



# Patient Information Forum

*For Professionals Working in Consumer Health Information*

## A beginner's guide to planning and developing high quality health information

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Developing and maintaining high quality health consumer health information requires careful organisation and planning.

This practical guide will help you to achieve success in producing quality health information materials. It references the accreditation requirements of 2.0 of The Information Standard - 'The Principles and Requirements of the Information Standard Assessment' (December 2013).

**PiF is a non-profit organisations working to improve the quality and accessibility of health information for patients and public across the UK. Our work involves focuses on delivering resources and events for information producers, influencing to raise the profile of health information, and bringing together those interested in the field of health information via the PiF network. You can find out more at [www.pifonline.org.uk](http://www.pifonline.org.uk) .**

Building on extensive research conducted for PiF, our guide reflects good practice and the best available evidence on what works best in developing relevant, meaningful and accessible health information that supports patients, and their carers or families, to act.

More detailed information and resources on the different steps outlined in this guide can be found on PiF's Toolkit which contains best practice guidance and key steps.

This Guide was produced for PiF by [Grant Riches](#), a communications consultancy with expertise in the health and social care sector. They also carried out the literature review that informed the development of PiF's best practice to create health information that works.

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# 1 Introduction

## 1.1 Scope of the guide

Health information may be produced in a wide variety of formats for many different purposes, and this guide cannot be a comprehensive manual covering every possible context or potential output.

It focuses primarily on the production of written information about health conditions and treatment options that patients may either access themselves or be given as part of their care.

You may need, therefore, to adapt the principles and approach advocated here to suit your particular purposes and circumstances.

The evidence and references referred to in this Guide can be found in the evidence review ['What does good information look like?'](#)

## 1.2 Key attributes of consumer health information

Various organisations and experts have sought to identify the key attributes of high quality patient information. Taken together their findings assert that patient information:

- should not be influenced by financial or intellectual interest
- should be developed together with patients / users

- should be based on the best available evidence
- should communicate levels of evidence and/or strength of recommendations
- should convey a realistic idea of any health condition (neither exaggerate nor trivialise)
- should describe all treatment options with their risks and benefits – communicating these in an understandable way, and referring to patient-centred outcomes (e.g. mortality, morbidity and quality of life).
- should address uncertainties like weak or missing evidence
- should be easy to read, understandable and accessible.

## 1.3 Structure of the guide

High quality information cannot be produced by accident – it requires purposeful planning and organisation, and effective teamwork. The production process is no less important than the content and is given equal weight in the principles and requirements of the Information Standard.

Our guide reflects this understanding – with the first main section looking at the process for developing consumer health information materials, and the second focusing on their content.

## 2 The process for developing high quality health information for patients and the public

### 2.1 Follow a systematic development process

#### 2.1a Have a clearly defined and documented process for developing your information

To satisfy Principle 1 of The Information Standard, you must have a documented process for producing your consumer health information. This should include details of your approval process and how final versions of your products will be authorised for publication.

This principle is designed to ensure that your information materials are produced to a consistently high standard. Everyone involved in the information production process should understand and be trained to follow your process.

There are a range of approaches you could use to define and document your process (for example, a flow chart or manual). For The Information Standard accreditation the approach you chose will need to make clear how you will meet the other key principles:

- only use current, relevant, balanced and trustworthy evidence sources – Principle 2
- understand user needs and to user-test your information – Principle 3
- double-check your end products – Principle 4
- manage feedback appropriately – Principle 5

- review your products and process on a planned and regular basis – Principle 6.

#### 2.1b Create resources that have a specific purpose

Health information is produced for a wide variety of purposes, including to:

- increase knowledge and understanding of a disease, health condition or treatment
- support patients in making complex and difficult treatment decisions
- increase ‘patient activation’
- enable people to participate in shared decision making
- assist in ensuring informed consent
- facilitate and support greater self-management and self-care
- encourage the adoption of positive health behaviours
- promote access to screening services
- help people identify / disclose health problems and relevant details
- improve skills in coping

- increase confidence
- signpost sources of more information and support.

Before going too far in developing any information product it is important to have a clear idea about exactly what it is you are trying to achieve. What is your information about? Who is it for? And what do you want users to do or be able to do once they have seen it?

### 2.1c Add value to the health information that already exists

Before developing a new resource, you need to be aware of the wider information environment so you can be confident that it will add value to information currently available.

You should consider whether what you might be thinking of producing will fill an information gap – or complement related resources that might already be produced by your own organisation or be available more widely.

## 2.2 Engage all key stakeholders in developing your information

### 2.2a Understand users' information needs

To ensure that your information materials are meaningful and have impact, you should make users' information needs and perspectives the starting point for planning your health information.

Where an important information gap is identified, it might not always be necessary to produce an entirely new resource. Where possible, and with permission and appropriate acknowledgement, you should consider adapting existing quality resources (such as those produced by many specialist charities) to make them suitable for your intended audience.

If you re-use another Information Standard organisation's approved information, you must:

- cross-reference that organisation's name
- state the production or last review date
- and give the date for the next review of the source material.

It is best practice, and in many cases a legal requirement, to get the permission of the producing organisation before adapting or reproducing existing information resources and tools

Producing good quality health information takes a lot of resources – skills, time and money – so you need to be sure that new information is needed before committing yourself to its production.

Good information already exists in many areas so you should focus the development of any new materials on:

- topics that are not already covered by existing information

- topics for which only poor quality information currently exists
- the needs of people who are not well served by the range of current materials.

Understanding users' needs is a key requirement of the Information Standard (Principle3). Feedback from potential information users – including through patient groups, surveys, comments forms, complaints, social media and research papers – can help you to decide on the need for new (or revised) information.

Health care professionals and other key stakeholders – such as charities, community groups, pressure groups and patient representatives – can also help you to establish information requirements and priorities, including potential target groups.

## **2.2b Involve users in developing your resources**

Involving users in developing your health information is an important step and results in materials that are more relevant, accessible and understandable. Users should be involved throughout the whole process – from deciding what is needed, through to content development, design, dissemination and evaluation.

Beginning with the user's perspective will help you to:

- understand the key characteristics of your intended audience and their 'patient journey'

- clarify the particular information needs, current knowledge and beliefs of your target audience, and to tailor your information accordingly
- decide on the appropriate media / format(s) for presenting your information to ensure that it will be accessible to your audience
- understand the context in which your information will be used
- where appropriate, provide information at a range of detail and levels of complexity.

Users also have a vital role in user-testing your developing information resources to ensure they achieve their purpose and that key messages are understood. Principle 3 of the Information Standard requires producers to show how they have taken account of user feedback in finalising their materials.

## **2.2c Engage clinical experts in developing and your information**

Health care professionals and other experts should also be engaged in developing and disseminating your information resources. 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 media production skills
- relevant clinical knowledge and expertise

- personal experience of the health condition or relevant interventions.

Although it may be possible to buy in certain types of advice on a consultancy basis, it is important to ensure that everyone in your 'core team' has a clear understanding of their role and is fully committed to the process and timescale.

As well as improving the relevance and quality of information, involving relevant health care professionals in the production process should also help to facilitate its successful implementation by addressing potential barriers to delivering or using your products.

#### **2.2d Provide health information in a choice of accessible formats, informed by user involvement**

It is crucial that health information materials can be understood and acted upon by the majority of people in your target audience. You should therefore try to establish target users' abilities and preferences for accessing information at the initial planning stage.

For many people, and particularly those with low health literacy, presenting health information in alternative formats may improve understanding. Evidence shows that interactive websites, short video clips, audio recordings of consultations, DVDs and other multimedia interventions can all be effective in increasing knowledge, satisfaction and patients' ability to make informed decisions. However, some of those with the greatest need for more accessible health information may not have access to the technology to use it.

Involving users from the outset will help you make decisions about the most appropriate format(s) for your new information products.

#### **2.2e Carry out user-testing and peer review**

User-testing and peer review are also key areas for involving target users and other key stakeholders.

Draft information materials should be field-tested by patients and carers that have not been involved in their development. Feedback should be sought on the content, tone, style, and presentation of your products, with appropriate changes being made to final versions to ensure they achieve your stated aims. Submitting your information for user-testing by representatives of your target group should assist you in addressing any health literacy concerns.

Your developing information products must also be subject to peer review by clinicians and other relevant experts – again, none of whom should have been involved their development – and be revised accordingly. This accords with Principle 2 of the Information Standard which specifies that the content, context and quality of evidence within health information products must be checked by a suitable peer reviewer.

Current materials should also be reviewed in the light of both patients' and clinicians' experience 'in the field'.

## **2.2f Manage and respond to feedback on your products**

You should include appropriate contact details on all your information materials so that people are able to submit comments and complaints about them or their use. This mechanism is especially helpful for you to be informed of any inaccurate, outdated or missing information in your products.

## **2.3 Produce current and reliable information**

### **2.3a Only use up-to-date, trustworthy evidence sources**

Your defined approach to producing health information should set out the explicit process you will follow to obtain the highest quality evidence available.

According to the Principle 2 of the Information Standard, this should include:

- 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.

Irrespective of the types of evidence utilised, information products must clearly state the evidence sources used in compiling the

Principle 5 of the Information Standard requires that you both record any feedback received and have a standard procedure for responding to this. Your process should include feeding back to the ‘complainant’ how their comment is being addressed, and also amending or updating your products (or processes) where deemed necessary.

information so that stakeholders can assess their validity and reliability. Any areas of uncertainty should be appropriately identified and honestly addressed.

A full list of references should be given wherever practical or, otherwise, be available on request. 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 and evidence used.

### **2.3b Disclose conflicts of interest**

Your resources should clearly state who was involved in the production of your information, and make clear any possible conflicts of interest. Details should also be given of funding sources for developing and distributing your materials.



### 2.3c Double-check your products before publication

Another key requirement of the Information Standard (Principle 4) is that you must double-check your products prior to publication to ensure that they satisfy all the requirements of the Standard and meet best practice standards.

The guidelines for Principle 4 include quite detailed system and product checklists. To achieve accreditation, you must be able to provide evidence that you have addressed each point in these checklists for all your information products.

### 2.3d Review your products and process on a planned and regular basis

The development of patient information materials requires a long-term commitment to produce regular updates, to withdraw out-of-date materials from circulation, to implement version control, and to maintain an archive of sources. Information producers should aim to stay up-to-date with developments in the evidence base.

## 2.4 Have an effective dissemination plan

### 2.4a Plan how users will access your information

There is no point in producing high quality health information unless it reaches your intended audience. You should plan and budget from the

To help users assess the quality and currency of information materials, Principle 6 of the Information Standard stipulates that each product should clearly display its publication date, the date it was last reviewed and the date for the next review. Review dates should be an appropriate length and not more than three years.

In requiring producers to review their products on a regular basis, the Information Standard states that organisations must have:

- an information product review process as part of their information production system
- and a planned review schedule for all their information products.

To ensure that information materials are reviewed by their due date, your process should include sufficient time to conduct new searches, analyse any new evidence and to update the product accordingly. You should also link the updating of resources to your dissemination activities.

The Information Standard also requires you to review your information production process on a regular basis and to update it, as required.

outset for how your information resources will be distributed and promoted, mapping out all potential dissemination routes.

Getting appropriate information at the right point of the patient journey is crucial. People need time to read, absorb, consider and act

on information. As far as possible, you should try to ensure that people receive appropriate information (and support) well in advance of any treatment options or medical procedures they may be considering.

Discussing with target users where would they look for particular information can help you to develop effective dissemination plans. However, the appropriateness of different outlets will depend on the aims, intended audience, format and content of your materials.

You should aim to link your health information with other organisations, networks and services that are connected with your target users. As well as accessing resources online, people may obtain health information from:

- health professionals directly involved in their care – doctors, dentists, nurses, midwives, therapists etc.
- healthcare venues – clinic waiting rooms, hospital information points, patient libraries etc.
- pharmacies
- community venues – shops and supermarkets, public libraries, community centres etc.
- self-help groups and voluntary organisations.

## **2.4b Plan how your information will be integrated into clinical care**

To be fully effective, information giving and support must be integrated into the care pathway. Health care professionals who do not trust or agree with the content of information materials are unlikely to use them or encourage others to do so. Involving potential 'gatekeepers' as part of your core team for developing high quality resources can greatly assist their penetration and reach.

Your dissemination plans should detail:

- agreed responsibilities with all stakeholders for disseminating (and supporting) your information products
- how clinicians will become aware of your information resources and how these will be integrated into clinical care
- at what point in their journey patients may need particular types of information
- how your health information links with (and signposts to) other organisations, networks and services that are connected with your target audience.

## 3 Developing the content of high quality health information for patients and the public

### 3.1 Produce relevant resources with impact

#### 3.1a Start with a clear statement of purpose

Every information product should start with a clear statement of aims – describing its purpose, what it covers and who it is aimed at. This will help readers to judge how relevant the material might be to them. It will also help to focus the efforts of everyone engaged in its production.

#### 3.1b Tailor your information for different audiences

It is unrealistic to expect one particular information package to cover all aspects of a health condition or possible healthcare intervention in a way that is appropriate for everyone affected by that condition or who might be offered that intervention.

Patients vary widely in their individual characteristics so there can be no ‘one size fits all’ approach to providing information. As far as possible, and where relevant, you should tailor your health information to meet the needs of different groups.

Such targeting accords with Principle 3 of the Information Standard which requires information producers to develop materials that successfully address the specific needs of a particular audience.

Patient groups vary by age, gender, socio-economic status, ethnic and cultural background, language, health literacy and a range of other factors.

Segmenting your audience into different target groups (with similar needs or characteristics) and tailoring your materials accordingly will help ensure equality of access. Target groups might include users who do not read or speak English, those with sensory impairments and those with low levels of health literacy.

Meeting the needs of different groups might involve adjusting the content, tone and presentation of information materials, as well as considering the most suitable format for making them available through print and electronic (including audio-visual) media. This highlights the importance of involving users from the relevant target group(s) in the process of identifying needs, and in developing and evaluating relevant materials.

The presentation and format of information materials is particularly important for people with low health literacy, and it is important to consider how low literacy may interact with other audience characteristics. Around half of the UK population have poor reading and comprehension skills, and around 20% of adults are functionally illiterate.

Making information available at different levels of detail can be a useful approach to meeting the needs of users with different interests and capabilities. With careful design and simple navigation, websites offer significant potential for layering information – enabling users to access more detailed content online as they choose – either on the same site or on via a linked site.

Resources must also be culturally sensitive. Illustrations and examples, as well as language and words, may need to be changed to ensure products are sensitive to important cultural differences.

### **3.1c Ensure your information is fit for purpose**

Information materials must be ‘fit for purpose’ – being well-designed to meet their particular aims. One information package cannot cover all aspects of a health condition and related treatments for everyone potentially affected.

## **3.2 Produce accurate and reliable information**

### **3.2a Use high quality research evidence**

Consumer health information materials must be based on valid, up-to-date and accurate evidence. Both patients and clinicians require reassurance that information materials have been produced to the highest standards.

However, an information package that is not comprehensive in its coverage can still be very useful, especially if provided as part of a series covering the full range of relevant topics and issues for different groups.

Information producers will always face difficult judgements about the scope of their products and how much detail to include. Too much information can cause confusion, and the NHS Brand Guidelines recommend that patient leaflets be limited to one or two subject areas and associated issues to help avoid this.

Information products should also signpost other reliable sources where users can access additional information and support. Producing packages of related information resources can also be a useful way of providing additional, more detailed information that may be required by some users.

Information about health conditions and treatments should include all possible options, and cover all relevant risks, benefits and uncertainties in a balanced, objective way.

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.

By itself, 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 reliability.

### 3.2b Important sources of evidence

Pre-appraised, high quality sources 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
- screening.

This hierarchy is dependent on the particular issue being researched, and the CEBM has published a table to identify the best types of

evidence potentially available to answer different types of medical question.

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 to make searching easier and more productive.

Useful sources of high quality evidence include:

- [NICE Evidence Search](#) – publishes Evidence Updates containing the best available evidence on major health conditions; access to clinical guidelines; Cochrane systematic reviews, NICE Clinical Knowledge Summaries and the UK Database of Uncertainties about the Effects of Treatments (UK DUETs).
- [TRIP Database](#) – clinical search engine providing easy access to high-quality clinical research evidence, synopses and other content types (including images, videos, patient information leaflets, educational courses and news).
- [Cochrane Library](#) – contains high quality systematic reviews.
- [Bandolier](#) – source of summarised, high quality evidence about the effectiveness 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 Appraisal Programme \(CASP\)](#) produces training, advice and free checklists for helping to appraise the validity, significance and usefulness of research studies.

[Patient.co.uk](http://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 conclusions.

### 3.2c Acknowledge uncertainty

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 effective. However, there are situations where the relevant research studies have not been done.

Honesty is the best policy here, with the Information Standard suggesting possible approaches to dealing with gaps and uncertainties in the evidence, or a lack of consensus:

- clearly acknowledging uncertainties where these do exist in the absence of high quality research evidence
- basing health information on any research studies that can be identified – as long as the source and quality of evidence used is made clear
- using 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 (which might even offer the patient the practical option of enrolling in a relevant clinical trial).

PiF's Toolkit also contains a section on communicating uncertainty.

### 3.2d Include non-clinical information and patient experiences, where appropriate

Depending on the target audience and the issue, it might sometimes be helpful and appropriate to include non-clinical information. This might include user-generated content – quotes, tips and stories – on how treatment choices (including the options of delaying or forgoing treatment) may affect overall quality of life, including day-to-day activities and relationships with family, friends and carers.

Many patients and their carers / families need information on wider economic, social and emotional impacts, and on what kind of help they may be able to get – when, from whom and how.

Patient narratives can help to educate and support patients. Users value other people's descriptions of their experiences, and patient testimonials can help make health information materials more memorable, realistic and comprehensible and assist patients in making decisions.

However, it is imperative that you present users with unbiased, balanced information. You must take great care not to 'steer' people facing difficult medical decisions by offering other individuals' experiences as potential 'role models' to follow or by presenting them in a sensational, emotive or alarmist way. You should also clearly distinguish personal experiences information from more scientific research evidence and statistics.

### 3.3 Communicate information clearly

#### 3.3a Use clear, simple language and strike the right tone

Much health information is far too complex. It is essential to use clear, simple language to communicate clearly and aid understanding.

Patient information materials should be produced in ‘plain language’ – communication that the user can understand the first time they hear or read it. This means using everyday words and an active voice, avoiding jargon (explaining medical terms) and presenting information in a logical order.

The Plain English Campaign advises using short sentences (with a good average being around 15 to 20 words) and mainly ‘active’ verbs – for example, “We will send a report to your doctor” (active), rather than “A report will be sent to your doctor” (passive).

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

You should also try to strike the right ‘tone’ in your communications. Patients prefer an informal tone that talks directly to them (i.e. as ‘you’). Users also prefer information that is honest, constructive, positive, realistic and practical, and that is neither condescending nor alarmist. Information about prognoses should avoid being overly optimistic or overly pessimistic.

#### 3.3b Keep numbers simple and use visual displays

Many people have poor numeracy skills, and most people might struggle to interpret data on risk reduction.

Presenting numerical information in tables rather than text can improve comprehension and help to mitigate the effects of low health literacy.

Well-designed visual displays (such as pictographs, bar charts or flow diagrams) can also help to improve patients’ understanding of statistical information, especially for people with low numeracy. However, people also vary in their ability to interpret such graphics and you should pilot test all visual aids for understanding.

#### 3.3c Present risk and probabilities in an understandable way

Understanding risk and benefit information is crucial to informed decision-making, including for patients to give their consent to treatment. The format in which risk information is presented affects understanding and perception of risk.

NICE guidance on improving patient experience provides a helpful, evidence-based summary of key principles to follow in presenting information about the risks and benefits of health interventions. It recommends that information producers should:

- 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).

### **3.3d Break complex information down**

The order in which information is presented can affect understanding. Presenting essential information by itself or first can improve comprehension.

When provided with less information, people are better able to comprehend more complex information. Ordering information from more to less important has similar (but slighter lesser) effects.

The Plain English Campaign advocates using bullet points to help break complex information down. Text can also be broken down into smaller blocks by using headings, paragraph breaks and/or a question and answer format.

Using images can also support what is being said in the text and help to convey more complex information. However, they should not interrupt the flow of the text, so you should consider placing images at the end of paragraphs and allow enough space between the text and the image.

### **3.3e Create visually attractive materials**

Involving users in the development of health information results in material that has more illustrations and is more readable.

Involving specialist designers is also beneficial, as good design can help to:

- control the flow of information
- bring a subject to life and make the information engaging and interesting
- shape a message to suit different audiences
- present a consistent message and branding – about who you are and what you are about



- inspire confidence and trust in you and your organisation.

### **3.3f Present information to aid understanding**

High quality design, typography, presentation and layout of health information materials also aids reading and comprehension.

The presentation of information 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 instructions.

The [NHS Brand Guidelines](#) for design and layout are comprehensive and consistent with the [RNIB's Clear Print guidelines](#) (based on the organisation's own research) for maximising the legibility of printed materials.

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.

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 standards.