Access and support and (5) Information.

5.3 What themes emerge from studies of patient experience?

Patient experience scoping study - a focused thematic qualitative overview

Method:

The frameworks presented provide a useful overview of important patient experiences themes, with significant overlaps. While they are helpful in demonstrating the potential range of experience dimensions, it is not always clear how these dimensions have been extracted from a wide and diverse body of research, the extent to which patients and the public have been involved in developing or selecting these dimensions, the extent to which the dimensions reflect patient-identified experiences, as opposed to those identified by researchers and clinicians or their utility in a UK context. Due to these uncertainties, a patient experience scoping study was commissioned from the RCN Institute at the University of Warwick to scope the evidence and identify a framework which captures generic dimensions of experiences and provides a very clear audit trail to the underpinning experiences evidence-base. The aims of the scoping study were to:

- Identify generic themes and sub-themes of patient experience in three clinical areas: cardiovascular disease, diabetes and cancer, all areas of significant disease burden.
- Use the themes and sub-themes identified in the three clinical areas to develop an overall generic patient experiences framework that has potential relevance for all patients.

The aim of this scoping study was to sample from a range of patient experiences studies, with the intention of reaching a level of data saturation, in terms of the generic themes being identified for each group. Data saturation describes the point at which no new generic themes are being identified from studies (Ritchie and Lewis 2003)[92]. It is not an absolute measurement but a judgement made by the researcher. The intention was not to conduct a systematic review, which would have been unfeasible in the time-scale, but some elements of systematic reviewing were adopted, for example in the development of search strategies and in the extraction of data from papers (Centre for Reviews and Dissemination Guidance 2009)[8]. The detailed methods used are reported in Appendix B.

In summary, the data extracted from studies in each clinical area were used to develop the themes and sub-themes relevant to each clinical area. The summary evidence tables and the full evidence tables are presented in Appendix B. In order to develop the overall generic experiences framework and to manage the process of synthesising data extracted from studies, the next stage utilised the Institute of Medicine[36] framework as a model against which to compare and contrast the themes identified in this study. Each element of the IoM[36] framework was examined according to each clinical area, to review its validity, that is, whether there is evidence to support its inclusion in an overall framework. Each dimension of the IoM framework was broken down, for example information and communication were considered separately rather than amalgamating them into one category, in order to explore whether they should stand alone as themes. Once this process was complete, the research team examined what generic themes might be missing in the IoM framework. It should be recognised that the final generic framework is by necessity a broad summary of a much wider body of evidence, with the underpinning evidence contained in the summary evidence tables in Appendix B. The final generic framework is presented in Table 6, with an illustrative narrative summary.

Table 6: Framework from the patient experience scoping study - a focused thematic qualitative overview

Generic theme	Narrative description
Patient as active participant	Reflects the role of patients as potential active participants in their health care, co-creators and co-managers of their health and use of services; responsible for self-care, participators in healthcare, shared decision-makers, self-managers,

Generic theme	Narrative description
	risk managers, life-style managers. Confidence in self-management is critical. Associated with issues of power and control.
Responsiveness of services -an individualised approach	Needing to be seen as a person within the healthcare system. The responsiveness of health services in recognising the individual and tailoring services to respond to the needs, preferences, and values of patients, taking into account both shared requirements and individual characteristics (such as individuals' expectations of service cultural background, gender, and subtle issues such as preferences for humour). Includes how well clinical needs are met (for example: pain management) and evaluation of how well services perform from a patient perspective.
Lived experience	The recognition that individuals are living with their condition and experiencing it in a unique way, that family and broader life need to be taken into account, and that all of these aspects of lived experience can affect self-care. Taking into account individual physical needs and cognitive needs because of condition. Everyday experiences, hopes, expectations, future uncertainty, feelings of loss, feelings of being morally judged, feelings of blame. Some of these experiences originate 'outside' of the health care system but are brought with the patient into the health system; other experiences may be affected by attitudes and expectations of health professionals.
Continuity of care and relationships	Initiating contact with services, interpretation of symptoms, co-ordination, access (barriers to), and availability of services, responsiveness of services, feelings of abandonment (when treatment ends or support is not made available). Being known as a person rather than 'a number'. Trust in health care professional built up over time. Recognition/questioning of expertise of health care professional. Respect, including respect for patient's expertise. Partnership in decision-making. Issues of power and control.
Communication	Needing to be seen as an individual; communication style and format (for example: over telephone or in person), skills and characteristics of health care professional; body language (which can convey different information from that spoken); two-way communication and shared decision-making; compassion, empathy; the importance of the set up of consultation (for example: appropriate time for questions, appropriate physical environment, number of peoples present). Listening, paying attention to the patient. Enabling questions and providing answers.
Information	Information to enable self-care and active participation in healthcare, importance of information in shared decision-making, tailored information to suit the individual, patient wanting/not wanting information, timely information. Sources of information, including, including outside the health service (for example: peer support, internet). Quality of information. Sources of further information and support. Developing knowledge and understanding, making sense of one's health.
Support	Different preferences for support: Support for self-care and individual coping strategies. Education. Need for emotional support, need for hope. Responsiveness of health care professionals to individual support needs (may vary according to gender, age, and ethnicity). Importance of peer-support, groups, voluntary organisations. Practical support. Family and friends support. Role of advocacy. Feeling over-protected, not wanting to be a burden.

5.4 What areas of patient experience are important to NHS patients?

Surveys are widely used to assess patient experience. They have been used to examine how the NHS performs and to identify which aspects of patient experience are most important to patients. The GDG wished to learn whether there are specific areas that are important to NHS patients and/or areas which need particular attention. We did not carry out an original evidence review but used existing NHS surveys and published analyses of these.

5.4.1 Themes from NHS patient surveys

The NHS national patient survey programme was established first under the Commission for Healthcare Improvement in 2002 and has subsequently reported to the Healthcare Commission until 31st March 2009 and currently to the Care Quality Commission.

Picker Institute Europe was founded in 2000 and co-ordinates a National NHS Patient Survey Co-ordination centre for the Care Quality Commission. NHS patient surveys have included condition specific surveys, surveys of mental health trusts, general practice, Primary Care Trusts, ambulance trusts, in-patient and outpatient surveys, including surveys of emergency and maternity care. The surveys are based on the original Picker principles and supported by ongoing work to enhance the validity of the methodology. The most recent survey is the Maternity services survey 2010. Key findings of surveys are reported on the NHS surveys website NHS Surveys: Focused on patients' experience: Publications. These are not replicated here

The Picker Institute reports the following eight aspects of healthcare as being most important to patients. The reference provided on the Picker Institute Europe website is Gerteis et al eds. (1993)[26].

These are:

1. Fast access to reliable health advice
2. Effective treatment delivered by trusted professionals
3. Involvement in decisions and respect for preferences
4. Clear, comprehensible information and support for self-care
5. Attention to physical and environmental needs
6. Emotional support, empathy and respect
7. Involvement of, and support for, family and carers
8. Continuity of care and smooth transitions.

5.4.2 Quest for Quality and Improved Performance Report

There are a number of studies and reports which aim to identify and rank the aspects of care most important to patients. Leatherman and Sutherland in a Quest for Quality and Improved Performance (QUIPP) report (2007)[44] attempt to draw together the evidence of what patients want from the NHS. They quote from a survey of in-patients by the Picker Institute Europe which asked patients to score the importance of 82 aspects of care (Boyd 2007)[5]. The top ten elements of care are reported below (in order of importance):

1. The doctors know enough about my medical history and treatment.
2. The doctors can answer questions about my condition and treatment in a way that I can understand.
3. I have confidence and trust in the hospital staff who treat me.
4. The doctors wash or clean their hands in between touching patients.
5. The nurses know enough about my medical history and treatment.
6. Before my operation or procedure, I get a clear explanation of what will happen.
7. The risks and benefits of my operation or procedure are explained to me in a way that I can understand.
8. The nurses wash or clean their hands between touching patients.
9. The rooms and ward are clean.

10.The doctors and nurses are open with me about my treatment or condition.

Leatherman and Sutherland (2007)[44] suggest that these priorities indicate a requirement for an NHS that places a high priority on communication, patient-professional interactions and treating patients as individuals.

A perspective from primary care is given using an international study by Grol (1999)[28] which reported that the five priorities for UK general practice are:

1. A GP should be able to provide a quick service in case of emergencies.
2. During the consultation a GP should have enough time to listen, talk and explain to me.
3. A GP should guarantee the confidentiality of information about all his/her patients.
4. A GP should make me feel free to tell him or her my problems.
5. A GP should tell me all I want to know about my illness.

Leatherman and Sutherland (2007)[44] concluded that there are several aspects of care that are consistently identified as important. They list these as:

- information and involvement in decision-making about care
- to be treated as an individual
- choice where it makes a difference
- predictable and convenient access to healthcare
- equitable treatment and chances for health
- safety from harm.

5.4.3 Picker Institute Europe: core domains of patients' experience

Picker Institute Europe published two discussion papers 'Core domains for measuring inpatients' experience of care' in 2009 (Sizmur and Redding 2009)[96] and 'Key domains of the experience of hospital outpatients' in 2010 (Sizmur and Reading 2010)[97]. The papers describe secondary analysis of NHS surveys of inpatient and outpatient care to answer the following questions: Which aspects of patient experience relate most strongly to patient satisfaction? Can these be grouped into 'core domains' for priority action? What would those 'core domains' be?

The methodology used was to find correlations between patient responses to survey questions and an overall expression of satisfaction. Factor analysis was used to identify responses that could be combined to produce scores on distinct areas of experience. An alternative composite score was also used in the analysis as overall satisfaction is a single item measure. Two sets of domains were identified with a wider and more diverse set of domains identified for outpatient care. The authors suggest that these domains may be useful to focus NHS quality improvement measures.

Table 7: Key domains identified from NHS surveys of inpatients and outpatients. Picker Institute 2010

National outpatient survey 2009	National inpatient survey 2008
Dealing with the (presenting) issue	Involvement in decisions
Doctors	Doctors
Other professionals	Nurses
Cleanliness	Cleanliness
Information about discharge	Pain control
Information about treatment	
Plus	
Organisation	Consistency and co-ordination

National outpatient survey 2009	National inpatient survey 2008
Respect and dignity	Respect and dignity

Questions contributing to domains

The analysis of domains includes a report of questions in surveys that particularly contributed to the domains identified. The GDG considered that these gave greater insight to patients concerns and might also be of value in informing measures for quality standards. They are therefore listed below.

Questions contributing to domains identified for inpatients

The questions in the surveys that particularly contributed to the domains identified for inpatients are as follows:

Consistency and coordination of care

Did members of staff say different things?

How would you rate how well the doctors and nurses worked together?

Treatment with respect and dignity

Overall, did you feel you were treated with respect and dignity while you were in the hospital?

Involvement

Were you involved as much as you wanted to be in decisions about your care and treatment?

How much information about your condition or treatment was given to you?

Did you find someone on the hospital staff to talk to about your worries and fears?

Did you feel you were involved in decisions about your discharge from hospital?

Doctors

When you had important questions to ask a doctor, did you get answers that you could understand?

Did you have confidence and trust in the doctors treating you?

Nurses

Did you have confidence and trust in the nurses treating you?

Did nurses talk in front of you as if you weren't there?

Cleanliness

In your opinion, how clean was the hospital room or ward that you were in?

How clean were the toilets and bathroom that you used while in hospital?

As far as you know, did doctors wash or clean their hands between touching patients?

As far as you know, did nurses wash or clean their hands between touching patients?

Pain control

Do you think the hospital staff did everything they could to help control your pain?

Questions contributing to domains identified for outpatients

The questions that particularly contributed to the domains identified for outpatients are as follows:

Dealing with the issue

While you were in the Outpatients Department, how much information about your condition or treatment was given to you?

Were you involved as much as you wanted to be in decisions about your care and treatment?

Was the main reason you went to the Outpatients Department dealt with to your satisfaction?

Doctors

Did you have enough time to discuss your health or medical problem with the doctor?

Did the doctor explain the reasons for any treatment or action in a way that you could understand?

Did the doctor listen to what you had to say?

If you had important questions to ask the doctor, did you get answers that you could understand?

Did you have confidence and trust in the doctor examining and treating you?

Did the doctor seem aware of your medical history?

Cleanliness

In your opinion, how clean was the Outpatients Department?

How clean were the toilets at the Outpatients Department?

Other professionals

If you had important questions to ask [the other professional], did you get answers that you could understand?

Did you have confidence and trust in [the other professional]?

Information about discharge

Did a member of staff tell you about medication side effects to watch out for?

Did you receive copies of letters sent between hospital doctors and your family doctor (GP)?

Did a member of staff tell you about what danger signals regarding your illness or treatment to watch for after you went home?

Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?

Information about treatment

Before the treatment did a member of staff explain what would happen?

Before the treatment did a member of staff explain any risks and/or benefits in a way you could understand?

Dignity and respect

Overall, did you feel you were treated with respect and dignity while you were at the Outpatients Department?

Organisation of the outpatients department

How well organised was the Outpatients Department you visited?

5.5 Guideline development group discussion of frameworks and themes

The GDG considered it important to agree themes that could apply throughout the NHS and that would encompass the areas of most importance to patients. The GDG considered the available frameworks, the results of the scoping study and the information from NHS surveys in their discussion. They also used noted areas of pre- existing guidance and used their own experience to agree themes that they considered most important within the NHS.

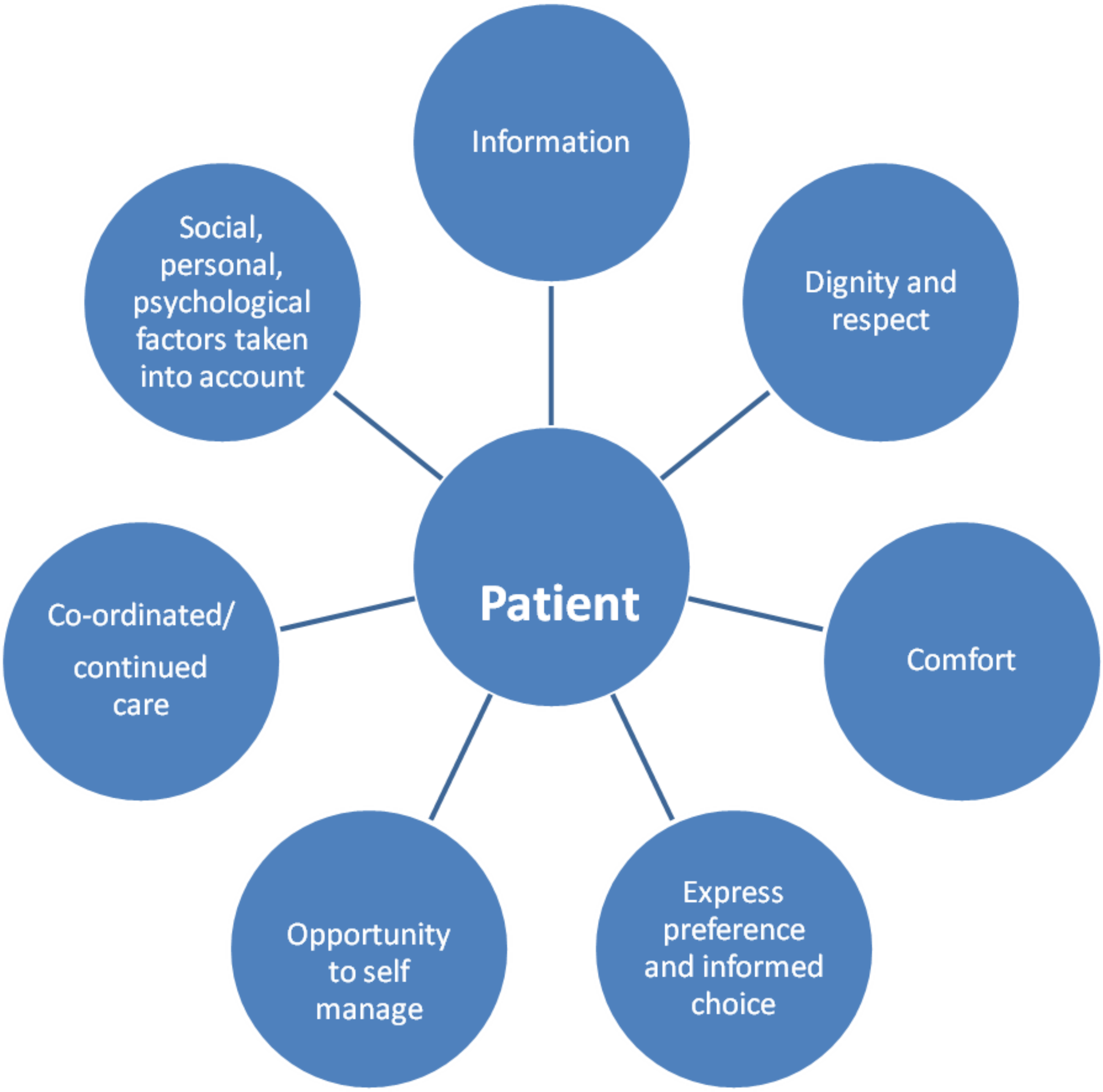
The GDG considered that the IOM framework and other frameworks developed from the early Commonwealth Fund/Picker work (which took place in a US setting almost 20 years ago) were potentially influenced by the hospital settings from which they were developed. The findings and themes found in the scoping study had greater face validity for the GDG and encompassed more of the issues they considered important. The theme of ‘lived experience’ was considered particularly important. This is the recognition that individuals are living with their condition and experiencing it in a unique way, that family and broader life need to be taken into account, and that all of these aspects of lived experience can affect self-care. The definition from the scoping study encompasses everyday experiences, hopes, expectations, future uncertainty, feelings of loss, feelings of being morally judged, and feelings of blame. Some of these experiences are seen to originate ‘outside’ of the health care system but are brought with the patient into the health system. Other experiences may be affected by attitudes and expectations of health professionals. However, the GDG found the term ‘lived experience’ unhelpful as it was considered to be a useful research term but difficult to use as a theme when advising NHS and individual healthcare professionals. The GDG also considered aspects of care that did not appear in the scoping framework but that are important and may be delivered badly, such as nutrition and access to food.

The GDG discussed alternate terms and grouping for themes. They felt that there were two different perspectives that required consideration:

1) That of the patient i.e. how the service should feel to the patient
2) That of the healthcare professional and service who are delivering the patient experience. These perspectives clearly overlap but are distinct from each other.

The preferred outcome for a patient as identified by the GDG is indicated in Figure 2. Patients want to be treated with dignity and respect, to have comfort, for their social, personal and psychological factors to be taken into account, for care to co-ordinated, to have opportunity to self-manage, to express preferences and have information to allow informed choice.

Figure 2: The outcome of good patient experience from the patient's perspective



The GDG decided that to achieve the patient experience described in Figure 2, individual healthcare professionals and services needed to respond to the patient as an individual, to address their fundamental human needs, to be informed and allowed to participate, to have the service respond to their individual circumstances, and to have continuity of care. These themes are outlined below with a fuller description of each theme as outlined by the GDG.

Table 8: Themes for patient experience recommendations and quality standards

Theme	Explanation
The patient as individual	Patients value health care professionals acknowledging their individuality and the unique way in which each 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 their family and broader life need to be taken into account insofar as they affect help and healthcare experience.
Essential requirements of care	Patients need to be recognised as having needs other than treatment of their physical symptoms. There should be recognition of the potential need for psychological and emotional support as well as meeting fundamental needs such as nutrition, safety and pain management.
Tailoring healthcare services to the individual	Patients wish to be seen as an individual within the healthcare system. This requires health services to recognise the individual and therefore to tailor services 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.
Continuity of care and relationships	Continuity and consistency of care and the establishment of 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.
Enabling patients to actively participate in their care	Patients wish to be considered as potential active participants in their own health care, involved in the creation and management of their health strategy and use of services. Potentially they could be responsible for self care, shared decisions and management of risk and life style choices.

6 The patient as an individual

6.1 Introduction

For people who make use of healthcare services, to be treated as an individual is an essential part of retaining their dignity during a stressful period. Each patient experiences healthcare in a unique and individual way. For many, healthcare forms a small, but nevertheless important part of their wider life. Therefore, being recognised and treated as an individual remains important to a person when they become a patient. In many ways the need is strengthened, particularly at a time when a person can feel vulnerable. In accordance with this, there is an important need for health services to recognise that individuals are living with their condition(s), experiencing it in a unique way, and that family and broader life need to be taken into account. Recognising individuals within the health service means understanding and acknowledging their experiences, hopes and expectations. It may mean considering future uncertainty, feelings of loss, guilt or shame and feelings of being morally judged or blamed by health care professionals. Some of these feelings originate ‘outside’ of the health care system but are brought with the patient into it. Other experiences may be affected by attitudes and expectations of health professionals. Recognising and responding to the needs of an individual forms an important underpinning to the concept of personalisation and to the development of a responsive service that is truly patient-centred. Therefore, seeing patients as individuals within a complex health service becomes an important requirement for a good patient experience.

6.2 Evidence reviews and other inputs

Each of the following sources of evidence and information has been used to inform the recommendations on patient as individual and a discussion of this is presented in section Recommendations and link to evidence.

6.2.1 Patient experience scoping study - a focused thematic qualitative overview review

The patient experience scoping study (please see Appendix B for the full report) identified aspects related to the patient as an individual in the three clinical areas examined. The findings are summarised in Table 9:

Table 9: Subthemes from the patient experience scoping study related to the patient as an individual

Cancer (Main theme: Support)	**Cardiovascular disease** (Main theme: Knowledge, understanding and making sense)	**Diabetes** (Main theme: Lived experience)
Identity	Education	Everyday lives
Advocacy	Patients ways of making sense vary from biomedical explanations	Perceived unrealistic goals
Individualised approach		Cultural issues
Stigma/taboos/culture		Interpretations, beliefs and meanings
Reassurance/hope		Psychological factors
		Perceived discrimination/injustice

In addition, the framework developed by on the basis of the scoping report also identified Lived Experience as a main theme, and is described as follows:

> Needing to be seen as a person within the healthcare system. The responsiveness of health services in recognising the individual and tailoring services to respond to the needs, preferences, and values of patients, taking into account both shared requirements and individual characteristics (such as individuals' expectations of service cultural background, gender, and subtle issues such as preferences for humour). Includes how well clinical needs are met (for example: pain management) and evaluation of how well services perform from a patient perspective.

6.2.2 NHS surveys

NHS Surveys are used to assess patient experience, to examine how the NHS performs and to identify which aspects of patient experience are most important to patients. Further information on patient surveys is in Section 5.4.

Leatherman and Sutherland in a Quest for Quality and Improved Performance (QUIPP) report (2007)[44] attempt to draw together the evidence of what patients want from the NHS. They concluded that 'to be treated as an individual' is an aspect of care that is consistently identified as important.

6.2.3 Existing NICE recommendations

The following recommendations, related to the patient as an individual, are already in existence in other published NICE guidelines (please see Appendix C for more details on existing NICE recommendations):

- Consider any factors such as physical or learning disabilities sight or hearing problems and difficulties with reading or speaking English, which may affect the patient's involvement in the consultation.
  (From 'Medicines adherence', R 1.1.2)[70]
- Be aware that patients' concerns about medicines, and whether they believe they need them, affect how and whether they take their prescribed medicines.
  (From 'Medicines Adherence', R 1.1.19)[70]
- Address any beliefs and concerns that patients have that can result in reduced adherence.
  (From 'Medicines Adherence', R 1.2.7)[70]
- Listen to patients and respect their views and beliefs.
  (From 'Chronic heart failure', R1.5.5.2)[54]
- Avoid making assumptions based on a woman's culture, ethnic origin or religious beliefs.
  (From 'Pregnancy and complex social factors', R 1.3.9)[74]
- Assessment and discussion of patients' physical, psychological, social, spiritual and financial circumstances should be undertaken at key points. Offer support where appropriate.
  (From 'Advanced breast cancer' R1.4.1)[60]

6.3 Recommendations and link to evidence

Recommendations	**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.** **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. **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.** **4. Be aware that a patient's beliefs and concerns affect how and whether they engage with treatment, and so may affect their care.** **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.** **6. Avoid making assumptions about the patient based on their:** • **culture, ethnic origin or religious beliefs** • **age, gender, educational level or socioeconomic status** • **disability or health status.** **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.**
Relative values of different outcomes	The GDG believed that treating the patient as an individual was an essential aspect of good patient care.
Trade off between clinical benefits and harms	The GDG considered that while the recognition and response to the patient as an individual was a right for each patient, consideration of the patient as an individual also improved safety, efficiency and effectiveness of health care. Recognising the individual needs of each patient for help with communication for example allows patients to benefit from services that are available and accessible in a timely way. The GDG considered no harms were likely.
Economic considerations	The GDG considered that some of the recommendations may have time, and therefore cost, implications; however they were considered an essential part of good patient care. They also considered that there may be cost offsets due to improved safety, efficiency and effectiveness of healthcare.
Quality of evidence	The GDG used evidence from the patient experience scoping study and consensus to develop the recommendations.
Other considerations	The GDG used their own professional and personal experiences to inform these recommendations. The GDG recognised that healthcare professionals working in the NHS can be under pressure to deliver care in busy environments. For the individual patient however each interaction with professionals and services is a unique experience and part of a wider life experience. The patient cannot be separated from their wider life experience and services need to recognise patient individuality. The GDG recognised that many healthcare professionals and patients achieve this balanced approach despite working in busy environments and that this was related to attitude and skills of those professionals. The GDG emphasised the importance of healthcare professionals seeing the patient as equal, and to value their lived experience. The GDG felt it was important for clinicians to establish the patient's background, such as personal circumstances, social and work situation, health literacy, and previous medical

	experience. The GDG believed that clinicians have an important role in helping patients to have realistic expectations of treatment. The first step of this process is to explore a patient's beliefs and understanding of their treatment and procedures. The GDG considered that it was essential for healthcare professionals to have a non-judgemental attitude towards the patient. A good patient experience should not be compromised because of the patient's ethnic origin, religious beliefs, gender, age or because of disabilities or fluency in English. The GDG felt it was important for clinicians to be supportive but not patronising, and to describe to patients the pertinent options and tools available to support them.

7 Essential requirements of care

7.1 Introduction

A good patient experience is underpinned by a number of essential requirements that reflect the core concepts of patient care. These requirements include meeting patients' needs in relation to continence care, nutrition, personal hygiene, prevention and management of pain and respect, confidentiality and dignity. The importance of recognising and providing essential requirements of care has been well documented over the past few years. The provision of these core fundamentals in the NHS have been outlined in the Essence of Care 2010[15], Fundamental Aspects of Health and Social Care 2003[109] and the Principles of Nursing Practice[94]. These documents focus on the provision of these essential aspects of care. While the meeting of such essential needs could be viewed as a basic component of care that should not be included in a guideline about patient experience, reported lapses in care and complaints data suggest that the reinforcement of the importance of these essential requirements, for a good patient experience, is vital[23,83]. This is also important as the meeting of such basic needs is a necessary pre-requisite for patients engaging in their own care and become active co-creators and co-managers of their health and well-being.

7.2 Evidence reviews and other inputs

Each of the following sources of evidence and information has been used to inform the recommendations on essential requirements of care and a discussion of this is presented in section Recommendations and link to evidence.

7.2.1 Patient experience scoping study - a focused thematic qualitative overview review

The patient experience scoping study (please see Appendix B for the full report) identified aspects related to essential requirements of care, although it was not identified as a generic theme. The sub themes found in the three areas examined in the scoping study are outlined in Table 10 below.

Table 10: Subthemes from the patient experience scoping study related to essential requirements of care

Cancer	Cardiovascular disease (Main theme: Lived experience)	Diabetes (Main theme: physical needs and comfort)
Character of healthcare professional	Communication style	Pain
Psychosocial needs	Patients experience a range of negative emotions related to their condition, symptoms, treatment and prognosis	Eating
Co-ordination	Feeling fearful	Psychological support
	Adopting new routines adapted to the condition / treatment	Empathy

7.2.2 NHS surveys

NHS surveys are used to assess patient experience, to examine how the NHS performs and to identify which aspects of patient experience are most important to patients. Further information on patient surveys is in Section 5.4.

Secondary analysis of NHS surveys of inpatient and outpatient care was carried out to develop 'core domains'. [96 97]. There were a number of questions under various themes that related to essential requirements of care. These are as follows:

Treatment with respect and dignity (inpatients)

Overall, did you feel you were treated with respect and dignity while you were in the hospital?

Nurses (inpatients)

Did nurses talk in front of you as if you weren't there?

Pain control (inpatients)

Do you think the hospital staff did everything they could to help control your pain?

Dignity and respect (outpatients)

Overall, did you feel you were treated with respect and dignity while you were at the Outpatients Department?

7.2.3 Existing NICE recommendations

The following recommendations, related to the essential requirements of care, are already in existence in other published NICE guidelines (please see Appendix C for more details on existing NICE recommendations):

- Respect the woman's right to confidentiality and sensitively discuss her fears in a non-judgemental manner.
  (From 'Pregnancy and complex social factors', R1.1.8)[74]
- Healthcare professionals should be prepared to broach sensitive issues with patients, such as sexual activity, as these are unlikely to be raised by the patient.
  (From 'Chronic Heart Failure', R 1.2.1.4)[54]
- If anxiety or depression is suspected, follow the stepped care models recommended in 'Anxiety' (NICE clinical guidelines 22*) and 'Depression' (NICE clinical guideline 23^)
  (From 'Critical illness rehabilitation', R 1.1.25)[76]
- Healthcare professionals should ensure that care provides:
  - food and fluid of adequate quantity and quality in an environment conducive to eating
  - appropriate support for example, modified eating aids, for people who can potentially chew and swallow but are unable to feed themselves.

  (From 'Nutrition support in adults', R1.1.3)[57]
- 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.
  (From 'Nutrition support in adults', R1.1.1)[57]

*replaced by CG113. ^ replaced by CG90

7.3 Recommendations and link to evidence

Recommendations	**8. Treat all patients with respect, kindness, dignity, compassion, understanding and honesty.** **9. Respect the patient's right to confidentiality.**

	10. Do not discuss the patient in their presence without addressing them directly. **11. Be prepared to broach sensitive issues, such as sexual activity, as these are unlikely to be raised by some patients.**
Relative values of different outcomes	
Trade off between clinical benefits and harms	The GDG considered no harms were likely.
Economic considerations	These recommendations were not considered to have economic implications.
Quality of evidence	Evidence from the framework review and NHS surveys and GDG consensus, indicates the importance of these for patient experience.
Other considerations	The GDG used their own professional and personal experiences to inform these recommendations. They considered that these were areas that were fundamental to enabling a good patient / provider relationship. They also felt that these applied to all involved in healthcare ; hospital porters, cleaning staff, reception, clerical or administrative staff as well as people with healthcare qualifications.

Recommendations	**12. Discuss any fears or concerns the patient has in a non-judgemental and sensitive manner.** **13. 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).**
Relative values of different outcomes	
Trade off between clinical benefits and harms	The GDG considered no harms were likely.
Economic considerations	These recommendations were not considered to have economic implications.
Quality of evidence	Evidence previous NICE guidelines and GDG consensus indicates the importance of these for patient experience.
Other considerations	The GDG used their own professional and personal experiences to inform these recommendations. They considered the importance of recognising the psychological impact of ill health and the existence of depression / anxiety as a co-morbidity. They wished to acknowledge the difficulty for patients in raising sensitive issues, the anxiety that such situations can cause and thus the need for sensitivity and understanding.

Recommendations	**14. 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.**

	15.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.** **16.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.** **17.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.** **18.Address the patient's personal needs (for example, relating to continence and personal hygiene) promptly, and ensure maximum privacy.**
Relative values of different outcomes	
Trade off between clinical benefits and harms	The GDG considered no harms were likely.
Economic considerations	The GDG considered that while some of these recommendations had potential cost implications for example in terms of training or additional nursing time these are fundamental aspects of good patient care.
Quality of evidence	Evidence from NHS surveys, Framework review and scoping studies, sources, previous NICE guidelines and GDG consensus indicates the importance of these for patient experience.
Other considerations	The GDG used professional and personal experience to develop these recommendations which refer to day patients and inpatients. The GDG considered it essential to ensure that patients' nutritional and personal needs are appropriately met. The GDG considered it important that consideration is given to whether patients can self medicate whilst in hospital to ensure continuity of their management of their health. GDG members recognised that this is potentially a difficult area but they were aware of services that had protocols and arrangements in place to allow this to happen. This should be considered for all medications and may be particularly useful for pain relief. The GDG regarded the area of pain management as being an area of poor practice. The GDG considered that it was essential for the healthcare professionals to have a non-judgemental attitude towards pain management and treat every patient as an individual.

Recommendations	**19.Ensure that the patient is given regular, accurate information about any delays during episodes of care.**
Relative values of different outcomes	

Trade off between clinical benefits and harms	The GDG considered no harms were likely.
Economic considerations	This recommendation was considered to have minimal economic implications.
Quality of evidence	Evidence from the scoping study indicated the importance of this for patient experience.
Other considerations	The experience of the GDG was that patients are often not adequately informed about what is happening both when receiving and awaiting treatment. It is a common experience for patients to be kept waiting for attention or treatment but not to be updated about how long they may have to wait. The GDG considered that such information was rarely shared with patients, that honesty was important and that information is helpful for patients to prevent false expectations and allow them to manage time well.

8 Tailoring healthcare services to the individual

8.1 Introduction

The development of evidence based medicine and the need to deliver efficient care risks industrialising the processes of care and potentially jeopardising the essential human nature of these interactions.   In order to ensure that the human nature of health care is not lost, it is necessary to understand what aspects of individuality and service responsiveness are important and valued by patients.

To provide the best experience of care health care professionals and health services must tailor services to recognise patients as individuals and to respond to their needs, preferences, and values, taking into account both shared requirements and individual characteristics (such as individuals' expectations of service, their cultural background, gender, and even subtle issues such as preferences for humour etc).

Services should recognise that the evaluation of patient experiences is complex and evolving. While patient-reported outcomes measures often have a history of robust development, the robustness of patient experiences measures, in terms of properties such as reliability and validity, is often less clear. Satisfaction as a concept that reflects the way in which patients evaluate their care has been challenged and further work is needed to develop instruments that better capture the ways In which patients want to report their experiences[20,102,103].

8.2 Evidence reviews and other inputs

Each of the following sources of evidence and information has been used to inform the recommendations on responsiveness of service – an individualised approach and a discussion of this is presented in section Recommendations and link to evidence.

8.2.1 Patient experience scoping study - a focused thematic qualitative overview review

The patient experience scoping study (please see Appendix B for the full report) identified aspects related to the patient as an individual in all the three areas examined. The findings are summarized in Table 11 below:

Table 11: Subthemes from the patient experience scoping study related to the patient as an individual

Cancer (Main theme: Support)	**Cardiovascular disease** (Main theme: Knowledge, understanding and making sense)	**Diabetes** (Main theme: Responsiveness)
Support of family/friends	Being left to figure it out yourself	Time spent with health professionals
Individualised approach	Translating knowledge into action	Time waiting
Responsiveness to needs		Response times
		Convenience
		Follow up
		Mistakes
		Tailoring care for individual rather than diabetes

Cancer (Main theme: Support)	**Cardiovascular disease** (Main theme: Knowledge, understanding and making sense)	**Diabetes** (Main theme: Responsiveness)
		Satisfaction

In developing an individualised approach to service provision, health services should regularly seek feedback and act on results, to ensure the care they provide is patient-centred. While major re-configurations in service provision can be difficult and costly, sometimes providing an individualised approach can be about the small things. For example ensuring consultations don't feel rushed so patients feel able to ask questions. Studies have found that where more time was allowed, patients felt care was more personal and they were able to participate[9,42,43,47,89-91,104].

8.2.2 Existing NICE recommendations

The following recommendations, related to the responsiveness of services, are already in existence in other published NICE guidelines (please see Appendix C for more details on existing NICE recommendations):

- Accept that patients may have different views from healthcare professionals about the balance of risks, benefits and side effects of medicines.
  (From 'Medicines Adherence', R1.1.13)[70]
- Accept that the patient has the right to decide not to take a medicine, 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 provided with the information needed to make such a decision.
  (From 'Medicines Adherence', R1.1.15)[70]
- Review patient knowledge, understanding and concerns about medicines, and a patient's view of their need for medicine at intervals agreed with the patient, because these may change over time. Offer repeat information and review to patients, especially when treating long-term conditions with multiple medicines.
  (From 'Medicines Adherence', R 1.3.1)[70]
- The named midwife or doctor should tell the woman about relevant services (such as drug and alcohol misuse support services) and encourage them to access these according to her individual needs.
  (From 'Pregnancy and complex social factors', R 1.2.9)[74]

8.3 Recommendations and link to evidence

Recommendations	**20. 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.** **21. Give the patient information about relevant and available treatment options, even if these are not provided locally.** **22. 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.**
Relative values of different	

outcomes	
Trade off between clinical benefits and harms	The GDG considered no harms were likely.
Economic considerations	The GDG considered that while tailoring services may require greater resource use than if this is not done, this is an essential part of good patient care. Other recommendations were considered to have minimal economic implications.
Quality of evidence	The evidence used was from the patient experience scoping study and consensus to develop the recommendations.
Other considerations	The GDG recognised that services are generally developed to cater for populations but considered that care must be taken to tailor services to individuals who require them. The GDG emphasised the importance of the patient being the centre of the healthcare service and as a consequence the healthcare professionals should respond to the patient's situation and requirement as much as possible. A common experience is for patients to be given appointments at times that are difficult for them and not to be given option of where they receive treatment. The GDG were clear that treatment and services needed to be centred on the individual rather than on the condition. For patients with multiple problems this requirement is particularly important. The GDG considered that patients have a right to be made aware of different treatment options even if the local service does not have the expertise or equipment to deliver that treatment. The individual patient need should be considered and the patient fully informed.

Recommendations	**23.Introduce all healthcare professionals involved in the patient's care and explain their roles. Introduce students and anyone else present at consultations, and allow the patient to decide if they want them to stay.** **24.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.** **25.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.**
Relative values of different outcomes	
Trade off between clinical benefits and harms	The GDG considered no harms were likely.
Economic considerations	The GDG considered that no additional costs were required.
Quality of evidence	The GDG considered these recommendations to have minimal economic implications.
Other considerations	Patients vary in regards to whether or not they wish for family and friends to be involved in their healthcare encounters and how much involvement they want their family and friends to have. This can only be ascertained by asking individual patients and should be clarified regularly with all patients. The GDG recognised the importance of confidentiality of patient information, but

	considered the difficulties involved when family and friends need information but the patient cannot give consent to share information. .

Recommendations	**26.Ensure that discussions are held using a style that allows the patient to express their personal needs and preferences for care, treatment and management.**
Relative values of different outcomes	
Trade off between clinical benefits and harms	The GDG considered no harms were likely.
Economic considerations	The GDG considered this recommendation to have no economic implications.
Quality of evidence	The GDG used evidence from the patient experience scoping study and consensus to develop the recommendations.
Other considerations	Allowing patients to express their personal needs and preferences is a pre-requisite to tailoring services to the individual patient. There can be an imbalance both in power and knowledge between healthcare professionals and patients. Effort is therefore required to both inform patients but also to ensure that they can express their personal needs and preferences. Attention to the environment such as adequate privacy and adequate time may need to be available to ensure the patient can express their needs and preferences.

Recommendations	**27.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.** **28.Accept that the patient may have different views from healthcare professionals about the balance of risks, benefits and consequences of treatments.** **29.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.** **30.Respect and support the patient in their choice of treatment, or if they decide to decline treatment.**
Relative values of different outcomes	
Trade off between clinical benefits and harms	The GDG considered no harms were likely.
Economic considerations	The GDG considered that no additional costs were required.
Quality of evidence	The GDG used evidence from the patient experience scoping study and consensus to develop the recommendations. These recommendations were also informed by the reviews and recommendations from Medicines Adherence guideline.

Other considerations	The GDG considered that a patient's view of their condition and its treatment is important in regards to how they *wish* to and how they *will* engage with services. Healthcare professionals however need to recognise that patients may have different views, about conditions and treatments, from healthcare professionals. The GDG considered that healthcare professionals have a duty to provide information to patients to ensure they are not making decisions without adequate information. However, the GDG noted that healthcare professionals must be aware that many decisions are based on patient values. The GDG discussed the importance of respect for the patient's right to make their own decision about their treatment and the need for healthcare professionals to support the patient in their choice.

Recommendations	**31. Give the patient opportunities to give feedback about their care, using different formats, and respond to any feedback given.**
Relative values of different outcomes	
Trade off between clinical benefits and harms	The GDG considered no harms were likely.
Economic considerations	The GDG considered that while this may require a greater resource use than if this is not done, this is an essential part of good patient care.
Quality of evidence	The GDG used evidence from the patient experience scoping study and consensus to develop the recommendations.
Other considerations	Individual healthcare practitioners and services need information and feedback about compliments and complaints to assess how well they are addressing patients' need. The GDG did not review evidence on methods of feedback but were aware that different methods can elicit different aspects of feedback and therefore multiple formats should be available and used.

9 Continuity of care and relationships

9.1 Introduction

In this review we have conceptualised continuity of care according to the definitions provided in the 2010 King's Fund report "continuity of care and the patient experience"[24]. Co-ordination of services is integral to this understanding. The types of continuity outlines are:

Relationship continuity: the ongoing therapeutic relationship with a healthcare professional.

Management continuity: continuous and consistent clinical management, including appropriate information transfer and care planning, as well as any necessary co-ordination of care required by the patient. This is relevant whenever a patient is receiving care from more than one clinician or provider.

Continuity of care is a concept relevant to all stages of the patient pathway and includes aspects of co-ordination, access or barriers to accessing services and the availability of services. There is potential overlap between continuity and the themes of treating the individual and responsiveness of services as services may need to respond to each individuals need for continuity. Continuity may rely on the development of good relationships and trust with health care professionals, which can take time to develop. Ensuring continuity of care in patients with multiple co-morbidities, as well as those who are aging or socially vulnerable, may be particularly important.

9.2 Evidence reviews and other inputs

Each of the following sources of evidence and information has been used to inform the recommendations on continuity of care and a discussion of this is presented in section 9.3.

9.2.1 Patient experience scoping study - a focused thematic qualitative overview review

The patient experience scoping study (see appendix B) identified continuity of care as a key theme in two of three therapy areas examined (cardiovascular disease and cancer). In the third, diabetes, continuity of care was a sub-theme within the key theme 'Relationships/partnership'. The sub-themes found are outline in Table 12 below.

Table 12: Sub-themes for continuity from patient experience scoping study

Sub-themes for diabetes	Sub-themes for cardiovascular disease	Sub-themes for cancer
Continuity of care not identified as a key theme – continuity of care was a sub-theme within the theme 'Relationships/partnership'.	Lack of continuity	Co-ordination
	Experiences of continuity	Availability/accessibility
	Poor communication between health care professionals and poorly coordinated services	Integration
	Feeling secure	Abandonment
		Relationship with health care professional
		Responsiveness to needs

9.2.2 NHS surveys

NHS Surveys are used to assess patient experience, to examine how the NHS performs and to identify which aspects of patient experience are most important to patients. Further information on patient surveys is in Section 5.4.

Findings from a survey by the Picker Institute Europe of inpatients which asked patients to score the importance of 82 aspects of care (Boyd 2007[5]) found that aspects relating to continuity of care were within the top ten. These were:

6. The doctors know enough about my medical history and treatment.
7. The nurses know enough about my medical history and treatment.

Secondary analysis of NHS surveys of inpatient and outpatient care was carried out to develop 'core domains'[96,97]. The questions that particularly contributed to the domain 'Consistency and co-ordination' for inpatients are listed below. In addition for outpatients, there were questions related to continuity of care listed as particularly contributing to the domain 'Information as discharge' and 'Doctors'. These questions are listed below.

Consistency and co-ordination (domain for inpatients)

Did members of staff say different things?

How would you rate how well the doctors and nurses worked together?

Information as discharge (domain for outpatients)

Did a member of staff tell you who to contact if you were worried about your condition or treatment after you left hospital?

Doctors (domain for outpatients)

Did the doctor seem aware of your medical history?

9.2.3 Existing NICE recommendations

The following recommendations pertaining to continuity of care were identified in recent NICE guidelines (see Appendix C for the full list of recommendations in all areas relating to Patient Experience) and used to inform recommendations pertaining to patient experience in general terms.

- At the booking appointment, give the woman a telephone number to enable her to contact a healthcare professional outside of normal working hours, for example the telephone number of the hospital triage contact, the labour ward or the birth centre.
  (From 'Pregnancy and complex social factors', R 1.1.13)[74]
- Work with social care professionals to overcome barriers to care for women who misuse substances. Particular attention should be paid to:
  - integrating care from different services
  - ensuring that the attitudes of staff do not prevent women from using services
  - addressing women's fears about the involvement of children's services and potential removal of their child, by providing information tailored to their needs
  - addressing women's feelings of guilt about their misuse of substances and the potential effects on their baby.
    (From 'Pregnancy and complex social factors', R 1.2.1)[74]
- Healthcare commissioners and those responsible for providing local antenatal services should work with local agencies, including social care and third-sector agencies that provide substance misuse services, to coordinate antenatal care by, for example:

  - jointly developing care plans across agencies
  - including information about opiate replacement therapy in care plans
  - co-locating services
  - offering women information about the services provided by other agencies.
    (From ‘Pregnancy and complex social factors’, R 1.2.2)[74]
- Offer the woman a named midwife or doctor who has specialised knowledge of, and experience in, the care of women who misuse substances, and provide a direct-line telephone number for the named midwife or doctor.
  (From ‘Pregnancy and complex social factors’, R 1.2.4)[74]
- Use a variety of methods, for example text messages, to remind women of upcoming and missed appointments.
  (From ‘Pregnancy and complex social factors’, R 1.2.8)[74]
- The named midwife or doctor should tell the woman about relevant additional services (such as drug and alcohol misuse support services) and encourage her to use them according to her individual needs.
  (From ‘Pregnancy and complex social factors’, R 1.2.9)[74]
- At the booking appointment discuss with the woman the importance of keeping her hand-held maternity record with her at all times.
  (From ‘Pregnancy and complex social factors’, R 1.3.8)[74]
- Offer the young woman aged under 20 a named midwife, who should take responsibility for and provide the majority of her antenatal care, and provide a direct-line telephone number for the named midwife.
  (From ‘Pregnancy and complex social factors’, R 1.4.4)[74]
- Offer patients the opportunity to see the same specialist healthcare team more than once to agree treatment.
  (From ‘Barrett's oesophagus - ablative therapy’, R 1.1.11)[79]
- Every hospital with a cancer centre or unit should assign a CUP specialist nurse or key worker to patients diagnosed with MUO or CUP. The CUP specialist nurse or key worker should:
  - take a major role in coordinating the patient’s care in line with this guideline
  - liaise with the patient’s GP and other community support services
  - ensure that the patient and their carers can get information, advice and support about diagnosis, treatment, palliative care, spiritual and psychosocial concerns.
  - meet with the patient in the early stages of the pathway and keep in close contact with the patient regularly by mutual agreement and
  - be an advocate for the patient at CUP team meetings.
    (From ‘Metastatic malignant disease of unknown primary origin’, R 1.1.1.3)[62]
- Refer outpatients with MUO to the CUP team immediately using the rapid referral pathway for cancer, so that all patients are assessed within 2 weeks of referral. A member of the CUP team should assess inpatients with MUO by the end of the next working day after referral. The CUP team should take responsibility for ensuring that a management plan exists which includes:
  - appropriate investigations
  - symptom control
  - access to psychological support and
  - providing information.
    (From ‘Metastatic malignant disease of unknown primary origin’, R 1.1.1.4)[62]
- Healthcare professionals involved in the care of patients with advanced breast cancer should ensure that the organisation and provision of supportive care services comply with the

recommendations made in ‘Improving outcomes in breast cancer: manual update’ (NICE cancer service guidance [2002]) and ‘Improving supportive and palliative care for adults with cancer’ (NICE cancer service guidance [2004]), in particular the following two recommendations:
  - ‘Assessment and discussion of patients’ needs for physical, psychological, social, spiritual and financial support should be undertaken at key points (such as diagnosis; at commencement, during, and at the end of treatment; at relapse; and when death is approaching).’
  - ‘Mechanisms should be developed to promote continuity of care, which might include the nomination of a person to take on the role of “key worker” for individual patients.’ (Breast cancer – advanced’, R 1.4.1)[60]

- All patients with breast cancer should be assigned to a named breast care nurse specialist who will support them throughout diagnosis, treatment and follow-up. (From ‘Breast cancer – early and locally advanced’, R 1.2.2)[61]
- Offer people with RA an annual review to:
  - assess disease activity and damage, and measure functional ability (using, for example, the Health Assessment Questionnaire [HAQ])
  - check for the development of comorbidities, such as hypertension, ischaemic heart disease, osteoporosis and depression
  - assess symptoms that suggest complications, such as vasculitis and disease of the cervical spine, lung or eyes
  - organise appropriate cross referral within the multidisciplinary team
  - assess the need for referral for surgery (see section 1.6)
  - assess the effect the disease is having on a person’s life. (From ‘Rheumatoid arthritis’, R 1.5.1.4)[65]
- People with RA should have access to a named member of the multidisciplinary team (for example, the specialist nurse) who is responsible for coordinating their care. (From ‘Rheumatoid arthritis’, R 1.3.1.2)[65]
- Offer people with satisfactorily controlled established RA review appointments at a frequency and location suitable to their needs. In addition, make sure they:
  - have access to additional visits for disease flares,
  - know when and how to get rapid access to specialist care, and
  - have ongoing drug monitoring. (From ‘Rheumatoid arthritis’, R 1.5.1.3)[65]
- To ensure continuity of care, healthcare professional(s) with the appropriate competencies
  - Ensure the short-term and medium-term rehabilitation goals are reviewed, agreed and updated throughout the patient’s rehabilitation care pathway. should coordinate the patient’s rehabilitation care pathway. Key elements of the coordination are as follows.
  - Ensure the delivery of the structured and supported self-directed rehabilitation manual, when applicable.
  - Liaise with primary/community care for the functional reassessment at 2–3 months after the patient’s discharge from critical care.
  - Ensure information, including documentation, is communicated between hospitals and to other hospital-based or community rehabilitation services and primary care services.
  - Give patients the contact details of the healthcare professional(s) on discharge from critical care, and again on discharge from hospital. (From ‘Critical illness rehabilitation’, R 1.1.1)[76]
- Ensure that the transfer of patients and the formal structured handover of their care are in line with ‘Acutely ill patients in hospital’ (NICE clinical guideline 50). This should include the formal

handover of the individualised, structured rehabilitation programme.
(From 'Critical illness rehabilitation', R 1.1.12)[76]

- Give patients the following information before, or as soon as possible after, their discharge from critical care. Also give the information to their family and/or carer, unless the patient disagrees.
  - Information about the rehabilitation care pathway.
  - Information about the differences between critical care and ward-based care. This should include information about the differences in the environment, and staffing and monitoring levels.
  - Information about the transfer of clinical responsibility to a different medical team (this includes information about the formal structured handover of care recommended in 'Acutely ill patients in hospital' (NICE clinical guideline 50).
  - If applicable, emphasise the information about possible short-term and/or long-term physical and non-physical problems that may require rehabilitation.
  - If applicable, information about sleeping problems, nightmares and hallucinations and the readjustment to ward-based care.
    (From 'Critical illness rehabilitation', R 1.1.13)[76]
- Give patients the following information before their discharge to home or community care. Also give the information to their family and/or carer, if the patient agrees.
  - Information about their physical recovery, based on the goals set during ward-based care if applicable.
  - If applicable, information about diet and any other continuing treatments.
  - Information about how to manage activities of daily living including self-care and re-engaging with everyday life.
  - If applicable, information about driving, returning to work, housing and benefits.
  - Information about local statutory and non-statutory support services, such as support groups.
  - General guidance, especially for the family and/or carer, on what to expect and how to support the patient at home. This should take into account both the patient's needs and the family's/carer's needs.
  - Give the patient their own copy of the critical care discharge summary.
    (From 'Critical illness rehabilitation', R 1.1.22)[76]
- Antenatal care should be provided by a small group of healthcare professionals with whom the woman feels comfortable. There should be continuity of care throughout the antenatal period.
  (From 'Antenatal care', R 1.2.2.1)[71]
- A system of clear referral paths should be established so that pregnant women who require additional care are managed and treated by the appropriate specialist teams when problems are identified.
  (From 'Antenatal care', R 1.2.2.2)[71]
- Women with diabetes who are planning to become pregnant should be advised:
  - that the risks associated with pregnancies complicated by diabetes increase with the duration of diabetes
  - to use contraception until good glycaemic control (assessed by HbA1c2
  - that glycaemic targets, glucose monitoring, medications for diabetes (including insulin regimens for insulin-treated diabetes) and medications for complications of diabetes will need to be reviewed before and during pregnancy) has been established
  - that additional time and effort is required to manage diabetes during pregnancy and that there will be frequent contact with healthcare professionals. Women should be given information

about the local arrangements for support, including emergency contact numbers. (From ‘Diabetes in pregnancy’, R 1.1.1.2)[72]

- In order to encourage the person to participate in reducing their CVD risk, the healthcare professional should:
  - find out what, if anything, the person has already been told about their CVD risk and how they feel about it
  - explore the person's beliefs about what determines future health (this may affect their attitude to changing risk)
  - assess their readiness to make changes to their lifestyle (diet, physical activity, smoking and alcohol consumption), to undergo investigations and to take medication
  - assess their confidence in making changes to their lifestyle, undergoing investigations and taking medication
  - inform them of potential future management based on current evidence and best practice
  - involve them in developing a shared management plan
  - check with them that they have understood what has been discussed. (from ‘Lipid modification’, R 1.2.5)[68]
- A young person with ADHD receiving treatment and care from CAMHS or paediatric services should be reassessed at school-leaving age to establish the need for continuing treatment into adulthood. If treatment is necessary, arrangements should be made for a smooth transition to adult services with details of the anticipated treatment and services that the young person will require. Precise timing of arrangements may vary locally but should usually be completed by the time the young person is 18 years. (From ‘Attention deficit hyperactivity disorder’, R 1.6.1.1)[66]

9.2.4 Literature review

9.2.4.1 What is the effectiveness of interventions to improve the continuity of care of patients in the National Health Service?

9.2.4.2 Clinical evidence

We searched for systematic reviews of RCTs and/or cohort studies assessing the effectiveness of interventions that might be applied to operationalise continuity of care with patient-focussed outcomes (for example: key workers, hand-held records, etc). The approach to searching and selection of interventions was deliberately kept broad in the hope the literature was well organised with patient-focussed outcomes that we could examine across as many interventions as possible in the time available to support guideline recommendations. Systematic reviews of efficacy data on nurse-led care, team-based interventions, the role of the pharmacist, discharge arrangements, shared care, midwife-led care, and nursing record systems were found. Most of these interventions were multifaceted and complex models of care with few patient-focussed outcome measures.

Midwife-led care was selected for review as there was a clear mechanism for operationalising continuity of care in that clinical area that was well defined in the literature. The applicability and transferability of these findings for a generic guideline would then be considered by the Guideline Development Group. It was not possible to conduct a review across all clinical areas to identify all potentially relevant studies and so mid-wife led care was viewed as a good proxy area which was likely to include many generic components. The aim of this review was to identify components of care that specifically improve continuity that could be generalised across disease areas.

One systematic review/meta-analysis by Devane 2011[16] that compared midwife-led models of care with other models of care for childbearing women and their infants was found. The systematic review was of good quality and included 17 RCTs (for details of the review and included studies, see Appendix F). See Table 13 for a summary of the primary results.

Table 13: Results of midwife-led models versus other models of care for childbearing women and their infants for selected outcomes.

Outcome	N	Effect size
Mean number of antenatal visits	1 study, 405 participants	Mean difference (MD) 1.50; 95% CI 0.96 to 2.04
Antenatal hospitalisation	6 trials, 5990 participants	Relative Risk 0.96; 95% CI 0.89 to 1.03,
Antepartum haemorrhage	5 trials, 5308 participants	RR 0.87; 95% CI 0.66 to 1.14,
Fetal loss/neonatal death before 24 weeks	11 trials, 16213 participants	RR 0.88; 95% CI 0.73 to 1.05,
Fetal loss/neonatal death equal to/after 24 weeks	12 trials, 17927 participants	RR 1.16; 95% CI 0.81 to 1.66,
Overall fetal loss and neonatal death	13 trials, 18129 participants	RR 0.93; 95% CI 0.79 to 1.09
Amniotomy	6 trials, 6068 participants	RR 0.80; 95% CI 0.75 to 0.85,
Augmentation/artificial oxytocin during labour	14 trials, 19035 participants	RR 0.85; 95% CI 0.81 to 0.89
No intrapartum analgesia/anaesthesia	8 trials, 11693 participants	RR 1.17; 95% CI 1.07 to 1.28
Regional analgesia (epidural/spinal)	16 trials, 19418 participants	RR 0.82; 95% CI 0.78 to 0.87
Opiate analgesia	14 trials, 17723 participants	RR 0.92; 95% CI 0.88 to 0.95
Mean labour length	4 trials, 5089 participants	MD 0.49; 95% CI 0.26 to 0.72
Induction of labour	13 trials, 17987 participants	RR 0.94; 95% CI 0.89 to 1.01
Attendance at birth by known midwife	6 trials, 5225 participants	RR 7.99; 95% CI 7.03 to 9.08
High perceptions of control during labour and childbirth	1 trial, 471 participants	RR 1.74; 95% CI 1.32 to 2.30
Caesarean birth	17 trials, 20010 participants	RR 0.94; 95% CI 0.87 to 1.02
Instrumental vaginal birth (forceps/vacuum assisted births)	16 trials, 19737 participants	RR 0.86; 95% CI 0.80 to 0.93
Spontaneous vaginal birth (as defined by trial authors)	14 trials, 17117 participants	RR 1.04; 95% CI 1.02 to 1.06
Episiotomy	17 trials, 19866 participants	RR 0.86; 95% CI 0.8 2 to 0.90
Perineal laceration requiring suturing	9 trials, 12052 participants	RR 0.97; 95% CI 0.94 to 1.01
Intact perineum	11 trials, 14360 participants	RR 1.06; 95% CI 1.00 to 1.11
Postpartum haemorrhage (as defined by trial authors)	10 trials, 12979 participants	RR 0.99; 95% CI 0.87 to 1.12

Outcome	N	Effect size
Maternal death	1 trial, 2801 participants	RR 1.50; 95% CI 0.06 to 36.88
Low birth weight (< 2500 g)	7 trials, 11528 participants	RR 0.97; 95% CI 0.83 to 1.15
Preterm birth (< 37 weeks)	7 trials, 11528 participants	RR 0.95; 95% CI 0.81 to 1.11
5-minute Apgar score below or equal to 7	13 trials, 12039 participants	RR 1.01; 95% CI 0.79 to 1.31
Admission to special care nursery/neonatal intensive care unit	14 trials, 19155 participants	RR 0.99; 95% CI 0.90 to 1.09
Mean length of neonatal hospital stay (days)	3 trials, 1912 participants	MD -1.83 (days); 95% CI -1.97 to -1.69
Neonatal convulsions (as defined by trial authors)	3 trials, 4738 participants	RR 1.43; 95% CI 0.38 to 5.34
Duration of postnatal hospital stay (days)	3 trials, 3597 participants	MD -0.10; 95% CI -0.21 to 0.01
Postpartum depression	1 trial, 1213 participants	RR 1.94; 95% CI 0.18 to 21.32
Breastfeeding initiation	3 trials, 3205 participants	RR 1.01; 95% CI 0.97 to 1.05
Prolonged backache (as defined by trial authors)	1 trial, 1822 participants	RR 1.40; 95% CI 0.62 to 3.13

9.2.4.3 Economic evidence

The approach taken to the economic literature review was to undertake targeted searches following the identification of specific interventions in the clinical review of systematic reviews. A search was therefore undertaken to look to economic evaluations about mid-wife led care compared to other models of maternity care.

Five studies were included that examined costs or outcomes of midwife-led care versus usual care[4,32,34,93,110]. These are summarised in the economic evidence profile below. See also the full study evidence tables in Appendix G.

Three potentially includable economic analyses were excluded due to either being judged not applicable to the current NHS or having very serious methodological limitations[6,16,22].

Table 14: Economic evidence profile – midwife-led care vs usual care

Study	Applicability (n)	Limitations (o)	Other comments	Incremental cost	Incremental effects(p)	ICER	Uncertainty
Begley 2009[4] (Ireland)	Partially applicable(d)(f)	Potentially serious limitations(k)(m)(l)	• Cost consequence analysis • Within-RCT analysis • Clinical study report – same publication	-£237(h)	• As safe • Less intervention • Higher satisfaction	n/a	CI: NR Deterministic sensitivity analysis around resource use and cost assumptions
Homer 2001[32] (Australia)	Partially applicable(d)(e)(f)	Potentially serious limitations(k)(m)(l)	• Cost consequence analysis • Within-RCT analysis • Clinical study report – Homer 2001[31]	-£438(i)	• Reduced caesareans	n/a	CI: NR Results sensitive to caesarean rate but still a cost saving when equivalent rate modelled
Hundley 1995[34] (Scotland)	Partially applicable(e)(f)	Potentially serious limitations(k)(m)(l)	• Cost consequence analysis • Within-RCT analysis • Clinical study report - Hundley 1994[35]	£40.71	• Significant differences in monitoring, fetal distress, analgesia, mobility, use of episiotomy; No difference in fetal outcome	n/a	CI: NR Deterministic scenario analysis: 2/9 scenarios resulted in cost saving.
Rowley 1995[93] (Australia)	Partially applicable(d)(e)(f)	Potentially serious limitations(k)(m)(l)	• Cost consequence analysis • Within-RCT analysis • Clinical study report – same publication • Inpatient care only	-£76(j)	• Higher satisfaction • Fewer adverse maternal and neonatal outcomes	n/a	CI: NR No sensitivity analysis
Young 1997[110] (Scotland)	Partially applicable(e)(f)	Potentially serious limitations(k)(m)(l)	• Cost consequence analysis • Within-RCT analysis • Clinical study report - Turnbull 1996[106]	£6.5	• Clinically safe and efficacious • Increased satisfaction • Enhanced continuity of care	n/a	CI: NR Increased caseload for midwives reduced difference in post-natal costs

CI = confidence interval; DCS = decisional conflict score; EQ5D = Euroqol five dimensions; ICER = incremental cost effectiveness ratio (incremental costs ÷ incremental effects); n/a not applicable; RCT = randomised clinical trial

(a) Directly applicable; partially applicable; not applicable

(b) Minor limitations; potentially serious limitations; serious limitations

(c) *For cost-consequence analyses (costs and various health outcomes reported separately and not combined into a cost-effectiveness ratio) only selected incremental effects are presented – see evidence table for full information about studies.*
(d) *Some uncertainty about applicability of non-UK resource use and costs*
(e) *Some uncertainty about applicability of resource use and costs from over 10 years ago*
(f) *QALYs not used*
(g) *Discount rates used not in line with NICE methodological guidance*
(h) *Converted from 2009 Euros (Ireland) using purchasing power parities*[85]
(i) *Converted from 2000 Australian dollars using purchasing power parities*[85]
(j) *Converted from 1999 Australian dollars using purchasing power parities*[85]
(k) *RCT-based analysis so from one study therefore by definition not reflecting all evidence in area*
(l) *Some limitations in cost estimation*
(m) *Limited sensitivity analysis*

9.2.4.4 Evidence statements

Clinical	One systematic review[16] found evidence of benefit and an absence of evidence of harm for midwife-led models of care for childbearing women. Midwife-led care was shown to significantly increase continuity of care (as defined by attendance at birth by known midwife).
Economic	Of five within-RCT cost consequence analyses (Begley 2009[4], Homer 2001[32], Hundley 1995[34], Rowley 1995[93], Young 1997[110] – all partially applicable, potentially serious limitations), three found that average costs per person were reduced with midwife-led care (-£76 to -£438), and two found that costs were modestly increased (£6.5 to £40.71), with benefits to patients such as higher satisfaction and reduced intervention rates. Statistical significance of cost differences was not assessed.

9.3 Recommendations and link to evidence

Recommendations	**32.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.** **33.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.** **34.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.** **35.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.** **36.Ensure clear and timely exchange of patient information between healthcare professionals.**
Relative values of different outcomes	The GDG considered continuity of care important to patients as identified by NHS survey, framework analysis and consensus. Continuity of care can mean a number of different things to people. The 2010 King's Fund report[24] defines continuity of care as constituting both "relationship continuity" (a continuous therapeutic relationship with a clinician) and "management continuity" (continuity and consistence of clinical management, including providing and sharing information and care planning, and any necessary co-ordination of care required by the patient). The GDG noted that few continuity of care outcomes had been reported and where they were, they focussed on a single aspect of continuity, for example, chronology of a patient's contact with healthcare providers over time, or relationship continuity only.

	Outcome data from the included review of midwife-led care evaluated the intervention, including a crude measure of continuity of care, but did not examine what things about continuity of care specifically impacted outcome.
Trade off between clinical benefits and harms	The GDG considered the importance of continuity of care in relation to patient experience and discussed how there is often a trade-off between rapid access to care and seeing a healthcare worker of their choice. The GDG agreed the importance of different aspects of continuity of care might vary according to a patient's personal circumstances and that they should be given the choice to decide what is best for them. The GDG considered midwife-led care as an example of an intervention that improves continuity of care, that has good evidence of benefit and an absence of evidence of harm. They highlighted how the 2008 Cochrane report on Midwife-led care[29] reported greater levels of maternal satisfaction associated with this model of care. The GDG considered the existing recommendations pertaining to continuity of care from published NICE guidance. They discussed how a number of the recommendations were based on evidence reviews from specific disease areas and may not be suitable for generalising across all settings and populations (for example key workers such as breast cancer nurses and named mid-wives for women with complex social factors). The GDG agreed these recommendations highlighted key themes that were generic to all patient experience of continuity of care: • Continuity of care can mean different things to different people and what is important for one person may not be for another, nor consistently important in all circumstance (for example, a patient might prefer rapid access to care as opposed to seeing their usual clinician of choice). • The communication and transfer of information between clinicians managing care, healthcare services (such as secondary to primary care), and to the patient themselves is imperative to ensuring continuity of care. They acknowledged sometimes discontinuity of care is inevitable (for example: discharge is done by another clinician), but the key is to ensure information is exchanged smoothly at the point of handover process, and there is consistency of understanding in order to mitigate against discontinuity of care.
Economic considerations	Improving continuity of care for patients may require an investment in developing systems that facilitate this. However, midwife-led care illustrates that an alternative model of care that offers more continuity of care does not necessary mean increased costs. Providing patients with better continuity of care may result is other benefits to the health service – better coordinated care may be more efficient and so save money in the long term. For example, the GDG were aware of an economic analysis commissioned by the department of health regarding providing one-to-one support for cancer patients with the aim of improving continuity of care that suggested that additional costs were likely be offset by cost savings due to improvements in quality and coordination of care[25]. Providing patients with information about who was responsible for their care and who to contact under different circumstances was considered to have minimal resource implications. In addition it may have cost savings if people access healthcare more appropriately; for example if they contact an assigned nurse instead of going to A&E.
Quality of evidence	Continuity of care is an important theme in patient experience as indicated by the review of patient frameworks, the patient experience scoping study, information from NHS surveys and the GDG. The systematic review on midwife-led care was of good methodological quality. The review assumed midwife-led care assumed enduring contact with a provider is linked to stronger relationships, better information transfer and

	more consistent management. It did not test this association directly.
Other considerations	The GDG considered how interventions to improve continuity of care are often complex and multifaceted, and combine components such as interdisciplinary care, education and involvement in decision-making, implementation of care plans, assessment of care needs and integration of care as a person transits through the health system. The approach to this review was iterative and aimed to identify as much relevant literature by adopting a broad search strategy and focussing only on systematic reviews. When considering the interventions that were found (for example, discharge planning, shared care and nursing records) it was difficult to identify key factors/facilitators of continuity of care that improved outcome, as the associations were not directly tested and definitions varied across studies. Midwife-led care was chosen for further consideration as it is thought to enable both relationship (i.e. known carer) and management continuity (for example, coordination of care) and the definition of continuity of care was clear. The review did not reveal key facilitators for continuity of care that can be generalised across disease areas so recommendations were based on the GDG's professional and personal experiences. The GDG acknowledge the limitations of their search which was based on continuity of care terms, meaning all papers retrieved must have mentioned continuity of care in their title/abstract. Searches were not conducted for specific interventions and we excluded qualitative literature. In general the GDG noted little attention has been given to the patient's perspective on continuity of care but considered it key to a good patient experience based on the information found in the NHS survey and GDG consensus. More research is needed that focuses on continuity of care using outcomes that are important to patients. Members of the GDG discussed their experiences of visiting multiple healthcare providers for the care of comorbidites and how important it was that information was effectively exchanged between these services as well as the relevant healthcare professionals. Patient with co-morbidities also often receive multiple appointments which conflict or result in them having to visit the same centre multiple times. The GDG recognised the difficult in co-ordination across specialities but considered that the impact on patient experience of a lack of co-ordination is unacceptable. Prioritisation may also be required to individualise care for patients with multiple problems. The GDG discussed the importance of building relationships with a usual professional who can help to coordinate care and relate to them as an individual who is experiencing their condition in a unique way.

10 Enabling patients to actively participate in their care

10.1 Introduction

The importance of enabling patients to be active participants in their care has received extensive policy attention in the last few years[10,100]. Patients have the primary responsibility for managing their health in the context of their wider lives and this needs to be recognised within the provision of services and in the ways health care professionals interact with patients.

While not all patients want an active role, health care professionals and services need to recognise that many individuals want to be active participants and partners in their own care. Patients are co-creators and co-managers of their own health when they are in receipt of services and not just recipients or receivers of services or advice. Health care professionals need to provide a context in which patients feel able to participate and to share decisions if they want to, thus ensuring a good experience for those patients.

The content of the recommendations in this area is divided into communication, information, decision making and education programmes. There is inevitable overlap in these areas and some recommendations might belong in several areas. The division is intended only to help structure the reviews and recommendations.

10.2 Communication

10.2.1 Evidence reviews and other inputs

Each of the following sources of evidence and information has been used to inform the recommendations on communication and a discussion of this is presented in section 10.2.2.

10.2.1.1 Patient experience scoping study – a focused thematic qualitative overview

The patient experience scoping study (see appendix B) differed from frameworks such as IOM framework by separating communication from information for the purposes of identifying the themes within each dimension which emerged from studies. We do acknowledge these are closely linked and overlap.   Communication included the style and content of verbal and non-verbal communication between patients and health care professionals and it was recognised that the style of communication can be an important way in which patients are enabled or indeed disabled in participating in their care. The sub themes found in the three areas examined in the scoping study are outline below.

Table 15: Sub themes for communication from patient experience scoping study

Sub themes for diabetes	Sub themes for cardiovascular disease	Sub themes for cancer
Importance of communication	Openness	Patient-centred communication
Quality of communication	Communication style	Individualised approach
Listening/paying attention/acknowledging patient expertise	Consistent information	Context
Language	Barriers to communication	Responsibility/control
Questions and answers	Importance of communication	Character of health care

Sub themes for diabetes	Sub themes for cardiovascular disease	Sub themes for cancer
		professional
Explanations	Consequences of poor communication	Reassurance/hope
Brusque manner	Characteristics of patient communication	Psychosocial needs
	Wanting more opportunity for communication with health care professionals	Humour
	Staff communication skills	Support of family and friends
	Content of communication with health care professionals	
	Communication aids	
	Reassurance	

10.2.1.2 NHS surveys

NHS Surveys are used to assess patient experience, to examine how the NHS performs and to identify which aspects of patient experience are most important to patients. Further information on patient surveys is in Section 3.4.

Findings from a survey by the Picker Institute Europe of inpatients which asked patients to score the importance of 82 aspects of care (Boyd 2007[5]) found that aspects relating to communication rated highly. Within the top ten were:

(a) The doctors can answer questions about my condition and treatment in a way that I can understand.

(b) Before my operation or procedure, I get a clear explanation of what will happen.

(c) The risks and benefits of my operation or procedure are explained to me in a way that I can understand.

(d) The doctors and nurses are open with me about my treatment or condition.

Secondary analysis of NHS surveys of inpatient and outpatient care was carried out to develop 'core domains'. [96 97]. The questions which contributed to the theme 'Doctors' were largely questions about communication. The individual items contributing to the domains of 'Nurses' and 'Other professionals' also included aspects of communication as seen below:

<u>Doctors (domains for inpatients)</u>

When you had important questions to ask a doctor, did you get answers that you could understand?

<u>Doctors (domain for outpatients)</u>

Did you have enough time to discuss your health or medical problem with the doctor?

Did the doctor explain the reasons for any treatment or action in a way that you could understand?

Did the doctor listen to what you had to say?

If you had important questions to ask the doctor, did you get answers that you could understand?

<u>Other professionals (outpatients)</u>

If you had important questions to ask [the other professional], did you get answers that you could understand?

10.2.1.3 Existing NICE recommendations

NICE recommendations do not usually cover attitudes and skills required for good communication. These are primarily covered in training and competencies of healthcare professionals and covered by professional codes. Recommendations covering good communication practice are found in some guidelines particularly in Medicines Adherence guideline which was a generic guideline (please see Appendix C for more details on existing NICE recommendations):

- Establish the most effective way of communicating with each patient and, if necessary, consider ways of making information accessible and understandable (for example, using pictures, symbols, large print, different languages, an interpreter or a patient advocate). (From 'Medicines Adherence', R1.1.3)[70]
- Use words the patients will understand; confirm understanding by questions; define unfamiliar words; write down key words; draw diagrams and keep a copy in the medical notes. (From 'Chronic heart failure', R 1.5.5.2)[54]
- Provide the most important information first. (From 'Chronic heart failure', R 1.5.5.2)[54]
- Ask patients open-ended questions because these are more likely to uncover patients' concerns. (From 'Medicines Adherence', R 1.1.5)[70]
- All members of the breast cancer clinical team should have completed an accredited communication skills training programme. (From 'Breast cancer –early and locally advanced', R 1.2.1)[61]
- Be aware that the consultation skills needed for increasing patient involvement can be improved. (From 'Medicines Adherence', R 1.1.6)[70]

10.2.2 Recommendations and link to evidence

Recommendations	**37. Ensure that the environment is conducive to discussion and that the patient's privacy is respected, particularly when discussing sensitive, personal issues.** **38. 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.** **39. Establish how the patient wants to be addressed and ensure that their choice is respected and used.** **40. 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.** **41. 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.** **42. Use words the patient will understand, define unfamiliar words and confirm understanding by asking questions. Avoid using jargon.**

	43. Use open-ended questions to encourage discussion. **44. Summarise information at the end of a consultation and check that the patient has understood the most important information.** **45. 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.**
Relative values of different outcomes	The GDG considered that good communication was an essential aspect of good patient care. Other important aspects of good patient experience will be undermined if communication is not appropriate.
Trade off between clinical benefits and harms	The GDG considered no harms were likely.
Economic considerations	The replacement of poor communication with better communication was not considered to have additional costs. Any additional cost required by extra time or use of interpreters was considered likely to be offset by better patient understanding and the need for fewer repeated consultations.
Quality of evidence	The GDG used evidence reviews from Medicines Adherence guideline and findings of NHS surveys to inform the recommendations.
Other considerations	The GDG used their own professional and personal experiences to inform these recommendations. They considered that good communication is an area that all involved in healthcare need to consider. This includes hospital porters, cleaning staff, reception, clerical or administrative staff as well as people with healthcare qualifications. There is a requirement under equality and diversity considerations to ensure that patients who need help with communication receive that help.

Recommendations	**46. All members of the healthcare team should have a demonstrated competency in relevant communication skills.** **47. Be aware that the consultation skills needed for increasing patient involvement can be improved.**
Relative values of different outcomes	
Trade off between clinical benefits and harms	The GDG considered there were no harms likely.
Economic considerations	The GDG considered that there is a potential cost to the provision of training in communication skills. However communication is now an integral part of most professional courses and most healthcare professionals are required to take part in professional development. Prioritising communication skills in induction and professional development training would not necessarily add costs.
Quality of evidence	The GDG drew on the evidence review for Medicine Adherence which indicated that communication skills can be improved.
Other considerations	Communication issues are highlighted by patients as being important yet the GDG were all aware of poor practice in this area. The GDG considered that although communication skills are taught to healthcare professionals in training and continuing development, there is the potential for attitudes and skills learnt in these settings to be forgotten when delivering healthcare. Poor communication practices are also common and the impact of exposure to this is potentially more powerful than formal courses. The continued need to

	demonstrate competency should therefore be required of all having contact with patients.

10.3 Information

10.3.1 Evidence reviews and other inputs

Each of the following sources of evidence and information has been used to inform the recommendations on information and a discussion of this is presented in section 10.3.2.

10.3.1.1 Patient experience scoping study - a focused thematic qualitative overview

The patient experience scoping study (see Appendix B) differed from frameworks such as the IOM framework by separating communication from information. There is however overlap between communication, information and decision-making. Information is a pre-requisite for self care and for involvement in decision-making. Patients however also need to make sense of their health and information is required for this. Information needs to be individualised to the patient. There was a sub theme in all clinical areas examined of patients not wanting or being ambivalent about information or knowledge. This highlights the need to consider the timing of information and how to deliver the information. Sources of information and support outside healthcare services were also important to patients. The sub themes in the individual areas are listed below.

Table 16: Sub themes for information from patient experience scoping study

Sub themes for diabetes	Sub themes for cardiovascular disease	Sub themes for cancer
Importance of information and advice	Satisfaction with information: Feeling informed	Individualised approach
Problems with information	Importance of information	Honesty/realism
Not wanting information	Wanting more information	Reassurance/hope
Feedback on condition	Wanting individualised information	Format and quality
Sources of further help	Format	Responsibility/control
Education and groups	Delivery	Information: Diagnosis
Peer support	Timing	Information: Treatment
Need for emotional support	Not wanting to know	Information: Prognosis
	Recall	
	Sources	
	Involvement of family/friends	
	Changing information	
	Inconsistent information	
	Sharing information	

10.3.1.2 NHS surveys

NHS Surveys are used to assess patient experience, to examine how the NHS performs and to identify which aspects of patient experience are most important to patients. Further information on patient surveys is in Section 5.4Chapter.

Secondary analysis of NHS surveys of inpatient and outpatient care was carried out to develop ‘core domains’. [96 97]. The questions which contributed to the theme ‘Doctors’ were largely questions about communication. The individual items contributing to the domains of ‘Nurses’ and ‘Other professionals’ also included aspects of information giving as seen below:

Involvement (domains for inpatient)

Were you involved as much as you wanted to be in decisions about your care and treatment?

How much information about your condition or treatment was given to you?

Did you feel you were involved in decisions about your discharge from hospital?

Doctors (domains for inpatient)

When you had important questions to ask a doctor, did you get answers that you could understand?

Dealing with the issue (domains for outpatient)

While you were in the Outpatients Department, how much information about your condition or treatment was given to you?

Were you involved as much as you wanted to be in decisions about your care and treatment?

Doctors (domains for outpatients)

Did the doctor explain the reasons for any treatment or action in a way that you could understand?

Other professionals (domains for outpatients)

If you had important questions to ask [the other professional], did you get answers that you could understand?

Information about discharge (domains for outpatients)

Did a member of staff tell you about medication side effects to watch out for?

Did you receive copies of letters sent between hospital doctors and your family doctor (GP)?

Did a member of staff tell you about what danger signals regarding your illness or treatment to watch for after you went home?

Information about treatment (domains for outpatients)

Before the treatment did a member of staff explain what would happen?

Before the treatment did a member of staff explain any risks and/or benefits in a way you could understand?

10.3.1.3 Existing NICE recommendations

Information and support for patients is part of core content of the majority of NICE clinical guidelines. The review of existing NICE guidelines found a large number of recommendations about the provision of information for patients. ‘Saturation’ was rapidly reached when reviewing guidelines i.e. further review of guidelines did not locate any additional themes and recommendations (please see Appendix C for more details on existing NICE recommendations):

- Provide people with advice and information to promote self-management of their low back pain. (From ‘Low back pain’, R 1.2.1)[69]
- Offer patients and carers clear, consistent information and advice throughout all stages of their care. This should include the risks of surgical site infections, what is being done to reduce them and how they are managed.
  (From ‘Surgical site infection’, R 1.1.1)[73]

- Pregnant women should be offered information based on the current available evidence together with support to enable them to make informed decisions about their care. This information should include where they will be seen and who will undertake their care.
  (From 'Antenatal care', R 1.1.1.4)[71]
- Offer people with CKD education and information tailored to the stage and cause of CKD, the associated complications and the risk of progression.
  (From 'Chronic Kidney Disease', R 1.3.1)[63]
- Give patients verbal and written information about their diagnosis, available treatments, patient support groups and the uncertainty of the long-term outcomes of ablative therapies. Give patients time to consider this information when making decisions about their care.
  (From 'Barrett's oesophagus - ablative therapy', R 1.1.9)[79]
- Offer people the opportunity to discuss their diagnosis, prognosis and treatment, and provide them with relevant information in an accessible format at initial and subsequent visits.
  (From 'Glaucoma', R 1.6.1)[58]
- Patients (or home carers) should be given appropriate information to enable them to fully understand the correct use of medications, including oxygen, before discharge.
  (From 'Chronic obstructive pulmonary disease', R 1.3.11.5)[55]
- Healthcare professionals should be aware of local cardiac support networks and provide this information to patients and carers.
  (From 'Chronic heart failure', R 1.5.7.1)[54]
- Men with prostate cancer should be offered advice on how to access information and support from websites (for example, UK Prostate Link – www.prostate-link.org.uk), local and national cancer information services, and from cancer support groups.
  (From 'Prostate cancer', R 1.1.3)[59]
- Suggest where patients might find reliable information and support after the consultation: for example, by providing written information or directing them to other resources (for example, NHS Choices [www.nhs.uk]).
  (From 'Medicines adherence', R 1.1.31)[70]

10.3.2 Recommendations and link to evidence

Recommendations	**48. Give the patient information in order to promote active participation in their care and self-management of their condition.** **49. 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.** **50. 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.**

	51.Ensure that mechanisms are in place to provide information about appointments to patients who require information in non-standard formats. **52.Give the patient both verbal and written information.** **53.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.**
Relative values of different outcomes	Information is an outcome in itself but is also an integral part of patient involvement in their care.
Trade off between clinical benefits and harms	The GDG considered that rate of delivery and type of information provided to patients has to be made according to the needs and wishes of individual patients but that information per se was unlikely to harmful.
Economic considerations	Patients with needs for information in different formats have a right to access information. There are potential cost implications to the provision of information in a variety of formats. Adequate information in a format that is useful to patients should however be offset by improved self-management.
Quality of evidence	The need for information in a number of areas was an important theme in the patient experience scoping study.
Other considerations	The GDG used professional and personal experience to develop these recommendations. The GDG considered it essential to provide information in different formats. They were concerned that patients who need information in alternate formats have access to this before they are seen in a service for example: information about appointments. If it is not available access to services may be affected. The GDG considered it important that patients are informed about the process of care as well as their condition and its treatment. They should therefore be given information about who is/will provide care and as much information on waiting times for investigations and treatments. The GDG recognised that it is common for patients to report not remembering what was said in a consultation. Exploration with the patient of mechanisms that may help them retain information such as taking notes, making a recording or having someone accompany them should be instigated and encouraged by healthcare professionals.

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Recommendations	**54.Give the patient (and/or their carers) information to enable them to use any medicines and equipment correctly. Ensure that the patient and their carers feel adequately informed, prepared and supported to carry out care.**
Relative values of different outcomes	The GDG considered that adequate information is an outcome in itself but is also a necessary step for patients to be able to use medicines and equipment.
Trade off between clinical benefits and harms	The GDG did not consider there were any harms.
Economic considerations	If this is not being done adequately at present, providing this information has potential time, and so cost, implications. . However, this is an essential part of safe and effective patient care and it is potentially more costly to provide medication or equipment which will not or cannot be used by patients and carers.
Quality of evidence	This recommendation was developed by consensus of the GDG and existing

	recommendations.
Other considerations	The recommendation was influenced by the professional and personal experiences of the GDG. The GDG discussed existing recommendations and the acknowledged the need to understand how medications and equipment should be correctly used to enable their greatest effect.

Recommendations	**55.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.**
Relative values of different outcomes	
Trade off between clinical benefits and harms	The GDG considered that people should be directed to known sources of quality information rather than be without guidance and use any source. There is potentially more harm is patients are not given some direction.
Economic considerations	There are no significant costs to this recommendation.
Quality of evidence	The requirement for direction to outside sources of information was an important theme in the patient experience scoping study of patient experiences. It has also been identified as an important area for recommendations in topic specific NICE guidelines.
Other considerations	

10.4 Decision making

10.4.1 Evidence reviews and other inputs

Each of the following sources of evidence and information has been used to inform the recommendations on decision making and a discussion of this is presented in section 10.4.2.

10.4.1.1 Patient experience scoping study - a focused thematic qualitative overview

The scoping study (see appendix B) identified decision making as a key theme in one of the three therapy areas examined (cancer). In the other areas, diabetes and cardiovascular disease, decision making was not identified as a key theme; however, in diabetes, shared decision making was identified as a sub-theme within the key theme ‘Relationships/partnership’. The sub-themes found are outlined in Table 17 below.

Table 17: Sub-themes for communication from patient experience scoping study

Sub-themes for diabetes	Sub-themes for cardiovascular disease	Sub-themes for cancer
Decision making was not identified as a key theme – shared decision making was a sub-theme within the key theme ‘Relationships/partnership’.	Decision making not identified as a key theme or subtheme.	Individualised approach
		Support of family-friends
		Responsibility/control
		Trust in expertise
		Relationship with health care professional
		Medical uncertainty

10.4.1.2 NHS surveys

NHS Surveys are used to assess patient experience, to examine how the NHS performs and to identify which aspects of patient experience are most important to patients. Further information on patient surveys is in Section 5.4.

Secondary analysis of NHS surveys of inpatient and outpatient care was carried out to develop 'core domains'. [96 97]. The questions which contributed to the domains 'Involvement' (for inpatients) and 'Dealing with the issue' (for outpatients) included some about decision making:

Involvement (domain for inpatients)

Were you involved as much as you wanted to be in decisions about your care and treatment?

Did you feel you were involved in decisions about your discharge from hospital?

Dealing with the issue (domain for outpatients)

Were you involved as much as you wanted to be in decisions about your care and treatment?

10.4.1.3 Existing NICE recommendations

The following recommendations, related to the decision making, are already in existence in other published NICE guidelines (please see Appendix C for more details on existing NICE recommendations):

- Explain the risks and benefits of treatment options to people with RA in ways that can be easily understood. Throughout the course of their disease, offer them the opportunity to talk about and agree all aspects of their care, and respect the decisions they make.
  (From 'Rheumatoid arthritis', R 1.2.11)[65]
- The risks and benefits of treatment options, taking into account comorbidities, should be communicated to the patient in ways that can be understood.
  (From 'Osteoarthritis', R 1.1.6)[64]
- Healthcare professionals should use everyday, jargon-free language to communicate information on risk. If technical terms are used, these should be clearly explained.
  (From 'Lipid modification' R 1.2.1)[68]
- Adequate time should be set aside during the consultation to provide information on risk assessment and to allow any questions to be answered. Further consultation may be required.
  (From 'Lipid modification', R 1.2.2)[68]
- People should be offered information about their absolute risk of CVD and about the absolute benefits and harms of an intervention over a 10-year period. This information should be in a form that:
  - presents individualised risk and benefit scenarios
  - presents the absolute risk of events numerically
  - uses appropriate diagrams and text.
    (From 'Lipid modification', R 1.2.4)[68]
- Healthcare professionals have a duty to help patients to make decisions about their treatment based on an understanding of the likely benefits and risks rather than on misconceptions.
  (From 'Medicines adherence', R 1.1.12)[70]
- To help men decide whether to have a prostate biopsy, healthcare professionals should discuss with them their PSA level, DRE findings (including an estimate of prostate size) and comorbidities, together with their risk factors (including increasing age and black African or black Caribbean ethnicity) and any history of a previous negative prostate biopsy. The serum PSA level alone

should not automatically lead to a prostate biopsy.
(From 'Prostate cancer', R 1.2.1)[59]

- Be aware of the potential risk of developing side effects (including non-fatal pneumonia) in people with COPD treated with inhaled corticosteroids and be prepared to discuss with patients.
(From 'Chronic obstructive pulmonary disease', R1.2.2.3)[55]
- Offer information about the risks of diagnostic testing, including any radiation exposure.
(From 'Chest pain of recent onset', R 1.1.1.5)[53]
- Offer patients clear information about the risks and benefits of the treatments offered so that they can make informed choices about management strategies. Information should be appropriate to the patient's underlying risk of a future adverse cardiovascular event and any comorbidities.
(From 'Unstable angina and NSTEMI', R 1.1.1)[52]
- The choice of treatment should be made after discussion between the responsible clinician and the woman about the risks and benefits of each option. Factors to consider when making the choice include whether the woman has received tamoxifen before, the licensed indications and side-effect profiles of the individual drugs and, in particular, the assessed risk of recurrence.
(From 'Breast cancer – early and locally advanced', R 1.7.7)[61]
- Perform investigations only if:
  - the results are likely to affect a treatment decision
  - the patient understands why the investigations are being carried out
  - the patient understands the potential benefits and risks of investigation and treatment and
  - the patient is prepared to accept treatment.
  (From 'Metastatic malignant disease of unknown primary origin', R 1.3.1.2)[62]
- Before starting non-invasive ventilation, the multidisciplinary team should carry out and coordinate a patient-centred risk assessment, after discussion with the patient and their family and carers. This should consider:
  - the most appropriate type of non-invasive ventilator and interfaces, based on the patient's needs and lifestyle factors
  - the patient's tolerance of the treatment
  - the risk, and possible consequences, of ventilator failure
  - the power supply required, including battery back-up
  - how easily the patient can get to hospital
  - risks associated with travelling away from home (especially abroad)
  - whether a humidifier is required
  - issues relating to secretion management
  - the availability of carers.
  (From 'Motor neurone disease - non-invasive ventilation', R 1.1.17)[80]
- Before starting VTE prophylaxis, offer patients and/or their families or carers verbal and written information on:
  - the risks and possible consequences of VTE
  - the importance of VTE prophylaxis and its possible side effects
  - the correct use of VTE prophylaxis (for example, anti-embolism stockings, foot impulse or intermittent pneumatic compression devices).
  - how patients can reduce their risk of VTE (such as keeping well hydrated and, if possible, exercising and becoming more mobile).
  (From 'Venous thromboembolism - reducing the risk', R 1.7.2)[56]

- Offer adjuvant radiotherapy to patients with DCIS following adequate breast conserving surgery and discuss with them the potential benefits and risks (see recommendation in section 1.3.1) (From 'Breast cancer – early and locally advanced', R 1.11.2)[61]
- Discuss the benefits and risks of stopping treatment with people with OHT or suspected COAG who have both:
  - a low risk of ever developing visual impairment within their lifetime
  - an acceptable IOP.

  If a person decides to stop treatment following discussion of the perceived risks of future conversion to COAG and sight loss, offer to assess their IOP in 1 to 4 months' time with further monitoring if considered clinically necessary.
  (From 'Glaucoma', R 1.2.11)[58]
- Men and their partners or carers should be given information, support and adequate time to decide whether or not they wish to undergo prostate biopsy. The information should include an explanation of the risks (including the increased chance of having to live with the diagnosis of clinically insignificant prostate cancer) and benefits of prostate biopsy.
  (From 'Prostate cancer', R 1.2.2)[59]
- In order to encourage the person to participate in reducing their CVD risk, the healthcare professional should:
  - find out what, if anything, the person has already been told about their CVD risk and how they feel about it
  - explore the person's beliefs about what determines future health (this may affect their attitude to changing risk)
  - assess their readiness to make changes to their lifestyle (diet, physical activity, smoking and alcohol consumption), to undergo investigations and to take medication
  - assess their confidence in making changes to their lifestyle, undergoing investigations and taking medication
  - inform them of potential future management based on current evidence and best practice
  - involve them in developing a shared management plan
  - check with them that they have understood what has been discussed.
    (From 'Lipid modification', R 1.2.5)[68]
- When lipid-modifying drug therapy is first considered for women and girls, the risks for future pregnancy and the fetus while taking lipid-modifying drug therapy should be discussed. This discussion should be revisited at least annually.
  (From 'Familial hypercholesterolaemia', R 1.4.2.1)[67]

10.4.1.4 Literature review: risk communication

Communicating risk to patients is a vital role for clinicians as it is important for patients to understand risk in order to make an informed choice and give consent to treatment. There is little guidance on how risk is communicated so this review examines available evidence pertaining to the format of presenting risk (for example: percentage [1% risk of adverse effect] or frequencies [1 in 100 risk of adverse effect]), hether individualising the risk to the patient has an effect, and framing. Framing can be positive (99 out of 100 risk that there will no adverse effect) or negative (1 in a 100 change of an adverse effect).

Review question: What methods of presenting information improve a patient's understanding of the risks and benefits associated with their treatment options?

Clinical evidence

There was no time limit placed on the literature search for systematic reviews addressing of methods of presenting information improve a patient's understanding of the risks and benefits associated with their treatment options. There were no limitations on type of studies included in the systematic review.

Systematic reviews were included which considered adults over the ages of 16 years old. Systematic reviews were excluded which included people using health services specifically for the treatment of mental health problems.

Six systematic reviews/meta-analyses [1,2,18,19,46,98] were identified which addressed the question and were included in the review. A summary of these reviews is presented in Table 18.

Table 18: Summary of systematic reviews

Study	Population	Type of communication
Akl 2011[1]	Chronic disease, genetic testing, vaccination	Types of statistical presentation or formats for standard information – comparing risk frequencies; relative risk reduction or absolute risk reduction to risk probabilities; absolute risk reduction or numbers needed to treat
Albada 2009[2]	Cancer knowledge and screening behaviour	Individualised compared to general information – Intervention groups receiving tailored information, based on more than one variable (behavioural change variables, cultural constructs, cancer risk factors); control groups receiving no information, standard information or usual care
Edwards 2001[19]	Epilepsy, cancer treatment, immunisation, screening	"Framing" effects – comparing negative framing (for example: chance of death) to positive framing (for example: change of survival); loss framing (for example: disadvantage of not undertaking screening) to gain framing (for example: advantage of screening); numerical and graphical information to numerical only; more data points to fewer data points; numerical information compared to verbal (qualitative) information (for example: " frequently", "rarely"); relative risk compared to absolute risk or number needed to treat; vivid portrayal (for example: detailed or personalised vignette) compared to abstract or general risk information; lay terminology (for example: loss of appetite) compared to medical terminology (for example: anorexia); Larger denominators compared to smaller denominators
Edwards 2006[18]	Screening for cancer, antenatal, genetic, cardiovascular, neonatal	Individualised compared to general information – personalised risk communication based on individual's risk factors (presented as absolute or relative risk or risk score or high/medium/low risk categories). Could come before screening, at the time of screening, or at the time of counselling or promotion of screening; could be oral, written, video or electronic compared to generalised risk information (for example: population risk estimate, general info on risk factors, general encouragement to acknowledge risks or change risk behaviour)
Lopez 2008[46]	Contraception	Types of statistical presentation or formats for standard

Study	Population	Type of communication
		information - Methods of communicating contraceptive effectiveness to consumers (educational programmes or materials and counselling sessions as individuals or groups) compared to usual practice or an alternative method
Smerecnik 2009[98]	Impact of genetic counselling on risk perception accuracy.	Types of statistical presentation or formats for standard information – genetic counselling: 4 studies used a protocol; 2 used standardised script; 3 used audiotapes to content check the counselling session; 12 did not mention any of these measures of content; the quality of the genetic counselling descriptions was poor compared to pre- to post-counselling measures of risk perception accuracy

Individualised compared to general information

Two systematic reviews[2,18] considered individualised information compared to general information. The two systematic reviews are presented individually below.

The first systematic review[2] considered the effects are found of tailored interventions on risk perception, cancer knowledge and screening behaviour the review included 40 studies considering people at risk of developing cancer.

The review included studies that compared groups receiving tailored information, based on more than one variable (behavioural change variables, cultural constructs, cancer risk factors) to groups receiving no information, standard information or usual care; the review considered the outcomes of cancer risk perception or knowledge or behaviour related to cancer screening.

The Table 19 below summarises the results reported in the review.

Table 19: Tailoring information

Outcome measure	Type of cancer/ screening/ outcome	Type of tailoring variables	Control group	No. of studies	Significant positive effect (p<0.05)	Best evidence synthesis
Knowledge of	Breast cancer and mammography	Risk factors and behavioural constructs	Standard reminder	1	2 low quality RCTs. At 24 months, intervention significantly improved knowledge compared to control; no difference at 12 months	indicative findings
	Breast cancer and heredity	Risk factors, behavioural constructs and information processing constructs	Standard info	1	1 low quality RCT: at 2-week follow up, intervention group had greater improvement in knowledge (p<0.0001)	indicative findings
	Melanoma	Risk factors	No intervention	1	1 high quality RCT: 6 months post-intervention: higher increase in knowledge (OR 0.51, 95% CI 0.30-0.72, p<0.001) in intervention group compared to control	limited evidence
Risk perception	Accuracy of perceived cancer risks	Risk factors	Standard info	2	1 moderate quality: no significant effects and 1 moderate quality RCT: group receiving personalised relative and absolute risk had greater improvement on relative risk accuracy than control (risk information only) p<0.01, as did a third group receiving absolute risk presentation only p<0.001	indicative findings
		Risk factors	No intervention	1	None	no evidence
		Risk factors and behavioural constructs	Standard reminder/ no intervention	2	2 low quality RCTs: 1 data not shown; the other found that individualised risk feedback	indicative findings

Outcome measure	Type of cancer/ screening/ outcome	Type of tailoring variables	Control group	No. of studies	Significant positive effect (p<0.05)	Best evidence synthesis
					reduced perceived cancer risk among over-estimators: OR 1.36, p<0.05 at 6 months	
Screening for (adherence to recommended screening interval)	Breast cancer (mammography)	Risk factors	Standard or personalised (i.e. named for that person but not with tailoring) info	3	1 low quality RCT: higher increase in mammography rate in intervention group (10.2% vs. 2.5% with standard info; p=0.05) 1 moderate quality RCT: women receiving personalised tailored letter had lower pap-test and mammography rate compared to control group and women receiving personalised form letter with risk factor information on BC and cervical cancer. Latter group had higher screening rates than control (p <0.001)	insufficient evidence
		Behavioural constructs	Standard info	4	none	no evidence
			No intervention	10	6 low quality RCTs: OR for screening ranged from 1.07 to 1.72 in the 4 studies reporting this; 1 study reported an ARR of 1.29 but it is unclear what this is referring to.	indicative findings
		Risk factors and behavioural constructs	Standard reminder/ no intervention	2	none	no evidence
		Behavioural and cultural constructs	No intervention	1	1 moderate quality RCT: OR for screening 2.6, 95% CI 1.1-6.1 at 17 months post-intervention	indicative findings
	Cervical cancer (pap test)	Risk factors	Personalised info	1	none	no evidence

Outcome measure	Type of cancer/ screening/ outcome	Type of tailoring variables	Control group	No. of studies	Significant positive effect (p<0.05)	Best evidence synthesis
		Behavioural constructs	No intervention	2	none	no evidence
	Colorectal cancer (faecal occult blood test)	Risk factors	Standard info	1	none	no evidence
		Risk factors and behavioural constructs	Standard info	1	none	no evidence
	Skin cancer (mole checking)	Risk factors	No intervention	1	1 high quality RCT: 6 months post-intervention: higher mole checking (OR 1.67, 95% CI 1.04-2.70) in intervention group	limited evidence

The second systematic review[18] considered different types of personalised/ individualised risk communication for consumers making decisions about screening tests. The review included 22 studies considering people making real life decisions about whether to undergo healthcare screening tests.

The review included studies that compared personalised risk communication based on individual's risk factors (presented as absolute or relative risk or risk score or high/medium/low risk categories). Could come before screening, at the time of screening, or at the time of counselling or promotion of screening; could be oral, written, video or electronic to generalised risk information (for example, population risk estimate, general info on risk factors, general encouragement to acknowledge risks or change risk behaviour). The outcomes reported were cognitive, affective or behavioural, health status outcomes/ quality of life measures and, economic outcomes. See Table 20 and Table 21 for results.

Table 20: Personalised/individualised risk communication for decisions about screening tests.

	Overall		Pap smears		Mammography		Cholesterol tests	
Outcome	Studies/people	Effect size	Studies/people	Effect size	Studies/people	Effect size	Studies/people	Effect size
Knowledge regarding screening test/ condition concerned	2/568	MD:2.45 (1.94 to 2.96)			1/804	OR:1.44 (0.95 to 2.19)		
Perceiving self as appropriate candidate for test	1/214	OR: 0.65 (0.35 to 1.19)						
Accurately perceived risk	3/1264	OR: 1.46 (1.13 to 1.88)			1/804	OR:1.17 (0.86 to 1.60)		
Anxiety	2/499	MD:-0.03 (-0.30 to +0.25)						
Intention to take screening test	5/2016	OR: 0.86 (0.71 to 1.03)	1/984	OR:0.58 (0.45 to 0.74)	1/478	OR: 0.53 (0.36 to 0.76)		
Uptake of screening test	14/7341	OR: 1.13 (1.02 to 1.24)	3/1552	OR:0.62 (0.50 to 0.77)	11/5234	OR: 1.11 (0.98 to 1.24)	1/276	OR: 0.98 (0.57 to 1.65)
Appropriate use of cholesterol test	1/3152	OR: 1.32 (1.14 to 1.55)					1/3152	OR: 1.32 (1.14 to 1.55)
Smoking	1/204	OR: 1.04 (0.60 to						

	Overall		Pap smears		Mammography		Cholesterol tests	
		1.82)						
Improvement in risk comprehension / perception	1/200	OR: 1.64 (0.83 to 3.25)						
Making a recommended behaviour change	1/890	OR: 0.98 (0.76 to 1.28)						

Table 21: Personalised/individualised risk communication for decisions about screening tests.

	High risk people		Colorectal screening		Prostate cancer screening	
Outcome	Studies/people	Effect size	Studies/people	Effect size	Studies/people	Effect size
Knowledge regarding screening test/ condition concerned	2/568	MD: 2.45 (1.94 to 2.96)				
Perceiving self as appropriate candidate for test	1/214	OR: 0.65 (0.35 to 1.19)				
Accurately perceived risk	2/460	OR: 2.25 (1.44 to 3.53)				
Anxiety	2/499	MD: -0.03 (-0.30 to +0.25)				
Intention to take screening test	2/540	OR: 0.84 (0.55 to 1.27)				
Uptake of screening test	5/3145	OR: 1.45 (1.23 to 1.71)	1/278	OR: 2.09 (0.76 to 5.75)	1/413	OR: 2.56 (1.70 to 3.84)

Types of statistical presentation or formats for standard information

Three systematic reviews[1,46,98] considered types of statistical presentation or formats for standard information.

The first systematic review[98] considered the impact of genetic counselling on risk perception accuracy, the review included 19 studies considering people at risk (not intermediaries, for example genetic counsellors or nurses).

The review included studies which compared genetic counselling using protocols or standard script or audiotapes to content check the counselling session to pre- to post-counselling measures of risk perception accuracy. The review considered the outcomes of the effect of genetic counselling on risk perception accuracy through changes in proportion of individuals who accurately perceive their risk or the degree of overestimation or underestimation of risk.

Table 22 and Table 23 below summarises the results reported in the review.

Table 22: Studies of changes in proportion of individuals who accurately perceive their risk

Study	N	Measurement moment	Accurate (%)	Underestimation (%)	Overestimation (%)	p value
Bjorvatn 2007	213	Pre-counselling	81	9	10	p<0.001
		Immediately post-counselling	86	9	5	
Hopwood 2003	158	Pre-counselling	7	52	38	p<0.001
		3 months post-counselling	68	9	20	
		6 months post-counselling	63	9	25	
		9 months post-counselling	63	9	25	
		12 months post-counselling	61	9	25	
Hopwood 2004	256	Pre-counselling	63	27	9	NS
		1 month post-counselling	71	21	8	
		12 months post-counselling	73	21	7	
Huiart 2002	397		Low risk:			p<0.001
		Pre-counselling	6.3	0	93.7	
		1-7 days post-counselling	23.8	0	76.3	
			High risk:			NS
		Pre-counselling	87.7	12.3	0	
		1-7 days post-counselling	89.5	10.5	0	
Lidén 2003	86	Pre-counselling	17	36	47	p<0.01
		Post-counselling	54	18	28	
		1 year post	28	33	39	
Lobb 2004	89	Pre-counselling	50	27	23	not stated
		Post-counselling	70	20	10	
Meiser 2001	218	Pre-counselling	54	12	34	NS
		12 months post-counselling	54	14	31	
Nordin 2002	63	Pre-counselling	18	38	44	not stated
		Post-counselling	57	18	25	
Pieterse 2006	51	Pre-counselling	48	not reported	not reported	NS
		Post-counselling	51			
Rimes 2006	150	Pre-counselling	12.6	3.3	84.1	NS
		6 months post-counselling	18	4.0	78.0	
Rothemund 2001	44	Post counselling counselees	39	0	48	NS (Note figures do not add up to 100% - may be error in paper)
		Controls	38	14	48	

Table 23: Studies of the degree of overestimation or underestimation of risk

Study	n	Time	Mean overestimation (SD)	p value
Bowen 2006	211	Pre-counselling 6 months post-counselling	19 6	p<0.001
Codori 2005	101	Pre-counselling Immediately post-counselling	30 30	not stated
Gurmankin 2005	108	Pre-counselling 1-7 days post-counselling	42% 19	p<0.001
Kaiser 2004	123	Pre-counselling Post-counselling	14.94 7.8	p<0.0005
Kelly 2003	99	Pre-counselling 1-2 days post-counselling	23 16.6	not stated
Kent 2000	90	Pre-counselling 3 month post-counselling 6 months post-counselling	not given	NS
Tercyak 2001	129	Pre-counselling Post-counselling	11.5 7.8	p<0.001
Van Dijk 2003	241	Low risk: post-counselling High risk: post-counselling	43.86 no data	not stated reported as NS

The second systematic review[46] considered strategies for communicating to people the effectiveness of contraceptives in preventing pregnancy, the review included five studies considering people or potential users (male or female) of the contraceptive methods.

The review included studies that compared methods of communicating contraceptive effectiveness to consumers through educational programmes or materials and counselling sessions as individuals or groups to usual practice or an alternative method. The review considered the outcomes of knowledge of contraceptive effectiveness, attitude about contraception or towards any particular contraceptive, choice or use of contraceptive method.

Table 24: Communicating contraceptive effectiveness

Study	n/sample	No. of sessions	Comparison	Outcomes	Results (OR; 95% CI)
Kraft 2007	301 heterosexual couples with risk factor for STD in US	Intervention group: 3 sessions of 2.5 hours each; control: 1 standard session of 1.5–2 hours	Control group had education about HIV, STDs and contraception including sample contraceptive methods, method use and effectiveness for preventing pregnancy and disease and	Use of effective contraceptives (effective or not); psychosocial factors affecting contraceptive use; relationship factors relevant to contraception. 6	Groups were similar at 6 months on perceived pregnancy risk; importance of not becoming pregnant; expectations for partner's support for contraception; participation in contraceptive

Study	n/sample	No. of sessions	Comparison	Outcomes	Results (OR; 95% CI)
			question and answer session; intervention group as above plus activities and discussion regarding perceived risk, expectations, norms, skills, self-efficacy regarding prevention	month follow-up	decision making
Marshall 1984	100 women requesting contraception in US	1	Information on conception and 6 methods of reversible birth control (advantages and disadvantages; effectiveness rates) conveyed through 5 different media: 1) pamphlet to read before exam; 2) AV presentation with unfamiliar voice; 3) AV presentation narrated by own physician (and informed it was own doctor); 4) personal communication by own physician of standard info in AV presentation; 5) combination of AV (as per group 3), pamphlet and oral communication from own physician	knowledge gained pre- to post-test (20 items); satisfaction with educational medium (including perceived learning) from 6 items; patients assessment of knowledge gain; physician's assessment of time spent with patient and time discussing contraceptives. Assessments conducted prior to intervention (pre-test) and after medical examination (post-test)	Knowledge gain favoured intervention 2 (mean difference -19.00, -27.52 to -10.48); other groups were similar in knowledge gain. All groups similar for satisfaction with method.
Omu1989	1012 women in Nigeria with 4 or more previous deliveries attending prenatal clinic	Intervention group: 4 sessions; control: standard family planning counselling in 1 session	Treatment group received information and education on health effects of high parity, benefits of family planning, all methods of contraception; voluntary sterilisation covered in detail with more in-depth counselling for those interested in sterilisation.	Percent sterilized; choice of contraceptive method and attitude towards sterilisation; use of specific contraceptive method at 6 weeks postpartum	Women in intervention group more likely to agree that sterilisation was safe (OR 9.15, 6.77 to 12.36), that a woman would still be strong after sterilisation (OR 9.67, 7.14 to 13.10), that sex drive would not change (OR 11.02, 8.08 to 15.03) and that a woman's status would not

Study	n/sample	No. of sessions	Comparison	Outcomes	Results (OR; 95% CI)
			Control group received standard family planning counselling at the clinic, including contraception methods available but not risks of high parity		change (OR 9.19, 6.86 to 12.31). They were more likely to be sterilised (OR 4.26, 2.46 to 7.37) and to use a “modern” or “effective” method (OR 2.35, 1.82 to 3.03) and were less likely to use no method by 6 weeks post-partum (OR 0.44, 0.32 to 0.61).
Steiner 2003	461 women recruited in 5 shopping malls across US	1	3 tables presenting info: 1) US FDA – 2 columns of numbers; 2) WHO – as 1 but methods grouped into 3 categories of effectiveness; 3) Developed by researchers – 3 categories of effectiveness along with limited info on STD prevention	Knowledge on effectiveness; perception of amount of information and whether easy to understand. Questions asked before randomisation and while looking at the assigned table.	For knowledge that hormone injections more effective than pills: Categories table vs. numbers table: OR 2.42 (1.43 to 4.12) Categories table vs. categories plus numbers table: OR 2.58 (1.50 to 4.42) For knowledge that combined pills more effective than condoms: Categories table vs. numbers table: OR 2.19 (1.21 to 3.97) Categories table vs. categories plus numbers table: OR 2.03 (1.13 to 3.64) For finding tool hard to understand: Categories table vs. numbers table: OR 0.29 (0.13 to 0.63) Categories table vs. categories plus numbers table: OR 0.38 (0.17 to 0.85)
Steiner 2006	900 women in Jamaica and India with basic English literacy	1	3 charts representing contraceptive methods by effectiveness categories: 1) from WHO – 3 categories stratified by a)	knowledge on effectiveness; perception of amount of information and whether easy to understand. Questions asked	Groups similar in understanding pregnancy risk. For feeling the chart gave enough information: Categories table vs. stratified table: OR

Study	n/sample	No. of sessions	Comparison	Outcomes	Results (OR; 95% CI)
			average and b) correct and consistent users; 2) WHO – 4 categories of effectiveness; 3) methods on continuum from least to most effective	pre-intervention and while looking at assigned table.	1.97 (1.13 to 3.44) For feeling the chart was easy to understand: Categories table vs. stratified table: OR 1.47 (1.03 to 2.10) Categories group similar to continuum group for these items.

The third systematic review[1] considered the effects of using alternative statistical presentations of the same risks and risk reductions on understanding, perception, persuasiveness and behaviour of health professionals, policy makers and “consumers”, the review included 35 studies considering people with chronic diseases, genetic testing and or having vaccinations.

The review included four comparisons, detailed in the table below and considered the outcomes of objective understanding; perception of effectiveness of intervention; persuasiveness; actual decisions or behaviours. For results see Table 25.

Table 25: Alternative statistical presentations for communicating risk

Comparison	Outcome	No. of studies	Overall results (pooled SMD and 95% CI)	No. of points difference on 10-point Likert scale	P value	Heterogeneity	Quality of evidence	Subgroup: consumers (pooled SMD and 95% CI)	Subgroup: health professionals (pooled SMD and 95% CI)	Sensitivity analysis
a) Natural frequencies vs. probabilities	Understanding	5	0.69 (0.45 to 0.93) in favour of natural frequencies	1.4	p=0.11	I2=43%,	Moderate	0.60 (0.31 to 0.88)	0.94 (0.53 to 1.34)	none
b) RRR vs. ARR	Understanding	2	0.02 (-0.39 to +0.43) NS all consumers	<0.1	p<0.007	I2=80%,	Moderate	all consumers: 0.02 (-0.39 to +0.43) NS	none	1 high quality study: SMD 0.33 (0.03 to 0.62) in favour of RRR
	Perception	4	0.41 (0.03 to 0.79) in favour of RRR perceived as larger	0.8	p<0.00001	I2=89%,	Low	0.44 (-0.68 to +1.57)	0.39 (-0.04 to +0.82)	2 high quality comparisons: SMD 0.42 (-0.34 to +1.19)
	Persuasiveness	23	0.66 (0.51 to 0.81) in favour of RRR	1.3	p<0.00001	I2=93%,	Moderate	0.62 (0.42 to 0.83)	0.71 (0.49 to 0.93)	4 high quality comparisons: 0.67 (0.57 to 0.76)
c) RRR vs. NNT	Understanding	1	all consumers: 0.73 (0.43 to 1.04) in favour of RRR	1.5	NA	NA	Moderate	all consumers: 0.73 (0.43 to 1.04)	none	none
	Perception	3	all health professionals: 1.15 (0.80 to	2.3	p=0.004	I2=82%,	Moderate	none	all health professionals: 1.15 (0.80 to	none

Comparison	Outcome	No. of studies	Overall results (pooled SMD and 95% CI)	No. of points difference on 10-point Likert scale	P value	Heterogeneity	Quality of evidence	Subgroup: consumers (pooled SMD and 95% CI)	Subgroup: health professionals (pooled SMD and 95% CI)	Sensitivity analysis
			1.50) in favour of RRR						1.50)	
	Persuasiveness	21	0.65 (0.51 to 0.80) in favour of RRR	1.3	p<0.00001	I2=91%,	Moderate	0.66 (0.46 to 0.86)	0.65 (0.42 to 0.87)	3 high quality comparisons: 0.62 (0.46 to 0.78)
d) ARR vs. NNT	Understanding	1	all consumers 0.42 (0.12 to 0.71) in favour of ARR	0.8	NA	NA	Moderate	all consumers 0.42 (0.12 to 0.71)	none	none
	Perception	3	all health professionals: 0.79 (0.43 to 1.15) in favour of ARR	1.6	p=0.002	I2=84%,	Moderate	none	all health professionals: 0.79 (0.43 to 1.15)	none
	Persuasiveness	19	0.05 (-0.04 to +0.15)	0.1	p<0.00001	I2=75%,	Moderate	0.05 (-0.04 to +0.14)	0.07 (-0.10 to +0.24)	8 high quality comparisons: 0.06 (-0.06 to +0.17)

"Framing" effects

One systematic review[19] considered "framing" of risk information affects key patients outcomes in a clinical setting, the review included 24 studies considering people with epilepsy, cancer treatment, immunisation, screening, in a healthcare setting including real or hypothetical choices about treatment or behaviour, or where choices are of current medical relevance (for example: skin cancer risks).

The review included nine comparisons, detailed in the table below and considered the outcomes of knowledge, anxiety, risk perception, intentions and actual behaviour: effect sizes calculated. For results see Table 26.

Table 26: "Framing" of risk information

Comparison	No. of studies	Significant effects found (including effect size [ES]); no. of studies showing significant effect [method scores]	Non-significant findings reported [method scores]	Narrative synthesis
1: Negative framing vs. Positive framing	4	Subjects more likely to choose lung cancer treatment option that was riskier in the short term if outcomes positively framed (42% vs. 25%, p<0.0001, ES 0.45); 1 study [low quality score 8/22]	Change in preference for epilepsy treatment 59.4% vs. 56.7%, p=0.83 [8/22]; 1% increase in uptake of influenza vaccine, p=0.86 [14/22]; 6.7% more patients agreed to participate in treatment trial in colorectal cancer, p=0.592 [17/22]	No clear pattern of effects evident from studies in this category
2: Loss framing vs. Gain framing	7	6 studies of detection behaviour (uptake of screening): Meta-analysis of 4 RCTs with a binary outcome for screening uptake: 601/1337 vs. 535/1316; OR 1.18 (95% CI 1.01 to 1.38). [quality scores 15/22, 17/22, 14/22, 8/22] 1 described as "quasi-experimental" but not RCT was not included in meta-analysis because of this study design; showed increased perceived risk, p=0.037, ES 0.09 (i.e. very small effect) [13/22] 1 used continuous outcome measure and found increase in breast self examination (mean change 0.68, p=0.046, ES 0.6), more positive attitudes to BSE (mean change 1.56, p=0.04, ES 0.61) and greater intention to perform BSE (mean change 1.53, p=0.044, ES 0.61) [8/22] 1 study of prevention behaviour (use of sunscreens): 1 study on collection of sunscreen in beach visitors: 18% increase in collection of sunscreens, p<0.01, ES	none	Clear pattern among the 6 studies of detection behaviour (uptake of screening) that supports the greater effect of loss framing; the study of prevention behaviour (use of sunscreens) found some evidence of the greater effect of loss framing.

Comparison	No. of studies	Significant effects found (including effect size [ES]); no. of studies showing significant effect [method scores]	Non-significant findings reported [method scores]	Narrative synthesis
		0.32; intention to use sunscreen also increased, p<0.01) but other intentions and anxiety not significantly different [11/22]		
3: Numerical and graphical information vs. Numerical only	1	none	No significant differences in intention to change general health behaviour; little data reported [low quality 9/22]	NA
4: More data points vs. Fewer data points	3	One study compared the presentation of 6 vs. 3 data points for survival/ mortality rates; more of those with more data intended to choose the long-term survival option (84% vs.49%, p=0.00002, ES 0.73) [12/22]. One study compared "limited explanation" (discussion of 3 data points) vs. "extensive explanation" (five key point) on a graph of survival; more with extensive explanation changed previously specified treatment choice (44% vs. 13%, p=0.00006, ES 0.67) [15/22]	The third paper compared more information vs. current standard information on side effects of carbamazepine; no significant difference on knowledge, anxiety or compliance [16/22]	2 out of 3 studies showed people were more cautious when presented with more data.
5: Numerical information vs. Verbal (qualitative) information	2	One study gave female cancer patients numerical or verbal descriptions of risks of treatment in chemotherapy trial; intention to choose the trial was lower in the numerical than the verbal group (34.7% vs.52.4%, p=0.01, ES 0.46) [16/22] The other study provided information on the risks of anaesthetics; correct knowledge of the risk of death was higher after numerical information (55% vs. 15%, p=0.008, ES 0.82) [19/22]	none	Patients were more wary when negatively framed risk information was presented numerically
6: Relative risk vs. Absolute risk/NNT	3	All three papers in this section are included in the Akl 2011 review so not data extracted again	-	-
7: Vivid portrayal vs. Abstract or general	2	none	One study found no significant differences in accuracy of recall of information, perceived vulnerability, or actual	These papers do not support the theoretical predictions that vivid information is more

Comparison	No. of studies	Significant effects found (including effect size [ES]); no. of studies showing significant effect [method scores]	Non-significant findings reported [method scores]	Narrative synthesis
risk information			calcium intake [14/22] The other study found no differences in "concern" or "value of the information" ; there was a small difference suggesting the vivid case history was more "persuasive" (mean change 0.94, p<0.02) but no differences at follow up in recall of risk factors or adoption of recommendations. [13/22]	persuasive or effective
8: Lay vs. Medical terminology	1	none	No significant differences in knowledge of risks and benefits, or anxiety, of simpler version of drug insert [14/22]	Insufficient evidence to judge the effect of simpler package inserts
9: Larger vs. Smaller denominators	1	Assessed the effect of manipulating information in relation to 11 common causes of death which were then ranked; rated judged more risky when denominator larger (p<0.05 for 7/11 causes of death) [7/16]	none	The results suggest that "base rate neglect" occurs and individuals' judgements have been influenced more by altering anchor points

Economic evidence

An economic evidence review was not undertaken for this question.

Evidence statement(s)

Clinical

One systematic review(Albada 2009[2]) found tailoring information based on behavioural constructs (for example: attitudes, intentions, stages of change) is more effective than tailoring information based on risk factors only (for example: family history) when communicating risk.

One systematic review (Edwards 2006[18]) found personalising risk information may have a small effect on increasing uptake of screening tests and there is only limited evidence that the interventions have promoted or achieved informed decision making by consumers.

Three systematic reviews looking at different types of statistical presentation or formats for standard information found:

- genetic counselling has a positive impact on risk perception accuracy, sustained even at follow up 1 year later, but some studies observed no effect (several of these had small sample sizes), or only in low-risk individuals (Smerecnik 2009 [98])

- there was limited evidence about what helps people choose an appropriate method of contraception (Lopez 2008[46]).
- Natural frequencies are better understood than probabilities when communicating risk (Akl 2011[1]).
- Relative risk reduction may be perceived to be larger than absolute risk reduction and numbers needed to treat (Akl 2011[1]).

One systematic review (Edwards 2001[19]) found no clear evidence of differences in outcome depending on how information about risks is framed.

10.4.1.5 Literature review: decision aids

Both patients and clinicians may need support to deliver effective engagement of patients in decisions where there are reasonable treatment or care options. The International Patient Decision Aids Standards (IPDAS) Collaboration[21] describes patient decision aids as evidence-based tools designed to prepare patients to participate in making specific and deliberated choices among healthcare options. Patient decision aids do not replace, but may act as an adjunct to good clinical practice. Patient decision aids are not necessary to deliver good shared decision-making, but where well developed patient decision aids exist, they facilitate patient engagement and can be used before, during or after a consultation to enable patient participation.

Review question: What is the clinical and cost-effectiveness of decision aids versus no intervention, usual care, alternative interventions, or a combination?

Clinical evidence

The GDG obtained access to the unpublished update of the Cochrane Review on decision aids for people facing health treatment or screening decisions. As this was a 2011 review of the literature on this topic, the GDG accepted if for inclusion in the review and did not update the searches[99] due to time and resource constraints.

The Stacey 2011 systematic review contains 86 RCTs from eight countries (Australia, Canada, China, Finland, Germany, Netherlands, United Kingdom and United States). All but 11 studies randomised individual patients. The studies evaluated decision aids focussed on 35 different decisions, the most common being prostate screening (n=12), hormone replacement therapy for menopausal women (n=10), breast cancer genetic testing (n=8), colon cancer screening (n=5), prenatal screening (n=5), medication for atrial fibrillation (n=3), and surgery (n=11). There was variability in risk of bias across studies and selective reporting.

Results were pooled across the studies where there were a) similar outcomes measures used and b) the effects were expected to be independent of the type of decision studied. Studies comparing usual care to decision aids were analysed separately from studies comparing simple to more detail decision aids. Results of the pooled outcomes are presented in Table 27, Table 28, Table 29, Table 30 and Table 31. Data about patient-practitioner communication and satisfaction was not pooled. For a summary of results refer to Table 32. Please note all of the data from Stacey 2011[99] has been submitted for publication but is currently deemed “academic in confidence”. The developers expect all data to be published in time for publication of the patient experience guideline.

Table 27: Summary of pooled outcomes

Academic in confidence data

Table 28: Decision aids versus usual care

Academic in confidence data

Table 29: Detailed versus simple decision aids

Academic in confidence data

Table 30: Accurate risk perceptions: Decision aid with outcome probabilities versus no outcome probability information

Academic in confidence data

Table 31: Informed values-based decision

Academic in confidence data

Table 32: Patient-practitioner communication and satisfaction

Academic in confidence data

Economic evidence

Six studies were included that examined costs or cost effectiveness of decision aids versus a comparator. All were within-RCT analyses. Four were included in the Cochrane review (Kennedy 2002[39], Murray 2001[49], Murray 2001a[50], Vuorma 2004[108]). One (Kennedy 2003[40]) was a second analysis based on an RCT included in the Cochrane review – as this reported a cost-utility analysis using QALYs this is reported over the cost-consequence analysis [Kennedy 2002[39]]). One (Hollinghurst 2010[30]) is a economic analysis published after the Cochrane cut-off date but from an RCT that is included in the Cochrane review and so was included. These are summarised in the economic evidence profile below (Table 33). See also Evidence Tables in Appendix G.

One study (Van der Wilt 2005[107]) was excluded due to not meeting the inclusion criteria of being based on data from randomised clinical trials.

Table 33: Economic evidence profile – decision aids

Study	Applicability (n)	Limitations (o)	Other comments	Incremental cost	Incremental effects(p)	ICER	Uncertainty
Hollinghurst 2010[30] UK	Partially applicable(q)	Potentially serious limitations(t)	• Delivery among women with previous caesarean section • RCT-based analysis (43 weeks) • Cost-consequence analysis	DA1: £95(x) DA2: -£5(y)	DA1 & 2 reduced mean DCS	n/a	DA1: 95% CI -£72 to £205 DA2: 95% CI -£172 to £107
Kennedy 2003[40] UK	Partially applicable(r)	Minor limitations(u)	• Menorrhagia treatment • RCT-based analysis (2 years) • Cost-utility analysis (QALYs)	DA1: -£477(z) DA2: -£799(aa)	DA1: -0.006 DA2: 0.009	DA2 dominant(cc)	Probability cost effective (£20,000/QALY threshold) = 84%
Murray 2001[49] UK	Partially applicable(q)(r)	Potentially serious limitations(v)	• Benign prostatic hypertrophy treatment • RCT-based analysis (9 months) • Cost-consequence analysis	£405	No difference in EQ5D Reduced mean DCS	n/a	95% CI £225 to £585 Excluding cost of trial technology reduced cost difference: £122 (95% CI -£59 to £302)
Murray 2001a[50] UK	Partially applicable(q)(r)	Potentially serious limitations(v)	• Hormone replacement therapy • RCT-based analysis (9 months) • Cost-consequence analysis	£216	No difference in EQ5D Reduced mean DCS	n/a	95% CI £203 to £228 Excluding cost of trial technology made cost difference non-significant (data not reported)
Vuorma	Partially	Potentially	• Menorrhagia treatment	-£358(bb)	Improvement in	n/a	CI not reported, p=0.2 for

Study	Applicability (n)	Limitations (o)	Other comments	Incremental cost	Incremental effects(p)	ICER	Uncertainty
2004[108] Finland	applicable(q)(s)	serious limitations(w)	• RCT-based analysis (1 year) • Cost-consequence analysis		Rand-36 'emotional role functioning'		cost difference

CI = confidence interval; DCS = decisional conflict score; EQ5D = Euroqol five dimensions; ICER = incremental cost effectiveness ratio (incremental costs ÷ incremental effects); n/a not applicable; RCT = randomised clinical trial

(n) Directly applicable; partially applicable; not applicable

(o) Minor limitations; potentially serious limitations; serious limitations

(p) For cost-consequence analyses (costs and various health outcomes reported separately and not combined into a cost-effectiveness ratio) only selected incremental effects are presented – see evidence table for full information about studies.

(q) Cost per QALY analysis not used

(r) Some uncertainty about applicability of resource use and costs from over 10 years ago

(s) Some uncertainty about applicability of Finnish resource use and costs from over 10 years ago

(t) Quality of life not assessed; cost of developing decision aid not incorporated; limited sensitivity analyses undertaken.

(u) Unclear if short time horizon will omit longer term quality of life differences but this is considered unlikely to impact conclusion; limited sensitivity analysis.

(v) Unclear if short time horizon will omit longer term quality of life differences; EQ5D assessed but not reported quantitatively; cost of intervention likely to be too high as out of date technology; only limited sensitivity analysis undertaken.

(w) Unclear if short time horizon will omit longer term quality of life differences; quality of life not assessed by a utility measure ; unclear if intervention cost includes development costs; only limited sensitivity analyses undertaken.

(x) Decision aid 1: information programme – risks/benefits numerical/pictorial via website

(y) Decision aid 2: decision analysis program – values of different outcomes elicited from patients then combined with probabilities to suggest a preferred option

(z) Decision aid 1: information only

(aa) Decision aid 2: information plus interview

(bb) Converted from 1999 Euros (Finland) using purchasing power parities

(cc) Dominant – lower costs and higher QALYs than other options

Evidence statements

Clinical	One systematic review of the effectiveness of patient decision aids (Stacey 2001[99]) found decision aids increase patient knowledge, reduce decisional conflict, provide patients with more realistic expectations of outcomes, improve the accuracy of patients' risk perception, increase patient participation in decisions, and increase the match between informed patient values and the choices they make. Decision aids were found to have little or no impact on satisfaction, anxiety, health outcomes, length of consultation, regret, or adherence to treatment.
Economic	A within-RCT cost utility analysis (Kennedy 2003[40], partially applicable, minor limitations) found that a decision aid plus interview was cost effective compared to the decision aid alone or usual care – reducing costs and marginally increasing QALYs. Two within-RCT cost consequence analyses (Murray 2001[49], Murray 2001a[50], partially applicable, potentially serious limitations) found a significant increase in costs with decision aids and no difference in EQ5D score. A within-RCT cost consequence analysis (Vuorma 2004[108], partially applicable, potentially serious limitations)) found costs were reduced, although not significantly; quality of life as assessed by RAND-36 showed a significant improvement in 'emotional role functioning' but not other domains. A within-RCT cost consequence analysis (Hollinghurst 2010[30], partially applicable, potentially serious limitations) found costs with decision aids were similar compared with usual care; quality of life was not an outcome.

10.4.2 Recommendations and link to evidence

Recommendations	**56. 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.** **57. Give the patient the opportunity to discuss their diagnosis, prognosis and treatment.** **58. 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.** **59. Clarify what the patient hopes the treatment will achieve and address any misconceptions** **60. 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. **61.Accept and acknowledge that patients may vary in their views about the balance of risks, benefits and side effects of treatments.**
Relative values of different outcomes	The GDG discussed how difficult it is to know if a patient understands risk, but that the communication of risk was very important for the patient experience and ensuring clear expectations.
Trade off between clinical benefits and harms	The GDG considered no harms were likely.
Economic considerations	The recommendations were considered to have minimal economic implications.
Quality of evidence	The GDG considered the existing NICE recommendations, themes identified in the patient experience scoping study and their clinical and personal experience as a basis for these recommendations on communicating risk.
Other considerations	The GDG agreed that how information about the risks and benefits of a treatment or test is communicated is very important for patient experience. Clinicians should communicate risk without bias and personal anecdotal information is not always appropriate. The GDG noted that while clinicians bring their clinical prospective and expertise to the consultation, both clinicians and patients have a role and responsibility for contributing to the decision process. Specifically clinicians contribute information about diagnosis, cause of disease, prognosis, treatment options and outcome probabilities, whereas patients contribute the experience of their illness, social circumstances, attitudes to risk, values and preferences. Enabling open and direct communication throughout the decision-making process, taking into consideration when and where the communication takes place, and allowing adequate time to discuss the risks and benefits of a treatment or test are integral to ensuring good patient experience. The GDG agreed that as well as risks and benefits, the consequences of treatment for example: what the treatment may entail has to be adequately explained to patients.

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Recommendations	**62.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).**
Relative values of different outcomes	The GDG discussed how difficult it is to measure a patient's understanding of risk, but that the communication of risk was very important for the patient experience and ensuring clear expectations.
Trade off between clinical benefits and harms	The GDG considered no harms were likely.
Economic considerations	It was considered that there was a potential time, and therefore cost, implication of personalising risks and benefits however it was considered that this was outweighed by the benefits to patients in terms of understanding and engagement.
Quality of evidence	The quality of evidence pertaining to the technicalities of how best to communicate risk was generally of low to moderate quality. The GDG also contributed their professional and personal experiences in developing parts of this recommendation.
Other considerations	The GDG agreed that how information about the risks and benefits of a treatment or test is communicated are very important for patient experience. The GDG considered/acknowledged the following: • Information pertaining to the risks and benefits of treatments and tests can be difficult to understand and communicate • Presenting risks in relative terms can lead to more misunderstanding in both patients and clinicians than use of absolute risks. Patients and clinicians might be more willing to recommend or undertake a treatment if the benefits are presented in relative compared to absolute risk terms, therefore information should be presented in absolute terms • Risk information is not always readily available in a format that is suitable for communication to the patient • People have different preferences in how they absorb information so the information should be presented in various formats • It is not expected that information is presented in all of the different formats in every situation – elicit from the patient what their preferred method of communication is. • Consideration should be made about where the communication takes place as clinicians need to be sensitive to the psychological impact of a diagnosis and the patient's ability to assimilate risk information. • As patients' perception and acceptance of risk varies, risk should be communicated in a clear and unbiased way so patients can choose between options.

1

Recommendations	**63.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.** **64.Offer support to the patient when they are making and reviewing decisions. If a patient decision aid or other decision support tool is 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.**
Relative values of different outcomes	
Trade off between clinical benefits and harms	Many health decisions require trading off benefits and harms while considering scientific uncertainty, and decision aids prepare patients to discuss decisions with their clinician. Patient decision aids are used an adjunct to counselling to prepare patients to discuss decisions and reach the goal of a well-informed decision. They describe options and outcomes relevant to the patient's health status and incorporate implicit methods to clarify values. The review found decision aids improved decision quality specifically, higher knowledge scores, more realistic expectations (probabilities) and a better match between values & choices. The GDG discussed how the quality of decision aids can vary and agreed only high quality tools should be used. The use of an inferior quality decision aid might reduce amount and quality of information available to support the decision making process and negatively impact the patient experience. International standards, or availability from recognised providers, can help evaluate the quality of available decision aids[21].
Economic considerations	Most studies did not assess cost effectiveness in terms of cost per QALY, and it was judged questionable as to whether the QALY would adequately capture the benefits of decision aids. However, one study that did do this found decision aids to be cost-effective. Published cost analyses were inconsistent in terms of whether decision aids reduced or increased overall costs. The GDG noted that the cost of using a specific decision aid in the NHS setting will depend on how it is developed, delivered and maintained. For example: some decision aids are already be available but may require a licensing cost to be paid; a decision aid may cost more to deliver if in DVD format compared to paper-based; some decision aids are available via NHS direct and so can be provided by hospitals to patients freely via the internet, but are developed and maintained by the NHS. Costs will also depend on whether additional time is required by healthcare professionals when decision aids are used. While there may be a perception that using a decision aid might increase the consultation time (and therefore have a resource use implication) the Cochrane review did not support this. It was also noted that use of formal decision aids may provide better documentation of informed consent and so potentially reduce litigation costs. The Cochrane review looked for evidence about impact on litigation costs but none was identified. Overall the GDG considered that there may be some additional costs of delivering decision aids but that this was likely to be small relative to the benefit to patients in terms of improved decision quality when effective decision aids are used.
Quality of evidence	The studies in the Cochrane review looked at a range of tools in a range of different conditions for a range of populations. There was variability in risk of bias across studies. There was significant heterogeneity in the results. There was variability in populations, measures, time frames and usual care interventions.
Other considerations	One GDG member noted it is important to distinguish between shared decision-makings and decision aids. Shared decision-making is a technique that

	can be used and get value from without decision aids. Decision aids can be part of the shared decision making process.

10.5 Education programmes

Education programmes are used in a number of long-term conditions. They aim to improve health outcomes by addressing a person's knowledge and attitudes and helping them to understand and manage their risk factors and treatment. They may aim to provide people with skills for self-monitoring and self-management. In some conditions they may form part of a rehabilitation programme that also contains physical therapy (for example cardiac rehabilitation).

10.5.1 Evidence reviews and other inputs

Each of the following sources of evidence and information has been used to inform the recommendations on education programmes of care and a discussion of this is presented in section 10.5.2.

10.5.1.1 Patient experience scoping study - a focused thematic qualitative overview

The scoping study (see appendix B) did not identify education programmes specifically as a key theme or subtheme; however the theme and subthemes related to information are relevant here also.

10.5.1.2 Existing NICE recommendations

- Specific educational packages should be developed for patients with COPD. Suggested topics for inclusion are listed in appendix C of the full guideline (see section 5 for details of the full guideline). The packages should take account of the different needs of patients at different stages of their disease.
  (From ‘Chronic Obstructive Pulmonary Disease’, R 1.2.12.19)[55]
- Do not assume that the patient information leaflets (PILs) that patients receive with their medicines will meet each patient's needs. Address concerns that patients may have after reading the standard PILs.
  (From ‘Medicines adherence’, R 1.1.28)[70]
- Include an educational component consistent with this guideline as part of other interventions, but do not offer stand-alone formal education programmes.
  (From ‘Low back pain’, R 1.2.3)[69]
- Select a patient-education programme that meets the criteria laid down by the Department of Health and Diabetes UK Patient Education Working Group3. Any programme should be evidence-based and suit the needs of the individual. The programme should have specific aims and learning objectives, and should support development of self-management attitudes, beliefs, knowledge and skills for the learner, their family and carers. The programme should have a structured curriculum that is theory driven and evidence-based, resource-effective, has supporting materials, and is written down. The programme should be delivered by trained educators who have an understanding of education theory appropriate to the age and needs of the programme learners, and are trained and competent in delivery of the principles and content of the programme they are offering. The programme itself should be quality assured, and be reviewed by trained, competent, independent assessors who assess it against key criteria to ensure sustained consistency. The outcomes from the programme should be regularly audited.
  (from ‘Type 2 Diabetes - newer agents’, R 1.1.2)[78]

- Offer group education programmes as the preferred option. Provide an alternative of equal standard for a person unable or unwilling to participate in group education.
  (from 'Type 2 Diabetes - newer agents', R 1.1.4)[78]
- Pregnant women should be offered opportunities to attend participant-led antenatal classes, including breastfeeding workshops.
  (Antenatal care R 1.1.16)[71]
- Offer people with CKD high quality information or education programmes at appropriate stages of their condition to allow time for them to fully understand and make informed choices about their treatment.
  (From 'Chronic Kidney Disease', R 1.3.3)[63]
- Healthcare professionals providing information and education programmes should ensure they have specialist knowledge about CKD and the necessary skills to facilitate learning.
  (From 'Chronic Kidney Disease', R 1.3.4)[63]

10.5.1.3 Literature review: components of education programmes

Clinical evidence

The aim of the literature review was to examine whether there was evidence about effectiveness of different generic components of education programmes for improving outcome, particularly as intervention methods are known to vary widely by setting and disease area.

There was no date limit placed on the literature search for systematic reviews investigating the efficacy of different education programme components. RCT and cohort design studies of adults over the age of 16 years were considered for inclusion.

Systematic reviews were excluded if their included studies were predominantly focusing on people using the health services for the treatment of mental health problems.

One systematic review[48] was identified that addressed the question. The systematic review[48] considered interventions to improve knowledge, adherence, and clinical outcomes in patients with chronic conditions. 70 studies conducted between 1961 and 1984 were included. 20 addressed hypertension, 13 diabetes, 9 mental problems, 6 asthma, 4 hormone therapy, 4 congestive heart failure and other cardiac conditions, 3 rehabilitation therapy, 2 anticoagulant therapy, and 1 each tuberculosis, epilepsy, renal transplants, chronic obstructive pulmonary disease, hyperlipoproteinemic conditions, chronic renal failure, hemophilia, glaucoma, and mixed chronic illnesses.

See Appendix F for details of studies that were included in the Mullens systematic review. The overall group of 27 studies that measured knowledge were not homogeneous (H=81.68, $p<0.05$). See Table 34 for a summary of results.

Table 34: Knowledge effects and test of homogeneity for each intervention

Strategy type	Number of studies	Pooled effect size (SD)	95% confidence interval	Test of homogeneity (Chi squared)
One-to-one counselling	3	1.13 (0.15)	0.83 to 1.41	2.20
Group education	3	0.75 (0.17)	0.38 to 1.05	2.13
Written and/or other audiovisual, except patient package insert	6	0.42 (0.09)	0.24 to 0.58	7.25
Patient package insert	6	-0.03 (0.10)	-0.25 to 0.13	0.26
Counselling or group plus materials	8	0.73 (0.12)	0.50 to 0.97	13.88

Strategy type	Number of studies	Pooled effect size (SD)	95% confidence interval	Test of homogeneity (Chi squared)
Behaviour modification	2	0.51 (0.21	-0.04 to 0.86	1.04

(a) A positive score favours the intervention, a negative score favours the control

A weighted least squares analysis was performed to test the impact of various strategy groups on effect size values in conjunction with other study variables that might have exerted an influence (study design, measurement quality, type of comparison group used, difference in educational rating score for the experimental and control groups, length of time the results were observed, strategy group, education rating score, type of ES calculation formula used). The residual sum of squares = 25.77, 24df, P>0.05, adjusted R^2 = 0.82.

See Table 35 for results of the analysis.

Table 35: Weighted least-squares analysis for knowledge effects

Variablea	β	Standard error of β	95% simultaneous confidence interval
Rating of educational quality	0.048	0.0007	±0.016
Patient package inserts	-0.757	0.122	±0.272
Written and/or other audiovisual materials	-0.343	0.114	±0.254
Rating of measurement quality	-0.252	0.092	±0.207

(a) Significant at P>0.05

Adherence was defined as probability or percentage of drug errors. For results of the analysis see Table 36 and Table 37.

Table 36: Drug utilisation errors and test of homogeneity for intervention grouping

Strategy type	Number of studies	Pooled effect size (SD)	95% confidence interval	Test of homogeneity (Chi squared)
One-to-one counselling	8	-0.43 (0.09)	-0.24 to -0.61	9.47
Group education	11	-0.34 (0.13)	-0.28 to -0.41	14.53
Written and/or other audiovisual, except patient package insert	2	-0.43 (0.17)	0.08 to -0.77	1.02
Patient package insert	4	-0.01 (0.12)	0.23 to -0.25	1.75
Counselling or group plus materials	13	-0.44 (0.08)	-0.28 to -0.60	10.17
Labels, special containers, or memory aids	3	-0.42 (0.15)	-0.13 to -0.71	3.23
Labels, containers, or memory aids plus counselling or group	6	-0.47 (011)	-0.25 to -0.70	1.93
Behaviour modification/self-administration	8	-0.50 (0.09)	-0.33 to -0.67	4.73

Table 37: Weighted least square analysis for drug errors

Variable[a]	β	Standard error of β	95% simultaneous confidence interval
Rating of educational quality	-0.024[b]	0.003	±0.007
Patient package inserts	0.391	0.131	±0.293
Rating of measurement quality	0.070	0.026	±0.058
Group education	0.101	0.056	±0.125

[a] *Significant at P<0.05*

[b] *The negative sign indicates this variable was positively associated with reduction in drug errors.*

Evidence statements

Clinical	One systematic review found evidence for one-to-one counselling, group education and one or both strategies in combination with audio-visual materials had the largest effect on increasing knowledge. Educational rating score was the strongest predictor of effect sizes for both knowledge and drug errors.
Economic	An economic evidence review was not undertaken for this question.

10.5.2 Recommendations and link to evidence

Recommendations	**65. 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).** **66. 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 65.**
Relative values of different outcomes	
Trade off between clinical benefits and harms	Recent NICE guidelines have made a number of recommendations about education programmes for specific conditions. The GDG considered that patient education programmes had an important role to play in certain conditions where they had been implemented following consideration of the evidence on effective and cost effective. However, it was noted that outcomes were likely to vary by specific intervention and specific condition (for example, people with more severe conditions may be more willing to make behavioural changes) and so this consideration was best retained within condition-specific guidelines. The GDG considered that although the literature review found positive effect sizes for one-to one counselling, group education, written/audiovisual information, and counselling or group plus material on knowledge, the quality of the evidence was not good enough to recommend these be included in all education programmes, particularly as the clinical and cost-efficacy have been shown to vary depending on the disease area and associated risk in existing NICE guidance. The GDG agreed there was no evidence of clinical harm so patients should be given the opportunity to participate in educational programmes if they already

	exist and meet the criteria specified in the recommendation.
Economic considerations	Effective patient education programmes have the potential to improve patients’ health and reduce healthcare resource use. However, as noted above, consideration of the effectiveness and cost effectiveness of specific interventions was considered best retained within condition-specific guidelines. The recommendation made promoting use of evidence-based education programmes is not considered to have additional economic considerations.
Quality of evidence	In the systematic review identified there was a problem with incomplete descriptions of interventions in individual studies, making it difficult to assess authors’ claims of what they were testing. The authors of individual studies rarely specified a reason for selecting a specific intervention or combination of interventions in their study. Many studies were conducted within special subgroups within the population which impacts our ability to generalise the findings to other target groups of patients.
Other considerations	The GDG considered that even when appropriate evidence-based education programmes were available, patients did not always get access to them, so made a recommendation that where available, patients should be offered the opportunity to take part in education programmes.

11 Bibliography

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