



Patient Information Forum

For Professionals Working in Consumer Health Information

Evidence Review: what does good health information look like?

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1 Background to the study

Key messages

This research report summarises the best evidence available – from both research and practice – on what approaches are most effective in ensuring the accuracy, readability, relevance and impact of consumer health information.

The growing recognition of information as the lifeblood of quality health services is reflected in legislation, the NHS Constitution and the NHS Patient Experience Framework.

However, despite the right to information, and clear evidence of the benefits, problems relating to poor communications and inadequate information have been one of the most common causes of complaints and patient dissatisfaction in the health service.

The biggest issue is not necessarily one of quantity – quality is paramount. How accessible, timely, readable, reliable and useful is the information provided? What does high quality health information really look like?

We found a mixture of evidence (based on primary research and systematic reviews) and good practice guidelines and quality checklists developed by official bodies and special interest groups. In particular, we have highlighted the Information Standard, the DISCERN criteria for assessing the quality of publications about treatment choices, and criteria from the Picker Institute's revisions to the checklist produced by IPDAS - the International Patient Decision Aid Standards Collaboration.

In some areas, for example on communicating risk, there is quite an extensive evidence base. In others, for example on revealing uncertainty or avoiding bias, there is more of an ethical (and legal) base for best practice.

Introduction

The Patient Information Forum (PiF) is committed, with its members, to developing practical, producer-led guidance and best practice advice on creating high-quality, consumer health information resources.

This research report summarises the best evidence available – from both research and practice – on what approaches are most effective in ensuring the accuracy, readability, relevance and impact of consumer health information. Taken together, these three elements represent one of the four critical areas that PiF members have prioritised for future guidance. The others are: making sure information works for users; formats for information products; and evaluation and measuring impact.

This works fits into a larger PiF project, funded by the Department of Health, to create the UK's first practical, producer-led guidance and best practice resource on creating great health information.

Project scope

For the purposes of this project, consumer health information is understood to include information about health conditions and treatment options, however published, that patients may either access themselves or be given as part of their care.

Verbal information conveyed as part of a clinical consultation, and information about social care, are excluded from the project's scope.

Research methods

We adopted the following methods in searching for evidence on the most effective approaches to ensuring the readability, accuracy, relevance and impact of consumer health information:

- Reviewing relevant evidence presented in existing research collections and reports covering this area – including key reports by National Voices¹, the Picker Institute², NHS Scotland³ and the Australian National Health and Medical Research Council⁴.
- Reviewing selected papers published in a special supplement to the November 2013 edition of *Medical Informatics and Decision Making*. These studies focused on the continued relevance of key criteria designed to underpin the development of high-quality patient decisions aids.
- The further review of relevant studies already considered in our earlier work on 'making the case for information' for both PiF and, subsequently, Macmillan Cancer Support.
- Assessing the evidence presented in a wide range of studies, reports and websites that PiF members had identified as providing key information on each objective.
- An additional review of other relevant materials referenced on PiF's website.

Policy context

Information, and access to it, is now firmly embedded in health policy across the UK. The NHS Constitution includes a commitment to shared decision making as one of its seven overarching principles. The Health and Social

¹ National Voices (2012) *Improving information and understanding*

² Picker Institute (2006) *Assessing the quality of information to support people in making decisions about their health and healthcare*

³ NHS Scotland (2003) *Draft Guide to the Production and Provision of Information about Health and Healthcare Interventions*

⁴ National Health and Medical Research Council (1999) *How to prepare and present evidence-based information for consumers of health services: A Literature review*

Care Act 2012 enshrined the legal foundation for the Constitution and placed new duties on the NHS Commissioning Board and clinical commissioning groups to promote it.

A new, strengthened constitution to reflect more clearly that the NHS supports individuals to manage their own health and involves them, their families and carers in decisions that affect them was launched in March 2013. Under the constitution, patients have the rights:

- To be given information about the test and treatment options available to them, what they involve, and their risks and benefits.
- To be involved in discussions and decisions about their health and care, including end of life care, and to be given information to enable them to do this.

Similar rights exist in the rest of the UK. Professional codes of conduct also now mandate information provision as a key part of ethical behaviour, shared decision-making and obtaining patients' informed consent.

In our previous work for PiF (*Making the Case for Information*, May 2013) and for Macmillan Cancer Support (*The Case for Cancer Information*, May 2014), we set out the evidence of the benefits of providing high quality health information and support. These included positive impacts on patients' experience of healthcare, health behaviour and status, as well as wider benefits such as improved service utilisation and reduced health costs. The provision of quality information and support is crucial to unlocking what has been termed the 'blockbuster drug' of patient engagement.

However, despite the right to information, and clear evidence of the benefits, problems relating to poor communications and inadequate information have been one of the most common causes of formal complaints in the health service and a significant source of patient dissatisfaction⁵. Despite evidence of some improvement in responses to questions about information provision, the latest inpatient survey for England still shows that:

- 20% of patients felt that they did not receive enough information about their condition or treatment
- 31% of patients did not receive any written discharge information about what to do or not to do after leaving hospital
- 28% of patients were not completely satisfied that they received clear written information about their medicine
- 50% of patients were not fully satisfied that their family / carer received all the information they needed to help care for them⁶.

We also know that health professionals tend to overestimate the amount of information they supply and that many people want more information than

⁵ Coulter A (2005) What do patients and the public want from primary care? *British Medical Journal*, Nov 19; 331(7526): 1199-1201

⁶ Care Quality Commission (2014) *Survey of adult inpatients 2013: Full national results with 2012 comparisons*

they currently receive⁷. However, the biggest issue is not necessarily one of quantity – because quality is paramount. How accessible, timely, readable, reliable and useful is the information provided? What does high quality health information really look like?

PiF consultations

PiF has consulted widely with its members and the wider health information community to identify the key areas where further evidence and best practice guidance may be needed. These consultations identified four main topic areas (and related principles) for producers of consumer health information:

1. Making sure information works for users.
2. Formats for information products.
3. Accuracy, readability, relevance and impact.
4. Evaluation and measuring impact.

Objectives

This review has focused on the third topic area – accuracy, readability, relevance and impact – to bring together and document the available evidence regarding each objective and supporting principles:

To ensure **relevance** and **impact** by:

- meeting the needs of the audience
- including non-clinical information and patient experiences, where appropriate
- tailoring/personalising information.

To ensure **accuracy** by:

- creating accurate and evidence-based resources
- detailing the date of publication and process of review
- being transparent if there is little or no evidence
- communicating risk effectively
- communicating benefits and uncertainties in a non-judgmental and unbiased way
- involving healthcare professionals and other experts in the development of information.

To ensure **readability** by:

⁷ National Voices (2012) *Improving information and understanding*

- keeping language and numbers simple, and communicating clearly
- breaking complex information down
- laying out information to aid navigation
- creating visually attractive materials.

PiF plans to use the evidence collated from this review to underpin a wider project to produce practical materials, tools and guidance that will help individuals and organisations to achieve consistently high standards in producing a broad range of consumer health information in a variety of formats.

Overview from this research

We have structured our report in line with the outcome of discussions among PiF members on what is most useful to guide the best possible standards in information production on the given topics.

During the course of the project we uncovered a mixture of evidence (based on primary research and systematic reviews) and good practice guidelines developed by official bodies and special interest groups.

In some areas, for example on communicating risk, there is quite an extensive evidence base. In others, for example on revealing uncertainty or avoiding bias, there is more of an ethical (and legal) base for best practice.

2 Quality checklists and the Information Standard

The nature of health service provision has changed markedly over recent decades, from the traditional, paternalistic model where doctors ‘knew best’ and patients had little voice, to a far more person-centred model of care that has regard for the ‘whole person’, respects individual autonomy and looks to share power and responsibility for health behaviour and decisions⁸.

Most patients now expect to be given good quality information about their condition and treatment options, and the potential risks and benefits of different procedures. They want clinicians to take account of their preferences and some expect to be actively engaged in the decision-making process, or to take decisions themselves⁹.

In tandem with the growth of person-centred care has been an increasing emphasis on the importance of patients’ experience as a key dimension of quality healthcare. Improving access to, and understanding of, good quality health information is therefore integral to delivering high quality, person-centred healthcare that places a premium on enhancing patient experience.

The growing recognition of information as the lifeblood of quality health services¹⁰ is reflected in legislation, the NHS Constitution and the NHS Patient Experience Framework¹¹. It also underlies the development of several quality checklists produced to help drive the improvement of consumer health information materials.

The earliest checklists were published in the mid-1990s by the NHS Executive¹² and The King’s Fund¹³. These helped to inform the subsequent development of some more comprehensive instruments, including the DISCERN criteria (for assessing the quality of publications regarding treatment choices), and the International Patient Decision Aid Standards (IPDAS) Collaboration criteria for judging the quality of patient decision aids.

Although the precise definitions vary, these checklists share the same consistent underlying criteria – proposing that patient information:

1. Should not be influenced by financial or intellectual interest; funding and potential conflicts of interest should be made transparent.
2. Should be developed together with patients / consumers.
3. Should be based on the best available evidence, that is: a systematic literature search and assessment of the existing evidence.
4. Should communicate levels of evidence and/or strength of recommendations.

⁸ The Health Foundation (2014) *What is person-centred care?* <http://personcentredcare.health.org.uk/person-centred-care/what-person-centred-care> [accessed 26 September 2014]

⁹ Coulter A & Ellins J (2006) *Patient-focused interventions: a review of the evidence*, Picker Institute Europe

¹⁰ Department of Health (2012) *The Power of Information*

¹¹ National Quality Board (2012) *NHS Patient Experience Framework*

¹² NHS Executive (1995) *Priorities and Planning Guidance*

¹³ Coulter A (1996) Give patients solid information, *Management in General Practice*, 20: 40-42

5. Should convey a realistic idea of the condition (neither exaggerate nor trivialise).
6. Should describe all treatment options with their risks and benefits – communicating these in an understandable way (e.g. not using relative risk or percentages) and referring to patient-centred outcomes (e.g. mortality, morbidity and quality of life).
7. Should address uncertainties like weak or missing evidence.
8. Should be easy to read, understandable and accessible¹⁴.

The DISCERN criteria (see Appendix 2) were developed and validated (in the light of extensive field testing) by an expert panel to become the first standardised index for assessing the quality of consumer health information¹⁵.

The IPDAS standards were founded on the basis of available research evidence (from an extensive literature review carried out by a large group of experts) and were developed following an extensive international consensus process involving a wide range of stakeholders¹⁶. They include two sets of criteria for assessing both the content of patient decision aids and, also, the process by which they are produced.

Revised IPDAS criteria

A study conducted by the Picker Institute¹⁷ for the English Department of Health drew vary heavily on the IPDAS standards because they had the advantage of being the most comprehensive, up-to-date, evidence-based guidelines available. The study was carried out to assess:

1. The quality of consumer health information available at that time to help people make decisions about their health and healthcare.
2. The potential added value of accrediting information providers.

Since the IPDAS criteria relate specifically to information materials designed to support decisions about treatment or screening options, the Picker research team adapted them to make them relevant to a broader range of patient information materials. In so doing, they drew on both the DISCERN criteria and their own expertise to address some important omissions. This led to additional criteria being included to ensure that any piece of information includes ‘a clear statement of its aims’ and gives sufficient weight to ensuring that it ‘contains accurate information’.

¹⁴ Guidelines International Network (2012) G-I-N Public Toolkit: Patient and Public Involvement in Guidelines

¹⁵ Charnock D, Shepperd S, Needham G & Gann R (1999) DISCERN: an instrument for judging the quality of written consumer health information on treatment choices, *Journal of Epidemiology and Community Health*, 53:105–111

¹⁶ International Patient Decision Aid Standards (IPDAS) Collaboration (2005) *IPDAS 2005: Criteria for judging the quality of decision aids*

¹⁷ Picker Institute (2006) *Assessing the quality of information to support people in making decisions about their health and healthcare*

Detailed criteria from the Picker Institute's revised IPDAS checklist are referred to in relevant sections below. The revised checklist is also reproduced in full in Appendix 1.

The Information Standard

In the light of this 2006 study, the Department of Health subsequently commissioned the Information Standard as an independent certification scheme for all organisations producing evidence-based health and care information for the public. Any organisation seeking to achieve the Information Standard has to undergo a rigorous assessment to check that the information it produces is clear, accurate, balanced, evidence-based and up-to-date. Information Standard-accredited organisations must also demonstrate that they are producing fully accessible health information by writing at a level that is appropriate for their target audience.

The detailed accreditation criteria and requirements for the Information Standard rest on six key principles:

1. Information Production – information producers must have a defined and documented process for producing high quality information.
2. Evidence Sources – information producers must only use current, relevant, balanced and trustworthy evidence sources.
3. User Understanding and Involvement – information producers must understand their users and user-test their information.
4. End Product – information producers must double-check their end products.
5. Feedback – information producers must manage comments / complaints / incidents appropriately.
6. Review – information producers must review their products and process on a planned and regular basis.

3 Ensuring relevance and impact

Key messages

Both the IPDAS guidelines and the Information Standard highlight the value and importance of information producers involving audiences at key stages of the process: from deciding what is needed, through to content development, design, dissemination and evaluation.

One systematic review found evidence that involving consumers in the development of patient information results in material that is more relevant, readable and understandable and which can improve knowledge without affecting anxiety.

A recent study for National Voices found that one of the single most important things you can do to improve consumer health information and to increase its impacts is to provide individuals with specific, tailored information and education.

These findings correspond with the conclusion of our earlier studies for PiF and Macmillan Cancer Support – that consumer health information has the greatest effects when it is tailored (as far as possible) to reflect an individual's particular needs, preferences and circumstances, throughout their 'patient journey'.

NICE guidance on *Patient experience in adult NHS services* recommends that healthcare services should be individualised as much as possible and tailored to the patient's needs and circumstances.

Information producers should consider segmenting audiences into different target groups. This might include groups who do not read or speak English, those with sensory impairments and those with low levels of health literacy.

Tailoring materials may involve transferring concepts into ways which are culturally sensitive to different groups, using different examples and illustrations as well as words.

The presentation and format of information materials is particularly important for people with low health literacy.

Patient stories are typically considered by consumers to be more concrete, familiar and vivid. However, information producers should be aware that evidence indicates that providing information within personal stories affects the judgments and values people have, and the choices they make, differentially from facts presented in non-narrative prose and/or statistical information.

Introduction

Consultations among PiF members highlighted the importance of ensuring the **relevance** and **impact** of information materials by:

- meeting the needs of the audience
- including non-clinical information and patient experiences, where appropriate
- tailoring / personalising information.

It is difficult to imagine that anyone would deliberately set out to produce an information product that had no relevance or effect – so, not surprisingly, we did not uncover any research that had sought to test the differential impact of relevant and irrelevant information. For this part of our review, we are therefore very much in the world of ethical / good practice guidelines and legislative requirements.

Clearly, to have any real and meaningful impact, health information must be relevant and accessible to the individual patient or consumers. However, many different issues and concerns can affect the relevance, accessibility and, ultimately, the impact of consumer health information materials, including:

- very diverse patient profiles – with patient groups varying by age, gender, socio-economic status, ethnic and cultural background, language, health literacy and a range of other factors
- consumers' needs for information on a broad range of different issues relating to health conditions and screening / treatment decisions¹⁸
- individuals' changing informational needs over the course of their 'patient journey'
- the quality of the information provided and its consistency across different applications and information channels.

Meeting the needs of the audience

Meeting the needs of the audience is the single most important (and obvious) requirement that information producers must meet if their product is to have any worthwhile impact. Patients and their families certainly need accurate and readable material too, but this is likely to be of little benefit unless it addresses their main requirement for accessible information on topics that speak directly to their particular issues or concerns.

In the past, healthcare professionals have tended to assume that they knew best what information people needed and wanted – with the result that much of what was developed failed to address issues that patients and their families thought important¹⁹.

Meeting users' needs can therefore only be achieved by information producers gaining a very good understanding of consumers' diverse

¹⁸ Coulter A, Entwistle V & Gilbert D (1998) *Informing patients: an assessment of the quality of patient information materials*, King's Fund

¹⁹ NHS Scotland (2003) *Draft Guide to the Production and Provision of Information about Health and Healthcare Interventions*

requirements through engaging them in the process. One systematic review by Nilson and colleagues found evidence from two trials that involving consumers in the development of patient information results in material that is more relevant, readable and understandable, and which can also improve knowledge without affecting anxiety²⁰.

Both the IPDAS guidelines and the Information Standard highlight the value and importance of information producers involving audience at key stages of the process: from deciding what is needed, through to content development, design, dissemination and evaluation.

Principle 3 of the Information Standard requires producers to demonstrate that they have a good understanding of who they are providing information for and why. Information products must be produced appropriately for that specific audience and their needs. They should also be user-tested with the intended audience and finalised in the light of user feedback.

To ensure the necessary engagement with the intended audience, the IPDAS criteria advocate a systematic development process for involving patients, carers and health professionals in the co-design of health information materials. The (amended) criteria also propose that each information product should start with a clear statement of aims – describing its purpose, what it covers and who it is aimed at – to help readers judge whether it is worth their carrying on.

As well as highlighting the importance of involving users, draft guidance produced by NHS Scotland also emphasises the importance of information materials being ‘fit for purpose’ – of being well-designed to meet their particular aims. It is unrealistic to expect one particular information package to cover all aspects of a health condition and potentially relevant treatments in a way that is appropriate for everyone potentially affected²¹.

Information producers will always face difficult judgements about the scope of information materials and how much detail to include. Because too much information on different (or related) subjects could cause confusion, the NHS Brand Guidelines advocate that patient leaflets should be limited to one or two subject areas and associated issues. The guidelines also propose that products should signpost other reliable sources where users can access additional information and support²².

Guidance from the US Office of Disease Prevention and Health Promotion (ODPHP) places similar emphasis on the value and importance of ‘user-centred design’ as an iterative process [develop – test – revise – repeat]. The guidelines suggest that involving consumers in developing online health information can help to generate uncluttered web sites with clearly written content and simple navigation that can dramatically improve the experience of

²⁰ Nilson E, Myrhaug H, Johansen M, Oliver S & Oxman A (2006) Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material, *Cochrane Database of Systematic Reviews*, 2006, Issue 3

²¹ NHS Scotland (2003) *Draft Guide to the Production and Provision of Information about Health and Healthcare Interventions*

²² NHS (undated) *NHS Brand Guidelines: Patient Information*

users. Such co-design is especially valuable in helping people with limited literacy skills to find, understand and use health information on a web site²³. In the absence of such an approach there is a real danger that the flaws of the current health system and existing inequalities could be reinforced or even aggravated online²⁴.

Targeting information

As already noted, people's information needs are very diverse and vary according to their age, sex, socio-economic status, ethnicity, beliefs, preferences and coping strategies. Their information needs also depend on their general literacy, knowledge, skills and abilities and the language they speak at home²⁵.

All patients and carers / families should have equal access to public health services and consumer health information. Since patients vary widely in their individual characteristics, circumstances, attitudes, preferences and beliefs, there can be no 'one size fits all' approach to providing information.

To help ensure equality of access, information producers should consider segmenting their audience into different target groups (with similar needs or characteristics) and tailoring their materials accordingly. Meeting the needs of different groups might involve adjusting the content and tone of information materials, as well as considering the most suitable format for making them available through print and electronic (including audio-visual) media. Again, this reinforces the importance of involving users from the relevant target group(s) in the process of identifying needs, and in developing and evaluating materials.

People who do not read or speak English

People who do not understand or read English often find it difficult to access the information they need. However, making information materials available for people who do not read or speak English usually involves more than a simple translation. It is important to transfer the concepts into a broader cultural sensitivity to ensure that the information will be relevant, useful and acceptable. This means that examples and illustrations might need to be revised as well as words²⁶.

People with sensory impairments

People with sight or hearing impairments or learning difficulties can face particular difficulties accessing information. Under the Disability Discrimination Act, service providers have to make 'reasonable adjustments' to their service to make it more accessible to people with a disability. This means information needs to be available in a range of reading formats such as Braille and audio,

²³ Office of Disease Prevention and Health Promotion (2010) *Health Literacy Online*, US Department of Health and Human Services

²⁴ eHealth Stakeholder Group (2014) *Health inequalities and eHealth*

²⁵ National Voices (2014) *Improving information and understanding*

²⁶ NHS Scotland (2003) *Draft Guide to the Production and Provision of Information about Health and Healthcare Interventions*

as well as in clear or large print²⁷. NHS England is currently consulting on a new accessible information standard that aims to ensure that patients and service users with information or communication support needs relating to a disability, impairment or sensory loss will have those needs met by health and social care services²⁸.

The NHS (through its Brand Guidelines) and a number of other organisations (including the RNIB²⁹, AbilityNet and the UK Association for Accessible Formats) provide helpful guidance on producing accessible information materials (including websites) for people with sight, reading and/or learning difficulties. PiF's Learning Disabilities Resource List also provides links to resources for making information accessible and for communicating with people with learning disabilities.

People with low health literacy

People with low health literacy are another key target group whose needs information producers must address. Health literacy concerns people's ability to read, understand and act upon health information. This is particularly important for patients needing to make complex and difficult treatment decisions, or to give their informed consent.

Around half of the UK population have poor reading and comprehension skills, and around 20% of adults are functionally illiterate. Although anyone can be affected, low health literacy is correlated with age, employment status, social status, financial deprivation and education. Limited health literacy follows a social gradient and can further reinforce existing inequalities. People with limited health literacy most often have lower levels of education, are older adults, are migrants and depend on various forms of public transfer payments³⁰.

Health literacy has very serious implications for health inequalities and outcomes as people with low literacy skills are less likely to adopt positive health behaviours, access screening services, understand their disease or disclose additional health problems. It also limits their capacity to prepare for follow-up appointments and self-care³¹.

However, the desire to receive information and to participate in decision-making is no different for those with low health literacy³². Patient information and education materials must therefore be produced at an appropriate level, utilising different methods and different modes of communication and support (by healthcare professionals and information specialists) to ensure adequate comprehension.

A systematic review by Morrison and colleagues found that low literacy interventions (such as an education booklet) targeted at parents in the US

²⁷ RNIB (2006) *About See it Right*

²⁸ NHS England (2014) *Making health and social care information accessible*

²⁹ RNIB ((2006) *About See it Right*

³⁰ NHS Education for Scotland (2014) Health literacy and health inequalities: Summary Overview

³¹ Manning D & Dickens C (2006) Health literacy: more choice, but do cancer patients have the skills to decide? *European Journal of Cancer Care*, 15: 448-452

³² *ibid.*

likely to have low health literacy can result in decreased use of accident and emergency (A&E) services³³. The research team assessed eight studies investigating the impact of low literacy interventions, four of which were asthma-specific interventions, with the other four relating to general paediatric health. In three of the four general interventions, the distribution of a health education book (with low grade reading levels) led to significant decreases in emergency department utilisation over the following 6-12 months. Morrison and colleagues concluded that targeted health literacy related educational interventions have the potential to reduce repeat A&E visits and healthcare expenditures, and to narrow health disparities by empowering parents with low health literacy to obtain appropriate care for their children.

As well as writing more accessible health information, the presentation of information materials is particularly important for people with low health literacy levels. Health information should be inviting and encourage people to apply it in practice. Visual aids and simple diagrams can help improve accessibility, although sometimes it may be necessary to simplify written instructions³⁴.

However, to fully respond to the needs of people with low health literacy, a range of accessible health information materials is required. For many people, and particularly those with low health literacy, presenting health information in alternative formats may aid understanding. There is clear research evidence that interactive websites, short video clips, audio recordings of consultations, DVDs and other multimedia interventions can be effective in increasing knowledge, satisfaction and patients' ability to make informed decisions^{35, 36, 37}. That said, there is inevitably a concern that those with the greatest need for more accessible health information are the least likely to have access to more advanced technologies³⁸.

Including non-clinical information and patient experiences, where appropriate

The proliferation of health information online and the rapid growth of social media have substantially increased people's ability to access and share personal health experiences online. A 1999 review for the Australian National Health and Medical Research Council (NHMRC) found that people particularly need to hear how others have dealt with similar situations, with evidence

³³ Morrison A, Myrvik M, Brousseau D, Hoffmann R & Stanley R (2013) The relationship between parent health literacy and pediatric emergency department utilization: a systematic review, *Academic Pediatrics*, 13(5): 421-429

³⁴ Hibbard J & Peters E (2003) Supporting informed consumer health care decisions: data presentation approaches that facilitate the use of information in choice, *Annual Review of Public Health*, 24: 413-433

³⁵ Ellins J & McIver S (2009) *Public information about quality of primary care services*, Health Services Management Centre, University of Birmingham

³⁶ Gysels M & Higginson I (2007) Interactive technologies and videotapes for patient education in cancer care: systematic review and meta-analysis of randomised trials, *Supportive Care in Cancer*, Jan; 15(1):

³⁷ Volandes A, Ferguson L, Davis A, Hull N, Green M, Chang Y, Deep K & Paasche-Orlow M (2011) Assessing end-of-life preferences for advanced dementia in rural patients using an educational video: a randomized controlled trial, *Journal of Palliative Medicine*, Feb; 14(2): 169-177

³⁸ Eysenbach G & Diepgen T (2001) The role of e-health and consumer health informatics for evidence-based patient choice in the 21st century, *Clinics in Dermatology*, 19(1): 11-17

showing that consumers value highly presentations of other people's descriptions of their symptoms, their treatment and side effects and how they coped with their illness³⁹.

A number of studies have explored access to and the production of user-generated health content and the impacts this has on personal health experiences. Eysenbach (2003) identified the growing importance of health 'communities' and virtual support groups as a key area of internet use⁴⁰; while Ziebland and colleagues (2004) also highlighted the value to cancer patients (and their families / friends) of seeking online support and experiential information from other patients⁴¹.

More recently, an online survey by O'Neill and colleagues of 1,000 UK internet users found that nearly one quarter (24%) of respondents reported accessing and sharing user-generated health content online. Just over one in five of those doing so accessed or shared personal health information on at least a weekly basis⁴².

In their review of 98 studies, Moorhead and colleagues found that social media are being used increasingly for health communications. 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 surveillance⁴³.

Aside from any concerns regarding reliability and confidentiality, this online explosion of user-generated health stories confirms that many consumers have a strong interest in 'personal experiences' information.

Bunge and colleagues (2010) noted that patient narratives (or testimonials) can be used in consumer health information materials to educate and support patients. In contrast to a statistical message, patient narratives present a definite experience rather than the probability of an experience. Consequently, they are typically considered by consumers to be more concrete, familiar and vivid⁴⁴. This presents the possibility that they might be used by information producers to help make their material more memorable, realistic and comprehensible⁴⁵.

³⁹ National Health and Medical Research Council (1999) *How to prepare and present evidence-based information for consumers of health services: A Literature review*

⁴⁰ Eysenbach G (2003) The impact of the Internet on cancer outcomes, *CA: A Cancer Journal for Clinicians*, 53(6): 356-371

⁴¹ Ziebland S, Chapple A, Dumelow C, Evans J, Prinjha S & Rozmovits L (2004) How the internet affects patients' experience of cancer: a qualitative study, *British Medical Journal*, Mar 6; 328(7439): 564

⁴² O'Neill B, Ziebland S, Valderas J & Lupiáñez-Villanueva F (2014) User-generated online health content: a survey of Internet users in the United Kingdom, *Journal of Medical Internet Research*, Apr 30; 16(4)

⁴³ Moorhead S, Hazlett D, Harrison L, Carroll J, Irwin A & Hoving C (2013) A new dimension of health care: systematic review of the uses, benefits, and limitations of social media for health communication, *Journal of Medical Internet Research*, 15(4)

⁴⁴ Bunge M, Mühlhauser I & Steckelberg A (2010) What constitutes evidence-based patient information? Overview of discussed criteria, *Patient Education and Counseling*, 78: 316-328

⁴⁵ *ibid.*

However, evidence indicates that providing information within personal stories affects the judgments and values people have, and the choices they make, differentially from facts presented in non-narrative prose and/or statistical information⁴⁶.

Decision aids are designed to encourage patients to evaluate relevant information in accord with their own values. There is a concern that the use of narratives within decision aids may reduce their effectiveness to facilitate informed decision-making by biasing the presentation of information and/or discouraging individuals to evaluate systematically the decision-relevant information. It is likely that personal stories encourage the use of more heuristic (rather than systematic) processing. In such circumstances, the context of the message (such as who is delivering the information or their personal characteristics) may be more influential in decision-making than the actual message content (such as information about the risks and benefits of treatment options)⁴⁷.

In their systematic review of primary research, Winterbottom and colleagues found some evidence that narrative information encouraged heuristic processing. However, the researchers consider it is unclear why narratives affect the decision making process, whether they facilitate or bias decision making, and if they affect the quality and/or outcome of the decision being made. Their recommendation was that designers of interventions to facilitate informed decision-making should avoid the use of patient testimonials until there is clearer evidence to explain what type of narrative encourages bias in information processing and decision making and which mechanisms are mediating the effect⁴⁸.

A later study by Entwistle and colleagues (2011) found that people use 'personal experiences' information in various ways to support their decision making, but exercise some discrimination as they do⁴⁹.

Participants reported having used personal experiences information to:

- recognise decisions that need consideration
- identify options
- appraise options and make selections (including by developing and reflecting on their reasoning about possible choices)
- support coping strategies (including living with decisions made).

⁴⁶ Bekker H, Winterbottom A, Butow P, Dillard A, Feldman-Stewart D, Fowler F, Jibaja-Weiss M, Shaffer V & Volk R (2013) Do personal stories make patient decision aids more effective? A critical review of theory and evidence, *BMC Medical Informatics and Decision Making*, 13(Supplement)

⁴⁷ Winterbottom A, Bekker H, Conner M & Mooney A (2008) Does narrative information bias individual's decision making? A systematic review, *Social Science and Medicine*, 67: 2079-2088

⁴⁸ *ibid.*

⁴⁹ Entwistle V, France E, Wyke S, Jepson C, Hunt K, Ziebland S & Thompson A (2011) How information about other people's personal experiences can help with healthcare decision-making: A qualitative study, *Patient Education and Counseling*, 85: e291–e298

Their inclination to use such information was apparently moderated by assessments of personal relevance, the motives of information providers and the 'balance' of experiences presented.

The use of personal experiences information did not replace the need for 'general facts' (the need for which is regarded as self-evident), and the authors warn that care should be taken when it is used in resources for patients. Healthcare providers who offer information about others' personal experiences need to think carefully about what they hope to achieve in terms of supporting decision-making, and what might influence this.

Issues regarding balance and potential bias remain particularly difficult here, and the study findings suggest that information providers need to be especially wary of appearing to 'steer' people by offering particular individuals' experiences as 'role models' to follow.

Entwistle and colleagues recognise that the selection of 'personal experiences' stories for possible inclusion in information resources continues to be challenging: the question of what constitutes an appropriately 'balanced' collection is not easily resolved. However, they do posit one possible 'solution' by suggesting that information providers might usefully explain the range and balance they have sought to achieve and their rationale for including particular examples. They might also help people make appropriately critical use of particular resources and stories by suggesting how and why these resources and stories might be helpful – and perhaps what they are not intended to do.

The systematic review by Bekker and colleagues (2013) examined whether the inclusion of personal stories enhances the effectiveness of patient decision aids to support people make informed decisions. The review concluded that there is insufficient evidence for this, and that more rigorous research is required to elicit evidence about the type of personal story that encourages people to make more reasoned decisions, while discouraging them from making choices based on another's values⁵⁰.

Tailoring and personalising information

A recent study for National Voices assessed the evidence from 85 systematic reviews published since 1998 to summarise the best research evidence available about improving information and understanding. This found that one of the single most important things you can do to improve consumer health information and to increase its impacts is to provide individuals with specific, tailored information and education⁵¹. The review concluded that personalised patient information (reinforced by professional or lay support) leads to:

- improvements in patients' knowledge and understanding of their condition

⁵⁰ Bekker H, Winterbottom A, Butow P, Dillard A, Feldman-Stewart D, Fowler F, Jibaja-Weiss M, Shaffer V & Volk R (2013) Do personal stories make patient decision aids more effective? A critical review of theory and evidence, *BMC Medical Informatics and Decision Making*, 13(Suppl 2)

⁵¹ National Voices (2014) *Improving information and understanding*

- increased sense of empowerment
- greater ability to cope with the effects of illness
- improved patient satisfaction
- and possible improvements in both health behaviour and outcomes.

These findings correspond with the conclusion of our earlier studies for PiF and Macmillan Cancer Support – that consumer health information has the greatest effects when it is tailored (as far as possible) to reflect an individual’s particular needs, preferences and circumstances, throughout their ‘patient journey’^{52, 53}. It is also consistent with the implication of a wide range of psychological theories that, for them to make decisions, patients need information that is relevant to their individual needs (which, unfortunately for information providers, vary considerably from one patient to the next)⁵⁴.

NICE guidance on *Patient experience in adult NHS services* recommends that healthcare services should be individualised as much as possible and tailored to the patient’s needs and circumstances. This includes taking into account personal preferences for the level and type of information they want, in order to give the patient (and their family members and/or carers if appropriate) clear, consistent, evidence-based, tailored information throughout all stages of their care⁵⁵.

While resource constraints may limit the extent to which providers can produce personalised health information tailored to meet individual needs, a number of studies have highlighted the potential benefits of doing so.

- In an updated Cochrane review on screening decisions, Edwards and colleagues (2013) looked at studies that provided personalised risk information for each participant, so that he or she could make a decision about whether to undergo screening, based on their personal risk profile. In assessing 41 studies with 28,700 participants, the review found that when such a personalised risk profile was included in the intervention, the participants made more informed decisions about screening, compared to people who were provided with more general risk information. Overall 45% of participants who received personalised risk information made informed choices as compared to 20% of those who only received generic risk information⁵⁶. The review also found that personalised risk interventions seemed to increase knowledge, may increase accuracy of risk perception in the trial participants, and resulted in a small increase in the number of people who undertook the screening procedure.

⁵² Patient Information Forum (2013) *Making the Case for Information*

⁵³ Coulter A & Ellins J (2007) Effectiveness of strategies for informing, educating, and involving patients, *British Medical Journal*, Jul 7; 35(7609): 24-27

⁵⁴ Feldman-Stewart D, O’Brien M, Clayman M, Davison B, Jimbo M, Labrecque M, Martin R & Shepherd H (2013) Providing information about options in patient decision aids, *BMC Medical Informatics and Decision Making*, 13(Suppl 2)

⁵⁵ NICE (2012) *Patient experience in adult NHS services: full guideline* (CG138)

⁵⁶ Edwards A, Naik G, Ahmed H, Elwyn G, Pickles T, Hood K & Playle R (2013) Personalised risk communication for informed decision making about taking screening tests, *Cochrane Database of Systematic Reviews*, Issue 2

- A systematic review by Skinner and colleagues (1999) found that tailored print communications were consistently better remembered, read, and perceived as relevant and/or credible than non-tailored information. It also found evidence that tailored print communications are more effective for influencing health behaviours⁵⁷.
- A systematic review by Albada (2009) of studies with interventions designed to provide tailored information on cancer risk and screening method showed that personally-tailored risk information improved subjects' knowledge and realistic perception of cancer risk, compared to the provision of generic risk information only⁵⁸.
- In another study looking at different forms of information provision for cancer patients, Jones and colleagues (2006) found that personalised booklets were more likely to tell patients something new. Patients with personalised information were also more likely to share their booklets with others and to think that it helped in discussing their cancer or its treatment⁵⁹.
- A systematic review by Treweek and colleagues (2002) of the impact of computer-generated patient education materials found evidence from one controlled trial that providing patients with computer-generated personal risk profiles (for developing coronary heart disease) led to a significant increase in the proportion of high-risk patients being reassessed at three months⁶⁰.
- A meta-analysis by Wantland and colleagues (2004) of results from 20 studies found substantial evidence that use of web-based interventions improve behavioural change outcomes - including increased exercise time, increased knowledge of nutritional status, increased participation in healthcare, slower health decline and longer-term weight loss maintenance. Interventions that directed the participant to individually tailored materials reported longer web site session times per visit and more visits⁶¹.
- A systematic review by Raynor and colleagues (2007) to establish the role, value and effect of written information available to patients about individual medicines revealed that patients particularly valued

⁵⁷ Skinner C, Campbell M, Rimer B, Curry S & Prochaska J (1999) How effective is tailored print communication? *Annals of Behavioral Medicine*, 21(4): 290-298

⁵⁸ Albada A, Ausems M, Bensing J & van Dulmen S (2009) Tailored information about cancer risk and screening: a systematic review, *Patient Education and Counseling*, 77(2): 155-171

⁵⁹ Jones R, Pearson J, McGregor S, Cawsey A, Barrett A, Craig N, Atkinson J, Gilmour W, McEwen J (1999) Randomised trial of personalised computer based information for cancer patients, *British Medical Journal*, 6 November; 319: 1241-1247

⁶⁰ Treweek S, Glenton C, Oxman A & Penrose A (2002) Computer-generated patient education materials: do they affect professional practice? A systematic review, *Journal of the American Medical Informatics Association*, 9(4): 346-358

⁶¹ Wantland D, Portillo C, Holzemer W, Slaughter R & McGhee EM (2004) The effectiveness of Web-based vs. non-Web-based interventions: a meta-analysis of behavioral change outcomes, *Journal of Medical Internet Research*, 6(4): e40

information that was tailored to their individual circumstances and illness, and that contained a balance of harm and benefit information⁶².

⁶² Raynor DK, Blenkinsopp A, Knapp P, Grime J, Nicolson D, Pollock K, Dorer G, Gilbody S, Dickinson D, Maule A & Spoor P (2007) A systematic review of quantitative and qualitative research on the role and effectiveness of written information available to patients about individual medicines, *Health Technology Assessment*, 11(5)

4 Ensuring accuracy

Key messages

There is general consensus among academics, clinicians and health information producers that consumer health information materials must be based on valid, up-to-date and accurate research evidence.

NHS Brand Guidelines stipulate that information should be evidence-based and up-to-date. The Information Standard requires organisations to have a clearly defined and documented process for information production using only current, relevant, balanced and trustworthy evidence sources.

Finding the best evidence is not always straightforward but there is a consensus that systematic reviews of appropriate studies will provide the highest quality evidence. Information producers need to apply critical appraisal skills and tools to evaluate the trustworthiness and relevance of research evidence.

The development of patient information materials should not be seen as a one-off exercise. It requires a long-term commitment to produce regular updates, to withdraw out-of-date materials from circulation and to maintain an archive of sources.

The clear consensus is that 'honesty is the best policy' and that glossing over or ignoring uncertainty and conflict of interest can be deceptive.

Providing evidence-based risk and benefit information to patients, and ensuring they understand it, forms the cornerstone of informed decision-making. Understanding risk is similarly important for patients to give their consent to treatment.

Despite a substantial and rapidly expanding evidence base – including strong evidence that the format in which risk information is presented affects patients' understanding and perception of risk – there still appears to be limited understanding of how best to present and discuss the risks and benefits of health treatments and screening for an individual.

Introduction

Consultations among PiF members highlighted the importance of ensuring the **accuracy** of consumer health information by:

- creating accurate and evidence-based resources
- including the date of publication and process of review
- being transparent if there is little or no evidence
- communicating risk effectively
- communicating benefits and uncertainties in a non-judgmental and unbiased way

- involving healthcare professionals and other experts in the development of information.

Creating accurate and evidence-based resources

In accordance with the principles of evidence-based medicine and clinical practice, there is general consensus among academics, clinicians and health information producers that consumer health information materials must be based on valid, up-to-date and accurate research evidence.

Accurate, evidence-based information is a cornerstone of high quality consumer information, and both patients and clinicians require reassurance that information materials have been developed according to the highest standards. Poor quality health information has the potential to cause serious harm so there can be “no excuse for palming patients off with unscientific clinical opinion which does not conform to the standards required for evidence-based medicine”⁶³. It is therefore essential that users are provided with sufficient information to check the validity and reliability of the processes employed or developing information materials, including the quality of evidence presented.

Not surprisingly, we found no reviews of studies that had sought to compare the effects of providing reliable, comprehensive and up-to-date health information with providing inaccurate, outdated and/or partial information. While Bunge and colleagues (2010) highlighted a lack of studies on the quality of evidence⁶⁴, a systematic review by Montori and colleagues (2013) found empirical evidence to suggest there is much room for improvement in how developers of patient decision aids identify, summarise and use research evidence to inform the content of their tools⁶⁵. Key concerns identified in reviewing a random sample of decision aids drawn from the Ottawa Decision Aid Inventory⁶⁶ included:

- too lengthy timescales for updating systematic reviews of the evidence
- inadequate (e.g. too narrow, poor quality) sources of evidence or not explicitly citing sources for evidence
- few attempts by developers to convey their degree of confidence in the estimates of effect⁶⁷.

⁶³ Coulter A (1998) Evidence-based patient information is important, so there needs to be a national strategy to ensure it, *British Medical Journal*, 317(7153): 225-22

⁶⁴ Bunge M, Mühlhauser I & Steckelberg A (2010) What constitutes evidence-based patient information? Overview of discussed criteria, *Patient Education and Counseling*, 78: 316-328

⁶⁵ Montori V, LeBlanc A, Buchholz A, Stilwell D & Tsapas A (2013) Basing information on comprehensive, critically appraised, and up-to-date syntheses of the scientific evidence: a quality dimension of the International Patient Decision Aid Standards, *BMC Medical Informatics and Decision Making*, 13(Suppl 2)

⁶⁶ Ottawa Hospital Research Institute, *A to Z inventory of decision aids*, <http://decisionaid.ohri.ca/azinvent.php> [accessed 15 October 2014]

⁶⁷ Montori V, LeBlanc A, Buchholz A, Stilwell D & Tsapas A (2013) Basing information on comprehensive, critically appraised, and up-to-date syntheses of the scientific evidence: a quality

Ethical, quality-of care and scientific arguments justify the requirement to produce only accurate, evidence-based resources as a crucial standard for consumer health information. The (amended) IPDAS criteria require the use of the latest scientific evidence in developing information products to ensure that they contain information in line with the latest clinical evidence.

NHS Brand Guidelines stipulate that information should be evidence-based and up-to-date⁶⁸. The Information Standard requires organisations to have a clearly defined and documented process for information production using only current, relevant, balanced and trustworthy evidence sources. It describes evidence-based practice as the integration of best research evidence with clinical expertise and patient values⁶⁹.

The Information Standard also sets out an explicit process for deriving evidence which includes:

- formulating key questions that need answering
- identifying the types of research and information that would best answer your questions
- identifying the key sources of evidence to search
- devising explicit search strategies for each source of evidence
- critically appraising the evidence collected.

Finding the best evidence is not always straightforward but there is a consensus that systematic reviews of appropriate studies will provide the highest quality evidence^{70, 71, 72}. In general, the hierarchy of studies for obtaining research evidence on the effectiveness of health interventions is:

- systematic reviews of randomised controlled trials
- randomised controlled trials
- controlled observational studies – cohort and case control studies
- uncontrolled observational studies – case reports⁷³.

Expert opinion represents the lowest level of acceptable evidence. In the absence of research evidence, this may sometimes be the best guide available. Generally, however, reliance on the knowledge of individual doctors is not sufficient as a guarantee of reliability⁷⁴. Irrespective of the types of

dimension of the International Patient Decision Aid Standards, *BMC Medical Informatics and Decision Making*, 13(Suppl 2)

⁶⁸ NHS (undated) *NHS Brand Guidelines: Patient Information*, <http://www.nhsidentity.nhs.uk/tools-and-resources/patient-information> [accessed 16 September 2014]

⁶⁹ Information Standard (2013) *The Principles and Requirements Of The Information Standard*

⁷⁰ NHS (undated) *NHS Brand Guidelines: Patient Information*, <http://www.nhsidentity.nhs.uk/tools-and-resources/patient-information> [accessed 16 September 2014]

⁷¹ Picker Institute (2006) *Assessing the quality of information to support people in making decisions about their health and healthcare*

⁷² NHS Scotland (2003) *Draft Guide to the Production and Provision of Information about Health and Healthcare Interventions*

⁷³ Tidy C (undated) *Different Levels of Evidence*, Patient.co.uk

⁷⁴ Coulter A, Entwistle V & Gilbert D (1999) Sharing decisions with patients: Is the information good enough? *British Medical Journal*, 318: 318-322

evidence utilised, information products must clearly state the evidence sources used in compiling the information⁷⁵ so that consumers and other stakeholders can assess their validity and reliability.

The NHS Brand Guidelines suggest that a full list of references should be given wherever practical. Otherwise, full references should be available on request. The guidelines also propose that an archive of sources should be maintained for all information materials, with contact details being given with each product so that people know how to obtain further details of the sources used⁷⁶.

Important sources for evidence

Pre-appraised, high quality sources (such as BMJ Clinical Evidence, Bandolier and NICE Clinical Knowledge Summaries) can be accessed for the latest medical knowledge on conditions and treatments. Information producers also need to be aware of the recommended norms and clinical practice guidelines for the management of different health conditions.

When no relevant guidelines are available, or where the information producer does not wish to rely on any external authority for evidence, the Oxford Centre for Evidence-Based Medicine (CEBM) has defined a hierarchy of the *likely* best types of evidence available on the following key health issues:

- the prevalence of a condition / problem
- the accuracy of diagnostic tests
- prognosis
- treatment benefits and harms
- screening⁷⁷.

This hierarchy is dependent on the particular issue being researched, and the CEBM has recently published a table to identify the best types of evidence potentially available to answer the following types of question:

- How common is the problem
- Is this diagnostic or monitoring test accurate? (*diagnosis*)
- What will happen if we do not add a therapy? (*prognosis*)
- Does this intervention help? (*treatment benefits*)
- What are the common (and rare) harms? (*treatment harms*)
- Is this (early detection) test worthwhile? (*screening*)

For information producers embarking on their own searches, the CEBM website also provides guidance on finding evidence. This emphasises the importance on formulating well-built clinical questions (using the P-I-C-O structure⁷⁸) to make the search easier and more productive.

⁷⁵ Picker Institute (2006) *Assessing the quality of information to support people in making decisions about their health and healthcare*

⁷⁶ NHS (undated) *NHS Brand Guidelines: Patient Information*, <http://www.nhs.uk/tools-and-resources/patient-information> [accessed 16 September 2014]

⁷⁷ OCEBM Levels of Evidence Working Group (2011) *The Oxford 2011 Levels of Evidence*, Oxford Centre for Evidence-Based Medicine

⁷⁸ Centre for Evidence-Based Medicine (undated) *Asking Focused Questions*

Useful sources of evidence include:

- NICE Evidence Search⁷⁹ – publishes Evidence Updates containing the best available evidence on major health conditions, based on systematic and comprehensive searching of the research evidence. It also provides access to clinical guidelines, Cochrane systematic reviews, NICE Clinical Knowledge Summaries and the UK Database of Uncertainties about the Effects of Treatments⁸⁰ (UK DUETs).
- TRIP Database⁸¹ – clinical search engine designed to provide quick and easy access to high-quality clinical research evidence and synopses. It also allows clinicians to search across other content types including images, videos, patient information leaflets, educational courses and news.
- Cochrane Library⁸² – contains high quality systematic reviews.
- Bandolier⁸³ – source of summarised, high quality evidence (from systematic reviews, meta-analyses, randomised trials and high quality observational studies) about the effectiveness (or lack of it) of treatments for a wide range of health conditions.

Whatever sources are accessed for evidence, it is also very important that information producers should apply critical appraisal skills and tools to evaluate the trustworthiness and relevance of research evidence. The Critical Skills Appraisal⁸⁴ (CASP) programme produces training, advice and free checklists for helping to appraise the validity, significance and usefulness of research studies.

Patient.co.uk also summarises the key attributes of high quality research and details some important issues that information producers should consider in appraising particular studies, including: study design and method, results, discussion and conclusions⁸⁵.

Detailing the date of publication and process of review

NHS Brand Guidelines specify certain information and design features which must be applied consistently and correctly across all NHS materials, including corporate information and date of publication.

The Information Standard goes further and stipulates that each information product should clearly display not only the publication date but the last reviewed date and next review due date.

⁷⁹ NICE, Evidence Search, <https://www.evidence.nhs.uk> [accessed 23 September 2014]

⁸⁰ UK Duets, <http://www.library.nhs.uk/duets/> [accessed 23 September 2014]

⁸¹ TRIP, <http://www.tripdatabase.com> [accessed 28 September 2014]

⁸² Cochrane Library, <http://www.thecochranelibrary.com/view/0/index.html> [accessed 28 September 2014]

⁸³ Bandolier, <http://www.medicine.ox.ac.uk/bandolier/index.html> [accessed 28 September 2014]

⁸⁴ Critical Skills Appraisal Programme, <http://www.casp-uk.net> [accessed 15 September 2014]

⁸⁵ Tidy C (undated) *Different Levels of Evidence*, Patient.co.uk

Principle 6 of the Standard requires producers to review their products on a planned and regular basis. It requires organisations to:

- have an information product review process as part of their information production system
- have a planned review schedule for their information products
- have a version control and archiving process in place
- regularly review their information production process and update it, if required.

To ensure that information products are reviewed by their due date, organisations also need to include sufficient time to conduct new searches, analyse any new evidence and to update the product accordingly⁸⁶.

Coulter and colleagues (1999) argue that the development of patient information materials should not be seen as a one-off exercise⁸⁷. It requires a long-term commitment to produce regular updates and to withdraw out-of-date materials from circulation. The authors suggest it would be helpful if materials indicate a 'shelf life', beyond which date readers should be warned to seek alternative sources of information.

By at least including a publication date, it becomes possible for readers to judge whether a product may be likely to contain out-of-date information. Many of the materials Coulter and colleagues reviewed had been in circulation for many years, were indeed out of date, and failed to include information about new treatments or recent research evidence.

Being transparent if there is little or no evidence

Ideally, consumer health information should be based on high quality research evidence. However, this will often be problematic because of gaps and uncertainties in the evidence or a lack of consensus⁸⁸. The Information Standard guidance acknowledges that there will often be situations where the relevant research studies have not been done⁸⁹.

There are various possible options for dealing with uncertainties in the research evidence. The NHMRC suggest information providers might consider:

- providing a grading for the amount of confidence which can be placed on any evidence that is available (e.g. good, reasonable or weak)
- excluding research which falls below a threshold of quality

⁸⁶ Information Standard (2013) *The Principles and Requirements Of The Information Standard*

⁸⁷ Coulter A, Entwistle V & Gilbert D (1999) Sharing decisions with patients: Is the information good enough? *British Medical Journal*, 318: 318-322

⁸⁸ National Health and Medical Research Council (1999) *How to prepare and present evidence-based information for consumers of health services: A Literature review*

⁸⁹ Information Standard (2013) *The Principles and Requirements Of The Information Standard*

- providing details of methods and results and encouraging people to critically appraise it⁹⁰.

Draft guidance from NHS Scotland suggests language and constructs for conveying uncertainty without confusing people. It suggests information producers might consider:

- qualifying statistics with words such as “about”, “roughly”, “approximately” or “on average”
- presenting a range, such as “between 2 and 8 out of every 10 people who are treated...”
- giving an upper or lower boundary, such as “up to 8 out of every 10...”
- use estimates and opinions if necessary, but make it clear that this is what you are doing⁹¹.

The Information Standard also suggests a number of possible approaches to dealing with uncertainty:

- clearly acknowledging uncertainties where these do exist in the absence of high quality research evidence (and which may also be recorded in the UK Database of Uncertainties about the Effects of Treatments)
- basing health information on any research studies that can be identified – for example, reports of single randomised controlled trials – as long as the information makes clear the source and quality of the evidence used
- utilising the best available evidence, including the experience and expertise of healthcare professionals and/or personal experiences information, so long as this is clearly acknowledged
- informing users about any research in progress – this alerts users to uncertainty in the research community and might even offer the patient the practical option of enrolling in a relevant clinical trial⁹².

NHMRC points out that different approaches will not overcome the difficulties inherent in contentious issues when even information produced according to the highest possible standards remains contestable (as, for example, with decisions about screening mammography for women aged 40–49 years). In such instances it seems there is little alternative but to provide the relevant research evidence and reassure consumers that the decision ultimately comes down to how each individual values the potential benefits and risks of intervention⁹³.

⁹⁰ National Health and Medical Research Council (1999) *How to prepare and present evidence-based information for consumers of health services: A Literature review*

⁹¹ NHS Scotland (2003) *Draft Guide to the Production and Provision of Information about Health and Healthcare Interventions*

⁹² Information Standard (2013) *The Principles and Requirements Of The Information Standard*

⁹³ National Health and Medical Research Council (1999) *How to prepare and present evidence-based information for consumers of health services: A Literature review*

The clear consensus apparent in guidelines developed, for example, by the Picker Institute, NHS Scotland and the Information Standard is that 'honesty is the best policy' and that glossing over or ignoring uncertainty can be deceptive.

Patients clearly want information about the full range of potential treatment options, and are likely to be frustrated and suspicious if some options they have heard about are not covered. This could lead them to draw erroneous conclusions about the information they have been given and/or about the new or alternative therapies excluded. Coulter and colleagues conclude that consumers prefer information to cover all options (including treatments that may not be available locally) together with an unbiased assessment of whether or not the treatments are known to be effective⁹⁴.

Communicating risk effectively

Ahmed and colleagues (2012) define risk as the probability that a hazard will give rise to harm. Communicating risk involves providing the patient with a balanced evidence-based summary of the risks and harms associated with a service, test, or treatment.

Risk communication has become an integral part of modern healthcare practice, being an important element in various strategies to assist individuals to make good (personal) choices. Providing evidence-based risk and benefit information to patients, and ensuring they understand it, forms the cornerstone of informed decision-making. Understanding risk is similarly important for patients to give their consent to treatment⁹⁵.

Despite a substantial and rapidly expanding evidence base⁹⁶ – including strong evidence that the format in which risk information is presented affects patients' understanding and perception of risk⁹⁷ – there still appears to be limited understanding of how best to present and discuss the risks and benefits of health treatments and screening for an individual⁹⁸.

NICE guidance on improving patients' experience of NHS services (CG138) provides a helpful, evidence-based summary of key principles for information providers to follow in presenting information about the risks and benefits of health interventions. The guiding principles reflect the findings from a systematic review undertaken to provide evidence on what methods of presenting information improve a patient's understanding of the risks and benefits associated with their treatment options.

⁹⁴ Coulter A, Entwistle V & Gilbert D (1999) Sharing decisions with patients: Is the information good enough? *British Medical Journal*, 318: 318-322

⁹⁵ NICE (2012) *Patient experience in adult NHS services: full guideline* (CG138)

⁹⁶ Trevena L, Zikmund-Fisher B, Edwards A, Gaismaier W, Galesic M, Han P, King J, Lawson M, Linder S, Lipkus I, Ozanne E, Peters E, Timmermans D & Woloshin S (2013) Presenting quantitative information about decision outcomes: a risk communication primer for patient decision aid developers, *BMC Medical Informatics and Decision Making*, 13(Suppl 2)

⁹⁷ Ahmed H, Naik G, Willoughby H & Edwards A (2012) Communicating risk, *British Medical Journal*, 344:e3996

⁹⁸ Edwards A, Naik G, Ahmed H, Elwyn G, Pickles T, Hood K & Playle R (2013) Personalised risk communication for informed decision making about taking screening tests, *Cochrane Database of Systematic Reviews*, Issue 2

CG138 states that healthcare / information providers should use the following principles when 'discussing' risks and benefits with a patient:

- personalise risks and benefits as far as possible
- use absolute risk rather than relative risk (for example, the risk of an event increases from 1 in 1000 to 2 in 1000, rather than the risk of the event doubles)
- use natural frequency (for example, 10 in 100) rather than a percentage (10%)
- be consistent in the use of data (for example, use the same denominator when comparing risk: 7 in 100 for one risk and 20 in 100 for another, rather than 1 in 14 and 1 in 5)
- present a risk over a defined period of time (months or years) if appropriate (for example, if 100 people are treated for 1 year, 10 will experience a given side effect)
- include both positive and negative framing (for example, treatment will be successful for 97 out of 100 patients and unsuccessful for 3 out of 100 patients)
- be aware that different people interpret terms such as rare, unusual and common in different ways, and use numerical data if available
- think about using a mixture of numerical and pictorial formats (for example, numerical rates and pictograms)⁹⁹.

These principles are consistent with findings from other recent reviews undertaken by Bunge and colleagues (2010) to survey quality criteria for evidence-based patient information and to compile the evidence for the identified criteria¹⁰⁰, and by Trevana and colleagues (2013) to summarise best practice in risk communication for developers of patient decision aids¹⁰¹.

Bunge and colleagues also found good evidence that:

- patients have a more accurate perception of risk if the probability of an event occurring is presented as numbers (e.g. 1 in 100) rather than in words (such as "rare", "common" etc.)
- consumers significantly overestimate the risk of side effects when interpreting verbal descriptors¹⁰².

The evidence from the systematic review undertaken by Trevana and colleagues also found that for both written and verbal information, patients have a more accurate understanding of risk if information about probability is

⁹⁹ NICE (2012) *Patient experience in adult NHS services: full guideline* (CG138)

¹⁰⁰ Bunge M, Mühlhauser I & Steckelberg A (2010) What constitutes evidence-based patient information? Overview of discussed criteria, *Patient Education and Counseling*, 78: 316-328

¹⁰¹ Trevana L, Zikmund-Fisher B, Edwards A, Gaissmaier W, Galesic M, Han P, King J, Lawson M, Linder S, Lipkus I, Ozanne E, Peters E, Timmermans D & Woloshin S (2013) Presenting quantitative information about decision outcomes: a risk communication primer for patient decision aid developers, *BMC Medical Informatics and Decision Making*, 13(Suppl 2)

¹⁰² Bunge M, Mühlhauser I & Steckelberg A (2010) What constitutes evidence-based patient information? Overview of discussed criteria, *Patient Education and Counseling*, 78: 316-328

presented as numbers rather than words, even though some may prefer receiving words. Presenting numeric estimates within patient decision aids significantly improves the accuracy of risk comprehension. 'Number needed to treat' is sometimes used to convey probabilities and risk but several studies suggest that this format is poorly understood by patients and may increase the perceived effect of treatment¹⁰³.

Communicating risk in patient information leaflets about medicines

Since 1999, in compliance with EU regulations, it has been a legal requirement that all licensed medical products in the UK are supplied with a patient information leaflet (PIL) if all of the required information cannot be displayed on the outer packaging. The EU Directive¹⁰⁴ governing the provision of full and comprehensible information so that people can use medicines safely and effectively was amended in March 2004 with the introduction of a new legal obligation for all PILs to be subject to user-testing¹⁰⁵.

Having been implemented into UK legislation, the regulations require PILs to present certain pieces of information (including possible side-effects) in a specific order. The European Commission has also published guidance on how to improve the accessibility of the information presented (including formats suitable for blind and partially-sighted patients) and on carrying out consultations with target patient groups¹⁰⁶. The Medicines and Healthcare Products Regulatory Agency has also published a Best Practice Guide on producing PILs¹⁰⁷.

An earlier version of the EU readability guidelines indicated that the frequency of side-effects could be denoted by the use of five verbal descriptions ("very common", "common", "uncommon", "rare", "very rare") as an alternative to numerical incident rates¹⁰⁸. However, a randomised controlled study by Knapp and colleagues (2004) found that these verbal descriptors are not effective in conveying the level of risk of side effects to people taking a medicine¹⁰⁹. Their research showed that the use of the EU-proposed verbal descriptors led patients to think that the given side-effects would be far more frequent than people given the numerical percentage equivalents. Such verbal descriptors also resulted in the overestimation of the level of harm and may lead patients to make inappropriate decisions about whether or not they take the medicine.

¹⁰³ Trevena L, Zikmund-Fisher B, Edwards A, Gaissmaier W, Galesic M, Han P, King J, Lawson M, Linder S, Lipkus I, Ozanne E, Peters E, Timmermans D & Woloshin S (2013) Presenting quantitative information about decision outcomes: a risk communication primer for patient decision aid developers, *BMC Medical Informatics and Decision Making*, 13(Suppl 2)

¹⁰⁴ European Commission (2001) *Directive 2001/83/EC of the European Parliament and of the Council of 6 November 2001 on the Community code relating to medicinal products for human use*

¹⁰⁵ European Commission (2004) *Directive 2004/27/EC of the European Parliament and of the Council of 31 March 2004 on the Community code relating to medicinal products for human use*

¹⁰⁶ European Commission (2009) *Guideline on the readability of the labelling and package leaflet of medicinal products for human use*, Revision 1, 12 January 2009

¹⁰⁷ Medicines and Healthcare Products Regulatory Agency (2012) *Best Practice Guide on Patient Information Leaflets*

¹⁰⁸ European Commission (1998) *Guideline on the readability of the label and package leaflet of medicinal products for human use*

¹⁰⁹ Knapp P, Raynor D & Berry D (2004) Comparison of two methods of presenting risk information to patients about the side effects of medicines, *Quality and Safety in Health Care*, 13:176-180

Despite being highly regulated, disquiet over the variable quality of PILs led to the Committee on Safety of Medicines establishing a Working Group on Patient Information to address concerns. Risk communication was one key area that the Group focused on – evaluating a range of ideas and publishing guideline proposals for presenting information on the risk of side effects. In responding to evidence that the EU guidelines on verbal descriptors are not correctly matched with statistical probabilities, the Group’s proposals on communicating risk highlighted the importance of:

- putting the most important information first
- using the right words to convey an accurate impression of the risk (without being alarmist)
- conveying risk with absolute numbers¹¹⁰.

In using numbers to describe risk, the Group also identified a number of key principles, including:

- Quantifying risk - use of absolute numbers eg 1 in 10,000 patients. If possible, baseline risk and absolute excess risks should be presented.
- Verbal descriptors of risk (eg ‘very rare’) - should only be used if accompanied by the equivalent statistical information. For example: “Very rarely (fewer than 1 in 10,000 patients treated)...”.
- Conveying uncertainty around risk estimates - imprecision of point estimates should be conveyed using terms such as ‘approximately’/‘about’/‘around’ when referring to estimates for major safety issues (for example “about 5 extra cancers for every 1000 patients treated”).
- Frequency ranges - to simplify descriptions, it is preferable to use only the upper bound for each range. For example, use ‘fewer than 1 in every 1,000’ rather than ‘between 1 in 10,000 and 1 in 1,000’.
- Duration of risk - it is important to state the duration over which the excess risk applies if this is known.
- Constant denominators - in some cases, it may sometimes be helpful to express the risk of adverse reactions using a constant denominator rather than a constant numerator. However, this can be confusing, especially when expressing small differences in risk, so user testing is key to ensuring that this concept is understandable.

Further research by Knapp and colleagues (2009) added weight to the growing body of research highlighting the deficiencies in using verbal descriptors for conveying side effect risk, and the strength of using absolute frequency descriptors. However, their study did not find the combination of verbal descriptors and frequency bands to be superior to absolute frequency alone¹¹¹.

¹¹⁰ Committee on Safety of Medicines (2005) *Always Read the Leaflet – getting the best information with every medicine*, Report of the Working Group on Patient Information

¹¹¹ Knapp P, Raynor D, Woolf E, Gardner P, Carrigan N & McMillan B (2009) Communicating the risk of side effects to patients: an evaluation of UK regulatory recommendations, *Drug Safety*, 32(10):837-849

Visual presentation of data

In reviewing the research evidence on the use of visual formats, Trevena and colleagues also found that presenting event rates with visual aids such as pictographs (also called icon arrays), bar charts, or flow diagrams may aid accurate understanding of probabilities.

Evidence suggests that visual displays can help reduce several biases, such as denominator neglect, framing effects, and the undue influence of anecdotes. They also can aid the comprehension of more complicated concepts such as incremental risk.

Although the use of visual displays is often recommended as an aid to interpretation for numerical data, one important caveat is that people vary in their ability to extract data and meaning from such presentations. While visual displays are helpful for understanding statistical information about health for people with low numeracy, people who lack graph literacy may be better off with just numbers. The authors therefore advocate that all visual aids should be pilot tested for understanding (not simply preferences), and that developers should take care to avoid using misleading images (such as graphs with misleading scales) or using different scales within the same product¹¹².

Visualizing Health is a website and project from the Robert Wood Johnson Foundation and the University of Michigan Center for Health Communications Research.

The site was set up to support professionals who need to communicate medical data, develop better and clearer ways to present information and support patients to understand what the data is saying.

The site contains 54 examples of graphic displays of health information that have been evaluated through research among the general public, creating a gallery of accessible graphs, charts, and images that effectively communicate risk information for 16 common 'use cases'. These graphics are distributed via a Creative Commons license, which allows anybody – academics, healthcare organisations, for-profit businesses — to adapt them for their own objectives.

Communicating benefits and uncertainties in a non-judgemental and unbiased way

NICE guidance recommends that patients should be given information and support to promote their active participation in care and self-management. Patients (and their family members and/or carers if appropriate) should be given clear, consistent, evidence-based, tailored information throughout all

¹¹² Trevena L, Zikmund-Fisher B, Edwards A, Gaissmaier W, Galesic M, Han P, King J, Lawson M, Linder S, Lipkus I, Ozanne E, Peters E, Timmermans D & Woloshin S (2013) Presenting quantitative information about decision outcomes: a risk communication primer for patient decision aid developers, *BMC Medical Informatics and Decision Making*, 13(Suppl 2)

stages of their care. This should include, but not be limited to, information on their condition and any treatment options¹¹³.

High quality health information, including patient decision aids, should not seek to steer people to choose one option over another but should help patients to make well-informed decisions in accordance with their personal values and priorities¹¹⁴.

To reach well-informed, quality decisions about their treatment or care, people therefore need accurate, up-to-date, balanced information about all their options (including the option to elect for no treatment) in order to reach a good understanding of the possible benefits, harms and uncertainties associated with different courses of action.

Abhyankar and colleagues (2013) carried out a literature review to examine the theoretical and empirical evidence related to balancing the presentation of health information and options. The attributes of balanced presentation identified by the review were integrated to provide the following definition of balance: “The complete and unbiased presentation of the relevant options and the information about those options - in content and in format - in a way that enables individuals to process this information without bias”¹¹⁵.

The Information Standard reflects the need for objective, unbiased information in requiring information producers to provide a balanced account, reflecting the weight of the available evidence and clearly identifying any uncertainties or unknowns. It also requires producers to make clear and explain any potential conflict of interest – for example, if funding has been provided by a commercial source¹¹⁶.

Similar requirements form part of the (amended) IPDAS criteria for assessing the quality of health information materials. These state the importance of providing unbiased and detailed information about the benefits and risks of options, of describing any uncertainties around the current evidence, and of disclosing conflicts of interest.

In reviewing evidence on dealing with conflict of interest, Barry and colleagues (2013) found a broad consensus in medicine that disclosure of conflicts of interest is desirable in such areas as research publication, guideline development, medical education, and clinical care. Moreover, people generally feel financial ties between clinicians or researchers and industry should be disclosed.

The authors consider that potential for bias in patient decision aids due to conflicts of interest seems as great as in these other areas of healthcare. They also contend that the phenomenon of patients making sub-optimal decisions based on biased information might have even more drastic

¹¹³ NICE (2012) *Patient experience in adult NHS services: full guideline* (CG138)

¹¹⁴ International Patient Decision Aid Standards (IPDAS) Collaboration (2005) *IPDAS 2005: Criteria for judging the quality of decision aid*

¹¹⁵ Abhyankar P, Volk R, Blumenthal-Barby J, Bravo P, Buchholz A, Ozanne E, Vidal D, Col N & Stalmeier P (2013) Balancing the presentation of information and options in patient decision aids: an updated review, *BMC Medical Informatics and Decision Making*, 13(Suppl 2)

¹¹⁶ Information Standard (2013) *The Principles and Requirements Of The Information Standard*

consequences, particularly for “high stakes” decisions about diagnosis and treatment of serious medical conditions. The research team therefore recommends that the requirement to disclose potential conflicts of interest should be retained as a key quality criterion. To ensure that users can readily find disclosure information and be likely to interpret it correctly, Barry and colleagues also recommended that such disclosure information should be “provided prominently and in plain language”¹¹⁷.

Involving healthcare professionals and other experts in the development of information

NHS Scotland suggests that producing good quality information materials should usually be a team effort as it requires a range of skills, including:

- relevant information searching, research and critical appraisal skills
- appropriate information handling, communication and basic media production skills
- relevant clinical knowledge and expertise
- personal experience of the health condition and/or relevant healthcare interventions¹¹⁸.

Coulter and colleagues (2013) lend support to this approach, advocating that a wide range of stakeholders should contribute to the design and development of decision aids. They suggest that the involvement of patients, clinicians, and other relevant experts – for example, patient educators, people with specific expertise in shared decision making or policy makers – can help to facilitate successful implementation by addressing barriers to delivering or using the tools. Clinicians who do not trust or agree with the content of information materials are unlikely to incorporate them in the care pathway or encourage their patients to view them¹¹⁹.

Field-testing and peer review are identified as important elements of the systematic development process for health information materials advocated by the (amended) IPDAS criteria¹²⁰. These propose that draft information materials should be reviewed by patients / family members, by clinicians and by other relevant experts – none of whom should have been involved their development – and be revised accordingly. Current materials should also be revised in the light of patients’ and clinicians’ experience ‘in the field’, and as a result of expert peer review. This accords with the Information Standard

¹¹⁷ Barry M, Chan E, Moulton B, Sah S, Simmons M & Braddock C (2013) Disclosing conflicts of interest in patient decision aids, *BMC Medical Informatics and Decision Making*, 13(Suppl 2)

¹¹⁸ NHS Scotland (2003) *Draft Guide to the Production and Provision of Information about Health and Healthcare Interventions*

¹¹⁹ Coulter A, Stilwell D, Kryworuchko J, Mullen P, Ng C & van der Weijden T (2013) A systematic development process for patient decision aids, *BMC Medical Informatics and Decision Making*, 13(Suppl 2)

¹²⁰ Picker Institute (2006) *Assessing the quality of information to support people in making decisions about their health and healthcare*

specification that the content, context and quality of evidence within health information products must be checked by a suitable peer review¹²¹.

5 Ensuring readability

Key messages

Supporting people's information needs is much more than simply providing health information. It is also about building competence to make health decisions. This 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.

There are various guidelines in place or being developed on producing accessible information, including from NHS England, NHS Wales, The Scottish Government and in online resources such as The Health Literacy Place.

The NHS Brand Guidelines, the (amended) IPDAS criteria and advice from the Plain English Campaign emphasise the crucial importance of using clear, simple language to communicate clearly.

Other important guidance focuses on keeping numbers simple, breaking complex information down and laying out information to aid navigation and creating visually attractive materials. Guidance is available on specific aspects and on ensuring accessibility online.

Many of the elements that improve written and oral communication can be applied to online information, including using plain language, large font, white space, and simple graphics.

Introduction

Consultations among PiF members highlighted the importance of ensuring the **readability** of consumer health information by:

- keeping language and numbers simple, and communicating clearly
- breaking complex information down
- laying out information to aid navigation
- creating visually attractive materials.

As our earlier research for PiF has shown, provision of health information is an important element in improving patients' experience, confidence and engagement. However, the provision of information is not helpful if patients are unable to understand or act upon it.

The earlier discussion on targeting information highlighted the close correlation between ill health and low levels of health literacy. Supporting

¹²¹ Information Standard (2013) *The Principles and Requirements Of The Information Standard*

people's information needs is therefore much more than simply providing health information. It is also about building competence to make health decisions. This 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.

Recent research into health literacy levels across England has shown that health information is generally far too complex. By applying the results of the latest *Skills for Life Survey* in England with an extensive sample of health information materials, an international research team estimated that 42% of people aged between 16 and 65 years would be unable to effectively understand and use everyday health information. This figure rose to 61% when the information also required numeracy skills. These findings suggest that 15 – 21 million people across England are not accessing the information they need to become and stay healthy¹²².

The 'readability' of consumer health information is therefore a key issue for most of the UK population, and the literacy level, language skills, and cognitive capabilities of patients must be considered in all patient information materials. These communication challenges can also be expected to increase as the elder portion of our population grows, and society becomes more culturally and language diverse¹²³.

Accessibility standards and guidance

NHS England is currently developing a new *Accessible Information Standard*¹²⁴ to help ensure that people with particular information or communication support needs because of a disability, impairment or sensory loss get the information they need in an appropriate format, for example in large print, Braille, easy read or via email.

The new guidelines will tell health and social care organisations how they should ensure that people with particular communication and information needs receive the help and support they require – for example, through having a British Sign Language interpreter or an advocate with them. The standard will also set out how organisations should find, write down and share details of people's accessible information and support needs.

NHS Wales has launched new *Standards for Accessible Communication and Information for People with Sensory Loss*¹²⁵. The document sets out the standards of service delivery that people with sensory loss should expect when they access healthcare.

¹²² London South Bank University (2012) *Research led by LSBU academic Professor Gill Rowlands highlights the need to simplify health information* <http://www1.lsbu.ac.uk/php5c-cgiwrap/hscweb/cm2/public/news/news.php?newsid=115> [accessed 16 September 2014]

¹²³ Fox M (2009) A systematic review of the literature reporting on studies that examined the impact of interactive, computer-based patient education programs, *Patient Education and Counseling*, 77(1): 6-13

¹²⁴ NHS England (2014) *Making health and social care information accessible – consultation document*

¹²⁵ NHS Wales (2013) *All Wales Standards for Accessible Communication and Information for People with Sensory Loss*

The Scottish Government has also recently launched a new national health literacy action plan, *Making it Easy*¹²⁶ which highlights the hidden problem of low health literacy and the impact it has on our ability to access, understand, engage and participate in our health and social care.

The action plan sets out an ambition for everyone in Scotland to have the confidence, knowledge, understanding and skills they need to live well, with any health condition.

Under the action plan, the Person-Centred Health and Care Collaborative will support teams to test and implement new ways of working, and to improve the effectiveness of communications – including by:

- checking understanding using the ‘Teach Back’ technique for confirming that people have understood what has been said
- sharing jargon-free copies of clinic and discharge correspondence, which use language that the person can understand
- providing test results in meaningful and accessible formats
- using clear jargon-free oral communication
- tailoring information to people’s needs.

In parallel, *The Health Literacy Place*¹²⁷, an online national health literacy resource, has also been created to:

- provide desktop access to examples of existing good practice, techniques and tools
- generate and disseminate practice-based evidence of emerging effective health literacy innovations, resources and technologies
- provide resources on the themes of Making it Easy, including improving access, collaboration and support for self-management
- create access to a community of practice for those engaged with health literacy developments.

Keeping language and numbers simple, and communicating clearly

Both the NHS Brand Guidelines and the (amended) IPDAS criteria emphasise the crucial importance of using clear, simple language to communicate clearly.

Using ‘plain language’ is a key communication strategy for organising and presenting information so that it is easy to follow and makes sense. Plain language means communication that the listener or reader can understand the first time they hear or read it¹²⁸. This can be defined as a simple, clear, conversational style that uses every day words and an active voice, avoids

¹²⁶ NHS Scotland (2014) *Making it Easy. A Health Literacy Action Plan for Scotland*

¹²⁷ NHS Education for Scotland (2014) *The Health Literacy Place*, <http://www.knowledge.scot.nhs.uk/healthliteracy.aspx> [accessed 14 October 2014]

¹²⁸ World Health Organization (2013) *Health Literacy. The solid facts*

jargon and long and complex sentences, and presents information in a logical order¹²⁹.

While using plain language for written communications is widely recommended, research studies have so far showed only marginal effects. However, one reason for this may be that the included participants did not represent the target audience (i.e. people with lower levels of health literacy) who would be likely to benefit most¹³⁰.

To improve readability, the NHS Brand Guidelines advise information producers to write from the patient's point of view, using everyday language but also avoiding overly simplistic or childish explanations, as well as acronyms and jargon. They also recommend using patient-friendly text (such as personal pronouns like 'we' and 'you'), avoiding language that might cause alarm, and highlighting the availability of alternative formats, for example Braille or audiotape¹³¹.

The NHS Brand Guidelines largely mirror recommendations (not rules) made by the Plain English Campaign. While recognising the need for flexibility, the Campaign also advises:

- using short sentences – a good average sentence length is 15 to 20 words
- ensuring longer sentences do not have more than three items of information – otherwise they get overloaded, and readers lose track
- using 'active' verbs mainly, not 'passive' ones – for example, "We will send a report to your doctor" (active), rather than "A report will be sent to your doctor" (passive)¹³².

However, language that is plain to one set of readers may not be so clear to others. This underlines the critical importance of knowing your audience and having them test information materials before, during, and after they are developed¹³³.

Reflecting the findings of research by Coulter and colleagues (1998), the NHS Scotland guidance emphasises the importance of information also striking the right 'tone'¹³⁴. Patients prefer information that is honest, constructive, positive, realistic, practical, not condescending and non-alarmist¹³⁵. In providing

¹²⁹ Bunge M, Mühlhauser I & Steckelberg A (2010) What constitutes evidence-based patient information? Overview of discussed criteria, *Patient Education and Counseling*, 78: 316-328

¹³⁰ *ibid.*

¹³¹ NHS (undated) *NHS Brand Guidelines: Patient Information*, <http://www.nhsidentity.nhs.uk/tools-and-resources/patient-information> [accessed 16 September 2014]

¹³² Plain English Campaign (2001) *How to write medical information in plain English*

¹³³ Office of Disease Prevention and Health Promotion (2014) *Quick Guide to Improving the Usability of Health Information*, US Department of Health and Human Services

¹³⁴ NHS Scotland (2003) *Draft Guide to the Production and Provision of Information about Health and Healthcare Interventions*

¹³⁵ Coulter A, Entwistle V & Gilbert D (1998) *Informing patients: an assessment of the quality of patient information materials*, King's Fund

information about prognoses with or without treatment, it is better to avoid being either overly optimistic or overly pessimistic¹³⁶.

Keeping numbers simple

Health information producers must also take account of the fact that many people have poor numeracy skills, and most people are unlikely to be adept at manipulating risk reduction information. The earlier section on ‘communicating risk effectively’ presented detailed guidelines and advice for keeping numbers as clear and simple and possible.

The same section also reviewed the use of visual formats for presenting numeric data. A systematic review by Sheridan and colleagues (2011) found evidence that presenting numerical information in tables rather than text, and adding icon arrays to numerical information, can both improve comprehension and help to mitigate the effects of low health literacy¹³⁷.

Breaking complex information down

The order in which information is presented can affect understanding. The review by Sheridan and colleagues (2011) suggests that presenting essential information by itself or first can improve comprehension. The evidence for this stems from randomised controlled trials conducted by Peters and colleagues (2007) to examine whether information presentation methods differentially influence consumers who differ in numeric skills. Their results support the idea that “less is more” when presenting consumers with comparative performance information to make hospital choices. Results were particularly strong for those with lower levels of numeracy. When provided with less information, respondents were better able to comprehend important cost and quality information, and they were more likely to choose a higher-quality hospital. Ordering information from more to less important had similar (but slighter lesser) effects¹³⁸.

The Plain English Campaign advocates using bullet points to help break complex information down. Breaking text up into logical ‘stepping stones’ makes it easier for the reader when there is a lot of information to convey¹³⁹. The NHS Brand Guidelines also suggest breaking text down into smaller blocks – using headings, paragraph breaks and/or a question and answer format to divide information up.

¹³⁶ NHS Scotland (2003) *Draft Guide to the Production and Provision of Information about Health and Healthcare Interventions*

¹³⁷ Sheridan S, Halpern D, Viera A, Berkman N, Donahue K, Crotty K (2011) Interventions for individuals with low health literacy: a systematic review, *Journal of Health Communication*, 16 (Suppl 3): 30-54

¹³⁸ Peters E, Dieckmann N, Dixon A, Hibbard J & Mertz C (2007) Less is more in presenting quality information to consumers, *Medical Care Research and Review*, 64(2), 169-190

¹³⁹ Plain English Campaign (2001) *How to write medical information in plain English*

Using images in a document can also support what is being said in the text and help to convey more complex information. AbilityNet advise that the use of appropriate images can often help readers with dyslexia and learning difficulties to follow what is happening in the text. However, the placement of images on the page should be carefully considered. Images placed in a random way can interrupt the flow of the text and make it even harder to follow. Information producers should consider placing images at the end of paragraphs and allow for space between the text and the image¹⁴⁰.

The review by Bunge and colleagues (2010) identified a number of studies that have demonstrated the effectiveness of visual illustrations in improving patients' knowledge and understanding, However, there are differences for the various types of pictures, and the authors concluded that clear and simple drawings which support textual information should be preferred. The same researchers also found evidence that involving consumers in the development of health information resulted in material that had more illustrations and was more readable¹⁴¹.

Laying out information to aid navigation

The presentation and layout of health information materials can facilitate reading and supports comprehension. Many recommendations exist to encourage high quality design and layout in the production of consumer health information, although no studies have been identified comparing information materials which only varied in their presentation.

As PiF's own guide to designing information states, typography is very important in design – its style, size, and layout can change the way somebody views a piece of work. Also, the layout and formatting of type can affect the understanding of any written work. For healthcare literature the key attributes are usually that it should be clear, readable and feel trustworthy.

Although there are keen debates about the relative merits of serif and sans-serif typefaces, there is little academic evidence to suggest that either is more or less readable than the other. Other typographical factors such as size, line length, justification, paragraph spacing and hyphenation all play a larger part in making text easy to read and understand¹⁴².

The NHS Brand Guidelines for design and layout are quite comprehensive. In addition to aspects already referred to above, they advocate the use of:

- Lowercase letters: are easier to read.
- White space: makes information easier to read.

¹⁴⁰ AbilityNet (undated) *Producing accessible materials for print and online*

¹⁴¹ Bunge M, Mühlhauser I & Steckelberg A (2010) What constitutes evidence-based patient information? Overview of discussed criteria, *Patient Education and Counseling*, 78: 316-328

¹⁴² Patient Information Forum (undated) *Designing information*, <http://www.pifonline.org.uk/topics-index/producing/designing-information/> [accessed 10 September 2014]

- Large bold font: very useful for highlighting and emphasising text, whereas uppercase letters, italics and underlining can make text more difficult to read.
- Numbers as words: from one to nine, numbers are easier to read (in normal text) if they are written as words. From 10 onwards, they should be represented as numbers¹⁴³.
- Font size of at least 12 point: any smaller than this, and text becomes difficult to read.
- Diagrams and pictures: can be very effective for illustrating and enhancing text. Make sure that all imagery you use supports our communications principles. You should clearly label all individual pictures and diagrams, but avoid printing over them. And never use clip-art, as this can detract from our professional reputation.

NHS information producers in England should also apply the following design principles to all documents:

- Use clear, legible print with well-spaced lines: this will make documents easier to read. This is particularly important, as a large number of people using the NHS are over the age of 40.
- Always use 14 point font size or larger if your materials are intended for an elderly audience.
- Use Frutiger Roman for professionally produced materials. If this is not available, use Arial instead.
- For the best print contrast, set dark print against a light background.
- You can use white print reversed out of a dark background for headings, but not for large sections of text.
- Always justify text to the left.
- To reduce print and production costs, use one or two colours only.
- Don't write text over background pictures, images or design features.
- Leave sufficient space between paragraphs and don't crowd a page with text.
- Make sure all headings are clear¹⁴⁴.

The above guidelines are consistent with the RNIB's Clear Print guidelines¹⁴⁵ (based on the organisation's own research) for maximising the legibility of printed materials.

¹⁴³ It is important to remember these are not strict rules. Risk communications and prescriptions information, for example, commonly present numbers below 10 as numerals (e.g. the risk is 1 in 100; take 2 tablets 4 times a day).

¹⁴⁴ NHS (undated) *NHS Brand Guidelines: Patient Information*, <http://www.nhsidentity.nhs.uk/tools-and-resources/patient-information> [accessed 16 September 2014]

¹⁴⁵ The RNIB's Clear Print guidelines are summarised by the Sensory Trust at http://www.sensorytrust.org.uk/resources/connect/infosheet_clearlargeprint.pdf [accessed 18 September 2014]

The RNIB have also produced Large Print guidelines as an alternative format to help meet the needs of many of the two million people living in the UK with a sight problem. Large Print is defined by the RNIB as being 16pt Arial or bigger. Other requirements are that:

- Large Print documents should also conform to other Clear Print guidelines concerning layout, use of fonts and images
- the length of text should be reduced as much as possible because reading long documents, even in Large Print, can be tiring for people with low vision
- if a Large Print version of a product is available, this should be clearly displayed at the beginning or on front, in text that conforms to Large Print standards¹⁴⁶.

Improving the accessibility of websites

The US Office of Disease Prevention and Health Promotion (ODPHP) has produced a helpful guide that presents six 'strategies' (or steps) for writing and designing health websites that are accessible to users with limited literacy skills. Each strategy includes actions, examples, and iterative design methods and tips on:

1. Learning about your users and their goals
2. Writing actionable content
3. Displaying content clearly on the page
4. Organising content and simplifying navigation
5. Engaging users with interactive content
6. Evaluating and revising your site¹⁴⁷.

More recently, the ODPHP has published a *Quick Guide to Improving the Usability of Health Information*, including on the internet. This notes that many of the elements that improve written and oral communication can be applied to online information, including using plain language, large font, white space, and simple graphics.

Other elements are specific to the internet, and include:

- enhancing text with video or audio files
- including interactive features and personalised content
- using uniform navigation
- organising information to minimise searching and scrolling
- giving users the option to navigate from simple to complex information.

¹⁴⁶ Sensory Trust (undated) *Accessible information – clear and large print*, http://www.sensorytrust.org.uk/resources/connect/infosheet_clearlargeprint.pdf [accessed 27 September 2014]

¹⁴⁷ Office of Disease Prevention and Health Promotion (2010) *Health Literacy Online*, US Department of Health and Human Services

The ODPHP also advise that a critical way to make information on the Internet more accessible to people with limited literacy and health literacy skills is to apply user-centered design principles and conduct usability testing¹⁴⁸. The RNIB has also developed its own approach – the *Surf Right* standard – to ensuring the accessibility of websites. This was developed after carrying out research aimed at addressing the most important challenges faced by disabled people in accessing information online. Most of the guidance and requirements that need to be met to reach the Surf Right standard are based on the World Wide Web Consortium (W3C) Web Accessibility Initiative (WAI) recommendations¹⁴⁹.

AbilityNet has also published some key design points to make websites more accessible for people with disabilities:

- Include a proper heading structure – a heading structure such as ‘h1, h2’ etc. will allow screen reader users to easily navigate around the page.
- Text should be of a good default size and resizable – when text is resizable ensure it does not overlap onto surrounding content.
- Important images should have alternative text while cosmetic images should be assigned an empty alt attribute. Avoid using images of text as these cannot be re-sized.
- Clear and easy to follow keyboard focus, allowing keyboard only users to follow their progress around the webpage.
- Ensure good colour contrast between text and background colour.
- Provide a site map and accessibility page¹⁵⁰.

Creating visually attractive materials

Bunge and colleagues (2010) emphasise how high quality design and layout of information materials can facilitate reading and support comprehension¹⁵¹. The influence of the graphical design of health information, regardless of the medium, is as important as the role of the content in producing something accessible, usable and meaningful for patients and the public.

Good design can help you to:

- control the flow of information: take the patient on a journey where the content flows and has meaning and which ends with understanding
- bring a subject to life and make the information engaging and interesting
- shape a message to suit different audiences

¹⁴⁸ Office of Disease Prevention and Health Promotion (2014) *Quick Guide to Improving the Usability of Health Information*, US Department of Health and Human Services

¹⁴⁹ RNIB (undated) Surf Right standard, <http://www.rnib.org.uk/about-rnib/web-accessibility-statement> [accessed 20 September 2014]

¹⁵⁰ AbilityNet (undated) *Producing accessible materials for print and online*

¹⁵¹ Bunge M, Mühlhauser I & Steckelberg A (2010) What constitutes evidence-based patient information? Overview of discussed criteria, *Patient Education and Counseling*, 78: 316-328

- present your audience with a consistent message and branding – about who you are and what you are all about
- inspire confidence and trust in you and your organisation¹⁵².

Appendix 1 – Amended IPDAS criteria – Picker Institute, 2006

Criteria for assessing the content of health information materials

Does the information leaflet / website

Start with a clear statement of aims?

- Describes its purpose (e.g. to aid decision-making).
- Describes what it covers (to help the reader judge whether it's worth carrying on).
- Describes who it is for (i.e. which patient groups).

Provide unbiased and detailed information about options?

- Describes the health condition.
- Describes the natural course without treatment.
- Lists the treatment/management/lifestyle options.
- Describes benefits of options.
- Describes risks options (harms/side-effects/disadvantages).
- Describes uncertainty around the current evidence (i.e. what is not known).
- Describes procedures (ie treatments, targets, monitoring, behaviour change, etc.).

Present probabilities of outcomes in an understandable way?

- Uses event rates specifying the population and, if appropriate, time period.
- Compares outcome probabilities using the same numerator/denominator, time period, scale (i.e. if numerators/denominators, time periods or scales are used, they need to be consistent).
- Uses visual diagrams and/or places probabilities in context of other familiar events.

Contain accurate information?

- Clearly states the evidence sources used in compiling the information.
- Information quoted is in line with the most up-to-date clinical evidence.
- Where mentioned, prevalence estimates give an accurate impression of how common/rare the condition is.
- Personal opinion and/or advertising are clearly distinguished from evidence-based information.

Help patients to make appropriate decisions?

- Acknowledges (explicitly or implicitly) that the patient has decisions to make.
- Helps patients to imagine what it is like to live with the condition and/or treatment effects.

¹⁵² Patient Information Forum (undated) *Designing information*, <http://www.pifonline.org.uk/topics-index/producing/designing-information/> [accessed 10 September 2014]

- Asks patients to consider factors (e.g. priorities, motivations, treatment outcomes) affecting possible courses of action.
- Suggests ways and/or provides tools to help patients make decisions.

Disclose conflicts of interest?

- Includes authors' / developers' credentials or qualifications.
- Reports source of funding to develop and distribute the patient decision aid.

Have a clear structure and layout?

- Is consistent in design and layout throughout.
- Includes aids to finding information (e.g. contents, index, site map, or search facility).
- Important points are emphasised through the use of summaries and/or bullet points.
- Illustrates information with diagrams and/or pictures.
- Where diagrams appear, they are labelled and relate to the subject matter.
- Sections are clearly separated.

Help the reader judge its reliability?

- Reports date of publication.
- Includes sources of further information.

Criteria for assessing the development process for health information materials

Does the information leaflet / website

Use a systematic development process?

- Finds out what information users (e.g. patients, carers, professionals) need to discuss options or decide on courses of action.
- Involves users throughout the development process (e.g. assessing information needs, selecting topics).
- Has materials field tested by patients/carers not involved in development.
- Has materials peer reviewed by patients/carers not involved in development.
- Has materials reviewed by professional experts not involved in development.
- If necessary, revise materials based on field testing and/or peer review.

Use up to date scientific evidence?

- Reviews the clinical research evidence and use systematic reviews where available.
- Has a procedure for regularly revising and updating information.

Address usability issues?

- Written at a level that can be understood by the majority of patients in the target group (e.g. tested using SMOG/Fry, received Crystal Mark or produced a glossary).
- Provides additional ways to help patients understand the information other than reading (e.g. audio, video).
- Field testing involves groups of patients with different needs and abilities.

Have a dissemination plan?

- Plan for how users will access the information.
- Plan for how clinicians will be informed about it.
- Plan for integrating it into clinical care.

Appendix 2 – The DISCERN Criteria

Generally, the instrument requires users to indicate whether certain criteria are true – answering on a scale of 1-5, corresponding to answers of No, Partially or Yes. Hints are given to help users make their judgement.

Section 1 Is the publication reliable?

1 Are the aims clear?

Look for a clear indication at the beginning of the publication of:

- what it is about
- what it is meant to cover (and what topics are meant to be excluded)
- who might find it useful.

2 Does it achieve its aims?

Consider whether the publication provides the information it aimed to as outlined in Question 1.

3 Is it relevant?

Consider whether:

- the publication addresses the questions that readers might ask
- recommendations and suggestions concerning treatment choices are realistic or appropriate.

4 Is it clear what sources of information were used to compile the publication (other than the author or producer)?

Check whether the main claims or statements made about treatment choices are accompanied by a reference to the sources used as evidence (e.g. a research study or expert opinion).

Look for a means of checking the sources used such as a bibliography/reference list or the addresses of the experts or organisations quoted.

5 Is it clear when the information used or reported in the publication was produced?

Look for:

- dates of the main sources of information used to compile the publication
- date of any revisions of the publication (but not dates of reprinting)
- date of publication (copyright date).

6 Is it balanced and unbiased?

Look for:

- a clear indication of whether the publication is written from a personal or objective point of view
- evidence that a range of sources of information was used to compile the publication (e.g. more than one research study or expert)
- evidence of an external assessment of the publication.

Be wary if:

- the publication focuses on the advantages or disadvantages of one particular treatment choice without reference to other possible choices

- the publication relies primarily on evidence from single cases (which may not be typical of people with this condition or of responses to a particular treatment)
- the information is presented in a sensational, emotive or alarmist way.

7 Does it provide details of additional sources of support and information?

Look for suggestions for further reading or for details of other organisations providing advice and information about the condition and treatment choices.

8. Does it refer to areas of uncertainty?

Look for discussion of the gaps in knowledge or divergences in expert opinion concerning treatment choices.

Be wary if the publication implies that a treatment choice affects everyone in the same way (e.g. 100% success rate with a particular treatment).

Section 2 How good is the quality of information on treatment choices?

N.B. The questions apply to the treatment (or treatments) described in the publication. Self-care is considered a form of treatment throughout this section.

9 Does it describe how each treatment works?

Look for a description of how a treatment acts on the body to achieve its effect.

10 Does it describe the benefits of each treatment?

Benefits can include controlling or getting rid of symptoms, preventing recurrence of the condition and eliminating the condition - both short-term and long-term.

11 Does it describe the risks of each treatment?

Risks can include side effects, complications and adverse reactions to treatment - both short-term and long-term.

12 Does it describe what would happen if no treatment is used?

Look for a description of the risks and benefits of postponing treatment, of watchful waiting (i.e. monitoring how the condition progresses without treatment) or of permanently forgoing treatment.

13 Does it describe how the treatment choices affect overall quality of life?

Look for:

- description of the effects of the treatment choices on day-to-day activity
- description of the effects of the treatment choices on relationships with family, friends and carers.

14 Is it clear that there may be more than one possible treatment choice?

Look for:

- a description of who is most likely to benefit from each treatment choice mentioned, and under what circumstances
- suggestions of alternatives to consider or investigate further (including choices not fully described in the publication) before deciding whether to select or reject a particular treatment choice.

15 Does it provide support for shared decision-making?

Look for suggestions of things to discuss with family, friends, doctors or other health professionals concerning treatment choices.

Section 3 Overall rating of the publication

16 Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices

Low (serious or extensive shortcomings)

Moderate (potentially important but not serious shortcomings)

High (minimal shortcomings).

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