

Prioritising person-centred care

Supporting shared decision-making



Summarising evidence from systematic reviews



National Voices

People shaping health and social care

Key themes

We compiled information from 48 systematic reviews and found that the top things that managers and clinicians can do to involve people more in making choices about their care are:

- provide decision aids to help people think through the pros and cons of options
- encourage people to use question prompts to help them interact
- provide coaching and education to support patients to be more engaged

The table signposts to evidence about what works best to enhance patient experience. Initiatives in bold have the most evidence to support them. Blank cells show where there is little good quality evidence.

Focus	Improves knowledge	Improves experience	Improves service use and costs	Improves health outcomes
Targets patients	<ul style="list-style-type: none"> • Evidence-based decision aids^{1,2,3,4,5,6,7,8,9,10,11,12,13} • Question prompts^{14,15,16,17,18} • Decision coaching¹⁹ • Giving patients access to their medical records^{20,21,22} 	<ul style="list-style-type: none"> • Evidence-based decision aids^{23,24,25,26,27,28,29,30} • Question prompts^{31,32,33,34,35,36,37} • Giving patients access to their medical records^{38,39,40,41,42,43,44} 	<ul style="list-style-type: none"> • Decision aids^{45,46,47,48,49,50,51,52,53,54,55} • Education and coaching⁵⁶ 	
Targets professionals		<ul style="list-style-type: none"> • Training for professionals⁵⁷ 		
Targets systems / organisations				

Supporting shared decision-making

Person-centred care involves placing people at the forefront of their health and care. This ensures people retain control, helps them make informed decisions and supports a partnership between people, families and health and social services.

Some of the core facets of person-centred care involve:

- supporting self-management
- supporting shared decision-making
- enhancing experience
- improving information and understanding
- and promoting prevention

We have a series of booklets for healthcare commissioners and health professionals summarising the best research evidence about what works in each of these areas. This booklet focuses on supporting shared decision-making.

What is shared decision-making?

One of the core components of person-centred care is engaging people in decisions about their own care and treatment. Sometimes choosing appropriate treatment is not just a question of clinical effectiveness, but of balancing the potential benefits and harms of different options to find what is most appropriate for the individual. In these situations the views, values and preferences of the patient and their life circumstances have a strong bearing on the choice.

Shared decision-making is a process in which patients are involved as active partners with the clinician in clarifying acceptable medical options and choosing a preferred course of care and treatment. People and professionals work together to clarify acceptable medical options and choose an appropriate treatment.

Choosing an appropriate treatment with full patient involvement can be a complex process. It involves a number of steps:

- recognise and clarify the problem
- identify potential solutions
- discuss options and uncertainties
- provide information about benefits and harms of each outcome
- check understanding and reactions
- agree a course of action
- implement the chosen treatment
- arrange follow-up
- evaluate the outcome

Shared decision-making relies on two sources of expertise: the health professional as an expert on the effectiveness, probable benefits, and potential harms of treatment options, *and* the patient as an expert on themselves, their social circumstances, attitudes to illness and risk, values and preferences. Both parties must be willing to share information and accept responsibility for joint decision-making. The clinician needs to provide information about the diagnosis and treatment options. The patient needs to tell the clinician about their preferences.

Shared decision-making is appropriate in any situation where there is more than one reasonable course of action and no one option is self-evidently the best one. This is a common situation. There are often many ways to treat a health problem, each with a different set of outcomes. In these cases the patient's attitude to the likely benefits and risks should be a key factor in the decision.

Evidence-based patient decision aids have been developed to help give people the information they need. Other strategies include counselling patients and encouraging them to ask appropriate questions in the consultation, and giving them access to their medical records.

Why is this important?

1. *People may want to be more involved*

Most people want more information and a greater share in decisions about how they will be treated. The most common cause of patient dissatisfaction is not being properly told about one's illness and the options for treatment.⁵⁸

True sharing of decisions is not yet widely practised.^{59,60} In national surveys of NHS patients nearly half of hospital inpatients and one third of primary care patients said they were not involved as much as they wanted to be in decisions about their care.⁶¹

About three quarters of all patients want clinicians to take account of their preferences and expect to have a say in treatment decisions. For example, shared decision making is an important underlying principle of end-of-life care policy and practice, with available evidence demonstrating that it contributes to achieving a 'good death.'⁶²

But people might want different levels of involvement. People who are relatively healthy may be more likely to want to be involved – in decisions about screening, for instance – than those who are very ill.⁶³ Most patients being treated for cancer prefer a collaborative or more active role in treatment decision making, though some prefer to be less involved.⁶⁴ Studies also suggest that older people are more likely to want the doctor to decide about care.⁶⁵ What is important is that the health professional should not make assumptions about the degree of involvement people desire. The professional should always try to find out people's preferences.

2. Policy and practice prioritises shared decision-making

The [Health and Social Care Act 2012](#) gives both the NHS Commissioning Board and clinical commissioning groups a duty, in all that they do, "to promote the involvement of patients, and their carers and representatives (if any), in decisions which relate to, (a) the prevention or diagnosis of illness in the patients, or (b) their care or treatment. The [Mandate](#) from the Secretary of State to the NHS Commissioning Board gives it an objective "to ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment."

The [NHS Constitution](#) in England also includes commitments that have a bearing on patient involvement in treatment decisions:

- You have the right to accept or refuse treatment that is offered to you, and not to be given any physical examination or treatment unless you have given valid consent. If you do not have the capacity to do so, consent must be obtained from a person legally able to act on your behalf, or the treatment must be in your best interests.
- You have the right to be given information about your proposed treatment in advance, including any significant risks and any alternative treatments which may be available, and the risks involved in doing nothing.
- You have the right to access your own health records. These will always be used to manage your treatment in your best interests.
- You have the right to be involved in discussions and decisions about your healthcare, and to be given information to enable you to do this.
- The NHS will strive to share with you any letters sent between clinicians about your care.

The [Care Quality Commission](#), which regulates the quality of health and social care on behalf of patients, service users, their carers and families, has issued extensive guidance about the statutory requirement to ensure people can participate in decisions about care and treatment.

Health professional bodies require and approve the underlying principles of shared decision-making. The [General Medical Council](#) says doctors must respect patients' right to reach decisions with you about their treatment and care." In any situation where informed consent is required, doctors are now required by their professional regulator to secure consent *in the context of* a shared decision with the patient about which treatment to select.

The [Nursing and Midwifery Council](#) says nurses and midwives must uphold people's rights to be fully involved in decisions about their care and the [Health Professions Council](#) says allied health professionals providing care must work in partnership with service users and involve them in their care as appropriate. This includes explaining treatments, risks and treatment options.

What works?

48 systematic reviews published between 1998-2013 have summarised the best research evidence about supporting shared decision-making. This section outlines key findings about what works to support shared decision-making so commissioners and health professionals know the most useful and cost-effective interventions to invest in. The appendix describes how we identified and analysed the research evidence.

What has been tested?

Systematic reviews have examined the following initiatives designed to involve patients in making treatment choices:

Patient decision aids:

- simple tools, such as leaflets and videos
- complex tools, such as interactive computer programs
- decision aids plus face-to-face counselling

Coaching and question prompts for patients:

- prompt cards with questions for patients to ask clinicians
- education and coaching for patients

Patient access to medical records:

- audiotapes of consultations
- patient-held records
- patient access to computerised records

Interventions for professionals

- training in consultation and shared-decision making skills

What are the impacts?

Improving knowledge

Decision aids

Decision aids exist in the form of brochures, decision tables, videos, and computer programs. They may cover various topics about disease prevention, diagnosis and treatment. Typically, they contain information about the advantages and disadvantages of the available options, as well as guidance to help personal decision-making. Decision aids may be used alone or as a part of patient education or counselling initiatives.⁶⁶

There is evidence that using **evidence-based decision aids** for patients leads to improvements in knowledge, better understanding of screening, prevention and treatment options, and more accurate perception of risks.^{67,68,69,70,71,72,73,74,75,76,77,78,79}

A review of computerised decision aids found that these were more effective than standard consultations or education regarding improving knowledge and reducing decisional conflict.⁸⁰

Question prompts and coaching

Decision coaching involves one-to-one non-directive facilitation to help people prepare for shared decision-making. Question prompts are checklists or documents to spark ideas about questions to ask during interactions with professionals.

Question prompts and coaching for patients can help to increase the number of questions asked in consultations. This does not always lead to improvements in patients' knowledge though, because studies have found mixed results.^{81,82,83,84,85}

A review found that **decision coaching** may be provided by nurses, pharmacists, doctors, psychologists, health educators or genetic counsellors. Compared with usual care, coaching has been found to improve knowledge and participation in decision making. Decision coaching plus patient decision aids was more cost-effective than using decision aids alone.⁸⁶

A review of patient-reported facilitators and barriers to shared decision-making found that factors related to how the healthcare system is organised and what happens during the decision-making interaction are important. Patients' knowledge and perceived power imbalance in the doctor-patient relationship were key. The reviewers concluded that interventions that seek to improve knowledge alone are not sufficient to improve participation in shared decision-making. Barriers are potentially modifiable, but need to be addressed by **attitudinal changes** at the levels of the patient, clinician/healthcare team and the organisation.⁸⁷

Another review found that individuals' preferences for health decision-making cannot be examined outside the context of family and community. Shared decision-making interventions may thus need to be expanded beyond the traditional patient-physician dyad to include other important stakeholders, such as **family or community leaders**.⁸⁸

Few studies have examined the involvement of children in shared decision making.⁸⁹

Access to records

Patient access to medical records and audiotapes of consultations helps to improve their knowledge and recall of information.^{90,91,92}

Improving experience

Decision aids

Decision aids help to increase patient involvement in decision-making and increase patients' confidence in the process. Some studies suggest they also produce a better match between patients' preferences and the treatments chosen, leading to increased satisfaction. There is no evidence that decision aids increase patients' general anxiety. Indeed, there is evidence that they can reduce people's anxiety about cancer screening, and reduce their feelings of conflict about screening and treatment decisions.^{93,94,95,96,97,98,99,100}

A review of interventions to involve **culturally and linguistically diverse** people in decision-making included studies about patient navigators, videos and decision aids. The impact on patient participation was varied. Decision aids and patient navigators generally improved communication with health providers. Decision aids also led to greater shared decision-making and treatment adherence.¹⁰¹

A review of decision support interventions in emergency departments found improved patient knowledge and satisfaction with the explanation of their care, increased preferences for involvement, and greater engagement in decision-making.¹⁰²

Computer decision aids have been found to improve satisfaction with the decision-making process compared to standard education.¹⁰³

Question prompts and coaching

Some studies of coaching and question prompts have found positive effects on active involvement in the consultation, on satisfaction and confidence and a reduction in anxiety. Others have produced conflicting results.^{104,105,106,107,108,109,110}

Overall, it appears that initiatives by professionals to engage people during consultations do increase levels of participation.¹¹¹

Access to records

There is evidence that patients like to have copies of their records or be able to check them online. This can increase their sense of empowerment. Patient-held records can also be helpful for informing family and friends.^{112,113,114,115,116,117,118}

Interventions for professionals

The way that health professionals interact with people impacts on their experience and the extent to which they take part in decision-making.¹¹⁹ Interventions to upskill professionals may thus impact on people's experience of care and the extent of their involvement.

A review of interventions to improve the use of shared decision-making by professionals in routine practice found that combining **education** for professionals plus a patient decision aid worked well. The reviewers concluded that multifaceted interventions that include educating health professionals about sharing decisions with patients and patient-mediated interventions, such as patient decision aids, appear promising for improving professionals' adoption of shared decision-making.¹²⁰ Auditing practice and providing professionals with feedback may also have potential, when used in tandem with other initiatives to increase uptake.¹²¹

A review of shared decision-making interventions relating to using or withdrawing life support in intensive care found that the interventions were not harmful. The interventions focused on improving communication between professionals and families. They decreased family member anxiety and distress, shortened the length of stay in intensive care and did not affect patient mortality.¹²²

Improving service use and costs

Decision aids

Decision aids have been found to have mixed effects on people's choice of treatment. There is no evidence that they increase demand for expensive treatments. On the contrary, trials that have measured economic outcomes have found them to be either cost-effective - because they lead patients to choose less expensive treatments - or cost-neutral.¹²³

In osteoporosis disease management, decision aids have been shown to increase uptake of bone mineral density investigations and initiation of treatment.¹²⁴

Evidence about the impact of **screening decision aids** on screening uptake is mixed.¹²⁵ Some studies show an impact, increasing screening uptake in some cases and appropriately reducing it in the case of prostate cancer screening.^{126,127,128,129,130,131,132,133}

A review found that **computerised decision support tools** in the emergency department helped to reduce healthcare use without evidence of harm.¹³⁴

Question prompts and coaching

A review of education and coaching interventions to support older people to take part in their care found that key success factors included providing culturally sensitive information, mutual goal setting and flexibility to adapt to people's needs. Educational interventions were associated with improved health behaviours and better clinical outcomes for people with long-term conditions.¹³⁵

Encouraging patients to ask questions does not appear to have a significant effect on the length of consultations.^{136,137,138,139,140,141,142}

Access to records

There is some limited evidence that patient-held maternity records are less likely to get lost than those held by staff.¹⁴³

Improving health behaviour and outcomes

Decision aids

Screening decision aids have a positive impact on people's intention to take part in relevant disease screening.¹⁴⁴

Some reviews suggest that treatment decision aids improve adherence to treatment recommendations when patients are encouraged to play an active role in consultations and decision-making. However, there is little evidence of improvements in health outcomes.^{145,146,147,148,149,150,151,152}

Coaching

There is insufficient evidence about the impact on health outcomes of coaching and educational support to foster increased participation.¹⁵³ However, one review found that the communication and relationship-building that may occur in co-produced consultations may lead to better medication adherence in mental healthcare.¹⁵⁴

What should we invest in?

Taking all of the evidence together, commissioners and providers wanting to support shared decision-making should consider investing in the initiatives listed below.

Improvement initiatives	Expected return on investment
Patient decision aids	<ul style="list-style-type: none"> • Increased patient involvement in decisions • Better understanding of treatment options • More accurate perception of risks • Improved quality of decision-making • Appropriate impact on uptake of screening • Does not increase patients' anxiety • <i>May</i> reduce intervention rates • <i>May</i> be cost-effective
Question prompts and coaching for patients	<ul style="list-style-type: none"> • Increased question-asking in consultations • <i>May</i> increase patients' knowledge and understanding • <i>May</i> empower patients and improve satisfaction • Does not necessarily increase length of consultations
Patient access to records	<ul style="list-style-type: none"> • Improved knowledge and recall • Greater sense of empowerment • <i>May</i> help to reduce incidence of lost records

Supporting shared decision-making is complex because it requires patients to have the skills, confidence and knowledge to take part and for professionals to actively encourage and support involvement.^{155,156,157} In consultations professionals need to recognise and acknowledge explicitly that a decision is required; know and understand the best available evidence and be able to share this clearly; and incorporate the patient's values and preferences into the decision in a shared manner.^{158,159} This requires training and support of both patients and professionals, but there is no evidence to suggest that one type of support intervention should be prioritised above others.¹⁶⁰

Learn more

You can access the abstracts of all the systematic reviews of evidence by clicking on the hyperlinks in the references section of this document.

There are a number of other resources available, such as:

- The Department of Health has produced a [list of 'prompt' questions](#) that patients may want to ask the clinicians treating them.
- Patient decision aids are tools that help people become involved in decision making by providing information about the options and outcomes and by clarifying personal values. The University of Ottawa's Health Research Institute has compiled a [database](#) of available decision aids.
- The Right Care Shared Decision Making Programme is designed to promote shared treatment decisions, supporting NHS organisations to meet QIPP targets. The programme signposts to **UK-specific patient decision aids** for conditions such as AAA screening and repair, cataracts, COPD, kidney failure, prostate cancer, lung cancer, osteoarthritis of the hip and of the knee and stable angina.
- The NHS Choices website includes the [Health A-Z](#), which gives information about diseases and treatments; and the Map of Medicine health guides which are designed to help doctors identify treatment options.
- The [Foundation for Informed Medical Decision Making](#) is dedicated to ensuring that people understand their treatment choices and have the information they need to make sound decisions. They promote understanding and adoption of informed medical decision-making, develop decision aids for patients and carry out research into how to improve decision quality in healthcare.
- NICE's Quality Standard 15 - [Quality standard for patient experience in adult NHS services](#) - includes a quality statement on supporting patient choice: "Patients are made aware that they have the right to choose, accept or decline treatment and these decisions are respected and supported [...] Patients have their choices respected and supported when deciding whether to accept or decline treatment, and when choosing between treatments."
- Surveys carried out as part of the Care Quality Commission's national NHS patient [survey](#) programme include questions about shared decision-making, which could be used to monitor changes over time. The government's [General Practice Patient Survey](#) also includes relevant questions.

Appendix: identifying evidence

Commissioners and professionals need accessible and accurate information upon which to make decisions. High quality research is one of the things that might be used to help guide decisions. This appendix describes how we compiled the highest quality research to support decision-making.

What type of evidence is included?

To find out what works best to prioritise person-centred care, we drew on systematic reviews. 'Systematic reviews' have traditionally been regarded as the best standard of evidence because they bring together the results of all relevant studies that meet specific quality criteria. A systematic review starts with a specific question or set of clearly defined questions and then identifies, appraises, selects and synthesises all high quality research evidence relevant to that question. Tried and tested methods are used to perform a thorough search of the literature and critical appraisal of individual studies to identify valid and applicable evidence.

Some groups, such as the Cochrane Collaboration have agreed a set of [standards](#) for gathering, analysing and reporting evidence, though not all reviews conform to these standards.

By drawing together the findings of systematic reviews, we compiled the highest quality evidence to support healthcare planners and practitioners. We focused on the extent to which interventions impacted on people's knowledge, people's experience, service use and costs and health outcomes and behaviours.

Identifying research

Two reviewers independently searched bibliographic databases to identify relevant systematic reviews and other high level narrative reviews. The databases were Medline / Pubmed, Embase, CINAHL, the Cochrane Library and Google Scholar. Specialist websites and the reference lists of identified articles were also searched. The databases were searched for systematic reviews published in English language journals between January 1998 and December 2013. Reviews were eligible for inclusion if they focused on interventions designed to enhance the active role of patients and lay people. Reviews where patients were solely the 'objects' of an intervention that targeted professionals were excluded.

Two reviewers independently assessed the relevance and quality of each review, first based on the abstracts and titles of identified studies and then based on full-text. Any review which focused on a relevant topic and outcome was included.

More than 40,000 studies were screened and a total of 779 systematic reviews were identified for inclusion, broken down into the following categories:

- supporting self-management (228 reviews)
- supporting shared decision-making (48 reviews)
- enhancing experience (110 reviews)
- improving information and understanding (85 reviews)
- and promoting prevention (308 reviews)

Things to remember when interpreting the findings

The evidence base is substantial and significant, but it is not perfect. It will not help to answer all questions about how best to prioritise person-centred care. Some interventions, such as education for self-management, have been very well studied. Others initiatives have been less well investigated, and few studies have examined the longer-term effects of interventions.

Much of the research is from North America, so commissioners and health professionals need to think about whether the findings translate easily to the local context.

Although there is good evidence that some things make a difference to how people feel and what people do, analysis of cost-effectiveness is sometimes lacking.

Acknowledgements

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Exploring the evidence

You can click on the hyperlinks to explore the evidence further.

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