HAS

HAUTE AUTORITÉ DE SANTÉ

Methodology guide

How to produce
an information brochure for patients
and users of the healthcare system

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Haute Autorité de santé

Communications Department

2 avenue du Stade de France - F 93218 Saint-Denis La Plaine CEDEX

Tél. :+33 (0)1 55 93 70 00 - Fax :+33 (0)1 55 93 74 00

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1   Introduction

1.1 Purpose of this guide

This guide describes the steps involved in producing brochures that provide patients, their relatives, and healthcare system users with easy-to-understand information based on valid sources. Healthcare professionals may find such information brochures useful as French law[1] obliges them to inform patients. The brochures should give relevant, clear, and concise information which can facilitate communication with patients. They can supplement any other information and advice given, thus helping patients make decisions about their health.

1.2 Target audience

Specialty societies and professional organisations wishing to provide patients and users with an information brochure based on available professional guidelines, which is an adjunct to verbal information, should find this guide useful.

1.3 Scope

Information brochures should not be a substitute for information given verbally.

- They are a supplement to verbal information. Patients/users may consult the brochures and/or discuss them with the healthcare professionals in charge of their care.

- Information brochures help patients/users understand the purpose of tests, interventions, and treatments, and of the procedures involved, so that they can take an active part in their own care[2].

- Brochures may be used in health promotion campaigns, health education, and patient education, but should not be the only resource used in these cases. The objectives, organisation, competencies, and resources of health promotion and education campaigns are not within the scope of this guide.

1.4 Background

This guide was drawn up at the request of the Scientific Council of ANAES[3] in response to the need for information brochures based on professional practice guidelines. It follows on the guidelines "*Information des patients: Recommandations destinées aux médecins*" (Patient information: guidelines for doctors) published in 2000 (1), which state that written information may supplement verbal information. A first version of the guide[4] was drawn up when ANAES produced an information brochure for asthma patients after publication of professional clinical guidelines on therapeutic patient education for asthmatics (2). It was felt that a document that could be "*read and taken in immediately*" would help them take better charge of themselves. The feedback from the brochure, coupled with the analysis of experiences in France and elsewhere, led to the present guide.

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[1] Law of 4 March 2002 concerning the rights of patients and the quality of the healthcare system

[2] Information brochures cover screening tests and diagnostic, preventive, therapeutic and care strategies. We shall use the generic term "care".

[3] ANAES: National Agency for Accreditation and Evaluation in Healthcare, the forerunner to HAS.

[4] At the request of the Directorate General for Health (DGS) and French national health insurance.

1.5 Purpose of information brochures

The need to inform patients using validated scientific data is acknowledged internationally[5] (3). Written information should be part of a coherent communication strategy aimed at facilitating patients' involvement in making decisions about their own care.

The Council of Europe acknowledges "*the right of patients and citizens to be provided with and to have easy access to relevant information about their health and healthcare in a format and language they can understand*". This information should:
- be based on scientific data derived from practice guidelines and apply to the national and local context,
- be made available in formats suited to several target audiences (healthcare professionals, patients, and decision-makers).

► Information provision is an obligation for healthcare professionals:

Healthcare professionals should always explain to patients/users why they intend to carry out a particular diagnostic test or care procedure[6] (4,5).

► Information brochures are a supplement to information provided verbally:

Information brochures supplement, but do not replace, verbal information (1). Verbal information is tailored to each individual patient. It informs them about their state of health, describes the type of care they will receive and the steps involved, and provides the basic information required to take part in informed decision-making. On the other hand, an information brochure meets the needs for information and advice of a large number of patients/users, by adding to their overall knowledge, so that they can better take part in the decision-making.

► Information brochures in the decision-making process:

An analysis of the doctor-patient relationship in the literature (6-8) shows that:
- some patients/users prefer to base their decisions on valid information supplied by the healthcare professional,
- some prefer to share decision-making with the healthcare professional on a partnership basis,
- some follow the suggestions of the healthcare professional without questioning their decision.

These different levels of patient/user involvement in decision-making, as well as healthcare professionals' attitudes to information provision, lead us to consider :
- the content of the information to be provided,
- the use of a brochure as a means of encouraging involvement in decision-making,
- the ways of delivering information and providing support to the target audience,
- how well the target audience understands the information provided,
- how to bring patients'/users' preferences to light,
- how to bring patients'/users' preferences to light.

1.6 Brochure topics

Information brochures can touch on all the topics covered by professional practice guidelines. Practice guidelines are drawn up by health technology assessment agencies, specialty societies, and professional organisations. They cover screening and prevention, diagnostic, therapeutic and

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[5] Recommendation Rec(2001)13 on developing a methodology for drawing up guidelines on best medical practices.

[6] Law n° 2002-303 of 4 March 2002 concerning the rights of patients and the quality of the healthcare system, Art. L 1111-4 and L 1111-5.

care strategies, therapeutic patient education, care by healthcare professionals or self-administered care, and summarising the results of systematic literature reviews (Table 1).

Table 1. Examples of brochure topics	
Topics	**Purpose of brochure**
Screening - mass - incidence	To understand the implications (collective and individual value) of screening in order to be able to request, accept or refuse it.
Prevention - primary	To gain awareness of a risk factor or risk behaviour and of the benefits in changing lifestyle or avoiding the risk
- secondary	To understand the benefits of receiving care to curb disease progression or stop a health problem
- tertiary	To understand how to prevent relapses, recurrences, and complications; and how to cope better
Strategies (diagnostic, therapeutic, care, care organisation)	To take part in the choice of a strategy and to identify a preferred strategy by considering pros and cons and predictable common or serious risks
Therapeutic patient education	To understand the value and benefit of developing skills in managing and coping better with a chronic disease or a situation which requires a learning process
Detailed description of self-administered care (self-care, self-monitoring)	To become more involved in treatment and care, and recall advice given
Results from systematic literature review	To have access to a summary of research results in the areas of screening, prevention, diagnosis, treatment, care, and care organisation

2   Method used to produce this guide

This guide is based on a critical review of the literature on producing information brochures for patients/users and on feedback obtained on ANAES brochures based on professional practice guidelines[7].

2.1 Steps of the method

A project manager identified, selected, analysed, and summarised the scientific literature on producing information brochures and drafted a first version of the guide. The draft was submitted to peer reviewers for their opinion on content and layout (readability, relevance, and usefulness). The guide was amended in the light of their comments and those of the ANAES Scientific Council.

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[7] *"Indications et modalités de l'électroconvulsivothérapie"* (Indications and methods for electroconvulsive therapy) (9), *"L'éducation thérapeutique pour bien gérer votre asthme au quotidien"* (Coping better with your asthma- therapeutic patient education to help you manage your asthma better in everyday situations) (10).

2.2 Literature search strategy

The literature search covered the period 1990-2004. The trend towards evidence-based medicine during this period led to an improvement in the content of information brochures for patients/users (3). The search was updated in June 2008 but the additional references retrieved did not provide any new information that required amendents to be made to the present guide.

The search focussed on:
- the steps in establishing brochure contents and design,
- rules for writing documents intended for the general public,
- methods to assess readability and comprehension.

It comprised three steps:

1. Consultation of the websites of specialty societies and government or non-government agencies in order to retrieve available methodology guides:
- in France: INPES (French Institute for Prevention and Health Education) and FNCLCC (French Federation of Cancer Centres),
- in other countries: *National Health and Medical Research Council* (Australia), *King's Fund Centre* (UK), *Centre for Health Information Quality* (UK), *Centers for Disease Control* (United States), Health Canada (Ministry of Health), Patient education centre in Yvoire (Belgium),
- at an international level: *World Health Organisation* (WHO), UNESCO, European Union.

2. Analysis of the systematic reviews of the *Cochrane Consumers Communication Group* (*Cochrane Library*, www.update-software.com).

3. Manual search of relevant journals (e.g. *Éducation pour la santé, La Santé de l'homme, Santé publique, Patient Education and Counselling, British Medical Journal, Health Expectations).*

2.3 Information retrieved

Government and non-government agencies, in France and elsewhere, have been producing brochures offering validated, intelligible information for patients/users for many years.[8] These brochures are often drawn up in conjunction with practice guidelines for healthcare professionals. Eight guides outlining the principles and steps in the production of brochures for patients/users and the general public were found (Table 2). Most refer to writing and formatting techniques that are used in enhancing public understanding of science. We found two French guides which offer advice on writing (20,21).

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[8] e.g. the FNCLCC (French Federation of Cancer Centres), the *Agency for Health Research and Quality* (US), the *National Health and Medical Research Council* (Australia), the *King's Fund Centre* (UK), the *Centre for Health Information Quality* (UK), the *Centers for Disease Control* (US), Health Canada (Ministry of Health), the Collège des médecins du Québec (Quebec College of Physicians) (Canada), and the Scottish Intercollegiate Guidelines Network (Scotland).

Table 2. Guides on how to produce information brochures (1980-2004).

Country	Organisation	Title
International 1982 (13)	United Nations Educational Scientific and Cultural Organization (UNESCO)	Guidelines for textbook writing
Australia, 2000 (14)	National Health and Medical Research Council (NHMRC)	How to present the evidence for consumers: preparation of consumer publications
Australia, 1999 (15)	National Health and Medical Research Council (NMRC)	How to prepare and present evidence-based information for consumers of health services: a literature review
UK, 1999 (16)	King's Fund Centre	Informing patients: an assessment of the quality of patient information materials
France, 2002 (11,12)	FNCLCC (French Federation of Cancer Centres)	SOR Savoir Patient project
UK, 2003 (17)	King's Fund Centre	Producing patient information. How to research, develop and produce effective information resources
UK, 2003 (19)	National Health Service (NHS)	Toolkit for producing patient information
UK, 2007 (18)	National Health Service (NHS)	User and community involvement: guidance for providing written information for service users and the community

3   Improving information brochures

3.1 Main criticisms of information brochures

The overall quality of information brochures depends on the quality of the scientific content, design and lay-out, and on acceptance of the brochure by the targeted audience.

The main criticisms concern the type of information given, lay-out, and consistency with professional practice guidelines. According to the King's Fund study of 128 brochures on ten common chronic conditions symptoms (e.g. back pain, depression, cataract, otitis media, high cholesterol levels) (6,16) and a study of 168 asthma brochures (22):
- there is a noticeable lack of scientific information (description of the disease and common symptoms, prevalence, causes and consequences),
- self-care and prevention methods are not sufficiently detailed to be of use in daily life,
- some information is inaccurate or out of date when compared with that in practice guidelines,
- the tone is often patronizing, even infantile, and the vocabulary is too technical,
- patients are invited to take part in the review of the final brochure only, and most brochures are written by experts in only one discipline.

3.2 Guidance on producing information brochures

All the guides on producing information brochures had in common the following advice on guaranteeing quality:

- *Patients/users* should be involved in each step of the design of information brochures targeted at them (6,11,12,14,16-19),
- *Scientific data* should be the basis of brochure content in order to ensure credibility (6,11,12,14,16-19),
- *Guidance on writing and layout techniques* given in works on journalism and the public understanding of science should be followed to ensure understanding by the lay reader (6,11,12,14,16-19),
- *Patients'/users' preferences* with regard to information desired (diseases, symptoms, and care) and layout should be taken into account (see *Box 1)*,
- *Readability, understanding, and layout* should be tested among the target audience (6,11,12,14,16-19). Stringent test methods have been developed in particular for packaging leaflets for medicinal products (23).

Box 1. Patients'/users' preferences with regard to brochure presentation

source: King's Fund focus group discussions (6,16)

☺	☹
• positive, reassuring, encouraging, optimistic, constructive tone/mood	• negative, alarmist tone, focusing too much on what is wrong
• honest, practical, understanding, not condescending tone/stance	• unrealistic, glossese over real problems and possible after effects, overoptimistic, childish, dismissive in tone
• personalised tone: talks to "you", treats you as an individual, warm, womanly, human touch	• impersonal tone: talking about patients in general, impersonal, cold, distant, too formal
• clear vocabulary, easy to read and understand, plain speaking, simple	• complicated language and explanation, too technical, badly written
• short sentences, explanation of terms	• dense text, too long, lacking any structure
• structured and concise text, clear headings, important sections highlighted, short block of text	• small print, hard to read, unattractive layout, boring presentation
• legible font size	• amateurish, looks "cheap", appearance of cost-cutting
• professional looking production	
• balanced mix of text and illustrations	

3.3 Assessment criteria

The quality of information brochures is analyzed using assessment criteria in order to be able to choose the best brochures. The DISCERN[9] consensus criteria assess the quality of documents on treatment options for a given health problem, but they can be used to assess any type of healthcare information brochure (24-26)*).* Quality criteria have also been developed by other bodies, e.g. the *International Patient Decision Aids Standards* (IPDAS).[10]. We have selected the simplest criteria for assessing brochure contents and production in this methodological guide (see *Appendix 3*).

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[9] http://www.discern.org.uk/
[10] http://ipdas.ohri.ca/index.html

4 Main steps in producing information brochures

The main steps are shown in *Figure 1* and are described in this section. They are based on published guides (6,11-14,16-19), and on ANAES experience in project management.
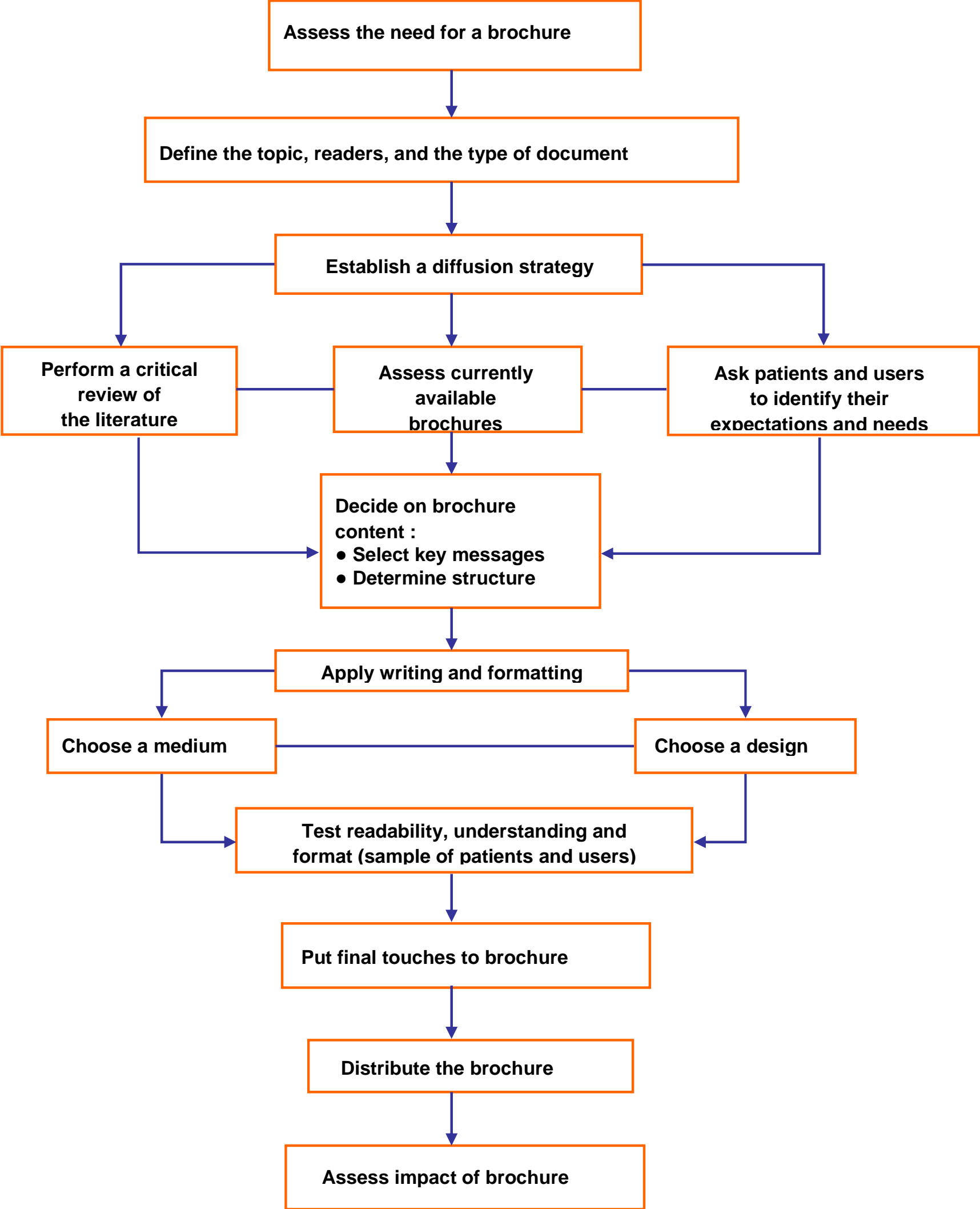
```
                    ┌─────────────────────────────────────┐
                    │   Assess the need for a brochure     │
                    └─────────────────────────────────────┘
                                     │
                                     ▼
              ┌──────────────────────────────────────────────┐
              │  Define the topic, readers, and the type of  │
              │                document                      │
              └──────────────────────────────────────────────┘
                                     │
                                     ▼
                    ┌─────────────────────────────────────┐
                    │     Establish a diffusion strategy   │
                    └─────────────────────────────────────┘
```

Perform a critical review of the literature	Assess currently available brochures	Ask patients and users to identify their expectations and needs

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                    ┌─────────────────────────────────────┐
                    │  Decide on brochure content :        │
                    │   ● Select key messages              │
                    │   ● Determine structure              │
                    └─────────────────────────────────────┘
                                     │
                                     ▼
                    ┌─────────────────────────────────────┐
                    │     Apply writing and formatting     │
                    └─────────────────────────────────────┘
```

Choose a medium	Choose a design

```
              ┌──────────────────────────────────────────────┐
              │  Test readability, understanding and         │
              │  format (sample of patients and users)       │
              └──────────────────────────────────────────────┘
                                     │
                                     ▼
                    ┌─────────────────────────────────────┐
                    │    Put final touches to brochure     │
                    └─────────────────────────────────────┘
                                     │
                                     ▼
                    ┌─────────────────────────────────────┐
                    │      Distribute the brochure         │
                    └─────────────────────────────────────┘
                                     │
                                     ▼
                    ┌─────────────────────────────────────┐
                    │     Assess impact of brochure        │
                    └─────────────────────────────────────┘
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Figure 1. Key steps in producing information brochure

4.1 Assessing the need for a brochure; the sponsor's objective

Assessing the need for an information brochure is the first step. It is also a key step.

Questions to be asked:
- Do patients/users need or want information on the given topic? If yes, when during their management do they need it (Information must be adapted to each stage of care as it varies throughout care)?
- Is there any literature on the topic that establishes patients' needs and that measures the impact of documentation (satisfaction, morbidity, etc.)?
- What does the sponsor expect in terms of objectives, patient/user behaviour, assessment, and impact?
- What is the information for (use and benefits)?
- Are the resources to produce a brochure (human and financial, skills) available?
- Are there any information brochures on the topic or a similar topic ? What is their quality? What will a new brochure add?
- Are there any professional practice guidelines on the topic?

The relevance and scope of the request for an information brochure can be gauged from surveys of patients/users, their representatives, and health professionals, or the analysis of available surveys.

4.2 Defining the topic, target audience, and objectives of the information brochure

- *The topic of the brochure* is expressed in the form of a main message and key points. Its scope is determined. Existing brochures should be consulted to avoid producing a redundant document that provides no new information. On the other hand, addressing a virgin area or updating existing documents may be particularly useful to patients/users.

- *The target audience* must be defined clearly in terms, for instance, of clinical status, age, gender, socio-economic and cultural attributes, management methods, etc.

- *The aim of the brochure* must be clear, e.g. enhancing patients'/users' knowledge of a disease or their understanding of the purpose, benefits and drawbacks of the care delivered; reminding them of the advice given by a healthcare professional; helping them to decide whether to take part in screening, or to accept or refuse a test, a treatment, or a care procedure, maybe among several proposed.

4.3 Choosing a distribution strategy

Using the information brochure to encourage patient/user involvement in decision-making must be given early consideration. The distribution strategy will depend on the brochure's use, and will also depend on its content and layout. It must take into account (see Box 2):
- the target audience,
- possible distribution channels,
- ways of making the document available,
- the document's life cycle (foreseeable update timeframe),
- costs (production, distribution, etc.).

Box 2. Distribution and use of an information brochure

- Identify the target audience
  - ◗ patients and users
  - ◗ close relatives
  - ◗ general public.
- Identify the most suitable distribution channels
  - ◗ partnership with patient/user associations or groups, specialty societies, national health insurance, health insurance companies, etc.
  - ◗ availability in waiting-rooms, pharmacies, etc.
- Determine availability measures
  - ◗ to be handed out directly by healthcare professionals during consultations, treatment, or a hospital stay, as an adjunct to verbal information
  - ◗ to be sent directly to patients by patient associations or other bodies (e.g. national health insurance, health insurance companies)
  - ◗ to be offered for free in certain public places
  - ◗ free or not

4.4 Establishing brochure content

Information that may be useful in producing the brochure is identified by:
- looking for existing scientific data and brochures,
- analysing the quality of this information,
- identifying patients'/users' needs and expectations,
- using the findings to define the content of the document.

The methods for searching for and evaluating data are described in *Table 3*.

► Identifying relevant data in the scientific literature

A search is carried out to identify non-obsolete professional practice guidelines. Examples of useful documentary sources are:
- Lemanissier library *www.bmlweb.org/consensus_lien.html*,
- Rouen University Hospital Centre website *www.chu-rouen.fr*,
- websites of the specialty societies associated with the topic in question,
- National Guideline Clearinghouse (US) *www.guideline.gov*.

The search may be extended to cover recent literature reviews.

The quality of the methodology used in the documents that are retrieved may be assessed using checklists for literature reviews (e.g. ANAES methodology guide) (27).

► Identifying available documents on the topic for the lay public
- Existing information brochures on the given topic targeted at patients/users may be found by consulting the websites of specialty societies and health technology agencies (see *Appendix 1*).
- The quality of their methodology and production methods may be evaluated using the assessment criteria in *Appendix 3*.

Due consideration should be given to the translation and adaptation of a document in a foreign language that meets the required quality criteria.

► **Identifying patients'/users' needs and expectations**

Patients'/users' needs, concerns, and expectations may be identified from:
- feedback meetings and focus groups
- database searches: qualitative research, opinion surveys
- surveys of the target audience.

Some patient/user queries that may be used during focus group discussions are given in *Appendix 2* (16).

► **Other information sources**

Statutory texts are a further source of information that should be used. For instance, the following points are raised in statutory texts and should be taken into account[11]: respect for the patient's wishes, need for informed consent, conditions for covering the costs incurred by measures for prevention, diagnosis and care, pain management, etc.

► **Use of data**

The data retrieved will be the basis of a detailed table of contents for the brochure. It is necessary to:
- select the main message and key points,
- identify essential secondary information,
- establish a structure,
- estimate the relative proportion of text and illustrations per section and page.

4.5   Guidance on writing and presenting information

The advice in this section will help our readers to get to grips with writing and will make reading and understanding of the brochure by the target audience easier (see *Box 3*) (20).

Box 3. Six key areas to be considered by authors.
(source: Centre for journalist training in France)
• *Semantics:* language, choice of terms
• *Syntax:* length and complexity of sentences, functions of the words in the sentence
• *Structure:* ranking information, highlighting the main message and key points, and flow of the text
• *Style guide:* choice of fonts and point sizes, use of colour
• *Tables and illustrations:* photographs, figures, boxes
• *Layout:* text and illustrations

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[11] Law no. 2002-303 of 4 March 2002 concerning the rights of patients and the quality of the healthcare system (4).

Table 3. Methods for retrieving and reviewing data.

Data required	Search method	Evaluation of data
Published scientific data		
● **Recent professional practice guidelines** **or** ● **Systematic reviews** **or** ● **Scientific data** ● **Feedback on producing and using written information on the selected topic**	● Database searches ● Websites of the specialty societies and professional associations	If guidelines are available ● Check the quality of the methodology used in guideline production[1], how comprehensive and up to date are the guidelines If not ● Check the quality of the methodology used in literature reviews and/or look for the evidence levels in relevant articles[1] If not ● Discuss the need for producing guidelines[2] or performing a systematic review (must be available and distributed before producing an information brochure)
Existing brochures on the topic		
● **Topics dealt with** ● **Presentation of information** ● **Use of illustrations** ● **Useful contacts (details of associations, telephone (freephone) numbers, website links)**	● Visiting websites or submitting queries to bodies and specialty societies producing information brochures on healthcare for the public (*Appendix 1*) ● Looking for best practice in the field (*Benchmarking*[3]).	● Evaluate methodological quality using the appropriate criteria (*Appendix 3*) ● Make provision for translating and/or adapting brochures
Needs and expectations of patients and users		
● **Need for information, patients'/users' most common concerns, queries, and expectations** ● **Their knowledge of the brochure topic** ● **Information they require for making decisions about their health**	● Database searches; manual search of the grey literature ● Focus groups[4] (patients, users and their representatives) using a list of their queries when they experience symptoms or disease progression (*Appendix 2*) ● Comparing feedback from healthcare professionals with focus group findings[4] ● Survey of the target audience	● Analyse the literature on the need for information, assistance and support and on satisfaction ● Analyse the contents of focus group discussions (be systematic, focus on the key issues, and make practical suggestions)

[1] "*Guide d'analyse de la littérature et gradation des recommandations*" (Guide for analysing the literature and grading guidelines), ANAES, 2000.

[2] "*Les recommandations pour la pratique clinique – Base méthodologique pour leur réalisation en France*" (Clinical practice guidelines - methodological basis for implementation in France), ANAES, 1999.

[3] Benchmarking involves looking for the best practices used by recognised bodies in order to adopt them with a view to making improvements: "*Méthodes et outils des démarches qualité pour les établissements de santé*" (Methods and tools used in carrying out quality procedures for healthcare institutions), ANAES, 2000.

[4] Focus groups are a qualitative method of information collection based on in-depth interviews of groups of people. They do not attempt reach a consensus: "*Méthodes et outils des démarches qualité pour les établissements de santé*" (Methods and tools used in carrying out quality procedures for healthcare institutions), ANAES, 2000.

► **Semantics: language and choice of terms**

The simpler, clearer, and more precise the language, the greater the potential audience.

- *Avoid jargon.* Use everyday language. Define or explain all technical terms. Be precise.

- *Avoid synonyms.* Use the same term throughout the document when referring to the same object or concept. The reader should know exactly what is being addressed in order to grasp the message correctly and swiftly.

- *Avoid abstract words.*

- *Avoid and/or define abbreviations and acronyms.* Some are standard (e.g. "ml" for millilitre) but many are obscure to the lay-reader.

- *Prefer the active to the passive voice* (direct *versus* impersonal style).

- *Use a personal tone* ("you", "we") to attract reader interest and involvement (e.g. expected behaviour) and *an impersonal tone* to present negative consequences and complications.

- *Personalise information* by describing an experience.

- *Present scientific data (e.g. statistical data) with care in order to avoid bias* (6,14-16) (see *Box 4*). (e.g, when addressing the benefits, foreseeable common or serious risks, and the relative effectiveness of a screening test, treatment or care strategy). The way data is presented (*framing effect*) can impact on the patient's decision (28-31)(negative presentation for risk of relapse, positive presentation for rates of survival or cure, or a mixed approach). Patient preferences with regard to presentation of statistical data has received little attention. Patients would seem to prefer bar charts to pie charts, survival curves, etc (30,31).

Box 4. Inclusion of numerical data (particularly on benefits and risks) in a brochure

- Present all the treatment and care options
- Present expected benefits before any drawbacks and risks of a given treatment (detail specific precautions, dietary requirements, exercise regime, and self-care procedures; be realistic; do not omit any constraints)
- Weigh up the benefits of diagnostic, therapeutic and care strategies against known, likely risks; provide information about how to cope with risks and limit their consequences.
- Select the numerical data to be included and express it intelligibly, e.g. :
  ◗ using figures (diagrams, graphs). The choice depends on the nature of the information and context
  ◗ providing information on any ongoing studies in the event of scientific uncertainty

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► **Syntax**
- *Use short, simple sentences* (a single idea per sentence, average length: 15-20 words) to achieve a clear, snappy text.
- *Use standard sentence structure* (subject - verb - complement) and reduce the distance (word or group of words) separating the subject and verb.
- *Use conjunctions* to structure complex sentences (e.g. in order to, so that, because), but do not overuse them.
- *Do not use too many long words.*
- *Get rid of redundant, useless words* which do not add to understanding.
- *Rephrase ambiguous sentences.*
- *Avoid using negative phrases* (negation in part of the sentence, several negations in the same sentence, double negation).

▶ Text structure

Readers will retain the structure of the text if it is simple (see examples in *Appendix 4)*.

● *Choose a clear, concise title.* It may be informative or catchy. A subtitle may be added, if necessary. It may indicate the type of document.

● *Limit the number of messages*: one key message, with 3-5 key points depending upon the document's objective.

● *Insert a topic sentence* at the start of the document and/or of each section to urge readers to read what follows.

● *Sort the information and structure the text* so that readers grasp the message (numbering; questions/answers; short, informative subheadings; clear paragraphs).

● *Take the reader by the hand* to help them to:
  ◗ identify the main message and key points,
  ◗ pick out definitions and identify them as such,
  ◗ make appropriate link between items of information (cause, effect, explanation, development),
  ◗ identify symmetrical statements, comparisons, or dissimilarities,
  ◗ identify an invitation, a piece of advice, or a recommendation,
  ◗ recognize an order of priority among different options (e.g. treatments, investigations, care procedures, training) and the criteria used in prioritization.

▶ Style guide: font size and lay-out

There is no single rule governing choice of font size or lay-out. The following should be adapted to the brochure's target audience and intended use:
● *Font size:* all commonly used fonts are legible above 10 point. However, font size will depend on the target audience (e.g. the partially sighted),
● *Case of the letters:* lower case is usually easier to read than upper case,
● *Justified or unjustified text:* this does not seem to affect reading speed. Unjustified text is easier to read and understand, in particular in table columns,
● *Line length:* unusually short or long lines hamper reading speed,
● *Spacing between lines and words:* spacing between lines (1, 1.5 or 2) is very important in highlighting the structure of a text. Spacing between lines that is too tight and spacing between words that is too small or too large hamper reading. There should be consistency in the use of spacing between lines throughout the text.

▶ Tables and illustrations

Tables and illustrations condense or add to information. Illustrations exemplify and explain ideas or show an action.

● *Photographs, figures (diagrams, graphs):* titles and footnotes to tables and legends to figures should be explicit enough to avoid reference to the main body of the text. The type of figure chosen depends on the nature of the statistical data and the authors' intention (21,29):
  ◗ curves highlight trends;
  ◗ bar charts compare numbers;
  ◗ pie charts show the contribution of each part to a given whole (mostly as a percentage). Although more attractive than bar charts, they are considered less easy to understand;
  ◗ *Boxes* draw attention to key points and lists;
  ◗ *Key words and expressions* should not be highlighted if they clash with headings and subheadings, thereby spoiling the text's visual structure.

► **Layout**

- Large expanses of text are seldom appealing. The correct use of paragraphs is essential. Illustrations are a convenient way of braking up the monotony.

- The text and illustrations are positioned in a balanced manner (see *Box 5*).

Box 5. Examples of balanced layout of text and illustrations
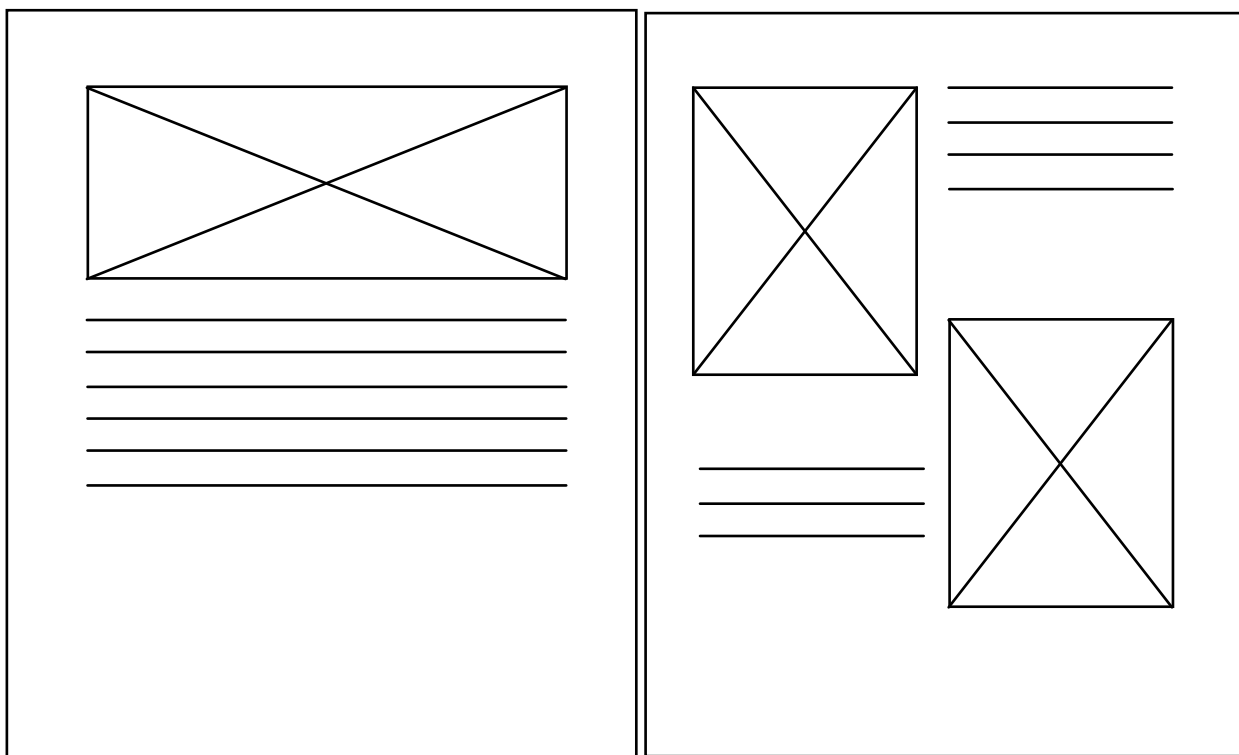
► **Use of colour**

Colour is used to highlight and rank information. The use of one or more colours (alternation and contrast) can make a page attractive but too much colour has the opposite effect. Use dark print against a light background, especially in brochures for the elderly and/or partially sighted.

4.6 Choosing the right medium and design

The printed brochure has long been the most common medium used to inform patients/users. Other media are websites, CD-ROMs, and video cassettes, each with its own production guidelines (32). Patients/users should be consulted on the choice of an appropriate medium with respect to several criteria.

In addition, the brochure producers should:
- draw up specifications for the designer and supplier (see example in *Appendix 5*),
- obtain design proposals from several suppliers,
- choose the mock-up(s) that best meet the selection criteria (compliance with specifications, experience in the field, creativity, design ergonomics, production and update costs, and distribution constraints),
- identify any need for a translation into other languages or an adaptation to a specific audience (the partially sighted, people who are not patients, children, adolescents, patients with chronic conditions) (9,10).

▶ **Printed brochures and their updating**

Printed documents have the advantage of a very wide target audience that does not, however, include everyone. In 1996, the illiteracy rate in France was 5-10% at the start of first year in secondary school (French Ministry of Education) and 10% for conscripts and 4% for adults (INSEE - National Institute for Statistics and Economic Studies).

Printed matt paper is easier to read than glazed paper (less reflection) but the rendering of colours and illustrations is not as good.

Updating printed information is costly as obsolete copies have to be withdrawn and replaced by the updated version. Combining printed and web-based information (see below) makes it easier to update information.

▶ **Video cassette and CD-ROM**

Video cassettes and CD-ROMs can be used to show interviews of people describing their experience of treatment, investigations, and care. In 2008, 96% of the French population owned at least one TV set[12]; And 5,9 millions watched video (Video cassette, CD-ROM). The proportion of this practice has increased (16 %) between 2005 and 2008 [13].

▶ **Websites**

Information supplied via the Internet is easy to update. The technology is increasing in popularity but computer equipment and some training are required to access websites. In 2008, more than half of the French population (62%) had one computer in their household. The Internet penetration rate has increased in France (53% used the Internet at home[12] in 2008; 44% in 2007)[12]. The number of internauts aged over 15 was higher in 2008 (32.1 millions) than in 2004 (20 millions)[14].

4.7 Testing the readability, understanding, and presentation of information brochures

▶ **Testing readability**

Reading difficulties may be prevented by following guidance on producing and presenting information brochures (see above) and by using recommended readability software (13,14,17,18) (*Box 6*). The software (e.g. the *Fog index* (*frequency of gobbledygook*) and the Rudolf Flesch formula) analyses the complexity of a text and helps improve readability (22,33,34). We recommend the Rudolf Flesch formula as it can be accessed via Microsoft Word[®].

The Rudolf Flesch reading ease readability score is calculated as follows:

Readability Ease (RE) = 206.835 − (1.015 x ASL) − (84.6 x ASW), where "ASL" is the Average Sentence Length (i.e., the number of words divided by the number of sentences (sentences which are long or have a complex structure are often difficult to understand) and "ASW" is the Average number of syllables per word (i.e., the number of words divided by the number of 100 consecutive words (long words, often rare words may not be understood by every reader). The outpout, i.e., RE, is a number ranging from 0 to 100. The higher the number, the easier the text is to read.

Box 6. Readability statistics and rules for interpretation

- *Occurrences*: number of characters, syllables, words, sentences, paragraphs; number of short, long, simple sentences; number of long words

- *Averages*: syllables per word, words per sentence, sentences per paragraph

- *Readability Ease (RE)* is a number ranging from 0 to 100. The higher the number, the easier the text is to read:
  - Scores between 90.0 and 100.0 are considered easily understandable by an average 5th grader
  - Scores between 60.0 and 70.0 are considered easily understood by 8th and 9th graders
    Scores between 0.0 and 30.0 are considered easily understood by college graduates

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Excessive use of the passive voice impairs readability. The text becomes difficult and boring to read. However, this is not taken into account in the Flesch formula.

Proofreading by an expert writer (journalist, communications or publications expert, linguist), or by a psychosociologist, may be useful. Care should, however, be taken that any amendments enhancing clarity do not change the message.

▶ **Testing the understanding and presentation of the brochure**

Readability covers not only easy reading but also easy understanding. Readability tests do not ensure that information is understood (33,34). Understanding is influenced by many factors, especially user characteristics (age, maturity, knowledge, motivation, etc.) and context. Understanding and presentation must therefore be tested on a sample of individuals from the target audience.

Why is it necessary to test an information brochure for patients/users?

The test tries to find out which aspects of the brochure's content and presentation can be improved. It asks the questions:
- can the desired information be found easily and quickly in the document?
- are the key messages understood?

What should be tested?

The test is carried out on the final version but one (same paper and format) and assesses:
- overall opinion,
- readability and comprehension: ease/difficulty in finding, reading and understanding the information and identifying the main message and key points,
- presentation and structure: information flow, links between key messages,
- amount of information (too much or not enough),
- usefulness and quality of illustrations,
- potential uses,
- methods of brochure distribution (who distributes it, where and when, how).

How to perform the test?

According to the literature review, qualitative and interactive methods - either individual semi-directive interviews (18,23) or focus groups (2,3,16,17,19,35-37) (see *Box 7)* - may be used to test patients'/users' reactions.
- Semi-directive interviews can identify highly specific points for improving the brochure that would not be revealed during focus group discussions.
- Focus groups require less time and fewer resources. The information gathered is useful for adapting a brochure to the needs of a specific group of patients/user (e.g. the partially sighted, those with language difficulties).

Box 8. Stages involved in testing an information brochure

- Semi-directive face-to-face interview
  - Explain purpose of test; obtain participant's consent
  - Leave the patient/user time to read the document
  - Structured interview: use an interview and observation guide (see *Appendix 6)* to describe how the patient/user looks for information (e.g. searching and handling the brochure to answer questions). Question order may be random (except for the introductory question and linked questions).
  - Analyse all objective and subjective data collected during the interview
  - Suggest improvements to the brochure
  - Discuss the changes to be made to the brochure with the working group (patients, users, healthcare professionals)

- Focus group
  - Introduce organisers and participants
  - Explain background to producing the brochure
  - Present the focus group's objective
  - Explain the instructions for conducting the focus group
  - Leave each patient/user time to read the document
  - Gather their views (take notes and, if possible, record discussions) on:
    - general opinion on the brochure
    - content
    - understanding
    - presentation
  - Analyse all objective and subjective data collected during discussions
  - Suggest improvements to the brochure

The test sample

It is not necessary to seek a representative sample of patients/users. The participants are people currently concerned by the topic (e.g. adult asthma patients regardless of disease severity or attendance at therapeutic patient education sessions), who have been concerned in the past (e.g. pregnant women), or who will be concerned in the future (e.g. screening, treatment). Healthy volunteers may offer an additional point of view even if the brochure is intended for patients, and, conversely, a brochure intended for users may be tested by patients or former patients. *S*everal versions of a brochure may need to be tested if different, specific audiences are targeted.

The number of participants should not exceed 10 to 12. Participants may be recruited during consultations, from patient groups, or elsewhere, depending on the topic.

Who carries out the test?

The test may be carried out by:
- an external supplier to the working group. This is the ideal solution but is not always practicable,
- members of the working group who have produced the brochure although their involvement may lead to some bias,
- sponsors who were not directly involved in producing the brochure.

ow are the results analysed?

The analysis covers the list of points in the paragraph titled *What should be tested?* (see above). Each key point is analyzed and improvements are decided.

The test must be repeated with another group of patients/users if participants of the first group requested major changes, in order to account for variability among patients/users.

4.8 Finalising and distributing the brochure

At the end of the test, the amendments to the content, layout, use of colours, and illustrations decided by the working group are sent to the supplier. The amended brochure is submitted for review to the organising committee in order to ensure that the key messages have not been modified during editing. The brochure is then finalised.

The brochure is made available to patients, users, the public, associations, and healthcare professionals in accordance with the distribution strategy established at the outset.

Press releases announcing publication may be issued to the general public, associations, and healthcare professionals, but should undergo review to ensure that the message is correct.

5 Evaluating the impact of a brochure

The impact of any measure aimed at improving the information given to patients/users and communication between them and healthcare professionals, i.e. its effectiveness, needs to be measured (14,16,17). Measurement of impact after the publication and distribution of the brochure:
- should be planned early on, when the brochure is being written,
- needs a reference measurement before the brochure is published and distributed,
- needs a rigorous method.

5.1 Aspects of impact measurement

Assessment methods and impact measurement are covered in guides on measuring the effectiveness of implementation methods for professional practice guidelines (38) and in some guides on brochure production (14,17).

Several dimensions of impact may be analysed individually or jointly (14,17,38, 39):

- *Target audience:* did the brochure reach the target audience? Did it meet its expectations?

- *Awareness of the brochure's existence and/or content:* was there sufficient media coverage? Were the distribution channels used effective?

- *Achieving the initial objective:* understanding of the key message or messages, acquisition of minimal knowledge expected, active involvement in decision-making,

- *Document's practicality and usefulness:* identifying different possible uses,

- *User satisfaction:* patients/users and health professionals.

5.2 Impact assessment methods

The measurement of each dimension of impact (see above) needs a specific study protocol. It can be based on published protocols such as those of EPOC (*Effective Practice and Organisation of Care - Cochrane Collaboration www.epoc.uottawa.ca*) or of ANAES ("*Efficacité des méthodes de mise en œuvre des recommandations médicales*" (Effectiveness of methods for implementing medical guidelines) (38).

According to the EPOC group, the preferred impact assessment methods are randomised trials, controlled trials, and controlled studies before/after using a control site concurrent with the intervention. However, they are best suited to more clinical assessments. The assessment of information brochures can be simpler, using smaller samples and methods that have been specifically adapted for qualitative assessments) It is possible, for instance, to compare two versions of a brochure.

The effectiveness of information brochures in knowledge acquisition and decision-making must be measured in the long term and must take account of non-biomedical dimensions such as distribution and the way they are used by patients, users and healthcare professionals. In view of this complexity, impact may be analysed using theories developed in the human sciences. The services of experts who specialise in carrying out surveys may be called upon. Survey feasibility depends in particular on the accessibility of the data to be collected and the available budget.

6 Participants in the work plan

To produce an information brochure for patients/users, ANAES recommends the procedure shown in *Figure 2*. This procedure is based on its own experience and that described in certain guides (17,19). It involves three participating groups: (i) the sponsor, (ii) an organising committee and steering committee (often merged into a single committee), and (iii) the working group. Representatives of patients/users sit on the organising committee and take part in the working group. They are involved in each stage of brochure production.

6.1 Sponsor

The sponsor may be a specialty society or an organisation of healthcare professionals, a group of experts, a health insurance organisation, a public health body or healthcare agency.

What does the sponsor do?
- Decides whether it is the right time to produce a brochure. The sponsor may draft the brochure or delegate the task to an organising committee or working group. The sponsor is regularly kept informed of progress.
- Specifies the objective of the brochure.
- Establishes expectations with regard to uses, behavioural changes, assessment, and impact.
- Gives a timescale.
- Provides or seeks the resources needed to produce and distribute the brochure, and measure its impact. Sources of funding are given in the brochure. Industry funding should, if possible, come from more than one source, especially if the firms have an interest in the brochure's subject matter.
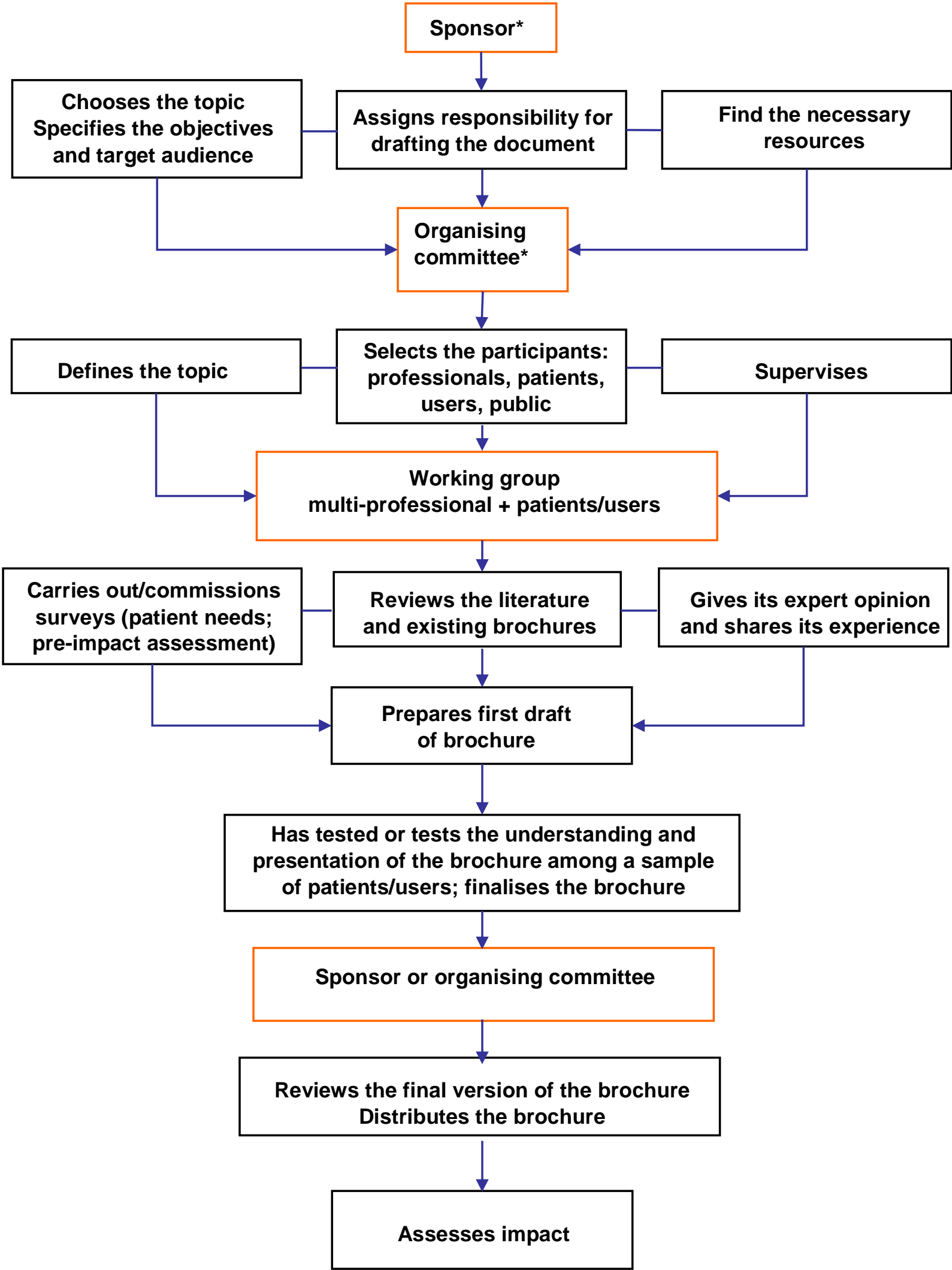
```
                          ┌──────────────┐
                          │  Sponsor*    │
                          └──────┬───────┘
                                 ▼
┌──────────────────┐   ┌──────────────────┐   ┌──────────────────┐
│ Chooses the topic│   │ Assigns          │   │ Find the         │
│ Specifies the    │   │ responsibility   │   │ necessary        │
│ objectives and   │   │ for drafting the │   │ resources        │
│ target audience  │   │ document         │   │                  │
└────────┬─────────┘   └────────┬─────────┘   └─────────┬────────┘
         │                      ▼                       │
         │            ┌──────────────────┐              │
         └───────────▶│   Organising     │◀─────────────┘
                      │   committee*     │
                      └────────┬─────────┘
                               ▼
┌──────────────────┐   ┌──────────────────┐   ┌──────────────────┐
│ Defines the topic│   │ Selects the      │   │ Supervises       │
│                  │   │ participants:    │   │                  │
│                  │   │ professionals,   │   │                  │
│                  │   │ patients, users, │   │                  │
│                  │   │ public           │   │                  │
└────────┬─────────┘   └────────┬─────────┘   └─────────┬────────┘
         │                      ▼                       │
         │            ┌──────────────────┐              │
         └───────────▶│ Working group    │◀─────────────┘
                      │ multi-profes-    │
                      │ sional +         │
                      │ patients/users   │
                      └────────┬─────────┘
                               ▼
┌──────────────────┐   ┌──────────────────┐   ┌──────────────────┐
│ Carries out/     │   │ Reviews the      │   │ Gives its expert │
│ commissions      │   │ literature and   │   │ opinion and      │
│ surveys (patient │   │ existing         │   │ shares its       │
│ needs; pre-impact│   │ brochures        │   │ experience       │
│ assessment)      │   │                  │   │                  │
└────────┬─────────┘   └────────┬─────────┘   └─────────┬────────┘
         │                      ▼                       │
         │            ┌──────────────────┐              │
         └───────────▶│ Prepares first   │◀─────────────┘
                      │ draft of brochure│
                      └────────┬─────────┘
                               ▼
                  ┌────────────────────────────┐
                  │ Has tested or tests the    │
                  │ understanding and          │
                  │ presentation of the        │
                  │ brochure among a sample of │
                  │ patients/users; finalises  │
                  │ the brochure               │
                  └─────────────┬──────────────┘
                                ▼
                  ┌────────────────────────────┐
                  │ Sponsor or organising      │
                  │ committee                  │
                  └─────────────┬──────────────┘
                                ▼
                  ┌────────────────────────────┐
                  │ Reviews the final version  │
                  │ of the brochure            │
                  │ Distributes the brochure   │
                  └─────────────┬──────────────┘
                                ▼
                  ┌────────────────────────────┐
                  │ Assesses impact            │
                  └────────────────────────────┘
```

Figure 2. Role of participants in brochure production

* Sponsor and organising committee are sometimes merged into a single committee

6.2 Organising committee

The organising committee usually has 5 to 10 members. It includes representatives of specialty societies and professional bodies with an interest in the brochure topic, and must also include representatives of patient associations, of an inter-association group, and of patients/users who are not members of any association. If the sponsor and organising committee are merged into one, the following tasks are added to those in Section VI.1.

▶ *What does the organising committee do?*

- Helps establish the literature search strategy. Database searches are preferably carried out by a research assistant.
- Selects the working method. It decides whether to produce an information brochure based on available professional practice guidelines straightaway or whether to produce or update guidelines beforehand (40).
- Plans surveys (identification of patients'/users' needs and expectations, pre-impact assessment).
- Specifies the main message and key points.
- Specifies the target audience and distribution channels.
- Selects working group members (healthcare professionals concerned by the topic, patients and patient representatives, users and user representatives).
- Establishes the work plan (see *Figure 1)*.
- Provides human and material resources (documentation, secretarial support, communications, and any participant honoraria (working group members, experts)); proposes a budget which it manages after the sponsor's acceptance.
- Monitors progress; informs the sponsor.

6.3 Working group

The working group must be multidisciplinary and represent the sectors (medical and non-medical) concerned by the topic. Depending on the topic, the group is made up of:
- healthcare professionals involved in managing the targeted patients: specialists, midwives, nurses, physiotherapists, dieticians, and other healthcare professionals,
- an equivalent number of patients/users who have or have had direct experience of management or care in the area, and individuals or representatives of associations or groups. All key groups or individuals should be represented as they determine the success of brochure distribution and use,
- people with expertise in preparing documents for the lay public: a journalist, communications expert, and maybe a linguist, a psychosociologist, and an expert in education sciences. Their role is to help choose the appropriate vocabulary, link ideas, decide on the format, and select strategies for distribution and document acceptance. The healthcare professionals must ensure that the messages contained in the document comply with objectives.

The working group should not exceed 10-12 members for an easy working relationship. It is run by a chairperson. Its members are selected by the organising committee from the names put forward by specialty societies, professional bodies, and patient/user associations. Members must be informed beforehand of the availability required of them.

The working group is seconded by a project manager who works closely with the chairperson to ensure the quality of literature retrieval, analysis, and review, and to help prepare the drafts of the brochure that include the amendments based on suggestions made by working group members and on test results.

► **What does the working group do (see example in Table 4)?**

- Selects the information that is essential from the literature review and from surveys and interviews of patients/users; lists and prioritises this information.

- Provides expertise and experience. It may consult outsiders to ensure that the main message and key points are relevant, or in cases of scant or conflicting data.

- Gives its opinion on the drafts prepared by the project manager and chairperson.

- Organises testing; prepares questionnaires and interview guides.

- Finalises the brochure.

Table 4. Example of working group activities

Steps	Outcome
1st meeting • Agrees on the brochure's objectives • Identifies needs/expectations of patients/users • Reviews the literature • Draws up the plan and mock-up • Discusses medium, distribution methods, and impact measurement	• Specifies target audience • Selects main message and key points • Suggests one or more types of medium • Outlines a distribution strategy • Informs the sponsor
Interim task • Draws up a structure for the text • Applies writing guidelines • Prepares the testing of the brochure	• Produces a draft version for the working group and outside experts • Drafts specifications and sends to suppliers (*Appendix 5*) • Drafts interview guide for testing
2nd meeting • Gives opinion on text and presentation • Analyses views of experts, if consulted • Gives opinion on mock-ups • Identifies the elements to be tested and organises the test • Establishes the strategy for brochure distribution and use • Discusses impact measurement	• Amends content • Chooses a mock-up • Plans tests • Establishes the strategy for brochure distribution and use • Prepares project for measuring the impact • Informs the sponsor
Interim task • Tests mock-up among patients/users • Contacts potential distributors	• Carries out interviews or focus groups with patients, users, close relatives • Lists distribution channels or methods
3rd meeting • Analyses test results and discusses amendments • Discusses the need to repeat the test or adapt the document to a specific audience	• Prepares final version of brochure • Submits to sponsor for opinion • Dispatches to supplier for publication

7 Conclusion

This guide on the production of information brochures for patients/users of the healthcare system was requested by the Scientific Council of ANAES in order that patients/users may be provided with objective information based on professional practice guidelines. The guide is based on a literature review, its own experience, and experiences abroad.

The guide will enable healthcare professionals to use an explicit, strict methodology to produce information brochures that provide answers to patients'/users', their families, and the public's queries about care.

The guide explains the key steps on brochure preparation and offers guidance on how to:
- retrieve and select information that is relevant to patients/users and meets their expectations,
- present this information in an attractive, accessible manner to a wide audience,
- make early preparations for distribution of the brochure to the public and healthcare professionals.

However, communication between patients, users and healthcare professionals should not be confined to the production of information brochures but should also be the subject of other initiatives (in terms of objectives, organisation, skills, and resources) that enable greater participation of patients/users in decisions concerning their health.

Appendix 1. Useful documentary sources to find information brochures

Health Technology Assessment agencies that produce clinical practice guidelines and some government bodies publish documents aimed at patients/users[a]. For example:

- Agency for Healthcare Research and Quality (United States): www.ahrq.gov
- FNCLCC (French Federation of Cancer Centres), Standards, Options and Recommendations '*Savoir Patient*' guides: www.sor-cancer.fr
- Health Canada: www.hc-sc.gc.ca
- INPES (French National Institute of Prevention and Health Education): www.inpes.sante.fr
- Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen (Germany): www.informedhealthonline.com
- Institute for Clinical Systems Improvement (United States): www.icsi.org
- National Institute for Health and Clinical Excellence (UK) www.nice.org.uk
- Ottawa Health Research Institute (Canada): http://decisionaid.ohri.ca
- Scottish Intercollegiate Guidelines Network (Ecosse) : *http://www.sign.ac.uk/patients/network.html*

[a] Non-exhaustive list. The information brochures produced by these agencies follow the steps recommended in the present methodological guide. All the listed websites are certified by Health On the Net (HON).

Appendix 2. Examples of questions asked by patients and users

- What has happened to me and how can my symptoms be explained?
- Am I alone? How does my experience compare with that of other consumers?
- Is there anything I can do myself to ameliorate the problem or prevent recurrence?
- What is the purpose of tests and investigations?
- Is it essential to have treatment for this problem?
- What are the different treatment options?
- What are the benefits of the treatment?
- What are the risks of the treatment?
- How likely are the benefits and risks?
- Will the treatment relieve the symptoms?
- How long will it take to recover?
- What are the possible short-term and long-term side effects?
- What effect will the treatment have on my feelings and emotions?
- What effect will the treatment have on my sex life?
- How will it affect my risk of disease in the future?
- Will the treatment prevent any relapses?
- How can I prepare myself for the treatment?
- How long will it take to recover?
- What procedures will be followed if I go to hospital?
- When can I go home?
- What do my carers need to know?
- What can I do to speed recovery process or facilitate management of my illness?
- What are the options for rehabilitation?
- How can I prevent relapses or future illness?
- Where can I get more information about the problem or treatments, or management of illness?

adapted from Coulter et al. (6,16)

Appendix 3. Criteria for evaluating information brochure

adapted from Coulter *et al.* (6,16), Charnok (24) and the *Health Consumers' Council* (41)

Criteria for evaluating the procedures for producing information brochure

- Involve patients or users in all steps, on a par with health professionals

- Involve experts from a variety of disciplines

- Specify the target patients/users and their needs and questions by means of surveys or meetings

- Specify the exact topic, purpose and potential users of the brochure

- Describe exactly the way the brochure is to be used

- Make sources of information explicit : scientific data, regulatory documents and information brochures on the topic (evaluate the content and methodological quality)

- Choose the most appropriate format for the intended target audience

- Choose a distribution channel suited to the chosen format and to the condition of use of the brochure

- Test the brochure's readability, presentation, and intelligibility of the information

- Schedule when the brochure needs to be updated

Criteria for evaluating the content of written information

- Have explicit aims

- Identify a main message and key points

- Be relevant to the target audience

- Take into account patients/users' needs and questions

- Be objective, do not dramatise, do not be overly optimistic

- Give numerical data for disease incidence and symptoms (i.e. frequency rates)

- Describe the benefits and risks of treatment, skills to be acquired, and their impact on the patient's daily life

- Suggest a list of questions that the patient can ask the healthcare professional

- Give sources for further information

- State: names of the authors and their sectors of activity, information sources, funding sources, and document production date

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Appendix 4. Examples of plans for producing written information

These examples are based on the main types of professional practice guidelines and should be adapted to each topic and choice of main message and key points.

Screening *"Understanding the objectives of a test and its procedures"* What disease is being screened for: frequency, severity? What does this test involve? What has to be done or not done before the test? How is the test carried out? What monitoring and precautions are required after the test? What results can be expected from the test? What follow-up will be carried out if the result turns out to be abnormal? Questions – answers Cost Useful contacts Where can further information be obtained from?	**Prevention** *"Becoming aware", "Understanding the benefit"* *Primary prevention* What am I at risk of? How do I go about protecting myself? What benefit is there in changing lifestyle? *Secondary prevention* What can I do to stop disease progression? *Tertiary prevention* How can I prevent relapses and recurrences? How can I cope better with the illness? Questions – answers Cost Useful contacts Where can further information be obtained from?
Diagnostic and/or therapeutic strategies *"Greater involvement in making choices"* What disease is involved, what are its symptoms? How is it diagnosed? What preventive, curative treatments are available, what are the other options? How is its management organised? What monitoring is carried out during treatment and/or care? How can I cope better with the illness? Questions – answers Cost Useful contacts Where can further information be obtained from?	**Therapeutic patient education** *"Understanding and coping better with the situation"* How many people are currently affected (prevalence)? Why does the *situation* need to be managed? How do you go about managing the *situation*? Skills which need to be acquired Practical steps Questions – answers Cost Useful contacts Where can further information be obtained from?
Detailed description of self-administered care (self-care, self-monitoring) *"Greater involvement in …" "Remembering to …"* What you can do yourself How do you do it? What do you do if you have problems, in an emergency? Questions – answers Cost Useful contacts Where can further information be obtained from?	**Summary of results from systematic literature review** *"Being better informed about …"* *A snappy introductory sentence:* informing the reader in the first few words which set the emphasis (25 words maximum) *Short text:* what is the healthcare problem being considered, its background,, signs and symptoms, prevalence, description of the intervention and the rationale for its use, main findings of the review in a straightforward style (max word count: 400 words).

Appendix 5. Example of a plan for specifications

Designing and producing an information brochure for patients/users must comply with a set of specifications which may include the following:

I. Introducing the sponsor

- Who is the sponsor?
- What does the sponsor do?

II. Presenting the requirement

- Description of the brochure
- The target audience

III. Preparing the brochure

- **What are its goals and objectives?**
  ‣ Improve patient's/user's knowledge
  ‣ Help understand the aim, benefits and drawbacks of the care being offered
  ‣ Prevent a risk, disease, complications, and relapses
  ‣ Remember advice given by a healthcare professional
  ‣ Help decide whether to take part in screening or agree to a test, treatment, or care procedure

- **What is its content?**
  ‣ Description of the main sections
  ‣ Consumer checklist forbasis of discussion between patient and doctor
  ‣ Practical information
  ‣ Bibliography ("to find out more")

- **How to make the brochure available**
  ‣ Available free in certain public places (pharmacies, doctors' surgeries, etc.)
  ‣ Sent directly to patients by patient groups other channels to be identified
  ‣ Handed to the patient by the doctor or nurse during a consultation or hospital stay
  ‣ Supplied with a guide for healthcare professionals and/or with a poster to be put up in waiting-rooms and places of treatment
  ‣ Free of charge or not

- **Expectations**
  ‣ Format, colour, paper, number of pages, logo
  ‣ Readability, clear presentation of information, suitable diagrams and illustrations

- **Services to be provided**
  ‣ Brochure design and production (specify the number of pages)
  ‣ Advice on choice of most suitable format
  ‣ Test of the document by a group of patients, users and their relatives
  ‣ Design of brochure jacket and internal pages
  ‣ Propose a time-schedule: usually, two sets of successive proofs with the requested amendments; printing of about 15 copies for the test; then two further sets of successive proofs with amendments

- **Order to supplier**
  ‣ Two design proposals for the brochure and cover
  ‣ Two mock-ups of a double-page spread
  ‣ A budget and production schedule
  ‣ A print proposal (specifying the number of copies)
  ‣ Review timeframe

Appendix 6. Example of interview guide

Guidelines for conducting a face-to-face interview

Adapted from guidelines drawn up by the European Commission for testing packaging leaflets for medicinal products (23) and used to test the brochure "*Mieux vivre avec votre asthme : l'éducation thérapeutique pour bien gérer votre asthme au quotidien*" (Coping better with your asthma - therapeutic education to help you manage your asthma better in everyday situations) (10).

Introductory question

1. Now that you have read the brochure, can you tell me in your own words what it is about?

   ☐ yes   ☐ no   ☐ with difficulty

Questions concerning the information's readability and comprehension

2. Can you find the place explaining what therapeutic patient education is?

   ☐ yes   ☐ no   ☐ with difficulty (after reading and searching through the document several times)

   Can you tell me what therapeutic patient education means?

   The reply indicates understanding of the text   ☐ yes   ☐ no

3. Are there indications in the text about how to gain access to this education?

   ☐ yes   ☐ no   ☐ with difficulty (after reading and searching through the document several times)

   Can you tell me what how you gain access to therapeutic patient education?

   The reply indicates understanding of the text   ☐ yes   ☐ no

4. Does the brochure say what is the point of therapeutic patient education?

   ☐ yes   ☐ no   ☐ with difficulty (after reading and searching through the document several times)

   Can you tell me what is the point of therapeutic patient education?

   The reply indicates understanding of the text   ☐ yes   ☐ no

5. Does the brochure say how therapeutic patient education is arranged?

   ☐ yes   ☐ no   ☐ with difficulty (after reading and searching through the document several times)

6. Can you find the steps that are part of this education in the brochure?

☐ yes ☐ no ☐ with difficulty (after reading and searching through the document several times)

Can you tell me what the steps are?

The reply indicates understanding of the text ☐ yes ☐ no

7. Are you able to find out what educational diagnosis is by looking through the brochure?

☐ yes ☐ no ☐ with difficulty (after reading and searching through the document several times)

Can you tell me what educational diagnosis is used for?

The reply indicates understanding of the text ☐ yes ☐ no

8. Are there examples in the brochure of the skills asthma patients should have to be able to cope with their asthma?

☐ yes ☐ no ☐ with difficulty (after reading and searching through the document several times)

Can you find some of them in the brochure?

☐ yes ☐ no ☐ with difficulty (after reading and searching through the document several times)

9. Assuming that you attend education sessions, does the brochure present the activities that you may be offered?

☐ yes ☐ no ☐ with difficulty (after reading and searching through the document several times)

Can you find some of them in the brochure?

☐ yes ☐ no ☐ with difficulty (after reading and searching through the document several times)

10. Does the brochure mention an assessment of acquired skills after several education sessions?

☐ yes ☐ no ☐ with difficulty (after reading and searching through the document several times)

Can you tell me what is included in this summary?

The reply indicates understanding of the text ☐ yes ☐ no

11. Are there tips in the brochure about obtaining further information?

☐ yes ☐ no ☐ with difficulty (after reading and searching through the document several times)

Questions about the brochure's presentation

12. What do you think of the illustrations?

13. Does the presentation make you want to read the brochure?
    ☐ yes   ☐ no

14. Do the illustrations help you understand the text better?
    ☐ yes   ☐ no

Concluding questions

15. In general, is the information contained in this brochure easy to understand?
    ☐ yes   ☐ no   ☐ with difficulty

16. In general, what do you think of the brochure and the information contained in it?
    -    Positive aspects

    -    Negative aspects

Is there anything else which we have not spoken about and which you would like to mention?

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Peer reviewers

Alexandre Biosse-Duplan, UFC *"Que Choisir"*, Paris

Karen Candau, HAS, Saint-Denis La Plaine

Julien Carretier, INCA (French National Cancer Institute), Boulogne Billancourt

Hélène Cordier, research assistant, IFROSS (Institute for training and research on healthcare and social organisations), Lyon

Professor Marie-Odile Carrere, health economist, Claude-Bernard University, Lyon I

Dr Emmanuel Corbillon, HAS, Saint-Denis La Plaine

Dr Michel Delcey, *Association des paralysés de France*, Paris

Professor Isabelle Durand-Zaleski, HAS, Saint-Denis La Plaine

Dr Cécile Fournier, INPES (French Institute for Prevention and Health Education), Saint-Denis

Gilles Gaebel, *Collectif de parents autour de la naissance* (parents group), Carrière-sur-Seine

Jacqueline Iguenane, Education studies, Bobigny

Jérôme Lemarié, HAS Saint-Denis La Plaine

Nora Moumjid, health economist, health economics and cancer care network research group, CNRS (National Centre for Scientific Research), Lyon

Tiiu Ojasoo, Ph.D, HAS, Saint-Denis La Plaine

Frédérique Pothier, Le Lien, Paris

Dr Patrice Roussel, expert in public health, ENSP (National School of Public Health), Rennes

Professor Alain Truchaud, Centre of research in biomedical technology, Institute of Biology, Nantes

Professor Alain Vergnenegre, lung specialist, Limoges

Dr Isabelle Vincent, INPES (French Institute for Prevention and Health Education), Saint-Denis

Summary data sheet

TITLE	**How to produce an information brochure for patients and healthcare system users**
Working method	Methodology guide.
Publication date	June 2008 (updated from March 2005)
Objective(s)	• To describe the steps involved in producing brochures that provide patients, their relatives, and healthcare system users with easy-to-understand information based on valid sources.
Professional(s) targeted	• Specialty societies and professional organisations • Patient associations
Request by	Scientific Council of ANAES (National Agency for Accreditation and Evaluation in Healthcare, the forerunner to HAS)
Sponsor	ANAES (National Agency for Accreditation and Evaluation in Healthcare, the forerunner to HAS), Guidelines Department
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Project management	Anne-Françoise Pauchet-Traversat, project manager, under the supervision of Dr Patrice Dosquet, head of the Guidelines Department. Secretarial services: Laetitia Gourbail.
Participants	Members of the working group; users and user representatives who took part in producing the brochure for asthma patients titled: "*Mieux vivre avec votre asthme - l'éducation thérapeutique pour bien gérer votre asthme au quotidien*" (Coping better with your asthma - therapeutic education to help you manage your asthma better in everyday situations); project managers from the Guidelines Department; peer reviewers, and members of the ANAES Scientific Council.
Literature search	Emmanuelle Blondet, research assistant, with the help of Maud Lefèvre, under the supervision of Frédérique Pagès, head of the documentation service.
Authors of the report on the evidence	Anne-Françoise Pauchet-Traversat, project manager, Guidelines Department.
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Other formats	Quick reference guide (in English) and brochure (in French): "*Mieux vivre avec votre asthme - l'éducation thérapeutique pour bien gérer votre asthme au quotidien*" (Coping better with your asthma - therapeutic education to help you manage your asthma better in everyday situations) available free of charge at www.has-sante.fr