How to develop information from guidelines for patients and the public

Karen Graham, Corinna Schaefer, Nancy Santesso

Corresponding author: karen.graham2@nhs.scot

Key messages of this chapter

- There are many patient-directed knowledge tools available for presenting recommendations to patients and the public. Guideline developers should consider the purpose of these tools when producing such recommendations. Purposes include informing or educating, providing recommendations, supporting decision making and engaging in shared decision making.

- Involving patients and the public in the development of patient information derived from guidelines (that is, guideline-based information) promotes readability and assures the information is relevant for readers.

- Ensuring high quality of information produced for patients and the public is essential. Tools such as The Patient Education Materials Assessment Tool (PEMAT) and the DISCERN questionnaire can be used to assess various aspects of patient information, such as understandability and actionability of patient information.

- Qualitative research suggests patients and the public want the following information to be available in guideline-based information:
    - Context: who is the information for?
    - Background information about the condition:
        ◊ What are the risk factors?
        ◊ How will the condition progress?
        ◊ How long will the condition last?
        ◊ What is the risk of other problems arising from the condition?
    - Information about how to live with a disease and the treatment interventions:
        ◊ What are the treatments, including the alternatives?
        ◊ What are the risks associated with treatments?
    - What can I do for myself (for example, self-management)?

- Where can I find more help (for example, phone numbers and websites for sources of support)?
- How are guidelines produced?

- When prioritising recommendations for inclusion in guideline-based information, it is important to consider the purpose of the information. For example, if the purpose of the information is to promote self-management, recommendations about self-management are the ones to prioritise.

- It is extremely important to communicate the rationale behind guideline recommendations to patients and the public. It is helpful if the strength of recommendations is communicated using both qualitative text and symbols. The use of symbols should be tested with the target audience.

- When presenting information about benefits and harms, evidence shows that people's understanding of risk can be improved by presenting them with absolute numbers rather than words. Even where people say they prefer words, giving them both improves understanding.

- The choice of format for information will depend on the purpose of the information, target audience, the topic, and budget available. If the audience is segmented into different groups, it may be beneficial to have multiple formats to ensure accessibility. Accessibility may mean adapting information (including web-based materials) for people who have low health literacy, translating the information into other languages, as well as making versions available as easy read documents, large print, audio or video.

- People like information presented in layers, which means that they can read as much, or as little as they want. A useful approach is to have short paper versions and longer electronic versions, with the latter in particular using a layered approach.

- Personalisation of guideline-based information, for example 'Who is this information for', is useful because it makes it easier for people to think about how the information is relevant to them.

- Guideline-based information should be easy to find by both healthcare professionals and patients. It may be helpful to provide the patient version along with the guideline itself to ensurethat healthcare professionals who look up the guideline will also find the patient version.

Top tips

- Involve patient and public members of guideline development groups in developing information for the public.
- Include those recommendations in patient information that patients can directly influence or that can empower them to make care and treatment choices.
- Clearly state how the information was produced and by which organisation.
- When developing guideline-based information, consider signposting to other reputable and high-quality sources of information, including organisations and websites.
- The format for patient information should take into account the needs of the target audience. Consider producing multiple formats to promote accessibility.
- Statistical information should be kept simple. Use visuals such as bar graphs, pictograms or tables when possible.
- When summarising evidence on treatment options for patients and the public, simple tabular format (with questions and answers) allows easy comparison and improves comprehension of treatment benefits and harms.
- Use words and symbols to communicate the strength of recommendations to patients and the public.
- Guidelines may use different systems to present uncertainty, and if not intuitive, it may be helpful to include a description of what the system means in information for patients and the public.
- Use colour to distinguish between information from the evidence and information from other sources, for example, patient experience.

Aims of the chapter

This chapter describes strategies and methods to directly communicate all or some of the recommendations contained in guidelines to patients and the public. The guidance in the chapter is based on current best evidence from qualitative research on how to produce useful guideline-based materials for the public and patients, and options for when evidence does not exist. It gives an overview of:

- why producing information for patients and the public may add value to guidelines and foster implementation

- what should be included in guideline-based material for patients and the public
- how to communicate information and strength of recommendations
- how to describe treatment options
- how to ensure material adheres to more general quality criteria for patient and public information.

The chapter also offers best practice examples for developing guideline-based materials for patients and the public.

Communicating guidelines to patients and the public

Many recommendations in guidelines directly affect care for patients and the public. Therefore, efforts should be made to produce knowledge tools for patients (that is, patient-directed knowledge tools) to facilitate patient participation in decision making about care and treatment. There are many ways in which patient-directed knowledge tools can present care and treatment options to patients and the public, including:

- a plain language summary as described in Glenton et al. (2010)
- an interactive summary of findings tables as described in the DECIDE interactive summary of findings table
- a patient version of a guideline, as highlighted in Schafer et al. (2015)
- promotion of single recommendations, as in the Association of the Scientific Medical Societies in Germany (2020)
- interactive patient decision aids, as done by the Ottawa Hospital Research Institute (2020) or 1-page tabular decision aids such as The Dartmouth Institute's Option Grids
- decision boxes, as highlighted in Giguere et al. (2012)
- facts boxes, as shown in Schwartz et al. (2007).

No single approach has proven to work substantially better than another, although interactive and tabular formats have generally been well received, according to DECIDE's work with patients and public. Whichever format is used, it is important to involve people from the target audience for the patient-directed knowledge tool when selecting and developing the tool (DECIDE patients and public, Stacey et al. 2014, Stacey et al. 2019).

Table 1 presents Dreesens et al.'s (2019) framework with the various tools and their purposes. The first part of the framework describes the tools' purposes and the second focuses on the tools' core elements.

Table 1 A conceptual framework for patient-directed knowledge tools to support patient-centred care (based on Dreesens et al. 2019)

Type of tool	Purpose: inform or educate	Purpose: provide recommendations	Purpose: support decision making	Purpose: engage in shared decision making
Patient information and educational material	+	-	-	-
Decision tree	-	+	+	-
Independent or pre- and post-encounter patient decision aid	+	-	+	-
Patient version of clinical practice guideline	+	+	+	-
Encounter patient decision aid	+	-	+	+

Patient decision aids

A Cochrane review on decision aids described them as an intervention designed to support patients' decision making by providing information about treatment or screening options and their associated outcomes compared with usual care and alternative interventions (Stacey et al. 2014). Decision aids inform patients clearly about their options and prepare them to participate in decisions about their care and treatment. Information on shared decision-making tools can be found in the upcoming chapter on guidelines and shared decision making.

Decision aids, such as Option Grids and Facts boxes, are based on the best evidence and input from patients and healthcare professionals. They are easy to

read and use. They can ensure decisions are well informed and made carefully considering patients' views (The Dartmouth Institute, Giguere et al. 2012).

Patient information

Patient information, such as leaflets, can empower patients to ask questions about decisions on diagnostic and treatment interventions. A patient leaflet may include one or a few recommendations from guidelines on a specific topic to help with decision making. Initiatives such as [Choosing Wisely](#), produce materials to promote conversations with healthcare professionals and patients and about what is appropriate and necessary treatment.

Patient versions of guidelines

Patient versions of guidelines are tools that 'translate' guideline recommendations and their rationales so patients and the public can easily understand them. Patient versions of guidelines can support individual decision making and help to foster a trustworthy patient clinician relationship in that they provide understanding about how, based on the evidence, clinicians should treat a condition. In turn, people may feel reassured and confident in their care. In situations where they are not offered care options recommended in a guideline, patients may intervene thus supporting guideline implementation (see the upcoming chapter on dissemination and implementation for further information). Box 1 describes the purposes of patient versions.

Box 1 Purpose of patient versions of guidelines

- Allow priorities to become clear to patients.
- Highlight to patients the benefits and harms of interventions to support decision making.
- Identify interventions for which there is good evidence that harms do outweigh the benefit, potentially reducing the use of or demand for unproven interventions.
- Point out other uncertainties and emphasise when a patient's own values and preferences are especially important for making a treatment choice.

> - Identify lifestyle interventions and ways in which the patient can take steps to manage their condition.

It is important that patient versions are derived from guidelines that have recommendations based on a high-quality systematic approach and a formal consensus process. Recommendations for or against interventions will involve the guideline development group's value judgements, which may be the wrong choice for individual patients. Hence, the adequate application of a guideline does not only imply strict adherence to guideline recommendations but also reasonable non-adherence because of a patient's individual preferences or circumstances. It is crucial that guidelines convey this idea to both healthcare professionals and patients, and provide information to facilitate decision making.

Although the word 'translate' suggests using a different language, producing a helpful patient version is about more than tailoring the language to patients and the public. It involves:

- the selection of recommendations and outcomes to present
- how to present the strength of the recommendations and uncertainty in the evidence
- how to present the options available to a patient, and
- decisions about general formatting because patient versions may vary widely in format, length and content.

Ensuring high-quality patient-directed knowledge tools

The quality of materials produced for patients and the public is key to making the information desirable (DECIDE patients and public). Guideline developers therefore require quality criteria to use when developing patient-directed knowledge tools. The International Patient Decision Aid Standards (IPDAS) collaboration has also developed validated quality criteria specific for patient decision aids. One example of national consensus-based quality criteria for development, content and governance of patient-directed knowledge tools is that produced by the National Healthcare Institute of the Netherlands (van der Weijden et al. 2019).

The Patient Education Materials Assessment Tool (PEMAT) is a systematic method to evaluate and compare the understandability and actionability of patient education materials (Shoemaker at al. 2013). It is designed as a guide to help determine whether patients will be able to understand and act on information. Separate tools are available for use with print and audiovisual materials.

We have developed a checklist for ensuring good-quality guideline-based information, shown in box 2. The information gives the essential requirements for producing such health information for the public (DISCERN, Shoemaker at al. 2013).

Box 2 Checklist for producing good-quality information for the public

> The material:
>
> - Makes its aims and purpose clear.
> - Provides details on funding, who produced the information, when it was produced, and what sources were used to compile it.
> - Follows a logical format and uses everyday language. Medical terms are defined when used.
> - Clearly presents information on treatment options, what will happen if no treatment is used and about the certainty of the evidence. Language reflects potential uncertainty.
> - Provides the information in chunks. Uses boxes, tables and bullets to break up text.
> - Provides easy to understand numbers.
> - Provides visual aids to promote understanding, for example, a picture of a healthy portion size.
> - Gives easy to read online information and spoken words can be clearly heard and understood, for example, pace is appropriate. Language is non-directive and non-persuasive.
> - Uses an active voice in written and online information.
> - Clarifies the actions for people to take.
> - Signposts to other sources of information.

Process for developing patient-directed knowledge tools

Ideally, patient-directed knowledge tools should be developed towards the end of the guideline development process, after confirmation of the full set of recommendations and their rationales. Recommendations change throughout the guideline development process and this will avoid having to revise the information each time. Patient-directed knowledge tools should preferably be produced by the patients and healthcare professionals who have already been involved in developing the guideline on which the information is based. During the guideline development process, the group can systematically prioritise situations that require in-depth conversations between healthcare professionals and patients (Association of the Scientific Medical Societies in Germany 2020).

The guideline group can also discuss content beyond that to be included in the guideline, which could or should be covered by patient-directed knowledge tools. So, it is helpful to have the tools in mind when starting the guideline to inform the process of tool development. Patient or consumer organisations may also produce patient-directed knowledge tools, such as educational materials and patient versions of guideines, all of which can then be reviewed by the healthcare professionals and patients who developed the guideline. Developing information for patients and the public together with them helps promote readability and ensures that information is relevant to its readers.

The case study in table 2 shows how the Scottish Intercollegiate Guidelines Network (SIGN) developed the patient version of their guideline on migraine.

There are many ways to ensure that the information in the patient version reflects patients' needs and experiences. Although collaboration of clinicians and patients during the whole development process of the patient version is desirable, it may be more feasible to have collaboration at particular stages of the process, for example at the planning and consultation stages (Schafer et al. 2017).

Table 2 Development of the patient version of the SIGN guideline on migraine

When did SIGN start developing the patient version and what was the timescale?	SIGN started developing the patient version when the guideline was at the editorial stage of the guideline development process. The production process for the patient version took 7 months, including consultation and editorial stages.
Who did SIGN involve in the development process?	Two clinicians and 2 patients from the guideline group were invited to participate in a subgroup responsible for producing the patient version of the guideline. This made it easier to make the guideline and patient version complementary. A volunteer member of the public was also invited to join this group to provide an objective user perspective. Members of the guideline group provided quality assurance checks on the patient version to make sure it accurately reflected recommendations in the guideline.
How were recommendations selected for inclusion in the patient version of the guideline?	The group held face-to-face meetings to select recommendations that patients would find helpful and could influence, for example choice of medication. Patient-important outcomes, patient values and preferences for a recommendation, and the need to consider these in the patient version, were discussed with the full guideline group during development of the guideline. The group agreed how much information on medication and side effects would be useful to help with decisions. The group discussed what other information would be required in the patient version to help with understanding the recommendations.
How did SIGN include information that was important to patients but not recommended in the guideline?	There were a few ideas for content from patients and the member of the public that did not come directly from the guideline. It was decided that these were important to include. So they were presented differently from recommendations, for example, not in recommendation boxes, to make this clear to the information users.
How did SIGN gather feedback on the patient version of the guideline?	The draft patient version was available for consultation for 4 weeks. The full guideline group, voluntary organisations and members of SIGN's patient and public involvement network were invited to provide feedback. Feedback was compiled into a consultation report and shared with the group responsible for developing the patient version. Feedback was used to improve the booklet.

How to select recommendations for inclusion in patient-directed knowledge tools

Patient-directed knowledge tools should prioritise the recommendations that patients can influence or discuss with their healthcare professional. For example, a

recommendation about how a pathologist should prepare a biopsy would not be helpful because patients would never be able to discuss this with the pathologist. Research conducted by DECIDE with patients and the public has shown that people would like recommendations about managing their own care. The challenge with this is finding a sensible way of selecting the recommendations that should be presented in patient-directed knowledge tools. The best way of doing this is to involve patients, their carers and the public in the selection of recommendations, either from within the guideline development group or through a parallel group working on patient-directed knowledge tools (SIGN 100 2019, van der Weijden 2019). Box 3 summarises the questions that can be used to aid selection of recommendations for inclusion in patient-directed knowledge tools. The case study in table 2 shows how recommendations were selected for inclusion in SIGN's guideline on migraine.

Being clear on the intended target group and situation, that is, when patients will receive patient versions of guidelines, is important because this will influence which recommendations should be included and how they should be presented. For example, will they receive it before a hospital appointment? Will they have the opportunity to discuss it with a healthcare professional? If a condition has been diagnosed before they get a patient version, it may not be helpful to include recommendations on diagnostics or risk factors.

Box 3 Questions to ask when choosing recommendations

- Do they highlight options for interventions or care?
- Do they assess harms and benefits of the intervention in question and empower patient to make informed decisions?
- Do they assess harms and benefits of the treatment intervention in question and empower patients to make informed decisions?
- Do they recommend lifestyle interventions and ways in which the patient can take steps to manage their condition?
- Do they identify treatments that have no evidence of benefit?
- Can the recommendations help patients to understand their own condition?

- Do patients and the healthcare professional see a need for intensive conversation?
- Do they address relevant situations of over- or underuse? (this is extremely relevant in the context of diagnostic or screening recommendations)
- Do they address adherence?
- Are there barriers to the implementation of the recommendation, that could be resolved through discussion with the patient (for example, safe use of medicines)?

After the development group has selected recommendations to be included in patient-directed knowledge tools, they should be translated into plain language to allow them to be easily understood by a wide audience. If further information is needed to understand the recommendations (like anatomy, physiology or other information), it should be provided either along with the recommendation or in specific sections or paragraphs.

Content for patient-directed knowledge tools

The information in patient-directed knowledge tools should reflect what is in the guideline. Only diagnostic and care options provided in the guideline should be included (SIGN 100 2019, van der Weijden 2019).

A series of focus groups and other qualitative work with patients and the public (DECIDE patients and public, SIGN 100 2019, Cronin et al. 2018) found that the following issues are considered important when using information from guidelines :

- Context: who is the information for?
- Background information about the condition:
  - What are the risk factors?
  - How will the condition progress?
  - How long will the condition last?
  - What is the risk of other problems arising from the condition?
- Information about the diagnostic and treatment interventions:

- What are the treatments, including the alternatives?
- What are the risks associated with treatments?
- What can I do for myself (that is, self-management)?
- Where can I find more help (for example, phone numbers and websites for sources of support)?
- How are guidelines produced?

Patient-directed knowledge tools, such as patient versions of guidelines, should highlight that there may be other well-known treatment options available but that they are not covered and thus not recommended by the guideline. This may be either because of lack of evidence, lack of resources and prioritisation or because they are outdated. This helps to clarify for patients that there are other options available but they have not been recommended by the guideline because of lack of evidence.

Additional information may be included in patient versions of guidelines if it helps to foster an understanding of the recommendations or supports self-management. Including information not directly linked to recommendations is of value and allows people to participate in shared decision making. If there is content in the patient version that is not in the guideline, this has to be made explicit. Furthermore, the guideline panel should check this type of information for consistency with the guideline. How the information was generated should be documented transparently (for example, based on patient experience, systematic search or qualitative research). The case study in table 2 explains how information that was important to patients but not recommended in SIGN's guideline was included in the patient version.

Tick boxes or other interactive tools are useful formats for information not linked to recommendations (DECIDE patients and public). Guideline producers committed to providing patient versions will need to consider each guideline individually to determine the intended purpose of the patient version and then decide on the content (van der Weijden et al. 2019).

Who is this information for?

Research has shown that people will often ignore health information if it does not seem to apply to their individual circumstances. Therefore, patient-directed

knowledge tools, such as patient versions of guidelines, should be clear about who the information is for. Making the applicability of a patient version of a guideline clear, using text such as 'what does this have to do with me?', is essential (DECIDE patients and public, Cronin et al. 2018, Loudon 2014, van der Weijden et al. 2019). However, around only half of current patient versions in the English language do this (Santesso et al. 2016). Figure 1 provides a simple example of how this can be done. It shows the information from a patient version in [SIGN's patient booklet on delirium](#), which explains who the booklet is for and what it is about. The context for using the booklet is clear; the information in the leaflet adds to the information provided by the people involved in a person's care. Although written for patients, the booklet acknowledges that family members and carers may also read it.

If treatment recommendations apply only to a specific type of disease, it is helpful to make it clear that only patients with this specific diagnosis will benefit from the information. For instance, a guideline for the treatment of exocrine pancreatic cancer will not be relevant to patients diagnosed with endocrine pancreatic cancer, although they themselves will not be aware of this difference. If there are subgroups that have a larger or lesser benefit from interventions, this should also be made clear in the patient version or knowledge tool.

Who is this booklet for?

This booklet is for you if:

- you are a relative or carer of someone who has delirium
- you are at risk of delirium
- you have experienced delirium.

What is this booklet about?

This booklet explains:

- what delirium is
- how to reduce the risk of experiencing delirium
- what it is like to have delirium
- how it is identified
- how it is treated
- the care provided.

This booklet describes recommendations in a clinical guideline, produced by the Scottish Intercollegiate Guidelines Network (SIGN), about how to reduce the risk of delirium and how to manage it when it occurs in adults. It applies to all care settings: home, long-term care, hospital, and hospice.

The clinical guidance is based on what we know from current medical research. It gives advice based on the opinion of healthcare professionals who are trained on how best to manage care for people with delirium. On page 24 you can find out how we produce guidelines.

Figure 1 Information from SIGN's patient version of the guideline on delirium

Downloading material from a guideline developer's website, or using an online tool, supports patients in discussing their care with healthcare professionals (Cronin et al. 2014, Utranker et al. 2018). Guideline producers should consider how the document might be used and word it accordingly.

Background information about the condition

Patients and the public have wider information needs than knowing the treatment options available for a particular condition or problem. When asked, many people thought guidelines could be a simple tool to provide health information, as well as recommendations (DECIDE patients and public). Focus group and user-testing work also found that participants had information needs that were more general than treatment recommendations. These included questions about whether the condition could be prevented, how it would progress, and would it lead to anything else. In particular, knowledge of progress and natural history of a condition may help to assess benefits and harms of different treatment options (DECIDE patients and public). Circumstances of the technical delivery of treatment options may influence the decision-making process (such as, weekly delivery instead of a single intervention, and inpatient instead of outpatient treatment or another arrangement).

Guidelines generally don't provide much of this sort of information as part of the standard guideline production process. For example, the [information for the public in the National Institute for Health and Care Excellence (NICE) guideline on depression in adults](#) (CG90 2009) contains little background information on depression. Guideline producers may have to make a choice between not providing information (even though patients and the public may want it) or doing extra work because their standard guideline production process does not routinely generate this information. Taking the former route may lead to information that is less useful than it could be. If taking the latter route, guideline producers may limit the need for extra work by asking patients on the guideline development group what information matters to them, especially those who are representing a wider group of patients. In the NICE depression guideline it was important to describe mild, moderate and severe depression because different recommendations are made for each type of depression. Some of this additional information may be sourced from the appropriate

patient information groups for use in patient-directed knowledge tools. Links to local sources of support for patients and the public can also be provided.

What are the treatments and risks associated with them?

Similar to in the section about background information, guideline producers will need to balance the amount of information to provide and what is available in the original guideline document. Again, producers may consider background information about the treatments or interventions that will assist people in understanding the recommendations and treatment implications (DECIDE patients and public, SIGN 100 2019).

What can I do for myself?

The importance of presenting recommendations that relate to self-management is one of the strongest messages coming from research with patients and the public (DECIDE patients and public). It also emerged in a review of patient and public attitudes to guidelines as one of the purposes of patient versions (Loudon et al. 2014). Relatively few patient versions of guidelines in the English language currently meet this need (Santesso et al. 2016). German patient versions have a mandatory section called living with the disease, in which recommendations for self-management are addressed.

Presenting recommendations linked to self-management are therefore ones to prioritise when deciding which recommendations to cover in guideline-based information. Guideline producers may also want to consider whether to provide additional information about how people could apply the recommendations in their daily lives. When presenting additional information alongside recommendations, it should be clear that this information is not evidence based and is based on patient or expert opinion. The guideline group should check that additional information is consistent with the guideline. However, additional information may be very helpful for other patients if based on patient experience (Schaefer et al. 2015). Guidelines rarely address issues that matter most to patients like treatment burden or the impact that a condition has on daily life and how to deal with that. Information reporting patient experience must be carefully checked to ensure that it contains no effectiveness claims regarding treatments.

The case in table 3 is based on a German guideline on gastric cancer. It shows an example of when patient knowledge and experience led to including additional information in a patient version that was more valuable for users than the guideline recommendations.

Table 3 Integrating patient experience in the German patient guideline on gastric cancer

What kind of patient experience did the patient guideline include?	There was a complete lack of evidence on what patients who had had surgery for gastric cancer should eat. The guideline did not address this question. However, the patient organisation involved stated that, based on their counselling experience, most patients reported that was the most important issue and barrier in their daily life and had much impact on their wellbeing.
How was this experience-based knowledge retrieved?	Based on collective experience retrieved through discussions in self-help groups, feedback from counselling (patient hotlines), and chats in patient forums, a patient group compiled a list of foods that seemed to be beneficial for patients after gastric surgery, and food that might be intolerable. They also provided experience-based strategies on how to start eating after surgery, and how to adapt nutrition to individual needs. This list was forwarded to the nutrition experts involved in developing the clinical practice guideline (CPG) and checked for plausibility.
How was the information presented in the guideline?	The patient version contained a chapter on nutrition. The introduction stated that the following information was not derived from the guideline but from patient experience. Important strategies and the lists of foods were presented. Information specialists checked that the wording was not directive but always reflected that the information was based on experience. For example, instead of writing 'Do not drink coffee' they suggested 'some patients have reported a bad experience with drinking coffee'.
How was this chapter received?	Patients reported that for them, this section contained the most helpful information of the whole patient version. This is especially important because this information was not in the CPG, indicating that information that truly helps patients may partly differ from guideline content.

Where can I find more help?

Many patient-directed knowledge tools provide links or contact information, such as telephone numbers for additional information and support, a need that has been highlighted by patients and the public (DECIDE patients and public). Those

developing guideline-based patient information should consider highlighting other sources of information including:

- contact details of relevant organisations
- relevant websites, including those focusing on financial benefits and returning to work
- other useful publications.

The sites or organisations listed in information should be reputable and assessed as providing high-quality support or information. Tools, such as the DISCERN questionnaire and the PEMAT, are a valid and reliable way for guideline developers to assess the quality of information provided by other organisations (DISCERN, Shoemaker et al. 2013).

Patient versions of guidelines might also provide practical advice, such as what to think of before an appointment with a doctor, or suggest questions to ask when talking to healthcare professionals. Patients involved in developing the patient version can compile their own experiences and offer tips on how to deal with the condition in daily life. For example, a patient version on diabetic foot problems could provide information on what to think of when buying shoes. This is an issue unlikely to be addressed by the guideline but which matters a lot to patients with diabetic foot syndrome. Also, patients involved in developing patient versions, as well as those involved in any wider consultation, can use their own experience and judgement to highlight further information they think would be important to other patients and information that goes beyond the information covered by the guideline. It should be clear in the patient version that further information is based on the experience of patients and not on a systematic search and appraisal of the evidence.

How are guidelines produced?

Patients and the public have very limited awareness of guidelines (Loudon et al. 2014, Sentell et al. 2013). When they are aware of them, they often think they are intended to restrict or ration the care available (van der Weijden at al. 2019). Research shows that some patients worry that guidelines might impair the relationship with their healthcare professionals by suggesting reduced confidence in them (Loudon et al. 2014). A patient version of a guideline is an opportunity to allay

these fears but care is needed to avoid providing too much, complex information about how the guidelines were developed. Some, but not all, people are interested in this information (DECIDE patients and public).

People have found process diagrams, such as the one in figure 2, useful and can help them to understand how information was produced. Although there are some differences in opinion, there is preference for this information to be at the back of the patient version. This is to ensure that the information that most people are interested in comes first, and those who want to can still navigate straight to the information on the guideline process (DECIDE patients and public). Nevertheless, patients taking part in German focus groups expressed a need to have this information at the beginning, because it would allow them to understand the extent to which the information that followed was reliable (Schaefer et al. 2015).
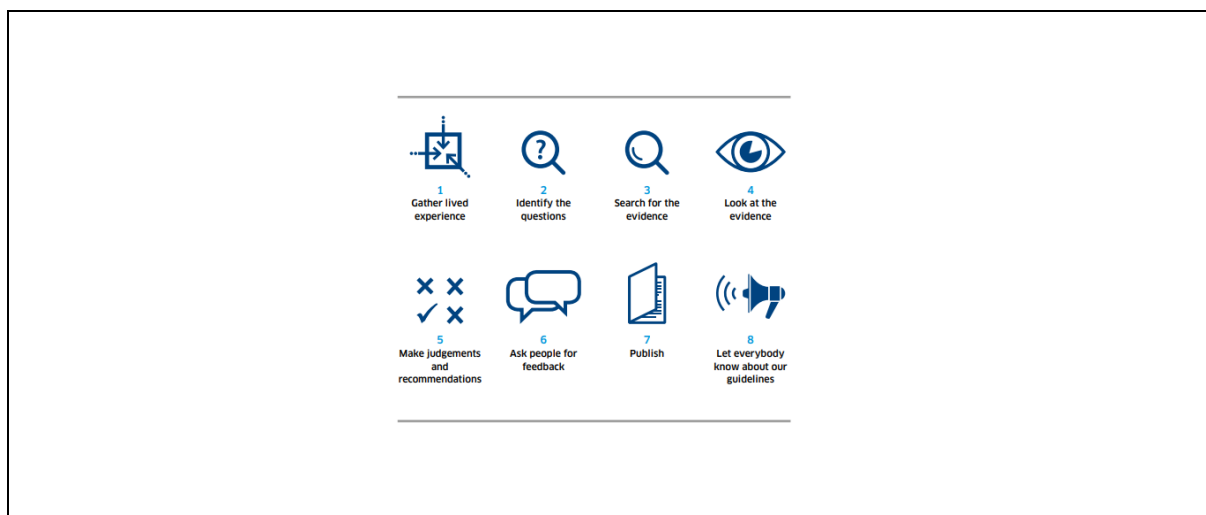

Figure 2 Example of a process diagram used by SIGN

Communicating the strength of a recommendation in patient-directed knowledge tools

Various standards for how to present recommendations advise that the strength of the recommendation and the level of evidence be presented separately (for example, a strong recommendation based on moderate quality evidence). The quality of evidence does, of course, affect the strength of the recommendation.

To enable patients to understand the strength of recommendations in patient versions, we suggest using several strategies, for example, using words and symbols. Some work has also indicated that people want to know why a recommendation is strong or not. Therefore, providing the reasons for a recommendation and what to consider may help.

Conveying the strength of the recommendation in words

Typically, guideline producers will use qualitative text to convey the strength of a recommendation in the original guideline document. For example, strong recommendations may be 'recommended' and weaker recommendations may be 'suggested'. Different guideline producers may use different labels to convey the strength of the recommendation. When using the GRADE approach, recommendations are labelled as 'strong', 'weak' or 'conditional' (Guyatt et al. 2008). It may be helpful, regardless of the system being used, to include a legend in the patient version for the definitions of the terms used (Ottawa Hospital Research Institute 2020).

Research, in particular with healthcare professionals, has indicated that words are interpreted differently (Nast et al. 2013). To minimise misunderstanding, guideline developers should include symbols, other labels and or reasons for the strength of the recommendation. The reasons may be based on the certainty of the evidence, the differences in people's preferences, resources or other issues, such as feasibility, accessibility or equity.

Using symbols to convey the strength of recommendations

Symbols were used in the [WHO's guideline on health worker roles in maternal and newborn health](#) (see figure 3). The guideline was aimed at a range of stakeholders (although not the public). The symbols were well received.

About the OptimizeMNH recommendations			
✅	✅ (dotted)	✖ (dotted)	❌
Recommended	Recommend with monitoring and evaluation	Consider in context of rigorous research	Recommend against
For more information, see www.optimizemnh.org			

Figure 3 Symbols in WHO's guideline on health worker roles in maternal and newborn health that were tested with the target audience

The solid green ticks are strong recommendations in favour of the intervention, and solid red crosses are strong recommendations against the intervention. The dotted ticks and crosses are weak recommendations for and against the intervention, respectively.

Having learned from work with patients and the public (Ottawa Hospital Research Institute 2020), SIGN uses a system of icons with text to flag recommendations and their evidence level. The symbols in figure 4 were adopted for SIGN's autism booklet for patients, carers and families of children and young people, which is the public version of the autism guideline.

There are four different types of recommendations in this booklet.

👍👍 **Strong recommendation** based on good-quality research evidence.

👍 **Recommendation** based on research evidence.

✔ **Recommendation** based on clinical experience.

❓ **Not enough research evidence** to tell us if something is of benefit.

Figure 4 symbols tested with parents and carers for SIGN's autism booklet

Use of symbols to express strength of evidence needs to be tested with the target audience. For example, parents and carers taking part in user testing of the symbols in figure 4, found the thumbs up, tick and question mark symbols clear and easy to understand. However, the response to the underlying 4 levels of evidence was mixed. Some parents appreciated the level of detail offered by the grades of evidence and recommendations, and others thought it would be sufficient simply to

know that SIGN recommended an intervention (DECIDE patients and public). The parents understood the essential message of the evidence levels, which is that one intervention is strongly recommended and another one less strongly recommended. But most did not understand why it is necessary to have these different levels of recommendation. Similarly parents found the not enough evidence icon disconcerting. Although they understood that the question mark and text was meant to convey uncertainty, they did not like this message, or understand why guideline producers would need to use it (DECIDE patients and public).

Presenting treatment options and communicating their risks and harms in patient-directed knowledge tools

Structuring the presentation

Structured presentations (especially with question and answer approaches) for presenting treatment options were well received and understood in work with patients and the public (DECIDE patients and public, Santesso et al. 2015). When summarising evidence on treatment options for patients and the public, a simple tabular format, as shown in figure 5, allows easy comparison and improves comprehension of treatment benefits and harms (DECIDE patients and public, Glenton et al. 2010, Loudon et al. 2014, Santesso et al. 2015, Santesso et al. 2016). 'No treatment' (doing nothing) should be considered and presented as an option to help people understand the benefits and risks of interventions. Presenting the benefits and harms for each option allows patients and the public to weigh these options against their personal values and preferences and can support conversations with healthcare professionals, something patients and the public have asked for (Santesso et al. 2016). It should be clear that information presented on the benefits and harms of treatment options is based on a systematic search and appraisal of the evidence.

What medication choices are available to me?

Medications		
Medicine	**Can I take if I'm pregnant?**	**Can I take if I'm breastfeeding?**
Antidepressants Selective serotonin reuptake inhibitors (SSRI) SSRI medications include paroxetine, sertraline and doxepin. Tricyclic antidepressants (TCAs)	**Yes** Paroxetine should not be the first choice during pregnancy. If you have already been taking it, your doctor will consider the risk and benefits to you and your baby. The doctor will then advise you to continue taking it or switch to another medication. It's not possible to say whether or not antidepressants increase the risk of miscarriage. There might be a low risk or no risk at all that SSRIs cause heart defects in babies.	**Yes** Sertraline or paroxetine are usually the first choice of antidepressants. But others may be chosen in some situations, for example, if you need to continue the medicine you took in pregnancy or you have depression that is hard to treat. You should avoid doxepin, fluoxetine, citalopram and escitalopram.

Medications		
Medicine	**Can I take if I'm pregnant?**	**Can I take if I'm breastfeeding?**
Anti-epileptic mood-stabilising medicine such as valproate.	**No** This medicine increases the risk of your baby having abnormalities, for example, spina bifida. If you have taken the medicine in early pregnancy, you may be offered extra ultrasound scans to monitor your baby's growth and development.	**Yes** If you need to take anti-epileptic medicines, you may still be able to breastfeed. The risks and benefits of taking these should be discussed with you.
Hypnotics and sedatives Medicines from the benzodiazepines group should not be stopped suddenly.	**Yes** If you already take these and your doctor thinks it would be useful to continue them during pregnancy, you should only take them for a short time and in the lowest dose possible.	**Should usually be avoided** They may make your baby sleepy and feel poorly. If they are needed, a short-acting drug should be prescribed in a low dose for a short time.

Figure 5 Example of presenting treatment options in SIGN's patient version of mood disorders in pregnancy

Using qualitative and quantitative statements about benefits and harms

Existing patient versions in the English language generally say little about potential benefits and harms of treatment options, and very few provide numerical information (Santesso et al. 2016). There is evidence that people's understanding of risk can be improved by presenting them with numbers rather than words and even when people say they prefer words, giving them both improves their understanding (Büchter et al. 2014, Knapp et al. 2014, Natter and Berry 2005). For numerical information, using absolute numbers, rather than relative numbers, and natural frequencies (for example, '50 of 100 people') are easiest to understand and are less confusing (Büchter et al. 2014, DECIDE patients and public, Knapp et al. 2014, Natter and Berry 2005). Evidence shows that patients and consumers overestimate risks when probabilities are presented in verbal terms. Using numbers results in more accurate estimates of risk (Büchter et al. 2014, Knapp et al. 2014, Natter and Berry 2005, Santesso et al. 2015, Trevana et al. 2013). There is good evidence, that presenting relative risk reduction alone leads to overestimation of treatment effects, so this should be avoided (Trevena et al. 2013). Although there is currently no certain way to present numerical information from guidelines to patients and the public, we

recommend guideline producers present information on benefits and harms and consider adding numerical information. Many people, although not all, would like to see such information on benefits and harms. Numerical information presented as a statement has been found to be more helpful than pictograms, but any numerical information should be tested with the target audience (Ottawa Hospital Research Institute 2020).

For qualitative text statements, standard text such as that shown in figure 6 provides consistency and includes both the size of the effect (for example, will not decrease, will decrease, probably decreases, may decrease, will not lead to more side effects) and the certainty and quality of the evidence (Büchter et al. 2014, Knapp et al. 2014, Natter and Berry 2005, Santesso 2015).

What happens to people who take vitamin C
This table provides more detail about what happens to people who take vitamin C. These numbers are based on the results of the research, when available. The quality of the evidence is either ranked as high, moderate, low or very low. The higher the quality, the more certain we are about what will happen.

What happens	Not taking Vitamin C	Taking Vitamin C (1 to 2 g per day)	Quality of evidence
Probably will not decrease how long the cold lasts if vitamin C taken as soon as the cold starts	The cold lasts **84 hours or 3 ½ days**	The cold lasts **2 fewer hours** (9 fewer to 4 more hours) *	⊕⊕⊕◯ Moderate
Will decrease how long the cold lasts if vitamin C taken before the cold	People at normal risk		⊕⊕⊕⊕ High
	The cold lasts **84 hours or 3 ½ days**	The cold lasts **7 fewer hours** (3 to 11 fewer hours)	
Probably decreases how long the cold lasts if vitamin C taken before the cold	People at high risk		⊕⊕⊕◯ Moderate
	The cold lasts **134 hours or 6 days**	The cold lasts **19 fewer hours** (8 to 30 fewer hours)	
Will not decrease the chance of catching a cold	People at normal risk		⊕⊕⊕⊕ High
	50 per 100 people	**49 per 100 people** (48 to 50 per 100)	
May decrease the chance of catching a cold	People at high risk		⊕⊕◯◯ Low
	70 per 100 people	**35 per 100 people** (27 to 46 per 100)	
Will not lead to more side effects	**6 per 100 people**	**6 per 100 people**	⊕⊕⊕⊕ High

Quality of evidence: The quality of the evidence is either ranked as high, moderate, low or very low. The higher the quality, the more certain we are about what will happen.
*The numbers in brackets show the range where the actual effect may be.

Figure 6 Format for presenting information from a Cochrane review of the effect of Vitamin C on the common cold in plain language (Hemillä et al. 2007)

Information about benefits and harms should refer to patient-relevant outcomes. Reporting on benefits could include controlling or getting rid of symptoms, prevention of recurrence, and eliminating the condition both short term and long term. Reporting on risks could include side effects, complications and adverse reactions to treatment, both short term and long term. Note that the harms of an option extend beyond clinical risks. For example, to make a treatment choice between radiation therapy and brachytherapy for prostate cancer, it may be important for some people that one

treatment is non-invasive and requires several sessions whereas the other is invasive and performed at a single session. If the effect of treatments on morbidity or mortality is unknown, this should be stated.

Presenting uncertainty

Patients and the public do want to know about uncertainty (Knapp et al. 2009). For example, how sure are we that X in 100 of those affected will have pain? This information can be understood if well presented. Most guideline producers will have a system to evaluate the quality or certainty of the evidence. Different systems such as symbols, words and letters may be used, and if not intuitive, it may be helpful to include a description of what the system means in the patient version.

In addition, if reference is made to treatments for which there is no or very low quality research, this should be made clear. It should not be confused with a treatment in which evidence has shown that the treatment has little to no effect. Figure 7 is an example of how SIGN has presented such information.

Dietary therapies

Not enough research evidence to tell us if something is of benefit

There is no evidence to suggest that special diets, vitamin supplements or mineral supplements can help to treat chronic pain.

Figure 7 Example from SIGN on presenting information about a treatment which is not supported by the evidence

Using graphical approaches to present information

Focus groups and user testing with patients and the public found that patients and the public liked graphics to break up the text, but that graphics and charts should be kept simple (DECIDE patients and public). Those who used numerical information to increase their understanding of the risks and benefits indicated a preference for the

information to be presented in pie charts. Evidence from a low-quality randomised controlled trial suggests that bars, pictographs and tables tend to be efficient tools to present numerical information (Trevena et al. 2013). The authors found that information seemed clearer when presented in this format. Simple bar charts were easily understood although they don't convey uncertainty. Graphs should present benefits and harms on the same scale and alternative treatment options should be reported for the same outcomes.

Formatting and style of patient-directed knowledge tools

There are many potential formats for patient information derived from guidelines and the format used should take account of the target audience. In addition to this, the choice of format will depend on the topic and budget available.

There is no one-size-fits-all approach to developing guideline-based patient information (DECIDE patients and public). But consider the information in the sections on using a layered approach, personalisation, accessibility, and colour, fonts and graphics.

Using a layered approach for presentation of information

The length of patient versions produced by different organisations varies, with them ranging from 2 to 3 pages to 40 or more pages. Patients and the public accessing information in guidelines don't want to be overwhelmed by the amount of information (Cronin et al. 2018, DECIDE patients and public, Loudon et al. 2014, Utrankar et al. 2018). A German qualitative study on a plain language version of a breast cancer screening guideline found that people consider a brochure of 15 or more pages as 'long' and that it makes no difference for readers if this 'long' brochure has 15 or 150 pages (Frauenselbsthilfe nach Krebs [Womens Health Coalition] 2012). People like information presented in layers, which means that they can read as much or as little as they want. A useful approach is to have short paper versions and longer electronic versions, with the latter in particular using a layered approach (Ottawa Hospital Research Institute 2020). However, people with chronic conditions may appreciate longer booklets that can be read and reread time after time, thereby accompanying them through the whole process of care (Frauenselbsthilfe nach Krebs [Womens Health Coalition] 2012). Exactly how much information should be

provided depends on the target group and may be discussed early in the development process.

The concept of layered presentation, that is, the most important information in the first layer, less important in the next layer, is one of the strongest findings on work with patients and the public (DECIDE patients and public). For paper documents, patients and the public could select the recommendations for inclusion in the document. In the German National Disease Management Guidelines Program, the most important information is presented in a short information 2-page leaflet. The leaflet then refers to a comprehensive brochure that provides in-depth information. An example is their [patient-information.de portal webpage on coronary heart disease](). If necessary, more than 1 leaflet on different topics can be derived from a sinlge guideline. For example, [SIGN's patient publications on the management of asthma]() present information from the guideline in various booklets, including a smaller booklet specifically on asthma in pregnancy. The flow of information in digital documents can be controlled by asking readers, who want more information on a topic, to click on text that has a link to another webpage or website.

Personalising the information

Many patient versions attempt to personalise the information provided. Participants in UK focus groups and user testing found personalisation useful because it makes it easier to think how the information is relevant to them. The same has been found in other fields (DECIDE patients and public, Glenton et al. 2010). The degree of personalisation that is possible and appropriate will be context specific.

The simplest personalisation is to have a statement at the beginning of the patient version saying to whom the information applies (see the [section who this information is for]()). Some patient versions use the words 'you' or 'I' in text or headings to refer directly to the reader. For example, a heading could be 'What you need to know', or 'How much fibre do I need?'

Other ways to personalise information include personal stories, or narratives, of people with the same problem (Hartling et al. 2010). But, personal stories are not without problems, particularly regarding how to select stories for inclusion. For example, should the aim be to provide balance, to downplay problems, or to

emphasise benefits? Selection of patient stories has proved difficult in decision-support work (Winterbottom et al. 2008). Evidence also suggests that personal stories may influence risk perception and lead to over or underestimation of treatment effects (Betsch et al. 2011, Betsch et al 2013, Winterbottom et al. 2008). So, if treatment or test options are presented in personal stories, it may be important to select the number of stories in proportion to their potential benefit. Furthermore, highly emotional narratives seem to have a greater impact on the perceived risk (Winterbottom et al. 2008).

In reality, it may be difficult to find the best story but readers do need to be able to connect with how information in patient versions affects them. Online websites focusing on patient views have been increasingly accessed and it might be helpful for guideline developers to signpost readers to popular websites, such as healthtalk.org or patientslikeme. These websites could provide personal stories for patient versions of guidelines.

Using quotations from people who have the condition may also be a useful way to personalise the information in patient versions and to engage readers (Loudon et al. 2014). Work with patients and the public highlights that patients find quotations useful, helping them to relate to the material (DECIDE patients and public). The use of quotations has the same challenge as using patient stories in terms of deciding which quotes to select. It may be difficult to find quotations that are consistent with the evidence base presented within the patient version. Figure 8 provides an example of quotations that SIGN used to personalise information in its guideline on managing diabetes.
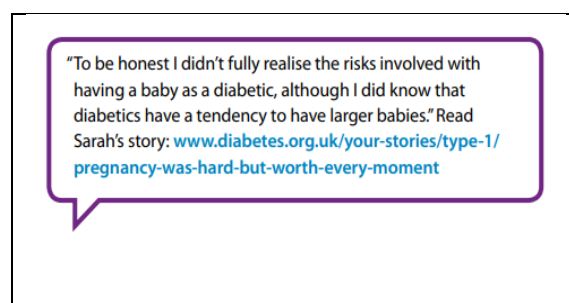
> "To be honest I didn't fully realise the risks involved with having a baby as a diabetic, although I did know that diabetics have a tendency to have larger babies." Read Sarah's story: www.diabetes.org.uk/your-stories/type-1/pregnancy-was-hard-but-worth-every-moment

Figure 8 Quotation to personalise information in SIGN's guideline on managinging diabetes

Ensuring accessibility

If the audience is segmented into different groups, it may be beneficial to have multiple formats to maximise accessibility and findability. This includes the availability of hard copies as well as online versions of the material, such as access through mobile phone application, patient portal and access, and social media (Cronin et al. 2018, DECIDE patients and public, Utrankar et al. 2018). More and more patients, including older people, search for health information on the internet.

It has also been suggested that information for patients and the public linked to guidelines could be embedded within the guideline itself. This would allow healthcare professionals to more easily access it when having conversations with their patients (DECIDE patients and public).

According to Santesso et al. (2016), about half of existing patient versions are intended to be printed (although they are also available as pdfs) and half are intended to be read on-screen (although they can also be printed). Increasing accessibility of these may mean translating the patient version into other languages, as well as making versions available in large print, as audio or video. For example, SIGN produced information from a guideline on perinatal exposure to alcohol in the form of a booklet for parents andcarers and a [YouTube video animation for young people on perinatal exposure to alcohol](#).

Guideline developers providing information in the form of web-based materials should ensure they are accessible for all. Careful consideration should be given to colour contrasts and making text clearer. Adding descriptions to images, which screen readers can then interpret, can give people access to all the information from guidelines. By adding descriptions to different command buttons, patients can more easily navigate the online information.

Patient information derived from guidelines should be easy to find. In Santesso et al.'s review (2016), the easiest patient versions to find were ones from a guideline organisation that also had a dedicated patient website. Of course not all guideline

producers can have a whole website, although it is still possible to make it easy to find patient versions. For example, by having a dedicated section of the guideline producer's website to list patient versions of guidelines. If the patient version is on another organisation's website, it should be easy for people to find it when searching for help on their condition. For example, [NHS Inform](#) (Scotland's single source of quality-assured health information) provides links to patient versions of guidelines on their website to help people to find them when searching for information on conditions. Evaluation of German patient versions has suggested that patients wanted healthcare professionals to forward the patient version to them (Schaefer et al. 2015).

If the patient version is designed for healthcare professionals to use in their conversations with patients, or to hand a printed copy to them, then it should also be simple for healthcare professionals to access. Therefore, it may be helpful to provide the patient version along with the guideline itself to ensure that healthcare professionals who look up the guideline will also find the patient version. Incentives for healthcare professionals to provide the patient version of the guideline may foster implementation. For example, a German survey found that most patients learned about patient versions of guidelines from their physicians (Schaefer et al. 2015).

Patients and the public have very low awareness of guidelines (Loudon et al 2014, Utramker et al. 2018), so it is likely that most people will not be looking specifically for guideline-related material when using, for example, internet search engines to find materials. Guideline producers may need to get professional help to assist them in getting 'hits' so that they reach their target audiences, and to ensure that the patient versions are indexed to their best advantage to allow search engines to find them. Patient organisations and other voluntary organisations should also be encouraged to promote patient versions of guidelines on their websites.

Patient information derived from guidelines should also be easy to read. Easy read is one form of accessible information. They use short, simple sentences and pictures to explain topics. For example, easy read documents provided by [Mencap on keeping clean and handwashing](#) help explain guidance during the Covid-19 outbreak.

The amount and level of technical terms that people are confronted with in patient versions of guidelines should be carefully considered (DECIDE patients and public) Health literacy varies and depends especially on socioeconomic status, education and ability to speak the language the patient version is written in, with lower levels of health literacy being associated with poorer health outcomes (Berry et al. 2010, Wolf et al. 2005). Plain language should be used, unless it is absolutely essential to use specialist language, so as to not exclude some of your audience. Using terms like 'lymphadenctomy' or 'types of pharmacological treatments' will make a leaflet or a brochure difficult to understand for many (perhaps most) of the people expected to read the material. On the other hand, these are the expressions patients may hear during their conversations with healthcare professionals. Health forums may also provide some indication of words that are presently being used by patients and the public. Current patient versions have provided terms and defined them in an understandable way, for example, in brackets after the term, separately in a box, or as part of a short glossary at the end of the document (both NICE and the German National Disease Management Guidelines Program do the latter for their guidelines).

Colour, fonts and graphics

The text size and colours used in graphics must be appropriate for the target audience (DECIDE patients and public).

Colours

Poor choice of colours can make a document hard to read; avoid using light text on light backgrounds and dark text on dark backgrounds. Some colour combinations may work better (or worse) on computer screens than in print.

Colour blindness affects about 1 in 8 men and 1 in 200 women, so should be considered when selecting colours for use in patient versions. Common types of colour blindness are:

- red/green colour blindness
- blue/yellow colour blindness

Avoid using these combinations of colours together. Similarly, the use of pale pastel colours is not helpful for people with visual impairments (DECIDE patients and public).

The use of colour can also convey meaning, which may not be what is intended. Black can sometimes be associated with death and red can be seen as highlighting danger (DECIDE patients and public). Inconsistent use of colour in documents can be confusing (DECIDE 2011 – 2015). Colour coding recommendations can be problematic and are required to take into account people's pre-existing associations with colour, for example, red for stop, green for go (DECIDE patients and public). The way that colour is used to differentiate between recommendations needs to be clear in patient versions of guidelines (DECIDE patients and public).

Fonts

A font with a clear design should be used to ensure accessibility. Use a minimum font size of 12 pt for standard versions and a minimum font size of 16 pt or larger for large print.

Graphics

Give careful thought to the use of graphics. Patients and the public like the text to be broken up (DECIDE patients and public), but the graphic should carry useful information, not simply be a decorative element.

The way information is presented can affect perceptions of its trustworthiness. Using cartoons in a physical activity patient version, for example, meant that people had less trust in the information it contained; indeed it led people to question whether adults were the target audience at all (Berry et al. 2010, Loudon et al. 2014). However, cartoons have been helpful when addressing people with learning disabilities. Logos can help if these are a recognised 'brand' for patients and the public, but too many becomes overwhelming and may be counter productive (DECIDE patients and public).

Table 4 provides some tips for using graphics.

Table 4Tips for using graphics in patient versions

Use	Avoid
• Graphics relevant to the topic to illustrate what the patient version is about • Annotated diagrams to explain conditions • Images to break up the text to make the patient version patient friendly • Metaphorical images such as a blocked pipe to illustrate blood clot	• Graphics that may be upsetting or patronising • Complex, technical diagrams • Cartoons, because these are difficult for patients to identify with • Too many logos, which can be confusing for patients and distracting

Ensuring transparency in patient-directed knowledge tools

The authors and organisations producing patient-directed knowledge tools should declare their financial and intellectual conflicts of interest (COI). This includes patient or consumer representatives and their organisations. It should be clear what influence, if any, individuals and organisations had, or could be perceived to have had, on the content of the patient version. The same COI declaration forms as used for guideline development groups may be used, showing that patient versions are linked to the guideline not only in terms of content but also in terms of methods and transparency. If all authors of the patient version have already been part of the guideline panel, a new declaration of COI might not be necessary.

Evaluating patient-directed knowledge tools

Users of patient-directed knowledge tools should be encouraged to provide feedback on the information. Feedback should be collected and considered when updating the information. Ways to collect feedback may include a structured questionnaire at the end of the information, tests with focus groups, or surveys. It can also be useful to ask for feedback from other stakeholder groups, because they might be able to assess the extent to which the patient-directed knowledge tool helped their patients who are members.

Getting feedback on patient versions of guidelines

Asking a wider group of patients and public for input and feedback on the patient version can help ensure it is accessible to the target audience (SIGN 2019, van der

Weijden et al. 2019). The chapter on how to conduct public and targeted consultation provides more details. The purpose of collecting feedback is to ensure the patient version:

- Provides useful information that helps patients make decisions.
- Provides patients with further experience and support regarding coping strategies or other issues that are not covered by the guidelines, but may matter to patients in their daily life. These can be provided directly in the patient version or indirectly through links to sources of further information and support.
- Is seen as relevant to patients and consumers.
- Has a useful layout that patients can effectively navigate.
- Uses appropriate language, fonts and graphics.

Various methods can be used to obtain feedback, depending on the intended audience and the intended goals. For example, an open consultation can help to foster ownership and transparency, whereas workshops can help to obtain specific feedback on relevance to readers and their level of understanding. Other methods include:

- Circulation of the document to guideline developers' own patient or consumer networks and voluntary organisations for written comment.
- Use of discussion groups to provide feedback, for example a discussion group with children and young people may be more effective than written consultation.
- Consulting patient organisations who have broad experience with patient counselling and collect data on individual experiences.

An example of questions guideline developers may want to ask patients and consumers is given in appendix 6.1. To ensure transparency, the methodology and process of development should be well documented. The case study in table 2 shows how SIGN gathered feedback on their patient version of the migraine guideline.

Acknowledgements

The authors would like to thank the following for their contributions to this chapter:

References

Association of the Scientific Medical Societies in Germany (AWMF) – Ad Hoc Commission on "Deciding Wisely Together" (2020) [A manual on developing recommendations within the "Deciding Wisely Together" Initiative. Version 1.3 of January 2020](#)

Berry TR, Witcher C, Holt NL et al. (2010) A qualitative examination of perceptions of physical activity guidelines and preferences for format. Health Promotion Practice 11(6): 908–16

Betsch C, Renkewitz F, Haase N (2013) Effect of narrative reports about vaccine adverse events and bias-awareness disclaimers on vaccine decisions: a simulation of an online patient social network. Medical Decision Making 33(1): 14–25

Betsch C, Ulshöfer C, Renkewitz F et al. (2011) The influence of narrative v. statistical information on perceiving vaccination risks. Medical Decision Making 31(5): 742–53

Büchter RB, Fechtelpeter D, Knelangen M et al (2014) [Words or numbers? Communicating risk of adverse effects in written consumer health information: a systematic review and meta-analysis](#). BMC Informatics and Decision Making 14: 76

Cronin RM, Mayo-Gamble TL, Stimpson S-J et al. (2018) [Adapting medical guidelines to be patient-centered using a patient-driven process for individuals with sickle cell disease and their caregivers](#). BMC Hematology 18:12

DECIDE (2011 – 2015) [Interactive summary of findings (iSoF) table](#)

[DECIDE (2011 – 2015) Patients and public](#)

DISCERN online [Quality criteria for consumer health information](#)

Dreesens D, Stiggelbout A, Agoritsas T et al. (2019) A conceptual framework for patient-directed knowledge tools to support patient-centred care: Results from an evidence-informed consensus meeting. Patient Education and Counseling 102(10): 1898–1904

Frauenselbsthilfe nach Krebs [Womens Health Coalition] (2012) Inanspruchnahme des qualitätsgesicherten Mammographie-Screenings: Follow-Up Studie 2012; wissenschaftlicher bericht

Giguere A, Légaré F, Grad R et al. (2012) Decision boxes for clinicians to support evidence-based practice and shared decision making: the user experience. Implementation Science 7:72

Glenton C, Santesso N, Rosenbaum S et al. (2010) Presenting the results of Cochrane Systematic Reviews to a consumer audience: a qualitative study. Medical Decision Making 30(5): 566–77

Guyatt GH, Oxman AD, Vist GE et al. (2008) GRADE: an emerging consensus on rating quality of evidence and strength of recommendations. British Medical Journal 336(7650): 924–6

Hartling L, Scott S, Pandya R et al. (2010) Storytelling as a tool for health consumers: development of an intervention for parents of children with croup. Stories to communicate health information. BMC Pediatrics 10: 64

Hemilä H, Chalker E, Douglas B (2007) Vitamin C for preventing and treating the common cold. Cochrane Database of Systematic Reviews 3: CD000980

Knapp P, Gardner PH, Carrigan N et al. (2009) Perceived risk of medicine side effects in users of a patient information website: a study of the use of verbal descriptors, percentages and natural frequencies. British Journal of Health Psychology 14(3): 579–94

Loudon K, Santesso N, Callaghan M et al. (2014) Patient and public attitudes to and awareness of clinical practice guidelines: a systematic review with thematic and narrative syntheses. BMC Health Services Research 14:321

Nast A, Sporbeck B, Jacobs A et al. (2013) Study of perceptions of the extent to which guideline recommendations are binding: a survey of commonly used terminology. Deutsches Arzteblatt International 110(40): 663–8

National Institute for Health and Care Excellence (2009) [Depression in adults: recognition and management. Information for the public](). NICE clinical guideline 90

Natter HM, Berry DC (2005) Effects of presenting the baseline risk when communicating absolute and relative risk reductions. Psychology, Health & Medicine 10(4): 326–334

Ottawa Hospital Research Institute (2020) [Patient Decision Aids]()

Santesso N, Morgano GP, Jack SM et al. (2016) Dissemination of clinical practice guidelines: a content analysis of patient versions. Medical Decision Making 36(6): 692–702

Santesso N, Radar T, Nilsen ES et al. (2015) [A summary to communicate evidence from systematic reviews to the public improved understanding and accessibility of information: a randomized controlled trial](). Journal of Clinical Epidemiology 68(2): 182–90

Schaefer C, Brunsmann F, Siegert S (2017) Verlässliche Gesundheitsinformationen zu seltenen Erkrankungen: Die Anforderungen des Nationalen Aktionsplans und deren praktische Umsetzung [Reliable health information for patients with rare diseases: Quality demands defined by the National Action Plan and how they are put into practice]. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz 60(5): 510–6

Schaefer C, Zowalla R, Wiesner M et al. (2015) Patientenleitlinien in der onkologie: zielsetzung, vorgehen und erste erfahrungen mit dem format. Zeitschrift Für Evidenz, Fortbildung Und Qualität Im Gesundhwesen. 109(6): 455–51

Scottish Intercollegiate Guidelines Network (2017) [Autism. A booklet for patients, carers and families of children and young people]()

Scottish Intercollegiate Guidelines Network (2019) [SIGN 100: A handbook for patient and carer representatives]()

Scottish Intercollegiate Guidelines Network (2020) [Delirium. A booklet for people who have experienced delirium, and for their carers]()

Sentell T, Braun K L, Davis J et al. (2013) Colorectal cancer screening: low health literacy and limited English proficiency among Asians and Whites in California. Journal of Health Communication 18(Suppl 1): 242–55

Schwartz LM, Woloshin S, Welch HG (2007) The drug facts box: providing consumers with simple tabular data on drug benefit and harm. Medical Decision Making 27(5): 655–62

Shoemaker SJ, Wolf MS, Brach C (2013) The Patient Education Materials Assessment Tool (PEMAT) and User's Guide. (Prepared by Abt Associates, Inc. under Contract No. HHSA290200900012I, TO 4). Rockville, MD: Agency for Healthcare Research and Quality; November 2013. AHRQ Publication No. 14-0002-EF. Agency for Healthcare Research and Quality

Stacey D, Légaré F, Col NF et al. (2014) Decision aids for people facing health treatment or screening decisions. The Cochrane Database of Systematic Reviews 1: CD001431

Stacey D, Suwalska V, Boland L et al. (2019) Are patient decision aids used in clinical practice after rigorous evaluation? A survey of trial authors. Medical Decision Making 39(7): 805–15

The Dartmouth Institute Option Grid decision aids

Trevena LJ, Zikmund-Fisher BJ, Edwards A et al. (2013) Presenting quantitative information about decision outcomes: a risk communication primer for patient decision aid developers. BMC Medical Informatics and Decision Making 13(Suppl 2) S7

Utrankar A, Mayo-Gamble TL, Allen W et al. (2018) Technology use and preferences to support clinical practice guideline awareness and adherence in individuals with sickle cell disease. Journal of the American Medical Informatics Association 25(8): 976–88

Van der Weijden T, Dreesens D, Faber MJ et al. (2019) Developing quality criteria for patient-directed knowledge tools related to clinical practice guidelines. A development and consensus study. Health Expectations 22(2): 201–8

Winterbottom A, Bekker HL, Connr MT et al. (2008) Does narrative information bias individual's decision making? A systematic review. Social Science and Medicine 67(12): 2079–80

Wolf MS, Gazmararian JA, Baker DW (2005) Health literacy and functional health status among older adults. Archives of Internal Medicine 165(17): 1946–52

Resources: appendix xx