NCGC National Clinical Guideline Centre

Draft for consultation

Patient experience in generic terms

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

Clinical Guideline Appendices

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Draft for Consultation

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Appendices

Appendix A: Scope

A.1 Title

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

A.1.1 Short title

Patient experience in generic terms

A.2 Introduction

A.2.1 Guidance

This guidance will make recommendations on the appropriate treatment and care of people within the NHS. The recommendations are based on the best available evidence.

This scope defines what the guidance will (and will not) examine, and what the guidance developers will consider. The scope is based on the referral from the Department of Health.

A.2.2 Quality standards

Quality standards are a set of specific, concise quality statements and measures that act as markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions.

For this topic a NICE quality standard will be produced based on the guidance recommendations. The guidance and the quality standard will be published at the same time.

This scope defines the areas of care for which specific quality statements and measures will (and will not) be developed.

A.3 The remit

The Department of Health has asked NICE: ‘to produce a quality standard and guidance on patient experience in generic terms’.

A.4 Need for guidance

A.4.1 Background

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

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

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

b) The King's Fund charitable foundation has developed a comprehensive policy resource – 'Seeing the person in the patient: the point of care review paper' (2008).

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

d) Despite these initiatives, there is evidence to suggest that further work is needed to deliver the best possible experience for patients who use NHS services.

e) High quality care should be clinically effective, safe and be provided in a way that ensures the patient has the best possible experience of care. This guidance, and the quality standard that will be developed from it, will aim to ensure that patients have the best possible experience of care from the NHS.

A.4.2 Current practice

a) Current practice varies across all healthcare settings.

A.5 The guidance and quality standard

The guidance and quality standard will outline a level of service that people using the NHS should expect to receive. 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.

A.5.1 Population

A.5.1.1 Groups that will be covered

a) People who use adult NHS services.

A.5.1.2 Groups that will not be covered

a) People using NHS services for mental health.

b) 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.

A.5.2 Healthcare setting

a) All settings in which NHS care is provided, except mental health care.

A.5.3 Objectives

a) Develop recommendations and quality standards to provide a framework that describes the key requirements for providing a high quality patient experience within the NHS. We do not expect the guidance to make recommendations on all elements of the framework.

b) Identify quality measures that set the expected degree of achievement. The NICE Quality Standards team will be responsible for the development of the quality measures.

c) Identify key areas for further research that are likely to improve our understanding of how to measure and improve the experience of care within the NHS.

A.5.4 Methods

a) The National Clinical Guidelines Centre will develop a framework of patient experience in the NHS.

b) A number of frameworks and reviews of frameworks already exist, developed and tested through differing approaches. The principles of these frameworks will be considered but a comparison will not be made between them.

c) The Guideline Development Group will consider these frameworks and their common themes, and agree a list of key themes from which recommendations will be developed. The quality standards will be framed by these recommendations. This process will be informed by the information gathered in 4.4 e and f.

d) NICE will also use the framework to develop quality measures.

e) A high level literature review will be conducted to identify and synthesise qualitative and quantitative studies that have examined patient experience and interventions to improve it.

f) NICE clinical guidelines and public health guidance published in the past 3 years will be reviewed to identify questions, evidence reviews and recommendations that the Guideline Development Groups considered important for improving patient experience.

g) The GDG will identify themes that underpin the experience of care for which quality standards will be developed. Statements will be developed to describe these themes. It is likely that these themes will already have been covered by recommendations in existing NICE guidelines, and will be ones for which there is an evidence base to inform quality standards. The GDG will choose areas for which the NCGC will develop reviews to inform quality standards.

h) Stakeholders will be invited to comment on the draft recommendations and quality standard through a formal consultation.

A.5.5 Economic aspects

Developers will take into account both the clinical and cost effectiveness of interventions. If interventions are identified that may improve patient experience, a cost impact analysis will be undertaken.

If there is sufficient evidence to offer a choice between alternative interventions, then a cost effectiveness analysis will be undertaken using existing NICE methods. The preferred unit of effectiveness for this will be the quality-adjusted life year (QALY), and the costs considered will usually be only from an NHS and personal social services (PSS) perspective.

A.5.6 Status

A.5.6.1 Scope

This is the final scope.

A.5.6.2 Timing

The development of guidance recommendations will begin in January 2011. There will be six guidance meetings. Publication of the guidance and quality standard is expected in October 2011.

A.6 Related NICE guidance

NICE is currently developing the following related guidance (details available from the NICE website):

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

Appendix B: Thematic qualitative review: scoping report

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B.1 Executive Summary

Patient experiences have become an important part of health care evaluation, contributing insights into the acceptability, relevance, appropriateness and effectiveness of health care. This scoping study has reviewed patient experiences in three clinical area, cancer, cardiovascular disease and diabetes, all areas of significant disease burden. We have extracted patient experiences data from a range of peer-reviewed studies and analysed them thematically, building on the sub-themes identified in the studies to develop generic patient experiences themes. Based on this analysis, we have developed a Generic Patient Experiences Framework that has potential relevance for all patients, but would need to be more widely tested. The Generic Patient Experiences Framework represents a synthesis of a wide and complex evidence base, building on the IoM framework, with some adaptation, and the addition of important themes that have emerged in this scoping study. The generic themes include patients as potential active participants, responsiveness of service – an individual approach, lived experience, continuity of care and relationships, communication, information and support. A set of evidence tables are included, providing a clear audit trail from the Framework to the underpinning evidence base. The Generic Patient Experiences Framework has the potential to contribute to the development of the Patient Experiences Guidance and the Quality Standard.

B.2 Introduction

The RCN Research Institute at the University of Warwick was commissioned by the Royal College of Physicians to undertake a scoping study of patient experiences literature, with the aim of identifying generic dimensions of experience that have relevance for all patients. This study, reported here, aims to inform the work of the Patient Experiences Guideline Group and the Quality Standard against which NHS care will be commissioned and evaluated.

B.2.1 Background

Patient experiences have become an important part of health care evaluation, contributing insights into the acceptability, relevance, appropriateness and effectiveness of health care, alongside clinical and economic forms of evidence (Staniszewska 2010). There is a large and diverse body of literature which documents the experiences of a range of patients in a variety of clinical areas, reflected in the large number of studies identified by searches of literature undertaken for this study (appendix 4). Research focusing on the effectiveness of interventions that aim to improve patients' experiences has not been assessed for effectiveness in this review as this would have required a systematic review. In addition to published peer-reviewed studies of experience, valuable online sources of information and databases of patient experiences exist which aim to enhance our understanding of what it is like to live with a particular condition, for example Healthtalkonline (http://www.healthtalkonline.org/) which includes interviews with individuals about a range of conditions and PRIME, which focused on ME/CFS (http://www.prime-cfs.org/).

In an attempt to draw together and summarise our understanding of experiences, a number of frameworks have emerged that try to capture the key dimensions of patient experiences, for example the Institute of Medicine (2001). By dimensions we mean a theme or an area of experience, such as information or communication. However, it is not always clear how these dimensions of experiences have been abstracted from a wider and diverse body of research, or the extent to which patients and the public have been involved in developing or selecting these dimensions, or the extent to which the dimensions reflect patient-identified experiences, as opposed to those identified by researchers and clinicians. With these uncertainties about the underpinning of some of the existing frameworks, this scoping study aimed to identify a framework which captures generic dimensions of experiences and provides a very clear audit trail to the underpinning evidence in three clinical areas.

B.3 Aims

The overall objective of this scoping study was to:

- 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.
- To 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.

B.4 Methods

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). 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).

B.4.1 Search strategy

The search strategies were developed and refined by an information specialist for each of the following key electronic databases: Medline, Cinahl, Assia, Embase and Psychinfo. Additional papers were identified from reference lists and specialist journals. Additional searches were carried out on PubMed and UK PubMed Central.

B.4.1.1 Inclusion criteria

Research papers that focus on exploring or identifying patient experiences in the three clinical areas: cardiovascular disease, diabetes and cancer. English language papers. **Search dates:**1995 – 2011.

B.4.1.2 Exclusion criteria:

Papers that primarily focus on interventions to enhance patient experiences. Papers that report development, testing or application of patient-reported outcome measures. Opinion articles or editorials about patient experience. Non-English language papers. Children's experiences. Carer's experiences. Grey literature.

B.4.1.3 Challenges in developing search strategies

In undertaking this study a number of challenges were identified with the development of search strategies. A key difficulty was the lack of MESH headings that relate to patient experiences, necessitating the use of free text searching, which can rely on poorly defined terminology sometimes inconsistently used across studies. The necessary use of many potentially relevant keywords initially produced a huge number of irrelevant hits that required refinement. The process of developing a search strategy was thus iterative and a range of combinations of key words were used in an attempt to maximise the relevance of the studies being identified. The complexity of searching for studies in patient experiences is illustrated by the initial strategies developed on Medline. A total of 10 strategies were recorded on the Medline database, but many more were trialled in an effort to obtain a manageable number of relevant results. A final version was decided on and in the Medline/Embase search, this strategy produced a relevancy rate of 20% in the area of cancer. The search strategy was then adapted for use with other databases, for example because none of the other databases had the refinements in terms of searching which were available on the Ovid versions of Medline and Embase. Other databases also posed problems because they did not always allow for the addition of particular filters to help refine the search in order to identify more manageable numbers of studies. Search strategies for each clinical area are included in section B.11.

B.4.1.4 Selection of papers

Titles and abstracts were read for relevance and papers judged to meet inclusion criteria were included in the study. While ideally, a second researcher would have cross-checked a sample of the studies for their relevance, in practice this was not possible because of the short time-scale and the large number of possible papers identified. However, the research team met regularly to discuss any ambiguous papers and a decision was reached about their inclusion. A number of key steps were followed in the identification and analysis of themes.

Data extraction of sub-themes and themes

Each paper that met the inclusion criteria was read in full by one researcher. Three researchers data extracted, each leading on one clinical area. As each paper was read, sub-themes were identified and linked to a generic theme. A sub-theme was defined as an aspect of patient experience, for example, patients experiencing poor information provision when making decisions. In this case the sub-theme would be linked to a broader generic theme of information. In some cases, sub-themes would relate to more than one generic theme. These themes and sub-themes were then recorded using a data extraction form, which provided a structured way of organising the information and an audit trail for how sub-themes and evolving generic themes were being linked. A key challenge in developing the themes and sub-themes was the varying level of detail provided in papers when describing sub-themes. Researchers undertook this analysis individually and any ambiguous sub-themes and their relationship to a broader generic theme were discussed within the research team. In addition to data about experiences, the data extraction sheet also recorded any key methodological limitations or fatal flaws (that would have justified exclusion), as a full quality assessment of studies was not possible within the timeframe of the study. The data extraction sheets that record all themes and sub-themes for each study are contained as a separate volume, which accompanies this report.

Developing themes and sub-themes for each clinical area

A summary evidence table of generic themes and underpinning sub-themes was then produced for each clinical area, with the references listed alongside each sub-theme. These summary tables brought together all the themes and sub-themes that emerged from the detailed data extraction sheets in a particular clinical area. See sections B.8, B.9 and B.10. A shortened version of these tables is provided in the results sections B.5.1, 0 and 0.

Developing the overall patient experiences framework

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 (2001) framework as a model against which to compare and contrast the themes identified in this study against the IoM framework (compassion, empathy and responsiveness, co-ordination and integration, information, communication and education, physical comfort, emotional support, relieving fear and anxiety and involvement of family and friends) identifying similarities and differences. Each element of the IoM (2001) 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 then 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 sections B.8, B.9 and B.10.

B.5 Results

Patient experiences varied across and within each clinical area. Each clinical area included a range of conditions including acute and chronic conditions, with patients accessing very different types of services. The first section reports the summary frameworks (generic and sub-themes) developed in each of the three clinical areas. The aim of these tables is to illustrate the generic themes and the sub-themes, with the detailed evidence tables presented in sections B.8, B.9 and B.10.

The second section reports the overall generic patient experiences framework developed in this scoping study.

B.5.1 Generic themes and sub-themes for Cancer

Generic theme	Sub-theme
Communication	Patient-centred communication
	Individualised approach
	Context
	Responsibility/control
	Character of health care professional
	Reassurance/hope
	Psychosocial needs
	Humour
	Support of family and friends
Information	Individualised approach
	Honesty/realism
	Reassurance/hope
	Format and quality
	Responsibility/control
	Information: Diagnosis
	Information: Treatment
	Information: Prognosis
Decision-making	Individualised approach
	Support of family-friends
	Responsibility/control
	Trust in expertise
	Relationship with health care professional
	Medical uncertainty

Generic theme	Sub-theme
Continuity of care	Co-ordination
	Availability/ accessibility
	Integration
	Abandonment
	Relationship with health care professional
	Responsiveness to needs
Support	Facilitating coping strategies
	Identity
	Advocacy
	Relationship with health care professional/character of health care professional
	Support of family/friends
	Individualised approach
	Peer support/expert panels
	Preparation for diagnosis/treatment
	Stigma/taboos/culture
	Reassurance/hope
	Responsiveness to needs

The full evidence table is in section B.8.

B.5.2 Generic themes and sub-themes for Cardiovascular disease

Generic theme	Sub-theme
Accessing Services	Efficient, reliable access
	Waiting
	Absence of services
	Skills needed to access services
	Barriers to accessing services
	Interpreting symptoms and deciding to seek help
Communication	Openness
	Communication style
	Consistent information
	Barriers to communication
	Importance of communication
	Consequences of poor communication
	Characteristics of patient communication
	Wanting more opportunity for communication with health care professionals
	Staff communication skills
	Content of communication with health care professionals
	Communication aids
	Reassurance
Continuity of Care	Lack of continuity

Generic theme	Sub-theme
	Experiences of continuity
	Poor communication between health care professionals and poorly coordinated services
	Feeling secure
Information	Satisfaction with information: Feeling informed
	Importance of information
	Wanting more information
	Wanting individualised information
	Format
	Delivery
	Timing
	Not wanting to know
	Recall
	Sources
	Involvement of family/friends
	Changing information
	Inconsistent information
	Sharing information
Knowledge, Understanding and making sense	Poor understanding
	Good knowledge and understanding
	Education
	Being left to figure it out yourself
	Importance of knowledge and understanding
	Translating knowledge into action
	Patients ways of making sense vary from biomedical explanations

1 The full evidence table is in section B.9.

2 B.5.3 Generic themes and sub-themes for Diabetes

Generic theme	Sub-themes
Patient as active participant	(Underpins all sub-themes)
Responsiveness (organisation of services to meet needs and preferences)	Time spent with health professionals
	Time waiting
	Response times
	Convenience
	Environment
	Co-ordination
	Resources
	Expertise
	Follow up
	Mistakes
	Tailoring care for individual rather than diabetes

Generic theme	Sub-themes
	Satisfaction
Relationships/partnership (issues to do with the relationship between patients and health professionals)	Trust
	Power
	Control
	Shared decision-making
	Judgemental attitude
	Being seen as a person
	Respect
	Continuity of care
	Approachability
	Empathy
Communication (style and content of verbal and non-verbal communication between patients and health professionals – overlap with all other categories)	Importance of communication
	Quality of communication
	Listening/paying attention/acknowledging patient expertise
	Language
	Questions and answers
	Explanations
	Brusque manner
Information and support for self-care (resources provided or required, including information, education, emotional support and peer support)	Importance of information and advice
	Problems with information
	Not wanting information
	Feedback on condition
	Sources of further help
	Education and groups
	Peer support
	Need for emotional support
Lived experience	Everyday lives
	Perceived unrealistic goals
	Importance of families
	Cultural issues
	Interpretations, beliefs and meanings
	Psychological factors
	Perceived discrimination/injustice
	Complexity of diabetes and self-care

The full evidence table is in section B.10.

B.5.4 Generic framework of patient experiences

B.5.4.1 Analysis of IoM Framework

The IoM framework provided a useful starting point for the analysis of the themes and sub-themes identified in this study as it provided us with a point of comparison on which to map our own themes and sub-themes and to revise and amend the original IoM framework according to our findings. Table 1 provides a narrative commentary of how the IoM themes were adjusted and added to.

Table 1: An analysis of the IoM Framework

IoM theme	Narrative commentary
Compassion, empathy and responsiveness	Compassion and empathy were both important themes, but appeared in more subtle forms within a number of wider generic themes, for example communication. Responsiveness emerged as a generic theme but was focused on the responsiveness of the service and the need for an individualised approach.
Co-ordination and integration	These themes were important but fitted more appropriately into the wider generic themes of continuity of care and responsiveness.
Information, communication and education	Information and communication emerged as two key themes but were separated to reflect the different content of the sub-themes identified. Education appeared in a number of the generic themes in different ways, including within support and information.
Physical comfort	Physical comfort was important but appeared in other more substantive generic themes, including responsiveness and lived experience.
Emotional support, relieving fear and anxiety	Emotional support was included in a much larger category of support. Elements of fear and anxiety were more subtle and appeared as part of a broader lived experience.
Involvement of family and friends	The role of family and friends was important and appeared in broader themes of lived experience and support.

An important difference between the IoM framework and the framework developed from this scoping study was the role of patients as potentially active participants in their care and the importance of lived experience as underpinning health service experiences.

B.5.4.2 Generic Patient Experiences framework

Table 2: Generic Patient Experiences framework

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, 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 (e.g. 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.

The aim of the framework presented in Table 2 is to summarise a complex patient experiences evidence base. The narrative description of each theme is thus illustrative, rather than exhaustive. The themes and sub-themes contained in the generic framework are complex and many connections exist between them. Themes such as 'responsiveness of service - an individualised approach' cut across other themes. Patients value health care professionals taking into account their individuality and the unique way in which they experience their condition the context of their own lives. Patients' values, beliefs and circumstances all inform their expectations of, as well as their needs for, services. Continuity of care and the establishment of trusting, empathetic and reliable relationships with competent and insightful health care professionals is key to patients receiving such individually orientated services, and enables patients to become active participants in their own care, in partnership with health care professionals. The framework also demonstrates that patients' experiences of health services and their experiences of living with the condition are often closely linked with their interpretations of how effectively the service meets their needs. In diabetes, some differences emerged with an over-riding emphasis on self-care and lifestyle issues in the research literature on patients' experiences with diabetes treatment and care. The ways in which health professionals encourage and support patients (or fail to do so) are described vividly in the literature. Diabetes care presents complex challenges to patients and to healthcare staff, because of its impact on everyday life as well as its changing course, complications and co-morbidities. Good relationships with health professionals are particularly important; issues of trust, respect, power and control are described in many accounts, as are needs for two-way communication, useful information and emotional support. Expert care and services organised to meet patients' needs (when these are available) are highly valued. While there were some differences, there were important overlaps in the generic themes and sub-themes identified in all three clinical areas.

B.6 Concluding comments

The aim of this scoping study was to identify the generic themes and sub-themes of patient experiences in three clinical area, cancer, cardiovascular disease and diabetes, all areas of significant disease burden, and to utilise these generic themes and sub-themes to develop a generic patient experiences framework that has potential relevance for all patients, but would need to be more widely tested. The Generic Patient Experiences Framework presented in table 2 of this report represents a synthesis of a wide and complex evidence base, building on the IoM framework, but changing and adding important themes that emerged in this scoping study. The generic themes included in this framework are purposefully broad, in order to capture the complexity of patient experiences that lies beneath it. The evidence tables for each clinical area aim to provide an audit trail of how generic themes and sub-themes were developed directly related to the papers from which they originated. As such the Generic Patient Experiences Framework has a strong evidence base, which has the potential to contribute to the development of the Patient Experiences Guidance and the Quality Standard.

B.7 References for the thematic qualitative review: scoping report

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B.8 Cancer Patient Experiences Generic and Sub-themes Evidence Table

Generic Theme	Sub-Theme (all themes that related to the generic theme)	Description	References
Communication	Patient Centred Communication	Importance of using language that patients understand and can relate to, avoidance of complex terminology.	C1, C10, C16, C17, C19, C24, C25, C26, C28, C34, C39, C49, C52
	Individualised Approach	Patients varied as to what they wanted from communication with health care professionals. Some were better prepared for diagnosis than others, some wanted people with them, others wanted to be alone during consultations. Health care professionals need insight into the individual's needs and concerns.	C1, C16, C20, C24, C25, C26, C29, C30, C33, C34, C36, C37, C38, C39,C40, C42, C43, C45, C47, C49, C50, C52, C54
	Context	Patients wanted good quality consultations: enough time to ask questions, and the environment of the consultation to be appropriate and private. Most patients wanted no other health care professional present at the diagnostic consultation.	C3, C4, C6, C16, C17, C20, C26, C28, C31, C33, C34, C39, C40, C42, C43, C45, C52, C53
	Responsibility/Control	Some patients wanted to take responsibility/control over communication with their doctors by asking the specific questions they wanted answered and by being allowed to contact them directly when they had specific queries.	C3, C12, C13, C14, C36
	Character of Health Care Professional	Patients valued certain 'types' of health care professional: those who expressed empathy and interest in patients. They needed to relate to the health care professional as a concerned individual, not detached professional in order to communicate effectively.	C1, C2, C24, C28, C33, C34, C38, C39, C41, C45
	Reassurance/Hope	Patients needed to feel that their doctors were allowing them to hope, even in cases of delivering bad news. Patients also wanted lots of reassurance in their contact with health care professionals throughout their treatment and during follow up care.	C13, C16, C24, C25, C26, C28, C39, C40, C42, C49

Generic Theme	Sub-Theme (all themes that related to the generic theme)	Description	References
	Psychosocial Needs	Patients had needs that were often not met during consultations with their doctors; e.g. around sexuality, identity, relationships, existential concerns, emotional support. These needs change and evolve over time.	C4, C10, C32, C42, C46, C47, C48, C50, C52
	Humour	Some patients used humour within their consultations with their doctors to diffuse emotionally charged conversations and establish a relationship/rapport with the health care professional.	C41, C42
	Support of Family/Friends	All studies reported that patients preferred friends/family members present at consultations (particularly diagnosis) to give a different perspective, remember information and offer emotional support. However studies C28 and C43 found that patients preferred to be on their own during consultations.	C1, C16, C25, C28, C33, C34, C41, C43, C47
Information	Individualised Approach	Patients appreciated an individualised approach to information giving. Patients differed in how much information they wanted about their condition, the point at which they wanted it and how prepared they were for the information. Some were ambivalent.	C1, C9, C13,C16, C20, C24, C25, C26, C29, C30,C31, C33, C34, C36, C37, C38, C39, C40, C42, C43, C47, C48, C49, C50, C52, C53, C54
	Honesty/Realism	Patients valued a balance being struck between allowing patients hope, but also being honest, direct and realistic about their condition.	C13, C20, C26, C38
	Reassurance/Hope	Patients appreciated honesty in the information they were provided, but nevertheless wanted health care professionals to appreciate their need for hope and reassurance with this information.	C3, C4, C6, C7, C8, C10, C11, C12,C13, C15, C16, C18, C24, C25, C26, C28, C31, C32, C39, C40, C41 C42, C49, C55
	Format and Quality	Most patients preferred to receive information about their diagnosis in person rather than over the phone. Many valued being given written information.	C3, C5, C10, C15, C17, C22, C26, C28, C35, C37, C39, C53
	Responsibility/Control	Many patients wanted to take control over how much information they had about their condition through asking questions and seeking information from alternative sources	C13, C14, C16, C17, C25, C28, C36, C37, C40, C41, C55

Generic Theme	Sub-Theme (all themes that related to the generic theme)	Description	References
		(internet, books, support groups, patients).	
	Information: Diagnosis	Patients valued most information at the time of diagnosis.	C19, C20, C23, C33, C34, C43,C44, C52
	Information: Treatment	Patients often felt that they were not given enough information about treatment and side effects, often they felt under-prepared for the consequences of their treatment (particularly in the long term). They also valued being informed of the consequences of delaying or avoiding treatment. (C52-satisfaction with treatment information was highest). Some patients had unrealistic views of the outcomes of treatment (e.g. C54) and thus may have avoided information on treatment that could have threatened this belief.	C1, C17, C20, C23, C25, C31, C33, C34, C37, C42. C52, C53, C54
	Information: Prognosis	Prognostic information was considered to be of lesser importance than diagnostic and treatment information, but patients nevertheless valued honesty in the delivery of this information, as well as an individualised approach.	C1, C12, C13, C19, C26, C33, C34, C42, C52, C54
Decision Making	Individualised Approach	Patients wanted their doctors to take an individualised approach to how much they were involved with decision making. Some wanted a lot of involvement, others wanted a more passive role.	C24, C36, C42, C54, C55
	Support of Friends/Family	Some patients involved their family/friends in their decision making.	C41
	Responsibility/Control	Some patients wanted to take on responsibility/control over decision making in their care.	C5,C14, C16, C17, C20, C23, C24, C25, C26, C36, C41, C42, C50, C54, C55
	Trust in Expertise	In order to trust health care professionals, patients needed to have faith in their expertise and competence. This expertise was often valued over patients' desire to be involved in their decision making, "doctor knows best".	C2, C8, C9, C10, C13, C16, C17, C18, C20, C25, C32, C36, C38, C41, C42, C47, C55
	Relationship with Health Care Professional	Patients needed an honest, trusting and open relationship with their health care professional to be involved in decision making.	C2, C6, C8, C15, C16, C19, C20, C31, C32, C33, C38, C41, C42
	Medical Uncertainty	Some patients acknowledged medical uncertainty to be an important aspect of their decision making. Medical knowledge	C5, C26, C29, C31, C40, C41, C55

Generic Theme	Sub-Theme (all themes that related to the generic theme)	Description	References
		was not infallible.	
Continuity of Care	Co-ordination	Patients often found themselves co-ordinating their own care. They appreciated well co-ordinated services and the avoidance of long delays between appointments.	C1, C15, C30, C32, C33, C34, C35, C38, C39, C43
	Availability/Accessibility	Patients valued the availability and accessibility of services, e.g. having access to a health care professional at the end of a phone when needed, even if this was never used.	C3, C15, C16, C17, C18, C19, C20, C37
	Integration	Patients valued services that were 'joined up' with appropriate communication between primary and secondary care.	C10, C12, C19, C25, C32, C53
	Abandonment	Some patients felt that once their treatment had been completed that they were 'abandoned' as their support stopped abruptly, despite their continued needs.	C8, C32, C41, C52
	Relationships with Health Care Professional	Patients valued seeing the same health care professional regularly, rather than seeing multiple members of the team. This enabled them to build up a good relationship with the health care professional.	C2, C6, C8, C15, C16, C19, C20, C31, C32, C33, C38, C41, C42
	Responsiveness to Needs	Patients appreciated services that were responsive to, and anticipated their needs.	C31, C30, C38
Support	Facilitating Coping Strategies	It was considered important that health care professionals recognise and facilitate the coping strategies of patients, whatever these may be.	C5, C17, C21, C29, C42
	Identity	Patients valued support around identity, and in particular, their gender identities.	C29, C36, C37, C41
	Advocacy	Cancer had an effect on every aspect of patients' lives and their appreciated health care professionals who could advocate for them.	C15, C20
	Relationship with Health Care Professional/Character of Health Care Professional	A good relationship with a health care professional who is empathetic, honest and reliable were central to patients feeling supported.	C1, C2, C6, C8, C15, C16, C19, C20,C24, C28, C31, C32, C33, C38, C39, C41, C42, C52

Generic Theme	Sub-Theme (all themes that related to the generic theme)	Description	References
	Support of Family/Friends	Patients recognised the importance of having strong support networks of family and friends. Some did not want to 'burden' those around them, however and some suggested that family and friends may need support themselves.	C5, C8, C10, C16, C17, C21, C24, C25, C29, C41
	Individualised Approach	Patients appreciated support that was tailored to their particular circumstances and needs—patients from particular social and ethnic backgrounds may have more need for support.	C1, C3, C13, C14, C16, C17, C18, C19, C25, C26, C29, C30, C31, C33, C34, C36, C37, C38, C39, C40, C41, C42, C43, C52
	Peer Support/Expert Patients	Some patients valued speaking to other patients with similar experiences.	C21, C24, C25, C35, C38
	Preparation for Diagnosis/Treatment	Patients often felt that there was a lack of support in preparing them for a diagnosis of Cancer and the associated treatment.	C34, C37, C43, C53
	Stigma/Taboos/Culture	The way in which Cancer is constructed in wider society, and its association with death, affected the way in which participants responded to their diagnosis and their shared understanding with their doctor.	C19, C32
	Reassurance/Hope	Offering reassurance and hope throughout a patient's treatment was an essential part of supporting them.	C3, C4, C6, C7, C8, C10, C11, C12, C13, C15, C16, C18, C24, C25, C26, C28, C31. C32, C39, C40, C41, C42, C49
	Responsiveness to Needs	Patients valued health care professionals who anticipated their support needs and gave appropriate support as their needs changed over time.	C31, C30, C38

B.9 Cardiovascular Patient Experiences Generic and Sub-themes Evidence Table

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
Accessing Services	Efficient, reliable access	Patients experienced efficient response of staff to their needs and felt well cared for	CV1 CV19 CV43 CV61 CV63
	Waiting	Long waiting lists for referral	CV1 CV3
	Absence of services	Several studies reported an absence of appropriate services especially after discharge from hospital. Feelings of fear, abandonment, vulnerability can result from a lack of services (CV53). Lack of accessibility of care, having to initiate contact, leads to feelings of mistrust, uncertainty and insecurity (CV57)	CV3 CV53 CV57 CV61
	Skills needed to access services	Skills, knowledge, assertiveness on part of patient needed to access services when communication failed. Also see Interpreting symptoms.	CV3
	Barriers to accessing services	Practical issues: Patients frequently report a range of practical barriers to accessing services including: Day-to-day life (childcare, employment, household responsibilities); Difficulties walking, problems with transport, not being able to get out the house, long distances to services; inconvenient appointment times, waiting lists.	CV3 CV12 CV14 CV28 CV30 CV39 CV42 CV48 CV56
		Individual factors:	CV3

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
		Other barriers to access include: disliking the break in routine necessary to access services (older patients) (CV3); not understanding the purpose of a service or its relevance (CV3); personal factors (e.g. fear and denial) (CV30) and cultural factors (e.g. strength and stoicism in the South Yorkshire mining community); past experiences of health care (CV30).	CV30
		Service provision: not receiving sufficient information about services on offer was a barrier to access (CV56); Perception that CR sessions were overcrowded discouraged participation (CV56); not knowing how to access support services (CV46); Perception that the group members are 'all old people' discouraged participation (CV12).	CV12 CV30 CV46 CV56
	Interpreting symptoms and deciding to seek help (emergencies)	The decision-making process by which people with MI seek help is a major concern in the literature. A wide-range of factors influence the decision to seek help and the timing of this: Gender: Women delay longer than men in seeking help (CV30, CV49) Perception of risk: belief that lifestyle changes and/or previous treatment protected them (CV30); CHD seen as a 'man's disease' and so women find it harder to interpret signs appropriately (CV15, CV30); assuming you will recover because of prior experience (CV14); not wanting to bother the health service unnecessarily (CV30, CV14, CV49, CV16) Social class: Patients from deprived backgrounds were more negative about their health and often did not seek medical help because they normalised their symptoms, attributed them to co-morbidities or did not want to overuse medical services (CV30) Severity of symptoms: (CV15); sudden onset often meant patients sought help quickly (CV15). Intermittent symptoms were particular difficult to interpret (CV30). Patients tend to minimise symptoms (denial) and this can delay treatment seeking (CV14) Recognition of symptom as heart related: (CV15, CV30, CV49, CV14) Involvement of family/friends: decision to call for help often made by someone other than the patient[a] (CV30, CV14, CV56)	CV14 CV15 CV16 CV30 CV49 CV56

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[a] Gender differences: Men more likely to seek help from spouse and men's partners more likely to encourage them to seek medical care. Women did not want to worry their husbands and did not seek their advice. Often persuaded to seek help by daughter. When women do seek help from family members this can result in delay as relatives minimise symptoms and reassure patients.

Generic theme	**Sub-theme** **(All sub-themes that relate to generic theme)**	**Description**	**References**
		Patients adopted a 'wait and see' approach at onset of symptoms. Patients tried to manage the symptoms with actions such as lying or sitting down, walking back and forth, keeping hand on chest, taking a bath or drinking water. Only when these measures did not work did they seek help (CV56, CV49)	
	Interpreting symptoms and deciding to seek help (non-emergency)	Patients report difficulties interpreting symptoms and so seeking appropriate help. Symptoms were associated with other conditions or older age (CV52, CV24). Symptoms were not always recognised as serious or treatable (CV46). Patients did not want to bother GPs who were perceived to be busy with more important cases (CV52).	CV24 CV46 CV52
Communication	Openness	Belief that doctors would not want to reveal likelihood of patient dying	CV28
	Communication style	Patients value calmness, reassurance, humour and empathy from staff. When carers indicate they are short of time, busy or have to much to do, patients perceive themselves as burdens, being reduced, objectified (CV57)	CV20 CV57
	Consistent information	Patients receive inconsistent information. See also Information.	CV3 CV24 CV63
	Barriers to communication	Patients experience a range of barriers to communication: Lack of interpreters; lack of communication aids; group communications are problematic for patients whose first language is not spoken English (CV3); confusion/short term memory problems associated with the condition; believing doctor knows best inhibits questioning (CV28)	CV3 CV28
	Importance/consequences of poor communication	Poor communication can mean: patients are less involved in decision-making (CV3); patients feel ignored or not taken seriously and they lose faith in the carers (CV57); Patients sometimes feel forced to do as the carers tell them without understanding why (CV57); patients experience fear, frustration, uncertainty or humiliation (CV57); Patients are left wondering what to do next when they do not hear from the hospital after discharge (CV3). Lack of communication leaves patients feeling abandoned (CV63).	CV3 CV57 CV63
	Characteristics of patient communication	Patients tend to minimise the severity of symptoms (CV3) and many did not mention unwelcome side effects to doctors (CV51).	CV3 CV51

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
	Wanting more opportunities for communication with health care professionals	Patients would have liked to have spoken to the surgeon who performed the operation (CV50); Wish for more follow-up phone calls after discharge(CV25); Patients would like more time with the doctor; Nobody asked if they needed support (CV29); Doctor-patient communication is mainly one-way (CV54). Doctors doing rounds get distracted by questions from interns (CV63).	CV25 CV29 CV50 CV54 CV63
	Staff communication skills	Good communication skills from health care professionals are valued, including: taking an interest, caring about the person, being pleasant, kind, helpful, professional, being easy to talk to. Fear/anxiety may increase if carers express confusing meanings with their body language (CV57).	CV24 CV29 CV53 CV57
	Content of communication with health care professionals	Communication did not always address issues of concern to patient (CV11); communication with carers is often factual and missed the existential, what it is like to live with a condition (CV57)	CV11 CV57
	Communication aids	Showing patients before and after angiogram was a powerful communication aid to give reassurance and motivate behaviour change	CV27
	Reassurance	Patients need reassurance from communicating with health care professionals about issues that are important to them.	CV11 CV20 CV52
Continuity	Lack of continuity	Patients experienced lack of continuity and coordination of care; they felt that care had been provided by too many different staff. Some patients were concerned that discharge was too quick.	CV37 CV43 CV53 CV63
	Experiences of continuity	Some patients had developed a long term relationship with a key professional. Proactive support from staff made patients feel looked after. Patients valued being able to call the hospital at any time for advice, reassurance and support. Being monitored is reassuring (CV52)	CV34 CV52 CV53
	Poor communication between health care professionals and	Lack of communication between health care staff was a problem for patients. When transferred between units, patients felt 'lost in the system' (CV3)	CV3 CV11

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
	poorly coordinated care		CV20 CV43 CV53 CV63
	Feeling secure	Feeling secure is dependent on being well supported and trusting professionals to alleviate suffering. Having a lot of people around and the use of monitoring create a sense of security as do medications. Infrequent contact with staff/services can make patients feel insecure. Patients need structure and information about their planned care in order to feel secure (CV57).	CV13 CV17 CV50 CV57
Information	Satisfaction – feeling informed	Studies reported that a proportion of patients were satisfied with the information they received and felt well informed. Many patients were not satisfied with information they received and did not feel well informed about their condition, treatment or prognosis. Some patients felt they had been told what they needed to know despite apparently limited recall of information (CV54).	CV1 CV24 CV50 CV54 CV61
	Importance of information/consequences	Information is important to patients for a sense of control, security and reassurance. Lack of information can cause fear and uncertainty. Some patients were following spurious advice (CV61) Information can help patients take precautions (e.g. make a will, review insurance documents), give patients the knowledge to make decisions, and ensure they do not expose themselves to danger (e.g. overstrain, drinking too much or too little liquid)	CV1 CV16 CV21 CV29 CV41 CV50 CV57 CV61
	Wanting more information	Patients wanted more information. Patients wanted more information about: medications (CV57), including purpose, times, complications, side effects, possible complications (CV50), services (CV39), permissible activities and everyday activities (CV12), resuming sexual activity (CV47), types of help and support available; convalescence and recovery, diet and exercise (CV18, CV27, CV62, CV56), tests and results (CV20), anatomy and heart disease (CV19, CV62, CV27, CV47), routines in hospital (CV62), procedures and treatments (CV62), prognosis (CV45	CV1 CV2 CV11 CV18 CV19

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
		CV23), what to expect after surgery (CV50 CV23), psychological adjustment (CV62 CV23) Patients needed to know how to undertake self-care tasks: how to take own blood pressure and pulse; how to manage an acute heart attack; activities to be learned after discharge; what conditions s/he should see a physician about after discharge; managing risk.	CV20 CV23 CV27 CV28 CV39 CV42 CV45 CV47 CV50 CV52 CV56 CV57 CV62
	Wanting individualised information	Patients wanted information tailored to them that was appropriate to their identity and related risks to their own case.	CV21 CV47 CV50 CV57
	Format of information	Patient preference for format varied (verbal, face-to-face, written, electronic). Information should be easily understood including by those with cognitive impairments (CV2, CV43), consistent, honest and non-judgemental (CV27). Information should be clear, objective and reasoned (CV29). Patients often had difficulties understanding information given (CV18, CV24). Written information could cause anxiety. Many patients wanted to discuss the written information they received with health care professionals (CV50).	CV2 CV18 CV24 CV27 CV29 CV43 CV50 CV57
	Delivery of information	The way in which information is delivered is significant, including: Tone of voice, choice of words, calmness (CV17); Choice of informant (CV27). Patients wanted reinforcement of	CV17 CV23

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
		information give (CV23)	CV27 CV57
	Timing of information	The timing of information is significant: Patients need time to ask questions or to comprehend the information given (CV57); Patients felt they were informed about the postponement of their surgery too close to the scheduled operation (CV29). Patients valued being told what was happening in the acute phase (despite not wanting to participate in decision-making at this time (CV55)	CV23 CV27 CV29 CV50 CV57
	Not wanting to know	Ambivalence towards knowing more about condition and prognosis. Denial, not wanting to know	CV28 CV36 CV48 CV50
	Recall of information	Patients have difficulty retaining information given, especially when acutely admitted.	CV18 CV27
	Sources of information	Physician was the main source of informational support for patients. But patients look for information themselves by reading books/on internet or visiting people who have already undergone the surgery	CV24 CV50
	Involvement of family and friends	Families need information and patients sometimes struggle to explain things to them	CV57
	Changing information	Patients expressed exasperation when recommendations and advice changed. Repeated changes reduced confidence in advice	CV32
	Inconsistent information	Patients receive inconsistent information. Also see communication.	CV32 CV63
	Sharing information	Sharing information between patient and care provider was highly valued and desired	CV55
Knowledge, understanding and making sense	Poor understanding of condition, treatment, complications and/or prognosis.	Many patients had a poor understanding of their condition, treatment, prognosis. Misconceptions were common. Patients used vague terms to describe their condition (CV45)	CV24 CV32 CV35 CV39

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
			CV45 CV46 CV47 CV53 CV54 CV61 CV68
	Good levels of knowledge and understanding	Knowledge of mechanisms associated with heart failure was generally good	CV28
	Education	Patients value educational resources and opportunities	CV19 CV24 CV52
	Being left to figure it out yourself	Difficulty understanding advice: Feeling you are left to 'figure it out' yourself.	CV24
	Importance of knowledge and understanding	Misconceptions partly account for adjustment difficulties; Lack of knowledge made it difficult for patients to self-monitor; Lack of understanding generated concern about side-effects. Patients value improved understanding. It is important to patients to find a rational explanation for symptoms and link them with life events (CV14)	CV14 CV24 CV41 CV42 CV47
	Translating knowledge into action	Many patients who had some knowledge were not able to effectively translate this knowledge into meaningful action to change behaviour, reduce risk, improve symptoms	CV46
	Patients' ways of making sense of their condition and its causes often vary from biomedical explanations.	Patients have ideas about the cause of heart disease drawn from lay knowledge and cultural context. There can be tensions between individual experiences and medical explanations. Patients draw inferences about their condition from their treatment, unintended by health care professionals (CV26)	CV4 CV30 CV32 CV35 CV37 CV59
Lived Experience	Patients experience a range of	Anxiety. For some patients anxiety delayed treatment-seeking, for others it acted as the	CV14

Generic theme	**Sub-theme** **(All sub-themes that relate to generic theme)**	**Description**	**References**
	negative emotions related to their condition, symptoms, treatment and prognosis.	trigger (CV14). It could be exacerbated when waiting for treatment (CV29)	CV29 CV41 CV47 CV52
		Loss of confidence	CV12 CV19 CV34 CV37 CV47 CV48
		Fear	CV47 CV52 CV56
		Hopelessness	CV56 CV57
		Anger and Frustration	Cv37 Cv48 CV52 CV57
		Uncertainty, hyper-vigilance. See also Uncertainty.	CV37 CV57
		Low mood, worry and depression. Could be exacerbated when waiting for treatment (CV29)	CV12 CV18 CV29 CV36 CV41

Generic theme	**Sub-theme** (All sub-themes that relate to generic theme)	**Description**	**References**
			CV47 CV48 CV52
		Helplessness, weakness, shame, self-reproach, feeling defeated. Feeling a failure.	CV18 CV30 CV56
		Loneliness. See also Support.	CV18 CV30
		Fear caused sleeplessness and anxiety. See also Physical needs/comfort	CV48
	Isolation and loneliness	Patients felt lonely and abandoned by friends and health care staff. They had a diminishing social network and desired more social contact.	CV13 CV52 CV53
		This problem was exacerbated by restrictions to patients' movements due to ill health, side-effects of medication (e.g. diuretic), being unable to drive and tiredness. Patients restricted visits from others to avoid becoming exhausted (CV31)	CV13, CV31, CV53
		Even with company, patients could feel psychologically isolated. One research team call it 'the paradox of living alone with supportive relations'	CV16
	Sense of self (disrupted)	Patients' sense of self is disrupted by a range of changes in cognitive and physical being: e.g. experience of cognitive reactions to surgery (e.g. hallucinations); bodily changes, unfamiliar sensations, unfamiliar emotions. There was a discrepancy between what they wanted to do and what they could do (CV46) Patients must find new ways to relate to themselves. Patients wanted to 'get back to normal' (CV12, CV43) Patients feel 'old' or 'useless' (CV57) Participants felt their physical limitations made them abnormal, conspicuous and different from others around them. They learned to hide their limitations from others (CV46). Men worried that being absent from work would mean people would see them as 'physically weak, impotent or incapable'(CV30) Participants felt that although they were still alive they were no longer the person they used to be.	CV16 CV30 CV37 CV46 CV57

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
	Loss	Patients want to remain as independent as possible but must come to terms with reduced independence and autonomy. They may find they are not able to fulfil usual social roles or to do things that they have been doing all their lives. Usual activities are limited or abandoned. Sexual activity is affected. Loss of pleasure in food. Patients perceived loss of control and physical abilities.	CV7 CV16 CV47 CV52 CV 53 CV57
	Feeling fearful	Patients report feeling fearful. They fear dependency, loss of control and an unknown future. Some patients fear death. Fears may be particularly acute when patients lack understanding of their condition or treatment (CV46). Patients felt fear about their care and treatment, including fear of possible errors by health care professionals (CV16), fear of the consequences of waiting for surgery(CV29) and fear of the first shock from an ICD (CV25). Patients were afraid of being alone in the early days of recovery and avoided being too far from home or activities that might induce another MI. Fear of imminent danger. Fear of death, pain, having another heart attack, going out alone, re-admission to hospital, further medical procedures.	CV4 CV16 CV25 CV27 CV29 CV36 CV46 CV48 CV56 CV57
	Confronting mortality	Patients became aware that their life was limited. For some, this meant: reassessing values (CV25) living life to the full and not taking their remaining time for granted (CV16, CV25, CV13, CV37, CV43) even taking risks (CV36); some focused less on the future, assuming they would not live long enough to follow through plans (CV25); some questioned after-life issues (CV13). Physiological measurements remind patients of their deteriorating health (CV13). Some patients were positive about available treatments and looked to the future (CV35)	CV13 CV16 CV25 CV35 CV36 CV37 CV43 CV56
	Illness trajectory.	Patients experience episodes of acute deterioration, punctuating a progressive decline with an unpredictable terminal phase.	CV53
	Cognitive changes	Finding it hard to accept deterioration of cognitive abilities. Feeling more emotional.	CV22

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
		Concentration problems, increased irritability, loss of short term memory, impaired ability to retain information.	CV25 CV34 CV41 CV56
	Patient Outlook	Positivity (CV34, CV36), acceptance (CV36), Stoicism (CV52), resignation (CV43). Attitude shaped by social class and approach to health (CV30). Patients employed individual resources such as will, determination, faith, and humour to cope with the threat of MI.	CV30 CV34 CV36 CV37 CV43 CV52 CV56
	Relationships with technology and medications	Patients took time to adjust to reliance on technologies such as pace-makers and implantable cardioverter defibrillator. Reliance on ICD seen as failure of body (CV21). Needing less technology is perceived as an indication of progress (CV16)Patients had concerns about technical failure (CV41). Medications are a reminder of the seriousness of their condition even when this is not felt in the body (CV57). Patient weary of changing drug regimes and express pessimism about likelihood of staying on the medication for the rest of their lives (CV32).	CV16 CV21 CV32 CV41 CV57
	Quality of life	Many patients left wondering about their quality of life. ‘It’s a life but it’s not much of a life’.	CV53
Making lifestyle changes	Making changes to diet, exercise, habits and routines.	Patients perceive they must live their life by new rules and boundaries to reduce risk (CV27)	CV27 CV36 CV37 CV42 CV47
	Scepticism about benefits of lifestyle change	Surgical, radiological and pharmacological interventions were perceived as more effective than lifestyle change (CV35, CV60). Patients combined medical points of view with their own common sense opinions about inappropriate habits. Sometimes the two perspectives were in conflict (CV26, CV56. CV35, CV60). Positive changes to lifestyle were not always assessed	CV26 CV35 CV56

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
		positively as participants attributed their MI to psychosocial strains or genetic factors and so believed lifestyles changes to be less important (CV56).	CV60
		Patients were reluctant to modify their lifestyle. Reasons include: They felt they had already made changes They felt they had good habits that did not need to be modified. They were not convinced that their habits were risk factors Their physical condition made it difficult to make changes e.g. take more exercise They felt the pressure to modify habits was coming from outside but was not a personal objective.	CV43
	Barriers to positive lifestyle change.	Family responsibilities, caring for others, work commitments made it difficult to find time and make changes to routines. Lifestyle changes require sometimes difficult communications at home about changing habits (e.g. diet (CV43). There may be gender differences in barriers: Women tend to put family responsibilities before lifestyle change e.g. reluctant to change diet of partner/children. Whereas men see lifestyle changes as a joint venture (CV30). Co-morbidities interfered with ability to adhere to exercise programme (CV42, CV43). Other factors: lack of motivation (CV42), not being able to find foods they could eat and enjoy (CV24). Patients were confused about the right things to do (CV61)	CV19 CV30 CV42 CV43 CV61
	Support for lifestyle change	Many patients reported lack of support from primary care with risk management (e.g. smoking cessation) (CV46). Families were important sources of support, often making lifestyles changes alongside the patient (CV19, CV42). Uncertainties about safe activity levels lead some patients to want to exercise under supervision of health care professionals (CV12, CV19, CV27, CV34). Professional supervision also supported motivation (CV12). Regular rehabilitation classes motivated patients to exercise and the group setting was valued by many patients (CV34, CV39, CV19)	CV12 CV19 CV27 CV34 CV39 CV42 CV46
	Motivation for positive lifestyle change	Patients were aware of recommended changes to their lifestyle even if they lacked the motivation to implement them (CV42) Many patients understood the importance of lifestyle change and expressed desire to get fitter, 'sort my life out' or to follow instructions for the sake of their health. Wanting to get fitter. Wanting to stay out of hospital (CV24)	CV12 CV19 CV24 CV31

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
			CV39 CV42 CV56
	Adopting new routines adapted to condition or treatment.	Participants demonstrated varying abilities to adapt their lifestyles to the disease and continue with their lives (CV46) Patients adapted their day to day activities to accommodate and manage symptoms, physical limitations, treatment and side- effects. Adopting a new routine to manage symptoms. See also Loss. Participants adopted a range of strategies to help successfully manage their medication: Simplification, Visual and tactile cues, establishing a routine, acquiring knowledge about medications, staying alert, determination (wanting to 'do it right'),having a care-giver set up the medications (CV40).	CV13 CV19 CV24 CV27 CV40 CV43 CV46 CV52 CV57
	Adapting lifestyle advice to suit the individual	Many patients chose not to cut out certain activities, as advised by their doctor, but instead cut down	CV45
Participation	Not feeling involved in care	Not feeling involved in medical decision-making. Hospitals failed to recognise involvement and expertise of carers (CV53)	CV1 CV29 CV53
	Timing	Timing – in emergencies, or acute phase patients don't want to be involved in decision-making.	CV1 CV55
	Trusting the experts	Many patients believe that the doctors know best and accept treatment passively, or do not question care. Older patients in particular are likely to defer to medical experts (CV1).	CV1 CV26 CV54
	Feeling 'underqualified'	Patients did not feel they had sufficient knowledge to participate in decision-making. Whereas some patients felt they were the best placed to evaluate their own needs (CV43)	CV54 CV55
	Expectations	Some patients did not necessarily expect to be part of medical decision-making. Patients recognised that lack of time and resources limited opportunities for patient involvement.	CV55

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
		Some patients lacked the knowledge that they could participate/be involved in medical decisions .	
		Some patients did expect to participate in decision-making about: Medical treatment protocols such as diet, medication, rehab, choice of primary care doctor, time of discharge etc.	CV62
	Self-care	Patients reported using a number of methods of self-care such as watching their diet, exercise, stress levels, managing medication regimens. See also Making Lifestyle Changes and Lived Experience.	CV4 CV24 CV53
	Control	Patients perceived a lack of control in acute stage (CV14). Patient varied in extent to which they felt they had control over their disease and outcome (CV46). Perceived control was associated with expressions of confidence in ability to manage the condition. Lack of control was accompanied by not knowing what the future held – uncertainty (CV46). Patients felt 'wrapped in cotton wool', and constantly controlled causing conflict, anger and irritation (CV56) Relief of relinquishing control – A&E (acute) (CV15)	CV14 CV15 CV46 CV56
	Patient preferences	Some patients appreciate services delivered in peer groups but some did not. Some patients seek alternatives to NHS care that fit better with their lives (incl. leisure clubs, private health care)	CV3 CV12 CV39
	Being treated as an individual	Patients valued being treated as individuals including participating in decision-making and receiving support for everyday activities.	CV13 CV17
Participation – compliance with advice	Variable compliance with medications, often deliberate.	Patients make deliberate omissions and changes to doses of medication often to manage side-effects (e.g. missing a dose of a diuretic when they want to go out). Some patients stopped taking their medication altogether because of unwelcome side effects. Some patients added to their regimen or substituted with herbal remedies (CV59)	CV24 CV48 CV51 CV57 CV59
	Resistance to use of pain relief.	Patients made individual adjustments to use of pain relief rather than taking analgesics as advised. They perceive painkillers as 'necessary evil' and prefer to experience pain than take 'too much' medication. Patients reduce activity rather than increasing pain medication. Some waited until the pain was 'unbearable' before taking medication	CV21 CV44

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
	Following instructions	Patients expressed strong wish to follow instructions given. They took their medication as directed or attended rehab because it is the 'sensible thing to do'. Sticking to recommendations gave patients a feeling that their condition was under control (CV35). Some heeded the advice about medication because they felt it was the only thing that could be done for their condition (CV45). Some needed elaborate memory aids were used to remember to take medication (CV24).	CV21 CV24 CV26 CV35 CV45 CV60
	Reasons for non-compliance	Feeling you are 'back to normal'; not seeing an improvement; symptoms subside; wanting to minimise time at hospital; perceived discouragement from family or health care professionals	CV45 CV60 CV61
	Measure of compliance	Patients see the achievement of a cholesterol level of under 5.0mmol/l as primary measure of adherence to clinical management regime.	CV32
	Barriers to compliance	Patients experienced a number of barriers to maintaining medication regime: Health related: Decreased mental or sensory alertness; Being out of routine; Falls/being unwell – leading to forgetting; Decreased gross or fine motor skills – not being able to get up to get the tablets, not being able to cut the tablets in half; Not being able to walk/breathe well; Physically restrictive or socially embarrassing problems such as arthritis or incontinence were disincentives to attending rehab classes (CV60) Practical problems: Obtaining or administering the medications is too complicated – ordering by mail, transport difficulties; Lack of money; Unavailability of recommended foods Memory: Some needed elaborate memory aids were used to remember to take medication (CV24) Hopelessness: feeling that nothing will help (CV60)	CV24 CV40 CV45 CV60 CV61
Physical needs and comfort (b)	Pain	Experiences of pain are widely described in the literature. Pain management is important and not always adequate (CV2, CV17, CV61). Pain interacts with other physical needs: Pain reduces sleep quality and reduced sleep makes pain worse (CV31). See also participation-compliance.	CV17 CV21 CV31 CV60
	Sleep	Patients report problems sleeping, often related to pain and/or anxiety.	CV2

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[b] Also see LIVED EXPERIENCE

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
		Sleep disturbed by clinical care given at night (CV63)	CV21 CV31 CV36 CV63
	Eating	Forcing oneself to eat – sometimes food provided is unpleasant (CV13, CV63). Food and eating have positive and negative psychosocial meanings for patients with heart failure (CV7). Patients experience invincible thirst.	CV7 CV13 CV63
	Physical limitations	Patients report experiencing limitations on their ability to perform everyday tasks and to participate in desired activities. Limits on ability to perform household tasks. Patients have to learn where their physical limits are and accept them (CV24, CV25, CV43). Confrontation with physical limitations, feeling the body 'let them down' (CV25) and feeling inadequate and isolated (CV46). Patients keenly experienced loss of everyday activities like going for a walk or doing the gardening. (CV48). See also Lived Experience.	CV13 CV21 CV24 CV25 CV43 CV46 CV48
	Fatigue	Patients experience increased fatigue and associated limitations on abilities and activities. This has knock on effects for the rest of the family as family members have to take on more responsibility or increase work hours. Tiredness gives a sense that the body is in charge. Periods of inactivity feel unfamiliar.	CV13 CV18 CV21 CV31 CV36 CV47 CV56 CV57 CV60
	Side effects of treatment	Patients experience welcome and unwelcome side-effects from medication. Patients balanced side-effects against perceived benefits of medication and found ways to manage side-effects with over the counter medications (CV51).	CV45 CV51

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
		Wearing a bra is uncomfortable due to post-operative wounds. Wearing elastic stocking uncomfortable, exertion to get it on and off.	CV21 CV31
Standards of care	Competency, efficiency, professionalism	Patients value technical skills and competency most highly in acute phase. They felt 'in good hands' Efficiency: Staff ready and waiting to assist. 'everything happened very quickly'; 'a lot of activity' Professionalism: patients felt nurses were skilful and knew exactly what to do and when to do it Frustration waiting for discharge once given the 'all clear' (CV20). Some patients experienced unprofessional conduct by staff (CV2)	CV2 CV17 CV20 CV50
	Time, care and attention	Patients value time and attention (CV20). They met kind and caring staff (CV50).They would like more time with health care professionals. When appointments are postpones, patients feel dismissed, disregarded, unimportant (CV57). A few patients complained that their doctor seemed rushed, inaccessible or uninformative (CV24). Some experienced feeling depersonalized. Not being listened to (CV2). See also Communication.	CV2 CV20 CV24 CV37 CV50 CV57
	Concerns about incompetent care	Some patients who experienced complications wondered whether this was due to maltreatment (CV50) Anger about misdiagnosis (CV63). Fear of potential mistakes (CV16)	CV16 CV50 CV63
	Care was based on current physical needs and lacked other dimensions.	Care was based on medical model and focussed on treatment. Failure by services to address end of life issues. Patients sometimes perceive the healthcare organisation as insufficient, ignorant to personal demands, needs or expectations (CV57). Few patients had discussed advance care planning (CV45). Lack of sensitivity to personal needs e.g. privacy (CV63, CV2)	CV2 CV45 CV53 CV57 CV63
	Experiences of discrimination.	Women felt they were treated differently or less seriously by health care professionals because they were women and relatively young (CV63).	CV63
	Delays	Patients were angry about delays to surgery.	CV29

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
	Expectations	Patients expectations of care are shaped by a variety of factors including media, experiences of family and friends. Expectations of services are not always met, sometimes because they are unrealistic (CV20, CV26). Sometimes patients are pleasantly surprised by level of care received (CV26)	CV2 CV20 CV26 CV30
Support	Variety of Sources	Variety of sources of emotional support – friends, family, neighbours, professionals (CV24) and non-humans (CV57)	CV24 CV56 CV57
	Peer Support	Peer support is highly valued. Some patients wished the hospital would arrange opportunities to meet peers (CV50, CV60, CV43). Patients want to learn from other patients, share experiences, learn from each other and provide or receive emotional support, compare progress. Patients found mutual understanding and empathy. Such meetings were a way of reducing social isolation. Sense of camaraderie. Patients compared progress (CV39). A few patients did not want to meet people with similar experiences. They did not wanting to be reminded of their condition. And patients with similar conditions do not necessarily perceive themselves as alike: differences of age, and gender. (CV18, CV38)	CV12 CV16 CV18 CV34 CV37 CV38 CV39 CV42 CV43 CV50 CV52 CV56 CV57
	Support of partner or spouse	Spouse was considered most important resource for support. But studies found variety in the extent to which women report being supported by their partners.	CV30 CV43 CV56
	Barriers to receiving support	Some men did not want to discuss health problems for fear of being seen as a ‘wimp’ or ‘unmanly’.	CV30

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
	Feeling stifled or over-protected	It was possible to have too much company and too much help. Over-protectiveness can become a barrier to independence. Better information for care-givers might solve the problem of over-protectiveness	CV24 CV25 CV37 CV43 CV47 CV56
	Practical support	Patients need practical support e.g. cleaning, bathing, meal preparation, transport, administrative task, exercise.	CV24 CV56 CV62
	Psychological support	Psychological support was valued but often lacking (CV3, CV12). This includes support from psychologists but also conversation, companionship, encouragement from others. Patients value learning to manage stress and anxiety (CV18, CV43). Some found it useful to talk, others preferred not to (CV37) Some patients need for support from prayer, meditation, reading Bible or scriptures, alone or with friends (CV62)	CV3 CV12 CV18 CV52 CV62
	Characteristics of supportive relationships	In supportive relationships there is an openness to challenging matters (CV56). Relationships with competent, knowledgeable health care professionals are valued (CV57). Patients want to be confirmed and respected by their carers who are present, who listen, respect ones' perceptions (CV57). Relationships with family, friends, colleagues and formal carers can be simultaneously supportive and not supportive (CV56).	CV56 CV57
	Balancing support needs with care for others	Patients want to share their experiences with others but this wish is intertwined with a desire to spare other people suffering (CV56). Women felt uncomfortable when their children had to help them and minimised symptoms so that they would be less of a 'burden' (CV30). Women in hospital spent a great deal of time worrying about how their families were coping. Many women engaged in housework against medical advice. Men tended to rest at home.	CV30 CV56
	Supportive relationships with health care staff	Staff provided reassurance through information giving, communication, attention, professionalism. Proactive support from staff was valued, especially phone calls post-discharge. It made patients feel looked after (not abandoned) (CV34)	CV16 CV18 CV34

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
			CV52
	Support from family	Support from family was highly valued. Some patients were satisfied with family support, others would like more family support. The experiences strengthened some family relationships and strained others. Participants in one study felt that getting older was the reason for lack of response to cries for help (CV48)	CV25 CV34 CV37 CV48 CV56
	Support needs and changes in social roles and relationships	Being dependent impacted on patients' roles and those of their carers. This has an emotional impact e.g. wife now has to do the gardening. This can lead to conflict.	CV30 CV37 CV46 CV47
	Finding it difficult to accept support from others.	Some find it difficult to accept help of others. They accept help only when necessary because accepting help causes feelings of frustration (CV52, CV48) and made participants feel 'old' (CV52). Many patients worried about 'being a burden' in terms of practical (CV57) and emotional support (CV48). Women accepted help with housework but wanted to organise activities (CV31)	CV25 CV31 CV48 CV52
Uncertainty	Uncertainty about risk	Patients were uncertain what level of activity was safe. They needed to know what to do to manage risk.	CV11 CV12 CV19 CV20 CV24 CV57
	Uncertain diagnosis	Not having a clear diagnosis or long delays in diagnosis. Wanting a better understanding of their health problem. See Knowledge, Understanding and Making Sense.	CV11 CV20 CV45 CV46
	Unpredictable symptoms	Having an unpredictable body/ unpredictable symptoms. Patients had to cope with variable symptoms and the uncertain course of cardiac failure. Factors like cholesterol level are	CV13 CV31

Generic theme	Sub-theme (All sub-themes that relate to generic theme)	Description	References
		invisible to patient, and so asymptomatic and are experienced as unpredictable. See also Lived Experience.	CV53
	Illness trajectory	Patients experience a gradual yet progressive decline with unpredictable episodes of acute exacerbation that led to hospitalisation (CV45). Enduring uncertainty about whether the disease could be cured and whether treatment would be effective (CV47). Constant changes in doses of medications made patients worry about what would happen when the dose could not be increased any further (CV48). See also Lived Experience.	CV45 CV46 CV47 CV48
	Uncertainty about the future	Patients experience their future as uncertain and unclear and they avoid making future plans and instead live in the present. Patients who had discussed their prognosis with their doctor often conveyed a sense of an uncertain future (CV45)	CV36 CV45 CV47 CV57
	Waiting	Waiting for surgery increased feelings of uncertainty and anxiety.	CV29

B.10 Diabetes Cancer Patient Experiences Generic and Sub-themes Evidence Table

Generic theme	Sub-themes (All sub-themes that relate to generic themes)	Description	Reference
Patient as active participant	(Underpins all sub-themes)	The emphasis on self-management and self-care in diabetes is apparent throughout the research literature.	All papers
Responsiveness (organisation of services to meet needs and preferences)	Time spent with health professionals	Short appointments, rushed consultations; patients feeling unable to ask questions because of time pressures; where more time was allowed patients felt care was more personal and they were able to participate	D4, D12, D21, D26, D30, D38, D44, D52
	Time waiting	Time spent waiting for doctors and other members of the healthcare team	D12, D33
	Response times	Need for quick response to unexpected situations	D23
	Convenience	Convenience was important to some patients	D4, D12, D41
	Environment	Rushed, problematic or fear-inducing healthcare environments	D12, D38
	Co-ordination	Co-ordination and integration important, but communication between healthcare professionals sometimes poor. Teamwork was assumed between doctors and specialist nurses and between healthcare teams. Problems with diabetes care on non-diabetes wards. Transitions may be difficult.	D3, D7, D23, D34, D39, D41
	Resources	Healthcare structures and constraints, and lack of some services and resources, can be problematic. More intensive, more generously funded care appreciated. Cost of care can be an issue to non-UK patients.	D8, D10, D21, D26, D34, D36, D41 D47
	Expertise	Specialist expertise of healthcare staff was appreciated; some healthcare professionals lacked necessary knowledge of diabetes and its management.	D12, D21, D31, D32, D36
	Follow up	Lack of follow up after diagnosis or after missed appointments. Follow up appointments appreciated.	D26, D29, D43, D50
	Mistakes	Incorrect or inadequate diagnosis/treatment	D31, D36, D43, D52
	Tailoring care for individual rather than diabetes	Healthcare not tailored to individual needs/preferences; focus on the diabetes rather than the patient; different requirements for services	D23, D24, D30, D31, D40, D49

Generic theme	Sub-themes (All sub-themes that relate to generic themes)	Description	Reference
	Satisfaction	Some reports of good care and general expressions of satisfaction, but in-depth discussion revealed problems that had not previously been reported. Patients felt efficiency was important, but accepted pros and cons of different kinds of care. Patients with complications more negative about services.	D3, D7, D21, D25, D26, D27, D34, D38, D49
Relationships/partnership (issues to do with the relationship between patients and health professionals)	Trust	Importance of being able to trust health professionals; trust based on good relationships; trust hindered by perception of lack of knowledge or mistakes; some patients trusted doctors to take responsibility for their care; health professionals sometimes appeared to distrust patients.	D5, D8, D23, D31, D36, D38, D41, D44
	Power	Perception of power differentials and demands for adaptation and submission. Some relatives reported to feel unable to question poor practice. For patients who took part in a trial, reciprocity seen as empowering (they could ask for practical and emotional support).	D21, D26, D31, D37, D38, D48
	Control	Issues of control common and complex, with different views on who is, and who should be, in control of diabetes management.	D2, D18, D19, D34, D37, D39, D44
	Shared decision-making	Differing views on patients' involvement in decision-making, with some, but not all, patients wanting more involvement. Expertise of patient reported as not acknowledged by some health professionals.	D9, D11, D19, D21, D28, D30, D53
	Judgemental attitude	Negative attitudes towards patients; perceptions of blame for high glucose levels, uncontrolled diabetes and obesity; insensitivity towards the feelings of patients and the difficulties of everyday diabetes management; judgemental attitude affects diabetes management negatively.	D10, D11, D31, D38, D40, D44, D48, D52, D53
	Being seen as a person	Patients valued being seen as a person; health professionals sometimes seemed more interested in the diabetes than the person.	D23, D33, D31, D38, D48, D52
	Respect	Respect for the patient was important; lack of respect undermined trust and confidence.	D31, D37, D44, D48, D52
	Continuity of care	Relational/longitudinal continuity of care seen as very important. Problems with continuity of care, especially in a hospital setting. Continuity of care is not a guarantee of diagnosis, which may result from some form of discontinuity.	D3, D12, D21, D23, D30, D33, D41, D43, D49, D51, D52
	Approachability	Importance of feeling welcome (which happened in some cases and not others).	D7, D12, D21,D28, D31,

Generic theme	Sub-themes (All sub-themes that relate to generic themes)	Description	Reference
		Doctors seen as too busy to approach. Barriers between patients and health professionals.	D35, D37
	Empathy	Patients expected a more caring approach; affective component sometimes missing from diabetes care.	D46, D48, D52
Communication (style and content of verbal and non-verbal communication between patients and health professionals – overlap with all other categories)	Importance of communication	Communication between health professionals and patients rated as very important. Verbal and non-verbal communication taken very seriously by patients, with associated impact on self-care. Reassurance and support increased confidence in self-care.	D18, D29, D38, D51
	Quality of communication	Poor communication between health professionals and patients is an important factor underlying obstacles to adherence to treatment. It may cause distress, or alternatively reassure patients inappropriately.	D5, D10, D11, D16, D18, D19, D25, D26, D30, D37, D46
	Listening/paying attention/acknowledging patient expertise	Patients value health professionals who listen and pay attention to them; they dislike lack of acknowledgement of patients' own expertise.	D23, D30, D33, D35, D41, D48, D52, D53
	Language	Poor access to effective translators hinders communication; some patients chose to be passive rather than risk being misunderstood.	D8, D26, D37
	Questions and answers	Patients value the opportunity to raise questions, but may not feel able to do so because of time pressures. Not providing answers to questions caused worry and frustration.	D4, D7, D30, D33, D35, D44, D49
	Explanations	Patients did not always understand the purpose of advice they were given. Taking time to explain was appreciated.	D5, D22, D48
	Brusque manner	Patients feel intimidated or defiant as a result of brusque, authoritarian or patronising manner of health professionals.	D26, D41, D44, D48
Information and support for self-care (resources provided or required, including information, education,	Importance of information and advice	Information and advice valued, especially at diagnosis, relevant to individual needs, and covering a broad range of lifestyle issues.	D4, D9, D24, D44
	Problems with information	Issues with quality, quantity, relevance and timeliness of information provided. Some patients felt they lacked information; others were overwhelmed by the amount of information provided at one time. Reports that reasons for	D2, D5, D9, D10, D15, D22, D27, D29, D31, D33, D39, D40, D44, D48, D50,

Generic theme	Sub-themes (All sub-themes that relate to generic themes)	Description	Reference
emotional support and peer support)		recommended lifestyle changes are not made clear.	D53
	Not wanting information	Some patients did not seek information because they were afraid, they did not think their condition was serious, or they preferred health professionals to take responsibility for their care.	D1, D2, D4, D19, D30, D53
	Feedback on condition	Patients valued up to date information on their condition and test results.	D12, D33, D35
	Sources of further help	Patients wanted to know about services and sources of further information. Search for information described as a coping strategy.	D18, D33
	Education and groups	Some patients valued formal education sessions; others found them insufficiently relevant to their needs, or became less confident as a result of course content. Diabetes manual not used as envisaged by designers. Many enjoyed and felt they benefited from group-based learning.	D12, D24, D28, D31, D32, D44
	Peer support	Patients valued contact with others who have similar conditions. Experiential knowledge and expertise were valued. Positive role models and hope/positivity about the condition were valued. Humour used in discussing ‘bad behaviour’.	D13, D14, D18, D24, D34, D36, D44, D50
	Need for emotional support	Emotional support valued and needed. Patients may feel alone and unsupported, grieving for previous identity, or anxious about the need for lifestyle and self-management changes. Guilt, self-blame and stigma were common causes of distress. Patients reported being affected by uncertainty, lack of knowledge and lack of confidence. Emotional needs reported as not taken into account by health professionals. Improved emotional and psychological support required. Encouragement, reassurance and support for patients’ efforts increased confidence. Knowing about risks may help with self-care but also makes patients anxious.	D3, D15, D17, D18, D19, D21, D24, D29, D32. D33, D36, D39, D44, D47, D48, D51, D53
Lived experience (diabetes care and everyday life, and needs for awareness of issues and difficulties)	Everyday lives	Need for health professionals to appreciate difficulties patients have in their everyday lives while dealing with diabetes and issues of self-care.	D10, D17, D24, D31, D41, D53
	Perceived unrealistic goals	Unrealistic expectations and goals set by health professionals seen as de-motivating.	D31, D44, D52
	Importance of families	Need for encouragement of family support and understanding of how families are helping or hindering patients.	D18, D26, D33

Generic theme	**Sub-themes** **(All sub-themes that relate to generic themes)**	**Description**	**Reference**
	Cultural issues	Understanding of cultural factors influencing diet and healthcare important in giving advice about self-care.	D8, D14, D25
	Interpretations, beliefs and meanings	Patients interpret practical healthcare arrangements as indications of the seriousness of their condition; different beliefs about diabetes and treatments affect communication between patients and health professionals.	D1, D5, D22, D25, D29,
	Psychological factors	Emotional impact of diabetes and psychological distress may affect glycaemic control. (Also see 'need for emotional support' in 'information and support for self-care'.)	D17, D45
	Perceived discrimination/injustice	Perception of discrimination/injustice	D8, D14, D34
	Complexity of diabetes and self-care	Self-care affected by multiple issues. The changing course of diabetes, often unpredictable and different for everyone, was perceived as challenging health professionals as well as patients. Some patients denied having diabetes or thought their diabetes had gone away. Patients may be aware of the risk of micro-vascular but not macro-vascular complications. Diagnosis may come as a shock when patients feel well.	D10, D24, D34, D43, D53

B.11 Search strategies

Cancer Search Strategy

Embase/Medline combined

Database: EMBASE <1980 to 2010 Week 47>, Ovid MEDLINE(R) <1950 to November Week 3 2010>

Search Strategy:

1	(patient* adj5 experience*).ab,ti. (166535)
2	(patient* adj5 expectation*).ab,ti. (9592)
3	(patient* adj5 preference*).ab,ti. (16417)
4	(patient* adj5 need*).ab,ti. (133276)
5	(Patient* adj5 perspective*).ab,ti. (14175)
6	(patient* adj5 attitude*).ab,ti. (13309)
7	(patient* adj5 view*).ab,ti. (20592)
8	(patient* adj5 opinion*).ab,ti. (6809)
9	(patient* adj5 choice*).ab,ti. (28784)
10	or/1-9 (384869)
11	exp "Delivery of Health Care"/ (1984785)
12	service delivery.ab,ti. (10886)
13	11 or 12 (1989119)
14	patient satisfaction.ab,ti. (31312)
15	exp patient satisfaction/ (108716)
16	14 or 15 (118255)
17	intervention*.ab,ti. (827093)
18	(patient adj reported adj outcome adj measure*).ab,ti. (451)
19	quality of life.ab,ti. (218664)
20	(SF36 or SF-36).ab,ti. (20584)
21	EQ5D.ab,ti. (202)
22	editorial.pt. (628387)
23	exp "Quality of Life"/ (253171)
24	or/17-23 (1727293)
25	10 and 13 and 16 (12437)

26 25 not 24 (9386)
27 limit 26 to (english language and humans) (8174)
28 limit 27 to yr="2000 -Current" (6238)
29 cancer.ab,ti. (1655267)
30 exp Neoplasms/ (4703833)
31 29 or 30 (4926196)
32 28 and 31 (761)
33 remove duplicates from 32 (665)

PsycInfo

No relevant year or language limiters available

Wed Dec 15 10:58:32 EST 2010

CSA

Database: PsycINFO

Query: (KW=cancer) and(((TI=((Patient experience*) or (Patient perspective*) or (patient attitude*)) or TI=((patient view*) or (patient opinion*) or (patient expectation*)) or TI=((patient satisfaction) or (patient need*))) or(AB=((Patient experience*) or (Patient perspective*) or (patient attitude*)) or AB=((patient view*) or (patient opinion*) or (patient expectation*)) or AB=((patient satisfaction) or (patient need*)))) or(DE=information)) **Total hits = 682**

Assia

Limited to 1995 - 2010 English only

Wed Dec 15 10:19:53 EST 2010

CSA

Multiple Databases

Query: (KW=cancer) and(((TI=((Patient experience*) or (Patient perspective*) or (patient attitude*)) or TI=((patient view*) or (patient opinion*) or (patient expectation*)) or TI=((patient satisfaction) or (patient need*))) or(AB=((Patient experience*) or (Patient perspective*) or (patient attitude*)) or AB=((patient view*) or (patient opinion*) or (patient expectation*)) or AB=((patient satisfaction) or (patient need*)))) or (DE=information)) **Total hits = 441**

Cinahl

EBSCOhost

Strategy 1

S5 S3 and S4 Search modes - Boolean/Phrase - View Results (**2657**)

S4 TX cancer Search modes - Boolean/Phrase - View Results (113199) Search

S3 S1 or S2 Search modes - Boolean/Phrase - View Results (73735

S2 MW information Limiters - Published Date from: 19950101-20101231; English Language; Exclude MEDLINE records - View Results (62075)

S1 TX Patient experience* or TX patient perspective* or TX patient attitude* or TX patient view* or TX patient opinion* or TX patient expectation* or TX patient experience* or TX patient satisfaction or TX patient need* Limiters - Published Date from: 19950101-20101231; English Language; Exclude MEDLINE records

Strategy 2

S4 (S1 and S2 and S3) Search modes - Boolean/Phrase - **CINAHL 72**

S3 TX cancer Limiters - Published Date from: 19950101-20101231; English Language; Exclude MEDLINE records - Database - CINAHL 36003

S2 MW Information Limiters - Published Date from: 19950101-20101231; English Language; Exclude MEDLINE records - Search modes - Boolean/Phrase Interface - Database - CINAHL 62154

S1 TX Patient experience* or TX patient perspective* or TX patient attitude* or TX patient view* or TX patient opinion* or TX patient expectation* or TX patient experience* or TX patient satisfaction or TX patient need* Limiters - Published Date from: 19950101-20101231; English Language; Exclude MEDLINE records Search modes - Boolean/Phrase Interface - EBSCOhost - database - CINAHL 12268

Cardiovascular Search Strategy

Embase/Medline combined

Duplicates excluded by system – Medline, Embase, Abstract preferences

Database: EMBASE <1980 to 2010 Week 50>, Ovid MEDLINE(R) <1950 to November Week 3 2010>

Search Strategy:

1 (patient* adj5 experience*).ab,ti. (167089)

2 (patient* adj5 expectation*).ab,ti. (9616)

3 (patient* adj5 preference*).ab,ti. (16462)

4 (patient* adj5 need*).ab,ti. (133721)

5 (Patient* adj5 perspective*).ab,ti. (14223)

6 (patient* adj5 attitude*).ab,ti. (13340)

7 (patient* adj5 view*).ab,ti. (20633)

8 (patient* adj5 opinion*).ab,ti. (6832)

9 (patient* adj5 choice*).ab,ti. (28880)

10 or/1-9 (386096)

11 exp "Delivery of Health Care"/ (1991091)

12 service delivery.ab,ti. (10910)

13 11 or 12 (1995428)

14 patient satisfaction.ab,ti. (31397)

15 exp patient satisfaction/ (109005)

16 14 or 15 (118553)

17 intervention*.ab,ti. (829630)

18 (patient adj reported adj outcome adj measure*).ab,ti. (457)

19 quality of life.ab,ti. (219606)

20 (SF36 or SF-36).ab,ti. (20681)

21 EQ5D.ab,ti. (204)

22 editorial.pt. (629780)

23 exp "Quality of Life"/ (254379)

24 or/17-23 (1732345)

25 10 and 13 and 16 (12447)
26 25 not 24 (9393)
27 limit 26 to (english language and humans) (8180)
28 limit 27 to yr="2000 -Current" (6244)
29 cardi*.ab,ti. (1432505)
30 exp Cardiovascular Diseases/ (3856886)
31 or/29-30 (4408820)
32 28 and 31 (424)
33 remove duplicates from 32 (**373**)

PsycInfo

PsycInfo – no relevant year or language limiters available

Wed Dec 15 10:35:31 EST 2010
CSA
Database: PsycINFO
Query: (KW=cardi*) and(((TI=((Patient experience*) or (Patient perspective*) or (patient attitude*)) or TI=((patient view*) or (patient opinion*) or (patient expectation*)) or TI=((patient satisfaction) or (patient need*))) or(AB=((Patient experience*) or (Patient perspective*) or (patient attitude*)) or AB=((patient view*) or (patient opinion*) or (patient expectation*)) or AB=((patient satisfaction) or (patient need*)))) or(DE=information)) Total hits = 131

Assia

Assia - Limited to 1995 – 2010, English only

Wed Dec 15 10:32:56 EST 2010 CSA
Query: (KW=cardi*) and(((TI=((Patient experience*) or (Patient perspective*) or (patient attitude*)) or TI=((patient view*) or (patient opinion*) or (patient expectation*)) or TI=((patient satisfaction) or

(patient need*))) or(AB=((Patient experience*) or (Patient perspective*) or (patient attitude*)) or AB=((patient view*) or (patient opinion*) or (patient expectation*)) or AB=((patient satisfaction) or (patient need*)))) or(DE=information)) Toal hits = 62

Cinahl

Via Ebsco

Search 1

S5 S3 and S4 Search modes - Boolean/Phrase - View Results (**1300**)

S4 S1 or S2 Search modes - Boolean/Phrase - View Results (73840)

S3 TX cardi* Search modes - Boolean/Phrase - View Results (133384)

S2 MW Information Limiters - Published Date from: 19950101-20101231; English Language; Exclude MEDLINE records Search modes - Boolean/Phrase - View Results (62154)

S1 TX Patient experience* or TX patient perspective* or TX patient attitude* or TX patient view* or TX patient opinion* or TX patient expectation* or TX patient experience* or TX patient satisfaction or TX patient need* Limiters - Published Date from: 19950101-20101231; English Language; Exclude MEDLINE records - View Results (12268)

Strategy 2

S4 S1 and S2 and S3 Search modes - Boolean/Phrase Interface - EBSCOhost

Search Screen - Advanced Search - Database - **Cinahl 13**

S3 TX cardi* Search modes - Boolean/Phrase Database - CINAHL 133384

S2 MW Information Limiters - Published Date from: 19950101-20101231; English Language; Exclude MEDLINE records - Search modes - Boolean/Phrase Interface - Database - CINAHL 62154

S1 TX Patient experience* or TX patient perspective* or TX patient attitude* or TX patient view* or TX patient opinion* or TX patient expectation* or TX patient experience* or TX patient satisfaction or TX patient need* - View Results (12268)

Diabetes Search Strategy

Medline/Embase combined

Database: EMBASE <1980 to 2010 Week 47>, Ovid MEDLINE(R) <1950 to November Week 3 2010>

Search Strategy:

1 (patient* adj5 experience*).ab,ti. (166535)
2 (patient* adj5 expectation*).ab,ti. (9592)
3 (patient* adj5 preference*).ab,ti. (16417)
4 (patient* adj5 need*).ab,ti. (133276)
5 (Patient* adj5 perspective*).ab,ti. (14175)
6 (patient* adj5 attitude*).ab,ti. (13309)
7 (patient* adj5 view*).ab,ti. (20592)
8 (patient* adj5 opinion*).ab,ti. (6809)
9 (patient* adj5 choice*).ab,ti. (28784)
10 or/1-9 (384869)
11 exp "Delivery of Health Care"/ (1984785)
12 service delivery.ab,ti. (10886)
13 11 or 12 (1989119)
14 patient satisfaction.ab,ti. (31312)
15 exp patient satisfaction/ (108716)
16 14 or 15 (118255)
17 intervention*.ab,ti. (827093)
18 (patient adj reported adj outcome adj measure*).ab,ti. (451)
19 quality of life.ab,ti. (218664)
20 (SF36 or SF-36).ab,ti. (20584)
21 EQ5D.ab,ti. (202)
22 editorial.pt. (628387)
23 exp "Quality of Life"/ (253171)
24 or/17-23 (1727293)
25 10 and 13 and 16 (12437)
26 25 not 24 (9386)
27 limit 26 to (english language and humans) (8174)

28 limit 27 to yr="2000 -Current" (6238)

29 exp Diabetes Mellitus/ (667847)

30 exp Diabetes Insipidus/ (15210)

31 diabetes.ab,ti. (535657)

32 or/29-31 (798468)

33 28 and 32 (179)

34 remove duplicates from 33 (150)

PsycInfo

No relevant year or language limiters available.

Wed Dec 15 10:40:36 EST 2010 CSA Database: PsycINFO

Query: (KW=diabet*) and(((TI=((Patient experience*) or (Patient perspective*) or (patient attitude*)) or TI=((patient view*) or (patient opinion*) or (patient expectation*)) or TI=((patient satisfaction) or (patient need*))) or(AB=((Patient experience*) or (Patient perspective*) or (patient attitude*)) or AB=((patient view*) or (patient opinion*) or (patient expectation*)) or AB=((patient satisfaction) or (patient need*)))) or(DE=information)) – Total hits = 136

Assia

Limited to 1995 – 2010, English only

Wed Dec 15 11:07:33 EST 2010 CSA

Query: (KW=diabet*) and(((TI=((Patient experience*) or (Patient perspective*) or (patient attitude*)) or TI=((patient view*) or (patient opinion*) or (patient expectation*)) or TI=((patient satisfaction) or (patient need*))) or(AB=((Patient experience*) or (Patient perspective*) or (patient attitude*)) or AB=((patient view*) or (patient opinion*) or (patient expectation*)) or AB=((patient satisfaction) or (patient need*)))) or(DE=information)) – Total hits = 74

Cinahl

Search 1

S5 S3 and S4 Search modes - Boolean/Phrase - View Results (**1616**)

S4 S1 or S2 Search modes - Boolean/Phrase - View Results (73840)

S3 TX diabet* Search modes - Boolean/Phrase - View Results (68559)

S2 MW Information Limiters - Published Date from: 19950101-20101231; English Language;

Exclude MEDLINE records - View Results (62154)

S1 TX Patient experience* or TX patient perspective* or TX patient attitude* or TX patient view* or TX patient opinion* or TX patient expectation* or TX patient experience* or TX patient satisfaction or TX patient need* Limiters - Published Date from: 19950101-20101231; English Language; Exclude MEDLINE records View Results (12268)

Search 2

S4 S1 and S2 and S3 Search modes - Boolean/Phrase - View Results (**32**)

S3 TX diabet* Search modes - Boolean/Phrase - View Results (68559)

S2 MW Information Limiters - Published Date from: 19950101-20101231; English Language;

Exclude MEDLINE records - View Results (62154)

S1 TX Patient experience* or TX patient perspective* or TX patient attitude* or TX patient view* or TX patient opinion* or TX patient expectation* or TX patient experience* or TX patient satisfaction or TX patient need* Limiters - Published Date from: 19950101-20101231; English Language; Exclude MEDLINE records - View Results (12268)

Appendix C: Existing NICE recommendations

Recommendation (reference)	**Evidence based?** **Consensus recommendation?**[c]
Pregnancy and complex social factors (September 2010)[41] **http://www.nice.org.uk/nicemedia/live/13167/50861/50861.pdf - Full** **http://www.nice.org.uk/nicemedia/live/13167/50822/50822.pdf - NICE**	
Commissioners should ensure that women with complex social factors presenting for antenatal care are asked about their satisfaction with the services provided; and the women's responses are: • recorded and monitored • used to guide service development. (R 1.1.3)	Consensus Section 3.3 pg 41
Commissioners should involve women and their families in determining local needs and how these might be met. (R 1.1.4)	Consensus Section 3.3 pg 41
Respect the woman's right to confidentiality and sensitively discuss her fears in a non-judgemental manner. (R 1.1.8)	Evidence Section 3.3, pg 42; section 4.3, pg 56; section 5.3, pg 87; section 6.3, pg 112; section 7.3, pg 147
For women who do not have a booking appointment at the first contact with any healthcare professional: discuss the need for antenatal care offer the woman a booking appointment in the first trimester, ideally before 10 weeks if she wishes to continue the pregnancy, or offer referral to sexual health services if she is considering termination of the pregnancy. (R 1.1.11)	Consensus Section 1.3.1 pg 11; section 3.3 pg 42-3
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. (R 1.1.13)	Evidence Section 3.3, pg 43; section 7.5, pg 156

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[c] Where no details were given in the guideline, it was assumed the recommendation was based on consensus. The phrase consensus based on evidence refers to recommendations where evidence has shown there is an issue or barrier but no evidence on how to over come this.

Recommendation (reference)	**Evidence based?** **Consensus recommendation?**[c]
In order to facilitate discussion of sensitive issues, provide each woman with a one-to-one consultation, without her partner, a family member or a legal guardian present, on at least one occasion. (R 1.1.14)	Consensus based on evidence Section 3.3, pg 42
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. (R 1.2.1)	Evidence Section 4.3, pg 56
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. (R 1.2.2)	Consensus based on evidence Section 4.3, pg 57
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. (R 1.2.4)	Consensus Section 4.4, pg 61 and supported by new HE model; section 4.7, pg 72–3
Use a variety of methods, for example text messages, to remind women of upcoming and missed appointments. (R 1.2.8)	Consensus Section 4.4, pg 61 and supported by new HE model; section 4.7, pg 72–3
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. (R 1.2.9)	Consensus Section 4.4, pg 61-2
Offer the woman information about the potential effects of substance misuse on her unborn baby, and what to expect when the baby is born, for example what medical care the baby may need, where he or she will be cared for and any potential involvement of social services. (R 1.2.10)	Consensus Section 4.6, pg 72
Offer information about help with transportation to appointments if needed to support the woman's attendance. (R 1.2.11)	Evidence Section 4.5, pg 70

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
Healthcare professionals should help support these women's uptake of antenatal care services by: using a variety of means to communicate with women telling women about antenatal care services and how to use them undertaking training in the specific needs of women in these groups. (R 1.3.1)	a) Consensus based on evidence Section 5.3, pg 87-8 and Appendix D, pg 205-6 b) Evidence Section 5.3, pg 88 c) Consensus based on evidence Section 5.6, pg 97
Those responsible for the organisation of local antenatal services should provide information about pregnancy and antenatal services, including how to find and use antenatal services, in a variety of: formats, such as posters, notices, leaflets, photographs, drawings/diagrams, online video clips, audio clips and DVDs settings, including pharmacies, community centres, faith groups and centres, GP surgeries, family planning clinics, children's centres, reception centres and hostels languages. (R 1.3.5)	Consensus based on evidence Section 5.3, pg 83, 88; section 5.6 pg 101
Offer the woman information on access and entitlement to healthcare. (R 1.3.7)	Evidence Section 5.3, pg 86
At the booking appointment discuss with the woman the importance of keeping her hand-held maternity record with her at all times. (R 1.3.8)	Consensus Section 5.4, pg 92-3
Avoid making assumptions based on a woman's culture, ethnic origin or religious beliefs. (R 1.3.9)	Consensus based on evidence Section 5.5, pg 97; section 5.3, pg 85-6
Provide the woman with an interpreter (who may be a link worker or advocate and should not be a member of the woman's family, her legal guardian or her partner) who can communicate with her in her preferred language. (R 1.3.10)	Consensus based on evidence Section 5.5, pg 97; section 5.3, pg 83-5, 87
When giving spoken information, ask the woman about her understanding of what she has been told to ensure she has understood it correctly. (R 1.3.11)	Consensus Section 5.5, pg 97
Healthcare professionals should encourage young women aged under 20 to use antenatal care services by: • offering age-appropriate services • being aware that the young woman may be dealing with other social problems • offering information about help with transportation to and from appointments • offering antenatal care for young women in the community • providing opportunities for the partner/father of the baby to be involved in the young woman's antenatal care, with her	Consensus based on evidence Section 6.3, pg 112-3; section 6.6, pg 130

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
agreement. (R 1.4.1)	
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. (R 1.4.4)	Consensus based on evidence Section 6.3, pg 112
Offer young women aged under 20 information that is suitable for their age – including information about care services, antenatal peer group education or drop-in sessions, housing benefit and other benefits – in a variety of formats. (R 1.4.6)	Consensus based on evidence Section 6.3, pg 112, 117; section 6.6, pg 130; appendix D, pg 205
Women who experience domestic abuse should be supported in their use of antenatal care services by: • training healthcare professionals in the identification and care of women who experience domestic abuse • making available information and support tailored to women who experience or are suspected to be experiencing domestic abuse • providing a more flexible series of appointments if needed • addressing women's fears about the involvement of children's services by providing information tailored to their needs. (R 1.5.1)	Consensus based on evidence Section 7.3, pg 147-9
Tell the woman that the information she discloses will be kept in a confidential record and will not be included in her hand-held record. (R 1.5.8)	Consensus based on evidence Section 7.3, pg 147-9
Offer the woman information about other agencies, including third-sector agencies, which provide support for women who experience domestic abuse. (R 1.5.9)	Consensus based on evidence Section 7.3, pg 143
Give the woman a credit card-sized information card that includes local and national helpline numbers. (R 1.5.10)	Consensus based on evidence Section 7.6, pg 156,158
Consider offering the woman referral to a domestic abuse support worker. (R 1.5.11)	Consensus Section 7.5, pg 157
Barrett's oesophagus - ablative therapy (August 2010)[46] **http://www.nice.org.uk/nicemedia/live/13096/50243/50243.pdf**	
Consider offering endoscopic therapy as an alternative to oesophagectomy to people with high-grade dysplasia and intramucosal cancer (T1a), taking into account individual patient preferences and general health. Endoscopic therapy is particularly suitable for patients who are considered unsuitable for surgery or who do not wish to undergo oesophagectomy. (R 1.2.2)	Evidence Section 2.2.4, pg 29
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	Consensus Section 2.6.3, pg 72

Recommendation (reference)	**Evidence based?** **Consensus recommendation?[c]**
decisions about their care. (R 1.1.9)	
Offer patients the opportunity to see the same specialist healthcare team more than once to agree treatment. (R 1.1.11)	Consensus; section 2.6.3, pg 72
Chronic heart failure (December 2010)[12] **http://www.nice.org.uk/nicemedia/live/13099/50514/50514.pdf - full** **http://www.nice.org.uk/nicemedia/live/13099/50517/50517.pdf - NICE**	
Healthcare professionals should discuss alcohol consumption with the patient and tailor their advice appropriately to the clinical circumstances. [2003] (R 1.2.1.3)	Consensus No details in guideline
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. [2003] (R 1.2.1.4)	Consensus No details in guideline
Patients who wish to be involved in monitoring of their condition should be provided with sufficient education and support from their healthcare professional to do this, with clear guidelines as to what to do in the event of deterioration. [2003] (R 1.4.1.4)	Consensus No details in guideline
Clear instructions should be given as to how the patient/carer can access advice, particularly in the high-risk period immediately following discharge. [2003] (R 1.5.2.3)	Consensus No details in guideline
Guidelines for good communication: • Listen to patients and respect their views and beliefs. • Give patients the information they ask for or need about their condition, its treatment and prognosis, in a way they can understand including information about any serious side effects of drugs to be prescribed. • Provide the most important information first. • Explain how each item will affect patients personally. • Present information in separate categories. • Make advice specific, detailed and concrete. • 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. • Repeat the information using the same words each time. • Prepare material, written or taped, to back up handwritten notes. • Share information with patients’ partners, close relatives or carers if they ask you to do so. When patients cannot indicate their consent for such sharing of information, it is advisable to share the information that those close to the patient need or want to know, except where you have reason to believe that the patient would object if able to do so. [2003] (R 1.5.5.2)	Evidence No details in guideline

Recommendation (reference)	**Evidence based?** **Consensus recommendation?**[c]
The content, style and timing of information provision should be tailored to the needs of the individual patient. [2003] (R 1.5.5.3)	Evidence No details in guideline
Healthcare professionals should be aware of local cardiac support networks and provide this information to patients and carers. [2003] (R 1.5.7.1)	Consensus No details in guideline
Issues of sudden death and living with uncertainty are pertinent to all patients with heart failure. The opportunity to discuss these issues should be available at all stages of care. [2003] (R 1.5.9.1)	Consensus No details in guideline
Hypertension in pregnancy (August 2010)[40] **http://www.nice.org.uk/nicemedia/live/13098/50475/50475.pdf - full** **http://www.nice.org.uk/nicemedia/live/13098/50418/50418.pdf - NICE**	
No recommendations	
Transient loss of consciousness in adults and young people (August 2010)[16] **http://www.nice.org.uk/nicemedia/live/13111/50432/50432.pdf** **http://www.nice.org.uk/nicemedia/live/13111/50452/50452.pdf**	
For people with orthostatic hypotension: explain the mechanisms causing their syncope discuss and review possible causes, especially drug therapy discuss the prognostic implications and treatment options available advise people what to do if they experience another TLoC. (R 1.5.4.2)	Consensus
Advise people waiting for a specialist cardiovascular assessment: what they should do if they have another event if appropriate, how they should modify their activity (for example, by avoiding physical exertion if relevant) and not to drive. (R 1.5.4.3)	Consensus based on DVLA guidance for driving section of recommendation
Offer advice to people waiting for specialist neurological assessment for their TLoC as recommended in 'The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care' (NICE clinical guideline 20). (R 1.5.4.4)	Consensus (from CG 20)
Delirium (July 2010)[14] **http://www.nice.org.uk/nicemedia/live/13060/49909/49909.pdf** **http://www.nice.org.uk/nicemedia/live/13060/49909/49909.pdf**	

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
Give a tailored multicomponent intervention package: • Within 24 hours of admission, assess people at risk for clinical factors contributing to delirium. • Based on the results of this assessment, provide a multicomponent intervention tailored to the person's individual needs and care setting as described in recommendations 1.3.3.1–1.3.3.10. (R 1.3.2)	Consensus Section 9.24.3, pg 437
Offer information to people who are at risk of delirium or who have delirium, and their family and/or carers, which: • informs them that delirium is common and usually temporary • describes people's experience of delirium • encourages people at risk and their families and/or carers to tell their healthcare team about any sudden changes or fluctuations in behaviour • encourages the person who has had delirium to share their experience of delirium with the healthcare professional during recovery • advises the person of any support groups. (R 1.7.1)	Consensus based on evidence Section 14.6, pg 561-2
Ensure that information provided meets the cultural, cognitive and language needs of the person. (R 1.7.2)	Consensus Section 14.6, pg 562
Metastatic malignant disease of unknown primary origin (July 2010)[23] **http://www.nice.org.uk/nicemedia/live/13044/49864/49864.pdf** **http://www.nice.org.uk/nicemedia/live/13044/49848/49848.pdf**	
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. (R 1.1.1.3)	Consensus Section 3.3, pg 15
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	Consensus Section 3.3, pg 16

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
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. (R 1.1.1.4)	
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. (R 1.3.1.2)	Consensus Section 5.2, pg 38
Explain to patients and carers if further investigations will not alter treatment options. Provide appropriate emotional and psychological support, information about CUP, treatment options and palliative care. (R 1.3.1.3)	Consensus Section 5.2, pg 38
Motor neurone disease - non-invasive ventilation (July 2010)[48] **http://www.nice.org.uk/nicemedia/live/13057/49885/49885.pdf**	
Offer to discuss the possible use of non-invasive ventilation with the patient and (if the patient agrees) their family and carers, at an appropriate time and in a sensitive manner. This may be at one or more of the following times: • soon after MND is first diagnosed • when monitoring respiratory function • when respiratory function deteriorates • if the patient asks for information. (R 1.1.2)	Evidence Section 2.5.2, pg 91
Discussions should be appropriate to the stage of the patient's illness, carried out in a sensitive manner and include information on: • the possible symptoms and signs of respiratory impairment (see table 1 in recommendation 1.1.7) • the natural progression of MND and what to expect in the future • the purpose, nature and timing of respiratory function tests, and explanations of the test results • available interventions for managing respiratory impairment, including the benefits and limitations of each intervention • accessing and using respiratory equipment, including that for non-invasive ventilation • how non-invasive ventilation (as a treatment option) can improve symptoms associated with respiratory impairment and	Evidence Section 2.5.2, pg 85; section 2.5.3, pg 91-2

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
can be life prolonging, but does not stop progression of the underlying disease • how non-invasive ventilation can be withdrawn • palliative strategies as an alternative to non-invasive ventilation. (R 1.1.3)	
Provide the patient and their family and carers with support and assistance to manage non-invasive ventilation. This should include: • training on using non-invasive ventilation and ventilator interfaces, for example: – emergency procedures – night-time assistance if the patient is unable to use the equipment independently (for example, emergency removal or replacement of interfaces) – how to use the equipment with a wheelchair or other mobility aids if required – what to do if the equipment fails • assistance with secretion management • information on general palliative strategies • an offer of ongoing emotional and psychological support1 for the patient and their family and carers. (R 1.1.5)	Evidence Section 2.5.2 pg 85, section 2.5.3 91-2
Ensure that families and carers: • have an initial assessment if the patient they care for decides to use non-invasive ventilation, which should include: – their ability and willingness to assist in providing non-invasive ventilation – their training needs • have the opportunity to discuss any concerns they may have with members of the multidisciplinary team and/or other healthcare professionals. (R 1.1.6)	Consensus Section 2.5.2 pg 85
If any of the results listed in table 2 is obtained, discuss with the patient and (if the patient agrees) their family and carers: • the impact of respiratory impairment • treatment options • possible referral to a specialist respiratory service for further assessment. (R 1.1.15)	Consensus based on the evidence Section 2.2.3, page 47
Base decisions on respiratory function tests for a patient with a diagnosis of dementia on considerations specific to their needs and circumstances, such as: • their ability to give consent4 • their understanding of the tests • their tolerance of the tests and willingness to undertake them	Consensus Section 2.2.3, pg 50; section 2.3.4, pg 75

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
• the impact on their family and carers • whether they are capable of receiving non-invasive ventilation. (R 1.1.16)	
Offer a trial of non-invasive ventilation if the patient's symptoms and signs and the results of the respiratory function tests indicate that the patient is likely to benefit from the treatment. • Discuss both the benefits and limitations of the intervention with the patient and their family and carers. • Only consider a trial of non-invasive ventilation for a patient who has severe bulbar impairment or severe cognitive problems that may be related to respiratory impairment if they may benefit from an improvement in sleep-related symptoms or correction of hypoventilation. (R 1.1.17)	Evidence Section 2.3.4, pg 74
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. (R 1.1.17)	Consensus Section 2.4.3, pg 77-8
Before starting non-invasive ventilation, the multidisciplinary team should prepare a comprehensive care plan, after discussion with the patient and their family and carers (who should be offered a copy of the plan). This should cover: long-term support provided by the multidisciplinary team the initial frequency of respiratory function tests and monitoring of respiratory impairment the frequency of clinical reviews of symptomatic and physiological changes the provision of carers arrangements for device maintenance and 24-hour emergency clinical and technical support secretion management and respiratory physiotherapy assessment, including cough-assist therapy (if required) training in and support for the use of non-invasive ventilation for the patient and their family and carers regular opportunities to discuss the patient's wishes in relation to continuing or withdrawing non-invasive ventilation, and	Consensus Section 2.4.3, pg 78

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
other end-of-life considerations (see also recommendations 1.1.24 and 1.1.25). (R 1.1.19)	
Discuss all decisions to continue or withdraw non-invasive ventilation with the patient and (if the patient agrees) their family and carers. (R 1.1.22)	Evidence Section 2.5.2, pg 90
Offer to discuss end-of-life care with the patient and (if the patient agrees) their family and carers, at an appropriate time and in a sensitive manner. This may be at one or more of the following times: • around the time that MND is first diagnosed (but only if requested by the patient explicitly, or if the patient's clinical condition indicates that ventilator support will be needed in the immediate future) • when non-invasive ventilation is accepted or declined • when the patient is becoming increasingly dependent on non-invasive ventilation • if the patient asks for information. (R 1.1.24)	Consensus based on evidence Section 2.5.3, pg 92
Discussions about end-of-life care should include: • planning of end-of-life care • considering advance decisions to refuse treatment • considering what to do if non-invasive ventilation fails because of either: – an acute, but potentially reversible, deterioration in health or – irreversible disease progression • strategies to withdraw non-invasive ventilation if the patient wishes • the involvement of family and carers in decision making (with the patient's consent if they have the capacity to give it). (R 1.1.25)	Consensus Section 2.5.3, pg 92
Alcohol-use disorders: physical complications (June 2010)[10] **http://www.nice.org.uk/nicemedia/live/13314/52667/52667.pdf - full guideline** **http://www.nice.org.uk/nicemedia/live/12995/48991/48991.pdf - NICE guideline**	
When considering liver biopsy for the investigation of alcohol-related liver disease: • take into account the small but definite risks of morbidity and mortality • discuss the benefits and risks with the patient and • ensure informed consent is obtained. (R 1.3.1.4)	Evidence Section 3.1.6, pg 120-1
For people who are alcohol dependent but not admitted to hospital, offer advice to avoid a sudden reduction in alcohol intake and information about how to contact local alcohol support services. (R 1.1.4)	Consensus Section 2.1.6, pg 31
Offer information about how to contact local alcohol support services to people who are being treated for acute alcohol	Consensus

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
withdrawal. (R 1.1.3.3)	Section 2.1.6, pg 31; section 2.2.6, pg 42
Chronic obstructive pulmonary disease (June 2010)[13] **http://www.nice.org.uk/nicemedia/live/13029/49425/49425.pdf - full guideline** **http://www.nice.org.uk/nicemedia/live/13029/49397/49397.pdf - NICE guideline**	
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. [new 2010] (R1.2.2.3)	Evidence Section 7.3.5, pg 131
Inhalers should be prescribed only after patients have received training in the use of the device and have demonstrated satisfactory technique. [2004] (R 1.2.2.3)	Consensus based on evidence Section 7.3.7, pg 209
If nebuliser therapy is prescribed, the patient should be provided with equipment, servicing, advice and support. [2004] (R 1.2.2.23)	Consensus based on evidence Section 7.3.7, pg 210
The following functions should be considered when defining the activity of the multidisciplinary team: assessing patients (including performing spirometry, assessing the need for oxygen, the need for aids for daily living and the appropriateness of delivery systems for inhaled therapy) care and treatment of patients (including non-invasive ventilation, pulmonary rehabilitation, hospital-at-home/early discharge schemes, providing palliative care, identifying and managing anxiety and depression, advising patients on relaxation techniques, dietary issues, exercise, social security benefits and travel) advising patients on self-management strategies identifying and monitoring patients at high risk of exacerbations and undertaking activities which aim to avoid emergency admissions advising patients on exercise education of patients and other health professionals. [2004] (R 1.2.12.2)	Consensus No details in GL
If patients have excessive sputum, they should be taught: the use of positive expiratory pressure masks active cycle of breathing techniques. [2004] (R 1.2.12.4)	Evidence Section 7.13.2, pg 308-9
Patients should be regularly asked about their ability to undertake activities of daily living and how breathless they become when doing these. [2004] (R 1.2.12.11)	Consensus based on evidence Section 7.13.6, pg 333
Specific educational packages should be developed for patients with COPD.	Consensus

Recommendation (reference)	**Evidence based?** **Consensus recommendation?[c]**
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. [2004] (R 1.2.12.19)	Section 7.13.9, pg 339-40
Patients at risk of having an exacerbation of COPD should be given self-management advice that encourages them to respond promptly to the symptoms of an exacerbation. [2004] (R 1.2.12.21)	Evidence Section 7.13.10, pg 344
Patients should be encouraged to respond promptly to the symptoms of an exacerbation by: starting oral corticosteroid therapy if their increased breathlessness interferes with activities of daily living (unless contraindicated) starting antibiotic therapy if their sputum is purulent adjusting their bronchodilator therapy to control their symptoms. [2004] (R 1.2.12.22)	Consensus based on evidence Section 7.13.10, pg 344
Patients' preferences about treatment at home or in hospital should be considered. [2004] (R 1.3.4.4)	Consensus Section 8.10, pg 361-2
Patients (or home carers) should be given appropriate information to enable them to fully understand the correct use of medications, including oxygen, before discharge. [2004] (R 1.3.11.5)	Consensus Section 8.17, pg 396
Arrangements for follow-up and home care (such as visiting nurse, oxygen delivery, referral for other support) should be made before discharge. [2004]	Consensus Section 8.17, pg 396
Before the patient is discharged, the patient, family and physician should be confident that he or she can manage successfully. When there is remaining doubt a formal activities of daily living assessment may be helpful. [2004] (R 1.3.11.7)	Consensus Section 8.17, pg 396
Lower urinary tract symptoms (June 2010)[15] **http://www.nice.org.uk/nicemedia/live/12984/48554/48554.pdf - full** **http://www.nice.org.uk/nicemedia/live/12984/48557/48557.pdf - NICE**	
Offer men with storage LUTS suggestive of overactive bladder (OAB) supervised bladder training, advice on fluid intake, lifestyle advice and, if needed, containment products. (R 1.3.4)	Consensus Section 5.5.2, pg 112
Offer supervised pelvic floor muscle training to men with stress urinary incontinence caused by prostatectomy. Advise them to continue the exercises for at least 3 months before considering other options. (R 1.3.6)	Evidence Section 5.2.2, pg 107
If offering long-term indwelling catheterisation, discuss the practicalities, benefits and risks with the man and, if appropriate, his carer. (R 1.3.12)	Consensus Section 5.10.2, pg 122
Ensure that, if appropriate, men's carers are informed and involved in managing their LUTS and can give feedback on treatments. (R 1.9.1)	Consensus Section 15.3.4, pg 323

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
Make sure men with LUTS have access to care that can help with: • their emotional and physical conditions and • relevant physical, emotional, psychological, sexual and social issues. (R 1.9.2)	Consensus Section 15.3.4, pg 324
Provide men with storage LUTS (particularly incontinence) containment products at point of need, and advice about relevant support groups. (R 1.9.3)	Consensus Section 15.3.4, pg 324
Chest pain of recent onset (March 2010)[11] **http://www.nice.org.uk/nicemedia/live/12947/47931/47931.pdf - full** **http://www.nice.org.uk/nicemedia/live/12947/47938/47938.pdf - NICE**	
Discuss any concerns people (and where appropriate their family or carer/advocate) may have, including anxiety when the cause of the chest pain is unknown. Correct any misinformation. (R 1.1.1.1)	Consensus based on evidence Section 3.1.4, pg 81
Offer people a clear explanation of the possible causes of their symptoms and the uncertainties. (R 1.1.1.2)	Consensus based on evidence Section 3.1.4, pg 81
Clearly explain the options to people at every stage of investigation. Make joint decisions with them and take account of their preferences: Encourage people to ask questions. Provide repeated opportunities for discussion. Explain test results and the need for any further investigations. (R 1.1.1.3)	Consensus based on evidence Section 3.1.4, pg 81
Provide information about any proposed investigations using everyday, jargon-free language. Include: their purpose, benefits and any limitations of their diagnostic accuracy duration level of discomfort and invasiveness risk of adverse events. (R 1.1.1.4)	Consensus based on evidence Section 3.1.4, pg 81
Offer information about the risks of diagnostic testing, including any radiation exposure. (R 1.1.1.5)	Consensus based on evidence Section 3.1.4, pg 81
Address any physical or learning difficulties, sight or hearing problems and difficulties with speaking or reading English, which may affect people's understanding of the information offered. (R 1.1.1.6)	Consensus based on evidence Section 3.1.4, pg 81
Offer information after diagnosis as recommended in the relevant disease management guidelines.(R 1.1.1.7)	Consensus based on evidence

Recommendation (reference)	**Evidence based?** **Consensus recommendation?**[c]
	Section 3.1.4, pg 81
Provide individual advice to people about seeking medical help if they have further chest pain. (R 1.1.19)	Consensus based on evidence Section 3.1.4, pg 81
Unstable angina and NSTEMI (March 2010)[9] **http://www.nice.org.uk/nicemedia/live/12949/47988/47988.pdf** **http://www.nice.org.uk/nicemedia/live/12949/47921/47921.pdf**	
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. (R 1.1.1)	Consensus based on evidence Section 5.1.7, pg 195-8
Before discharge offer patients advice and information about: • their diagnosis and arrangements for follow-up (in line with 'MI: secondary prevention', NICE clinical guideline 48) • cardiac rehabilitation (in line with 'MI: secondary prevention', NICE clinical guideline 48) • management of cardiovascular risk factors and drug therapy for secondary prevention (in line with 'MI: secondary prevention', NICE clinical guideline 48, and 'Lipid modification', NICE clinical guideline 67) • lifestyle changes (in line with 'MI: secondary prevention', NICE clinical guideline 48). (R 1.5.10)	Consensus based on evidence Section 5.7.6, pg 239-40
All patients who smoke should be advised to quit and be offered support and advice, and referral to an intensive support service (for example, the NHS Stop Smoking Services) in line with 'Brief interventions and referral for smoking cessation in primary care and other settings' (NICE public health guidance 1). (This recommendation is adapted from 'MI: secondary prevention', NICE clinical guideline 48.) (R 1.5.12)	Consensus based on evidence Section 5.7.6, pg 239-40
Neuropathic pain - pharmacological management (March 2010)[49] **http://www.nice.org.uk/nicemedia/live/12948/47949/47949.pdf**	
Address the person's concerns and expectations when agreeing which treatments to use by discussing: • the benefits and possible adverse effects of each pharmacological treatment • why a particular pharmacological treatment is being offered • coping strategies for pain and for possible adverse effects of treatment • that non-pharmacological treatments are also available in non-specialist settings and/or through referral to specialist services (for example, surgical treatments and psychological therapies). (R 1.1.3)	Consensus based on evidence Section 2.5.6, pg 129
When selecting pharmacological treatments, take into account: • the person's vulnerability to specific adverse effects because of comorbidities	Consensus Section 2.5.6, pg 129

Recommendation (reference)	**Evidence based?** **Consensus recommendation?**[c]
• safety considerations and contraindications as detailed in the SPC • patient preference • lifestyle factors (such as occupation) • any mental health problems (such as depression and/or anxiety7 • any other medication the person is taking. (R 1.1.4)	
Explain both the importance of dosage titration and the titration process, providing written information if possible. (R 1.1.5)	Evidence Section 2.5.3, pg 125; section 2.5.6, pg 129
If satisfactory pain reduction is not achieved with first-line treatment at the maximum tolerated dose, offer treatment with another drug instead of or in combination with the original drug, after informed discussion with the person. • If first-line treatment was with amitriptyline* (or imipramine* or nortriptyline*), switch to or combine with oral pregabalin. • If first-line treatment was with pregabalin, switch to or combine with oral amitriptyline* (or imipramine* or nortriptyline* as an alternative if amitriptyline* is effective but the person cannot tolerate the adverse effects; see recommendation 1.1.12). • For people with painful diabetic neuropathy: – if first-line treatment was with duloxetine, switch to amitriptyline* or pregabalin, or combine with pregabalin – if first-line treatment was with amitriptyline*, switch to or combine with pregabalin. Dosage and titration should be the same as in recommendation 1.1.10. (R 1.1.13)	Consensus for patient part of recommendation, evidence for intervention part of recommendation Section 2.5, pg 120-8
Donor breast milk banks (February 2010)[47] **http://www.nice.org.uk/nicemedia/live/12811/47545/47545.pdf**	
Conduct the screening interview, detailed in recommendations 1.2.12 and 1.2.13, with potential donors at a mutually acceptable time and place, either face-to-face or by telephone. (R 1.2.15)	Consensus based on evidence Section 2.6.4, pg 38
Use clear, non-technical language when communicating the use of donor milk and the process of donor milk banking in any written information and activities (Rec 1.2.10 p33)	Evidence Section 2.5.3, pg 30
Provide ongoing support to all donors according to their individual needs until no longer required. This may include: information and ongoing support on milk bank requirements for their diet and alcohol consumption continued support for collecting expressed milk and maintaining lactation emotional support. (R 1.1.28)	Evidence Section 2.8.3, pg 45
Provide donors who are stopping their breast milk donations with as much advice and support as needed. (R 1.2.3.4)	Consensus No details in GL
Actively encourage donors to hand express milk; however, accept pump-expressed milk if donors prefer this method. (R	Evidence

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
1.2.3.7)	Section 2.10.3, pg 53-4
Venous thromboembolism - reducing the risk (March 2010)[17] **http://www.nice.org.uk/nicemedia/live/12695/47920/47920.pdf** **http://www.nice.org.uk/nicemedia/live/12695/47195/47195.pdf**	
Be aware that heparins are of animal origin and this may be of concern to some patients. For patients who have concerns about using animal products, consider offering synthetic alternatives based on clinical judgement and after discussing their suitability, advantages and disadvantages with the patient. (R 1.7.1)	Consensus No details in GL
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). (R 1.7.2)	Evidence Section 32.5, pg 441-2
As part of the discharge plan, offer patients and/or their families or carers verbal and written information on: the signs and symptoms of deep vein thrombosis and pulmonary embolism the correct and recommended duration of use of VTE prophylaxis at home (if discharged with prophylaxis) the importance of using VTE prophylaxis correctly and continuing treatment for the recommended duration (if discharged with prophylaxis) the signs and symptoms of adverse events related to VTE prophylaxis (if discharged with prophylaxis) the importance of seeking help and who to contact if they have any problems using the prophylaxis (if discharged with prophylaxis) the importance of seeking medical help and who to contact if deep vein thrombosis, pulmonary embolism or other adverse events are suspected. (R 1.7.3)	Evidence Section 32.6, pg 444-5
Ensure that patients who are discharged with anti-embolism stockings: understand the benefits of wearing them understand the need for daily hygiene removal are able to remove and replace them, or have someone available who will be able to do this for them know what to look for, such as skin marking, blistering or discolouration, particularly over the heels and bony prominences	Evidence Section 32.6, pg 444-5

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
know who to contact if there is a problem. (R 1.7.4)	
Ensure that patients who are discharged with pharmacological and/or mechanical VTE prophylaxis are able to use it correctly, or have arrangements made for someone to be available who will be able to help them. (R 1.7.5)	Evidence Section 32.6, pg 444-5
Skin tumours including melanoma (May 2010)[24] **http://www.nice.org.uk/nicemedia/live/10901/48878/48878.pdf**	
All healthcare professionals managing BCCs in the community should provide information, advice and support for patients and their families or carers.	Consensus Section 5 pg 43
2009	
Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence (January 2009)[35] **http://www.nice.org.uk/nicemedia/live/11766/42971/42971.pdf** **http://www.nice.org.uk/nicemedia/live/11766/43042/43042.pdf**	
Healthcare professionals should adapt their consultation style to the needs of individual patients so that all patients have the opportunity to be involved in decisions about their medicines at the level they wish. (R 1.1.1)	Consensus Section 4.15.1; Page 131
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. (R 1.1.2)	Consensus Section 4.8.1; Page 92
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). (R 1.1.3)	Evidence Section 4.9.1; Page 101
Encourage patients to ask about their condition and treatment. (R 1.1.4)	Consensus based Section 4.8.1; Page 92
Ask patients open-ended questions because these are more likely to uncover patients' concerns. (R 1.1.5)	Evidence Section 7.3.3; Page 186
Offer all patients the opportunity to be involved in making decisions about prescribed medicines. Establish what level of involvement in decision-making the patient would like. (R 1.1.7)	Consensus Section 4.5.1; Page 69
Discuss with the patient why they might benefit from the treatment. Clearly explain the disease or condition and how the medicine will influence this. (R 1.1.8)	Consensus Section 4.5.1; Page 69
Explain the medical aims of the treatment to patients and openly discuss the pros and cons of proposed medicines. The discussion should be at the level preferred by the patient. (R 1.1.9)	Evidence Section 4.10.2.2; Page 112

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
Clarify what the patient hopes the treatment will achieve. (R 1.1.10)	Consensus Section 4.8.1; Page 92
Avoid making assumptions about patient preferences about treatment. Talk to the patient to find out their preferences, and note any non-verbal cues that may indicate you need to explore the patient's perspective further. (R 1.1.11)	Consensus Section 4.5.1; Page 69
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. (R 1.1.12)	Consensus based on external guidance Section 3.4; Page 54
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. (R 1.1.15)	Consensus based on external guidance Section 3.4; Page 54
Encourage and support patients, families and carers to keep an up-to-date list of all medicines the patient is taking. The list should include the names and dosages of prescription and non-prescription medicines and herbal and nutritional supplements. If the patient has any allergic or adverse reactions to medicines, these should be noted. (R 1.1.18)	Consensus based on external report Section 6.3.3; Page 177
Be aware that patients' concerns about medicines, and whether they believe they need them, affect how and whether they take their prescribed medicines (R 1.1.19)	Evidence
Ask patients what they know, believe and understand about medicines before prescribing new treatments and when reviewing medicines. (R 1.1.20)	Evidence Section 5.3.1; Page 156
Ask if the patient has any specific concerns about their medicines, whenever you prescribe, dispense or review medicines. These may include concerns about becoming dependent on medicines and concerns about adverse effects. Address these concerns. (R 1.1.21)	Evidence Section 5.3.1; Page 156
Be aware that patients may wish to discuss: • what will happen if they do not take the medicine suggested by their healthcare professional • non-pharmacological alternatives to medicines • how to reduce and stop medicines they may have been taking for a long time, particularly those known to be associated with withdrawal symptoms • how to fit taking the medicine into their daily routine • how to make a choice between medicines if they believe they are taking too many medicines. (R 1.1.23)	Evidence Section 5.3.4; Page 159
Offer patients information about medicines before the medicines are prescribed. (R 1.1.24)	Evidence Section 4.10.2.2; Page 111
Offer patients information that is relevant to their condition, possible treatments and personal circumstances, and that is easy	Evidence

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
to understand and free from jargon. (R 1.1.25)	Section 4.10.2.1; Page 105
Discuss information on medicines with the patient rather than just presenting it. The discussion should take into account what the patient understands and believes about the condition and treatment. (R 1.1.27)	Consensus Section 3.3; Page 54
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. (R 1.1.28)	Consensus Section 4.10.1; Page 104
Patients differ in the type and amount of information they need and want. Therefore the provision of information should be individualised and is likely to include, but not be limited to: what the medicine is how the medicine is likely to affect their condition (that is, its benefits) (R 1.1.29)	Consensus Section 4.10.1; Page 104
Be careful not to make assumptions about a patient's ability to understand the information provided. Check with the patient that they have understood the information. Information for patients should be clear and logical and, if possible, tailored to the needs of the individual patient. (R 1.1.30)	Consensus Section 4.10.1; Page 104
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]). (R 1.1.31)	Consensus Section 4.10.1; Page 104
Provide inpatients with the same information as patients in other settings. Information should include: • what the medicine is • how the medicine is likely to affect their condition (that is, its benefits) • likely or significant adverse effects and what to do if they think they are experiencing them • how to use the medicine • what to do if they miss a dose • whether further courses of the medicine will be needed after the first prescription • how to get further supply after discharge. (R 1.1.32)	Consensus Section 6.3.1; Page 176
Be aware that although adherence can be improved, no specific intervention can be recommended for all patients. Tailor any intervention to increase adherence to the specific difficulties with adherence the patient is experiencing. (R 1.2.5)	Consensus Section 8.4; Page 207
Find out what form of support the patient would prefer to increase their adherence to medicines. Together, you and your patient should consider options for support. (R 1.2.6)	Consensus Section 8.10.1; Page 238
Address any beliefs and concerns that patients have that result in reduced adherence. (R 1.2.7)	Consensus Section 8.4; Page 205

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
Side effects can be a problem for some patients. If this is the case you should: discuss how the patient would like to deal with side effects discuss the benefits, side effects and long-term effects with the patient to allow them to make an informed choice consider adjusting the dosage consider switching to another medicine with a different risk of side effects consider what other strategies might be used (for example, timing of medicines). (R 1.2.9)	Consensus based on evidence Section 8.11.1; Page 248
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. (R 1.3.1)	Consensus based on evidence Section 9.3.1; Page 292
Review at regular intervals the decision to prescribe medicines, according to patient choice and need. (R 1.3.2)	Consensus Section 9.3.1; Page 293
Be aware that patients sometimes evaluate prescribed medicines using their own criteria such as their understanding of their condition or the symptoms most troubling to them. They may, for example, stop and start the medicine or alter the dose and check how this affects their symptoms. Ask the patient whether they have done this. (R 1.3.4)	Consensus Section 9.3.1; Page 292
Breast cancer (advanced)[21] **http://www.nice.org.uk/nicemedia/live/11778/43305/43305.pdf**	
Assess the patient's individual preference for the level and type of information. Reassess this as circumstances change. (R 1.2.1)	Evidence Section 3; Page 13
On the basis of this assessment, offer patients consistent, relevant information and clear explanations, and provide opportunities for patients to discuss issues and ask questions. (R 1.2.2)	Evidence Section 3; Page 13
Assess the patient's individual preference for how much they wish to be involved in decision making. Reassess this as circumstances change. (R 1.2.3)	Evidence Section 3; Page 14
Be aware of the value of decision aids and the range available. Make the most appropriate decision aid available to the patient. (R 1.2.4)	Evidence Section 3; Page 14
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	Consensus Section 5.2; Page 37

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
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.’ (R 1.4.1)	
Provide patients with lymphoedema with clear, written information and the contact details of local and national lymphoedema support groups. (R 1.5.5)	Consensus Section 6.1; Page 40
Provide clear, written information about cancer-related fatigue, organisations that offer psychosocial support and patient-led groups. (R 1.5.7)	Consensus based on evidence Section 6.2; Page 41
A palliative care team should assess all patients with uncontrolled local disease in order to plan a symptom management strategy and provide psychological support. (R 1.5.11)	Consensus based on evidence Section 6.3; Page 43
Breast cancer (early & locally advanced)[22] **http://www.nice.org.uk/nicemedia/live/12132/43312/43312.pdf**	
All members of the breast cancer clinical team should have completed an accredited communication skills training programme. (R 1.2.1)	Evidence Section 2.5; Page 24
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. (R 1.2.2)	Evidence Section 2.5; Page 24
All patients with breast cancer should be offered prompt access to specialist psychological support, and, where appropriate, psychiatric services. (R 1.2.3)	Evidence Section 2.5; Page 24
Decisions about adjuvant therapy should be made based on assessment of the prognostic and predictive factors, the potential benefits and side effects of the treatment. Decisions should be made following discussion of these factors with the patient. (R 1.6.6)	Consensus Section 4.3; Page 50
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 recurrence11. (R 1.7.7)	Consensus based on external guidance (NICE TA) Section 5.2; Page 60, TA recommendation decision in TA is based on consensus (TA 112: Section 4.3.10; Page 26)
Offer adjuvant radiotherapy to patients with DCIS following adequate breast conserving surgery and discuss with them the	Consensus based on evidence

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
potential benefits and risks (see recommendation in section 1.3.1) (R 1.11.2)	Section 6.2; Page 73
Offer information and counselling for all women about the possibility of early menopause and menopausal symptoms associated with breast cancer treatment. (R 1.13.10)	Consensus Section 8.3; Page 93
Rheumatoid arthritis[28] **http://www.nice.org.uk/nicemedia/live/12131/43327/43327.pdf**	
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. (R 1.2.11)	Consensus based on evidence Section 5.1.6, p61
Offer verbal and written information to people with RA to: • improve their understanding of the condition and its management, and • counter any misconceptions they may have. (R 1.2.1.2)	Consensus based on evidence Section 5.2.6, p68/9
People with RA who wish to know more about their disease and its management should be offered the opportunity to take part in existing educational activities, including self-management programmes. (R 1.2.1.3)	Consensus based on evidence Section 5.2.6, p68/9
People with RA should have ongoing access to a multidisciplinary team. This should provide the opportunity for periodic assessments (see 1.5.1.3 and 1.5.1.4) of the effect of the disease on their lives (such as pain, fatigue, everyday activities, mobility, ability to work or take part in social or leisure activities, quality of life, mood, impact on sexual relationships) and help to manage the condition. (R 1.3.1.1)	Consensus based on evidence Section 6.1.6, p75/6; and section 5.1.6, p61
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. (R 1.3.1.2)	Consensus Section 6.1.6, p75/6
People with RA should have access to specialist occupational therapy, with periodic review (see 1.5.1.3 and 1.5.1.4), if they have: • difficulties with any of their everyday activities, or • problems with hand function.(R 1.3.1.4)	Evidence Section 6.3.7, p94/5
Offer psychological interventions (for example, relaxation, stress management and cognitive coping skills3 (R 1.3.1.5)	Evidence Section 6.3.7, p94/5
All people with RA and foot problems should have access to a podiatrist for assessment and periodic review of their foot health needs (see 1.5.1.3 and 1.5.1.4).) to help people with RA adjust to living with their condition. (R 1.3.1.6)	Consensus based on evidence Section 6.4.6, p99
Offer people with satisfactorily controlled established RA review appointments at a frequency and location suitable to their needs. In addition, make sure they:	Consensus

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
• have access to additional visits for disease flares, • know when and how to get rapid access to specialist care, and • have ongoing drug monitoring. (R 1.5.1.3)	Section 8.2.5, p188/9
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. (R 1.5.1.4)	Consensus based on evidence Section 8.2.5, p188/9 and section 5.1.6, p61
Critical illness rehabilitation[43] **http://www.nice.org.uk/nicemedia/live/12137/43526/43526.pdf**	
To ensure continuity of care, healthcare professional(s) with the appropriate competencies1 • 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. (R 1.1.1)	Consensus based on evidence Section 2.2.4; Page 49
For patients at risk, agree short-term and medium-term rehabilitation goals, based on the comprehensive clinical assessment. The patient's family and/or carer should also be involved2. (R 1.1.4)	Consensus Section 2.1.4; Page 36
For patients at risk, start rehabilitation as early as clinically possible, based on the comprehensive clinical assessment and the rehabilitation goals. Rehabilitation should include: • measures to prevent avoidable physical and non-physical morbidity, including a review of previous and current medication	Consensus Section 2.2.4; Page 49

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
• nutrition support, based on the recommendations in 'Nutrition support in adults' (NICE clinical guideline 32) • an individualised, structured rehabilitation programme with frequent follow-up reviews. The details of the structured rehabilitation programme and the reviews should be collated and documented in the patient's clinical records. (R 1.1.6)	
Give patients the following information during their critical care stay. Also give the information to their family and/or carer3 • Information about the patient's critical illness, interventions and treatments. , unless the patient disagrees. • Information about the equipment used during the patient's critical care stay. • If applicable, information about any possible short-term and/or long-term physical and non-physical problems which may require rehabilitation. Deliver all the above information more than once during the patient's critical care stay. (R 1.1.7)	Evidence Section 2.3.3; Page 62
For patients at risk, and patients who started the individualised, structured rehabilitation programme in critical care, perform a comprehensive clinical reassessment to identify their current rehabilitation needs. The comprehensive reassessment should pay particular attention to: • physical, sensory and communication problems (see table 2) • underlying factors, such as pre-existing psychological or psychiatric distress • symptoms that have developed during the critical care stay, such as delusions, intrusive memories, anxiety, panic episodes, nightmares, flashback episodes or depression. (R 1.1.9)	Consensus Section 2.1.4; Page 36
For patients who were previously identified as being at risk during critical care, the outcomes of the comprehensive reassessment should inform the individualised, structured rehabilitation programme (recommendation 1.1.6). (R 1.1.10)	Consensus Section 2.1.4; Page 37
For patients at risk, agree or review and update the rehabilitation goals, based on the comprehensive reassessment. The family and/or carer should also be involved, unless the patient disagrees. (R 1.1.11)	Consensus Section 2.1.4; Page 37
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. (R 1.1.12)	Consensus Section 2.3.4; Page 64
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	Consensus based on evidence Section 2.3.4; Page 63

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
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. (R 1.1.13)	
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. (R 1.1.22)	Based on qualitative evidence and consensus Section 2.3.4; Page 63
The functional reassessment should be face to face in the community or in hospital, performed by an appropriately-skilled healthcare professional(s) who is familiar with the patient’s critical care problems and rehabilitation care pathway. (R 1.1.24)	Consensus Section 2.1.4; Page 37
Based on the functional reassessment. • Refer the patient to the appropriate rehabilitation or specialist services if: – the patient appears to be recovering at a slower rate than anticipated, according to their rehabilitation goals, or – the patient has developed unanticipated physical and/or non-physical morbidity that was not previously identified. • Give support if the patient is not recovering as quickly as they anticipated. • If anxiety or depression is suspected, follow the stepped care models recommended in ‘Anxiety’ (NICE clinical guideline 22) and ‘Depression’ (NICE clinical guideline 23). • If PTSD is suspected or the patient has significant symptoms of PTS, refer to ‘Post-traumatic stress disorder (PTSD)’ (NICE clinical guideline 26). (R 1.1.25)	Consensus Section 2.2.4; Page 50
Glaucoma[18] **http://www.nice.org.uk/nicemedia/live/12145/43839/43839.pdf**	
Discuss the benefits and risks of stopping treatment with people with OHT or suspected COAG who have both:	Consensus

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
• 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. (R 1.2.11)	Section 5.6.2; Page 102
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. This may include information on the following: • their specific condition (OHT, suspected COAG and COAG), its life-long implications and their prognosis for retention of sight • that COAG in the early stages and OHT and suspected COAG are symptomless • that most people treated for COAG will not go blind • that once lost, sight cannot be recovered • that glaucoma can run in families and that family members may wish to be tested for the disease • the importance of the person's role in their own treatment – for example, the ongoing regular application of eye drops to preserve sight • the different types of treatment options, including mode of action, frequency and severity of side effects, and risks and benefits of treatment, so that people are able to be active in the decision-making process • how to apply eye drops, including technique (punctal occlusion and devices) and hygiene (storage) • the need for regular monitoring as specified by the healthcare professional • methods of investigation during assessment • how long each appointment is likely to take and whether the person will need any help to attend (for example, driving soon after pupil dilatation would be inadvisable) • support groups • compliance aids (such as dispensers) available from their community pharmacist • Letter of Vision Impairment (LVI), Referral of Vision Impairment (RVI) and Certificate of Vision Impairment (CVI) registration • Driver and Vehicle Licensing Agency (DVLA) regulations. (R 1.6.1)	Consensus Section 11.1.2; Page 244
Coeliac disease[42] **http://www.nice.org.uk/nicemedia/live/12166/44356/44356.pdf**	
No specific recommendations identified.	
Low back pain[34] **http://www.nice.org.uk/nicemedia/live/11887/44343/44343.pdf**	

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
Provide people with advice and information to promote self-management of their low back pain. (R 1.2.1)	Consensus Section 5.2.3; Page 67
Offer educational advice that: • includes information on the nature of non-specific low back pain • encourages the person to be physically active and continue with normal activities as far as possible. (R 1.2.2)	Consensus Section 5.2.3; Page 67
Include an educational component consistent with this guideline as part of other interventions, but do not offer stand-alone formal education programmes. (R 1.2.3)	Consensus based on evidence Section 5.2.3; Page 67
Take into account the person's expectations and preferences when considering recommended treatments, but do not use their expectations and preferences to predict their response to treatments. (R 1.2.4)	Consensus Section 5.2.3; Page 67
Offer one of the following treatment options, taking into account patient preference: an exercise programme (see section 1.3.3), a course of manual therapy (see section 1.4.1) or a course of acupuncture (see section 1.6.1). Consider offering another of these options if the chosen treatment does not result in satisfactory improvement. (R 1.2.5)	Consensus Section 1.2.5; Page 4
Base decisions on continuation of medications on individual response. (R 1.8.9)	Consensus Section 11.2.9; Page 192
Type 2 Diabetes - newer agents (partial update of CG66)[45] **http://www.nice.org.uk/nicemedia/live/12165/44320/44320.pdf**	
Offer structured education to every person and/or their carer at and around the time of diagnosis, with annual reinforcement and review. Inform people and their carers that structured education is an integral part of diabetes care. (R 1.1.1)	Consensus based on evidence Section 5.1.4; Page 29
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. (R 1.1.2)	Consensus based on evidence Section 5.1.4; Page 28
Offer group education programmes as the preferred option. Provide an alternative of equal standard for a person unable or	Consensus

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
unwilling to participate in group education. (R 1.1.4)	Section 5.1.4; Page 29
Ensure the patient-education programmes available meet the cultural, linguistic, cognitive and literacy needs in the locality. (R 1.1.5)	Consensus Section 5.1.4; Page 29
2008	
Irritable bowel syndrome[30] **http://www.nice.org.uk/nicemedia/live/11927/39622/39622.pdf**	
People with IBS should be given information that explains theimportance of self-help in effectively managing their IBS. This should include information on general lifestyle, physical activity, diet and symptom-targeted medication. (R 1.2.1.1)	Evidence Section 11.3; Page 520
Healthcare professionals should assess the physical activity levels of people with IBS, ideally using the General Practice Physical Activity Questionnaire (GPPAQ; see appendix J of the full guideline). People with low activity levels should be given brief advice and counselling to encourage them to increase their activity levels. (R 1.2.1.3)	Consensus for patient part of recommendation, evidence for intervention part of recommendation Section 7.2; Page 143
Osteoarthritis[26] **http://www.nice.org.uk/nicemedia/live/11926/39557/39557.pdf**	
People with symptomatic osteoarthritis should have periodic review tailored to their individual needs. (R 1.1.2)	Consensus Section 4.1.1, p25
Healthcare professionals should formulate a management plan in partnership with the person with osteoarthritis. (R 1.1.3)	Consensus Section 4.1.1, p25
Healthcare professionals should offer all people with clinically symptomatic osteoarthritis advice on the following core treatments. •Access to appropriate information (see section 1.2.1). •Activity and exercise (see section 1.3.1). •Interventions to achieve weight loss if person is overweight or obese (see section 1.3.2 and 'Obesity' [NICE clinical guideline 43]). (R 1.1.5)	Consensus based on evidence Section 4.1.1, p25; section 5.1.4 and section 6.1.11
The risks and benefits of treatment options, taking into account comorbidities, should be communicated to the patient in ways that can be understood. (R 1.1.6)	Consensus Section 4.1.1, p25
Healthcare professionals should offer accurate verbal and written information to all people with osteoarthritis to enhance understanding of the condition and its management, and to counter misconceptions, such as that it inevitably progresses and cannot be treated. Information sharing should be an ongoing, integral part of the management plan rather than a single event	Consensus Section 5.1.4, p45/6

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
at time of presentation. (R 1.1.2.1)	
Individualised self-management strategies should be agreed between healthcare professionals and the person with osteoarthritis. Positive behavioural changes, such as exercise, weight loss, use of suitable footwear and pacing, should be appropriately targeted. (R 1.2.2.1)	Consensus Section 5.2.3, p46/7
Self-management programmes, either individually or in groups, should emphasise the recommended core treatments (see recommendation 1.1.5) for people with osteoarthritis, especially exercise. (R 1.2.2.2)	Consensus Section 5.2.3, p46/7
Decisions on referral thresholds should be based on discussions between patient representatives, referring clinicians and surgeons, rather than using current scoring tools for prioritisation. (R 1.5.1.4)	Consensus based on evidence Section 8.1.7, p296
Prostate cancer[20] **http://www.nice.org.uk/nicemedia/live/11924/39626/39626.pdf**	
The recommendations on communication and patient-centred care made in the two NICE cancer service guidance documents 'Improving outcomes in urological cancers' (2002) and 'Improving supportive and palliative care for adults with cancer' (2004) should be followed throughout the patient journey. (R 1.1.1)	Consensus Section 2.2; Page 8
Men with prostate cancer should be offered individualised information tailored to their own needs. This information should be given by a healthcare professional (for example, a consultant or specialist nurse) and may be supported by written and visual media (for example, slide sets or DVDs). (R 1.1.2)	Consensus Section 2.2; Page 9
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. (R 1.1.3)	Consensus Section 2.2; Page 9
Healthcare professionals should seek feedback from men with prostate cancer and their carers to identify the highest quality information resources. (R 1.1.5)	Consensus Section 2.2; Page 9
Healthcare professionals caring for men with prostate cancer should ascertain the extent to which the man wishes to be involved in decision making and ensure that he has sufficient information to do so. (R 1.1.6)	Consensus Section 2.2; Page 9
A validated, up-to-date decision aid is recommended for use in all urological cancer multidisciplinary teams (MDTs). It should be offered to men with localised prostate cancer when making treatment decisions, by healthcare professionals trained in its use3. (R 1.1.7)	Evidence Section 2.3; Page 10
Healthcare professionals should discuss all relevant management options recommended in this guideline with men with prostate cancer and their partners or carers, irrespective of whether they are available through local services. (R 1.1.8)	Consensus Section 2.3; Page 10
Healthcare professionals should ensure that mechanisms are in place to allow men with prostate cancer and their primary	Consensus

Recommendation (reference)	**Evidence based?** **Consensus recommendation?**[c]
care providers to gain access to specialist services throughout the course of their disease. (R 1.1.9)	Section 2.4; Page 10
Healthcare professionals should adequately inform men with prostate cancer and their partners or carers about the effects of prostate cancer and the treatment options on their sexual function, physical appearance, continence and other aspects of masculinity. Healthcare professionals should support men and their partners or carers in making treatment decisions, taking into account the effects on quality of life as well as survival. (R 1.1.10)	Consensus based on evidence Section 2.4; Page 11
Healthcare professionals should offer men with prostate cancer and their partners or carers the opportunity to talk to a healthcare professional experienced in dealing with psychosexual issues at any stage of the illness and its treatment. (R 1.1.11)	Consensus based on evidence Section 2.4; Page 11
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. (R 1.2.1)	Consensus based on evidence Section 3.1; Page 14
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. (R 1.2.2)	Consensus based on evidence Section 3.1; Page 14
Men should decide whether or not to have a re-biopsy following a negative biopsy, having had the risks and benefits explained to them. (R 1.2.6)	Consensus Section 3.2; Page 15
The decision to proceed from an active surveillance regimen to radical treatment should be made in the light of the individual man's personal preferences, comorbidities and life expectancy. (R 1.3.10)	Consensus Section 4.4; Page 25
Healthcare professionals should discuss personal preferences for palliative care as early as possible with men with metastatic prostate cancer, their partners and carers. Treatment/care plans should be tailored accordingly and the preferred place of care should be identified. (R 1.7.2.6)	Consensus based on evidence Section 7.13; Page 67
Antenatal care[36] **http://www.nice.org.uk/nicemedia/live/11947/40115/40115.pdf**	
Antenatal information should be given to pregnant women according to the following schedule. • At the first contact with a healthcare professional: – folic acid supplementation – food hygiene, including how to reduce the risk of a food-acquired infection – lifestyle advice, including smoking cessation, and the implications of recreational drug use and alcohol consumption in pregnancy	Consensus based on evidence Section 3.3.2; Page 64

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
– all antenatal screening, including screening for haemoglobinopathies, the anomaly scan and screening for Down's syndrome, as well as risks and benefits of the screening tests. • At booking (ideally by 10 weeks): – how the baby develops during pregnancy – nutrition and diet, including vitamin D supplementation for women at risk of vitamin D deficiency, and details of the 'Healthy Start' programme (www.healthystart.nhs.uk) – exercise, including pelvic floor exercises – place of birth (refer to 'Intrapartum care' [NICE clinical guideline 55], available from www.nice.org.uk/CG055) – pregnancy care pathway – breastfeeding, including workshops – participant-led antenatal classes – further discussion of all antenatal screening – discussion of mental health issues (refer to 'Antenatal and postnatal mental health' [NICE clinical guideline 45], available from www.nice.org.uk/CG045). • Before or at 36 weeks: – breastfeeding information, including technique and good management practices that would help a woman succeed, such as detailed in the UNICEF 'Baby Friendly Initiative' (www.babyfriendly.org.uk) – preparation for labour and birth, including information about coping with pain in labour and the birth plan – recognition of active labour – care of the new baby – vitamin K prophylaxis – newborn screening tests – postnatal self-care – awareness of 'baby blues' and postnatal depression. • At 38 weeks: – options for management of prolonged pregnancy1 (R 1.1.1.1)	
Information should be given in a form that is easy to understand and accessible to pregnant women with additional needs, such as physical, sensory or learning disabilities, and to pregnant women who do not speak or read English. (R 1.1.1.2)	Consensus Section 3.3.2; Page 64
Information can also be given in other forms such as audiovisual or touch-screen technology; this should be supported by written information. (R 1.1.1.3)	Evidence Section 3.3.2; Page 64

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
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. (R 1.1.1.4)	Consensus Section 3.3.2; Page 64
At each antenatal appointment, healthcare professionals should offer consistent information and clear explanations, and should provide pregnant women with an opportunity to discuss issues and ask questions. (R 1.1.1.5)	Consensus Section 3.3.2; Page 64
Pregnant women should be offered opportunities to attend participant-led antenatal classes, including breastfeeding workshops. (R 1.1.16)	Evidence Section 3.3.2; Page 64
Women's decisions should be respected, even when this is contrary to the views of the healthcare professional. (R 1.1.17)	Consensus Section 3.3.2; Page 64
Pregnant women should be informed about the purpose of any test before it is performed. The healthcare professional should ensure the woman has understood this information and has sufficient time to make an informed decision. The right of a woman to accept or decline a test should be made clear. (R 1.1.1.8)	Consensus Section 3.3.2; Page 64
Information about antenatal screening should be provided in a setting where discussion can take place; this may be in a group setting or on a one-to-one basis. This should be done before the booking appointment. (R 1.1.19)	Evidence Section 3.3.2; Page 64
Information about antenatal screening should include balanced and accurate information about the condition being screened for. (R 1.1.1.10)	Consensus based on evidence Section 3.3.2; Page 64
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. (R 1.2.2.1)	Evidence Section 4.2; Page 69
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. (R 1.2.2.2)	Consensus Section 4.2; Page 69
Antenatal care should be readily and easily accessible to all pregnant women and should be sensitive to the needs of individual women and the local community. (R 1.2.3.1)	Evidence Section 4.3; Page 69
The environment in which antenatal appointments take place should enable women to discuss sensitive issues such as domestic violence, sexual abuse, psychiatric illness and recreational drug use. (R 1.2.3.2)	Consensus Section 4.3; Page 69
Early in pregnancy, all women should receive appropriate written information about the likely number, timing and content of antenatal appointments associated with different options of care and be given an opportunity to discuss this schedule with their midwife or doctor. (R 1.2.5.2)	Consensus Section 4.5; Page 72
Pregnant women should be informed of their maternity rights and benefits. (R 1.3.1.3)	Evidence

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
	Section 5.3; Page 83
The majority of women can be reassured that it is safe to continue working during pregnancy. Further information about possible occupational hazards during pregnancy is available from the Health and Safety Executive (www.hse.gov.uk). (R 1.3.1.2)	Consensus Section 5.3; Page 83
Pre-conception counselling (supportive listening, advice-giving and information) and carrier testing should be available to all women who are identified as being at higher risk of haemoglobinopathies, using the Family Origin Questionnaire from the NHS Antenatal and Newborn Screening Programme. (www.sickleandthal.org.uk/Documents/F_Origin_Questionnaire.pdf) (R 1.6.3.1)	Evidence Section 8.3.5; Page 132
Information about screening for Down's syndrome should be given to pregnant women at the first contact with a healthcare professional. This will provide the opportunity for further discussion before embarking on screening. Refer to 1.1.1 for more information about giving antenatal information. Specific information should include: • the screening pathway for both screen-positive and screen-negative results • the decisions that need to be made at each point along the pathway and their consequences • the fact that screening does not provide a definitive diagnosis and a full explanation of the risk score obtained following testing • information about chorionic villus sampling and amniocentesis • balanced and accurate information about Down's syndrome. (R 1.7.2.5)	Evidence Section 9.2.6; Page 176
Diabetes in pregnancy[37] **http://www.nice.org.uk/nicemedia/live/11946/41342/41342.pdf**	
Healthcare professionals should seek to empower women with diabetes to make the experience of pregnancy and childbirth a positive one by providing information, advice and support that will help to reduce the risks of adverse pregnancy outcomes for mother and baby. (R 1.1.1.1)	Consensus Section 3.1; Page 30
Women with diabetes who are planning to become pregnant and their families should be offered information about how diabetes affects pregnancy and how pregnancy affects diabetes. (R 1.1.1.3)	Consensus Section 3.1; Page 30
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	Consensus Section 3.2; Page 33

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
healthcare professionals. Women should be given information about the local arrangements for support, including emergency contact numbers. (R 1.1.1.2)	
Women with diabetes who are planning to become pregnant should be offered individualised dietary advice. (R 1.1.3.1)	Evidence Section 3.3; Page 36
Individualised targets for self-monitoring of blood glucose should be agreed with women who have diabetes and are planning to become pregnant, taking into account the risk of hypoglycaemia. (R 1.1.4.1)	Consensus Section 3.4; Page 41
Women with diabetes who are planning to become pregnant should be offered a meter for self-monitoring of blood glucose. (R 1.1.5.2)	Consensus Section 3.5; Page 42
Pre-conception care for women with diabetes should be given in a supportive environment and the woman's partner or other family member should be encouraged to attend. (R 1.1.8.3)	Consensus Section 3.8; Page 57
Women with diabetes who are planning to become pregnant should be offered pre-conception care and advice before discontinuing contraception. (R 1.1.9.2)	Evidence Section 3.9; Page 58
Women with gestational diabetes should be instructed in self-monitoring of blood glucose. Targets for blood glucose control should be determined in the same way as for women with pre-existing diabetes. (R 1.2.2.5)	Consensus Section 4.3; Page 74
Women with gestational diabetes should be offered information covering: • the role of diet, body weight and exercise • the increased risk of having a baby who is large for gestational age, which increases the likelihood of birth trauma, induction of labour and caesarean section • the importance of maternal glycaemic control during labour and birth and early feeding of the baby in order to reduce the risk of neonatal hypoglycaemia • the possibility of transient morbidity in the baby during the neonatal period, which may require admission to the neonatal unit • the risk of the baby developing obesity and/or diabetes in later life. (R 1.2.2.7)	Consensus based on evidence Section 4.3; Page 76
Antenatal appointments for women with diabetes should provide care specifically for women with diabetes, in addition to the care provided routinely for healthy pregnant women (see 'Antenatal care: routine care for the healthy pregnant woman' [NICE clinical guideline 62], available from www.nice.org.uk/CG062). Table 1 describes where care for women with diabetes differs from routine antenatal care. At each appointment women should be offered ongoing opportunities for information and education. (R 1.3.8.3)	Consensus Section 5.8; Page 107
Prophylaxis against infective endocarditis[50]	

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
http://www.nice.org.uk/nicemedia/live/11938/40039/40039.pdf	
No recommendations identified.	
Perioperative hypothermia (inadvertent)[31] **http://www.nice.org.uk/nicemedia/live/11962/40432/40432.pdf**	
Patients (and their families and carers) should be informed that: •staying warm before surgery will lower the risk of postoperative complications •the hospital environment may be colder than their own home •they should bring additional clothing, such as a dressing gown, a vest, warm clothing and slippers, to help them keep comfortably warm •they should tell staff if they feel cold at any time during their hospital stay. (R 1.1.1.1)	Consensus Section 4.2.2; Page 39
On transfer to the theatre suite: •the patient should be kept comfortably warm •the patient should be encouraged to walk to theatre where appropriate. (R 1.1.2.7)	Consensus Section 4.2.6; Page 52
Lipid modification[33] **http://www.nice.org.uk/nicemedia/live/11982/40689/40689.pdf**	
Healthcare professionals should use everyday, jargon-free language to communicate information on risk. If technical terms are used, these should be clearly explained. (R 1.2.1)	Consensus based Section 4.3.1.1; Page 93
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. (R 1.2.2)	Consensus based Section 4.3.1.1; Page 93
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. (R 1.2.4)	Consensus based on evidence Section 4.3; Page 93
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)	Consensus based Section 4.5; Page 103

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
• 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. (R 1.2.5)	
Advice about physical activity should take into account the person's needs, preferences and circumstances. Goals should be agreed and the person should be provided with written information about the benefits of activity and local opportunities to be active, in line with 'Physical activity' (NICE public health intervention guidance 2). (R 1.3.11)	Consensus based on external guidance Section 5.5.6; Page 130
People who want to stop smoking should be offered support and advice, and referral to an intensive support service (for example, the NHS Stop Smoking Services). (R 1.3.16)	Consensus based on external guidance Section 5.9; Page 135
The decision whether to initiate statin therapy should be made after an informed discussion between the responsible clinician and the person about the risks and benefits of statin treatment, taking into account additional factors such as comorbidities and life expectancy.17 (R 1.4.4)	Consensus based on external guidance Section 7.3.3; Page 175
Once a person has been started on a statin for primary prevention, repeat lipid measurement is unnecessary. Clinical judgement and patient preference should guide the review of drug therapy and whether to review the lipid profile. (R 1.4.10)	Consensus based Section 6.3.2.2; Page 148
The decision whether to initiate statin therapy should be made after an informed discussion between the responsible clinician and the person about the risks and benefits of statin treatment, taking into account additional factors such as comorbidities and life expectancy. (R 1.4.20)	Evidence Section 6.3.1 pg 143 ; section 7.3.1 pg 171
Induction of labour[38] **http://www.nice.org.uk/nicemedia/live/12012/41256/41256.pdf**	
Women should be informed that most women will go into labour spontaneously by 42 weeks. At the 38 week antenatal visit, all women should be offered information about the risks associated with pregnancies that last longer than 42 weeks, and their options. The information should cover: •membrane sweeping: –that membrane sweeping makes spontaneous labour more likely, and so reduces the need for formal induction of labour to prevent prolonged pregnancy –what a membrane sweep is –that discomfort and vaginal bleeding are possible from the procedure	Consensus based on evidence Section 3.1, p22/23

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
•induction of labour between 41+0 and 42+0 weeks •expectant management. (R 1.1.1.1)	
Healthcare professionals offering induction of labour should: •allow the woman time to discuss the information with her partner before coming to a decision •encourage the woman to look at a variety of sources of information •invite the woman to ask questions, and encourage her to think about her options •support the woman in whatever decision she makes. (R 1.1.1.3)	Consensus based on evidence Section 3.1, p22/23
Women with uncomplicated pregnancies should usually be offered induction of labour between 41+0 and 42+0 weeks to avoid the risks of prolonged pregnancy. The exact timing should take into account the woman's preferences and local circumstances. (R 1.2.1.2)	Consensus based on evidence Section 4.1, p28/29
If a woman chooses not to have induction of labour, her decision should be respected. Healthcare professionals should discuss the woman's care with her from then on. (R 1.2.1.3)	Consensus based on evidence Section 4.1, p28/29
In the event of an intrauterine fetal death, healthcare professionals should offer support to help women and their partners and/or family cope with the emotional and physical consequences of the death. This should include offering information about specialist support. (R 1.2.9.1)	Consensus Section 4.9, p28/29
During induction of labour, healthcare professionals should provide women with the pain relief appropriate for them and their pain (as described in 'Intrapartum care' [NICE clinical guideline 55]). This can range from simple analgesics to epidural analgesia. (R 1.6.2.3)	Consensus Section 7.2, p74/75
Birth attendants (carers and healthcare professionals) should offer women support and analgesia as required, and should encourage women to use their own coping strategies for pain relief. (R 1.6.2.4)	Consensus Section 7.2, p74/75
Respiratory tract infections[51] **http://www.nice.org.uk/nicemedia/live/12015/41323/41323.pdf**	
Patients' or parents'/carers' concerns and expectations should be determined and addressed when agreeing the use of the three antibiotic prescribing strategies (no prescribing, delayed prescribing and immediate prescribing). (R 1.1.2)	Evidence and consensus SECTION 2.2.3; p45 and p52 patient satisfaction; Consensus - p62, unclear which sections fed into recommendation
Stroke[27] **http://www.nice.org.uk/nicemedia/live/12018/41331/41331.pdf**	

Recommendation (reference)	**Evidence based?** **Consensus recommendation?**[c]
No recommendations identified.	
Familial hypercholesterolaemia[32] **http://www.nice.org.uk/nicemedia/live/12048/41697/41697.pdf**	
Decisions about the choice of treatment should be made following discussion with the adult or child/young person and their parent/carer, and be informed by consideration of concomitant medication, comorbidities, safety and tolerability. (R 1.3.1.28)	Consensus based Section 5.2.3; Page 118
During the assessment and communication of familial risk, people should receive clear and appropriate educational information about FH, the process of family testing, DNA testing and the measurement of LDL-C concentration. R 1.4.1.1)	Consensus based Section 6.2.1; Page 159
A healthcare professional with expertise in FH should provide information to people with FH on their specific level of risk of coronary heart disease, its implications for them and their families, lifestyle advice and treatment options. (R 1.4.1.2)	Consensus based Section 6.2.1; Page 159
Healthcare professionals with expertise in FH should encourage people with FH to contact their relatives to inform them of their potential risk and so that cascade testing can take place. (R 1.4.1.3)	Consensus based Section 6.2.1; Page 159
When considering cascade testing, a healthcare professional with expertise in FH should offer to facilitate the sharing of information about FH with family members. (R 1.4.1.4)	Consensus based Section 6.2.1; Page 159
Healthcare professionals should offer people with FH and their families written advice and information about patient support groups. (R 1.4.1.5)	Consensus based Section 6.2.1; Page 159
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. (R 1.4.2.1)	Consensus based Section 8.3.1; Page 214
Healthcare professionals should give women and girls with FH specific information tailored to their needs and should offer a choice of effective contraceptive methods. (R 1.4.2.2)	Consensus based Section 8.3.1; Page 214
Women with FH who have conceived while taking statins or other systemically absorbed lipid-modifying drug therapy and have had a fetal assessment should be given time, opportunity and full information to consider their options (including the advantages and disadvantages) of continuing with their pregnancy. (R 1.4.3.4)	Consensus based Section 8.3.3; Page 220
Attention deficit hyperactivity disorder (ADHD)[29] **http://www.nice.org.uk/nicemedia/live/12061/42059/42059.pdf**	
Healthcare professionals should develop a trusting relationship with people with ADHD and their families or carers by: • respecting the person and their family's knowledge and experience of ADHD	Consensus Unclear in guideline

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
• being sensitive to stigma in relation to mental illness. (R 1.1.2.1)	
Healthcare professionals should provide people with ADHD and their families or carers with relevant, age-appropriate information (including written information) about ADHD at every stage of their care. The information should cover diagnosis and assessment, support and self-help, psychological treatment, and the use and possible side effects of drug treatment. (R 1.1.2.2)	Consensus Unclear in guideline
Adults with ADHD should be given written information about local and national support groups and voluntary organisations. (R 1.1.2.6)	Consensus Unclear in guideline
Healthcare professionals should ask families or carers about the impact of ADHD on themselves and other family members, and discuss any concerns they may have. Healthcare professionals should: • offer family members or carers an assessment of their personal, social and mental health needs • encourage participation in self-help and support groups where appropriate • offer general advice to parents and carers about positive parent– and carer–child contact, clear and appropriate rules about behaviour, and the importance of structure in the child or young person's day • explain that parent-training/education programmes do not necessarily imply bad parenting, and that their aim is to optimise parenting skills to meet the above-average parenting needs of children and young people with ADHD. (R 1.1.2.7)	Consensus Unclear in guideline
In determining the clinical significance of impairment resulting from the symptoms of ADHD in children and young people, their views should be taken into account wherever possible. (R 1.3.1.5)	Consensus Section 5.16/5.17.
Following a diagnosis of ADHD, healthcare professionals should consider providing all parents or carers of all children and young people with ADHD self-instruction manuals, and other materials such as videos, based on positive parenting and behavioural techniques. (R 1.4.1.1)	Consensus Section 5.16/5.17
If there has been a poor response following parenttraining/education programmes and/or psychological treatment and treatment with methylphenidate and atomoxetine in a child or young person with ADHD, there should be a further review of: • the diagnosis • any coexisting conditions • response to drug treatment, occurrence of side effects and treatment adherence • uptake and use of psychological interventions for the child or young person and their parents or carers	Consensus based Section 10.17; Page 303

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
• effects of stigma on treatment acceptability • concerns related to school and/or family • motivation of the child or young person and the parents or carers • the child or young person's diet.	
A young person with ADHD receiving treatment and care from CAMHS or paediatric services should be reassessed at schoolleaving 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. (R 1.6.1.1)	Consensus based Section 6.2.4; Page 138
During the transition to adult services, a formal meeting involving CAMHS and/or paediatrics and adult psychiatric services should be considered, and full information provided to the young person about adult services. For young people aged 16 years and older, the care programme approach (CPA) should be used as an aid to transfer between services. The young person, and when appropriate the parent or carer, should be involved in the planning. (R 1.6.1.2)	Consensus based Section 6.2.4; Page 138
Healthcare professionals should consider suggesting peer-support groups for the child or young person with ADHD and their parents or carers if adherence to drug treatment is difficult or uncertain. (R 1.8.5.2)	Consensus based Section 7.2.8; Page 166
Where necessary, healthcare professionals should help parents or carers develop a positive attitude and approach in the management of medication, which might include praise and positive reinforcement for the child or young person with ADHD. (R 1.8.5.7)	Consensus based Section 10.17; Page 302
An individual treatment approach is important for adults, and healthcare professionals should regularly review (at least annually) the need to adapt patterns of use, including the effect of drug treatment on coexisting conditions and mood changes. (R 1.8.7.2)	Consensus based Section 10.17; Page 302
Chronic kidney disease[25] **http://www.nice.org.uk/nicemedia/live/12069/42117/42117.pdf**	
Offer people with CKD education and information tailored to the stage and cause of CKD, the associated complications and the risk of progression. (R 1.3.1)	Consensus based on evidence Section 15.1.5, p180/181
When developing information or education programmes, involve people with CKD in their development from the outset. The following topics are suggested. • What is CKD and how does it affect people? • What questions should people ask about their kidneys when they attend clinic? • What treatments are available for CKD, what are their advantages and disadvantages and what complications or side effects	Consensus based on evidence Section 15.1.5, p180/181

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
may occur as a result of treatment/medication? • What can people do to manage and influence their own condition? • In what ways could CKD and its treatment affect people's daily life, social activities, work opportunities and financial situation, including benefits and allowances available? • How can people cope with and adjust to CKD and what sources of psychological support are available? • When appropriate, offer information about renal replacement therapy (such as the frequency and length of time of dialysis treatment sessions or exchanges and pre-emptive transplantation) and the preparation required (such as having a fistula or peritoneal catheter). • Conservative management may be considered where appropriate. (R 1.3.2)	
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. (R 1.3.3)	Consensus based on evidence Section 15.1.5, p180/181)
Healthcare professionals providing information and education programmes should ensure they have specialist knowledge about CKD and the necessary skills to facilitate learning. (R 1.3.4)	Consensus based on evidence Section 15.1.5, p180/181
Healthcare professionals working with people with CKD should take account of the psychological aspects of coping with the condition and offer access to appropriate support – for example, support groups, counselling or a specialist nurse. (R 1.3.5)	Consensus based on evidence Section 15.1.5, p180/181
Take into account the individual's wishes and comorbidities when considering referral. (R 1.6.4)	Consensus Section 7.1.5, p87/88
Where the clinician in discussion with the patient has decided that dietary intervention to influence progression of CKD is indicated, an appropriately trained professional should discuss the risks and benefits of dietary protein restriction, with particular reference to slowing down the progression of disease versus protein-calorie malnutrition. (R 1.7.2)	Evidence and consensus Section 8.2.5, p99/100
To improve concordance, inform people who are prescribed ACE inhibitors or ARB therapy about the importance of: • achieving the optimal tolerated dose of ACE inhibitor/ARB, and • monitoring eGFR and serum potassium in achieving this safely. (R 1.8.9)	Evidence and consensus Section 9.2.6, p121/122
Surgical site infection[39] **http://www.nice.org.uk/nicemedia/live/11743/42379/42379.pdf**	
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. (R 1.1.1)	Consensus Section 4.1; Page 21
Offer patients and carers information and advice on how to care for their wound after discharge. (R 1.1.2)	Consensus Section 4.1; Page 21

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
Offer patients and carers information and advice about how to recognise a surgical site infection and who to contact if they are concerned. Use an integrated care pathway for healthcare-associated infections to help communicate this information to both patients and all those involved in their care after discharge. (R 1.1.3)	Consensus Section 4.1; Page 21
Always inform patients after their operation if they have been given antibiotics. (R 1.1.4)	Consensus Section 4.1; Page 21
Give patients specific theatre wear that is appropriate for the procedure and clinical setting, and that provides easy access to the operative site and areas for placing devices, such as intravenous cannulas. Consider also the patient's comfort and dignity. (R 1.2.4)	Consensus Section 5.3; Page 28
Metastatic spinal cord compression[19] **http://www.nice.org.uk/nicemedia/live/12085/42653/42653.pdf**	
Ensure that communication with patients with known or suspected MSCC is clear and consistent, and that the patients, their families and carers are fully informed and involved in all decisions about treatment. (R 1.2.1.2)	Consensus Section 3.2; Page 17
Offer patients with MSCC and their families and carers specialist psychological and/or spiritual support appropriate to their needs at diagnosis, at other key points during treatment and on discharge from hospital. (R 1.2.2.1)	Consensus based Section 3.2; Page 18
Provide information to patients with MSCC in an appropriate language and format that explains how to access psychological and/or spiritual support services when needed. (R 1.2.2.2)	Consensus based Section 3.2; Page 18
Offer bereavement support services to patients' families based on the three component model outlined in 'Improving supportive and palliative care for adults with cancer' (NICE cancer service guidance CSGSP). (R 1.2.2.3)	Consensus based Section 3.2; Page 18
Inform patients at high risk of developing bone metastases, patients with diagnosed bone metastases, or patients with cancer who present with spinal pain about the symptoms of MSCC. Offer information (for example, in the form of a leaflet) to patients and their families and carers which explains the symptoms of MSCC, and advises them (and their healthcare professionals) what to do if they develop these symptoms. (R 1.3.1.3)	Consensus based Section 4.2; Page 19
Ensure that patients with MSCC and their families and carers know who to contact if their symptoms progress while they are waiting for urgent investigation of suspected MSCC. (R 1.3.1.2)	Consensus Section 4.2; Page 19
All decisions on the most appropriate combinations of treatment for pain or preventing paralysis caused by MSCC should be made by relevant spinal specialists in consultation with primary tumour site clinicians and with the full involvement of the patient. (R 1.5.1.14)	Consensus Section 6.2; Page 35
Take into account the preferences of patients with MSCC as well as their neurological ability, functional status, general health and fitness, previous treatments, magnitude of surgery, likelihood of complications, fitness for general anaesthesia and overall	Consensus Section 6.4; Page 39

Recommendation (reference)	Evidence based? Consensus recommendation?[c]
prognosis when planning treatment. (R 1.5.3.4)	
Carefully plan surgery to maximise the probability of preserving spinal cord function without undue risk to the patient, taking into account their overall fitness, prognosis and preferences. (R 1.5.4.3)	Evidence Section 6.5; Page 45
Ensure that all patients admitted to hospital with MSCC have access to a full range of healthcare professional support services for assessment, advice and rehabilitation. (R 1.6.5.1)	Consensus Section 7.6; Page 60
Focus the rehabilitation of patients with MSCC on their goals and desired outcomes, which could include promoting functional independence, participation in normal activities of daily life and aspects related to their quality of life. (R 1.6.5.2)	Consensus Section 7.6; Page 60
Discharge planning and ongoing care, including rehabilitation for patients with MSCC, should start on admission and be led by a named individual from within the responsible clinical team. It should involve the patient and their families and carers, their primary oncology site team, rehabilitation team and community support, including primary care and specialist palliative care, as required. (R 1.6.5.4)	Consensus Section 7.6; Page 61
Ensure that community-based rehabilitation and supportive care services are available to people with MSCC following their return home, in order to maximise their quality of life and continued involvement in activities that they value. (R 1.6.5.5)	Consensus Section 7.6; Page 61
Ensure that people with MSCC are provided with the equipment and care they require in a timely fashion to maximise their quality of life at home. (R 1.6.5.6)	Consensus Section 7.6; Page 61
Offer the families and carers of patients with MSCC relevant support and training before discharge home. (R 1.6.5.7)	Consensus Section 7.6; Page 61
Clear pathways should be established between hospitals and community-based healthcare and social services teams to ensure that equipment and support for people with MSCC returning home and their carers and families are arranged in an efficient and coordinated manner. (R 1.6.5.8)	Consensus Section 7.6; Page 61

Appendix D: Literature review questions and protocols

Review questions	**What is the clinical and cost-effectiveness of decision aids versus no intervention, usual care, alternative interventions, or a combination?**
Objectives	To compare the clinical and cost effectiveness of decision aids with no intervention, usual care, alternative interventions in of adults making decisions about screening or treatment for themselves, for a child, or for an incapacitated significant other.
Criteria	Population: Adults (≥ 18 years old) making decisions about screening or treatment for themselves, for a child, or for an incapacitated significant other. Excluded: studies in which people were making hypothetical choices. Intervention: Decision aids Comparison: No intervention, Usual care, Alternative interventions, Combination Primary outcomes: • Evaluation criteria which map onto the IPDAS criteria • Attributes of the decision • Attributes of the decision process • Decisional conflict • Patient-practitioner communication • Participation in decision making • Satisfaction Secondary Outcomes: • Decisions (proportion undecided, option selected) • Adherence to chosen option • Health status and quality of life (generic and condition specific) • Anxiety, depression, emotional distress, regret, confidence • Patients' and physicians' satisfaction • Costs, cost effectiveness • Consultation length • Litigation rates Study Design: RCT Population size and directness: • No limits of sample size • Studies with indirect populations will not be considered
Search strategy	No search to be undertaken – Cochrane review to be accepted as is (search cut-off Dec 2009) (confirmed with NICE)
Review strategy	The methodology and results of the 2011 Cochrane review “decision aids for people facing health treatment or screening decisions” will be presented to the guideline development group for consideration.
Economic review strategy	The Cochrane review included cost and cost-effectiveness as outcomes but was restricted to RCTs. Additional search to be run on NHS EED, HTA and HEED only with aim of checking for cost-effectiveness models based on RCT data. Note deviation from Guidelines Manual – we will not run search in Medline/Embase for past year – this is considered a reasonable pragmatic approach given the Cochrane cut-off is Dec 2009. Study design: cost-utility analysis, cost-benefit analysis, cost-effectiveness analysis, cost-consequence analysis, comparative cost analysis Each study is assessed using the NICE economic evaluation checklist – NICE (2009)

	Guidelines Manual, Appendix H. See also table below 'Economic review – inclusion/exclusion criteria'

Review question	**What is the effectiveness of interventions to improve the continuity of care of patients in the National Health Service?**
Objectives	To evaluate the effectiveness of interventions used to improve continuity of patient care.
Criteria	Population: Adults Exclusions: People under the age of 18 years, people using health services specifically for the treatment of mental health problems. Interventions: For example: centralised records, electronic patient records, established routines for handovers and exchange of information, proactive follow-up of patients after significant life events or health events, key workers, nurse-led care Comparison: Usual care Outcomes: These will be determined once relevant interventions have been identified. Study Design: Systematic reviews of RCTs or cohort studies Setting: All settings where NHS care is delivered
Search strategy	Searches were conducted in Medline, Embase, PsychInfo, CINAHL and the Cochrane Library, with a cut-off date of 9th May 2011. For full search strategies see Appendix E.
Review strategy	Appraisal of methodological quality: the methodological quality of the systematic reviews will be appraised using NICE checklists.
Economic review strategy	Targeted searches to be undertaken following clinical review looking for specific interventions identified from clinical review. Study design: cost-utility analysis, cost-benefit analysis, cost-effectiveness analysis, cost-consequence analysis, comparative cost analysis. Each study assessed using the NICE economic evaluation checklist – NICE (2009) Guidelines Manual, Appendix H. See also table below 'Economic review – inclusion/exclusion criteria'.

Review questions	**Risk Communication**
Objectives	What methods of presenting information improve a patient's understanding of the risks and benefits associated with their treatment options?
Criteria	Population: Adults Excluded: People under the age of 18 years, people using health services specifically for the treatment of mental health problems. Intervention: data will be extracted for risk language, design of visual presentations, tailored risk language and format of communication Outcomes: will be determined once relevant papers have been identified. Study Design: systematic reviews of RCTs and/or cohort studies Setting: all settings
Search strategy	Searches were conducted in Medline, Embase, PsychInfo, CINAHL and the Cochrane Library, with a cut-off date of 9th May 2011. For full search strategies see Appendix E.
Review strategy	Appraisal of methodological quality: the methodological quality of each systematic review/meta-analysis will be assessed using NICE checklists.
Economic review strategy	An economic search will not be undertaken for this review question. It is considered that in most cases there will not be cost differences between strategies (e.g. using different language to communicate risk).

Review	**What components of patient education programmes improve patient experience?**

questions	
Objectives	To determine what components of patient education programmes improve patient-related outcomes and are transferable across disease populations.
Criteria	Population: Adults (≥ 18 years old). Excluded: People under the age of 18 years, people using health services specifically for the treatment of mental health problems. Intervention: Any variation on components of patient education programmes (for example, one-on-one counselling, group work, audiovisual presentations) Comparison: usual care Study Design: Systematic reviews of RCTs and cohort studies Population size and directness: • No limits of sample size • Studies with indirect populations will not be considered
Search strategy	Searches were conducted in Medline, Embase, PsychInfo, CINAHL and the Cochrane Library, with a cut-off date of 9th May 2011. For full search strategies see Appendix E.
Review strategy	Appraisal of methodological quality: the methodological quality of the systematic reviews will be appraised using NICE checklists.
Economic review strategy	An economic search will not be undertaken for this review question.

Economic review – inclusion/exclusion criteria

Each study is assessed using the NICE economic evaluation checklist – NICE (2009) Guidelines Manual, Appendix H.

Inclusion/exclusion criteria

- If a study is rated as both ‘Directly applicable’ and ‘Minor limitations’ (using the NICE economic evaluation checklist) then it should be included in the guideline. An evidence table should be completed and it should be included in the economic profile.
- If a study is rated as either ‘Not applicable’ or ‘Very serious limitations’ then it should be excluded from the guideline. It should not be included in the economic profile and there is no need to include an evidence table.
- If a study is rated as ‘Partially applicable’ and/or ‘Potentially serious limitations’ then there is discretion over whether it should be included. The health economist should make a decision based on the relative applicability and quality of the available evidence for that question, in discussion with the GDG if required. The ultimate aim being to include studies that are helpful for decision making in the context of the guideline. Where exclusions occur on this basis, this should be noted in the relevant section of the guideline with references.

Also exclude:

- unpublished reports unless submitted as part of the call for evidence
- abstract-only studies
- letters
- editorials
- reviews of economic evaluations *0*
- foreign language articles

Where there is discretion

The health economist should be guided by the following hierarchies.

Setting:

- UK NHS
- OECD countries with predominantly public health insurance systems (e.g. France, Germany, Sweden)
- OECD countries with predominantly private health insurance systems (e.g. USA, Switzerland)
- Non-OECD settings (always ‘Not applicable’)

Economic review – inclusion/exclusion criteria
Economic study type: • Cost-utility analysis • Other type of full economic evaluation (cost-benefit analysis, cost-effectiveness analysis, cost-consequence analysis) • Comparative cost analysis • Non-comparative cost analyses including cost of illness studies (always ‘Not applicable’) *Year of analysis:* • Studies that are based on resource use and unit costs from more than 10 years ago will be downgraded in terms of applicability • Studies that are based on resource use and unit costs from more than 20 years ago will be judged not applicable *Quality and relevance of effectiveness data used in the economic analysis:* • The more closely the effectiveness data used in the economic analysis matches with the studies included for the clinical review the more useful the analysis will be to decision making for the guideline.

(a) Recent reviews will be ordered although not reviewed. The bibliographies will be checked for relevant studies, which will then be ordered.

Appendix E: Literature search strategies

Search strategies used for the patient experience guideline are outlined below and were run as per the NICE Guidelines Manual 2009[44].

Searches for the **thematic qualitative review** were run as part of the Warwick University scoping report. See Appendix B for further details of these search strategies.

Searches for **patient experience frameworks** were run in Medline (OVID), Embase (OVID), HMIC (Ovid), PsychInfo (OVID), the Cochrane Library, Cinahl (EBSCO) and ASSIA (ProQuest).

Searches for the **literature reviews** were run in Medline (OVID), Embase (OVID), PsychInfo (OVID), the Cochrane Library and Cinahl (EBSCO). Searches were conducted by combining study filter terms with the question terms using the AND Boolean operator.

Searches for the **health economic reviews** were run in Medline (Ovid), Embase (Ovid), the NHS Economic Evaluations Database (NHS EED), the Health Technology Assessment (HTA) database and the Health Economic Evaluation Database (HEED). NHS EED and HTA were searched via the Centre for Reviews and Dissemination (CRD) interface. Searches in NHS EED, HTA and HEED were constructed only using population terms. For Medline and Embase an economic filter (instead of a study type filter) was added to the clinical search strategy.

All searches were run up to 9th May 2011 unless otherwise stated. Any studies added to the databases after this date were not included unless specifically stated in the text.

The search strategies are presented below in the following order:

Section E.1	Patient experience frameworks terms by database
Section E.2	Study filter terms by database. These include filters for epidemiological study designs and health economic studies
Section E.3	Searches run for specific questions with the literature review terms by database
Section E.3.1	Continuity of care
Section E.3.2	Education programmes
Section E.3.3	Risk communication
Section E.4	Economics searches
Section E.4.1	Decision aids
Section E.4.2	Midwife-led care

E.1 Patient experience frameworks search terms

Search constructed by combining the columns in the following table using the AND Boolean operator

Population	Intervention / exposure	Comparison	Study filter used	Date parameters
Patient experience	Frameworks			Searches run to 10/02/2011

Medline search terms

1	(patient$ adj (experience or centre$ or center$)).ti.
2	framework$.ti,ab.
3	Models, Theoretical/
4	or/2-3
5	1 and 4

Embase search terms

1 (patient$ adj (experience or centre$ or center$)).ti.
2 framework$.ti,ab.
3 conceptual framework/
4 theoretical model/
5 or/2-4
6 1 and 5

Cinahl search terms

S1 TI patient* n1 experience or TI patient* n1 centre* or TI patient* n1 center*
S2 framework*
S3 (MH "Conceptual Framework") OR (MH "Models, Theoretical")
S4 S2 or S3
S5 S1 and S4

Cochrane search terms

#1 (patient* NEAR (experience or centre* or center*)):ti
#2 framework*:ti,ab,kw
#3 MeSH descriptor Models, Theoretical, this term only
#4 (#2 OR #3)
#5 (#1 AND #4)

PsychInfo search terms

1 (patient$ adj (experience or centre$ or center$)).ti.
2 framework$.ti,ab.
3 models/
4 or/2-3
5 1 and 4

HMIC search terms

1 (patient$ adj (experience or centre$ or center$)).ti.
2 framework$.ti,ab.
3 exp frameworks/
4 or/2-3
5 1 and 4

ASSIA search terms

1 (EXACT("Models" OR "Conceptual Models") OR framework*) AND (patient* near/1 (experience OR centre* OR center*))

E.2 Study filter search terms

E.2.1 Systematic review search terms

Medline search terms

1 meta-analysis/
2 (metaanalys$ or meta-analys$ or meta analys$).tw.
3 exp "review literature"/
4 (systematic$ adj3 (review$ or overview$)).tw.
5 (selection criteria or data extraction).ab. and review.pt.

6 (cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or cinhal or science citation index or bids or cancerlit).ab.
7 (reference list$ or bibliograph$ or hand search$ or hand-search$ or manual search$ or relevant journals).ab.
8 or/1-7
9 (comment or letter or editorial).pt.
10 exp animal/ not human/
11 or/9-10
12 8 not 11

Embase search terms

1 meta analysis/
2 (metaanalys$ or meta-analys$ or meta analys$).tw.
3 systematic review/
4 (systematic$ adj3 (review$ or overview$)).tw.
5 (selection criteria or data extraction).ab. and Review.pt.
6 (cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or cinhal or science citation index or bids or cancerlit).ab.
7 (reference list$ or bibliograph$ or hand search$ or manual search$ or relevant journals).ab.
8 or/1-7
9 (letter or editorial or conference abstract).pt.
10 (exp animal/ or nonhuman/ or exp animal-experiment/) not exp human/
11 or/9-10
12 8 not 11

Cinahl search terms

S1 (MH "Meta Analysis")
S2 (MH "Literature Review+")
S3 meta analy* or metaanaly* or systematic n1 review* or systematic n1 overview*
S4 PT systematic review or PT meta analysis
S5 S1 or S2 or S3 or S4

PsychInfo search terms

1 "literature review"/ or meta analysis/
2 (metaanalys$ or meta-analys$ or meta analys$).tw.
3 (systematic$ adj3 (review$ or overview$)).tw.
4 (reference list$ or bibliograph$ or hand search$ or hand-search$ or manual search$ or relevant journals).ab.
5 or/1-4

E.2.2 Randomised controlled trials (RCTs) search terms

Medine search terms

1 Randomized-Controlled-Trials/ or Random-Allocation/ or Double-Blind-Method/ or Single-Blind-Method/ or exp Clinical-Trials as topic/ or Cross-Over-Studies/ or Prospective-Studies/ or Placebos/
2 (Randomized-Controlled-Trial or Clinical-Trial or Controlled-Clinical-Trial).pt.
3 (((clinical or control or controlled) adj (study or trial)) or ((single or double or triple) adj (blind$3 or mask$3)) or (random$ adj (assign$ or allocat$ or group or grouped or patients or study or trial or distribut$)) or (crossover adj (design or study or trial)) or placebo or placebos).ti,ab.
4 ((Case-Reports not Randomized-Controlled-Trial) or Letter or Historical-Article or Review-Of-

Reported-Cases).pt.
5 or/1-4
6 exp Animal/ not Human/
7 5 not 6

Embase search terms

1 Clinical-Trial/ or Randomized-Controlled-Trial/ or Randomization/ or Single-Blind-Procedure/ or Double-Blind-Procedure/ or Crossover-Procedure/ or Prospective-Study/ or Placebo/
2 (((clinical or control or controlled) adj (study or trial)) or ((single or double or triple) adj (blind$3 or mask$3)) or (random$ adj (assign$ or allocat$ or group or grouped or patients or study or trial or distribut$)) or (crossover adj (design or study or trial)) or placebo or placebos).ti,ab.
3 Case-Study/ or Abstract-Report/ or Letter/ or (case adj report).tw. or conference abstract.pt.
4 (exp Animal/ or Nonhuman/ or exp Animal-Experiment/) not exp Human/
5 or/1-2
6 or/3-4
7 5 not 6

E.2.3 Observational studies search terms

Medline search terms

1 Epidemiologic studies/
2 exp case control studies/
3 exp cohort studies/
4 Cross-sectional studies/
5 case control.ti,ab.
6 (cohort adj (study or studies or analys$)).ti,ab.
7 ((follow up or observational or uncontrolled or non randomi#ed) adj (study or studies)).ti,ab.
8 ((longitudinal or retrospective or prospective) and (study or studies or review or analys$ or cohort$)).ti,ab.
9 cross sectional.ti,ab.
10 or/1-9

Embase search terms

1 Clinical study/
2 exp case control study/
3 family study/
4 longitudinal study/
5 retrospective study/
6 prospective study/
7 cross-sectional study/
8 cohort analysis/
9 follow-up/
10 cohort$.ti,ab.
11 9 and 10
12 ((follow up or observational or case control or uncontrolled or non randomi#ed or epidemiologic$) adj (study or studies)).ti,ab.
13 ((longitudinal or retrospective or prospective or cross sectional) adj3 (study or studies or review or analys$ or cohort$)).ti,ab.
14 (cohort adj (study or studies or analys$)).ti,ab.

15 or/1-8,11-14

E.2.4 Health economic and economic model search terms

Medline search terms

1 exp "costs and cost analysis"/
2 economics/ or exp economics, hospital/ or exp economics, medical/ or economics, nursing/ or economics, pharmaceutical/
3 exp "fees and charges"/ or exp budgets/
4 budget$.tw.
5 cost$.ti.
6 (cost$ adj2 (effective$ or utilit$ or benefit$ or minimi$)).ab.
7 (economic$ or pharmacoeconomic$ or pharmaco-economic$).ti.
8 (price$ or pricing$).tw.
9 (financial or finance or finances or financed).tw.
10 (fee or fees).tw.
11 (value adj2 (money or monetary)).tw.
12 exp models, economic/ or *models, theoretical/ or *models, organizational/
13 economic model$.tw.
14 markov chains/
15 markov$.tw.
16 monte carlo method/
17 monte carlo.tw.
18 exp decision theory/
19 (decision$ adj2 (tree$ or analy$ or model$)).tw.
20 or/1-19
21 (letter or editorial or comment).pt.
22 20 not 21

Embase search terms

1 exp *economic aspect/
2 cost$.ti.
3 (cost$ adj2 (effective$ or utilit$ or benefit$ or minimi$)).ab.
4 (economic$ or pharmacoeconomic$ or pharmaco-economic$).ti.
5 (price$ or pricing$).tw.
6 (financial or finance or finances or financed).tw.
7 (fee or fees).tw.
8 (value adj2 (money or monetary)).tw.
9 exp *mathematical model/
10 economic model$.tw.
11 markov$.tw.
12 monte carlo method/
13 monte carlo.tw.
14 decision theory/
15 (decision$ adj2 (tree$ or analy$ or model$)).tw.
16 or/1-15
17 (comment or letter or editorial).pt.
18 16 not 17

E.3 Searches by specific questions

E.3.1 Continuity of care

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

Search constructed by combining the columns in the following table using the AND Boolean operator

Population	Intervention / exposure	Comparison	Study filter used	Date parameters
Continuity of care			Systematic reviews of RCTs or observational studies (Medline and Embase only); systematic reviews (Cinahl and PsychInfo only)	Searches run to 09/05/2011

Medline search terms

1	"Continuity of Patient Care"/
2	((coordinat$ or co ordinat$ or co-ordinat$ or integrat$ or collaborat$ or continu$ or shared) adj3 (care$ or manage$)).ti,ab.
3	or/1-2

Embase search terms

1	*patient care/
2	((coordinat$ or co ordinat$ or co-ordinat$ or integrat$ or collaborat$ or continu$ or shared) adj3 (care$ or manage$)).ti,ab.
3	or/1-2

Cinahl search terms

S1	(MH "Continuity of Patient Care+")
S2	coordinat* n3 care* or co ordinat* n3 care* or co-ordinat* n3 care* or integrat* n3 care* or collaborat* n3 care* or continu* n3 care* or shared n3 care*
S3	coordinat* n3 manage* or co ordinat* n3 manage* or co-ordinat* n3 manage* or integrat* n3 manage* or collaborat* n3 manage* or continu* n3 manage* or shared n3 manage*
S4	S1 or S2 or S3

Cochrane search terms

#1	MeSH descriptor Continuity of Patient Care, this term only
#2	((coordinat* or co ordinat* or co-ordinat* or integrat* or collaborat* or continu* or shared) NEAR/3 (care* or manage*)):ti,ab,kw
#3	(#1 OR #2)

PsychInfo search terms

1	"continuum of care"/
2	((coordinat$ or co ordinat$ or co-ordinat$ or integrat$ or collaborat$ or continu$ or shared) adj3 (care$ or manage$)).ti,ab.
3	or/1-2

E.3.2 Education programmes

What components of patient education programmes improve patient experience?

Search constructed by combining the columns in the following table using the AND Boolean operator

Population	Intervention / exposure	Comparison	Study filter used	Date parameters
Education programmes	Components		Systematic reviews of RCTs (Medline and Embase only); systematic reviews (Cinahl and PsychInfo only)	Searches run to 09/05/2011

Medline search terms

1	((educat$ or train$ or teach$ or instruct$ or skill$ or support$) adj2 (program$ or course$ or intervention$)).ti,ab.
2	(component$ or element$ or principle$ or constituent$ or contents).ti,ab.
3	1 and 2

Embase search terms

1	education program/
2	((educat$ or train$ or teach$ or instruct$ or skill$ or support$) adj2 (program$ or course$ or intervention$)).ti,ab.
3	or/1-2
4	(component$ or element$ or principle$ or constituent$ or contents).ti,ab
5	3 and 4

Cinahl search terms

S1	educat* n2 program* or educat* n2 course* or educat* n2 intervention* or train* n2 program* or train* n2 course* or train* n2 intervention*
S2	teach* n2 program* or teach* n2 course* or teach* n2 intervention* or instruct* n2 program* or instruct* n2 course* or instruct* n2 intervention*
S3	skill* n2 program* or skill* n2 course* or skill* n2 intervention* or support* n2 program* or support* n2 course* or support* n2 intervention*
S4	component* or element* or principle* or constituent* or contents
S5	S1 or S2 or S3
S6	S4 and S5

Cochrane search terms

#1	((educat* or train* or teach* or instruct* or skill* or support*) NEAR/2 (program* or course* or intervention*)):ti,ab,kw
#2	(component* or element* or principle* or constituent* or contents):ti,ab,kw
#3	(#1 AND #2)

PsychInfo search terms

1	educational programs/
2	((educat$ OR train$ OR teach$ OR instruct$ OR skill$ OR support$) adj2 (program$ OR course$ OR intervention$)).ti,ab
3	or/1-2
4	(component$ OR element$ OR principle$ OR constituent$ OR contents).ti,ab

5 3 and 4

E.3.3 Risk communication

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

Search constructed by combining the columns in the following table using the AND Boolean operator

Population	Intervention / exposure	Comparison	Study filter used	Date parameters
Risk	Communication, presentation		Systematic reviews of RCTs (Medline and Embase only); systematic reviews (Cinahl and PsychInfo only)	Searches run to 09/05/2011

Medline search terms

1 exp *risk/
2 risk$.ti,ab.
3 or/1-2
4 exp communication/ or audiovisual aids/ or data interpretation, statistical/
5 1 and 4
6 (fram$ adj2 (effect$ or positiv$ or negativ$)).ti,ab.
7 (information$ adj5 display).ti,ab.
8 ((graph$ or visual$ or statistic$) adj3 (present$ or format$)).ti,ab.
9 framing.ti.
10 or/6-9
11 3 and 10
12 (risk$ adj2 (language$ or communicat$ or presentation$ or presenting or inform$ or tailor$ or individuali?e$ or personal$ or rate$ or reference class$)).ti,ab.
13 or/5,11-12

Embase search terms

1 exp *risk/
2 risk$.ti,ab.
3 or/1-2
4 exp interpersonal communication/
5 audiovisual equipment/
6 statistical analysis/
7 or/4-6
8 1 and 7
9 (fram$ adj2 (effect$ or positiv$ or negativ$)).ti,ab.
10 (information$ adj5 display).ti,ab.
11 ((graph$ or visual$ or statistic$) adj3 (present$ or format$)).ti,ab.
12 framing.ti.
13 or/9-12
14 3 and 13

15 (risk$ adj2 (language$ or communicat$ or presentation$ or presenting or inform$ or tailor$ or individuali?e$ or personal$ or rate$ or reference class$)).ti,ab.
16 or/8,14-15

Cinahl search terms

S1 (MM "Risk Factors+")
S2 (MM "Attributable Risk") OR (MM "Relative Risk")
S3 (MH "Communication+")
S4 (MH "Audiovisuals")
S5 (MH "Data Analysis, Statistical")
S6 S3 or S4 or S5
S7 S1 or S2
S8 S6 and S7
S9 risk*
S10 fram* n2 effect* or fram* n2 positiv* or fram* n2 negativ*
S11 information* n5 display
S12 graph* n3 present* or graph* n3 format* or visual* n3 present* or visual* n3 format* or statistic* n3 present* or statistic* n3 format*
S13 TI framing
S14 S10 or S11 or S12 or S13
S15 S7 or S9
S16 risk* n2 language* or risk* n2 communicat* or risk* n2 presentation* or risk* n2 presenting or risk* n2 inform* or risk* n2 tailor* or risk* n2 individuali?e* or risk* n2 personal* or risk* n2 rate* or risk* n2 reference class*
S17 S14 and S15
S18 S8 or S16 or S17

Cochrane search terms

#1 MeSH descriptor Risk explode all trees
#2 MeSH descriptor Communication explode all trees
#3 MeSH descriptor Audiovisual Aids, this term only
#4 MeSH descriptor Data Interpretation, Statistical, this term only
#5 (#2 or #3 or #4)
#6 (#1 AND #5)
#7 risk*:ti,ab,kw
#8 (#1 OR #7)
#9 (fram* NEAR/2 (effect* or positiv* or negativ*)):ti,ab,kw
#10 (information* NEAR/5 display):ti,ab,kw
#11 ((graph* or visual* or statistic*) NEAR/3 (present* or format*)):ti,ab,kw
#12 framing:ti
#13 (#9 OR #10 OR #11 OR #12)
#14 (#13 AND #9)
#15 (risk* NEAR/2 (language* or communicat* or presentation* or presenting or inform* or tailor* or individuali?e* or personal* or rate* or reference class*)):ti,ab,kw
#16 (#6 OR #14 OR #15)

PsychInfo search terms

1 risk assessment/ or risk factors/ or risk perception/
2 risk$.ti,ab

3 or/1-2
4 audiovisual communications media/
5 statistical analysis/
6 communication/ or exp augmentative communication/ or exp electronic communication/ or exp interpersonal communication/ or exp nonverbal communication/ or exp persuasive communication/ or scientific communication/ or exp verbal communication/
7 or/4-6
8 1 and 7
9 ((fram$ adj2 (effect$ OR positive$ OR negative$))).ti,ab
10 ((information$ adj5 display)).ti,ab
11 (((graph$ OR visual$ OR statistic$) adj3 (present$ OR format$))).ti,ab
12 framing.ti
13 or/9-12
14 3 and 13
15 (risk$ adj2 (language$ OR communicat$ OR presentation$ OR presenting OR inform$ OR tailor$ OR individualis$ OR individualiz$ OR personal$ OR rate$ OR reference class$)).ti,ab
16 or/8,14-15

E.4 Economics searches

E.4.1 Decision aids

As the Cochrane review used to inform this area included economic considerations as an outcome searches were only run in NHS EED, HTA and HEED in order to supplement that data.

Economic searches were conducted in HEED and CRD for NHS EED and HTA.

Population	Intervention / exposure	Comparison	Study filter used	Date parameters
Decision aids				Searches run to 10/05/2011

CRD search terms

#1 "decision support"
#2 "shared decision"
#3 "decision aid*"
#4 #1 or #2 or #3

HEED search terms

1 AX='decision aids' OR 'decision aid'
2 AX='shared decision'
3 AX='decision support'
4 CS=1 OR 2 OR 3

E.4.2 Midwife-led care

Economic searches were conducted in Medline, Embase, HEED and CRD for NHS EED and HTA.

Population	Intervention / exposure	Comparison	Study filter used	Date parameters
Midwife-led care			Economic (Medline and Embase only	Searches run to 10/05/2011

CRD search terms

#1 (midwif* NEAR team*) OR (midwif* NEAR model*) OR (midwif* NEAR led) OR (midwif* NEAR manag*)

#2 MeSH DESCRIPTOR continuity of patient care WITH QUALIFIER undefined

#3 (multidisciplinary NEAR team*) OR (share* NEAR care) OR (medical* NEAR led) OR (medical* NEAR manag*)

#4 #2 OR #3

#5 MeSH DESCRIPTOR pregnancy EXPLODE ALL TREES WITH QUALIFIER undefined

#6 MeSH DESCRIPTOR pregnancy EXPLODE ALL TREES WITH QUALIFIER undefined

#7 MeSH DESCRIPTOR obstetrics WITH QUALIFIER undefined

#8 MeSH DESCRIPTOR maternal health services EXPLODE ALL TREES WITH QUALIFIER undefined

#9 MeSH DESCRIPTOR midwifery WITH QUALIFIER undefined

#10 (pregnan*) OR (midwif*)

#11 #5 OR #6 OR #7 OR #8 OR #9

#12 #4 AND #10

#13 #1 OR #11

HEED search terms

1 AX=midwif*

2 AX=led or manag* or model* or team*

3 CS=1 AND 2

4 AX='multidisciplinary team' or 'multidisciplinary teams' or 'shared care'

5 AX=midwif* or pregnan*

6 CS=4 AND 5

7 CS=3 OR 6

Medline search terms

1 (midwif$ adj led).ti,ab.

2 (midwif$ adj2 team$).ti,ab.

3 (midwif$ adj model$).ti,ab.

4 (midwif$ adj manag$).ti,ab.

5 or/1-4

6 "Continuity of Patient Care"/

7 (medical adj manag$).ti,ab.

8 (medical$ adj led).ti,ab.

9 (multidisciplinary adj team$).ti,ab.

10 (share$ adj care).ti,ab.

11 or/6-10

12 exp Pregnancy/

13 Obstetrics/

14 exp Maternal Health Services/

15 Midwifery/

16 (pregnan$ or midwif$).ti,ab.

17 or/12-16

18 11 and 17

19 5 or 18

Embase search terms

1 (midwif$ adj2 team$).ti,ab.

2 (midwif$ adj model$).ti,ab.
3 (midwif$ adj led).ti,ab.
4 (midwif$ adj manag$).ti,ab.
5 or/1-4
6 *patient care/
7 exp *nursing care delivery system/
8 (multidisciplinary adj team$).ti,ab.
9 (share$ adj care).ti,ab.
10 (medical$ adj led).ti,ab.
11 (medical adj manag$).ti,ab.
12 or/7-11
13 exp *pregnancy/
14 exp *midwife/
15 exp *obstetric care/
16 (pregnan$ or midwif$).ti,ab.
17 or/13-16
18 12 and 17
19 5 or 18

Appendix F: Evidence tables: clinical studies

F.1 Decision aids

Table 3: Clinical evidence profile on Decision Aids.

Reference	Methodological quality of the included studies	Study type / quality	Patient characteristics	Intervention Comparison	Outcome measures	Source of funding
STACEY 2011[53]	Each study was assessed for risk of bias. Included studies ranged from low to high quality.	RCTs comparing decision aids to no intervention, usual care, alternative interventions, or a combination. Studies were excluded that looked at hypothetical. Lifestyle, clinical trial entry of advance directive choices; education programmes: no decision, promoting compliance; or passive informed consent materials.	People making decisions about screening or treatment options for themselves, for a child, or for an incapacitated significant other. Excluded: People making hypothetical choices.	Decision aids compared to to no intervention, usual care, alternative interventions, or a combination Excluded: Studies where people are not making an active treatment or screening decision. Studies where interventions focussed on decisions about lifestyle changes, clinical trial entry, general advance directives (e.g. do not recusitate), education programs not geared to a specific decision, interventions	Primary outcomes: evaluation criteria that map to IPDAS criteria – attributes of the choice and attributes of the decision making process, other decision making process variables. Secondary outcomes: choice (actual choice implemented, option preferred as surrogate measure), adherence to choice, health status and quality of life, anxiety, depression, emotional distress, regret, confidence, costs, cost-effectiveness,	Not reported

Reference	Methodological quality of the included studies	Study type / quality	Patient characteristics	Intervention Comparison	Outcome measures	Source of funding
				designed to promote adherence or to elicit informed consent. Studies on decision aids that were not available to the authors.	consultation length, litigation rates.	

F.2 Continuity of care (midwife-led care)

Table 4: Evidence table – continuity of care – midwife-led versus other models of care for childbearing women

Reference	Study type, question and search dates	Number of studies, study types and patients with references	Study/patient characteristics	Intervention	Comparison	Outcome measures	Funding
DEVANE 2011[3]	Systematic review questions: Compares midwife-led models of care with other models of care for childbearing women and their infants. Determines whether midwife-led care is influenced by 1) models of midwifery care that provide differing levels of	17 studies included (Begley et al., 2009, Biro et al., 2000, Byrne et al., 2000, Chambliss et al., 1992, Flint and Poulengeris, 1987, Harvey et al., 1996, Hicks et al., 2003, Homer et al., 2001, Hundley et al., 1994, Kenny et al., 1994, Law and Lam, 1999, MacVicar et al., 1993, North Staffordshire Changing Childbirth Research Team,	RCTs, CCT and controlled before and after studies. All pregnant women who access midwife-led model at booking, during pregnancy or at the onset of labour. The risk of bias of included studies was assessed using the Cochrane	Midwife led care: midwife is the lead professional and lead carer in the planning, organisation and delivery of care given to a woman from initial booking to the postnatal period.	Medical and shared models of care. E.g. Physician/obstetrician led care: physician/obstetrician is the lead professional and midwives and/or nurses provide	Antenatal Mean number of antenatal visits Antenatal hospitalisation Antepartum haemorrhage Fetal loss/neonatal death before 24 weeks Fetal loss/neonatal death equal to/after 24 weeks Overall fetal loss and neonatal death	Royal College of Midwives

Reference	Study type, question and search dates	Number of studies, study types and patients with references	Study/patient characteristics	Intervention	Comparison	Outcome measures	Funding
	continuity; 2) varying levels of obstetrical risk and 3) practice setting (community or hospital based). Search date: not reported	2000, Rowley et al., 1995, Turnbull et al., 1996, Waldenstrom et al., 2001, Waldenstrom et al., 1997)	Collaboration's risk of bias assessment tool. Heterogeneity was explored using pre-specified sub-group analyses in a manner similar to the Cochrane analysis[6]		intrapartrum care under medical supervision Shared care: lead professional changes depending on whether the woman is pregnant, in labour or has given birth, and on whether the care is given in the hospital, birth centre or community setting.	Labour Amniotomy Augmentation/artificial oxytocin during labour No intrapartum analgesia/anaesthesia Regional analgesia (epidural/spinal) Opiate analgesia Mean labour length Induction of labour Attendance at birth by known midwife High perceptions of control during labour and childbirth Birth and immediate postnatal Caesarean birth Instrumental vaginal birth (forceps/vacuum assisted births) Spontaneous vaginal birth (as defined by trial authors) Episiotomy Perineal laceration requiring suturing Intact perineum Postpartum haemorrhage (as defined by trial authors)	

Reference	Study type, question and search dates	Number of studies, study types and patients with references	Study/patient characteristics	Intervention	Comparison	Outcome measures	Funding
						Maternal death Neonatal Low birth weight (< 2500 g) Preterm birth (< 37 weeks) 5-minute Apgar score below or equal to 7 Admission to special care nursery/neonatal intensive care unit Mean length of neonatal hospital stay (days) Neonatal convulsions (as defined by trial authors)	

Effect sizes:

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

Reference	Study type, question and search dates	Number of studies, study types and patients with references	Study/patient characteristics	Intervention	Comparison	Outcome measures	Funding
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			
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			

Reference	Study type, question and search dates	Number of studies, study types and patients with references	Study/patient characteristics	Intervention	Comparison	Outcome measures	Funding

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

F.3 Risk communication

Table 5: Individualised information: tailored interventions in screening

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding
Edwards AG, Evans R, Dundon J, Haigh S, Hood K, Elwyn GJ. Personalised Risk Communication for Informed Decision Making About Taking Screening	Systematic review: different types of personalised/ individualised risk communication for consumers making decisions about screening tests Medline, CENTRAL, MEDLINE, Embase, CINAHL, PsychINFO; hand searching Preventative medicine; citation searches and	22 studies (13 for mammography; 4 breast cancer genetic testing; 3 cervical screening; 2 cholesterol screening; 2 colorectal cancer screening; 1 prostate cancer screening; some covered more than 1 topic); 5 studies of people at higher risk. Bastani 1999*; Bowen 2002; Campbell 1997; Champion 1994; Champion 1995; Champion 2000; Champion 2002; Champion 2003; Curry	RCTs (excluding those of mass communication or military, school or prison-based interventions where consumers are less free to choose than in other settings) Consumers making real life (not	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	Generalised risk information (e.g. population risk estimate, general info on risk factors, general encouragement to acknowledge risks or change risk behaviour)	Up to 3 years	Cognitive (e.g. knowledge or risk perception), affective (e.g. anxiety, satisfaction with decision made, decisional conflict [i.e. whether individual feels that decision is consistent with their values and certainty about	Department of Health UK, Cochrane Health Promotion and Public Health Field, Australia

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding
Tests. Cochrane Database of Systematic Reviews. 2006;(4):CD001865. (Guideline Ref ID EDWARDS 2006)[4]	reference lists to December 2005	1993*; Hutchison 1998; Jibaja-Weiss 2003*; Kreuter 1996*; Lee 1991; Lerman 1995; Lerman 1997; Lipkus 2005*; Myers 1999*; Rimer 2002*; Saywell 1999; Schwartz 1999; Skinner 1994*; Skinner 2002*; *Also in Albada 2009 No overlap with Akl 2011, Edwards 2001, Lopez 2008, Smerecnik 2009. N of studies ranged from 160 to 3,152	hypothetical) decisions about whether to undergo healthcare screening tests (individuals, couples or immediate families e.g. parents making decisions on behalf of young children)	screening, or at the time of counselling or promotion of screening; could be oral, written, video or electronic			making the right decision, emotional wellbeing, intention to take up screening) or behavioural outcomes (e.g. uptake of screening tests, adherence to choice, "appropriate" uptake), health status outcomes/ quality of life measures (e.g.SF-36), economic outcomes (cost of intervention)	

Effect size

	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	2/568	MD:2.45 (1.94 to 2.96)			1/804	OR:1.44 (0.95 to		

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding
concerned						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 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)						

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding

	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)

Authors’ conclusions

Personalised 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.

Table 6: Genetic counselling: increase in risk perception accuracy

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding
Smerecnik CM, Mesters I, Verweij E, de Vries NK, de Vries H. A Systematic Review of the Impact of Genetic Counseling on Risk Perception Accuracy. Journal of Genetic Counseling. 2009; 18(3):217-228. (Guideline Ref ID SMERECNIK2009)[5]	Systematic review: impact of genetic counselling on risk perception accuracy. Search from 2000 to February 2007: PubMed; EMBASE, Web of Science; ERIC; PsycInfo; Google Scholar for papers and grey literature; hand searching of specific journals; key author and reference list searches.	19 studies (Bjorvatn 2007; Bowen 2006; Codori 2005; Gurmankin 2005; Hopwood 2003; Hopwood 2004; Huiart 2002; Kaiser 2004; Kelly 2003; Kent 2000; Lidén 2003; Lobb 2004; Meiser 2001; Nordin 2002; Pieterse 2006; Rimes 2006; Rothemund 2001; Tercyak 2001; Van Dijk 2003). No overlap with Akl 2001, Albada 2009, Edwards 2001, Edwards 2006, Lopez 2008 N of studies ranged from 44 to 397	Prospective or randomised controlled studies published after 2000; focus on genetic risk perception; effect of genetic counselling on risk perception accuracy assessed quantitatively; original research published in English in peer reviewed journals. Excluded if examined changes in risk perception not linked to objective risk estimate; risk perception as determinant of genetic counselling participation; or decision aids vs. standard genetic counselling; qualitative only. Patients at risk (not intermediaries e.g. genetic counsellors or nurses).	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.	Pre- to post-counselling measures of risk perception accuracy	Up to 1 year after counselling	The effect of genetic counselling on risk perception accuracy. Measured by: 1) changes in proportion of individuals who accurately perceive their risk; 2) degree of overestimation or underestimation of risk	Maastricht University

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding

Effect size

Given the heterogeneity of the studies (including definitions of risk perception accuracy and potentially substantial differences between counselling sessions' content and quality), they were not pooled in a meta-analysis; results of each study were tabulated.

1) 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

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding

		Post-counselling	70	20	10	
Meiser 2001	218	Pre-counselling 12 months post-counselling	54 54	12 14	34 31	NS
Nordin 2002	63	Pre-counselling Post-counselling	18 57	38 18	44 25	not stated
Pieterse 2006	51	Pre-counselling Post-counselling	48 51	not reported	not reported	NS
Rimes 2006	150	Pre-counselling 6 months post-counselling	12.6 18	3.3 4.0	84.1 78.0	NS
Rothemund 2001	44	Post counselling counselees Controls	39 38	0 14	48 48	NS (Note figures do not add up to 100% - may be error in paper)

2) 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	not given	NS

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding

		3 month post-counselling 6 months post-counselling		
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

Authors' conclusions

Overall, the studies indicate that 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.

The proportion of people who correctly assessed their risk increased from mean of 42% pre- to 58% post-counselling. But on average 25% (range 5-76%) still overestimated their risk and 19.5% (7-55%) underestimated it after counselling.

In studies assessing mean overestimation of risk, mean overestimation reduced from 25% (range 11.5-42%) before counselling to 18% (6-40%) after counselling.

Studies in which the counsellor interpreted information about family history and heredity as well as personal risk estimates positively influenced risk perception accuracy, although this was not significant in 2 studies. Studies not mentioning giving counselees this information did not see an improvement in risk perception accuracy, except in 1 study.

Some studies that educated counselees about heredity, preventive options and personal risk observed a positive impact on risk perception accuracy but others did not.

Similarly, some studies identified as facilitating informed decisions and adaptation to personal risk observed a positive impact but others did not.

Table 7: Tailored interventions in cancer risk (based on a person's behavioural change variables, cultural constructs, cancer risk factors)

Reference	Study type	Number of studies/patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding
Albada A, Ausems MG, Bensing JM, van Dulmen S. Tailored Information About Cancer Risk and Screening: A Systematic Review. Patient Education & Counseling. 2009; 77(2):155-171. (Guideline Ref ID ALBADA2009)[2]	Systematic review: What effects are found of tailored interventions on risk perception, cancer knowledge and screening behaviour? Search to June 2007: PubMed; Embase; CINAHL; PsychInfo; Cochrane	40 studies included (Bastani 1999; Champion 2007; Champion 2006; Champion 2002; Clark 2002; Curry 1993; Emmons 2004; Glazebrook 2006; Jerant 2006; Jibaja-Weiss 2003; Kreuter 2005; Kreuter 1996; Kreuter 1995; Lipkus 2006; Lipkus 2000; Marcus 2005; McBride 2002; McCaul 2002; Prochaska2005; Rakowski 1998; Rimer 2002; Rimer 2001; Rimer 1999; Saywell 2004; Skinner 2007; Skinner 2002; Skinner 1994; Weinstein 2004). 12 "included" but not presented in synthesis (Campbell 2004; Campbell 2002; Emmons 2005; Gelle 2006; Jibaja 2000; Lipkus 2005; Marcus 1992; Myers 1999; Rakowski 2003; Smit West 2004; Valanis 2003; Valanis 2002). No overlap with	37 RCTs remaining 3 described randomised designs with a comparison but no control group. Patients or individuals at risk of developing cancer (35 studies had participants at population risk of cancer; 5 aimed at high-risk respondents i.e. those with abnormal screening result, cancer history, first-degree relative of cancer patient, counselees in cancer genetic counselling) 19 studies on breast cancer; 6 breast and ovarian/cervical cancer; 1 cervical cancer only; 7 colorectal cancer; 2 general/several cancers; 2 skin cancer; 2 lung cancer; 1 prostate cancer. 2 high quality; 7 moderate; 19 low quality. Quality was assessed according to the minimal checklist for	Intervention groups receiving tailored information, based on more than one variable (behavioural change variables, cultural constructs, cancer risk factors) Most comprised letters, booklets or magazines; 6 were computer-delivered	Control groups receiving no information, standard information or usual care	Up to 2 years post-intervention	Cancer risk perception (7 studies) or knowledge (4 articles) or behaviour related to cancer screening (18 mammography; 3 pap test; 2 faecal occult blood test; 1 mole checking)	Dutch Cancer Society

Reference	Study type	Number of studies/patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding
		Akl 2001, Edwards 2001, Lopez 2008, Smerecnik 2009. See below for overlap with Edwards 2006 N of studies ranged from 49 to 5407	assessing quality of RCTs of the Cochrane Collaboration (high = ≥4/7; moderate = 3/7; low = ≤2/7)					

Effect size

Significant effects only were tabulated for each included study (some data shown; others only described as significant without presentation of data).

A “best evidence synthesis” was carried out, not a meta-analysis, due to heterogeneity. This technique does not consider insignificant results or weights of studies and is thus less sensitive than meta-analysis. It does take into account the design, methodological quality and outcomes of the studies.

Only the 28 RCTs without co-intervention or with similar co-intervention in intervention and control groups were assessed for methodological quality and presented in the best evidence synthesis. The outputs were classified as “evidence” (consistent significant findings in at least 2 high-quality RCTs), “moderate evidence” (consistent significant findings in at least 1 high quality and at least 1 moderate or low quality RCT), “limited evidence” (significant findings in at least 1 high quality RCT), “indicative findings” (significant findings in at least 1 moderate or low quality RCT) or “no/insufficient evidence” (significant findings in <50% of studies with the same quality and design or results do not meet the above criteria for higher levels of evidence or conflicting results among RCTs or no eligible studies).

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	indicative findings

Reference	Study type	Number of studies/patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding
					difference at 12 months			
	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 reduced perceived cancer risk among over-estimators: OR 1.36, p<0.05 at 6 months		indicative findings	
Screening for ... (adherence to recommended	Breast cancer (mammography)	Risk factors	Standard or personalised (i.e. named for that	3	1 low quality RCT: higher increase in mammography rate in intervention group (10.2% vs. 2.5%		insufficient evidence	

Reference	Study type	Number of studies/patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding
screening interval)			person but not with tailoring) info		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)			
		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	
		Behavioural constructs	No intervention	2	none		no evidence	
	Colorectal cancer (faecal occult blood	Risk factors	Standard info	1	none		no evidence	

Reference	Study type	Number of studies/patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding

	test)					
		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

Authors’ conclusions

This review indicated that tailoring based on behavioural constructs (e.g. attitudes, intentions, stages of change) seems more effective than tailoring based on risk factors only (e.g. family history); it might be advisable to use both behavioural constructs and risk factors, and possibly other variables such as cultural characteristics.

Table 8: Tailored interventions in screening

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding
Edwards AG, Evans R, Dundon J, Haigh S, Hood K, Elwyn GJ. Personalised Risk Communication for	Systematic review: different types of personalised/ individualised risk communication for consumers making decisions about screening tests Medline, CENTRAL, MEDLINE, Embase,	22 studies (13 for mammography; 4 breast cancer genetic testing; 3 cervical screening; 2 cholesterol screening; 2 colorectal cancer screening; 1 prostate cancer screening; some covered more than 1 topic); 5 studies of people at higher risk.	RCTs (excluding those of mass communication or military, school or prison-based interventions where consumers are less free to	Personalised risk communication based on individual’s risk factors (presented as absolute or relative risk or risk score or high/medium/lo	Generalised risk information (e.g. population risk estimate, general info on risk factors, general encouragemen	Up to 3 years	Cognitive (e.g. knowledge or risk perception), affective (e.g. anxiety, satisfaction with decision made, decisional conflict [i.e. whether	Department of Health UK, Cochrane Health Promotion and Public Health Field, Australia

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding
Informed Decision Making About Taking Screening Tests. Cochrane Database of Systematic Reviews. 2006;(4):CD001865. (Guideline Ref ID EDWARDS2006)[4]	CINAHL, PsychINFO; hand searching Preventative medicine; citation searches and reference lists to December 2005	Bastani 1999*; Bowen 2002; Campbell 1997; Champion 1994; Champion 1995; Champion 2000; Champion 2002; Champion 2003; Curry 1993*; Hutchison 1998; Jibaja-Weiss 2003*; Kreuter 1996*; Lee 1991; Lerman 1995; Lerman 1997; Lipkus 2005*; Myers 1999*; Rimer 2002*; Saywell 1999; Schwartz 1999; Skinner 1994*; Skinner 2002*; *Also in Albada 2009 No overlap with Akl 2011, Edwards 2001, Lopez 2008, Smerecnik 2009. N of studies ranged from 160 to 3,152	choose than in other settings) Consumers making real life (not hypothetical) decisions about whether to undergo healthcare screening tests (individuals, couples or immediate families e.g. parents making decisions on behalf of young children)	w 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	t to acknowledge risks or change risk behaviour)		individual feels that decision is consistent with their values and certainty about making the right decision, emotional wellbeing, intention to take up screening) or behavioural outcomes (e.g. uptake of screening tests, adherence to choice, “appropriate” uptake), health status outcomes/ quality of life measures (e.g.SF-36), economic outcomes (cost of intervention)	
Effect size								

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding

	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 1.82)						
Improvement in risk comprehension/ perception	1/200	OR: 1.64 (0.83 to 3.25)						

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding

Making a recommended behaviour change	1/890	OR: 0.98 (0.76 to 1.28)							

	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)

Authors' conclusions

Personalised 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.

Table 9: Alternative statistical formats for presenting information

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding
Akl EA, Oxman AD, Herrin J, Vist GE, Terrenato I, Sperati F, Costiniuk C, Blank D, Schunemann H. Using Alternative Statistical Formats for Presenting Risks and Risk Reductions. Cochrane Database of Systematic Reviews. 2011; 3:CD006776. (Guideline Ref ID AKL2011)[1]	Systematic review: To evaluate 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. Search to October 2007 of Medline, Embase, PsychLit, Cochrane Controlled Trials Register; related articles in Medline; articles published by first authors of included/excluded but closely related studies; reference lists; experts in the field.	35 studies (Adily 2004; Bobbio 1994; Bramwell 2006 (midwives, obstetricians, pregnant women); Brotons 2002; Bucher 1994; Carling 2008; Carling 2009; Chao 2003; Cranney 1996; Damur 2000; Davey 2005; Fahey 1995; Forrow 1992 (a=cholesterol, b=hypertension); Gigerenzer 1996; Heller 2004; Hux 1995; Kurzenhäuser 2002; Lacy 2001; Loewen 1999; Malenka 1993; Mellers 1999; Misselbrook 2001; Natter 2005 (RRR and ARR with or without baseline risk); Naylor 1992; Nexoe 2002a; Nexoe 2002b; Nikolajevic-Sarunac 1999; Sarfati 1998; Schwartz 1997 (ARR	Randomised (30 studies) and non-randomised (4 studies) parallel (22 studies) and crossover (19 studies) studies. Excluded if compared positive and negative framing of same message; alternative graphical or verbal presentations of the same evidence; alternative orders of comparing risks or comparisons; alternative media to present same information; studies in which participants chose between different interventions with different benefits and harms using alternative presentations formats as differences in	a) Risk frequencies (e.g. 1 in 20) b) Relative risk reduction (RRR) c) RRR d) ARR	a) Risk probabilities (e.g. 0.05) b) Absolute risk reduction (ARR) c) Number needed to treat (NNT) d) NNT	Not applicable	Objective understanding (e.g. correctly stating which treatment is more effective); perception of effectiveness of intervention (e.g. perceived effectiveness of vaccination); persuasiveness (how likely participants are to make a decision in favour of an intervention e.g. cholesterol treatment); actual decisions or behaviours (the primary outcome, but no studies reported this); the other 3 secondary outcomes were considered surrogates for behaviour.	Norwegian Research Council; European Commission

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding
		and RRR with or without baseline risk); Sedlmeier 2001; Sheridan 2003; Straus 2002; Ward 1999; Wolf 2000; Young 2003). No overlap with Albada 2009, Lopez 2008, Smerecnik 2009 See below for overlap with Edwards 2001 N of studies ranged from 17 to 2978	presentation confounded by those in benefits/harms. Health professionals, policy makers or consumers (patients, general public, students) eligible; no studies found including policy makers; 14 assessed health professionals, 20 consumers and 1 both. Studies covered chronic diseases, genetic testing and vaccination					

Effect size

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	Understanding	5	0.69 (0.45 to 0.93) in favour	1.4	p=0.11	I2=43%,	Moderate	0.60 (0.31 to 0.88)	0.94 (0.53 to 1.34)	none

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding		
vs. probabilities			of natural frequencies							
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 1.50) in favour of RRR	2.3	p=0.004	I2=82%,	Moderate	none	all health professionals: 1.15 (0.80 to 1.50)	none
	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.	Understanding	1	all consumers	0.8	NA	NA	Moderate	all	none	none

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding

NNT			0.42 (0.12 to 0.71) in favour of ARR					consumers 0.42 (0.12 to 0.71)		
	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)

Authors' conclusions

Natural frequencies are probably better understood than probabilities. Relative risk reduction may be perceived to be larger and is more likely to be persuasive compared to absolute risk reduction and numbers needed to treat, however it is unclear if relative risk reduction is likely to help people make decisions or could lead to misinterpretation. More research is needed to further explore this question

Table 10: “Framing”: Epilepsy, cancer treatment, immunisation, screening

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding
Edwards A, Elwyn G, Covey J, Matthews E, Pill R. Presenting Risk Information--A Review of the Effects of "Framing" and Other Manipulations on Patient Outcomes. Journal of Health Communication. 2001; 6(1):61-82. (Guideline Ref ID EDWARDS2001)[5]	Systematic review: how different “framing” of risk information affects key patients outcomes in a clinical setting: Medline, Embase, CINAHL, PsycLit, SCI, ASSIA, CancerLit up to 1999, plus key review articles and reference lists	24: 1) Jacoby 1993, Llewellyn-Thomas 1995, McNeil 1982, O’Connor 1996; 2) Banks 1995, Detweiler 1999, Lauver 1990, Lerman 1992, Meyerowitz 1987, Myers 1991, Rothman 1993; 3) Greenwood 1992; 4) Mazur 1990, Mazur 1994, Quaid 1990; 5) Fetting 1990, Inglis 1993; 6) Hux 1995*, Malenka 1993*, Sarfati 1998*; 7) Rook 1986, Rook 1987; 8) Van Haecht 1991; 9) Yamagishi 1997. *Studies also included in Akl 2011	Interventions with patients in a healthcare setting including real or hypothetical choices about treatment or behaviour, or where choices are of current medical relevance (e.g. skin cancer risks). Excluded if data for relevant group of subjects could not be distinguished from a total group including irrelevant topics.	1) Negative framing (e.g. chance of death) 2) Loss framing (e.g. disadvantage of not undertaking screening) 3) Numerical and graphical information 4) More data points 5) Numerical information 6) Relative risk 7) Vivid portrayal (e.g. detailed or personalised vignette) 8) Lay terminology (e.g. loss of appetite) 9) Larger denominators	1) Positive framing (e.g. chance of survival) 2) Gain framing (e.g. advantage of screening) 3) Numerical only 4) Fewer data points 5) Verbal (qualitative) information (e.g. “ frequently”, “rarely”) 6) Absolute risk or number needed to treat 7) Abstract or general risk information 8) Medical terminology (e.g. anorexia) 9) Smaller denominators	not stated	Knowledge, anxiety, risk perception, intentions and actual behaviour: effect sizes calculated	UK National Health Service Research and Development Programme

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding
		N of studies ranged from 20 to 2201						

Effect size

The authors stated that “the paucity of data in most categories made meta-analysis unlikely to be meaningful and this was not undertaken.” The results for each study (both significant and non-significant) are presented in a table, followed by a narrative synthesis of each category (i.e. comparisons 1-9 listed above).

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 thi 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,	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.

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding

		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 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

Reference	Study type	Number of studies/ patients	Study/patient characteristics	Intervention	Comparison	Length of follow-up	Outcome measures	Source of funding

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 risk information	2	none	One study found no significant differences in accuracy of recall of information, perceived vulnerability, or actual 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]	These papers do not support the theoretical predictions that vivid information is more 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

Authors’ conclusions

There is a paucity of framing studies in clinical settings; the findings of the review must be interpreted with caution until further research is conducted.

F.4 Patient Education

Table 11: Evidence table – education programmes

Reference	Question and search dates	Number of studies, study types and patients with references	Study/patient characteristics	Intervention	Comparison	Outcome measures	Funding
MULLEN 1985[8]	What components of patient education programmes improve patient experience? Searches were conducted up to January 1984.	70 studies were included in the review. RCTs, pre-test post-test study designs were included in the review.	Adults with long-term health problems. The study must have measured either knowledge about medications or adherence to a regimen that included drugs. All studies were individually assessed for quality.	A range of education interventions selected using basic criteria suggested in educational literature (consonance, individualisation, feedback, reinforcement, facilitation): one-to-one counselling; group education (with or without counselling)[1]; written and/or other audiovisual materials; patient package inserts, written and/or other AV materials plus one-to-one group education, labels, special containers and memory aides; labels, special containers, and memory aids plus one-to-one or group education; behaviour modification/medication self-administration. Education interventions were rated according to education principles based on a rating scheme adapted from Neufeld.	Own control, usual care, and minimal treatment	Knowledge of drug, adherence, and clinical outcomes. The quality of the measures varied greatly.	Supported in part by Pharmaceutical Manufacturers Association

Reference	Question and search dates	Number of studies, study types and patients with references	Study/patient characteristics	Intervention	Comparison	Outcome measures	Funding

Summary of 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
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

Table 12: Summary of education principles scored in included studies

Education principle	Description
Consonance	Degree to which an intervention was directed toward effecting the intended outcome.
Relevance	Degree to which the education programme appeared to be geared to knowledge, reading level, visual acuity, beliefs, circumstances, and prior experience of the learners.
Individualisation	Assessed on the principle that learning is an individual process that occurs at different rates and through varying types of experiences.
Feedback	Feedback facilitates learning by showing the patient the extent to which he or she is achieving progress.
Reinforcement	Designed to reward desired behaviour.
Facilitation	Degree to which the intervention provided the means for people to take action and/or reduced barriers to their action.
Combination	Scored on whether the intervention provided multiple or alternative learning experiences.

(a) See Appendix :Intervention Scoring in Mullen 1985[8]

Table 13: Characteristics of studies included in Mullen 1985

Strategy	Subjects, clinical condition, and drug	Average time observed	Methods scorea	Intervention scoreb	Knowledge effectc	Drug errorsc	Clinical effectc	Ref.
One-to-one counselling only								
Reinforcement of M.D. Instruction by pharmacist x 1d	Hospitalized and clinic neurological patients (n=68)	2 months	13(R)	22(19)	1.48			Woroniecki, C.L. et al, 1982
M.D. More specifically directive re: drug taking and patients aware of being monitored	Children with asthma (3-16 years) attending inner-city OPD (theophylline) (n=90)	2 hours	11	25(17)		-1.43		Eney, R.D. et al, 1976
Brief counselling x 1 forewarning of side effects	Patients with depression attending clinic and taking drug for 1st time (Dothiepen) (n=89)	2 weeks	11	16(13)		-0.37		Myers, E.D. et al, 1976
Counselling x 4 by R.N. Pre-hospital discharge, at first clinic visit, and at 2 home visits	Adults with tuberculosis receiving outpatient chemotherapy (n=23)	1 month	18	32(18)		-0.70		Hecht, A.B., 1974

Strategy	Subjects, clinical condition, and drug	Average time observed	Methods scorea	Intervention scoreb	Knowledge effectc	Drug errorsc	Clinical effectc	Ref.
Counselling by pharmacist x 5	Adults with hypertension attending a neighbourhood clinic (n=45)	5 months	10	32(17)	0.96	-0.25	-0.71 BP (diastolic)	McKenney, J.M. et al, 1973
Counselling by M.D. In course of regular clinic visits	Low-income adults with hypertension attending inner city OPD (n=102)	6 months	13	29(20)	1.01	-0.71	-0.82 BP (diastolic)	Inui, T.S. et al, 1976
Counselling x 2 + educational program by health-care team	Children with renal transplants who were attending a clinic (azothioprine and prednisone) (n=42)	6 months	8	27		-0.61		Beck, D.E. et al, 1980
Inpatient counselling and instruction by M.D. Dietician, and R.N. X 5 days + follow-up x 7 by M.D. + telephone access to R.N. + diaries	Diabetics (16-57 years) receiving inpatient education and OPD care (insulin) (n=77)	18 months	13(R)	26(22)	4.36		-0.08 BP (metabolic) index	Korhonen, T. Et al, 1983
Counselling (multiple sessions) by graduate research assistant at clinic visits	Low- to low-middle income adults with hypertension attending an inner-city hospital OPD (n=39)	6 months	14(R)	28(24)			-1.09 BP	Zismer, D.K. et al, 1982
Counselling x 6 by a social worker	Low-middle income adults with hypertension attending a university family practice clinic (n=70)	3-4 months	15(R)	30(16)			-0.13 BP	Webb, P.A. 1980
Group education only								
Follow-up group session with R.N. And R.D.	Adults with diabetes who had been hospitalised and given an inpatient education session (insulin) (n=171)	2-6 weeks	5	28(24)			-0.49 rehospitalisation	Whitehouse, F.W. et al, 1979
Inpatient group teaching of self-management skills x 1 by health team + telephone and visit access	Patients with Type I diabetes treated with 1 subcutaneous insulin injection admitted to 2	22 months	18	26			-0.08 glycosylated Hb	Muhlhauser, I. Et al, 1983

Strategy	Subjects, clinical condition, and drug	Average time observed	Methods scorea	Intervention scoreb	Knowledge effectc	Drug errorsc	Clinical effectc	Ref.
	university hospitals in Austria or Germany (n=156)							
Series of classes on 5 topics by health team + referral to diabetic association + counselling x 1 by dietician + home visit x 1 by R.N.	patients with diabetes referred by M.D.s to one of 26 education sites in Maine in 1980 (n=830)	1 year	7	22			-0.26 hospitalization	Zaremba, M., 1984
Series of classes on 5 topics by health team + referral to diabetic association + counselling x 1 by dietician + home visit x 1 by R.N.	Patients with diabetes referred by M.D.s to one of 26 education sites in Maine in 1981 (n=1150)	1 year	7	22			-0.42 hospitalizations	Zaremba, M., 1984
Series of classes on 5 topics by health team + referral to diabetic association + counselling x 1 by dietician + home visit x 1 by R.N.	Patients with diabetes referred by M.D.s to one of 26 education sites in Maine in 1982 (n=996)	1 year	7	22			-0.38 hospitalizations	Zaremba, M., 1984
2-hr weekly group sessions x 6 by R.N. Including lectures, discussions and role-playing	Adult hypertensive outpatients (n=65)	9 weeks	14	32(18)			-0.47 BP	Caplan, R.D. et al, 1976
Group discussions + role-playing + problem scenarios + puppet shows, all x 6	Children with asthma and their parents attending one of four allergy clinics or private allergy clinics or private practice (n=178)	1 year	11(R)	26(17)			-0.08 ER visits	Clark, N.M. et al, 1981 Clark, N.M. et al, 1984
Group teaching program x 4 by clinic R.N.	Low-income black adults with hypertension or diabetes, newly accepted by university hospital (n=81)	unknown	12(R)	31(19)		-0.19		Tagliacozzo, D.M. et al, 1974
Group discussions with mothers x 2 by social worker	Children with seizures attending a clinic (Phenobarbital and phenytoin) (n=53)	11 weeks	16(R)	27(18)	0.58	-0.87		Shope, J.T., 1980
Team conference + home visits + group sessions (varying attendance from 0 to 10 sessions)	Adults with congestive heart failure attending OPD (n=64)	1 year	13	32(15)	1.08		-0.39 rehospitalisation	Rosenberg, S.G., 1971

Strategy	Subjects, clinical condition, and drug	Average time observed	Methods scorea	Intervention scoreb	Knowledge effectc	Drug errorsc	Clinical effectc	Ref.
Lecture and discussion x 5 by 2 R.N.s and dietician + visual aids and filmstrip series x 1 + procedure demonstration by R.N.	Adults with diabetes attending hospital OPD (insulin) (n=51)	6 months	14	27(21)	0.55		0.02 blood sugar	Bowen, R.G. et al, 1961
Written and/or audiovisual (AV) material								
Leaflet at easy reading material	Psychiatric outpatients using tranquilizers or antidepressants (n=75)	1 month	8(R)	25(20)		-0.59		Ley, P. Et al, 1976
"Auto-tutor" video screen with programmed instructions (for children)	Children (9-18 years) with diabetes (n=132)	3 months	7	28	0.51			Etzwiler, D.D. et al, 1972
"Auto-tutor" video screen with programmed instructions (for parents)	Parents of children with diabetes (n=228)	3 months	7	26	0.52			Etzwiler, D.D. et al, 1972
Book + game/quiz played to 100% mastery level	Children (7-12 years) with diabetes, from a university OPD, hospital, and local school (n=32)	1 month	9(R)	25(17)	2.48			Heston, J.V. et al, 1980
Programmed instruction booklet	Adults on anti-coagulant therapy (n=30)	48 days	6(R)	26(16)	0.96			Clark, C.M. et al, 1972
55-min educational videotape	Adults with asthma attending asthma clinic (inhaled/oral bronchodilators, sodium cromoglycate, corticosteroids) (n=62)	16 months	15(R)	21(17)	0.00		8.23 days lost	Moldofsky, H. Et al, 1979
Slide-tape presentation + printed material to reinforce prior educational program	Adults with diabetes attending inner city hospital OPD (insulin) (n=60)	1 month	9	31(21)	0.08	-0.23		Powell, M.F., 1979
Improved leaflet from M.D. + 15-min slide-tape with voice of M.D.	Adults with hypertension receiving care from private GP (n=46)	1 week	8(R)	22(17)	0.38			St. George, I.M., 1983

Strategy	Subjects, clinical condition, and drug	Average time observed	Methods scorea	Intervention scoreb	Knowledge effectc	Drug errorsc	Clinical effectc	Ref.
Patient package inserts (PPIs)								
High explanation, high specificity	Adults presenting prescriptions at 1 of 69 community pharmacies [flurazepam (Dalmane)] (n=68)	15 days	16(R)	26(23)	-0.12	-0.01		Berry, S.H. et al, 1981
Risk emphasis, simplified writing style	Adults presenting prescriptions at 1 of 69 community pharmacies [flurazepam (Dalmane)] (n=73)	15 days	16(R)	25(23)	0.01	0.20		Berry, S.H. et al, 1981
Outline format, full length	Adults presenting prescriptions at 1 of 69 community pharmacies [flurazepam (Dalmane)] (n=27)	15 days	16(R)	25(23)	-0.06	-0.38		Berry, S.H. et al, 1981
High explanation, high specificity	Women presenting prescriptions at one of 69 community pharmacies (oestrogen) (n=94)	18 days	15(R)	26(23)	-0.07	-0.06		Kanouse, D.E. et al, 1981
Risk emphasis, simplified writing style	Women presenting prescriptions at one of 69 community pharmacies (oestrogen) (n=84)	18 days	15(R)	25(23)	0.00	0.83		Kanouse, D.E. et al, 1981
Outline format, full length	Women presenting prescriptions at one of 69 community pharmacies (oestrogen) (n=81)	18 days	15(R)	25(23)	0.01	0.93		Kanouse, D.E. et al, 1981
Written and/or other AV + interpersonal								
Counselling x 1 by industrial M.D. + slide-tape and booklet + periodic "information check-ups" by educator	Newly diagnosed male steelworkers with hypertension seeking private or industrial M.D. (n=69)	6 months	17(R)	24(19)		-0.01		Sackett, D.L. et al, 1975
Exit interview at ER visit by asthmatic R.N. (identified as being asthmatic) + booklet	Adults with asthma using an inner city ER (n=96)	6 weeks	13(R)	26(19)			-0.68 ER visits	Maiman, L.A. et al, 1979

Strategy	Subjects, clinical condition, and drug	Average time observed	Methods scorea	Intervention scoreb	Knowledge effectc	Drug errorsc	Clinical effectc	Ref.
Counselling and teaching program x 1 by pharmacist + pamphlet	Adults attending a hospital outpatient pharmacy (oral anticoagulants) (n=80)	3 months	4	27	1.05			Witte, K. Et al, 1980
Written instructions x 1 + verbal information x 1 + follow-up card x 1, all by M.D. + prompts to remain in treatment x 1-4	Adults with untreated hypertension from screening survey in Finland (chlorthalidone, methyldopa, alprenolol, moduretic, triamterene) (n=145)	1 year	14(R)	25(19)			-0.19 BP (% controlled)	Takala, J., 1979
Instruction x 1 by M.D. + intensive instruction x 4 by R.N. + booklet +telephone access + diary	Children (2-14 years) attending clinic or allergist's office (bronchodilators, aerosol steroids, Cromolyn) (n=26)	13 months	10	29(19)			-0.57 school absences	Fireman, P. et al, 1981
Booklet + pamphlet + learning objectives explained x 1 by R.N. + counselling x 2 by investigator	Adult inpatients treated for myocardial infarctions in two hospitals (n=24)	1 month	6	23(19)	0.56	-0.40		Bille, D.A., 1977
1-h lessons x 7 + 1-h group discussions x 5, all by R.N. And nutritionist + written material x 1	Indigent adults with diabetes receiving care from a neighbourhood health centre without access to private M.D. (n=20)	1 week	9	30(22)	1.03		-0.57 urinalysis	Cohen, R.Y., 1982
1-h lessons x 5 + 1-h discussions x 5, all by R.N. And nutritionist + written material x 1	Indigent adults with hypertension and obesity receiving care from a neighbourhood health centre without access to private M.D. (n=20)	1 week	8	28(22)	1.23		-0.15 BP (diastolic)	Cohen, R.Y., 1982
Audiovisual program x 1 by pharmacist	Adults with congestive heart failure (n=15)	6 days	8(R)	28(14)	2.02			Soflin, D. Et al, 1977
Brief counselling x 1 + leaflet forewarning of side effects	Adults with depression attending clinic and taking drug (Dothiepin,	6 weeks	13(R)	24(20)		-0.62		Myers, E.D. et al, 1984

Strategy	Subjects, clinical condition, and drug	Average time observed	Method s scorea	Intervention scoreb	Knowledge effectc	Drug errorsc	Clinical effectc	Ref.
	benzodiazepam hypnotics) (n=50)							
Tape recording x 1 + pamphlet x 1 + self-support x 5 + instructions on importance of regimen and use of blood pressure monitoring x 1 by pharmacist	Adults with primary hypertension attending a university OPD (guanethidine sulfate, reserpine, hydralazine aldactazide, spironolactone, potassium chloride supplements) (n=24)	5 months	17(R)	25(24)		-0.35		Ogbuokiri, J.E., 1980
Counselling x 2 by pharmacist + written materials	Adults with hyperlipoproteinemic conditions attending VA-OPD (halofenate, clofibrate) (n=20)	20 days	15(R)	29(19)				Chubb, J.M. et al, 1974
Counselling x 2 by pharmacist + written materials	Adults with cardiac conditions attending a VA-OPD (digoxin, diuretics) (n=14)	20 days	15(R)	29(19)		-0.59		Chubb, J.M. et al, 1974
Written material (unspecified) + counselling x 80 + written reminders, all by pharmacist	Patients with chronic renal failure attending university hospital haemodialysis centre (antihypertensives, multivitamins, folic acid, antacids)(n=36)	4 months	13(R)	26(26)	0.94	-0.71		Skoutakis, V.A. et al, 1978
Counselling x 1 by pharmacist + 2 audiovisual tapes x 1	Adult in-patients with COPD (bronchodilators) (n=60)	6 months	5	17	0.34	-2.48		Darr, M.S. et al, 1981
Slide-tape + leaflet x 1 + counselling and tailoring of meds x 1 by ophthalmology assistant	Adults with chronic simple glaucoma attending hospital OPD (pilocarpine) (n=73)	20 days	15(R)	28(17)		-0.67		Norell, S.E., 1979
90-min audiovisual teaching program x 8 + counselling by R.N. X 10 +	Adults with hypertension attending a university hospital OPD (n=52)	6 months	15(R)	25(23)	0.19	-0.78	-1.13 BP (diastolic)	Nessman, D.G. et al, 1980
Labels, special containers PAK	Adults with hypertension	None given	14(R)	15(13)		-0.80		Eshelman,

Strategy	Subjects, clinical condition, and drug	Average time observed	Methods score[a]	Intervention score[b]	Knowledge effect[c]	Drug errors[c]	Clinical effect[c]	Ref.
dispenser	attending OPD (chlorthalidone) (n=65)							F.M. et al, 1976
Individual calendar pak (unit dose)	Geriatric inpatients in private rehabilitation unit (n=78)	1 month	8(R)	18(16)		-0.24		Crome, P. et al, 1982
Special unit-dose container for self-administration	Geriatric females hospitalized in private rehabilitation unit (n=44)	5 days	8(R)	22(21)		-0.23		Crome, P. et al, 1980
Labels, special containers + interpersonal								
Counselling x 1 by pharmacist + special medication container	Adults with hypertension with -2 meds/day attending a hospital OPD (n=20)	3 months	10(R)	24(17)		-0.95		Rehder, T.L. et al, 1980
Exit interview x 1 by health educator + home visit + booklet to patient and significant other x 1 by community aide + 1-hr small group sessions x 3	Adults with hypertension attending a hospital OPD (n=84)	2 years	19(R)	32(18)			-0.56 BP	Levine, D.M. et al, 1979 and Morisky, D.E. et al, 1983
Counselling by pharmacist + reminder chart	Low socioeconomic geriatric patients with hypertension attending a community clinic/pharmacy (n=79)	3 months	9(R)	24(19)		-0.38		Gabriel, M., et al, 1977
Counselling x 1 by pharmacist at discharge + memory aids	Discharged geriatric patients tested as non-competent (n=59)	3 months	11	29(18)		-0.31		MacDonald, E.T. et al, 1977
Counselling x 1 by pharmacist at discharge + memory aids	Discharged geriatric patients tested as competent (n=46)	3 months	11	29(18)		-0.58		MacDonald, E.T. et al, 1977
Verbal instruction + tear off calendar	Geriatric patients on rehabilitation unit (n=32)	2 weeks	10(R)	26(25)		-0.34		Wandless, I. Et al, 1977
Behaviour modification: Medication self-administration								
Self-monitoring of blood pressure	Adults beginning treatment for	6 months	11(R)	32(28)			-0.55 BP	Carnahan,

Strategy	Subjects, clinical condition, and drug	Average time observed	Methods scorea	Intervention scoreb	Knowledge effectc	Drug errorsc	Clinical effectc	Ref.
at home	hypertension at VA hospital OPD (n=97)							J.E. et al, 1975
Self-monitoring, tailoring, supervision, and reinforcement	Canadian steel workers with hypertension not adhering to drug regimen and not at goal BP (n=38)	6 months	18	32(17)		-0.51	-0.57 BP (diastolic)	Haynes, R.B. et al, 1976
Self-help group x 1 by medical student + diary + discussion	Youth and adults with asthma attending hospital ER (n=44)	1 year	10(R)	26(22)			-0.63 ER visits	Green, L.W. et al, 1977
Counselling and lecture x 1 to family by M.D. + skills training + telephone access	males with haemophilia A or B attending a hospital OPD (lymphilised factor VIII and IX concentrates) (n=90)	1 year	15	29			-0.79 days lost	Levine, P.H. et al, 1973
Counselling x 10 by M.D. At clinic visits + telephone access + counselling by dietician (some) + alternating use of various self-tests for 3 months each	Diabetics on twice-daily insulin attending university diabetic clinic and receiving intensive counselling (n=86)	1 day	11	24			-0.32 glycosylated Hb	Worth, R. Et al, 1982
Counselling x 1 by R.N. + booklet + patient-R.N. Signed contract	Adults with hypertension attending a clinic (n=60)	1 month	7(R)	24	0.69			Steckel, S.B. et al, 1977
Self-monitoring of blood pressure or medications + telephone call x 1 by R.N. + visit x 1 by R.N. To patient and support person + follow-up telephone calls x 1 to both	Adults with hypertension attending private practices (n=52)	4 months	17(R)	30(14)		-0.13		Kirscht, J.P. et al, 1981
Home visits by public health R.N. Or pharmacist + self-monitoring of blood pressure at home + active participation by significant other	Adults with essential hypertension attending a hospital OPD and family practice clinic (n=93)	6 months	18(R)	27(17)			-0.43 BP (diastolic)	Earp, J.L. et al, 1982
Lectures x 9 by R.N. And M.D. Staff including small group discussions and reinforcement of behaviour +	Psychiatric patients with Dx of schizophrenia, and bipolar and unipolar affective disorders	5 months	16	32(11)	0.25	-0.65		Seltzer, A. Et al, 1980

Strategy	**Subjects, clinical condition, and drug**	**Average time observed**	**Methods score[a]**	**Intervention score[b]**	**Knowledge effect[c]**	**Drug errors[c]**	**Clinical effect[c]**	**Ref.**
data sheets	(antidepressants, lithium) (n=41)							

Appendix G: Evidence tables: economic studies

G.1 Decision aids

Hollinghurst S, Emmett C, Peters TJ, et al. Economic evaluation of the DiAMOND randomized trial: cost and outcomes of 2 decision aids for mode of delivery among women with a previous cesarean section. Medical Decision Making 2010;30:453-63.

Study details	Population & interventions	Costs	Health outcomes	Cost effectiveness
Economic analysis: CCA **Study design:** within-RCT analysis **Approach to analysis:** Units costs were applied to resource use data collected within trial. **Perspective:** UK NHS **Time horizon:** Outcomes: 37 weeks gestational; Costs: 37 weeks gestational, 6 weeks post-natal **Treatment effect duration:** n/a **Discounting:** n/a	**Population:** Pregnant women with a previous caesarean section N = 742; complete cases = 524; imputed cost data = 598; imputed cost and outcome data = 713 Mean age = 32.6 Mean baseline DCS = 38.6 Setting = 3 units England, 1 unit Scotland **Intervention 1:** Usual care **Intervention 2:** Usual care + decision aid 1 – (information program – risks and benefits numerical and pictorial via website) **Intervention 3:** Usual care + decision aid 2 (decision analysis program – values of different outcomes elicited from patients then combined with probabilities to suggest a preferred option)	**Total costs – complete cases (mean per patient):** Intvn 1: £1986 (SD 696) Intvn 2: £2082 (SD 762) Intvn 3: £1982 (SD 763) Incremental (2-1):95.46 (CI -72, 205) Incremental (3-1):-£4.52 (CI -172, 107) **Currency & cost year:** 2005 UK pounds **Cost components incorporated:** Primary care, including out of hours, professionals' time, cost of delivery (normal, assisted, caesarean section), outpatient appointments, inpatient stays, medication, training time for use of decision analysis program. NB. Cost of development of	**Primary outcome measure:** Mean DCS at 37 weeks Intvn 1: 28.1 (SD 14.3) Intvn 2: 22.7 (SD 13.2) Intvn 3: 24.5 (SD 15.2) Incremental (2-1): 5.4 (CI 2.5, 8.7) Incremental (3-1): 3.6 (CI 0.5, 6.7) **Other outcome measures (mean):** Proportion with decisional conflict score below 25 Intvn 1: 0.38 (CI: 0.30-0.45) Intvn 2: 0.47 (CI: 0.39-0.54) Intvn 3: 0.42 (CI: 0.34-0.49) Proportion of caesarean deliveries Intvn 1: 0.68 (CI 0.61-0.75) Intvn 2: 0.75 (CI 0.68-0.81) Intvn 3: 0.60 (CI 0.53-0.67)	**Primary ICER (Intvn 2 vs Intvn 1):** ICER: n/a Probability cost-effective: n/a **Other:** n/a **Subgroup analyses:** n/a **Analysis of uncertainty:** 1 way sensitivity analysis used in investigate cost of delivery as uncertainty existed due to poor coding of data. Imputed missing data analyses: imputed cost data; imputed cost and outcome data. In the analyses the additional cost with Intvn 2 relative to Intvn 1 was reduced slightly, and the reduction in cost with Intvn 3 versus Intvn 1 was increased slightly.

Hollinghurst S, Emmett C, Peters TJ, et al. Economic evaluation of the DiAMOND randomized trial: cost and outcomes of 2 decision aids for mode of delivery among women with a previous cesarean section. Medical Decision Making 2010;30:453-63.				
		decision aids not included.		
Data sources				
Health outcomes: within-RCT analysis **Quality-of-life weights:** n/a **Cost sources:** resource use = within-RCT analysis; unit costs = standard UK unit cost sources.				
Comments				
Source of funding: Bupa Foundation; **Limitations:** Cost per QALY analysis not used. Some uncertainty about applicability of resource use and costs from over 10 years ago. Quality of life not assessed. Cost of developing decision aid not incorporated. Limited sensitivity analyses undertaken; **Other:**				
Overall applicability*: Partially applicable **Overall quality**:** Potentially serious limitation				

Abbreviations: CCA = cost-consequence analysis; CEA = cost-effectiveness analysis; CI = 95% confidence interval; CUA = cost-utility analysis; DCS = decisional conflict score; ICER = incremental cost-effectiveness ratio; NR = not reported; RCT = randomised clinical trial; QALY = quality-adjusted life years

** Directly applicable / Partially applicable / Not applicable; ** Minor limitations /Potentially serious Limitations / Very serious limitations*

Kennedy AD, Sculpher MJ, Coulter A, et al. A multicentre randomised controlled trial assessing the costs and benefits of using structured information and analysis of womens preferences in the management of menorrhagia. Health Technology Assessment 2003;7:1-86. **Kennedy AD, Sculpher MJ, Coulter A, et al. Effects of decision aids for menorrhagia on treatment choices, health outcomes, and costs: a randomized controlled trial.[Erratum appears in JAMA. 2003 Feb 12;289(6):703.]. JAMA 2002 Dec 4;288:2701-8.**				
Study details	**Population & interventions**	**Costs**	**Health outcomes**	**Cost effectiveness**
Economic analysis: CUA, CCA **Study design:** within-RCT analysis **Approach to analysis:** Units costs were applied to resource use data collected within trial. **Perspective:** UK NHS	**Population:** Women with menorrhagia N = 894 Mean age = 40yrs Setting = 6 hospitals England **Intervention 1:** Usual practice (n=298) **Intervention 2:** Information only (n=296)	**Total costs (mean per patient):** Intvn 1: £1810 Intvn 2: £1333 Intvn 3: £1030 Incremental (2-1): -£477 (CI -1071, -141) Incremental (3-1):-£779 (CI -1388, -450) Incremental (3-2):-£303 (CI -458, -155)	**Primary outcome measure:** QALYs (mean per patient) Intvn 1: 1.574 Intvn 2: 1.567 Intvn 3: 1.582 Incremental (2-1): -0.006 (CI -0.057, 0.048) Incremental (3-1): 0.009 (CI -.043, 0.060) Incremental (3-2):0.015 (CI -0.041, 0.066)	**Primary ICER (Intvn 2 vs Intvn 1):** ICER: Intvn 3 dominant (lower costs, higher QALYs). CI: NR. Probability cost-effective (£20,000/QALY): 84% **Other:** **Subgroup analyses:** **Analysis of uncertainty:** Excluding inpatient, outpatient and GP visti costs unrelated to mennorrhagia. Costs: Incremental (2-1): -£452 (CI -783, -190); Incremental (3-1):-£539 (CI -865, -270); Incremental (3-2):-£88

Kennedy AD, Sculpher MJ, Coulter A, et al. A multicentre randomised controlled trial assessing the costs and benefits of using structured information and analysis of womens preferences in the management of menorrhagia. Health Technology Assessment 2003;7:1-86.

Kennedy AD, Sculpher MJ, Coulter A, et al. Effects of decision aids for menorrhagia on treatment choices, health outcomes, and costs: a randomized controlled trial.[Erratum appears in JAMA. 2003 Feb 12;289(6):703.]. JAMA 2002 Dec 4;288:2701-8.

Time horizon: 2 years **Treatment effect duration:** n/a **Discounting:** none	**Intervention 2:** Information + interview (n=300)	**Currency & cost year:** 1999-2000 UK pounds **Cost components incorporated:** Intervention cost (fixed development costs averaged over potential population; variable production costs based on 550x video, 1000x booklets; delivery of interview by nurse). Tests, drugs, surgery/procedures, all inpatient, outpatient and GP visits.		(CI -195, 22). ICER: Intvn 3 dominant (lower costs, higher QALYs) - Probability cost-effective (£20,000/QALY): 72% Excluding all inpatient costs and unrelated outpatient and GP costs. Incremental (2-1): £59 (CI -67, 185); Incremental (3-1):-£35 (CI -146, -70); Incremental (3-2):-£94 (CI -206, 15). Intvn 3 dominant (lower costs, higher QALYs) - Probability cost-effective (£20,000/QALY): 58%. Higher cost of producing information – authors report has little effect on cost-effectiveness. 50% longer consultation for interview group – authors report has little effect on cost-effectiveness.

Data sources

Health outcomes: within-RCT analysis

Quality-of-life weights: EQ5D administered to patients within RCT, UK population tariff

Cost sources: resource use = within-RCT analysis; unit costs = standard UK national sources supplemented by published literature

Comments

Source of funding: NHS R&D HTA Programme; **Limitations:** Some uncertainty about applicability of resource use and costs from over 10 years ago. Unclear if short time horizon will omit longer term quality of life differences but this is considered unlikely to impact conclusion. Limited sensitivity analysis; **Other:**

Overall applicability*: Partially applicable **Overall quality**:** Minor limitations

Abbreviations: CCA = cost-consequence analysis; CEA = cost-effectiveness analysis; CI = 95% confidence interval; CUA = cost-utility analysis; DCS = decisional conflict score; ICER = incremental cost-effectiveness ratio; NR = not reported; RCT = randomised clinical trial; QALY = quality-adjusted life years

** Directly applicable / Partially applicable / Not applicable; ** Minor limitations /Potentially serious Limitations / Very serious limitations*

Murray E, Davis H, Tai SS, et al. Randomised controlled trial of an interactive multimedia decision aid on benign prostatic hypertrophy in primary care. BMJ 2001 Sep 1;323:493-6.

Study details	Population & interventions	Costs	Health outcomes	Cost effectiveness
Economic analysis: CCA **Study design:** within-RCT analysis **Approach to analysis:** Units costs were applied to resource use data collected within trial. Complete case analysis (ITT analysis did not alter results). **Perspective:** UK NHS **Time horizon:** 9 months **Treatment effect duration:** n/a **Discounting:** n/a	**Population:** Men with benign prostatic hypertrophy N = 112 (completed trial = 187) Mean age = 64yrs Setting = 33 general practices in England **Intervention 1:** Usual care **Intervention 2:** Decision aid (multimedia program with booklet and printed summary) provided with nurse supervision	**Total costs (mean per patient):** Intvn 1: £188.8 Intvn 2 (2-1): £594.1 Incremental: £405.4 (CI 224.9, 585.8) **Currency & cost year:** 1999 UK pounds **Cost components incorporated:** Intervention (equipment and staff time), number and duration of GP consultations, referrals to urologists, other referrals, drugs related to BPH, tests and diagnostic and surgical procedures.	Study reported no difference in trends over time for EQ5D and also for SF36 (not quantitatively reported). Mean DCS at 3 months Intvn 1: 2.6 (SD 0.5) Intvn 2: 2.3 (SD 0.4) Incremental (2-1): -0.3 (CI -0.5, -0.1) Mean DCS at 9 months Intvn 1: 2.55 (SD 0.50) Intvn 2: 2.23 (SD 0.38) Incremental (2-1): -0.33 (CI -0.51, -0.14) Outcomes also reported included perception about who made decision, satisfaction with treatment choice, treatment choice, anxiety (Spielberger state trait anxiety score) and prostatic symptoms.	**Primary ICER (Intvn 2 vs Intvn 1):** n/a **Other:** n/a **Subgroup analyses:** n/a **Analysis of uncertainty:** When cost of trial technology excluded no significant difference in costs (difference 2-1 = 121.5 [CI-58.9, 302.0]).

Data sources

Health outcomes: within-RCT analysis

Quality-of-life weights: EQ5D administered to patients within RCT, UK population tariff

Cost sources: resource use = within-RCT analysis; unit costs = standard UK national sources

Comments

Source of funding: BUPA Foundation and Kings Fund; **Limitations:** Cost per QALY analysis not used. Some uncertainty about applicability of resource use and costs from over 10 years ago. 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; **Other:** Cost of video technology in decision aid arm was £278 per patient – video

Murray E, Davis H, Tai SS, et al. Randomised controlled trial of an interactive multimedia decision aid on benign prostatic hypertrophy in primary care. BMJ 2001 Sep 1;323:493-6.
hardware system cost £24,300 plus cost of a secure cupboard. Software cost £1118 per video disc giving total of £5590 plus £400 shipping).Shared with other trial so total technology cost for trial £15,840.
Overall applicability*: Partially applicable **Overall quality**:** potentially serious limitations

Abbreviations: CCA = cost-consequence analysis; CEA = cost-effectiveness analysis; CI = 95% confidence interval; CUA = cost-utility analysis; DCS = decisional conflict score;EQ-5D = Euroqol 5 dimensions; ICER = incremental cost-effectiveness ratio; NR = not reported; RCT = randomised clinical trial; QALY = quality-adjusted life years

** Directly applicable / Partially applicable / Not applicable; ** Minor limitations /Potentially serious Limitations / Very serious limitations*

Murray E, Davis H, Tai SS, et al. Randomised controlled trial of an interactive multimedia decision aid on hormone replacement therapy in primary care. BMJ 2001 Sep 1;323:490-3.

Study details	Population & interventions	Costs	Health outcomes	Cost effectiveness
Economic analysis: CCA **Study design:** within-RCT analysis **Approach to analysis:** Units costs were applied to resource use data collected within trial. Complete case analysis (ITT analysis did not alter results). **Perspective:** UK NHS **Time horizon:** 9 months **Treatment effect duration:** n/a **Discounting:** n/a	**Population:** Women eligible for hormone replacement therapy N = 205 (completed trial = 187) Mean age = 50yrs Setting = 26 general practices in England **Intervention 1:** Usual care **Intervention 2:** Decision aid (multimedia program with booklet and printed summary) provided with nurse supervision	**Total costs (mean per patient):** Intvn 1: £90.9 Intvn 2 (2-1): £306.5 Incremental: £215.5 (CI 203.1, 228.0) **Currency & cost year:** 1999 UK pounds **Cost components incorporated:** Intervention (video costs, nurse time, accommodation), number and duration of GP consultations, referrals to specialist, use of HRT and related drugs.	Study reported no significant difference in change from baseline at 9 months for EQ5D and also for SF36 (not quantitatively reported). Mean DCS at 3 months Intvn 1: 2.8 (SD 0.6) Intvn 2: 2.5 (SD 0.5) Incremental (2-1): -0.3 (CI -0.5, -0.2) Mean DCS at 9 months Intvn 1: 2.80 (SD 0.61) Intvn 2: 2.45 (SD 0.56) Incremental (2-1): -0.35 (CI -0.53, -0.16) Outcomes also reported included perception about who made decision, treatment preference, persistence	**Primary ICER (Intvn 2 vs Intvn 1):** n/a **Other:** n/a **Subgroup analyses:** n/a **Analysis of uncertainty:** When cost of trial technology excluded no significant difference in costs. Noted that delivering programme through standard PCs via internet would reduce the cost per session from £177 to £5 (excluding cost of software).

Murray E, Davis H, Tai SS, et al. Randomised controlled trial of an interactive multimedia decision aid on hormone replacement therapy in primary care. BMJ 2001 Sep 1;323:490-3.

			with treatment, anxiety (Spielberger state trait anxiety score) and MenQoL (menopausal symtpoms).	

Data sources

Health outcomes: within-RCT analysis

Quality-of-life weights: EQ5D administered to patients within RCT, UK population tariff

Cost sources: resource use = within-RCT analysis; unit costs = standard UK national sources

Comments

Source of funding: BUPA Foundation and Kings Fund; **Limitations:** Cost per QALY analysis not used. Some uncertainty about applicability of resource use and costs from over 10 years ago. 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; **Other:** Cost of video technology in decision aid arm was £216 per patient. Video hardware system cost £24,300 plus cost of a secure cupboard. Software cost £1118 per video disc giving total of £5590 plus £400 shipping).Shared with other trial.

Overall applicability*: Partially applicable **Overall quality**:** potentially serious limitations

Abbreviations: CCA = cost-consequence analysis; CEA = cost-effectiveness analysis; CI = 95% confidence interval; CUA = cost-utility analysis; DCS = decisional conflict score; EQ-5D = Euroqol 5 dimensions; ICER = incremental cost-effectiveness ratio; NR = not reported; RCT = randomised clinical trial; QALY = quality-adjusted life years

** Directly applicable / Partially applicable / Not applicable; ** Minor limitations /Potentially serious Limitations / Very serious limitations*

Vuorma S, Teperi J, Aalto AM, et al. A randomized trial among women with heavy menstruation -- impact of a decision aid on treatment outcomes and costs. Health Expectations 2004 Dec;7:327-37.

Study details	Population & interventions	Costs	Health outcomes	Cost effectiveness
Economic analysis: CCA **Study design:** within-RCT analysis **Approach to analysis:** Units costs were applied to resource use data collected within trial.	**Population:** Women with heavy menstruation N = 569 Mean age = NR Setting = 14 hospitals Finland **Intervention 1:**	**Total costs (mean per patient):** Intvn 1: £2,016 Intvn 2: £1,662 Incremental (2-1): -£358 (CI NR ; p=0.2) **Currency & cost year:** 1999 Euros (Finland)	Study reported “no marked disparities in health outcomes, satisfaction with treatment” A significant difference in RAND-36 ‘emotional role functioning’. Significant differences not seen in other domains or other outcome measures (perceived health, anxiety, psychosomatic	**Primary ICER (Intvn 2 vs Intvn 1):** n/a **Other:** n/a **Subgroup analyses:** n/a **Analysis of uncertainty:** Menorrhagia related costs only analyses: difference 2-1 = -£52 (CI

Vuorma S, Teperi J, Aalto AM, et al. A randomized trial among women with heavy menstruation -- impact of a decision aid on treatment outcomes and costs. Health Expectations 2004 Dec;7:327-37.				
Perspective: Finland societal but costs disaggregated so only health system costs reported here **Time horizon:** 1 year **Treatment effect duration:** n/a **Discounting:** n/a	Usual care **Intervention 2:** Decision aid booklet mailed to patients	**Cost components incorporated:** Intervention, use of hospital services (operations, inpatient days, procedures, outpatient visits), other doctor visits, medication (reported by authors but not included here: sick-leave days, health care travel costs and sanitary pads).	symptoms, sexuality, menstrual symptoms or satisfaction).	NR, p=NR)
Data sources				
Health outcomes: within-RCT analysis **Quality-of-life weights:** n/a **Cost sources:** resource use = within-RCT analysis; unit costs = Finland national costs, reported as from standard sources.				
Comments				
Source of funding: STAKES – National Research and Development Centre for Welfare and Health, and Public Health Doctoral Programmes of Helsinki and Tampere universities; **Limitations:** Cost per QALY analysis not used. Some uncertainty about applicability of Finnish resource use and costs from over 10 years ago. 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; **Other:** Information booklet was costed at £7 – it is unclear if this included development of the aid or just cost of production of booklet.				
Overall applicability*: Partially applicable **Overall quality**:** potentially serious limitations				

Abbreviations: CCA = cost-consequence analysis; CEA = cost-effectiveness analysis; CI = 95% confidence interval; CUA = cost-utility analysis; DCS = decisional conflict score; ICER = incremental cost-effectiveness ratio; NR = not reported; RCT = randomised clinical trial; QALY = quality-adjusted life years

** Directly applicable / Partially applicable / Not applicable; ** Minor limitations /Potentially serious Limitations / Very serious limitations*

G.2 Continuity of care (midwife-led care)

C. Begley, D. Devane, and M. Clarke. An evaluation of midwifery-led care in the Health Service Executive North Eastern Area: the report of the MidU study. Anonymous. Anonymous. Dublin: School of Nursing and Midwifery, Trinity College Dublin. 2009. MIDWIFE LED CARE.

Study details	Population & interventions	Costs	Health outcomes	Cost effectiveness
Economic analysis: CCA **Study design:** Within-RCT analysis for clinical outcomes; costs modelled **Approach to analysis:** Cost analysis based on resource use estimates from people involved in RCT; clinical outcomes from RCT analysis. **Perspective:** Health Services Executive (HSE-NE), Ireland **Time horizon:** Not clear (assumed capital costs over 50 years), outcomes: immediate **Treatment effect duration:** n/a **Discounting:** 5%	**Population:** Healthy women, without risk factors for labour and delivery, aged between 16-40 years N= 1539 **Intervention 1:** Standard care in a consultant led unit (CLU) **Intervention 2:** Midwifery led care in a midwifery led unit (MLU)	**Total costs – mean cost of care per person:** Intvn 1: £2047 Intvn 2: £1810 Incremental (2-1): -£237 (CI: NR; p = NR) **Currency & cost year:** Euros 2005/2006 inflated to 2009 (presented here as 2009 UK pounds) **Cost components incorporated:** Capital costs (building, birthing pools etc.), antenatal clinics, staff costs (consultant, midwife, sonographer, nurse), hospital stay, home visits, drugs, ultrasound scans, anaesthetic, epidural, surgery.	Clinical study report concludes that "MLU is as safe as CLU, results in less intervention and is viewed by women with greater satisfaction in some aspects of care".	**Primary ICER (Intvn 2 vs Intvn 1):** ICER: n/a Probability cost-effective: n/a **Other:** n/a **Subgroup analyses:** Normal births only Intvn 1: £449 Intvn 2: £408 Incremental (2-1): -£41 **Analysis of uncertainty:** Several scenarios where analysed in deterministic sensitivity analysis - Reducing consultants commitment to MLU - Reduce admin of nurse - Increase in visits of midwife after birth - Number of antepartum cardiotocographs - Length of postnatal hospital stay - Total cost per birth - Mean increase/decrease in cost of CLU

Data sources

Health outcomes: within-RCT analysis (same report)

C. Begley, D. Devane, and M. Clarke. An evaluation of midwifery-led care in the Health Service Executive North Eastern Area: the report of the MidU study. Anonymous. Anonymous. Dublin: School of Nursing and Midwifery, Trinity College Dublin. 2009. MIDWIFE LED CARE.
Quality-of-life weights: n/a **Cost sources:** resource use = estimates from midwifery unit from two hospitals in RCT; unit costs = financial data gathered from two hospitals in RCT; data regarding building and equipping the units = gathered from capital division of Health Service Executive – North Eastern Area
Comments
Source of funding: Health Service Executive – North Eastern Area. **Limitations:** QALYs not used and quality of life not assessed; Some uncertainty about applicability of Irish resource use and costs; Some limitations in resource used estimates; Limited sensitivity analyses undertaken. **Other:**
Overall applicability*: Partially applicable **Overall quality**:** Potentially serious limitations

Abbreviations: CCA = cost-consequence analysis; CEA = cost-effectiveness analysis; CI = 95% confidence interval; CUA = cost-utility analysis; ICER = incremental cost-effectiveness ratio; NR = not reported; RCT = randomised clinical trial; QALY = quality-adjusted life years

** Directly applicable / Partially applicable / Not applicable; ** Minor limitations /Potentially serious Limitations / Very serious limitations*

C. S. Homer, D. V. Matha, L. G. Jordan, J. Wills, and G. K. Davis. Community-based continuity of midwifery care versus standard hospital care: a cost analysis. ***Australian Health Review*** **24 (1):85-93, 2001.**

Study details	Population & interventions	Costs	Health outcomes	Cost effectiveness
Economic analysis: CCA **Study design:** Within-RCT analysis **Approach to analysis:** Total costs calculated using costs and resource collected within trial supplemented by some additional data; bootstrapping to calculate CI. **Perspective:** health system	**Population:** Pregnant women less than 24 weeks after gestation N = 1089 **Intervention 1:** Standard care (physician led) **Intervention 2:** STOMP model (midwife led continuously the same caregiver)	**Mean cost per woman:** Intvn 1: £1689 Intvn 2: £1251 **Incremental (2-1):** -£438 (CI: NR; p=NR) **Currency & cost year:** Australian Dollars 2000 (presented here as 2000 UK pounds) **Cost components incorporated:** Salary and wages, ultrasound, staff on time, preparation/admin, travel, site costs, training,	Clinical study report concluded that midwife-led care "resulted in a significantly reduced caesarean section rate. There were no other differences in clinical outcomes."	**Primary ICER (Intvn 2 vs Intvn 1):** ICER: n/a Probability cost-effective: n/a **Other:** n/a **Subgroup analyses:** n/a **Analysis of uncertainty:** 1. Throughput – when reduced to <10 women for STOMP no longer a saving (30 in basecase vs 50 in hospital clinic) 2. Excluding costs due to neonatal admission to special care nursery – cost saving reduced to -£67

C. S. Homer, D. V. Matha, L. G. Jordan, J. Wills, and G. K. Davis. Community-based continuity of midwifery care versus standard hospital care: a cost analysis. *Australian Health Review* 24 (1):85-93, 2001.

Time horizon: covered antenatal, intrapartum and postnatal period – assumed <1 year **Treatment effect duration:** n/a **Discounting:** n/a		hospital care, assessment unit, equipment, length of stay, anaesthetic, surgery time.		3. Caesarean section rate – as difference in caesarean rate reduces, cost saving is reduced, but there is still a cost saving with STOMP when no difference.

Data sources

Health outcomes: within-RCT analysis (separate report[7]). **Quality-of-life weights:** n/a. **Cost sources:** Resource use – collected within trial or assumptions; Unit costs – collected within trial or from local sources.

Comments

Source of funding: National health and medical research council centres of excellence in hospital based research grant **Limitations:** Cost per QALY analysis not used; Quality of life not assessed; no effectiveness measure considered.

Overall applicability*: Partially applicable **Overall quality**:** potentially serious limitations

Abbreviations: CCA = cost-consequence analysis; CEA = cost-effectiveness analysis; CI = 95% confidence interval; CUA = cost-utility analysis; ICER = incremental cost-effectiveness ratio; NR = not reported; RCT = randomised clinical trial; QALY = quality-adjusted life years

** Directly applicable / Partially applicable / Not applicable; ** Minor limitations /Potentially serious Limitations / Very serious limitations*

V. Hundley, C. Donaldson, and G. et al Lang. Cost of intrapartum care in a midwife managed delivery unit and a consultant led labour ward. *Midwifery* 11 (3):103-109, 1995.

Study details	Population & interventions	Costs	Health outcomes	Cost effectiveness
Economic analysis: CCA **Study design:** Within-RCT analysis **Approach to analysis:** Significantly different	**Population:** Women at low obstetric risk N = 2844 **Intervention 1:** Standard care in a consultant led unit	**Incremental costs – extra cost per woman as a result of introduction of MU care** Staff costs: +£44.69 Consumable Costs: -£3.25 Capital Costs: -£0.73 Total Costs: +£40.71	Paper states that the clinical report found "significant differences in monitoring, fetal distress, analgesia, mobility, use of episiotomy; There was no difference in fetal outcome."	**Primary ICER (Intvn 2 vs Intvn 1):** ICER: n/a Probability cost-effective: n/a **Other:** n/a **Subgroup analyses:** n/a

V. Hundley, C. Donaldson, and G. et al Lang. Cost of intrapartum care in a midwife managed delivery unit and a consultant led labour ward. *Midwifery* 11 (3):103-109, 1995.				
resources between each arm of the trial were included and costed using standard unit costs. These costs were calculated for staff costs, consumables and capital costs. **Perspective:** Health care provider **Time horizon:** Intrapartum period only **Treatment effect duration:** n/a **Discounting:** n/a	(CLU) **Intervention 2:** Midwifery led care in a midwifery led unit (MLU)	**Currency & cost year:** UK pounds 1992 **Cost components incorporated:** Fetal scalp electrode, epidural, continuous and intermittent heart rate monitors, TENS, episiotomy. Assisted vaginal delivery, caesarean section, general anaesthetic, administration of neonatal Nalaxone. Building cost of converting a wing.		**Analysis of uncertainty:** Nine scenarios where analysed in deterministic sensitivity analysis - 1,2 and 3: Baseline cost per woman of introducing MLU - 4. Only statistically significant costs are included and clinically significant costs are excluded - 5. Conversion costs were not due to the midwives unit. - 6. Cost of using lower grade midwives. - 7. Assumptions 5 and 6 combined. - 8. Effect of not lowering staff levels. - 9. No change in staffing levels.
Data sources				
Health outcomes: within-RCT analysis (different report). **Quality-of-life weights:** n/a. **Cost sources:** resource use – mostly as collected within-RCT; unit costs – local drug costs if available if not BNF, other cost sources unclear.				
Comments				
Source of funding: Scottish Office of Home and Health Department. **Limitations:** Cost per QALY analysis not used; Some uncertainty about applicability of resource use and costs; Quality of life not assessed; no effectiveness measure considered. **Other:**				
Overall applicability*: Partially applicable **Overall quality**:** Potentially serious limitations				

Abbreviations: CCA = cost-consequence analysis; CEA = cost-effectiveness analysis; CI = 95% confidence interval; CUA = cost-utility analysis; ICER = incremental cost-effectiveness ratio; NR = not reported; RCT = randomised clinical trial; QALY = quality-adjusted life years

** Directly applicable / Partially applicable / Not applicable; ** Minor limitations /Potentially serious Limitations / Very serious limitations*

M. J. Rowley, M. J. Hensley, M. W. Brinsmead, and J. H. Wlodarczyk. Continuity of care by a midwife team versus routine care during pregnancy and birth: a randomised trial. *Medical Journal of Australia* 163 (6):289-293, 1995.				
Study details	**Population & interventions**	**Costs**	**Health outcomes**	**Cost effectiveness**

M. J. Rowley, M. J. Hensley, M. W. Brinsmead, and J. H. Wlodarczyk. Continuity of care by a midwife team versus routine care during pregnancy and birth: a randomised trial. *Medical Journal of Australia* 163 (6):289-293, 1995.

Economic analysis: CCA **Study design:** Within-RCT analysis **Approach to analysis:** Costs applied to outcomes/resource use collected in trial. **Perspective:** Health care payer **Time horizon:** covers antenatal, intrapartum and early postnatal period (<1yr) **Treatment effect duration:** n/a **Discounting:** n/a	**Population:** Pregnant women who had not chosen to receive care through a GP or who had a substance abuse problem N = 1700 **Intervention 1:** Standard Care (variety of midwives and medics) **Intervention 2:** Team care (continuously from the same team)	**Average cost per delivery:** Intvn 1: £1749 Intvn 2: £1673 Incremental (2-1): -£76 **Midwife salary analysis:** Intvn 1: £346 Intvn 2: £329 Incremental (2-1): -£18 **Currency & cost year:** Australian Dollars 1999 (presented here as 1999 UK pounds) **Cost components incorporated:** Diagnosis-related group costs applied to outcomes. Analysis of salaries were also undertaken.	• Fewer adverse outcomes for women receiving intvn 2. • Reduction in emergency and elective caesarean rate in intvn 2. • Reduction in neonatal rescucitation and Apgar scores of less than 7 at one minute for babies in intvn 2. • Fewer neonatal ICU admissions and more babies breastfed in Intvn 2. • More smaller and high risk babied in Intvn 2. • Maternal satisfaction was higher in Intvn 2.	**Primary ICER (Intvn 2 vs Intvn 1):** ICER: n/a Probability cost-effective: n/a **Other:** n/a **Subgroup analyses:** n/a **Analysis of uncertainty:** none

Data sources

Health outcomes: Within-RCT analysis (same report). **Quality-of-life weights:** n/a. **Cost sources:** resource use – within-RCT analysis; costs - Australian national cost weights for diagnosis-related groups, salary source unclear.

Comments

Source of funding: Commonwealth Department of Human Services and Health, Australia. **Limitations:** Cost per QALY analysis not used; Quality of life not assessed; effectiveness measure not expressly analysed alongside cost, uncertainty not analysed.

Overall applicability*: Partially applicable **Overall quality**:** potentially serious limitations

Abbreviations: CCA = cost-consequence analysis; CEA = cost-effectiveness analysis; CI = 95% confidence interval; CUA = cost-utility analysis; ICER = incremental cost-effectiveness ratio; NR = not reported; RCT = randomised clinical trial; QALY = quality-adjusted life years

** Directly applicable / Partially applicable / Not applicable; ** Minor limitations /Potentially serious Limitations / Very serious limitations*

D. Young, A. Lees, and S. Twaddle. Professional issues. The costs to the NHS of maternity care: midwife-managed vs shared. *British Journal of Midwifery* 5 (8):465-472, 1997.

Study details	Population & interventions	Costs	Health outcomes	Cost effectiveness
Economic analysis: CCA **Study design:** Within-RCT analysis **Approach to analysis:** - Identification of relevant costs - Measurement of resource use - Valuation of resource use depending on period of pregnancy **Perspective:** Health care provider **Time horizon:** covers antenatal, intrapartum and postnatal period (assumed <1 year) **Treatment effect duration:** n/a **Discounting:** n/a	**Population:** Women experiencing normal pregnancy N = 1299 **Intervention 1:** Shared Care (multi disciplinary care) (SC) **Intervention 2:** Midwifery led care in a midwifery led unit (MC)	**Total mean costs per person:** Intvn 1: £1061.06 Intvn 2: £1067.06 Incremental (2-1): £6.5 (CI: NR, p=NR) **Antenatal period mean costs per person:** Intvn 1: £383.59 Intvn 2: £357.15 Incremental (2-1): -£26.44 (CI: NR, p=NR) **Intrapartum period mean costs per person:** Intvn 1: £280.37 Intvn 2: £276.07 Incremental (2-1):- £40.3 (CI: NR, p=NR) **Postnatal period mean costs per person:** Intvn 1: £397.10 Intvn 2: £496.83 Incremental (2-1): £73.24 (CI: NR, p=NR) **Currency & cost year:** UK pounds 1994 **Cost components incorporated:** Clinics, Tests and investigations, Day care, referrals, procedures/treatments, operations, inpatient days, mode of delivery, fetal monitoring, antenatal and postnatal visits	States that study found that midwife-led care was: • Clinically safe and efficacious • Increased satisfaction • Enhanced continuity of care	**Primary ICER (Intvn 2 vs Intvn 1):** ICER: n/a Probability cost-effective: n/a **Other:** n/a **Subgroup analyses:** n/a **Analysis of uncertainty:** - Case load of midwife - Location of care

D. Young, A. Lees, and S. Twaddle. Professional issues. The costs to the NHS of maternity care: midwife-managed vs shared. *British Journal of Midwifery* 5 (8):465-472, 1997.
Data sources
Health outcomes: within-RCT analysis (different report). **Quality-of-life weights:** n/a. **Cost sources:** resource use – within-RCT analysis supplemented by other sources; unit costs – states most from NHS trust.
Comments
Source of funding: Scottish Office of Home and Health Department; **Limitations:** Cost per QALY analysis not used; Some uncertainty about applicability of resource use and costs; Quality of life not assessed; no effectiveness measure considered.
Overall applicability*: Partially applicable **Overall quality**:** Potentially serious limitations

Abbreviations: CCA = cost-consequence analysis; CEA = cost-effectiveness analysis; CI = 95% confidence interval; CUA = cost-utility analysis; ICER = incremental cost-effectiveness ratio; NR = not reported; RCT = randomised clinical trial; QALY = quality-adjusted life years

** Directly applicable / Partially applicable / Not applicable; ** Minor limitations /Potentially serious Limitations / Very serious limitations*

Appendix H: Declarations of Interest

All members of the GDG and all members of the NCGC staff were required to make declarations of interest at the outset, and these were updated at every subsequent meeting throughout the development process. No interests were declared that required actions.

Sophie Staniszewska

GDG meeting	Declaration of Interest
Chair recruitment	The National Clinical Guideline Centre (NCGC) commissioned the University of Warwick to conduct a scoping study for the Patient Experiences Guideline in December 2010. The Warwick Research team was led by Dr Sophie Staniszewska. This work was undertaken prior to the interviews for the role of Chair of the guideline group which Sophie applied for and was successful after an open competitive interview process. The Warwick scoping study formed part of a much larger evidence base which informed the Guideline Development Group in the development of the Patient Experiences Guideline.
First GDG meeting (2nd February 2011)	No change to declarations
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th May 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

David Martin

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	No change to declarations
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th May 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

Poonam Jain

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	No change to declarations
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th May 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

Miranda Dodwell

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	Personal non-pecuniary interest - Written and presented views on the importance of patient experience as a measure of the quality of care.
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th May 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

Suzannah Power

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	Personal non-pecuniary interest - Patient representation on the British Heart Foundation Council. This is an unpaid role.
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations

GDG meeting	Declaration of Interest
Fifth GDG meeting (12th May 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

Christianne Forrest

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	No change to declarations
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th May 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

Tom McLoughlin-Yip

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	Personal pecuniary interest - NHS employee working in administration for the Heart of England NHS Foundation Trust – Patient/Public Engagement, part-time. Non-personal pecuniary interest - Voluntary member for Transforming Community Services and Transforming Adult Social Care supported by the Department of Health. - Birmingham LINks member – Birmingham East and North Action group. - Cystic Fibrosis Chair, West Midlands Fundraising Branch.
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th March 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

1 **Jo Adams**

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	No change to declarations
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th March 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

2 **Eloise Carr**

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	No change to declarations
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th March 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

3 **Melanie Gager**

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	No change to declarations
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (3rd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th March 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

1 Annette Gibb

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	No change to declarations
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th May 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

2 Alan Nye

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	Non-personal pecuniary interest - Associate Director for NHS Direct which has been commissioned by the Department of Health to develop patient aids for the NHS.
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th May 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

3 Amanda Smith

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	Personal pecuniary interest - NHS employee since 1984 currently working as Clinical (Therapies) Director for Powys Teaching Health Board in Wales.
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th May 2011)	No change to declarations

GDG meeting	Declaration of Interest
Sixth GDG meeting (26th July 2011)	

1 **Richard Thomson**

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	Non-personal pecuniary interest - Undertakes research in patient engagement in decision making (shared decision making) and hold and compete for grants from appropriate funding bodies to support research into, and implementation of, shared decision making. - Deputy director of the Institute for Health and Society. Members of the Institute for Health and Society have worked with NICE on other guideline groups, and colleagues have been involved in exploring the evidence base on behalf of NICE and providing health economics advice to NICE. Personal non-pecuniary interest - Written on shared decision making and the role of the NHS within this area.
Second GDG meeting (1st March 2011)	Personal non-pecuniary interest - Member of the International Patient Decision Aids Standards (IPDAS) collaboration. This is an international body, from which I receive no funding, that takes a collaborative role to develop standards and summarise the evidence base for patient decision aids. Co-applicant on a grant for development of an instrument (IPDASi) which seeks to be useful as an evaluative and/or accrediting tool for patient decision aids.
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th May 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

2 **Chandi Vellodi**

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	No change to declarations
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations

GDG meeting	Declaration of Interest
Fifth GDG meeting (12th May 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

1 **Barrie White**

GDG meeting	Declaration of Interest
GDG recruitment	None
First GDG meeting (2nd February 2011)	Personal pecuniary interest - GDG Chair – NICE Lung Cancer Guideline - Senior mentor for NICE fellows/scholars Personal non-pecuniary interest - Vice-Chair NICE Interventional Procedures Advisory Committee
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th May 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

2 **Declarations of interests of the NCGC members**

GDG meeting	Declaration of Interests of NCGC members
First GDG meeting (2nd February 2011)	None
Second GDG meeting (1st March 2011)	No change to declarations
Third GDG meeting (2nd March 2011)	No change to declarations
Fourth GDG meeting (5th April 2011)	No change to declarations
Fifth GDG meeting (12th May 2011)	No change to declarations
Sixth GDG meeting (26th July 2011)	

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