

# Patient experience in adult NHS services

Evidence Update February 2014

A summary of selected new evidence relevant to NICE clinical guideline 138 'Patient experience in adult NHS services: improving the experience of care for people using adult NHS services' (2012)

**Evidence Update 52**



Evidence Updates provide a summary of selected new evidence published since the literature search was last conducted for the accredited guidance they relate to. They reduce the need for individuals, managers and commissioners to search for new evidence. Evidence Updates highlight key points from the new evidence and provide a commentary describing its strengths and weaknesses. They also indicate whether the new evidence may have a potential impact on current guidance. For contextual information, this Evidence Update should be read in conjunction with 'Patient experience in adult NHS services' ([NICE clinical guideline 138](#)).

**Evidence Updates do not replace current accredited guidance and do not provide formal practice recommendations.**

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## Introduction

This Evidence Update identifies new evidence that is relevant to, and may have a potential impact on, the following reference guidance:

<sup>1</sup>  [Patient experience in adult NHS services](#). NICE clinical guideline 138 (2012)

A search was conducted for new evidence from 9 May 2011 to 9 August 2013. A total of 4985 pieces of evidence were initially identified. Following removal of duplicates and a series of automated and manual sifts, 13 items were selected for the Evidence Update (see Appendix A for details of the evidence search and selection process). An [Evidence Update Advisory Group](#), comprising topic experts and patient and carer members, reviewed the prioritised evidence and provided a commentary.

Although the process of updating NICE guidance is distinct from the process of an Evidence Update, the relevant NICE guidance development centres have been made aware of the new evidence, which will be considered when guidance is reviewed.


## NICE Pathways

- [Patient experience in adult NHS services](#). NICE Pathway

## Feedback

If you have any comments you would like to make on this Evidence Update, please email [contactus@evidence.nhs.uk](mailto:contactus@evidence.nhs.uk)

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<sup>1</sup> NICE-accredited guidance is denoted by the Accreditation Mark 

## Key points

The following table summarises what the Evidence Update Advisory Group (EUAG) decided were the key points for this Evidence Update. It also indicates the EUAG's opinion on whether the new evidence may have a potential impact on the current guidance listed in the introduction. For further details of the evidence behind these key points, please see the full commentaries.

The section headings used in the table below are taken from the guidance.

**Evidence Updates do not replace current accredited guidance and do not provide formal practice recommendations.**

Key point	Potential impact on guidance	
	Yes	No
<p><b>Essential requirements of care</b></p> <ul style="list-style-type: none"> <li>• Patients should be supported at meal times, be given guidance on how to overcome eating difficulties, and preferences for eating alone or with others should be respected.</li> <li>• Patient-centred interventions (education, self-management), provider-centred interventions (education reminders) and interventions to integrate palliative care principles in daily practice resulted in limited improvement in pain management of patients with advanced and serious illness receiving palliative care.</li> </ul>		<p>✓</p> <p>✓</p>
<p><b>Tailoring healthcare services for each patient</b></p> <ul style="list-style-type: none"> <li>• Training of healthcare providers may help to promote a patient-centred approach to clinical consultations, with short-term interventions (less than 10 hours of training) seemingly as effective as longer training.</li> <li>• Patient views of caring behaviour, and their priorities and strategies for management of multiple conditions, may be different from those of healthcare professionals and may change over time.</li> </ul>		<p>✓</p> <p>✓</p>
<p><b>Continuity of care and relationships</b></p> <ul style="list-style-type: none"> <li>• Continuity of care is a dynamic concept that may be defined in terms of a single framework with multiple components.</li> <li>• A wide range of interventions can have a positive impact on transition from hospital to primary care, including those aimed at improving exchange of information between providers, coordination of care and communication. Evidence to establish the most effective of these interventions is lacking.</li> <li>• It is important to inform patients about the roles and responsibilities of healthcare professionals, particularly when care has been transferred from other care settings or services, so that patient expectations can be managed.</li> </ul>		<p>✓</p> <p>✓</p> <p>✓</p>

Key point	Potential impact on guidance	
	Yes	No
<p><b>Enabling patients to actively participate in their care</b></p> <ul style="list-style-type: none"> <li>• Patients across different European countries appear to have similar views about patient-centred care, with provision of information consistently rated as an important dimension.</li> <li>• Important aspects of patient-centred care include communication and understanding, with other concepts (such as legitimising the illness experience and offering realistic hope) also of relevance to interactions between patients with chronic diseases and primary healthcare professionals.</li> <li>• Healthcare professional nonverbal communication skills – particularly listening, warmth, and avoiding negativity – are associated with improved patient satisfaction.</li> <li>• The provision of information to patients can be seen as an ongoing and flexible process to support navigation through the illness and care landscape.</li> <li>• Decision aids are effective tools to improve the quality of decision-making, by improving people’s knowledge of treatment options and accuracy of risk perception, reducing feelings of being uninformed or unclear about values, stimulating people to take a more active role in decision-making and supporting concordance between patient values and the choice made.</li> </ul>		<p>✓</p> <p>✓</p> <p>✓</p> <p>✓</p> <p>✓</p>

## Commentary on new evidence

These commentaries analyse the key references identified specifically for the Evidence Update. The commentaries focus on the 'key references' (those identified through the search process and prioritised by the EUAG for inclusion in the Evidence Update), which are identified in bold text. Section headings are taken from the guidance.

### 1.1 Knowing the patient as an individual

No new key evidence was found for this section.

### 1.2 Essential requirements of care

#### **Nutrition**

NICE clinical guideline 138 ([NICE CG138](#)) recommends that all healthcare professionals directly involved in patient care should receive education and training, relevant to their post, on the importance of providing adequate and appropriate nutrition. It should also be ensured that the patient's nutrition and hydration are adequate at all times, if the patient is unable to manage this themselves, by:

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

A systematic review by [Larsen and Uhrenfeldt \(2013\)](#) examined the impact on patient nutrition of:

- provision and serving of food and drink
- patients' illness
- nutritional care provided by healthcare professionals.

The review included studies published in peer-reviewed journals with the main theme of patient experience of nutrition during illness. It excluded studies of specific diets or compliance, and studies involving children, palliative care, or people with dementia or psychiatric diagnoses. Of the 13 included studies (n=366), all were conducted in the UK, Sweden or Denmark and reported qualitative data; 1 study also reported quantitative data. The studies were analysed by themes corresponding to the aims of the review.

The food and drink provided to patients, and the way it was served, was evaluated in 6 studies. Although there was general satisfaction with the food served in hospitals, nutritional supplement drinks received negative comments in 3 studies because of texture and flavour. An influence of the surroundings and eating environment was observed in 5 studies, with the eating difficulties and care needs of other patients having an adverse impact. Disruptions to meals and organisational difficulties (such as timing of meals, and time given to eat) could also lead to inadequate intake of food and drink. Patient preferences (for example, to eat with others or alone) differed and affected food intake.

Physical changes affecting food and drink intake were reported in 12 studies, most commonly due to neurological illnesses (5 studies). Changes included motor or sensory problems with cutting food, transferring food from plate to mouth, and difficulties with chewing and swallowing. Psychological reactions affecting intake of food and drink (reported in 6 studies) included shame from lack of control (for example, leakage of saliva) and embarrassment

about mess created when eating. Nutritional care provided by healthcare professionals was reported in 8 studies, with 4 studies reporting that patients did not get the help they needed in specific meal situations, or advice on how to handle eating difficulties.

Limitations of the review included the potential bias from selection and data analysis conducted by a single author. The use of predefined themes may also have influenced the analysis. There was no time limit included in the search strategy, so studies covered a period of 15 years, during which clinical practice may have changed.

The authors concluded that:

- patients should be informed about the importance of nutrition, given guidance on how to overcome difficulties and be supported at meal times
- patient preference for eating alone or with others should be respected, with safe environments provided where those with difficulties can eat without feeling ashamed or nervous
- nutritional supplement drinks should meet patient preferences for taste and texture.

The findings are consistent with the recommendations of [NICE CG138](#) and offer additional practical insights on how adequate nutrition and hydration may be achieved.

#### **Key reference**

Larsen LK, Uhrenfeldt L (2013) [Patients' lived experiences of a reduced intake of food and drinks during illness: a literature review](#). *Scandinavian Journal of Caring Sciences* 27: 184–94

#### **Requirements of palliative care**

[NICE CG138](#) recognises the potential need for psychological and emotional support, as well as the importance of meeting fundamental needs such as nutrition and pain management, in all settings where healthcare is provided. Although not specifically mentioned by the guideline, these settings encompass palliative care.

[Dy et al. \(2012\)](#) conducted a systematic review to evaluate the effectiveness of patient-centred interventions (education and self-management), provider-centred interventions (education reminders) and interventions to integrate palliative care principles into daily practice on the quality of palliative care for patients with advanced and serious illness in both inpatient and outpatient settings. The review included 90 studies published in 96 articles; most studies included under 200 patients. Studies published before 2000, and those with a retrospective or uncontrolled design were excluded. Outcome measures assessed included:

- patient and family satisfaction and perceptions of palliative care
- patient symptoms, needs, distress and quality of life
- hospital admissions and other forms of healthcare utilisation (excluding costs)
- quality of care measures (for example, timeliness of response to pain and other symptoms)
- family and caregiver psychosocial symptoms, support, needs, quality of life and grief or bereavement.

Results were presented as the number or percentage of studies with a significant improvement in outcomes with the intervention compared with control.

Interventions to target pain were reported in 21 studies (19 studies in patients with cancer; 16 studies of outpatients). Pain management was significantly improved in 10 of the 21 studies (48%), though only 1 of 8 studies reporting the effect of the intervention on quality of life found a significant impact. Of 2 studies targeting pain in patients with end-stage dementia receiving care in nursing homes, both found a significant impact of the intervention. Interventions to target patient distress were reported in 7 studies (6 studies in patients with cancer; 4 studies of outpatients). Only 2 of the 7 studies (29%) demonstrated significant



improvement with the intervention (detailed distress screening combined with telephone triage for referral in 1 study and telephone-based skills training in lung transplant candidates in the other). The review also evaluated the effect of interventions on continuity of care (see [‘Discharge from hospital to primary care’](#) in section 1.4).

Limitations of the review included the diversity of interventions, outcomes and outcome reporting that prevented meta-analysis. Although evidence was of moderate strength for interventions targeting pain, the evidence was of low strength for interventions targeting patient distress. Common quality issues included small sample sizes and limited descriptions of interventions.

This review, which evaluated different aspects of quality of care for patients receiving palliative care, adds to the evidence base for [NICE CG138](#). Patient-centred interventions (education, self-management), provider-centred interventions (education reminders) and interventions to integrate palliative care principles in daily practice resulted in limited improvement in pain management of patients with advanced and serious illness receiving palliative care. There remains a need for further research, particularly in illnesses other than cancer and in hospice settings.

Additional information about the study by Dy et al. (2012) is also available from an independent [critical appraisal report](#) produced for the Centre for Reviews and Dissemination’s Database of Abstracts of Reviews of Effects.

#### **Key reference**

Dy SM, Aslakson R, Wilson RF et al. (2012) [Improving health care and palliative care for advanced and serious illness](#). Agency for Healthcare Research and Quality – Evidence Report No. 208

## **1.3 [Tailoring healthcare services for each patient](#)**

### **Training providers to deliver patient-centred consultations**

[NICE CG138](#) states that healthcare professionals should recognise patients as individuals, and that advice on treatments and care, including risks and benefits, should be individualised as much as possible. It recommends that healthcare services should be tailored to the patient’s needs and circumstances, taking into account personal preferences.

A Cochrane review by [Dwamena et al. \(2012\)](#) evaluated randomised controlled trials of interventions for healthcare providers that aimed to promote a patient-centred approach in clinical consultations (defined as shared control in the consultation, shared decision-making or focus on the patient as a whole person rather than a body part or disease). The review updated an earlier review that had included a range of study designs, and now included 43 studies (29 of which were not in the previous review). Most studies were conducted in the USA (16 studies) and UK (10 studies).

All studies evaluated training for providers (predominantly primary care physicians); additional components included training or educational materials for patients (7 studies), condition-specific training or materials for providers (7 studies) and condition-specific training or materials for both providers and patients (6 studies). Studies evaluated adults with general medical problems (17 studies), specific medical conditions (15 studies) such as diabetes and cancer, or undergoing surgery (3 studies); 6 studies used simulated patients and 2 studies were of children with asthma. Outcomes reported in the studies were grouped to evaluate direct effects on the consultation process and effects on patient outcomes (satisfaction, healthcare behaviour change, health status). Results of the studies were pooled and reported as standardised mean difference (SMD) and relative risk (RR), applying a fixed-effect model.

Consultation process outcomes were reported in 16 studies. In the studies reporting dichotomous variables, the pooled analysis showed no effect (RR=0.96, 95% confidence

interval [CI] 0.82 to 1.13,  $p=0.63$ ; 4 studies,  $n=876$ ). In the studies reporting continuous variables, the intervention showed a beneficial effect (SMD=0.70, 95% CI 0.57 to 0.82,  $p<0.00001$ ; 12 studies,  $n=1046$ ). Effects seen with short-term training of less than 10 hours (SMD=0.58, 95% CI 0.28 to 0.89,  $p=0.00019$ ; 4 studies,  $n=177$ ) appeared similar to results obtained with extensive training lasting more than 18 hours (SMD=0.36, 95% CI 0.01 to 0.71,  $p=0.044$ ; 3 studies,  $n=132$ ).

Interventions showed a positive effect on patient satisfaction in studies using continuous measures (SMD=0.35, 95% CI 0.20 to 0.49,  $p<0.00001$ ; 7 studies,  $n=813$ ) but not in studies using dichotomous variables (RR=0.99, 95% CI 0.93 to 1.06,  $p=0.83$ ; 4 studies,  $n=988$ ). Healthcare behaviour showed a beneficial impact in studies using dichotomous variables (RR=1.28, 95% CI 1.18 to 1.38,  $p<0.00001$ ; 4 studies,  $n=1097$ ) but not in studies using continuous measures (SMD=-0.04, 95% CI -0.28 to 0.20,  $p=0.72$ ; 3 studies,  $n=288$ ). Interventions had a positive impact on health status in studies evaluating continuous variables (SMD=-0.25, 95% CI -0.36 to -0.15,  $p<0.00001$ ; 8 studies,  $n=1373$ ) and dichotomous variables (RR=1.36, 95% CI 1.01 to 1.83,  $p=0.042$ ; 2 studies,  $n=261$ ). The impact of training intensity on patient outcomes was unclear for healthcare behaviour and was not reported for satisfaction and health status.

Limitations of the study included heterogeneity in study outcome measures and possible selection bias in the majority of studies.

Despite these limitations, the evidence suggests that training of healthcare providers may help achieve the [NICE CG138](#) recommendation for a patient-centred approach to clinical consultations, with short-term interventions (less than 10 hours of training) seemingly as effective as longer training.

#### Key reference

Dwamena F, Holmes-Rovner M, Gaulden CM et al. (2012) [Interventions for providers to promote a patient-centred approach in clinical consultations](#). *Cochrane Database of Systematic Reviews* issue 12: CD003267

#### Patient views of care

[NICE CG138](#) recommends that healthcare professionals hold discussions in a way that encourages patients to express their personal needs and preferences for care, treatment, management and self-management. There should be acceptance that the patient may have different views from healthcare professionals.

[Papastavrou et al. \(2011\)](#) undertook a systematic review of quantitative studies that compared nurses' and adult patients' perceptions of caring behaviour in hospital or institutional settings. After quality appraisal, a total of 23 studies (1229 patients or family members; 1351 nurses and other healthcare workers) were included. Most studies were conducted in oncology units. Caring behaviour was most commonly assessed (in 18 of 23 studies) using the Care-Q instrument (or a modification). The instrument comprises a questionnaire measuring perceived importance of nurse caring behaviours in 6 categories: 'accessible', 'explains and facilitates', 'comforts', 'anticipates', 'trusting relationship', and 'monitors and follows through'. The majority of studies reported the most and least important nurse caring behaviours. The review reported outcomes as a narrative summary.

The majority of studies using the Care-Q instrument reported significant differences in nurses' and patients' perceptions of caring. Nurses assigned a significantly higher importance to the psychological skills of 'comforts', 'anticipates' and 'trusting relationships' than patients, with 'comforts' consistently ranked as most important. In contrast, patients considered technical skills and behaviours demonstrating competency in nursing activities as more important than nurses, with 'monitors and follows through' and 'explains and facilitates' considered important.

Limitations of the review included the exclusion of qualitative studies and the inclusion of some studies with small sample sizes. Caring was not defined, and few studies related nursing behaviour to patient outcomes other than satisfaction.

[Morris et al. \(2011\)](#) conducted a longitudinal qualitative study using semi-structured interviews to examine influences on self-management priorities in 21 patients with multiple long-term conditions (diabetes, irritable bowel disease or chronic obstructive pulmonary disease, and 1 or more comorbid condition). The study was conducted at 2 general practices in an economically depressed area in the north west of England, and formed part of a larger randomised controlled trial of self-management interventions. Initial and final interviews (1 year later) were conducted face-to-face, with interim telephone interviews to allow for detailed discussion of emerging topics. All interviews were transcribed and key concepts and themes identified.

The review found that although managing multiple conditions could become complex and burdensome, patients minimised the burden by applying strategies that worked for 1 condition to other conditions. In the face of limited resources for management, most respondents also reprioritised conditions over time, often in response to a negative impact of 1 condition (or its treatment) on another. Tipping points for reprioritisation arose in response to medication management, lifestyle changes, new understanding of a particular condition or additional diagnoses. Patients typically viewed management practices across conditions, with uncertainty over which symptoms are caused by which condition. This is in contrast to the way healthcare professionals typically managed multiple conditions sequentially, with little interaction between conditions. When self-management instructions and information from the healthcare professional conflicted with patient priorities, there was a negative impact on patient engagement with health management.

Limitations of the study included the recruitment via another study that was not based on multiple conditions. Participants identified themselves as having multiple conditions, and some had comorbid conditions that may not be defined by healthcare professionals as long-term. The sample was also small, restricting the scope to evaluate participants with a range of socioeconomic variables.

Taken together, these studies show that patient views of caring behaviour, and their priorities and strategies for the management of multiple conditions, may be different from those of healthcare professionals and may change over time. These findings reinforce the importance of holding discussions with patients so their views, preferences and expectations can be expressed, as recommended in [NICE CG138](#).

#### **Key references**

[Morris RL, Sanders C, Kennedy AP et al. \(2011\) Shifting priorities in multimorbidity: a longitudinal qualitative study of patient's prioritization of multiple conditions. Chronic Illness 7: 147–61](#)

[Papastavrou E, Efstathiou G, Charalambous A \(2011\) Nurses' and patients' perceptions of caring behaviours: quantitative systematic review of comparative studies. Journal of Advanced Nursing 67: 1191–1205](#)

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

### **Defining continuity of care**

[NICE CG138](#) states that continuity and consistency of care, and establishing trusting, empathetic and reliable relationships with competent and insightful healthcare professionals is key to patients receiving effective, appropriate care. Although continuity of care is discussed in several recommendations, it was not explicitly defined in the guideline.

A review by [Parker et al. \(2011\)](#) assessed what defines and influences continuity of care. The review also set out to confirm or refine the Freeman conceptual model of care. The Freeman model was originally developed in 2001 as part of the National Institute for Health Research (NIHR) Service Delivery and Organisation Programme, and simplified in 2007 following an interim review of the programme and findings from other sources. The 2007 model describes 3 major types of continuity:

- management continuity (communicating both facts and judgements across team, institutional and professional boundaries, and between professionals and patients)
- informational continuity (timely availability of relevant information)
- relationship continuity (a therapeutic relationship with 1 or more health professionals over time).

The present review used data from 3 scoping studies and 7 main empirical studies that formed the NIHR Service Delivery and Organisation Programme. The scoping studies covered the transition from child to adult health services, human resources in healthcare, and mental illness. The empirical studies covered primary care, stroke, learning disabilities, cancer (2 studies), diabetes and severe mental illness. The studies used a variety of methodological approaches, including qualitative interviews, focus groups and case note reviews. More than 5000 people took part in the programme of studies, including patients, carers and service providers. The outputs and data from the final reports for each study were included in a qualitative analysis that maintained the coherence of individual projects, but allowed cross-project themes to emerge. The findings were presented as a narrative synthesis.

The analysis found that the Freeman model of continuity of care remained valid as a broad framework for understanding continuity, although some further refinements were suggested. With regard to management continuity, the review found that this concept should be extended to include family and carers, particularly relating to their involvement in discharge planning and maintaining treatment. It was also felt that informational continuity was more complex than suggested in the current model, with understanding being more important than the provision of information. With respect to relationship continuity, the review found that service users valued having a good relationship more than familiarity. Patients accepted that professionals had different roles in care pathways and therefore accepted that they were likely to see a range and succession of different staff. Although the Freeman model considered access as closely linked with continuity, the review found it to be of greater importance, encompassing not only quick and appropriate contact but also proactive and preventive elements of care. Consequently, it was found that access contributes in its own right to continuity of care.

The analysis also identified 7 sources of influence on the experience of continuity:

- individual patient characteristics, circumstances and preferences
- family and people close to the individual patient
- care trajectories (which differ for different illnesses and over time)
- wider context of the 'whole person' (including family and life experiences, family roles and responsibilities, and social context)
- structure and administration of services
- characteristics and behaviour of healthcare professionals
- satisfaction and judgements of service users (influenced particularly by expectations of care and treatment, the quality of the first appointment and the establishment of trust at an early stage).

Discontinuities in care were not always seen as negative (for example, cancer users valued being able to return to normal activities and being able to forget the illness during periods

between treatment). Patients appear to give different weights to the components of continuity, and these may vary over time, suggesting that there may be many ways of delivering continuity of care. It may also be useful to focus on continuity as a dynamic concept that arises from the interplay between users and providers of the healthcare service.

Limitations of the evidence included the lack of any formal assessment of quality of the studies reviewed. The review was restricted to analysis of studies within a pre-existing programme of research, and did not include a systematic review of the literature on continuity of care. The programme included only limited information on interventions to improve continuity. The analysis also included studies in mental health, which is outside the scope of [NICE CG138](#).

The evidence shows that continuity of care is a dynamic concept that may be defined in terms of a single framework with multiple components. In establishing a more detailed concept of continuity of care, this evidence adds to [NICE CG138](#).

#### **Key reference**

Parker G, Corden A, Heaton J (2011) [Experiences of and influences on continuity of care for service users and carers: synthesis of evidence from a research programme](#). *Health and Social Care in the Community* 19: 576–601

#### **Discharge from hospital to primary care**

[NICE CG138](#) recommends ensuring clear and timely exchange of patient information between healthcare professionals, particularly at the point of any transitions in care.

A systematic review by [Hesselink et al. \(2012\)](#) assessed interventions that aimed to improve patient discharge from hospital to primary care. Randomised controlled studies were included if they: used an explicitly described intervention; reported at least 1 outcome measure addressing the quality, safety or outcomes of handovers from hospital; and were published during or after 1990. Studies of children, pregnant women and patients with a psychiatric diagnosis were excluded. In the 36 studies included, the number of participants ranged from 14 to 1107. Half of the studies consisted of elderly patients with a range of diagnoses. All but 2 studies used multicomponent interventions, and 26 studies consisted of interventions performed by designated care providers (for example, case manager, multidisciplinary team). Analysis was by the proportion of studies reporting a significant effect of the intervention.

Of the 36 included studies, 25 (69%) reported significant effects in favour of the intervention. Interventions to improve the quality of information exchanged between providers at discharge (for example, medication reconciliation, database-generated structured discharge summaries) were effective in 14 of 22 studies. Interventions to improve coordination of care (for example, organising post-discharge follow-up, discharge planning protocol) were effective in 20 of 27 studies. Interventions to improve communication (for example, telephone outreach from hospital to home care, case conferences) were effective in 22 of 31 studies.

Limitations included heterogeneity of the interventions and study characteristics, which prevented meta-analysis. Most of the studies included in the review had methodological shortcomings (for example, diffuse aims and poor descriptions of the interventions).

Consistent with [NICE CG138](#), this review shows that interventions to improve the exchange of information can have a positive impact on transition from hospital to primary care. It also provides evidence that a wide range of interventions can have beneficial effects on discharge from hospital. However, the authors noted that because of the complexity of interventions and outcome measures, they could not firmly establish which interventions were most effective. Further research is needed.

The evidence from [Dy et al. \(2012\)](#), which focused on patients with advanced and serious illness (see '[Requirements of palliative care](#)' in section 1.2 for details) also found that a range

of interventions to improve continuity, coordination or transitions of care had beneficial effects on patient-reported outcomes. Most studies evaluated multiple outcome measures. The interventions significantly increased patient satisfaction (4 out of 6 studies) and family satisfaction (3 out of 5 studies), though there was less impact on patient quality of life (significant impact in 3 out of 9 studies) and healthcare utilisation (5 out of 16 studies). Interventions had no impact on patient symptoms in any of the 8 studies evaluating this outcome.

#### **Key reference**

Hesselink G, Schoonhoven L, Barach P et al. (2012) [Improving patient handovers from hospital to primary care: a systematic review](#). *Annals of Internal Medicine* 157: 417–28

#### **Roles and responsibilities**

[NICE CG138](#) recommends that all healthcare professionals directly involved in a patient's care should introduce themselves to the patient. Additionally, patients should be informed about who is responsible for their clinical care and treatment, the roles and responsibilities of the different members of the healthcare team and the communication about their care that takes place between members of the healthcare team.

[Wilson et al. \(2012\)](#) evaluated patient perceptions about the role of nurses involved in chronic disease management at 7 sites in England and Wales. The sites were chosen to reflect different models of delivery and different types of population with varying geographical spread.

- Sites 1 and 2 (1 rural, 1 inner city): a community matron providing nurse-led case management to older people with complex needs.
- Sites 3 and 4: disease management by a condition-specific nurse specialist in secondary care among adults with epilepsy (at a district general hospital) or diabetes (at teaching hospitals in a large city).
- Sites 5 and 6: nurse-led disease management of chronic diseases in primary care.
- Site 7: a public health model of support for self-care in children from urban schools with asthma, delivered by health advisors.

At each site, patient users of chronic disease management services were invited to participate in the study. Of the 1635 users invited, 84 adults and younger people (aged 11–16 years) agreed to take part in interviews, and 6 children and younger people agreed to take part in focus groups. Interviews were also conducted with 32 nurses and 19 other healthcare professionals or managers. Transcripts of interviews and focus groups were analysed thematically.

The nurse contribution was valued most when patients felt particularly vulnerable (for example, at initial diagnosis or on acute exacerbation). Although patients wanted continuity of care, it was rarely achieved by service models comprising a team of nurses and other practitioners. Even where services were provided by a single nurse, some patients preferred to see the doctor. However, this preference was often offset by ease of access to the nurse, reflected in practical terms by reduced waiting time and in psychological terms by less formal communication style that made it easy for patients to discuss the realities of living with the condition.

Patients were most satisfied with nurse-led delivery of services if they saw the nurse as responsible for diagnosis, prescribing and management of the condition (that is, emulating a medical approach). Patients were less satisfied if they had been transferred from a GP-led service or from a secondary care setting to a nurse-led service.

Limitations of the study included the potential for variation in interpretation, and the merging of information from interviews and focus groups. The study included some children and young



people, and a study site (school asthma care), that is not relevant to [NICE CG138](#) (which focuses only on adults).

The study highlights the importance of informing patients about the roles and responsibilities of healthcare professionals, particularly when care has been transferred from other care settings or services, so that patient expectations can be managed. This evidence is consistent with [NICE CG138](#).

#### **Key reference**

Wilson PM, Brooks F, Procter S et al. (2012) [The nursing contribution to chronic disease management: a case of public expectation? Qualitative findings from a multiple case study design in England and Wales](#). *International Journal of Nursing Studies* 49: 2–14

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

### **Views on patient-centred care across Europe**

[NICE CG138](#) recognises that many patients wish to be active participants in their own healthcare, and to be involved in creating and managing their health strategy and use of services. The guideline notes that self-care and self-management are particularly important for people with long-term conditions. Aspects highlighted by the guideline to enable active participation of patients in their care include communication, information, shared decision making and education programmes.

[Dancet et al. \(2012\)](#) conducted a qualitative study to determine the specific aspects of care that are important to patients undergoing infertility treatment across Europe. Physicians at 4 participating infertility centres invited consecutive heterosexual patients (diagnosed with infertility or receiving infertility treatment) to participate in the study. Focus groups (4–8 participants, 2 hour duration, 2 groups per country) were held with 24 heterosexual couples recruited from infertility clinics in the UK (4 couples), Austria (8 couples), Spain (5 couples) and Belgium (7 couples). Focus groups were moderated in the local language by local researchers who were all given the same interviewing training by an international study coordinator. Participants were asked to discuss their most positive and negative experiences of infertility care. They also explored experiences related to care from a topic list covering 10 dimensions of patient-centred care that were previously identified from a literature review:

- information
- competence of clinic and staff
- coordination and integration
- continuity and transition
- accessibility
- physical comfort
- communication
- attitude and relationship with staff
- emotional support
- patient involvement and privacy.

Transcripts of the focus groups were analysed by deductive coding (that is, going from the general to the specific) to determine if patients from different European countries valued the same aspects of patient-centred fertility care.

No new aspects of care were identified, and the detailed description of what was valued by patients for each dimension of care showed little difference across the study centres. There was moderate-to-good agreement between countries for the ranking of importance of the dimensions (Kendall's coefficient of concordance 0.577,  $p < 0.0001$ ). Participants in all the

countries involved ranked provision of information in the top 4 most important dimension of patient-centred care, and accessibility was ranked in the bottom 4.

Limitations of the study included the small number of participants involved from only 4 European countries. It is possible that participant perspectives were conditioned by their specific experiences in a specific clinic. Patients were not asked explicitly about what patient-centred care meant to them.

The authors concluded that perspectives of patients across different European countries on important aspects of patient-centred care appear to be similar, with provision of information consistently rated as an important dimension. Current recommendations in [NICE CG138](#) appear to be aligned with these perspectives, and the evidence therefore indicates that the patient-centred approach as described in the guideline is likely to be appropriate for Europeans who access care in the UK.

#### **Key reference**

[Dancet EA, D'Hooghe TM, Sermeus W et al. \(2012\) Patients from across Europe have similar views on patient-centred care: an international multilingual qualitative study in infertility care. Human Reproduction 27: 1702–11](#)

#### **Patient-centred care in chronic disease management**

[NICE CG138](#) recommends that, when offering any investigations or treatments, healthcare professionals should clarify what the patient hopes the treatment will achieve and discuss any misconceptions. The guideline further recommends discussing with the patient their need for psychological, social and spiritual support, and also to hold discussions in a way that encourages the patient to express their personal needs and preferences for care, treatment, management and self-management.

[Hudon et al. \(2012\)](#) conducted a systematic review of patient-centred care in adult chronic disease management in primary care, using thematic analysis to identify key themes. A total of 32 studies were included (15 papers developing theories or providing commentaries or opinions; 10 qualitative studies; 3 quantitative studies; 3 studies using mixed methods; 1 review). The most common locations for studies were the USA (10 studies), UK (7 studies) and Canada (5 studies). Diabetes (9 studies) and cancer (6 studies) were the most common chronic diseases studied. The number of study participants was not reported.

The major themes emerging from the analysis were:

- acquiring a comprehensive understanding of the patient's situation, including their background and unique experience of illness (mentioned in 94% of articles)
- developing an ongoing partnership (84% of articles)
- acknowledging the patient's expertise on his/her own life (44% of articles)
- providing advocacy for the patient in the healthcare system (28% of articles)
- legitimising the illness experience (16% of articles)
- offering realistic hope (6% of articles).

Limitations of the study included methodological shortcomings (for example, no quality assessment was reported, language restrictions and omission of articles in the broader literature such as nursing and psychology). Some themes were identified in only a few publications (for example, offering realistic hope was noted in 2 articles; legitimising the illness experience was noted in 5 articles).

The authors suggested that interactions between patients with chronic diseases and primary healthcare professionals should encompass legitimising the illness experience and offer realistic hope, in addition to other previously recognised aspects of patient-centred care.



This review adds to the evidence base on conceptual frameworks for patient-centred care, providing further insights that are consistent with [NICE CG138](#). Important aspects of patient-centred care include communication and understanding, with other concepts (such as legitimising the illness experience and offering realistic hope) also of potential relevance to interactions between patients with chronic diseases and primary healthcare professionals.

#### Key reference

Hudon C, Fortin M, Haggerty J et al. (2012) [Patient-centered care in chronic disease management: a thematic analysis of the literature in family medicine](#). *Patient Education and Counseling* 88: 170–6

#### Non-verbal communication

[NICE CG138](#) recommends that all staff involved in providing NHS services should have demonstrated competency in relevant communication skills. They should maximise patient participation in communication by, for example, maintaining eye contact with the patient (if culturally appropriate). The guideline also recommends that healthcare professionals listen to and address any health beliefs, concerns, fears and preferences of the patient.

A systematic review and meta-analysis by [Henry et al. \(2012\)](#) included experimental or observational studies of interactions between adult patients and healthcare professionals that examined associations between non-verbal communication and clinically relevant outcomes. Only studies of interactions with real patients and healthcare professionals (including physicians, nurses and therapists) that took place for the purpose of managing actual health problems were included. Non-verbal communication was assessed by direct observation and included facial expression, gaze or eye contact, body language, ratings of voice tone and affect rating (that is, evaluation of emotional state). Three measures of non-verbal communication among healthcare professionals were evaluated:

- warmth (including caring and sensitivity)
- negativity (including anger, hostility, and being argumentative)
- listening (including interest).

Clinically relevant outcomes included clinician or patient satisfaction, patient adherence or understanding of recommendations, and patient mental or physical health. Meta-analysis was conducted for studies in which the communication variable, outcome variable and estimate of effect were similar for at least 3 studies.

The review identified 26 studies for inclusion (23 cohort studies and 3 case-control studies). Most studies were conducted in the USA (77%) and in primary care settings (65%). The studies involved approximately 900 healthcare professionals and 3300 patients in over 3700 visits or interactions. Patient satisfaction was the most commonly assessed outcome (reported in 17 of the studies), and the only outcome suitable for meta-analysis.

Increasing healthcare professional warmth was associated with significantly increased patient satisfaction (pooled effect size=0.31, 95% CI 0.23 to 0.38,  $p<0.001$ ). Nurse warmth was associated with greater patient satisfaction than nurse competence (pooled effect size=0.32, 95% CI 0.21 to 0.42,  $p<0.001$ ). The greater the negativity of nurses, the less patients were satisfied (pooled effect size=-0.35, 95% CI -0.53 to -0.17,  $p<0.001$ ) but the relationship was not significant for all healthcare professionals considered together or physicians alone. There was a positive association between healthcare professionals listening and patient satisfaction (pooled effect size=0.25, 95% CI 0.13 to 0.37,  $p<0.001$ ).

Limitations of the study included heterogeneity in measures of body language, lack of information in studies about potential participant selection bias, and shortcomings in the statistical approaches used in many studies.

The study demonstrates the importance of healthcare professional non-verbal communication skills – particularly listening, warmth, and avoiding negativity – in achieving patient

satisfaction. The study adds to the evidence base for [NICE CG138](#), and provides insights that could inform healthcare professional skills training.

#### Key reference

Henry SG, Fuhrel-Forbis A, Rogers MA et al. (2012) [Association between nonverbal communication during clinical interactions and outcomes: a systematic review and meta-analysis](#). *Patient Education and Counseling* 86: 297–315

#### Information

[NICE CG138](#) recommends that patients should be given information, and the support they need to make use of the information, in order to promote their active participation in care and self-management. Patients should be given both oral and written information. The patient (and their family members and/or carers if appropriate) should be given clear, consistent, evidence-based, tailored information throughout all stages of their care. This should include, but not be limited to, information on their condition and any treatment options, where they will be seen, who will undertake their care and expected waiting times for consultations, investigations and treatments.

[Kazimierczak et al. \(2013\)](#) conducted a synthesis of publications about information for patients with cancer. The initial searches included quantitative and qualitative studies, theoretical and discussion papers, and policy documents. After applying exclusion criteria (for example, publications on general health education or cancer knowledge, cancer genetic testing and screening, cancer clinical trials, end-of-life planning and palliative care, and complementary or alternative medicine), over 700 papers were analysed and thematically categorised to identify key concepts. Other publications related to these concepts were identified and evaluated. A final sample of 138 publications was selected from which papers with theoretical relevance were prioritised, resulting in 57 papers included in the synthesis (number of participants not reported).

Thematic analysis of the included papers identified the following key topics:

- position of patient information in clinical interaction
- links between patient information and patient engagement in healthcare
- relationship between patient information and cancer care pathways.

Patient information was not seen in isolation, but located within the broader context of the healthcare professional–patient relationship. Patients showed differing needs and preferences for information or participation, depending on their individual characteristics and healthcare interactions. When receiving and using information, patients were selective and creative, with their preference for learning closely linked to emerging practical and emotional needs. Patients who prefer minimal information or do not choose to participate in medical decision making may be interpreted as having chosen dependency, rather than indicating a failure to be engaged in healthcare. The patient information pathway reflected the patient care journey – a dynamic process that unfolds alongside patients' experiences of illness and healthcare.

Limitations of the review included the lack of reproducibility and potential for selection bias. Studies were included on the basis of theoretical contribution to emerging themes, rather than on predefined criteria as used for systematic reviews. Critical appraisal of the quality of studies was not conducted.

The study suggests that the provision of information to patients can be seen as an ongoing and flexible process that supports navigation through the illness and care landscape. This evidence is consistent with [NICE CG138](#) and provides additional insight on information provision.

### Key reference

Kazimierczak KA, Skea ZC, Dixon-Woods M et al. (2013) [Provision of cancer information as a “support for navigating the knowledge landscape”](#): findings from a critical interpretive literature synthesis. *European Journal of Oncology Nursing* 17: 360–9

### Shared decision-making

[NICE CG138](#) recommends awareness of the value and availability of patient decision aids and other forms of decision support, such as counselling or coaching. If suitable high-quality decision aids are available, they should be offered to the patient.

A Cochrane review by [Stacey et al. \(2014\)](#) evaluated the effectiveness of decision aids for people facing health treatment or screening decisions, updating an earlier review by the addition of 33 new studies published since 2009. The review included a total of 115 RCTs (14 studies conducted in the UK) comparing decision aids with no intervention, usual care, alternative interventions, or a combination. The studies involved 34,444 people who were making decisions for themselves, a child, or an incapacitated significant other. Studies in which participants made hypothetical choices were excluded. Decision aids were defined as interventions designed to help people make specific and deliberate choices by making the decision explicit and by providing information on the options and outcomes relevant to a person’s health status and implicit methods to clarify values. Studies were excluded if interventions focused on decisions about lifestyle change, clinical trial entry, general advance directives, education programmes not geared to a specific decision and interventions designed to promote adherence.

The primary outcomes, based on the International Patient Decision Aids Standards, were:

- decision attributes (that is, knowledge, accurate risk perceptions, and agreement between values and the chosen option)
- decision-making process attributes (that is, recognising that a decision needs to be made, understanding options and their features, understanding that values affect the decision, being clear about the option features that matter most, discussing values with their healthcare practitioner, and becoming involved in preferred ways).

Of the 115 studies included in the review, 88 (76.5%) reported 1 or more of the primary outcomes. Where similar outcome measures were used, scores were standardised using a scale of 0 to 100 to facilitate pooling of data, and results presented as mean difference (MD; used for continuous measures) and relative risks (RR; used for dichotomous outcomes) applying a random effects model. The analysis compared use of decision aids with usual care, and simple decision aids with more detailed decision aids.

Of the studies examining decision attributes, 76 reported knowledge outcomes, 25 reported risk perception and 20 reported agreement with values, though not all reported data that could be pooled. People using decision aids had higher average knowledge scores than usual care (MD=13.34, 95% CI 11.17 to 15.51,  $p<0.00001$ ; 42 studies,  $n=10,842$ ). People using decision aids that included descriptions of outcome probabilities were more likely to have accurate risk perceptions than those who did not receive this information (RR=1.82, 95% CI 1.52 to 2.16  $p<0.00001$ ; 19 studies,  $n=5868$ ). Decisions that were consistent with values were increased in people who used a decision aid with explicit clarification of values (RR=1.51, 95% CI 1.17 to 1.96,  $p=0.0017$ ; 13 studies,  $n=4670$ ).

Of the studies examining decision-making process attributes, no studies evaluated helping patients to recognise the need for a decision or that values affect decisions; 9 studies assessed patient–practitioner communication with 8 reporting a beneficial impact of decision aids but results could not be pooled. Compared with usual care interventions, decision aids reduced feelings of being uninformed about options (MD=-7.26, 95% CI -9.73 to -4.78,  $p<0.00001$ ; 22 studies,  $n=4343$ ) and feeling unclear about personal values (MD=-6.09, 95%

CI -8.50 to -3.67,  $p < 0.00001$ ; 18 studies,  $n = 3704$ ). Decision aids reduced the proportion of practitioner-controlled decisions (RR=0.66, 95% CI 0.53 to 0.81,  $p = 0.000073$ ; 14 studies,  $n = 3234$ ) and the proportion of patients who remained undecided after the intervention (RR=0.59, 95% CI 0.47 to 0.72,  $p < 0.00001$ ; 18 studies,  $n = 4753$ ).

Compared with simple decision aids, more detailed decision aids significantly improved knowledge (MD=5.52, 95% CI 3.90 to 7.15,  $p < 0.00001$ ; 19 studies,  $n = 3531$ ) and reduced feelings of being uninformed (MD=-2.39, 95% CI -4.39 to -0.39,  $p = 0.019$ ; 10 studies,  $n = 1264$ ). The complexity of the decision aid had no significant impact on the proportion of patients who remained undecided after the intervention (RR=0.98, 95% CI 0.69 to 1.37,  $p = 0.89$ ; 3 studies,  $n = 352$ ). The effect on other decision attributes and decision-making process attributes could not be pooled or was not reported.

Limitations of the study included the wide variability in the elements included in the decision aids, in the type of comparison interventions and in the evaluation procedures. There was also significant heterogeneity in several of the outcome measures. Studies were not powered to detect important differences in effectiveness of decision aids in subgroups of patients. The small number of studies for most outcomes precluded analysis of publication bias.

Consistent with the recommendations in [NICE CG138](#), this evidence shows that decision aids are effective tools to improve the quality of decision-making, by improving people's knowledge of treatment options and accuracy of risk perception, reducing feelings of being uninformed or unclear about values, stimulating people to take a more active role in decision-making and supporting concordance between patient values and the choice made.

#### **Key reference**

Stacey D, Légaré F, Col NF et al. (2014) [Decision aids for people facing health treatment or screening decisions](#). Cochrane Database of Systematic Reviews issue 1: CD001431

## 2 New evidence uncertainties

During the development of the Evidence Update, the following evidence uncertainties were identified for the UK Database of Uncertainties about the Effects of Treatments (UK DUETs).

### **Tailoring healthcare services for each patient**

- [Interventions for providers to promote a patient-centred approach in clinical consultations](#)

Further evidence uncertainties for patient experience in adult NHS services can be found in the [UK DUETs database](#) and in the [NICE research recommendations database](#).

UK DUETs was established to publish uncertainties about the effects of treatments that cannot currently be answered by referring to reliable up-to-date systematic reviews of existing research evidence.

# Appendix A: Methodology

## Scope

The scope of this Evidence Update is taken from the scope of the reference guidance:

- [Patient experience in adult NHS services](#). NICE clinical guideline 138 (2012)

## Searches

The literature was searched to identify studies and reviews relevant to the scope. Searches were conducted of the following databases, covering the dates 9 May 2011 (the end of the search period of NICE clinical guideline 138) to 9 August 2013:

- ASSIA (Applied Social Sciences Index and Abstracts)
- CDSR (Cochrane Database of Systematic Reviews)
- CINAHL (Cumulative Index to Nursing and Allied Health Literature)
- DARE (Database of Abstracts of Reviews of Effects)
- EMBASE (Excerpta Medica database)
- HTA (Health Technology Assessment) database
- MEDLINE (Medical Literature Analysis and Retrieval System Online)
- MEDLINE In-Process
- NHS EED (Economic Evaluation Database)
- PsycINFO.

An Evidence Update search strategy replicates the strategy used by the original guidance as far as possible. For this Evidence Update, it was not possible to recreate the exact search strategy as other methods were used to inform the guideline recommendations, for example existing NICE guidance and patient experience frameworks.

The Evidence Update search strategy therefore combined the following strategies used for the original guideline: the core search strategy for patient experience from the scoping study; and the strategies for the specific reviews about continuity of care, risk communication and patient education programmes. Additional key words were used to identify studies on these aspects. While some of the searches for the guideline development were focused on specific clinical conditions, the search strategies for the Evidence Update were not restricted by condition to ensure that evidence about patient experience in all clinical areas was captured. A more focused search strategy and a modified qualitative studies search filter were used to improve the precision of search results.

Table 1 provides details of the MEDLINE search strategy used (based on the search strategy for the original guidance), which was adapted to search the other databases listed above.

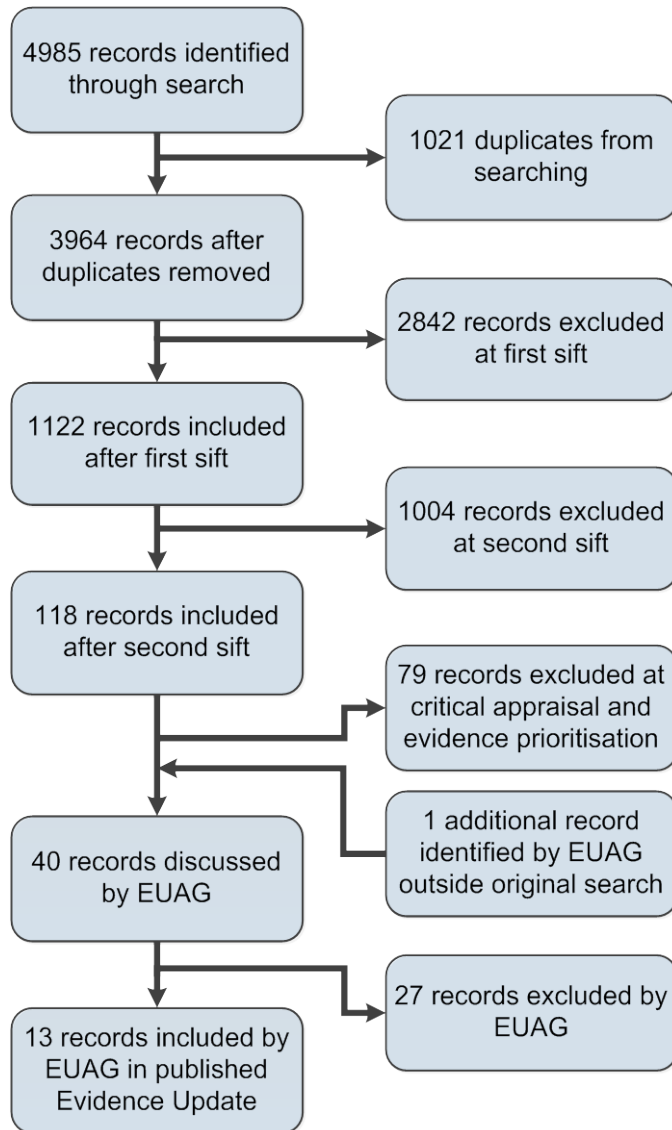
Additionally, 1 study (Stacey et al. 2014) was identified outside of the literature search. Figure 1 provides details of the evidence selection process. The long list of evidence excluded after review by the Chair of the EUAG, and the full search strategies, are available on request from [contactus@evidence.nhs.uk](mailto:contactus@evidence.nhs.uk)

There is more information about [how NICE Evidence Updates are developed](#) on the NICE Evidence Services website.

**Table 1 MEDLINE search strategy (adapted for individual databases)**

1	(patient\$ adj5 (experience\$ or expectation\$ or preference\$ or need\$ or perspective\$ or attitude\$ or view\$ or opinion\$ or choice\$)).ti,ab.		instruct\$ or skill\$ or support\$) adj2 (program\$ or course\$ or intervention\$)).ti,ab.
2	(patient\$ adj5 (centre\$ or center\$)).ti,ab.	25	(component\$ or element\$ or principle\$ or constituent\$ or contents).ti,ab.
3	1 or 2	26	24 and 25
4	exp *"Delivery of Health Care"/	27	exp *risk/
5	service delivery.ti,ab.	28	risk\$.ti,ab.
6	4 or 5	29	27 or 28
7	3 and 6	30	exp communication/
8	patient satisfaction.ti,ab.	31	Audiovisual Aids/
9	exp *patient satisfaction/	32	Data Interpretation, Statistical/
10	8 or 9	33	30 or 31 or 32
11	7 and 10	34	29 and 33
12	intervention\$.ti,ab.	35	(fram\$ adj2 (effect\$ or positiv\$ or negativ\$)).ti,ab.
13	(patient adj reported adj outcome adj measure\$).ti,ab.	36	(information\$ adj5 display).ti,ab.
14	quality of life.ti,ab.	37	((graph\$ or visual\$ or statistic\$) adj3 (present\$ or format\$)).ti,ab.
15	(SF36 or SF-36).ti,ab.	38	framing.ti.
16	EQ5D.ti,ab.	39	35 or 36 or 37 or 38
17	editorial.pt.	40	29 and 39
18	exp "Quality of Life"/	41	(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.
19	or/12-18	42	34 or 40 or 41
20	11 not 19	43	shared decision making.ti,ab.
21	*"Continuity of Patient Care"/	44	*Patient Participation/
22	((coordinat\$ or co ordinat\$ or co-ordinat\$ or integrat\$ or collaborat\$ or continu\$ or shared) adj3 (care\$ or manage\$)).ti,ab.	45	43 or 44
23	21 or 22	46	20 or 23 or 26 or 42 or 45
24	((educat\$ or train\$ or teach\$ or		

**Figure 1 Flow chart of the evidence selection process**



EUAG – Evidence Update Advisory Group



# Appendix B: The Evidence Update Advisory Group and Evidence Update project team

## Evidence Update Advisory Group

The Evidence Update Advisory Group is a group of topic experts and patient and carer members who review the prioritised evidence obtained from the literature search and provide the commentary for the Evidence Update.

### **Sophie Staniszewska – Chair**

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### **Jo Adams**

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