

How to find and use research on patient and public views

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Key messages

- Evidence about patient or public views can come from many sources, including research that is already published (such as from studies, reviews, and grey literature).
- Research can be used at all steps of the guideline development process - from scope and priority setting to dissemination and use.
- Both quantitative and qualitative research on patient or public views can provide relevant evidence.
- Several factors will influence how to plan for effective and efficient use of research evidence, such as: the sources, amount and relevance of the evidence; the resources available; and the potential impact of the evidence on the guideline and recommendations.
- Methods to identify, synthesise, assess, present and, most importantly, incorporate research on patient or public views are relatively new, but tools are currently available.

Top tips

- Consider using research, whether in traditional published sources or in reports, as part of a strategy to include patient or public views in a guideline.
- Balance the potential impact of and resources for using research about patient or public views in the various stages of the guideline process.
- Use current methods to find, synthesise, assess and present research about patient or public views. When not possible, be transparent about the methods used.

- When using previously published research, additional time may be needed to assess the relevance of the research to the guideline and specific recommendations.
- For a more efficient process, search for and use previously synthesised research rather than conducting a new evidence synthesis.
- Remember to clearly document in the guideline and recommendations how evidence for patient views was used.

Aims of this chapter

This chapter provides practical advice on how to incorporate research evidence on patient or public views in all stages of the guideline process. It is not a review of the literature about how patient or public views are not widely included in guidelines, nor a summary of where further exploration of methods are needed. This chapter is meant to assist guideline developers to find, summarise and use research about patient or public views that is already available in order to develop a guideline. The term ‘patient or public views’ (from this point referred to as ‘patient views’) covers several different terms currently in use, including values, preferences, experiences, perspectives, opinions and attitudes. There are many ways to gather information about patient views to inform the guideline development process and the evidence used to make decisions, including by engagement (see the chapters on how to conduct public and targeted consultation and how to recruit and support patients and the public, and overcome barriers to their involvement in guideline development). However, this chapter focuses on evidence from research that has already been conducted or published, whether in peer-reviewed journals or as research reports and other on-line documents. Methods for when and how to find evidence for patient views are relatively new, and we provide guidance based on what is currently known and being done, as well as references for more detailed guidance and other chapters in the toolkit.

This chapter answers the following questions:

- How can we plan for using research about patient views?
- At what stage of the guideline development process can research about patient views be used?
- What types of research can provide evidence about patient views?
- How can we search for research about patient views?
- How can the certainty of evidence on patient views be assessed?
- How can the research be summarised and presented for use?
- How can the research evidence be summarised in the guideline?
- What to do when no methods are available?

How can we plan for using research about patient views?

When making a plan on how to use research about patient views, you will need to balance resources, skills and time with the potential impact of that information on the guideline recommendations. Table 1 summarises the factors to balance when planning to use research about patient views.

Resources needed will depend on the evidence sources, and the amount and type of research available. Evidence about patient views can come from many sources (for example, journals, databases, websites, reports), consist of sparse individual studies or several reviews, span various study designs, and range in their relevance to the guideline topic. So, the plan could require a few to many resources to identify, synthesise, assess, present, and incorporate it into a guideline. The resources needed will also depend on whether the guideline group has capacity to use other methods to gather the evidence. If the existing evidence is limited in scope or relevance, guideline groups may decide to gather their own information about patient views through consultation with an advisory group, guideline panel members, or the general public. Or, they may gather information through primary research by conducting focus groups and interviews. Generally, consultation and primary research may provide evidence that is directly applicable to the guideline, whereas using research that has been previously conducted or published could not be as directly applicable.

In addition, the research could have limited or considerable impact on the guideline recommendations. If there is little debate about the value patients consistently place on the outcomes critical for decision making, meaning that it would be likely to have little impact on the final recommendation, a guideline group may determine that searching for this research evidence may not be an efficient use of resources.

Table 1 Factors to balance when planning to use research about patient views

| | |
|----------------------------|---|
| Resources | The time, budget, and expertise available to gather, synthesise, assess and present the research. |
| Impact | The research could have a large or small impact on the final recommendations. |
| Sources | Available sources of research may be different depending on the topic (for example, databases, websites, organisations). |
| Amount | The amount of research, which can range from sparse to many systematic reviews. |
| Relevance | How applicable the available research evidence may be to the guideline topic or specific recommendation. |
| Alternative sources | The capacity and resources to obtain patient views from other sources, such as by patient consultation or by conducting primary research. |

At what stage of the guideline development process can research evidence about patient views be used?

Evidence about patient views and experiences can be used throughout the development of a guideline, including its recommendations. This section provides an overview of the development stages with a brief description relating using research on patient views to each stage. (The sections on how research can be summarised and presented for use, how research evidence can be summarised in the guideline, and what to do when no methods are available provide more detail about how to incorporate this evidence.) Each step in the guideline development process is illustrated in figure 1, from the [GIN-McMaster Guideline Development Checklist](#) (2014). Although research evidence can be used at all stages, most opportunities are in the inner area of the diagram (outlined by the black box and from Question Generation to Dissemination & Implementation), because many of the stages on the outer perimeter (including Priority Setting, Organisation, and Conflict of Interest Consideration) will be predetermined by macro- and organisational level decisions.

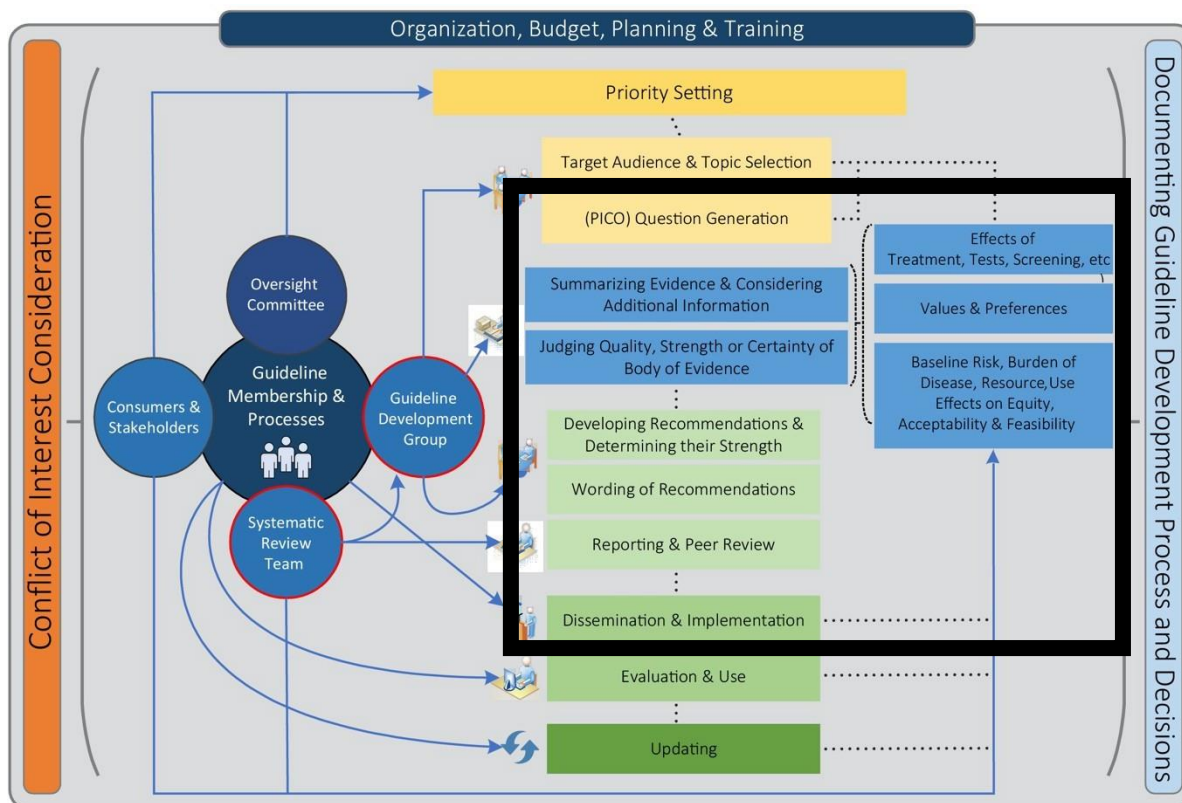


Figure 1 Diagram outlining stages of guideline development provided in the [GIN-McMaster Guideline Development Checklist](#)

One of the earliest and most important steps to ensure the usefulness of a guideline and its recommendations is answering **questions** that stakeholders (for example, practitioners, policy makers, patients and public) have about a topic. Typically, a guideline group will generate a list of questions about the interventions or tests that should be covered, and the **important outcomes** for which evidence is needed. The questions and the outcomes identified will in turn determine the direction of the systematic reviews to **summarise the evidence**. The group, however, may need to prioritise that list when there are many questions. Guideline developers can consult and conduct their own research with patients and the public, and key population groups, to determine what is important to them (see the chapter on how to conduct public and targeted consultation). However, before embarking on this research, developers may investigate what research is already available (published in

traditional journals or in the grey literature in patient organisations and websites) to inform their own research and avoid conducting new research.

When **developing recommendations**, a guideline group will consider the evidence for benefits and harms of an intervention or test, and in doing so will need to consider the **magnitude of the benefit or harm** and the **value** placed on those outcomes. For example, suppose the question is about whether to recommend a new intervention to prevent cancer that may also have some side effects? The new intervention may reduce the risk of cancer by 5/100,000 over 20 years, but increase the risk of a debilitating stroke by 10/100,000. If the values placed on the risk of cancer and strokes are equal, then the new intervention may not be recommended because it increases strokes. However, if the value placed on the risk of cancer is greater than the value placed on a stroke, then the recommendation may be to provide the new intervention. This is because, although there are fewer cancers, reducing the risk of cancer has a greater weight than the risk of strokes. Another consideration is whether patients value outcomes differently from each other, which may also have an impact on weighing the benefits and harms. It is clear from this example, how important it is to consider the value placed on outcomes. But developers may not consider this information and, in particular, may not consider the value that patients place on those outcomes (Gärtner et al. 2019).

Considerations of the effects of interventions is 1 component of developing recommendations for which evidence should be summarised. But other factors, such as acceptability and burden of an intervention to stakeholders, costs and resource use, effects on equity, and feasibility, will also need to be considered. The Evidence to Decision framework can be used to help guideline groups move from evidence to making recommendations or /decisions by considering all of the factors (Alonso-Coello et al. 2016). To illustrate the importance of summarising and using this type of information, consider that there may be evidence that 1 intervention is more **acceptable** to (or preferred by) most patients because it involves less burden. For example, patients might prefer a single intramuscular injection every 6 months rather than a pill once daily. This preference could have an impact on whether 1 intervention is recommended rather than another. In the same way, **costs and resources** may influence recommendations. If patients consider a new intervention

to prevent cancer more costly compared with a currently used intervention, decision makers may decide to recommend against it. In another example, if an intervention is more **accessible** with good uptake by patients, for example, in poorly-resourced settings (potentially increasing **equity** as well), a guideline group may consider recommending it rather than less accessible treatments. Or the guideline group may consider how to make other treatments equally accessible.

Information from research on patient views about the challenges when **disseminating and implementing** recommendations may also be used to inform the guideline. Some research has indicated that the wording of recommendations can have an impact (Gagliardi et al. 2011). For example, the language used, if appropriate to the context of the specific patient population, may predict the success of implementation. Therefore, research on terminology and phrasing for patients on a topic or disease area may be helpful when **writing recommendations** (see more in chapter about how to develop information from guidelines for patients and the public)]. In addition, research evidence about different strategies to reach patients that is related to the guideline topic will also be useful when a guideline group is determining how to disseminate and implement their specific guideline and recommendations to the target population. Examples include use of decision aids, pamphlets, or social media. (See more in the chapter on involving patients and the public in guideline dissemination and implementation.)

What types of research can provide evidence about patient views?

Published and unpublished research about patient views can come from a single study or from a systematic review, and can include of a variety of study designs for different purposes:

- qualitative research, such as interviews and focus groups
- surveys
- comparative studies (non-randomised and randomised)
- studies providing utility and non-utility estimates for an outcome, and
- studies that determine minimally important differences (MIDs) in an outcome.

Qualitative research studies

Information about patient views will often come from qualitative research studies, such as interviews and focus groups. This evidence can highlight areas of concern to patients, which may inform the scope of the guideline, the significance of guideline questions, the relative importance of outcomes, and acceptability of interventions. In turn, these concerns can be considered by the guideline group when deciding which questions and outcomes to address, and when incorporating values and other factors into recommendations. For example, in a guideline about different care models for people with haemophilia, a qualitative study, consisting of interviews with patients and the results of a thematic analysis, was published (Lane et al. 2016). The study reported important aspects to patients related to different models of care, 2 of which were equal access to comprehensive models of care, and the perception that integrated care is better. Consequently, when making the recommendation for the integrated care model, the guideline panel included additional guidance about overcoming system level and patient level barriers to ensure equal access.

Surveys

Surveys can provide valuable information about patient views. In particular, surveys are often used to ascertain the important questions patients have about a topic. An example of a primary study is an online self-administered survey of members of the Canadian Osteoporosis Patient Network, who were asked what priority interventions should be covered in a new guideline for osteoporosis management (Morin et al. 2020). Over 1,000 people rated interventions, such as physical activity or nutrition, from '1 = not important' to '5 = critical'. The ratings were used to prioritise topics for the new guideline. Published surveys can also be used to determine the important outcomes to review for a particular question. The [Core Outcome Measures in Effectiveness Trials \(COMET\)](#) initiative is a database of studies, including surveys, that identifies outcomes to measure and report in trials for different health conditions. The surveys can be used to inform guideline developers about which outcomes should be covered in the systematic reviews and should be weighed when making the recommendations.

Comparative studies

Although quantitative research is typically used to determine the effects of interventions and tests, comparative studies can also include outcomes directly

related to patient views. Acceptability of an intervention can be assessed in participants and compared between a group that receives the intervention and a group that does not. Whether patients experience barriers or other challenges because of costs, resources, equity or feasibility issues can also be measured and compared between groups. Both randomised controlled trials and comparative non-randomised studies may provide this evidence. For example, for a World Health Organization (WHO) guideline with recommendations on treatments for precancerous lesions, the guideline group was considering whether to recommend 1 surgical treatment (loop electrosurgical excision procedure) rather than another (cryotherapy). A randomised controlled trial measured important health outcomes with either treatment and also how many participants felt the procedure they received was acceptable (Chirenje et al. 2001). Acceptability was found to be similar and contributed to the decision of the guideline group to suggest treatment with either procedure.

In another WHO guideline, recommendations for treatment of chlamydia were made. Randomised controlled trials provided information about the difference in effects of various treatments and adherence to those treatments. The information about adherence was used to inform decisions about patient preference for single-dose compared with multi-dose regimens (Hillis et al. 1998)

Studies providing utility and non-utility estimates

Studies may also quantify the value placed on an outcome as utility and non-utility estimates. The use of these estimates in guideline development is relatively new and methods for incorporating this evidence are still being developed (Zhang et al. 2017). Essentially, studies will use different methods to measure utilities (such as Standard gamble or Time trade off) and report the utility of a health state (for example, a health outcome) on a scale from 0 (death) to 1 (perfect health). When comparing utilities for different outcomes, guideline groups could consider outcomes with lower utilities as an indicator of less desirable outcomes that may carry greater weight when balancing effects, and a wide range in a utility score as an indicator that patients may not value the outcome (or health state) similarly.

Studies that determine MIDs

Another type of study related to patient experiences and views is a study that measures MIDs, defined as the smallest change, either positive or negative, that patients perceive as important (Schünemann and Guyatt 2005). This information can be used by guideline developers to interpret the magnitude of the effect of an intervention on an outcome. For example, in a guideline comparing a surgical procedure with non-operative treatment for shoulder pain, studies were available that determined the MIDs for instruments used to assess shoulder pain, function, and health-related quality of life (Hao et al. 2019). When the guideline panel had to decide how large the benefits of the surgery were and how large the harms were, they used the MIDs identified by patients. They determined that the magnitude of the benefits of surgery were less than the MIDs, and magnitude of the harms were greater than the MIDs, and therefore recommended against the surgery.

Systematic reviews

Finally, guideline groups can use the evidence from any of the above studies individually or synthesise such studies. If a systematic review of these studies is already available, that may be preferable because it reduces time and resources necessary to gather evidence about patient views. It could also save resources if there is a diverse or large body of evidence already available. When searching for systematic reviews, guideline groups should be aware that there is no standard for reviews of patient views, and groups will likely need to delve into the reviews for the details. Systematic reviews will have different purposes and therefore specific inclusion and exclusion criteria that guideline developers will need to assess as relevant before using the reviews. Systematic reviews may

- cover broad questions about patient views related to priority questions (see the series about how to use this type of review [Downe et al. 2019])
- cover all factors related to patient views, such as values, and acceptability and equity issues (see the series on how to use this type of review [Lewin et al. 2019])
- cover implementation issues (see the series about how to use a review for this topic [Glenton et al. 2019], and box 1 for an example), or
- restrict types of study designs included, such as qualitative research (see the series on how to use this type of review [Lewin et al. 2019]).

BOX 1: A systematic review of patient values and preferences

The American Society of Hematology developed guidelines for management of venous thromboembolism (VTE) disease. There are important trade-offs in VTE management, in particular, because interventions that reduce the risk of thrombosis increase the risk of bleeding. A systematic review of patient values and preferences related to VTE was conducted (Etxeandia-Ikobaltzeta et al. 2020). Multiple databases were searched for both quantitative and qualitative studies.

When summarising the data, the authors combined the results of quantitative and qualitative studies, and also conducted a separate analysis of the themes and quotes from the qualitative studies. The evidence from quantitative studies included utility estimates for outcomes (for example, deep vein thrombosis, gastrointestinal tract bleeding), and non-utility estimates about outcome priorities (for example, VTE risk reduction), willingness to accept a particular intervention (for example, treatment burden of vitamin K agonists), treatment method preference (for example, injection compared with oral medication), and testing method preference (for example, thrombophilia testing). The qualitative studies provided important information from patients related to disease treatment benefits and burden, healthcare provider communication and relationships, awareness and perceptions of risk, and day-to-day routines. Overall, the evidence suggested that patients put higher value on VTE risk reduction than on the potential harms of the treatment, and likely prefer oral medication rather than subcutaneous medication.

The guideline panel used this information to inform the:

- values placed on outcomes and whether the values are consistent across populations, and
- acceptability and feasibility of the interventions when making the recommendations and writing additional guidance about implementation.

When systematic reviews are not available, a guideline group may decide to conduct their own systematic review. In this chapter, we do not provide details of how to conduct a systematic review, but we will describe some of the unique elements pertaining to syntheses of research about patient views in the next sections. For details about how to conduct systematic reviews that include a variety of different study designs, the resources in table 2 may be helpful.

Table 2 Resources for how to conduct systematic reviews

| Type of systematic review | Guidance for conducting the review |
|---|---|
| Review of randomised and non-randomised studies | Cochrane Handbook |
| Synthesis of qualitative research | Cochrane Handbook: Chapter 21: Qualitative evidence Additional guidance – Cochrane Qualitative & Implementation Methods Group |
| Synthesis specific to quantitative patient values | General guidance: Zhang Y, Coello PA, Brožek J et al. (2017) Using patient values and preferences to inform the importance of health outcomes in practice guideline development following the GRADE approach . Health Quality Life Outcomes, 15: 52 |
| Overviews of reviews | Cochrane handbook: Chapter 5: Collecting data |
| Rapid reviews | Cochrane Rapid Reviews Methods Group |

How can we search for research about patient views?

Evidence for patient views and preferences may be found by searching traditional databases, such as Medline, Embase or the Cochrane Library. Other sources of this evidence may include:

- grey literature, such as health technology reports (whether indexed or not)
- patient organisation websites and forums
- professional organisation websites (in particular, in other guidelines), and
- research sites.

The [James Lind Alliance website](#), for example, is dedicated to communicating research priorities and can inform questions about topics of interest to patients.

Finding research about patient views in the published literature can be challenging, but some work has been done to create standard search strategies for key databases that can focus the search. The choice of strategy may often depend on the breadth of your topic area (for example, broad strategies may be appropriate in very specific diseases or conditions). Or the choice may depend on the expected types of studies conducted on the topic (for example, search strategies with specific terms for qualitative research or for studies measuring utilities are available). Guideline groups will need to consider their time and resources when choosing a strategy. A restricted search rather than a comprehensive search may be best if resources are limited (see table 3). When searching within specific organisation websites or in Google, for example, guideline groups could also consider using terms that are similar to those used in the strategies in table 3.

Table 3 Search strategies to find research in traditional databases related to patient views able

| Search strategy | |
|--|---|
| Search strategy to systematically identify evidence addressing views and preferences with terms specific to different study designs | Selva A, Solà I, Zhang Y et al. (2017) Development and use of a content search strategy for retrieving studies on patients' views and preferences . Health and Quality of Life Outcomes 15(1):126 |
| Search strategy from Scottish Intercollegiate Guidelines Network (SIGN) for publications related to 'patient issues' | SIGN search filters for patient issues |
| Further development of a search strategy for literature addressing patients' knowledge, views, and values based on the SIGN strategy | Wessels M, Hielkema L, van der Weijden T. How to identify existing literature on patients' knowledge, views, and values: the development of a validated search filter . Journal of the Medical Library Association 104(4):320–324 |
| Search strategy available from the Health Information Research Unit for finding studies in qualitative research | Health Information Research Unit Qualitative – Medline |

Alternatively, a search for already published systematic reviews may be preferred if reviews are potentially available. If a guideline group has decided to search for

systematic reviews (as opposed to individually published studies), groups can consider:

- adding a search filter for systematic reviews, such as the [McMaster University Health Information Research Unit's Clinical Hedges database](#)
- searching databases of systematic reviews, such as the [Cochrane Library](#) or [Epistemonikos](#), or
- searching in other guidelines for synthesised evidence in the [G-I-N International Guidelines Database](#) or the [TRIP database](#).

How can the certainty of evidence on patient views be assessed?

When thinking about the certainty of evidence, guideline groups will typically think about certainty or confidence in the evidence for benefits and harms. Consider a group making a recommendation who have been presented with the benefits and harms of an intervention from a systematic review of the literature. Drug X increases the number of people cured by 10 out of 100, and the risk of stroke increases by 5 out of 100 compared with no drug. The evidence that contributed to the estimates of the cures is very different from the evidence that contributed to the strokes. So, the certainty of the evidence is different. There is very low certainty that 10 more cures may occur, but high certainty that 5 more strokes could occur. Because of the certainty in the evidence, a guideline group may make a recommendation against the drug to avoid the 5 more strokes that could occur. In contrast, if the certainty was the other way around, that is, high certainty of 10 more cures, and very low certainty of 5 more strokes, the group may decide to suggest the drug as treatment because they are very uncertain about the increase in strokes. Assessing and presenting the certainty of evidence for benefits and harms is therefore important, and various systems do this, such as the GRADE approach (see the [GRADE Handbook](#)).

These systems can also be used to assess the evidence for patient views. If a guideline group is conducting a systematic review of research on patient views (using rigorous methods provided in [table 2](#)), the group should also convey the certainty of the results about those views. Consider a guideline group deciding whether to recommend a procedure with outcomes for precancerous cervical lesions and infertility. Research evidence about the value that couples place on fertility could

be gathered. If evidence is certain that women who are trying to conceive place a very high value on avoiding infertility compared with preventing recurrence of a precancerous lesion, more so than women not trying to conceive, the guideline group may make a recommendation against the procedure for women trying to conceive, but a recommendation for the procedure in women not trying to conceive. In contrast, if the research evidence is very uncertain about the values, then the guideline group may make the same recommendation for both groups of women. In this way, the certainty of the evidence can have an impact on the recommendations that are made, and it is therefore important to assess the certainty of the research evidence about patient views.

One component of assessing the certainty of evidence is to judge the quality or limitations of the studies. For individual qualitative studies, there is no agreement on the best tool to use, but 2 have been more widely used:

- the [CASP qualitative studies checklist](#)
- an adapted version of the CASP tool (Atkins et al. 2008).

These tools continue to be developed as methods progress and as the debate persists about the impact of the assessment criteria, such as ethics approval, on the validity of a study. For now, either of these tools could be used to assess the limitations of each study that contributes information on patient views. However, assessing the limitations of studies is only 1 part of the overall assessment of evidence. There are other factors that need to be considered when evaluating the certainty of the evidence, and these factors depend on the study design contributing to the evidence.

To assess and present **confidence in the evidence from a review of qualitative research studies**, reviewers may use the [GRADE-CERQual approach](#). GRADE-CERQual asks groups to assess 4 domains:

- quality or limitations of the studies
- whether the results from the studies are directly relevant to the recommendation question
- whether the results are coherent across the studies, and

- whether the data from the studies is sufficiently rich or adequate.

Together, consideration of these domains determines the confidence in the conclusions from a review of qualitative research about patient views. For example, a systematic review of qualitative research was conducted to synthesise evidence about parents' and informal caregivers' views and experiences of how information about routine childhood vaccination is communicated (Ames, Glenton, and Lewin 2017). The authors found that scientific sources of vaccine information were seen to be more reliable than discussion forums or lay opinions. The review authors then assessed the certainty of the evidence using GRADE-CERQual. They had minor concerns with the limitations in the studies, no concern with coherence of the results across studies, but moderate concern with the setting of the original studies (being directly applicable to their question), and the richness of the data. They therefore had low confidence that scientific sources were seen as more reliable than discussion forums or lay opinions. Details about how to assess the confidence in qualitative research findings using the GRADE-CERQual approach can be found in a series of papers, each addressing how to assess 1 domain (Lewin et al. 2018).

To assess the **certainty of evidence specific to the importance of health outcomes**, a new method has been developed (Zhang et al. 2019a, Zhang et al. 2019b). The method is based on the GRADE approach in which evidence for patient values is assessed using the domains: risk of bias, inconsistency, indirectness, imprecision, publication bias, and others. Details are provided in the articles published by Zhang et al. 2019a and 2019b, but the concept for each domain is similar to what would be applied to a review of studies evaluating benefits and harms of an intervention. Of note is the consideration of inconsistency across study results. When research shows that values are variable, further exploration, for example by subgroups, is recommended in order to determine if there are true differences in how people value a health outcome. Differences in values would likely influence whether different recommendations are made for 1 group compared with another based on what they value most, or whether there should be a conditional rather than a strong recommendation (that is, a conditional recommendation requires shared decision making).

For **evidence about patient views from a synthesis of studies, such as randomised controlled trials or non-randomised studies**, GRADE or other systems for assessing the certainty of evidence from these study designs should be used. For example, if there was a review of randomised controlled trials that reported the acceptability of 1 procedure compared with another. In this hypothetical review, the difference in how acceptable the 1 procedure is compared to how acceptable the other procedure was calculated from each study and then the differences from each study were pooled together to create 1 estimate of the difference. To express the certainty in such estimated differences, groups should assess the risk of bias of all the studies providing data, the number of participants providing data, the width of the confidence interval around the difference, the heterogeneity of the overall difference, and the applicability and risk of publication bias. Based on this assessment, the guideline group will know how certain to be in the difference from the review of studies.

Finally, in special circumstances when a guideline group is not using a standard approach to assess the evidence, there should be some description about how believable the overall conclusions are about the patient views and why they are believable. The following principles should be considered and communicated:

- whether the individual studies were well done
- how many studies (or participants) were included
- how relevant the studies are to the recommendation topic, and
- how consistent or coherent the results are across the studies.

How can the research be summarised and presented for use?

As explained in the section on the stage of the guideline development process at which research evidence about patient views can be used, research about patient views may contribute to multiple stages of a guideline and to many factors when making a recommendation. In this section, we provide several examples of how this research may be summarised and presented so it can be incorporated into guideline recommendations.

A list of patient research priorities based on research

At the guideline development stage of generating questions to cover in a guideline, the guideline group may search the grey literature for research about what is important to key stakeholders. The [James Lind Alliance website](#) can be searched to find research about patients' top research priorities for a topic. Figure 2 shows the [James Lind Alliance website's top 10 questions on diabetes and pregnancy](#) (as well as information about how the research was conducted to inform the priorities). Presented this way, the guideline panel can easily incorporate this information when generating questions.



You are in: [Home](#) » [The PSPs](#) » [Diabetes and Pregnancy](#) » [Top 10 priorities](#)

Diabetes and Pregnancy Top 10

1. How can diabetes technology be used to improve pregnancy, birth, and mother and child health outcomes?
2. What is the best test to diagnose diabetes in pregnant women?
3. For women with diabetes, what is the best way to manage blood sugar levels using diet and lifestyle during pregnancy?
4. What are the emotional and mental well-being needs of women with diabetes before, during, and after pregnancy, and how can they best be supported?
5. When is it safe for pregnant women with diabetes to give birth at full term compared with early delivery via induction or elective caesarean?
6. What are the specific postnatal care and support needs of women with diabetes and their infants?
7. What is the best way to test for and treat diabetes in late pregnancy, i.e. after 34 weeks?
8. What is the best way to reduce the risk or prevent women with gestational diabetes developing other types of diabetes any time after pregnancy?
9. What are the labour and birth experiences of women with diabetes, and how can their choices and shared decision making be enhanced?
10. How can care and services be improved for women with diabetes who are planning pregnancy?

Figure 2: Information from the [James Lind Alliance website about priority questions related to diabetes and pregnancy](#)

A thematic summary of patient views from evidence syntheses of qualitative research about acceptability presented narratively and in a table with rating of certainty

A synthesis of systematic reviews of qualitative research was conducted and informed the development of the [WHO guideline: recommendations on digital interventions for health system strengthening](#) (2019a). It includes recommendations on using digital health interventions for reproductive, maternal, newborn, child and adolescent health, in particular, for the use of telemedicine. An overview of systematic reviews of qualitative research on patient views of telemedicine was conducted. The evidence was summarised in themes and presented narratively and in tables, along with the confidence in the evidence. Figure 3 shows the research evidence on acceptability that was used to make the recommendation for using client-to-provider telemedicine (Glenton et al. 2019). The evidence statement ‘Some clients believe that telemedicine has increased their independence and self-care, but some healthcare workers may be concerned about clients’ ability to manage their own conditions (low confidence)’ from the thematic text is reflected in the table item F7.

Some clients see client-to-provider telemedicine services as offering reassurance and a sense of safety and appreciate the increased access, consistency and continuity of care (low confidence). Some clients appreciate the convenience of telemedicine as it saves time and money and reduces the burden of travel, although others may see it as difficult to engage with or too time consuming (low confidence). Some clients also appreciate being able to communicate with healthcare workers from their home environment, while others miss face-to-face contact (low confidence). Some clients believe that telemedicine has increased their independence and self-care, but some healthcare workers may be concerned about clients' ability to manage their own conditions (low confidence). Telemedicine services can give clients who speak minority languages access to providers who speak these languages. However, access may be difficult for others to achieve, for instance because of hearing impairments, poor computer literacy or technical issues (high confidence).

Summary of Qualitative Findings

| Summary of overview finding | Reviews contributing to the overview finding | Methodological limitations | Relevance | Adequacy | Coherence | Overall CERQual assessment of confidence in the evidence |
|--|--|----------------------------|--|--|---------------------------|---|
| F7 Some clients may believe that telemedicine has increased their independence and self-care, but healthcare workers may be concerned about this transfer of responsibilities | Brewster 2013 ¹ ; Cox 2017 ² ; Raphael 2016 ⁴ | No or very minor concerns | Moderate concerns because of partial relevance. Healthcare provider perspectives are from review of cancer patients only, while client perspectives are from COPD and from adults over 65. | Moderate concerns because of thin data | No or very minor concerns | Low confidence because of concerns about partial relevance and data adequacy |

Figure 3: Narrative summary of the themes from the systematic reviews and summary in a table

A narrative summary of themes from a systematic review of qualitative research as evidence of benefits and harms

A systematic review of qualitative research was conducted for the Scottish Intercollegiate Guidelines Network (SIGN) guideline on managing long-term effects of COVID-19. Based on a search of bibliographic databases, grey literature and pre-print databases, 6 studies were included, and a thematic synthesis was done. Each of the themes was summarised and presented in the [COVID-19 rapid evidence review. Managing the long-term effects of COVID-19: the views and experiences of patients, their families and carers](#) (Healthcare Improvement Scotland 2020). One of the themes (Analytical theme 9) identified desirable features of healthcare services or service delivery, which in turn led to recommendations for health care professionals to perform person-centred assessments (figure 4).

Analytical theme 9: desirable features of healthcare services/service delivery

Patients asked for face-to-face assessments; they talked about the need for one-stop clinics with multidisciplinary teams (MDT) who could look at their wide-ranging symptoms and treat them holistically. A case manager to oversee individual patients and ensure that all aspects of their care had been considered was suggested, along with meaningful referral pathways and criteria.

“What would be most helpful is if all main hospitals could have a Covid clinic that had experts from respiratory, cardiology, rheumatology, neurology, physiotherapy etc, so you could go along for half a day and see people from these different departments, they can refer you for tests and you can get a plan in place, we are having such a range of symptoms that GPs are struggling to know what to do with you” (Maxwell, p17)⁴

“... there was a view that it would be helpful if people living with Covid19 could have a ‘quarter back’ or case manager to oversee and coordinate investigations and support services across different medical specialities.” (Maxwell, p17)⁴

When asked what features of healthcare delivery or services they would like to see, patients with long-term symptoms spoke about wanting to be listened to, to be believed and understood, and to be offered practical advice on coping.

“... actually just the experience of being heard and feeling like somebody got it and was being kind about it, but you know it was okay that they couldn’t do anything, I just kind of needed to know that I wasn’t losing it really and it was real what I was experiencing, I think so that was really helpful.” (Kingstone *et al*, p8)²

Figure 4: Example of a narrative summary of themes from qualitative research on the views and experiences of patients, their families and carers (Healthcare Improvement Scotland 2020)

A table summarising a synthesis of quantitative studies about patient acceptability and the certainty of that evidence along with other benefits and harms

A systematic review of randomised and non-randomised studies was conducted to inform recommendations for treatments, including thermal ablation or cryotherapy, to treat precancerous lesions in the [WHO guideline on for the use of thermal ablation for cervical pre-cancer lesions](#) (2019b). Acceptability was measured in the trials. The

effects from the individual studies were pooled and presented along with the benefits and harms of the treatments in a Summary of Findings Table (Annex D Evidence to decision frameworks, page 43), shown in figure 5. The effect was that it was likely that there was little difference in acceptability between the 2 treatments.

| Outcome N° of participants (studies) | Relative effect (95% CI) | Anticipated absolute effects (95% CI) | | | Certainty |
|--|--|---------------------------------------|--|--|-----------|
| | | Risk with cryotherapy | Risk with thermal ablation | Difference with thermal ablation | |
| Cure N° of participants: 85 (1 RCT) | RR 1.14 (0.89 to 1.46) | Moderate | | | Moderate |
| | | 90.0% | 100.0% (80.1 to 100.0) | 12.6% more (9.9 fewer to 41.4 more) | |
| Cure N° of participants: 157 (1 observational study) | RR 1.01 (0.89 to 1.14) | Moderate | | | Very low |
| | | 90.0% | 90.9% (80.1 to 100.0) | 0.9% more (9.9 fewer to 12.6 more) | |
| Cure N° of participants: (23 case series) | not estimable | Moderate | | | Low |
| | | 90.0% (87 to 93) | 92% (90 to 95) 2 probe: 95 (93 to 98) Not 2 probe: 85 (80 to 90) | | |
| Pain immediately N° of participants: 413 (4 RCTs) | RR 0.93 (0.76 to 1.15) | 65.4% | 60.8% (49.7 to 75.2) | 4.6% fewer (15.7 fewer to 9.8 more) | Moderate |
| Pain immediately N° of participants: (case series) | not estimable | Moderate | | | Low |
| | | 30.0% (19 to 41) | 63% (42 to 83) | 33% more | |
| Major bleeding N° of participants: 817 (6 RCTs) | RR 0.62 (0.37 to 1.02) | 1.7% | 1.0% (0.6 to 1.7) | 0.6% fewer (1.1 fewer to 0 fewer) | Moderate |
| Major bleeding N° of participants: (case series) | not estimable | 4 / 9941 | 9 / 4634 | | Low |
| Infection (including fever) N° of participants: 816 (6 RCTs) | RR 0.81 (0.10 to 6.33) | 0.3% | 0.2% (0.0 to 1.6) | 0.0% fewer (0.2 fewer to 1.3 more) | Moderate |
| Infections (including fever) (45 case series) | not estimable | 60 / 8674 | 17 / 4082 | | Low |
| Acceptability – whether they would recommend it N° of participants: 631 (3 RCTs) | Acceptability is likely not different between thermal ablation and cryotherapy. Risk Ratio 1.01 (0.99 to 1.02) | | | | Moderate |

Figure 5: Summary of findings table including patient acceptability between 2 treatments (WHO 2019b)

A summary of quantitative and qualitative research about patient views related to equity using the Evidence to Decision framework to present the evidence

A systematic review of research was conducted for a recommendation comparing different models of care for people with haemophilia (Pai et al. 12016). The review included any quantitative or qualitative research, such as focus groups, interviews and surveys, about barriers to accessing an integrated model of care. The review provided evidence about the impact of the model on health inequities and was summarised by analysis of thematic areas. The evidence was presented to the guideline group in a section on Equity in the Evidence to Decision Framework and then used by the group to make the recommendation (see figure 6).

| | Criteria | Judgements | Research evidence | Additional considerations |
|--------|--|---|--|--|
| Equity | What would be the impact on health inequities? | <input type="radio"/> Increased <input type="radio"/> Probably increased <input type="radio"/> Uncertain <input checked="" type="radio"/> Probably reduced <input type="radio"/> Reduced <input type="radio"/> Varies | <p>Summary of the evidence</p> <p>There are no randomized controlled trials or non-randomized studies comparing integrated care to non-integrated care for people with hemophilia</p> <p>There are 7 non-randomized studies which provided data from one group of people who received integrated care.</p> <p>Ethnicity/race</p> <ul style="list-style-type: none"> Baker 2013 analyzed data from the U.S. HTC network (129 HTCs) from 1990-2010. In 2010, 71% of HTC patients were White, 13% Hispanic, 9% Black and 7% 'Other' (this was slightly lower than U.S. population of 64% White, 16% Hispanic, 13% Black and 6% 'Other'). From 1990 to 2010, the numbers of HTC Hispanic and Black patients grew, but remained under represented. Monahan 2011 analyzed data from >130 HTCs from 1998-2008 in boys with hemophilia and found that the racial/ethnic composition reflected general demographics. Forsberg 2014 (supplemented by Aschman 2014) report survey of 4,004 households with people with hemophilia in HTCs in 2013. The odds of having 5 or more problems were twice as high for minority groups relative to Whites categories, and almost thrice as high for African Americans. <p>Distance/access</p> <ul style="list-style-type: none"> Soucie 2000 analyzed data from 1993-1995 and found more people with severe hemophilia accessed HTCs than mild or moderate (and more than non-HTCs). Zhou 2011 (from the HUGS study) interviewed 327 adults and parents with children with hemophilia. 14% reported barriers to HTC, which included distance. Hacker 2006 conducted a survey from 1999-2001 of ~120 adults and parents with children hemophilia at an HTC. 32% had limited access to HTC often due to transportation, inconvenient times, or problems with staff. Forsberg 2014 (supplemented by Aschman 2014) found that moderate or severe barriers included time off from work/school for appointments (11% moderate, 4% severe), and distance to HTC (14%, 4%). The odds of having 5 or more problems were twice as high for minority groups relative to Whites categories (African Americans almost 3 times). Nugent 2015 (from the HERO study) surveyed people with and parents of children with hemophilia in 10 countries [supplementary data also was available]. In the U.S., 22% of people with hemophilia report that it is quite/very difficult to visit HTCs in the U.S. Accessibility was the key issue; 71% of 42 respondents cited the long distance to their HTC, and 45% cited long/expensive travel. | <p>Core question: will we do away with equity problems if we do away with HTCs? Or will we introduce more inequity?</p> <p>General demographic data on PWH is scant. Further, the bulk of published data is from HTCs. Thus we don't know if inequity also exists in individuals outside of HTCs.</p> <p>The issue of capacity looms large – does it affect access issues? Panelists felt that the HTC system's capacity was not truly a problem, but that access is being limited by insurance companies.</p> <p>Modifiers of inequity may include telehealth, empowering local healthcare providers, broader access to HTCs (e.g. through more appropriate implementation of recommendations and optimized utilization).</p> |

Figure 6: Equity section of an Evidence to Decision Framework with a summary of the studies by theme ([Pai et al. 2016, see hae13008-sup-0003-AppendixS3-S4.docx](#))

A summary of a systematic review of research about values placed on outcomes

As described in box 1, a systematic review of patient values and preferences was conducted for the American Society of Hematology guidelines for management of venous thromboembolism (VTE) disease (Etxeandia-Ikobaltzeta et al. 2020) Multiple databases were searched for both quantitative and qualitative studies. The authors summarised the research from non-utility studies on which outcomes patients with cancer valued more (along with the certainty of that evidence). This information was used when deciding how much weight to put on the benefits and harms of the different treatments (see table 7).

| | | |
|---|---|--|
| Trade-off between treatment burden and benefits with LMWH (Cajfinger et al, ⁴⁶ Noble et al ⁵⁴) | Cancer patients place highest value on "the interference with cancer treatment," followed by "efficacy of the VTE treatment" and "risk for major bleeding." They place low value on monitoring through blood tests, frequency of administration, mistakes, and costs. | ⊕⊕⊕○ Moderate certainty due to RoB ^a |
| 509 participants from 2 cross-sectional studies | | |

Figure 7: Summary of non-utility studies about the value placed on different outcomes in the treatment of venous thromboembolism (in [table 4 of Etxeandia-Ikobaltzeta et al. 2020](#))

How can research evidence be summarised in the guideline?

The previous evidence presentations are most useful to the guideline group when making recommendations. After the evidence has been used in the guideline process there are 2 options for how to write about patient views in the final guideline. Options can include:

- summarising the evidence on patient views across many recommendations in 1 section of the guideline
- providing the patient views for each recommendation.

The choice may depend on how many recommendations are in the guideline. If there are few recommendations, then 1 summary may be appropriate because readers will

be able to apply the summary easily to each recommendation. If there are many recommendations, readers may appreciate having a summary of the views and experiences for each recommendation. If the recommendations are closely related and the views and experiences are similar across those recommendations, then 1 summary is adequate. However, if views, values, and experiences differ from recommendation to recommendation, specific descriptions within each recommendation would be necessary. Finally, if it is expected that each recommendation may not be read, may be made into a stand-alone document, or be copied into other related guidelines (that is, not necessarily always together with the other recommendations) then including a summary with each recommendation is likely the better choice.

For an example of how to summarise patient views **across multiple recommendations in 1 section**, see the [American Society of Hematology 2018 guidelines for management of venous thromboembolism](#).

For an example of how to summarise patient values and preferences **for a recommendation in a guideline**, see the [CMAJ recommendation on screening for chlamydia and gonorrhea in primary care for individuals not known to be at high risk](#).

What to do when no methods are available?

This chapter has provided practical advice on how to incorporate research evidence about patient views in the guideline process using examples. There are many more examples and more detailed guidance available in the references. However, there are still gaps in these methods, and guideline developers may need to develop novel methods when there are gaps. We suggest the following if no guidance is available:

- **be transparent** about what was done or not done
- **document** in the guideline or evidence syntheses what was done
- determine if it is possible to **adapt** methods for including stakeholder views from other fields to methods for including patient views in guideline development
- **conduct research** into what does and does not work, and
- **share** experiences.

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