



Patient Education Material Guidelines

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*Many thanks to the following persons
for their help and support in creating this document:*

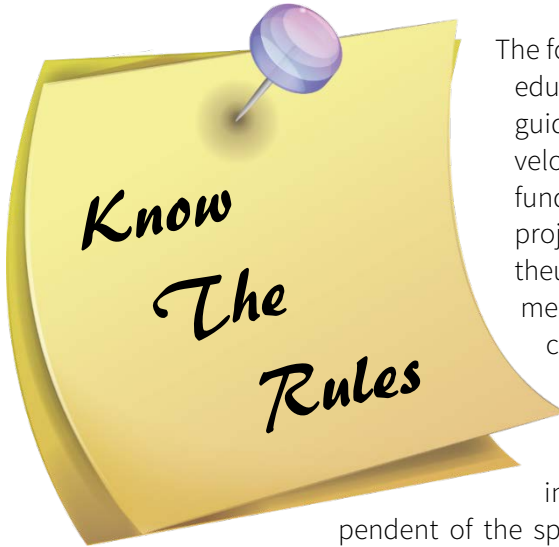
*Almut Kalz
Georg Böhler
Danial Osmonov
Klaus-Peter Jünemann*

and most of all: our patients

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INTRODUCTION



The following patient education material guidelines were developed in the EU-funded Interreg 5a project Prometheus. They are meant to help educators design effective materials for educating patients in general, inde-

pendent of the specific health issue the material is intended to address. The main goals are to facilitate understanding, support patient-doctor communication, encourage shared decision-making, and further patient empowerment. These guidelines are an amalgamation of external research and our own design, and are tested for effectiveness with actual patients in real-life scenarios. We have deliberately refrained from utilizing theoretical scholarly approaches as our intent is centered on providing readily accessible support than can be directly applied by professionals in the field.

BACKGROUND

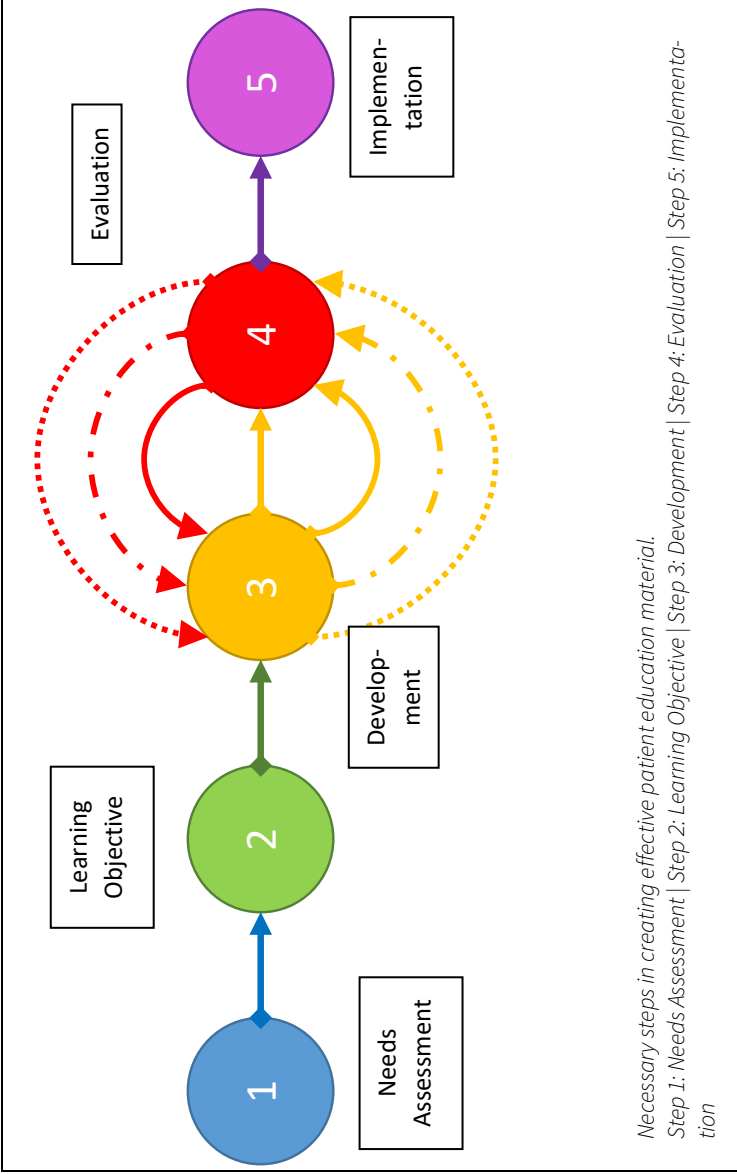
After reviewing a lot of material used in patient education today, we have concluded that often patients are not the central concern. Understandably, the authors first considered the wishes of the institutions that order and use the material. Consequently, focus on limiting legal responsibilities and favors exact medical correctness over understandability. While this seems to be distinctly more of a problem in Germany than in Denmark, it is still an issue that affects healthcare in both countries.

The problem is that this form does not really take into account the patient's situation. But clearly, it should, as patients' attitudes, feelings, and active cooperation are important for relations with doctors and caregivers and optimal treatment.

So patient education material need not only be medically and legally correct, but also easy to understand, and even sympathetic in tone. It is therefore of paramount importance to develop material that does help patient understand what is going on. We need material that puts patients in a position in which they can make truly informed decisions because they know what they consent to. They know what the pros and cons are, and which alternatives exist.

METHOD

The basic method for creating efficient patient education material is adhering to a simple structure of five successive steps. In the first step the patients' needs are identified, in the second step the intended learning outcome is defined, in step three the actual material is created, in step four that learning material is evaluated, and in step five the material is finally implemented, i.e. printed, distributed, put online. Be aware that the whole procedure should be an iterative process. Especially steps three and four might need to be repeated multiple times, until the desired outcome is achieved.



Necessary steps in creating effective patient education material.

Step 1: Needs Assessment | Step 2: Learning Objective | Step 3: Development | Step 4: Evaluation | Step 5: Implementation

Here is an overview of activities to be performed

1.) Needs Assessment

Define Target Audience (consider educational level, preexisting knowledge, age-related issues, cultural issues, and gender issues), clarify usage (In which situation will the material be used?), think about relevance. (What does the patient need and want to know?)

2.) Learning Objective

Define what effect the educational material is to have on the patient

3.) Development

Develop the actual educational material. Consider intelligibility, readability, design, media idiosyncrasies

4.) Evaluation

Perform professional assessment (consider readability, clarity, relevance, medical accuracy), subjective patient assessment (consider patients' response), and objective patient testing (consider knowledge check)

5.) Implementation

Print, distribute, put online

Step 1 – Needs Assessment

Step 1 – Needs Assessment

“Learning needs assessment is a crucial stage in the educational process” (01) because everything else is built on it. If major mistakes are made in this step, the outcome cannot be successful.

“Many factors influence the effectiveness of written health education materials, including patients’ age and education [...]” (10). It is therefore important to tune the material to fit patients’ level of education and the knowledge they already have as a basis.

- **Target Audience**
 - Educational level
 - Preexisting knowledge
 - Age-related issues
 - Cultural issues
 - Gender issues

(01) Grant, Janet: Learning needs assessment: assessing the need, in BMJ. 2002 Jan 19; 324(7330): 156–159

(10) Freda, Margaret Comerford EdD, RN, and Damus, Karla, PhD, RN, and Merkatz, Irwin R. MD: Evaluation of the Readability of ACOG Patient Education Pamphlets. In: Ob-stetrics & Gynecology, May 1999 - Volume 93 - Issue 5, Part 1 - p 771–774

- **Usage**

- In which situation will the material be used?
(At home? At the hospital? Is the patient agitated?)

- **Relevance**

- What does the patient need to know?
- What does the patient want know?

Many educational materials use information that patients have no interest in. Superfluous data increases cerebral load and irritates readers. Such information should be left out.

Step 2 – Learning Objective

Step 2 – Learning Objective

- **Define a clear learning objective.**

⇒ *What effect should the educational material have on the patient?*

Example

Situation:

A patient has been diagnosed with prostate cancer. To help inform and prepare him for a consultation with the doctor he is handed an information pamphlet to read.

Learning Objective:

After reading the material, the patient should know about the different available treatment options with their respective pros and cons.

Step 3 – Development

This is the step in which material is actually produced. We have put together a number of relevant issues and compressed them into the following topics:

- Writing Style
- Content
- Design
- Illustrations
- Videos
- Apps

General instructions are sometimes hard to put into real-life context. We have therefore provided examples wherever possible.

Writing Style

Writing style has a tremendous impact on how helpful the material is for patients. If the manner in which educational texts are written does not fit the purpose, patients' entire state of being can easily be affected quite negatively.

Here are some basic rules that can make patients' reading experiences worthwhile. We are fully aware that some of these hints go straight against what other people might have told you before, but they do help patients understand. Remember, this endeavor is not a literary quest, this is not to satisfy the peculiar needs of language teachers and English professors; this is to help patients. If texts are simple and patients understand – good. If texts are eloquent and patients don't understand – bad. Sometimes it really is that simple.



With that in mind, let us now take a look at a couple of rules and examples.

| Rule | Negative Example | Positive Example |
|--|---|---|
| <p>Write at a level appropriate for the target audience Don't use words with more than 3 syllables unless absolutely necessary. Use short sentences (< 12 words).</p> | <p>Prostate artery embolization is an innovative novel treatment alternative for males suffering from the benign prostatic hyperplasia condition.</p> | <p>PAE is a new treatment option for men with enlarged prostates.</p> |
| <p>Use easily understandable words instead of complicated synonyms.</p> | <p>exacerbate micturition</p> | <p>worsen urinating</p> |
| <p>Use medical terms only when necessary. If used, define them. Abbreviations should be spelled out if the long form helps understanding. If the long form confuses rather than helps, leave it out.</p> | <p>PSMA-PET/CT is an abbreviation for prostate-specific membrane antigen positron emission tomography computed tomography.</p> | <p>PSMA-PET/CT is a type of imaging that helps detect relapse of prostate cancer.</p> |
| <p>Use terms consistently throughout the entire text</p> | <p>Breast cancer is a widespread health issue. Mammary carcinoma has a genetic component.</p> | <p>Breast cancer is a widespread health issue. Breast Cancer has a genetic component.</p> |


| Rule | Negative Example | Positive Example |
|--|--|--|
| Use the active voice. It is shorter and easier to understand than the passive. | Ointment should be applied by the patient each morning. | The patient should apply ointment each morning. |
| Address the patient directly | The patient should refrain from showering for 2 days after the operation. | Do not shower for 2 days after surgery. |
| Be concrete | You can shower after a short period of time. | You can shower 48 hours after the operation. |
| Limit the content of each sentence to one idea or concept. | After prostatectomy, which is often performed when there is aggressive cancer, i.e. with a Gleason Score of 7 or above on the 2-10 point Gleason scale, patients sometimes have problems with incontinence issues. | The aggressiveness of prostate cancer is measured on the Gleason scale. The higher the score the more aggressive the cancer. In high Gleason score cases the prostate is often removed surgically (prostatectomy). After this operation, some patients become incontinent. |
| Use examples as often as possible and sensible | Drink lots of clear fluids. | Drink lots of clear fluids such as water or tea. |
| Logical Sequence | 1) Treatment 2) Diagnosis 3) Follow-Up | 1) Diagnosis 2) Treatment 3) Follow-Up |
| Provide a Summary, listing the key elements. | | |

Content

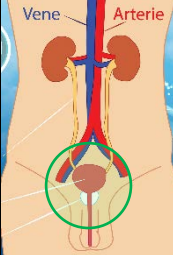
| Rule | Negative Example | Positive Example |
|--|---|---|
| <p>Concentrate on what patients need and want to know</p> | <p>The Gleason Score is the sum of two values derived from the microscopic cancer appearance and histologic patterns, called primary and secondary grade. Sometimes a tertiary grade is determined as well. These values depend on the degree of cell degeneration.</p> | <p>The higher the Gleason Score, the more aggressive the cancer.</p> |
| <p>Leave out content / information that has no value for the patient</p> | <p>PSMA-PET/CT is a diagnostic tool for identifying infected lymph nodes using gallium Ga 68 (68Ga)-labeled PSMA ligands for positron emission tomography.</p> | <p>PSMA-PET/CT is a diagnostic tool for identifying infected lymph nodes.</p> |

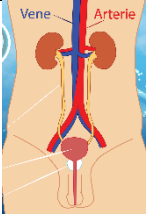
| Rule | Negative Example | Positive Example |
|---|---|--|
| <p>If you want to provide more in-depth information, split the material into “basic survival skills” and “further information”, and mark them clearly</p> | <p>This is a negative example text just going on and on and on without ever stopping. This is a negative example text just going on and on and on without ever stopping. This is a negative example text just going on and on and on without ever stopping. This is a negative example text just going on and on and on without ever stopping. This is a negative example text just going on and on and on without ever stopping.</p> | <div data-bbox="714 379 736 475" style="text-align: center;">  </div> <p data-bbox="773 379 919 496">This is the first and most important information, also known as basic survival skills people really absolutely have to read.</p> <div data-bbox="692 552 745 624" style="text-align: center;">  </div> <p data-bbox="773 539 919 639">And this is added and really extended information for people who want to know more.</p> |
| <p>Actionability</p> <p>Include advise as to what patients can do themselves</p> | <p>No info</p> | <ul style="list-style-type: none"> <li data-bbox="695 783 902 879">- Do not eat for 12 hours before the exam <li data-bbox="695 922 913 986">- Drink 3-4 liters of water or herbal tea |

| Rule | Bad | Good |
|--|---|---|
| <p>Split the text into short, easy to handle paragraphs (chunking)</p> <p>Ensure that letters are large enough (≥ 12 points)</p> <p>Be generous with white space</p> | <p><i>A radical prostatectomy is an operation aimed at eradicating the prostatic gland as well as partially removing the surrounding tissue, which is implemented in order to remove malignant prostatic carcinomas. This operation may be executed via open surgery or it may alternatively be conducted by laparoscopic surgery, in which surgeons operate through minute incisions. While Laparoscopic surgery may be performed manually, i.e. by hand, several urologic surgeons now prefer implementing laparoscopic procedures as so-called robotically-assisted prostatectomy, that is by meticulously guiding robotic limbs which in turn can grasp a wide variety of necessary surgical instruments.</i></p> | <p>Radical prostatectomy is an operation to remove the prostate. Some of the tissue around it is removed as well. It is done to remove prostate cancer.</p> <p>This operation may be done by open surgery or laparoscopic surgery through small cuts.</p> <p>Laparoscopic surgery may be done by hand. But some doctors now do it by guiding robotic arms. This is called robot-assisted prostatectomy.</p> |

| Rule | Bad | Good |
|--|---|---|
| Use Visual Cues (arrows, boxes, checkmarks, icons) to visually guide attention to key points | None |  |
| Use informative and clear Titles and Captions | <i>Consider this</i> <i>The procedure</i> <i>Possibilities</i> <i>Other Stuff</i> | Preparation Surgery Side Effects Alternatives |
| Use Color Coding for quicker orientation | <p>Preparation</p> <p>This text explains what you need to do before we start. This text explains what you need to do before we start. This text explains what you need to do before we start.</p> <p>Side Effects</p> <p>Read here what could happen, how your body could react and how often these issues happen. Read here what could happen and how your body could react.</p> <p>Alternatives</p> <p>The proposed procedure is not the only option. There are other possibilities you should know about. Only then can you decide what is right for you.</p> | <p>Preparation</p> <p>This text explains what you need to do before we start. This text explains what you need to do before we start. This text explains what you need to do before we start.</p> <p>Side Effects</p> <p>Read here what could happen, how your body could react and how often these issues happen. Read here what could happen and how your body could react.</p> <p>Alternatives</p> <p>The proposed procedure is not the only option. There are other possibilities you should know about. Only then can you decide what is right for you.</p> |

Illustrations

| Rule | Bad | Good |
|--|---|---|
| <p>Illustrations are essential – use them whenever they would help understanding</p> | <p><i>The bladder is a hollow muscular organ that sits on the pelvic floor.</i></p> | <div style="display: flex; align-items: center;"> <div style="margin-right: 10px;"> <p style="font-size: small; color: blue;">Vene</p> <p style="font-size: small; color: red;">Arterie</p> </div>  <div style="margin-left: 10px;"> <p><i>The bladder is a hollow muscular organ that sits on the pelvic floor.</i></p> </div> </div> |
| <p>Illustrations need to be simple and clear</p> <p>Illustrations are meant to help readers understand. Gorgeous photo-realistic graphics might look great, but they do not support patients in understanding the issue at hand. In most cases simple 2D drawings that are reduces to the relevant features do a much better job at fostering comprehension.</p> | | |

| Rule | Bad | Good |
|--|---|--|
| <p>Use one illustration to explain once concept or idea at a time (Do Not use one graphic to illustrate multiple issues)</p> | | |
| <p>Put illustrations as close as possible to the text they relate to</p> | <p>Text on the front side, illustration on the back</p> | <p>This text here is right next to the illustration so people can refer to the picture while reading the text. This text here is right next to the illustration so people can refer to the picture while reading the text. This text here is right next to the illustration so people can refer to the picture while reading the text. This text here is right next to the illustration so people can refer to the picture while reading the text. This text here is right next to the illustration so people can refer to the picture while reading the text.</p>  |
| <p>Don't use illustrations that are nothing but window-dressing</p> | | |

Videos

In many ways, the same tips and pointers apply as for printed material. Often they apply even more as in videos viewers have to understand the presented material in real time. Therefore, it is vital to use short sentences, easy vocabulary, and very clear illustrations.

- **Vocabulary**
Use easy and short words.
- **Length of Video**
Keep the video as short as possible. If there are multiple issues to address, consider splitting the content into multiple videos.
- **Illustrations**
Use them often. Keep the illustrations very simple. Build them up sequentially over time. In this way, viewers do not have to take in all the information at once.

Apps

Apps are essentially a mixture of audio, video, text and animations, enriched with some degree of self-guided navigation and interactivity. Therefore, most hints about educational videos and informational texts apply in exactly the same manner.

What is important in addition is orientation. It is vital that users can orient themselves quickly and easily know where they are at all times.

Consider for good interface design:

- self-explaining symbols
- Clear Interface
- sensible order/ arrangement
- easy access
- Adhere to generally accepted and widely used standards

Users are used to certain types of layouts and interfaces on their tablets and smartphones, which differ from operating system to operating system, e.g. Android vs iOS. Creating a completely unique interface might have a special appeal for many designers and developers, but it creates additional cerebral load for the users. This should definitely be avoided, so patients can concentrate on the content without having to learn how to use the interface first. The entire app should be as intuitive as possible. No manual should be required. If at any point there is a function or behavior that needs explaining, then there is probably a design flaw. You then need to consider restructuring or adaptation.

Step 4 – Evaluation

- **Professional Assessment**
 - Readability (e.g. SMOG) (PEMAT?)
 - Clarity
 - Relevance
 - Accuracy (medical correctness)

- **Patient Assessment**
 - Patients' Response
Talk to patients after reading or viewing the education / information material. Get their unfiltered response directly after.
Develop a short standardized questionnaire. Use Likert scales of the same range for all questions.

- **Patient Test**
 - Objective knowledge testing
Have patients answer knowledge questions about content covered in the material to find out how much they have truly understood. Explain clearly that you are NOT evaluating THEM, but the material.

Step 5 – Implementation

Step 5 – Implementation

- **Print**
- **Distribute**
- **Put Online**

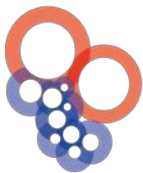
The last step is actually implementing the new information or education material. This takes place only after multiple development and adaptation cycles. When the different methods of evaluation indicate that the material has reached a state in which the learning outcome is actually met, you can go into production. Have the material printed, put it online and distribute it to the patients.

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