Prioritising person-centred care

Improving information and understanding

Summarising evidence from systematic reviews
Key themes

We compiled information from 85 systematic reviews and found that the top things that managers and clinicians can do to improve patient information and understanding are:

- provide specific and tailored information and education
- make information and support available electronically
- provide telephone helplines, teleconsultations, telehealth and telemonitoring

The table signposts to evidence about what works best to enhance patient experience. Initiatives in bold have the most evidence to support them.

<table>
<thead>
<tr>
<th>Focus</th>
<th>Improves knowledge</th>
<th>Improves experience</th>
<th>Improves service use and costs</th>
<th>Improves health outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Targets patients</td>
<td>• Personalised information(^1,2)</td>
<td>• Printed and electronic information(^15,16,17,18,19,20,21,22)</td>
<td>• Pre-operative and pre-discharge information(^35,36,37,38,39,40)</td>
<td>• Personalised information, including tailored for minority groups(^37,58)</td>
</tr>
<tr>
<td></td>
<td>• <strong>Printed and electronic information</strong>(^3,4,5,6,7,8,9,10)</td>
<td>• Telephone helplines, telecounselling, and telemonitoring(^23,24,25,26,27,28,29,30)</td>
<td>• Personalised information(^41)</td>
<td>• Clear information about medicines(^59)</td>
</tr>
<tr>
<td></td>
<td>• Verbal reinforcement from clinicians(^11,12)</td>
<td>• Digital interactive tv(^31)</td>
<td>• Reminder packaging for medicine(^42,43)</td>
<td>• Telehealth interventions(^60,61,62,63,64,65,66)</td>
</tr>
<tr>
<td></td>
<td>• Audio-taped consultations(^13)</td>
<td>• Social media(^32)</td>
<td>• Written and telephone reminders for screening and appointments(^44,45)</td>
<td>• E-learning and online initiatives(^67,68),(^69,70,71,72,73,74,75,76,77,78)</td>
</tr>
<tr>
<td></td>
<td>• Education programmes(^14)</td>
<td>• Education programmes, especially active initiatives(^33,34)</td>
<td>• Telemonitoring and teleconsultations(^46,47,48,49,50,51,52,53,54,55,56)</td>
<td>• Group and individual education(^79)</td>
</tr>
<tr>
<td>Targets professionals</td>
<td>• Using wider range of community groups(^80)</td>
<td>• Clinical information systems / decision support(^81,82)</td>
<td>• Education by non-clinical staff(^83)</td>
<td>• Food labels(^85)</td>
</tr>
<tr>
<td>Targets systems /</td>
<td>• Improved information style(^84)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>organisations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Improving information and understanding

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 improving information provision and understanding.

What is health literacy?

Ensuring that people are provided with clear, useful information about health and healthcare is an important component of supporting people to be involved in decisions and to make positive choices. Health literacy has been defined as “the ability to read, understand and act upon health information.” This involves much more than simply ensuring that people can read and understand health information. It is also about building competence to make health decisions. In other words, health literacy refers to the knowledge, motivation and competencies of accessing, understanding, appraising and applying health-related information within the healthcare, disease prevention and health promotion. Therefore it is relevant to the whole population, not just those with low basic literacy and numeracy skills. Being able to obtain, understand and use information is essential for good health.

Three distinct levels of health literacy have been described:

- functional: basic skills in reading and writing for understanding health information
- interactive: more advanced skills to enable active participation in health care choices
- critical: the ability to critically analyse information about health and health care and make effective use of it
Low health literacy is associated with health inequalities. People with low health literacy tend to have poorer health and a greater risk of hospitalisation. Health literacy interventions have three key objectives: to provide information, to encourage appropriate and effective use of healthcare resources and to tackle health inequalities. Improving the way that information is provided is therefore a key part of supporting person-centred care.

**Why is this important?**

1. **Access to information helps people stay central to their care**

People need to be able to understand their health and healthcare in order to:

- understand what is wrong
- gain a realistic idea of prognosis
- make the most of consultations
- understand tests and treatments
- assist in self-care
- find services and sources of help
- find reassurance and help to cope
- help others understand
- learn how to prevent further illness
- find ‘the best’ health care providers for them

Information needs may change during the course of an illness. When people first receive a diagnosis, for example, they may want practical information to support treatment decisions, as well as reassurance to reduce anxiety. Later, when the focus moves to long-term management and self-care, they may have more specific and in-depth information needs.

People's information needs are very diverse and vary according to their age, sex, socio-economic status, beliefs, preferences and coping strategies. Their information needs also depend on their general literacy, knowledge, skills and abilities and the language they speak at home.

There is a vast amount of information about health, healthcare, diseases and treatments available. But research has found that people want more information than they currently receive and that health professionals tend to overestimate the amount of information they supply. Thus the problem is not one of scarcity. It is about the accessibility, timeliness, quality, readability, reliability and usefulness of the available information.

2. **Access to information can impact on people’s health**

Having good access to information and being able to understand it is crucial because it can have a significant effect on people’s health. The American Medical Association concluded that health literacy is a stronger predictor of health status than age, income, employment status, education level, race or ethnic group.

Improving information provision and people's overall health literacy is important in tackling health inequalities because people with low health literacy:

- have poorer health status
- undergo more hospital admissions
- are less likely to adhere to treatment recommendations
- experience more drug and treatment errors, and
- make less use of preventive services.

Failure to give patients full information about their medicines contributes to the low levels of adherence to treatment recommendations reported in many studies. 87
3. Current health materials may be too complex

A study of health literacy in England compared the ‘difficulty levels’ of health information materials with assessments of over 7,000 people’s literacy and numeracy skills. The health information materials were generally too complex. 42% of people aged between 16 and 65 years were unable to effectively understand and use everyday health information. This figure rose to 61% when the information also required numeracy skills. This suggests that between 15-1 million people across the country are not accessing the information they need to become and stay healthy.

Another study tested functional health literacy in the UK using materials that people might encounter in healthcare settings (for example, instructions for taking medicines). About 11% of adults in the UK had marginal or inadequate health literacy. Those with poor literacy skills were more likely to be:

- older
- male
- lower educational attainment
- lower income
- worse diet
- less exercise
- smokers
- worse self-rated health

4. Policies and regulations require good information provision

In the UK, there are many policy documents and regulations requiring health organisations to provide clear information and address health inequalities. For example, a ‘Strategic review of health inequalities in England’ was published in 2010 and the Health and Social Care Act 2012 gave NHS commissioners and Public Health England duties to reduce health inequalities. The NHS Commissioning Board is supposed to facilitate new approaches to health information and health literacy. The board’s Mandate requires it to promote people’s access to their health records and join up these records across organisations. Health and Wellbeing Boards, which assess local needs and coordinate strategies to meet them, are also pursuing the health inequalities agenda.

The Health and Social Care Act requires all health and social care providers to "provide service users with appropriate information and support in relation to their care or treatment; encourage service users, or those acting on their behalf, to understand the care or treatment choices available to the service user, and discuss with an appropriate health care professional, or other appropriate person, the balance of risks and benefits involved in any particular course of care or treatment,"
The **NHS Constitution** for England includes the following commitments that have a bearing on information provision and health literacy:

- the NHS will strive to make decisions in a clear and transparent way, so that patients and the public can understand how services are planned and delivered.
- 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.
- the NHS will strive to inform you about what healthcare services are available to you, locally and nationally.
- the NHS will strive to offer you easily accessible information to enable you to participate fully in your own healthcare decisions and to support you in making choices. This will include information on the quality of clinical services where there is robust and accurate information available.
- 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 provide you with the information you need to participate effectively to influence the planning and delivery of NHS services.

The **Care Quality Commission** (CQC) regulates the quality of health and social care on behalf of patients, service users, their carers and families. It has issued extensive guidance to providers on meeting the statutory requirements to inform service users about their care and treatment, and to ensure that they are enabled to understand the choices available to them.

There is also specific guidance for health professionals. The General Medical Council’s (GMC) guidance for doctors on standards for professional practice, *Good Medical Practice* states that they must give patients the information they want or need in a way they can understand. Doctors must make sure, wherever practical, that arrangements are made to meet patients’ language and communication needs.

The **Nursing and Midwifery Council** (NMC) code requires nurses and midwives to make arrangements to meet people’s language and communication needs. They must share with people, in a way they can understand, the information they want or need to know about their health.

The **Health Professions Council** (HPC) standards require allied health professional registrants to communicate properly and effectively with service users.
What works?

85 systematic reviews published between 1998-2013 have summarised the best research evidence about improving information and understanding. This section outlines key findings about what works 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 explored the provision of printed materials, electronic health information and telephone support. The main interventions tested include:

Information for people undergoing treatment:
- leaflets and booklets about diseases and treatments
- printed material that is specially tailored for individual patients
- information about medicines and how to take them
- medication reminders and special packaging to improve treatment adherence
- combined provision of written materials and verbal information
- pre-operative information for patients undergoing surgical procedures
- information for people when they are discharged from hospital
- interventions to mitigate the effects of low literacy

Electronic health information and 'virtual' support:
- computer-generated patient information and education
- health websites
- 'virtual' communities
- audio and videotapes / dvds

Telephone based care:
- tele-consultation using real-time interactive video
- home tele-monitoring
- telephone counselling, tele-health, tele-care and health coaching
- automated telephone reminders

Initiatives to support self-management are described in another booklet in this series.
What are the impacts?

Improving knowledge

Written information

A number of reviews suggest that providing written information can improve people’s knowledge. The impact is greater when written information is **personalised** and reinforced by verbal information from clinicians. Material may need to be targeted towards particular ethnic and demographic groups.

A review identified characteristics that improved the **clarity of information** and comprehension, including presenting essential information by itself or first, presenting information so that the higher number is better, adding icons to numerical information and adding video to verbal narratives.

Another review found that five interventions have commonly been used to enhance patient engagement in hospitals: entertainment, generic health information, patient-specific information, advanced communication tools and personalised decision support.

However other reviews have highlighted that much information used routinely in health services is too complex. For example, one review found that standard leaflets in pill packets did not meet patients’ needs adequately.

Using technology

There is evidence that both **printed and electronic information** materials and educational programmes can have a beneficial effect on patients’ knowledge and understanding of their condition.

A review examining online health information tutorials found mixed results. There was some evidence of improved knowledge and confidence, but the quality and quantity of evidence was low.

A review of internet use by the carers of people with cancer identified two main activities: information searching and support group activity. Carers accessed online information to increase their knowledge and problem solve. They valued e-mail communication with health professionals to ask questions and clarify information and found online support groups useful for gaining information tailored to individual needs and peer support.

A number of electronic screening tools are available to identify people with poor health literacy for further intervention.
Other information and education

Other approaches have also been tested. For instance, one review found that question prompt sheets and audiotapes of consultations improved recall of medical information provided within clinical consultations. 109

Specially targeted interventions can help to increase knowledge and understanding in people with low health literacy or from low socio-economic groups or rural areas. 110,111,112 For instance, a review of functional and interactive health literacy education programmes found improved health literacy skills of older adults, though longer-term impacts remained uncertain. 113

In the US, health information interventions have been set up in barbershops to target minority ethnic groups. A review found that barbers were able to provide health education, screening and referrals to health services. In studies where barbers received training, their knowledge of health conditions increased significantly and they were able to increase knowledge and promote positive health behaviours among their customers. 114

However, it is difficult to recommend one type of education or information provision over others to support health literacy. Many reviews are not specific about the exact interventions included and others point out issues with the scope of current initiatives. 115 For example, reviews of health literacy screening tools or educational interventions have suggested the need to use more comprehensive assessment approaches that move beyond readability and numeracy to address the full spectrum of health literacy factors. 116,117,118,119,120 Older people and those from minority ethnic groups may be in need of special attention. 121

Improving experience

Written information

Providing written and electronic information can increase people’s sense of empowerment. It can also improve their ability to cope, increase satisfaction and may help to reduce anxiety in certain cases. 122,123,124,125,126,127,128,129

Using technology

There is some evidence that telephone helplines, telecounselling, and telemonitoring can reduce social isolation, increase decision-making confidence and self-efficacy and improve satisfaction. 130,131,132,133,134,135,136,137 For example, initiatives that allow patients to share symptom data with providers via the internet or telephone lines have been found to improve experience. 138 Interactive digital television has also shown promise. 139

Clinical information systems, used to prompt health professionals to offer advice or support for certain conditions, have been found to improve care processes and people’s experience of care. 140,141

Social media has also been used for health communication. Reported benefits include increasing interactions with others, more readily available shared and tailored information, increased accessibility and widening access to health information, peer / social / emotional support and public health surveillance. 142

A review found that online pharmacies may improve access to medication, but that the information contained on websites may be poor. 143
Other information and education

A review found improved mental wellbeing after people took part in an educational intervention to improve health literacy.144

One review found that among people who experience a stroke, information strategies that actively involve patients and their caregivers are more effective in reducing anxiety and depression than passive information sources.145

Improving service use and costs

Written information

Reviews have also examined the impact of various information strategies on service use and costs. For instance, a number of reviews report that pre-operative and pre-discharge information may help to reduce consultations, length of stay in hospital and follow-up visits.146,147,148,149,150,151

A review of targeted information and support for parents with low health literacy found that this reduced the number of times they took their children to the emergency department.152

Reminders in print, email or telephone form have been found to increase the uptake of preventive screening for cancer.153

Reviews suggest that leaflets in pill packets do not help to improve adherence to medicine taking.154,155

Using technology

Telephone reminders can help to increase attendance rates and improve medication adherence.156

Home-based telemonitoring and telecare may be cost-effective but studies have produced conflicting results.157,158,159,160

There is evidence that specifically targeted information and tele-consultations can improve diagnostic accuracy, reduce consultation rates, waiting times and out-of-pocket costs to patients, but studies have found conflicting results.161,162,163,164,165,166,167

Other information and education

Reminder packaging (such as pills in calendar packs) may improve adherence to self-administered long-term medication.168,169

Improving health behaviour and outcomes

There is evidence that people with poor health literacy may have worse clinical outcomes or may be less likely to take steps to safeguard their health.170,171,172,173 A number of initiatives have been tested to address this, and to provide enhanced information more generally.

Written information

There is little evidence of a direct effect on health status or health behaviour from printed information on its own, but more complex tailored interventions may improve adherence, health behaviours and treatment outcomes.174
One review found evidence of a reduction in medical errors when people were given clear information about medicines.175

A review about adding information about healthy and unhealthy nutrients on food labels found no effects on whether people purchased foods. Interventions were more likely to be effective when they lasted for a longer time, included other components in addition to labels, and when they focused on the absence of unhealthy nutrients instead of or in addition to the presence of healthy nutrients.176

Using technology

Some reviews have found evidence of improvements in quality of life and health status as a result of telehealth interventions.177,178,179,180,181,182,183

For example, a review of various interventions to improve medication adherence in older people with cognitive impairment had mixed findings. Reminder systems generally had no benefit but telephone and televideo reminders at each dosing interval improved adherence.184

Patient portals allow people to electronically access health information, including information managed by a healthcare organisation. A review found no impact of accessing and using information in this way on health outcomes, though there was some evidence of better adherence to treatment.185

There is some evidence of a beneficial impact on health behaviour, uptake of screening, and clinical outcomes resulting from e-learning programmes, online initiatives and ‘virtual’ support.186,187,188,189,190,191,192,193,194,195,196,197

Other information and education

People with low health literacy have worse health outcomes. There is some evidence that the effects can be mitigated with well-designed interventions.198 Some reviews suggest that targeted support is needed.199 One review reported that group and individual education interventions of varying intensity in primary care and community settings are useful for supporting sustained change in health literacy and this may have a follow-on effect on behavioural risk factors. Primary care interventions were more effective than those in the community for supporting smoking cessation whereas the reverse was true for diet and physical activity interventions.200

Another review found that interventions of a moderate to high intensity were most effective for improving health literacy and subsequent lifestyle change. Non-medical healthcare staff were more effective in improving health literacy than clinical staff.201

Another review found that structured interventions, tailored to ethnic minority groups by integrating elements of culture, language, religion and health literacy skills, had a positive impact on a range of patient outcomes.202

Intensive individual educational interventions for patients with acute and sub-acute lower back pain have been found to be effective on short and longer term outcomes including pain intensity, function and return-to-work.203 Similarly, a review found that intensive disease management interventions providing information reduced disease severity.204

On the other hand, a review found no improvement in medication adherence following an educational initiative to improve health literacy.205 Another review found no link between improved health literacy and better self-management.206
What should we invest in?

Taking all of the evidence together, commissioners and providers wanting to enhance experience should consider investing in the initiatives listed below.

<table>
<thead>
<tr>
<th>Improvement initiatives</th>
<th>Expected return on investment</th>
</tr>
</thead>
</table>
| Personalised patient information (paper and electronic) reinforced by professional or lay support | • Improvements in patients’ knowledge and understanding of their condition  
• Increased sense of empowerment  
• Greater ability to cope with the effects of illness  
• Improved patient satisfaction  
• *May* lead to improvements in health behaviour and better health outcomes |
| Telephone reminders | • Improved attendance rates |
| Telephone counselling and helplines, tele-care, tele-health, tele-monitoring | • Less social isolation  
• Improved self-efficacy and satisfaction  
• *May* improve diagnostic accuracy  
• *May* lead to fewer consultations and shorter waiting times  
• *May* lead to improved health status and better quality of life |
| E-learning and online resources | • Improved knowledge  
• Improved access to information  
• Improved self-management  
• *May* impact on clinical outcomes |
| Pre-operative and pre-discharge information materials | • *May* lead to shorter length of stay and fewer follow-up visits |

The top three things to explore further are:

1. **Clear and simple information**
   There is good evidence that well-designed printed and electronic information can help to improve patients’ knowledge and understanding of their condition. Written health information materials must be well-targeted and available at the time and place when needed. Information materials have greater impact when the information is personalised and reinforced by verbal information from clinicians.

2. **Telephone support**
   Telephone counselling, helplines and reminders can be beneficial to patients, helping to boost their confidence to look after themselves.

3. **Electronic initiatives**
   Novel approaches such as e-learning modules, patient portals, websites and social media may all have a role to play in disseminating health information.
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:

- Information should be readily accessible, clearly written and reliable. A number of tools and checklists have been developed to assist in the production of good quality information including DISCERN quality criteria for consumer health information; IPDAS (International Patient Decision Aids Standards Collaboration) and Health on the Net Foundation code of conduct (HON Code).

- The Department of Health supports an information accreditation scheme to 'kite mark' health information producers. The scheme supports information producers to improve the quality of their information. It is open to all organisations producing health information – public, voluntary, and commercial.

- NHS Choices is the NHS’s online service for the public. It first went live in June 2007 and now contains a wealth of information on all aspects of health and healthcare.

- Healthtalkonline reports people’s real-life experiences of health and illness. Covering 50 health conditions, it aims to inform and educate people about patients' and carers' experience of illness and treatment. There is an additional young people’s website.

- The Patient Information Forum is an independent association for professionals that work in the field of consumer health information. It promotes high-quality information for patients, carer and their families.

- Surveys carried out as part of the Care Quality Commission’s national NHS patient survey programme include a number of questions about information provision that could be used to monitor trends. Examples include the Community Mental Health Service User Survey and the Inpatient Survey. The GP Patient Survey also includes relevant questions.

- Information prescriptions may be offered to people with a long-term condition or social care need. They aim to guide people to relevant and reliable sources of information to allow them to feel more in control and better able to manage their condition and maintain their independence.

- Skilled for Health (SfH) is a set of teaching resources which evolved from the national adult basic skills programme, Skills for Life, and a series of pilot studies.

- The Marmot review website from the Institute of Health Equity showcases the 2010 strategic review of health inequalities and data and reports published since then.

- The Health Literacy Group brings together academics and practitioners with an interest in health literacy.
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

The material was prepared by The Evidence Centre for National Voices. Some of the work was based on a project originally funded by the Department of Health via the Picker Institute Europe.
Exploring the evidence

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


Clark RA, Inglis SC, McAlister FA, Cleland JGF, Stewart S. Telemonitoring or structured telephone support programs for patients with chronic heart failure: systematic review and meta-analysis. BMJ 2007;334(7600):942.


