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# BMJ Open

## A checklist for communicating evidence-based information about the effects of healthcare interventions

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## A checklist for communicating evidence-based information about the effects of healthcare interventions

*To make informed decisions, people need information that is easy to find, based on the best available evidence, easy to understand, and trustworthy.*

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## Abstract

**Background:** To make informed decisions about healthcare, patients and the public, health professionals and policymakers need information about the effects of interventions. People need information that is based on the best available evidence and that is presented in a complete and unbiased way. People also need information that is relevant, trustworthy and easy to use and to understand. The aim of this paper is to provide guidance to those producing and communicating evidence-based information about the effects of interventions intended to inform decisions about healthcare.

**Methods:** To inform the development of this checklist, we identified research evidence relevant to communicating evidence-based information about the effects of interventions. We used an iterative, informal consensus process to synthesize our recommendations. We began by discussing and agreeing on some initial recommendations, based on our own experience and research over the past 20 to 30 years. Subsequent revisions were informed by the literature we examined and feedback. We also compared our recommendations to those made by others. We sought structured feedback from people with relevant expertise, including people who prepare and use information about the effects of interventions for the public, health professionals, or policymakers.

**Results:** We produced a checklist with ten recommendations. Three recommendations focus on making it easy to quickly determine the relevance of the information and find the key messages. Five recommendations are about helping the reader understand the size of effects and how sure we are about those estimates. Two recommendations are about helping the reader put information about intervention effects in context and understand if and why the information is trustworthy.

**Conclusion:** These ten recommendations summarise lessons we have learned developing and evaluating ways of helping people to make well-informed decisions by making research evidence more understandable and useful for them. We welcome feedback for how to improve our advice.

## Strengths and limitations

- We have provided explanations of the basis for each recommendation and references to supporting research.
- We did not conduct a systematic review to inform our guidance.
- To facilitate use of the checklist, we have prepared a flow chart with examples.

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## Summary points

To make informed decisions, patients and the public, health professionals and policymakers should look for (and be provided with) information about the effects of interventions that is trustworthy and understandable.

It should be easy to quickly determine the relevance of the information, and to find the key messages.

For each outcome, it should be easy to understand the size of the effect and how sure we can be about that; and misleading presentations should be avoided.

It should be easy to put the information about intervention effects in context and to understand if and why the information is trustworthy.

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## Introduction

Access to healthcare information is necessary if people are to be involved in decisions regarding their own health [1]. Recognising this, governments in several countries have included the right to healthcare information in patients' charters. These charters commonly establish people's right to access information about treatments (e.g. [2]), including the benefits and harms of these treatments (e.g. [3]). Patients' charters also underline the need to provide this information in a way that people can understand and that is adapted to each individual's needs (e.g. [2,4]).

Having the *right* to information does not necessarily mean that this information is available, and many patients and members of the public struggle to find information that is relevant to their circumstances. At the same time, most people are bombarded with claims in the media and other aspects of day-to-day life about what they should and should not do to maintain or improve their health.

Many health claims are unreliable and conflicting [5-14]. When they are purported to be based on research, this might also contribute to a lack of trust in research. For example, surveys in the UK have shown that only about one third of the public trust evidence from medical research, while about two thirds trust the experiences of friends and family [15].

It cannot therefore be assumed that people will trust advice simply because it is based on research evidence and given by authorities. Nor should they, as the opinions of experts or authorities do not alone provide a reliable basis for judging the benefits and harms of interventions [16,17]. Doctors, researchers, and public health authorities – like anyone else – often disagree about the effects of interventions. This may be because their opinions are not always based on systematic reviews of fair comparisons of interventions [18]. Government authorities and professional organisations host many websites that provide health advice to the public. However, these websites often provide information that is unclear, incomplete, and misleading [11]. We were able to find only three websites that provide information about the effects of healthcare interventions that was explicitly based on systematic reviews [19]. Even where information *is* based on systematic reviews, it may still be unclear, incomplete, and misleading.

People who summarise lengthy research reports to make them more accessible are faced with many choices. This includes decisions about which evidence to present, how this evidence should be interpreted, and the format in which it should be presented. Our own experiences creating summaries based on Cochrane Reviews have shown us that there are many pitfalls [20-25]. A fundamental challenge is to find an appropriate balance between accuracy and simplicity. On the one hand, summaries should give a reasonably complete, nuanced, and unbiased representation of the evidence. On the other, they should be succinct and understandable to people without research expertise.

Another challenge to making research evidence easier to use is that people with expertise in a field have been found to pay attention to, read, and interpret information differently from people without expertise [26]. A common publishing strategy is to accommodate these differences by creating different versions of information for experts and non-experts; for example, for health professionals and for patients. However, both health professionals and patients frequently lack research expertise [22,26-29]. In terms of understanding evidence-based information about the effects of treatments, 'experts' are the people who have acquired the skills needed to understand and interpret results from quantitative studies and systematic reviews. Everybody else could be considered 'non-experts' in this area.

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This does not mean that this large group of non-experts are universally similar regarding their information needs. They may have different levels of language literacy, health literacy and numeracy, or they may need to use evidence for different kinds of decision-making tasks. However, when it comes to the specific task of understanding research evidence and using this information to weigh the trade-offs between possible benefits and harms, most users are non-experts. Consequently, most people would benefit from information about the effects of interventions that is presented in a way that recognizes the needs of non-experts. This includes patients, health professionals, and policymakers.

In summary, to make informed choices or decisions, people need information that is accessible, easy to find, relevant, based on the best available evidence, accurate, complete, not misleading, nuanced, unbiased, easy to understand, and trustworthy.

The aim of this paper is to provide guidance to people preparing and communicating evidence-based information on the effects of interventions that is intended to inform decisions by patients and the public, health professionals, or policymakers.

## Methods

### Ethical considerations

Development of this checklist was guided by ethical considerations underlying informed consent and patients' rights. Informed consent in medical research has received a huge amount of attention [30]. Informed consent in clinical and public health practice has received far less attention [31], and a double standard has existed for at least 50 years [32]. Consent in clinical and public health practice is reviewed, if at all, only in retrospect. Health professionals are exhorted to obtain informed consent, but in daily practice, as opposed to in clinical trials, they often minimise uncertainties about interventions and they may feel duty-bound to provide unequivocal recommendations [32].

Our starting point in preparing this checklist was the belief that patients and the public have the right to be informed when making health choices – such as a personal choice about whether to adhere to advice, a decision about whether to participate in research, or in taking a position regarding a health policy. Specifically, they should have access to the best available research evidence, including information about uncertainty, summarised in plain language. We do not assume that everyone wants this information.

Many people are not interested or prefer for someone else to make healthcare decisions on their behalf. For example, a systematic review of patient preferences for decision roles found that a substantial portion of patients prefer to delegate decision-making to their physician, although in most studies most patients reported a preference for shared decision-making [33]. Some patient's rights charters take this into account – for instance, the right to waive one's 'right to be informed' is specifically mentioned in the Norwegian Patient Rights legislation [4]. We would argue that under most circumstances it is good clinical practice to respect patient preferences [31]. Those people who do not want information on the effects of treatments do not need to read or listen to information, but it should be there for those who want it.

### Literature review

To inform the development of this checklist, we compiled research evidence that is relevant to giving guidance on how to communicate evidence-based information about the effects of interventions.



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We started with our own research and then identified related research through a snowballing and citation reference method. We supplemented this with broad searches for evidence on communicating research evidence and intervention effects, and specific searches for each item in the checklist. We did not conduct a systematic review. We have, however referenced systematic reviews to support each item in the checklist when one was available. When we were not able to find a relevant systematic review, we have referenced the best available evidence that we have found. In addition, we have reviewed relevant guidance and reference lists. This included guidance for plain language summaries of research evidence [34], for reporting and using systematic reviews [35,36], for making judgements about the certainty of evidence and for going from evidence to recommendations [37-39], and for risk communication [40].

## Synthesis

We used an iterative, informal consensus process to synthesize our recommendations. This was informed by our own experience and research spanning over three decades, our review of the literature, comparing our recommendations to other relevant guidance, and feedback from colleagues. We met initially to discuss our recommendations, divided up tasks, prepared drafts, and then discussed these until we reached agreement on a final set of recommendations. In addition to the checklist summarising our main recommendations, we prepared a flow chart, providing guidance for implementing our recommendations. After agreeing on a set of recommendations, we compared these to recommendations made by others and sent a draft report to 40 people and received feedback from 30 (see acknowledgements) requesting structured feedback (Additional file 1).

## Results

Our recommendations are summarised in a checklist with 10 items (Box 1). The basis for each recommendation is provided in Additional file 2 and explanations for each of the recommendations is provided in Additional file 3. All of our recommendations could be considered “good practice statements”. Good practice statements are recommendations that do not warrant formal ratings of the certainty of the evidence [41]. One way of recognising such recommendations is to ask if the unstated alternative is absurd [41]. Arguably, that is the case for all the recommendations in Box 1.

### Box 1. Checklist for communicating effects

#### **Make it easy for your target audience to quickly determine the relevance of the information, and to find the key messages.**

1. Clearly state the problem and the options (interventions) that you address, using language that is familiar to your target audience – so that people can determine if the information is relevant to them.
2. Present key messages up front, using language that is appropriate for your audience and make it easy for those who are interested to dig deeper and find information that is more detailed.
3. Report all potentially important benefits and harms, including outcomes for which no evidence was found – so that there is no ambiguity about what was found for each outcome that was considered.

#### **For each outcome, help your target audience to understand the size of the effect and how sure we can be about that; and avoid presentations that are misleading.**

4. Explicitly assess and report the certainty of the evidence.
5. Use language and numerical formats that are consistent and easy to understand.
6. Present both numbers and words, and include summary of findings tables.
7. Report absolute effects.
8. Avoid misleading presentations and interpretations of effects.
  - Help your audience to avoid misinterpreting continuous outcome measures.

**DRAFT:** 11 December 2019**Box 1. Checklist for communicating effects**

- Explicitly assess and report the credibility of subgroup effects.
- Avoid confusing “statistically significant” with “important”, or a “lack of evidence” with a “lack of effect”.

**Help your target audience to put information about the effects of interventions in context, and to understand why the information is trustworthy.**

9. Provide relevant background information, help people weigh the advantages against the disadvantages of interventions, and provide a sufficient description of the interventions.
10. Tell your audience how the information was prepared, what it is based on, the last search date, who prepared it and whether the people who prepared the information had conflicts of interest.

## Flow chart

The flow chart (Figure 1) outlines a process for producing evidence-based information about the effects of interventions. It provides examples that illustrate each step of the process. The process begins with making sure that you know your target audience. It is important to consider how members of your target audience will be involved in the process. The next steps in the process are designing and user testing a template for the information that you will prepare, organising an editorial process and training, and considering ways of making it easy for your target audience to find your information. Although the flow chart suggests a linear process, development should be approached as an iterative, cyclical process. The last step in Figure 1 is to collect feedback on each individual piece of information from people in your target audience; to make changes if needed (to your template as well as to individual pieces of information); and to evaluate again, if needed. It also includes establishing routines for updating the information that you prepare, if this is planned.

## Discussion

### How our checklist compares to related checklists and guidance

Although our guidance overlaps with other guidance [38,48-55], we are not aware of other guidance specifically addressing preparation of evidence-based information for decision makers about the effects of interventions. Comparison of our guidance with other guidance is summarised in Table 1.

The Ensuring Quality Information for Patients (EQIP) tool [50] and the International Patient Decision Aid Standards (IPDAS) checklist [52,53] include specific recommendations related to using plain language (short sentences and a reading level not exceeding a reading age of 12). We have included key principles for plain language in our detailed guidance (Additional file 3).

The EQIP tool [50], the IPDAS checklist [52,53] as well as a systematic review on evidence-based risk communication by Zipkin and colleagues [51] recommend using visual aids. The last two recommend using graphs to show probabilities. We agree that information for people making decisions about interventions should be visually appealing and that well-designed visualisations can help some people to understand information about the effects of interventions. Spiegelhalter [54] recommends visualisations in communication about risk and uncertainty, which seems sensible. However, we do not think there currently is enough evidence to support recommendations about when to use visualisations or what type of visualisation to use [51,54,56,57].

The systematic review on evidence-based risk communication [51] suggests being aware that positive framing (stating benefits rather than harms) increases acceptance of therapies. The IPDAS checklist [52,53] recommends presenting probabilities using both positive and negative frames (e.g.

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1  
2  
3 showing both survival and death rates). We do not think there currently is enough evidence for  
4 either of these recommendations [58].  
5

6 Zipkin and colleagues [51] suggest placing a patient's risk in context by using comparative risks of  
7 other events. We do not think there is currently is enough evidence to support this recommendation  
8 and question its relevance for many decisions about interventions.  
9

10 The IPDAS checklist [52,53] recommends allowing patients to select a way of viewing the  
11 probabilities (e.g. words, numbers, diagrams). We agree this is sensible and, in previous work, we  
12 have designed an interactive Summary of Findings with this in mind [46]. However, there is limited  
13 evidence to support this recommendation. We attempted to test this hypothesis in a randomised  
14 trial [59]. Because of technical problems (the interactive Summary of Findings and data collection did  
15 not work for some participants), we were not able to complete the trial. The qualitative data that we  
16 collected suggested that participants (people in Scotland with an interest in participating in  
17 randomised trials of interventions [60]) had mixed views about their preferences for an interactive  
18 versus a static presentation. They also had mixed views regarding which initial presentation they  
19 preferred in the interactive presentation.  
20  
21  
22

23 Lastly, the IPDAS checklist [52,53] recommends including stories of other patients' experiences and  
24 using audio and video to help users understand information. We agree that this may be helpful.  
25 However, it is also possible that stories of other patients can have unintended effects. For example,  
26 people can be influenced by whether they identify with the person telling the story or not. We are  
27 not aware of evidence from randomised trials comparing information with and without patients'  
28 experiences, audio, or video; or comparing different types of presentations. A recent systematic  
29 review on the use of narratives to impact health policymaking did not find any trials [61].  
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### 35 **Strengths and weaknesses of our checklist**

36 We did not conduct a systematic review to inform our guidance, review non-English language  
37 literature, assess the certainty of the evidence supporting each recommendation, grade the strength  
38 of our recommendations, or use a formal consensus process. However, we have provided  
39 explanations of the basis for each recommendation and references to supporting research. Our  
40 approach to preparing this checklist has been pragmatic in terms of the methods we have used. We  
41 hope that others will find the checklist practical and helpful. To facilitate use of the checklist, we  
42 have prepared a flow chart with examples (Figure 1).  
43  
44

45 Implementation of the guidance can be facilitated by developing a template, specific guidance for  
46 those charged with using the template to prepare the information, and training for those people.  
47 Links to examples of these can be found in the flow chart. User testing can help to ensure that  
48 people in your target audience experience the information positively and as intended. We have  
49 provided links to examples of user tests of information about the effects of interventions and to  
50 resources for user testing in the flow chart.  
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### 56 **Implications for research**

57 There remain many important uncertainties about how best to present evidence-based information  
58 about the effects of interventions to people making decisions about those interventions. We have  
59 summarised key uncertainties that we identified while preparing this checklist in Table 2.  
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## Conclusions

The checklist that we have developed, which includes ten items, is the top layer of our recommendations for how to prepare evidence-based information on the effects of interventions that is intended to inform decisions by patients and the public, health professionals, or policymakers. These ten recommendations summarise the lessons that we have learned from our review of relevant research. The recommendations draw on our own experience over the past 20 to 30 years in developing and evaluating ways of helping people to make well-informed health choices by making research evidence more understandable and useful to them. We welcome feedback and suggestions for how to improve our advice.

## Contributors

ADO, CG, SF, SL and AF are health service researchers. SR is a designer and researcher. The authors have worked together for over two decades studying ways to help health professionals, policymakers, patients and the public make well-informed healthcare decisions. All the authors participated in discussions about the recommendations and this report, helped to review the literature and respond to external feedback on a draft report, and provided feedback on each draft of the report. ADO is the guarantor of the article.

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## Competing interests

We have no competing interests.

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## Checklist for communicating effects tables and figure legend

**Table 1. Comparison of our checklist with other guidance**

Guidance	Purpose	Comparison to our checklist
<b>The Conference On Guideline Standardization (COGS) checklist for reporting clinical practice guidelines [50]</b>	<i>The checklist is intended to minimize the quality defects that arise from failure to include essential information and to promote development of recommendation statements that are more easily implemented.</i>	Focus is on content of a full guideline report rather than on presentation of information. It does not include guidance for how to present information about benefits and harms. It is consistent with our checklist for the items that overlap. Some of the 18 items are outside of the scope of our checklist.
<b>DISCERN instrument for judging the quality of written consumer health information on treatment choices [51]</b>	<i>To enable patients and information providers to judge the quality of written information about treatment choices; and to facilitate the production of new, high quality, evidence-based consumer health information.</i>	There is some overlap, but the focus is on content of information for patients and the public rather than on presentation of that information; and the checklist is presented as an instrument for assessing the quality of information rather than as a guide for preparing it.
<b>Ensuring Quality Information for Patients (EQIP) tool [52]</b>	<i>To provide a practical measure of the presentation quality for all types of written healthcare information.</i>	There is some overlap, but it does not address how to present evidence-based information about the effects of interventions. It includes some relevant suggestions that we have not included: <ul style="list-style-type: none"> <li>• Use short sentences</li> <li>• Personally address the reader</li> <li>• Be respectful</li> <li>• Include easy-to-understand illustrations</li> </ul>
<b>Evidence-Based Risk Communication [53]</b>	<i>Key findings to inform best practice from a systematic review of the comparative effectiveness of methods of communicating probabilistic information to patients that maximize their cognitive and behavioural outcomes.</i>	The findings from this systematic review are largely consistent with our recommendations for how to help people understand the size of effects. It includes some suggestions that we have not: <ul style="list-style-type: none"> <li>• Add bar graphs or icon arrays to natural frequencies or event rates</li> <li>• Consider the use of icon arrays with smaller numerators and bar graphs with larger numerators</li> <li>• Place a patient's risk in context by using comparative risks of other events</li> <li>• Realize that positive framing (stating benefits rather than harms) increases acceptance of therapies</li> </ul>
<b>GRADE guidelines [40]</b>	<i>To provide guidance for use of the GRADE system of rating the certainty of evidence and grading the strength of recommendations in systematic reviews, health technology assessments, and clinical practice guidelines.</i>	This is a series of articles that provides detailed guidance for people preparing systematic reviews, health technology assessments, or guidelines. We have helped to develop this guidance and have drawn on it. Our checklist is consistent with GRADE guidance for Summary of Findings tables and communicating information about uncertainty.

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Guidance	Purpose	Comparison to our checklist
<p>International Patient Decision Aid Standards (IPDAS) Patient Decision Aid User Checklist [54,55]</p>	<p><i>To provide a set of quality criteria for patient decision aids.</i></p>	<p>Many of the items in the IPDAS checklist overlap with our checklist. It also includes items that are outside of the scope of our checklist (e.g. decision aids for tests, helping users to clarify their values, and evaluation of decision aids), as well as some items that are within our scope, which we have not included. They are reformulated here as guidance:</p> <ul style="list-style-type: none"> <li>• Use visual diagrams to show the probabilities (e.g. faces, stick figures, or bar charts).</li> <li>• Allow patients to select a way of viewing the probabilities (e.g. words, numbers, diagrams).</li> <li>• Present probabilities using both positive and negative frames (e.g. showing both survival and death rates).</li> <li>• Describe the features of options to help patients imagine what it is like to experience their physical, emotional, and social effects.</li> <li>• Provide stories of other patients' experiences.</li> <li>• Identify the reading level at which it is written and the formula [method] used to determine the level.</li> <li>• Provide ways to help patients understand information other than reading (e.g. audio, video, or in-person discussion).</li> </ul>
<p><b>Risk and uncertainty communication</b> [56]</p>	<p><i>Explores the major issues in communicating risk assessments arising from statistical analysis and concludes with a set of recommendations.</i></p>	<p>Largely consistent with our checklist. Includes a set of recommendations about visualisations, such as:</p> <ul style="list-style-type: none"> <li>• Illuminate graphics with words and numbers.</li> <li>• Design graphics to allow part-to-whole comparisons on an appropriate scale.</li> <li>• Helpful narrative labels are important.</li> <li>• Be cautious about interactivity and animations.</li> <li>• Avoid chart junk.</li> <li>• Most importantly, assess the needs of the audience, experiment, test, and iterate toward a final design.</li> </ul>
<p><b>US National Standards for the Certification of Patient Decision Aids</b> [57]</p>	<p>To provide criteria for a potential decision aid certification process in the U.S.</p>	<p>Although there is some overlap with our checklist, the criteria do not address how to present information about the effects of interventions other than “adopting risk communication principles”.</p>

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**Table 2. Important uncertainties about how to present evidence-based information about the effects of interventions to people making decisions**

Question	What is known	Research that is needed
<b>What are the effects of alternative visual displays of intervention effects on understanding and users' experience of the information?</b>	Not all visual displays are more intuitive than text or numbers, some visual displays can be misleading, some may require explanation in order for people to understand them, and people tend to prefer simplicity and familiarity, which may not be associated with accurate quantitative judgements [53,56,59,62,63].	Design and user testing of ways of visualising effects of multiple outcomes; randomised trials comparing different graphs or visualisations to each other and to information (tables and text) without visualisations; and a systematic review of those trials
<b>What are the effects of positive versus negative framing for different types of decisions on people's understanding and decisions?</b>	Low to moderate certainty evidence suggests that both attribute and goal framing may have little if any consistent effect on patients' behaviour [60]. Unexplained heterogeneity between studies suggests the possibility of a framing effect under specific conditions.	Randomised trials comparing positive to negative framing for different types of decisions; and a systematic review of those trials
<b>What are the effects of interactive presentations of information about the effects of interventions compared to static presentations, on comprehension, ease of use and usefulness in decision making for people across a broad range of target audiences?</b>	Different people prefer different types of presentation formats, and access information for different reasons that require different amount of detail. Instead of offering multiple tailored static formats to different audiences, an alternative solution is making multiple types of presentations available to all viewers through an interactive solution. Unpublished qualitative data from a failed trial with patients and the public [61] suggests that there may be mixed preferences for an interactive versus a static presentation. There is also uncertainty about which initial presentation to use for interactive presentations.	Design and user testing of interactive presentations; randomised trials comparing interactive to static presentations in a heterogeneous group, comparing alternative initial presentations across different sub-groups; and a systematic review of this evidence
<b>What are the effects of including stories of patients' experiences in patient information?</b>	People want this information and value it [22].	Design and user testing of ways of incorporating patients' experiences; randomised trials comparing information with and without patients' experiences; and a systematic review of this evidence
<b>What are the effects of audio and video presentations of information about the effects of interventions on peoples' understanding, decisions, and experience of the information?</b>	Audio and video presentations are likely to be helpful for people with poor reading skills and some people may prefer these presentations either as an alternative or as a supplement to reading.	Design and user testing of audio and video presentations; randomised trials comparing information with and without audio and video presentations; and a systematic review of this evidence

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**Figure 1. Flow chart outlining a process for producing evidence-based information about the effects of interventions**

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**Examples**

Summary of Findings tables for Cochrane reviews [24], SUPPORT Summaries [44,45], Plain language summaries [36, 46], Evidence-based policy briefs [47]

Summary of Findings tables for Cochrane reviews [24], SUPPORT Summaries [44,45], Interactive Summary of Findings [48], Plain language summaries [36, 46], Rapid responses [27], Evidence-based policy briefs [47], EPOC guidance [49]

SUPPORT Summaries [44,45], Rapid responses [27], Evidence-based policy briefs [47]

Review of websites that provide evidence-based information about treatment effects [21]

Summary of Findings tables for Cochrane reviews [24], Plain language summaries [36, 46], Rapid responses [27], Evidence-based policy briefs [47]

Summary of Findings tables for Cochrane reviews [24], SUPPORT Summaries [44,45], Plain language summaries [36, 46], Rapid responses [27]

Make sure you know your audience

- Consider your target audience and their information needs.
- Consider establishing an advisory group with people from your target audience, if you have not already done this.
- Consider other ways of involving members of your target audience in preparing the information.

Design and user test your format template

- Develop a template and guidance for those responsible for preparing the information, if you do not have this.
- Take account of recommendations 1-9 in the template and guidance.
- Make sure it includes dates (recommendation 10).
- Prepare prototypes, get feedback from your advisory group, and user test prototypes.

Organise an editorial process and training

- Establish an editorial process.
- Train the people who will be preparing the information.

Make it easy for your target audience to find information

- Make it easy for your target audience to recognise that the information is for them.
- Make it easy for your target audience to find information when they need it.

Tell your audience how you prepared the information

- Tell your audience how you prepared the information

Feedback, iteration, and evaluation

- Produce information iteratively by collecting feedback on each individual piece of information.
- Make changes, if needed to your template as well as to individual pieces of information.
- Evaluate again, if needed.
- Establish routines for updating, if this is planned.

**Additional file 1:****Feedback on the CIHC guidance for preparing evidence-based information about the effects of interventions****Name:****1. Are recommendations included that should not be?**

No

Uncertain

Yes

If yes or uncertain, which ones and why?

**2. Are there important recommendations that are missing?**

No

Uncertain

Yes

If yes or uncertain, which concepts are missing?

**3. Are the recommendations organised in a logical way?**

No

Uncertain

Yes

If no, what suggestions do you have for changes in how the concepts are organised?

**4. Are there systematic reviews or other research that we should consider, which are not referenced?**

No

Uncertain

Yes

If yes, can you list them?

**5. How might the checklist, flow chart and (planned) video be made more understandable/helpful for people preparing information?***Use next page if you need more space***6. Please include any other comments you have.***Use next page if you need more space*

## Additional file 2. Basis for the recommendations, caveats and risk mitigation

Recommendation	Research evidence	How this can affect use of the information and decision-making	Caveats and risk mitigation
<b>Make it easy for your target audience to quickly determine the relevance of the information, and to find the key messages.</b>			
<p>1. Clearly state the problem and the options (interventions) that you address, using language that is familiar to your target audience – so that people can determine if the information is relevant to them.</p>	<p>People commonly use search engines to find health information, they often do not go beyond the first results page, and they examine and abandon pages quickly.<sup>1,4</sup> People quickly make judgments about the potential relevance of information before considering the quality of the information; and relevance and ease of access can affect judgements about the trustworthiness or credibility of information.<sup>2,5-7</sup></p>	<p>The harder it is to find information and the longer it takes people to assess its relevance, the less likely it is that it will be used. Making it possible to quickly determine whether the information addresses a problem (or risk) and options (interventions) that are relevant, can increase the likelihood that people in your target audience will use it. People are most likely to seek information that is relevant to specific problems or concerns that they have or specific interventions that they are considering.</p>	<p>The more likely it is that people will find and use your information, the more important it is to ensure that it is informed by the best available evidence and that it is usable and useful. Many decision-makers are unlikely to use Boolean operators when searching, and are likely to search using a single search term.<sup>1,8</sup> It may be important to consider how people in your target audience are likely to search for information and what terms they are likely to use; and to include multiple terms, when relevant. It may also be important to consider ways of increasing the ranking of your information by search engines, such as Google. For users who are directed to your website, it is important to ensure that information is easy to find using the website's search function.<sup>3,9</sup></p>
<p>2. Present key messages up front, using language that is appropriate for your audience and make it easy for those who are interested to dig deeper and find information that is more detailed.</p>	<p>Too much text contributes to the rejection and mistrust of websites, and reduces the likelihood that information will be used; people examine and abandon online information quickly; and much online health information has a readability level that is inappropriate for general public use.<sup>2,10,11</sup> Decision-makers want and are more likely to read short, clear summaries with brief key messages rather than large blocks of text, and layered information, beginning with a concise summary through to detailed information and links to systematic reviews, caters for varying needs, time demands, and expertise.<sup>5,12-25</sup></p>	<p>The more quickly that people find and understand the key messages, the more likely it is that they will use the information. Poor readability can reduce the likelihood of information being used, and can result in misunderstanding and misinformation.</p>	<p>Repetition of information in more than one layer can be off-putting, and should be minimised.</p>

Recommendation	Research evidence	How this can affect use of the information and decision-making	Caveats and risk mitigation
<p>3. Report all potentially important benefits and harms, including outcomes for which no evidence was found – so that there is no ambiguity about what was found for each outcome that was considered.</p>	<p>It is frequently ambiguous whether unreported outcomes - particularly harms - were considered and no evidence was found or they were not considered; and outcomes are frequently reported selectively.<sup>26-36</sup></p>	<p>Reporting all of the potentially important benefits and harms that were considered, including ones for which little or no evidence was found, can reduce ambiguity and misleading reporting of key findings.</p>	<p>How important outcomes are to people varies. Patients, health professionals, policymakers, and researchers may have different views about which outcomes are important. It may be important to engage people in your target audience (or the people affected by a decision) in making judgements about the relative importance of outcomes. If there is a large number of outcomes, this can be overwhelming. It may be desirable to report the most important outcomes in the top layer (summary information) and other important outcomes in other layers.</p>
<p><b>For each outcome, help your target audience to understand the size of the effect and how sure we can be about that; and avoid presentations that are misleading.</b></p>			
<p>4. Explicitly assess and report the certainty of the evidence.</p>	<p>Several factors affect the certainty (or quality) of the evidence for estimates of effect, and the certainty of the evidence can vary from very low to high.<sup>37-44</sup></p>	<p>The certainty of the evidence can affect the decisions that people make. Assuming the purpose is to inform people rather than to persuade them, it is necessary to include information about the certainty of the evidence. Not doing so can be misleading. Unsystematic and nonexplicit assessments of the certainty of the evidence also can be misleading.</p>	<p>Assessments of the certainty of the evidence requires judgements. The underlying judgements and the basis for those judgements should be available. Uncertainty might sometimes be misunderstood or misused as an excuse for not taking appropriate actions, particularly for health system and public health interventions.<sup>45</sup> Clear explanations of what is meant by different levels of certainty should be provided (e.g. as scroll-overs); and care should be taken not to imply that uncertainty about effects necessarily means that an intervention should not be used.</p>
<p>5. Use language and numerical formats that are consistent and easy to understand</p>	<p>Verbal expressions of uncertainty or probability often mean different things to different people and some verbal expressions may be easier to understand than others.<sup>46-52</sup> Inconsistent use of language increases the risk of spin and verbal descriptions that are inconsistent with the evidence.<sup>53,54</sup> Use of consistent language that has been tested can improve the understanding, usability, and usefulness of information about intervention effects.<sup>55,56</sup></p>	<p>Using consistent language with well defined meanings can help reduce the risk of misunderstandings and misleading descriptions of the certainty of the evidence and the size of the effects.</p>	<p>Overly rigid application of consistent descriptions can result in awkward sentences that are difficult to understand. The language that is use to describe the certainty of the evidence and the size of the effects should be chosen carefully and, ideally, tested.</p>

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Recommendation	Research evidence	How this can affect use of the information and decision-making	Caveats and risk mitigation
6. Present both numbers and words, and include summary of findings tables.	Words may be easier to understand than numbers, and words used to express probabilities are often ordered consistently, but their interpretation is highly variable and may result in inappropriate perceptions and decisions. <sup>47-49,51,57</sup> Numbers are more accurate, but many people have poor numeracy skills and may have problems understanding effect estimates. <sup>50,51,58</sup> People differ in their preferences for words, numbers, or both. <sup>47</sup> Combinations of words and quantitative presentations are likely to have advantages over quantitative presentations alone as this can help to interpret and ensure understanding of numbers. <sup>51</sup> Summary of findings tables are perceived as understandable and useful, and they can improve how quickly people find key information, understanding, accurate perceptions of effects, and choices. <sup>13,56,59-61</sup>	Presenting both numbers and words, and including summary of findings tables can help to ensure correct understanding of effect estimates, and may improve decision-making.	Words alone may be sufficient for communicating vague or very uncertain effects. <sup>48</sup> Some people may be put-off by numbers or overwhelmed by summary of findings tables. One strategy for mitigating this risk is to partially hide the tables (e.g. by only showing the top of the table or a thumbnail image), so that they can be quickly accessed by those who want that information, while not putting off those who do not. Another strategy is to use <a href="#">interactive summary of findings tables</a> , which enable users to modify what information is displayed.
7. Report absolute effects.	A relative effect may give readers the impression that a difference is more important than it actually is when the likelihood of the outcome is small to begin with. <sup>62,63</sup>	Absolute effects generally are less likely to be misleading than relative effects and are easier to understand and use when making a decision.	For some target audiences it may be desirable to report both absolute and relative effects. Absolute effects may be difficult to calculate or interpret for some outcomes. In those cases it may be best not to report an absolute effect. Consideration should be given to providing help with interpreting such effect estimates, when needed.
8. Avoid misleading presentations and interpretations of effects.			
<ul style="list-style-type: none"> <li>Help your audience to avoid misinterpreting continuous outcome measures.</li> </ul>	Important continuous outcome measures, such as pain or quality of life, are easily misinterpreted and it is often difficult to make sense of them. <sup>29,64-66</sup>	Interpretation of continuous outcome measures is challenging. Careful reporting and explanations may help your target audience to make sense of them and to avoid misinterpreting them.	Although guidance is available for reporting continuous outcome measures, <sup>64</sup> alternative presentations all have merits and limitations.
<ul style="list-style-type: none"> <li>Explicitly assess and report the credibility of subgroup effects.</li> </ul>	Most differential effects suggested by subgroup results are likely to be due to the play of chance and are unlikely to reflect true differences. <sup>67</sup>	Using explicit criteria to make judgements about the credibility of subgroup effects can help to avoid misleading presentations. <sup>68-71</sup>	Assessments of the credibility of subgroup effects requires judgements. The underlying judgements and the basis for those judgements should be available.

Recommendation	Research evidence	How this can affect use of the information and decision-making	Caveats and risk mitigation
<ul style="list-style-type: none"> <li>Avoid confusing “statistically significant” with “important”, or a “lack of evidence” with a “lack of effect”.</li> </ul>	<p>Whether or not an effect is “statistically significant” is frequently confused with whether or not an effect is important.<sup>72-77</sup></p>	<p>Considering the precision of effect estimates when making judgements about the certainty of the evidence,<sup>78,79</sup> and not reporting effects as “statistically significant” or “statistically non-significant” can reduce the chances of misleading your target audience.</p>	<p>Although confidence intervals are more informative than p-values, confidence intervals can also be misinterpreted.<sup>80-83</sup> There are pros and cons to reporting confidence intervals and little evidence to support a recommendation either to include them or exclude them, or how to present and explain them, if they are included. Deciding whether and how to report confidence intervals may depend on the target audience.</p>
<p><b>Help your target audience to put information about the effects of interventions in context, and to understand why the information is trustworthy.</b></p>			
<p>9. Provide relevant background information, help people weigh the advantages against the disadvantages of interventions, and provide a sufficient description of the interventions.</p>	<p>Absolute effects may vary widely across subgroups with different baseline risks.<sup>84-87</sup> How much people value different outcomes also can vary widely.<sup>88-90</sup> Interventions are frequently inadequately described in trial reports and in systematic reviews.<sup>91,92</sup> Other factors besides treatment effects and the certainty of the evidence can affect people’s decisions.<sup>93-99</sup></p>	<p>Differences in baseline risk, differences in values, and other factors, including costs, acceptability, and feasibility can affect decisions. It may not be possible or appropriate to provide all of this information outside of the context of guidelines or recommendations. Nonetheless, decision-makers may find it helpful to have potentially important considerations flagged,<sup>15</sup> and doing so may reduce the risk of other important factors not receiving appropriate consideration. If a decision is made to use an intervention, decision-makers cannot implement it if it is not adequately described.</p>	<p>When additional information is provided, care should be taken to ensure that it is trustworthy.</p>
<p>10. Tell your audience how the information was prepared, what it is based on, the last search date, who prepared it and whether the people who prepared the information had conflicts of interest.</p>	<p>This information is often lacking or difficult to find.<sup>100</sup> Information from reputable sources often is not based on systematic reviews, not clear, incomplete, and misleading.<sup>100-102</sup> Information may become out-of-date if new research evidence has been reported since it was prepared.<sup>103-110</sup> Conflicts of interest are common, frequently are not disclosed, and can lead to biased reporting.<sup>111-121</sup></p>	<p>The source of information about the effects of treatments does not alone provide a reliable basis for judging how reliable the information is. Empowering people to make well-informed decisions about interventions requires that they have access to trustworthy information and that they are able to assess the trustworthiness of information based on how it was prepared, when it was prepared, and the extent to which conflicts of interest may have distorted the information.</p>	<p>This information should be up-to-date, easy for the target audience to understand, and easy to find.</p>

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## Additional file 3. Detailed guidance

- 1. Clearly state the problem and the options (interventions) that you address, using language that is familiar to your target audience – so that people can determine if the information is relevant to them.**

When searching for or considering information about the effects of interventions, people must decide whether the information is relevant to them. This requires a clear statement of the questions that you address, including the problem that you address. Unless an intervention is compared to something else, it is not possible to know what would happen without the intervention, so it is difficult to attribute outcomes to the intervention. Consequently, it is essential to specify at least two options (the intervention and a comparison intervention) whenever presenting information about the effects of interventions. Ideally, you should consider all of the relevant options, since people making choices want to know what their options are.

- 2. Present key messages up front, using language that is appropriate for your audience and make it easy for those who are interested to dig deeper and find information that is more detailed.**

Such a “layered” format is helpful to readers for several reasons:

- People tend to scan information first, to estimate its relevance and potential value, before deciding to read it. Short summaries can facilitate scanning.
- When people decide to start to read, many jump straight to the abstract and conclusions. Many people only read the abstract. Providing a short summary up front makes the parts readers are looking for easier to find.
- Different audiences have different needs regarding the amount of detail they want. When content is layered, readers can control the amount of detail presented to them according to their own needs, which may differ over time.
- A layered document structure encourages information providers to write clearly and succinctly, something they might not otherwise prioritize.

It is common to use three or four layers: the key messages, a brief summary, a full report, and appendices.

- 3. Report all potentially important benefits and harms, including outcomes for which no evidence was found – so that there is no ambiguity about what was found for each outcome that was considered.**

Information about the effects of treatments should include information about both desirable and undesirable effects. When reliable evidence for potentially important harms or benefits is not available, you should clearly report this, rather than saying nothing about those outcomes.

Both short and long-term outcomes should be reported. Whenever possible, surrogates for important outcomes should be avoided. When the best available evidence only reports surrogate outcomes (e.g. hypertension) and not important outcomes (e.g. myocardial infarction and stroke), this should be made clear.

In order not to overwhelm the target audience with information when there is a large number of potentially important outcomes, it may be desirable to omit less important outcomes [1]. Alternatively, less important outcomes can be omitted from the top layer but included in other layers. Decisions regarding which outcomes are more important require judgment and should be informed by how much people affected by the intervention value the outcomes of interest [2].

#### 4. Explicitly assess and report the certainty of the evidence.

The quality or certainty of the evidence (the extent to which research provides a good indication of the likely effects of interventions) can affect the healthcare decisions people make [3]. For example, someone might decide not to use or to pay for an intervention if the certainty of the evidence is low or very low. Information about the effects of interventions should include explicit judgements about the certainty of the evidence, based on the GRADE approach or similar approaches [4]. Consistent definitions of different levels of certainty should be used, such as those shown in Table 1. The definitions that are used should be easily accessible, for example using a pop-up or scroll-over for online information.

**Table 1. Definitions of different levels of certainty of the evidence**

Assessment	Definition
⊕⊕⊕⊕ High	This research provides a very good indication of the likely effect. The likelihood that the effect will be substantially different* is low.
⊕⊕⊕○ Moderate	This research provides a good indication of the likely effect. The likelihood that the effect will be substantially different* is moderate.
⊕⊕○○ Low	This research provides some indication of the likely effect. However, the likelihood that it will be substantially different* is high.
⊕○○○ Very low	This research does not provide a reliable indication of the likely effect. The likelihood that the effect will be substantially different* is very high.

\* Substantially different = a large enough difference that it might affect a decision

#### 5. Use language and numerical formats that are consistent and easy to understand.

The language that you use to report effects should reflect the importance of the effect and the certainty of the evidence, and it should be consistent. It is easy to cause confusion and misinterpretation by using words inconsistently or by using overly complicated phrases such as “a high likelihood of a somewhat small but possibly important effect”.

The importance of the effect depends on the size of the effect and how important the outcome is to people. For example, a small effect, say a difference of 5%, for an outcome that is not very important, such as mild discomfort, might be considered an unimportant effect. On the other hand, the same effect on an important outcome, such as strokes or death, is likely to be considered an important effect.

These can be difficult judgements to make. To help formulate clear, consistent expressions of the effects of interventions, we have developed standard expressions (Table 2) [3,5]. These describe effects in plain language, using similar words for similar combinations of importance and certainty.

Although these words can have different meanings to different people, consistent use of words such as these, and clear explanations of the meanings of the words that are used to express uncertainty, can reduce confusion, misunderstandings, and misleading presentations of how sure we can be about effects.

**Table 2. Standard expressions for communicating effects**

	Important benefit/harm	Less important benefit/harm	No important benefit/harm
<b>High quality / certainty<sup>1</sup> evidence</b>	<i>[Intervention]</i> improves/reduces <i>[outcome]</i> (high quality / certainty evidence)	<i>[Intervention]</i> slightly improves/reduces <i>[outcome]</i> (high quality / certainty evidence)	<i>[Intervention]</i> makes little or no difference to <i>[outcome]</i> (high quality / certainty evidence)
<b>Moderate quality / certainty<sup>1</sup> evidence</b>	<i>[Intervention]</i> probably improves/reduces <i>[outcome]</i> (moderate quality / certainty evidence)	<i>[Intervention]</i> probably slightly improves/reduces / probably leads to slightly better/worse <i>[outcome]</i> (moderate quality / certainty evidence)	<i>[Intervention]</i> probably makes little or no difference to <i>[outcome]</i> (moderate quality / certainty evidence)
<b>Low quality / certainty<sup>1</sup> evidence</b>	<i>[Intervention]</i> may improve/reduce <i>[outcome]</i> (low quality / certainty evidence)	<i>[Intervention]</i> may slightly improve/reduce <i>[outcome]</i> (low quality / certainty evidence)	<i>[Intervention]</i> may make little or no difference to <i>[outcome]</i> (low quality / certainty evidence)
<b>Very low quality / certainty<sup>1</sup> evidence</b>	We / The review authors are uncertain whether <i>[intervention]</i> improves/reduces <i>[outcome]</i> as the quality / certainty of the evidence has been assessed as very low		
<b>No studies</b>	None of the studies looked at <i>[outcome]</i>		

Using “plain language” means writing in a way that helps readers understand the content in a document the first time they read it. Although the use of plain language is commonly associated with information that is written for non-professionals, the principles underlying plain language [6] apply to any audience. This includes, for example, using:

- Words that are easily understood by the target audience
- Active verbs and personal pronouns
- Bullets, tables, and other design features that break up the text and add visual interest
- Short sentences and paragraphs

Terms that are unfamiliar to the target audience should be used only when necessary, and their meaning should be explained. Information about the effects of treatments should be as concise as possible. Extra or elaborate words reduce clarity and they should be avoided. Acronyms and abbreviations should also be avoided. Although they may be more concise, acronyms and abbreviations that are not familiar to the target audience make information more difficult to understand.

## 6. Present both numbers and words, and include summary of findings tables.

People's interpretations of the words used to describe treatment effects varies [7-9]. Patients' preferences for words, numbers, or both also vary [7]. More importantly, these different presentations can affect decisions. For example, women who received verbal information about disease-free survival for an experimental cancer treatment were more likely to select the treatment than those who received numerical information [7].

Words and numbers have different strengths and weaknesses for presenting the effects of interventions. The main argument for using numbers is that they are precise, whereas words can mean different things to different people. This can lead to misunderstanding. On the other hand, words are easier and more natural to use than numbers, allowing for fluidity in communication. They also may be easier to understand for people with poor numerical skills. In addition, words can quickly convey the "gist" of effects. This can be useful in situations where a precise understanding is not necessary and a rough understanding of the direction of effect is sufficient. Brief verbal summaries can also help people decide whether to continue on to more precise or detailed information [10]. Moreover, some people may not want numbers.

Because people have different preferences, and because numbers and words support different kinds of cognitive tasks (e.g. establishing gist, or determining precise effect differences), it is helpful to use both words and numbers to present the effects of interventions. The fact that some people may not be interested in numbers is not a reason not to provide them for those who can benefit from numerical information. This recommendation is supported by findings from user tests of various formats of Cochrane Review summaries using words, numbers, or both; which suggest that users prefer a combination [11]. Care must be taken to label numbers so that people can understand what they are referring to (e.g. "7 per 100 adults"). Standard expressions, such as those suggested above, presented alongside numerical results can help users feel more confident in their understanding of the numbers [3].

People's preference for words or numbers also depends on the manner in which they are presented. For example, people may experience numbers inserted in text as off-putting and complicated, and therefore prefer numbers in tables. Summary of findings tables show size of the effect and the certainty of the evidence for each important outcome [10-14]. Other advantages of using summary of findings tables to present numerical information about the effects of treatments, include:

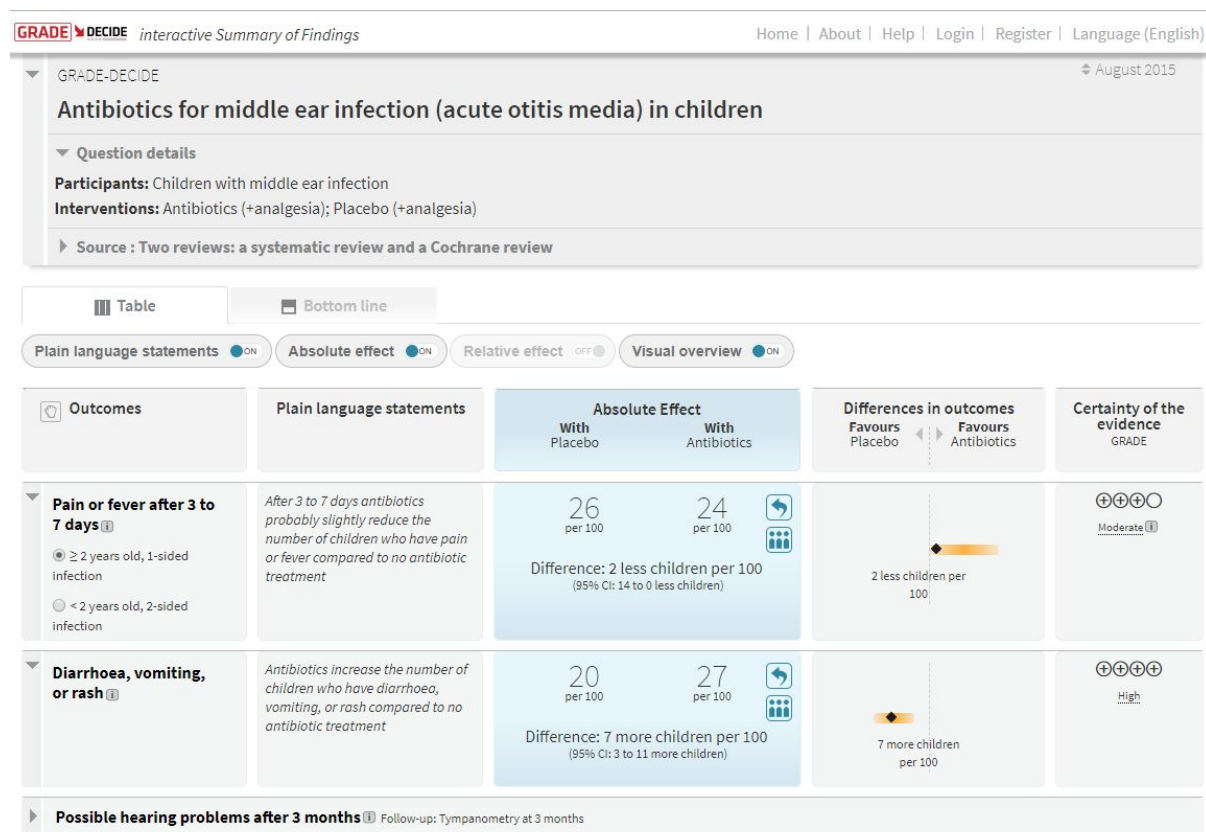
- Tables are more efficient for presenting numbers in the text, since the headings do not need to be repeated.
- Tables facilitate putting standard expressions alongside the numbers.
- People who are not interested or have difficulties with numbers can easily hop over tables or can just focus on selected information in tables, such as standard expressions.

Graphs or visual displays are appealing because they are visually interesting and they take advantage of rapid visual perception skills. Visual displays of effects can help people to comprehend proportions and the size of effects. However, not all visual displays are more intuitive than text or numbers, some visual displays can be misleading, some may require explanation in order for people to understand them, and people tend to prefer simplicity and familiarity, which may not be associated with accurate quantitative judgements [8,9,15-17]. There is not sufficient evidence for us to recommend any specific visual display for presenting the effects of interventions, and people vary in their preferences. Thus, although well-designed visual displays can be used to supplement

numerical and verbal presentations of effects, they should not be considered as a substitute in most circumstances.

An illustration of these principles can be found in interactive Summary of Findings tables [18]. These tables enable the presentation of a visual display of effect sizes (Figure 1) and provide explanations of the visual displays, the size of the effects, and the confidence interval. Different columns in the tables can be turned on or off by the target audience, based on their needs.

**Figure 1. Screen shot of an interactive Summary of Findings with a visual display of effects\***



\*[View an interactive version of this table](#)

## 7. Report absolute effects.

Three of the most commonly used formats for presenting effects of interventions are relative risk reduction, absolute risk reduction and number needed to treat (NNT). The relative risk reduction is the risk in the intervention group relative to the risk in the control group. If the risk is 10% in the intervention group and 20% in the control group, the risk in the intervention group is halved, i.e. a 50% relative risk reduction. The absolute risk reduction is the difference in risk between the two groups, i.e. 10% (or 10 percentage points), using the same example. The NNT is the number of patients you need to treat in order to prevent one bad outcome. It corresponds to the inverse of the absolute risk reduction. With the same example, the NNT is 10 (1/0.1).

A relative effect may give readers the impression that a difference is more important than it actually is when the likelihood of the outcome is small to begin with [19,20]. On the other hand, the absolute effect of a treatment is likely to vary for people at different baseline risk. Therefore, when people with different baseline risks may make different decisions because of this, absolute effects should be

presented for people at different levels of risk. This should be done in such a way that the target audience can easily identify which information is relevant for them, either based on the description that is provided (see, for example, Figure 1), or by using a risk calculator.

Although it has been argued that natural frequencies (e.g. 26 per 100 or 3 per 1000) are preferable to percentages (26% or 0.3%), the evidence used to support this argument has come from studies of presenting information about diagnostic or screening tests [19]. Two randomised trials that compared using natural frequencies to percentages to present information about the effects of interventions found that understanding was slightly better when percentages were used for levels of risk that are high enough that whole numbers can be used when percentages are presented [20,21].

In light of this evidence, it may be appropriate to use either percentages or natural frequencies. When natural frequencies are used, the denominator should be kept constant across outcomes (typically per 1000) to avoid misleading numerators [16]. For very low levels of risk, natural frequencies may be preferable to percentages using decimal numbers (such as 0.26% or 0.026%).

The number needed to treat (NNT) is a popular alternative way of presenting absolute effects and is preferred over the risk difference by some health professionals. However, NNTs (and, for adverse effects, numbers needed to harm) are more difficult to understand than risk differences [19,22].

## 8. Avoid misleading presentations and interpretations of effects.

Three common mistakes in presenting and interpreting treatment effects are:

- Help your audience to avoid misinterpreting continuous outcome measures.
- Explicitly assess and report the credibility of subgroup effects.
- Avoid confusing “statistically significant” with “important”, or a “lack of evidence” with a “lack of effect”.

Help your audience to avoid misinterpreting continuous outcome measures.

Average effects do not apply to everyone. For outcomes that are assessed using scales (for example, measuring weight, or pain) the difference between the average among people in one treatment group and the average among those in a comparison group may not make it clear how many people experienced a big enough change for them to notice it, or that they would regard as important. Whenever possible, this information should be presented. When it is not possible, this should be explained.

In addition, many scales are difficult to interpret and are reported in ways that make them meaningless. This includes not reporting the lower and upper ‘anchor’, for example, if a scale goes from 1 to 10 or 1 to 100; whether higher numbers are good or bad; and whether someone experiencing an improvement of, say, 5 on the scale would barely notice the difference, would consider it a meaningful improvement, or would consider it a large improvement. It is also difficult to understand the meaning for standardised mean differences (the difference in standard deviations between two comparison groups) when these are reported. Several strategies have been suggested for helping people to understand differences on unfamiliar scales [23]. Because there are limitations for each alternative, we suggest using more than one presentation for these outcomes and providing comments to help with correct interpretation [23].



### Explicitly assess and report the credibility of subgroup effects.

Estimates of effects from studies or systematic reviews do not apply to everyone. Comparisons of treatments often report results for selected groups of participants to assess whether the effect of a treatment is different for different types of people (e.g. men and women or different age groups). These analyses are often poorly planned and reported. Most differential effects suggested by these “subgroup results” are likely to be due to the play of chance and are unlikely to reflect true differences [24]. Judgements about the credibility of the size of an effect being different for a subgroup should be assessed using explicit criteria [25], and an explicit judgement should be made about how credible such a difference is [26].

### Avoid confusing “statistically significant” with “important”, or a “lack of evidence” with a “lack of effect”.

“Statistically significant” is so commonly misreported and misinterpreted that we recommend avoiding terms such as “not significant”, “not statistically significant”, “significant”, “statistically significant”, “trend towards [an effect]”, and “borderline significant” [27,28]. These terms are based on an arbitrary cut-off for statistical significance (typically 0.05). ‘Statistical significance’ (a ‘positive’ study) is often confused with ‘clinical significance’ (importance), especially when ‘significant’ is used rather than ‘statistically significant’. People also often misinterpret it as meaning that the certainty of the evidence is high, when it might not be for other reasons, such as a high risk of bias. Conversely, ‘statistically non-significant’ is ambiguous. It is often misinterpreted as evidence of ‘no effect’ (a ‘negative’ study). However, results that are ‘not statistically significant’ can either be informative (if the confidence interval, and the certainty of the evidence, suggests that there is unlikely to be an important effect) or uninformative (inconclusive, if the confidence interval does not rule out an important effect). It is better to consider explicitly estimates of effect and confidence intervals, and to use plain language to describe effects based on the size of the effect and the certainty of the evidence, as suggested above.

Systematic reviews sometimes conclude that there is “no evidence of an effect” when there is uncertainty about the effect. This is often misinterpreted as meaning that there is “no effect” [29]. However, lack of evidence of an effect is not the same as evidence of “no effect”. When there is a lack of evidence or very low certainty of the evidence (Table 1), we recommend using expressions such as the ones suggested in Table 2.

Although confidence intervals are more informative than p-values, confidence intervals can also be misinterpreted [3,30]. There are pros and cons to reporting confidence intervals and little evidence to support a recommendation either to include them or exclude them, or how to present and explain them, if they are included. Deciding whether and how to report confidence intervals may depend on the target audience.

## **9. Provide relevant background information, help people weigh the advantages against the disadvantages of interventions, and provide a sufficient description of the interventions.**

Information about the benefits and harms of interventions is essential but not sufficient for informed decisions. Decisions about whether or not to use an intervention depend on the balance between the potential benefits and the potential harms, costs, and other advantages and disadvantages of the intervention. This balance often depends on the baseline risk or severity of the

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3 symptoms. The balance between the advantages and disadvantages of a treatment is more likely to  
4 favour the use of an intervention by people with a higher baseline risk, or more severe symptoms.  
5 The balance also depends on how much people value (how much weight they give to) the  
6 intervention's advantages and disadvantages. Different people may value outcomes differently and  
7 sometimes make different decisions because of this. In addition, people usually place more value on  
8 things that happen soon than on things that happen years into the future. In other words, the  
9 further into the future something is (for example, reducing the chance of heart disease or cancer  
10 after many years) the more people tend to "discount" its value or importance. The balance between  
11 the advantages and disadvantages of treatments may also depend on how much costs and events in  
12 the future are discounted.  
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16 If a recommendation is made, those making the recommendation should take all these factors into  
17 account. Ideally, the criteria that they use to make a decision should be explicit, the judgements that  
18 they made for each criterion should be explicit, the evidence to inform each judgement should be  
19 explicit, and the justification for the recommendation should be clearly spelled out. GRADE Evidence  
20 to Decision frameworks provide a tool for doing this [31]. When a recommendation is not made,  
21 Evidence to Decision frameworks can provide a useful framework for considering factors that may  
22 help your target audience to make a decision [32]. For difficult clinical or personal decisions,  
23 providing or linking to a decision aid can be helpful [33].  
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26 Interventions are frequently inadequately described in trial reports and in systematic reviews  
27 [34,35]. If a decision is made to use an intervention, decision-makers cannot implement it if it is not  
28 adequately described. Therefore, it is essential to provide a sufficient description of interventions.  
29

30 Examples of other key types of information that can be helpful for patients and the public, health  
31 professionals, and policymakers are summarised in Table 3.  
32

33 **Table 3. Additional information that can be helpful to different target audiences**

34 Patients and the public	35 Health professionals	36 Policymakers
37 What is (are) the intervention(s)?	38 Indications and contraindications	39 What are the policy options?
40 Who can use the intervention(s)?	41 Delivery of the intervention(s)	42 Equity considerations
43 What other options are there?	44 Cautions	45 Economic considerations
46 How do people experience the intervention(s)	47 Counselling patients	48 Monitoring and evaluation considerations
49 Is there anything else that someone should know before using the intervention(s)	50 Anything else that health professionals should know before using the intervention(s)	51 Anything else that policymakers should know before deciding on one of the policy options

52 **10. Tell your audience how the information was prepared, what it is based on, the last  
53 search date, who prepared it and whether the people who prepared the information  
54 had conflicts of interest.**  
55

56 You should tell your audience when the information was last updated and when the last search for  
57 research evidence was done, so that they know how up-to-date the information is. If relevant,  
58 provide information about plans for updating the information.  
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3 Conflicts of interest are common, frequently are not disclosed, and can lead to biased reporting  
4 [36,37]. Therefore, it is important to tell your audience whether the people who prepared the  
5 information had conflicts of interest.  
6

7  
8 In order to earn their trust, and for transparency, you should tell them how the information was  
9 prepared, what evidence it is based on – and specifically whether the information about the effects  
10 of interventions is based on systematic reviews. Lastly, you should tell them who prepared the  
11 information and who paid for it, disclose any conflicts of interest, and provide a contact address for  
12 feedback and questions. It is not necessary to repeat all of this information in each summary, but all  
13 of this information should be clearly identified in the summary as available elsewhere and easy to  
14 find via links or instructions. When we reviewed websites that provide information about the effects  
15 of treatments for patients and the public [38], we found that very few websites provided all of this  
16 information. It was frequently difficult to establish what information was available and seldom  
17 obvious where it was located.  
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# BMJ Open

## Development of a checklist for people communicating evidence-based information about the effects of healthcare interventions: a mixed methods study

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# Development of a checklist for people communicating evidence-based information about the effects of healthcare interventions: a mixed methods study

*To make informed decisions, people need information that is easy to find, based on the best available evidence, easy to understand, and trustworthy.*

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## Abstract

**Objectives:** To make informed decisions about healthcare, patients and the public, health professionals and policymakers need information about the effects of interventions. People need information that is based on the best available evidence; that is presented in a complete and unbiased way; and that is relevant, trustworthy and easy to use and to understand. The aim of this paper is to provide guidance and a checklist to those producing and communicating evidence-based information about the effects of interventions intended to inform decisions about healthcare.

**Design:** To inform the development of this checklist, we identified research relevant to communicating evidence-based information about the effects of interventions. We used an iterative, informal consensus process to synthesize our recommendations. We began by discussing and agreeing on some initial recommendations, based on our own experience and research over the past 20 to 30 years. Subsequent revisions were informed by the literature we examined and feedback. We also compared our recommendations to those made by others. We sought structured feedback from people with relevant expertise, including people who prepare and use information about the effects of interventions for the public, health professionals, or policymakers.

**Results:** We produced a checklist with ten recommendations. Three recommendations focus on making it easy to quickly determine the relevance of the information and find the key messages. Five recommendations are about helping the reader understand the size of effects and how sure we are about those estimates. Two recommendations are about helping the reader put information about intervention effects in context and understand if and why the information is trustworthy.

**Conclusions:** These ten recommendations summarise lessons we have learned developing and evaluating ways of helping people to make well-informed decisions by making research evidence more understandable and useful for them. We welcome feedback for how to improve our advice.

## Strengths and limitations

- Our approach to preparing this checklist has been pragmatic in terms of the methods we have used.
- We have provided explanations of the basis for each recommendation and references to supporting research.
- We did not conduct a systematic review to inform our guidance.
- We did not review non-English language literature.
- We did not systematically grade the certainty of the evidence or strength of our recommendations.

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## Introduction

Access to healthcare information is necessary if people are to be involved in decisions regarding their own health [1]. Recognising this, governments in several countries have included the right to healthcare information in patients' charters. These charters commonly establish people's right to access information about treatments (e.g. [2]), including the benefits and harms of these treatments (e.g. [3]). Patients' charters also underline the need to provide this information in a way that people can understand and that is adapted to each individual's needs (e.g. [2,4]).

Having the *right* to information does not necessarily mean that this information is available, and many patients and members of the public struggle to find information that is relevant to their circumstances. At the same time, most people are bombarded with claims in the media and other aspects of day-to-day life about what they should and should not do to maintain or improve their health.

Many health claims are unreliable and conflicting [5-14]. When they are purported to be based on research, this might also contribute to a lack of trust in research. For example, surveys in the UK have shown that only about one third of the public trust evidence from medical research, while about two thirds trust the experiences of friends and family [15].

It cannot therefore be assumed that people will trust advice simply because it is based on research evidence and given by authorities. Nor should they, as the opinions of experts or authorities do not alone provide a reliable basis for judging the benefits and harms of interventions [16,17]. Doctors, researchers, and public health authorities – like anyone else – often disagree about the effects of interventions. This may be because their opinions are not always based on systematic reviews of fair comparisons of interventions [18]. Government authorities and professional organisations host many websites that provide health advice to the public. However, these websites often provide information that is unclear, incomplete, and misleading [11]. We were able to find only three websites that provide information about the effects of healthcare interventions that was explicitly based on systematic reviews [19]. Even where information *is* based on systematic reviews, it may still be unclear, incomplete, and misleading.

People who summarise lengthy research reports to make them more accessible are faced with many choices. This includes decisions about which evidence to present, how this evidence should be interpreted, and the format in which it should be presented. Our own experiences creating summaries based on Cochrane Reviews have shown us that there are many pitfalls [20-25]. A fundamental challenge is to find an appropriate balance between accuracy and simplicity. On the one hand, summaries should give a reasonably complete, nuanced, and unbiased representation of the evidence. On the other, they should be succinct and understandable to people without research expertise.

Another challenge to making research evidence easier to use is that people with expertise in a field have been found to pay attention to, read, and interpret information differently from people without expertise [26]. A common publishing strategy is to accommodate these differences by creating different versions of information for experts and non-experts; for example, for health professionals and for patients. However, both health professionals and patients frequently lack research expertise [22,26-29]. In terms of understanding evidence-based information about the effects of treatments, 'experts' are the people who have acquired the skills needed to understand and interpret results from quantitative studies and systematic reviews. Everybody else could be considered 'non-experts' in this area.

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3 This does not mean that this large group of non-experts are universally similar regarding their  
4 information needs. They may have different levels of language literacy, health literacy and  
5 numeracy, or they may need to use evidence for different kinds of decision-making tasks. However,  
6 when it comes to the specific task of understanding research evidence and using this information to  
7 weigh the trade-offs between possible benefits and harms, most users are non-experts.  
8 Consequently, most people would benefit from information about the effects of interventions that is  
9 presented in a way that recognizes the needs of non-experts. This includes patients, health  
10 professionals, and policymakers.  
11  
12

13 In summary, to make informed choices or decisions, people need information that is accessible, easy  
14 to find, relevant, based on the best available evidence, accurate, complete, not misleading, nuanced,  
15 unbiased, easy to understand, and trustworthy.  
16  
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18 The aim of this paper is to provide guidance and a checklist to anyone who is preparing and  
19 communicating evidence-based information on the effects of interventions (i.e. information based  
20 on systematic reviews of fair comparisons) that is intended to inform decisions by patients and the  
21 public, health professionals, or policymakers.  
22  
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## 24 25 26 **Methods**

### 27 28 **Ethical considerations**

29 Development of this checklist was guided by ethical considerations underlying informed consent and  
30 patients' rights. Informed consent in medical research has received a huge amount of attention [30].  
31 Informed consent in clinical and public health practice has received far less attention [31], and a  
32 double standard has existed for at least 50 years [32]. Consent in clinical and public health practice is  
33 reviewed, if at all, only in retrospect. Health professionals are exhorted to obtain informed consent,  
34 but in daily practice, as opposed to in clinical trials, they often minimise uncertainties about  
35 interventions and they may feel duty-bound to provide unequivocal recommendations [32].  
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38 Our starting point in preparing this checklist was the belief that patients and the public have the  
39 right to be informed when making health choices – such as a personal choice about whether to  
40 adhere to advice, a decision about whether to participate in research, or in taking a position  
41 regarding a health policy. Specifically, they should have access to the best available research  
42 evidence, including information about uncertainty, summarised in plain language. We do not assume  
43 that everyone wants this information.  
44  
45

46 Many people are not interested or prefer for someone else to make healthcare decisions on their  
47 behalf. For example, a systematic review of patient preferences for decision roles found that a  
48 substantial portion of patients prefer to delegate decision-making to their physician, although in  
49 most studies most patients reported a preference for shared decision-making [33]. Some patient's  
50 rights charters take this into account – for instance, the right to waive one's 'right to be informed' is  
51 specifically mentioned in the Norwegian Patient Rights legislation [4]. We would argue that under  
52 most circumstances it is good clinical practice to respect patient preferences [31]. Those people who  
53 do not want information on the effects of treatments do not need to read or listen to information,  
54 but it should be there for those who want it.  
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## Literature review

To inform the development of this checklist, we compiled research evidence that is relevant to giving guidance on how to communicate evidence-based information about the effects of interventions. We started with our own research and then identified related research through a snowballing and citation reference method. We supplemented this with broad searches for evidence on communicating research evidence and intervention effects, and specific searches for each item in the checklist. We did not conduct a systematic review. We have, however referenced systematic reviews to support each item in the checklist when one was available. When we were not able to find a relevant systematic review, we have referenced the best available evidence that we have found. In addition, we have reviewed relevant guidance and reference lists. This included guidance for plain language summaries of research evidence [34], for reporting and using systematic reviews [35,36], for making judgements about the certainty of evidence and for going from evidence to recommendations [37-39], and for risk communication [40].

## Synthesis

We used an iterative, informal consensus process to synthesize our recommendations. This was informed by our own experience and research spanning over three decades, our review of the literature, comparing our recommendations to other relevant guidance, and feedback from colleagues. We met initially to discuss our recommendations, divided up tasks, prepared drafts, and then discussed these until we reached agreement on a final set of recommendations. In addition to the checklist summarising our main recommendations, we prepared a flow chart, providing guidance for implementing our recommendations. After agreeing on a set of recommendations, we compared these to recommendations made by others and sent a draft report to 40 people and received feedback from 30 (see acknowledgements) requesting structured feedback (Additional file 1).

## Patient and public involvement

We did not directly involve patients in planning or executing this study.

## Results

Our recommendations are summarised in a checklist with 10 items (Box 1). The basis for each recommendation is provided in Additional file 2 and explanations for each of the recommendations is provided in Additional file 3. All of our recommendations could be considered “good practice statements”. Good practice statements are recommendations that do not warrant formal ratings of the certainty of the evidence [41]. One way of recognising such recommendations is to ask if the unstated alternative is absurd [41]. Arguably, that is the case for all the recommendations in Box 1.

### Box 1. Checklist for communicating effects

#### **Make it easy for your target audience to quickly determine the relevance of the information, and to find the key messages.**

1. Clearly state the problem and the options (interventions) that you address, using language that is familiar to your target audience – so that people can determine if the information is relevant to them.
2. Present key messages up front, using language that is appropriate for your audience and make it easy for those who are interested to dig deeper and find information that is more detailed.
3. Report the most important benefits and harms, including outcomes for which no evidence was found – so that there is no ambiguity about what was found for each outcome that was considered.

#### **For each outcome, help your target audience to understand the size of the effect and how sure we can be about that; and avoid presentations that are misleading.**

**DRAFT:** 8 April 2020**Box 1. Checklist for communicating effects**

4. Explicitly assess and report the certainty of the evidence.
5. Use language and numerical formats that are consistent and easy to understand.
6. Present both numbers and words, and consider using tables to summarise benefits and harms, for instance using GRADE summary of findings tables or similar tables.
7. Report absolute effects.
8. Avoid misleading presentations and interpretations of effects.
  - Help your audience to avoid misinterpreting continuous outcome measures.
  - Explicitly assess and report the credibility of subgroup effects.
  - Avoid confusing “statistically significant” with “important”, or a “lack of evidence” with a “lack of effect”.

**Help your target audience to put information about the effects of interventions in context, and to understand why the information is trustworthy.**

9. Provide relevant background information, help people weigh the advantages against the disadvantages of interventions, and provide a sufficient description of the interventions.
10. Tell your audience how the information was prepared, what it is based on, the last search date, who prepared it and whether the people who prepared the information had conflicts of interest.

**Flow chart**

The flow chart (Figure 1) outlines a process for producing evidence-based information about the effects of interventions. It provides examples that illustrate each step of the process [42-46]. The process begins with making sure that you know your target audience. It is important to consider how members of your target audience will be involved in the process. The next steps in the process are designing and user testing a template for the information that you will prepare, organising an editorial process and training, and considering ways of making it easy for your target audience to find your information. Although the flow chart suggests a linear process, development should be approached as an iterative, cyclical process. The last step in Figure 1 is to collect feedback on each individual piece of information from people in your target audience; to make changes if needed (to your template as well as to individual pieces of information); and to evaluate again, if needed. It also includes establishing routines for updating the information that you prepare, if this is planned.

[Figure 1 goes here]

**Discussion****How our checklist compares to related checklists and guidance**

Although our guidance overlaps with other guidance [38,47-54], for the most part other guidance does not specifically addressing preparation of evidence-based information for decision makers about the effects of interventions. The one exception or which we are aware is the “Guideline for evidence-based health information” prepared by the German Network for Evidence-Based Medicine (DNEbM) [55], which is only partially translated to English as of April 2020. The DNEbM recommendations are consistent with or recommendations to present both numbers and words and report absolute effects. They do not explicitly address our other recommendations. Comparison of our guidance with other guidance is summarised in Table 1.

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Table 1. Comparison of our checklist with other guidance

Guidance	Purpose	Comparison to our checklist
<b>The Conference On Guideline Standardization (COGS) checklist for reporting clinical practice guidelines</b> [47]	<i>The checklist is intended to minimize the quality defects that arise from failure to include essential information and to promote development of recommendation statements that are more easily implemented.</i>	Focus is on content of a full guideline report rather than on presentation of information. It does not include guidance for how to present information about benefits and harms. It is consistent with our checklist for the items that overlap. Some of the 18 items are outside of the scope of our checklist.
<b>DISCERN instrument for judging the quality of written consumer health information on treatment choices</b> 48]	<i>To enable patients and information providers to judge the quality of written information about treatment choices; and to facilitate the production of new, high quality, evidence-based consumer health information.</i>	There is some overlap, but the focus is on content of information for patients and the public rather than on presentation of that information; and the checklist is presented as an instrument for assessing the quality of information rather than as a guide for preparing it.
<b>Ensuring Quality Information for Patients (EQIP) tool</b> [49]	<i>To provide a practical measure of the presentation quality for all types of written healthcare information.</i>	There is some overlap, but it does not address how to present evidence-based information about the effects of interventions. It includes some relevant suggestions that we have not included: <ul style="list-style-type: none"> <li>• Use short sentences</li> <li>• Personally address the reader</li> <li>• Be respectful</li> <li>• Include easy-to-understand illustrations</li> </ul>
<b>Evidence-Based Risk Communication</b> [50]	<i>Key findings to inform best practice from a systematic review of the comparative effectiveness of methods of communicating probabilistic information to patients that maximize their cognitive and behavioural outcomes.</i>	The findings from this systematic review are largely consistent with our recommendations for how to help people understand the size of effects. It includes some suggestions that we have not: <ul style="list-style-type: none"> <li>• Add bar graphs or icon arrays to natural frequencies or event rates</li> <li>• Consider the use of icon arrays with smaller numerators and bar graphs with larger numerators</li> <li>• Place a patient's risk in context by using comparative risks of other events</li> <li>• Realize that positive framing (stating benefits rather than harms) increases acceptance of therapies</li> </ul>
<b>GRADE guidelines</b> [38]	<i>To provide guidance for use of the GRADE system of rating the certainty of evidence and grading the strength of recommendations in systematic reviews, health technology assessments, and clinical practice guidelines.</i>	This is a series of articles that provides detailed guidance for people preparing systematic reviews, health technology assessments, or guidelines. We have helped to develop this guidance and have drawn on it. Our checklist is consistent with GRADE guidance for Summary of Findings tables and communicating information about uncertainty.

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Guidance	Purpose	Comparison to our checklist
International Patient Decision Aid Standards (IPDAS) Patient Decision Aid User Checklist [51,52]	<i>To provide a set of quality criteria for patient decision aids.</i>	<p>Many of the items in the IPDAS checklist overlap with our checklist. It also includes items that are outside of the scope of our checklist (e.g. decision aids for tests, helping users to clarify their values, and evaluation of decision aids), as well as some items that are within our scope, which we have not included. They are reformulated here as guidance:</p> <ul style="list-style-type: none"> <li>• Use visual diagrams to show the probabilities (e.g. faces, stick figures, or bar charts).</li> <li>• Allow patients to select a way of viewing the probabilities (e.g. words, numbers, diagrams).</li> <li>• Present probabilities using both positive and negative frames (e.g. showing both survival and death rates).</li> <li>• Describe the features of options to help patients imagine what it is like to experience their physical, emotional, and social effects.</li> <li>• Provide stories of other patients' experiences.</li> <li>• Identify the reading level at which it is written and the formula [method] used to determine the level.</li> <li>• Provide ways to help patients understand information other than reading (e.g. audio, video, or in-person discussion).</li> </ul>
<b>Risk and uncertainty communication</b> [53]	<i>Explores the major issues in communicating risk assessments arising from statistical analysis and concludes with a set of recommendations.</i>	<p>Largely consistent with our checklist. Includes a set of recommendations about visualisations, such as:</p> <ul style="list-style-type: none"> <li>• Illuminate graphics with words and numbers.</li> <li>• Design graphics to allow part-to-whole comparisons on an appropriate scale.</li> <li>• Helpful narrative labels are important.</li> <li>• Be cautious about interactivity and animations.</li> <li>• Avoid chart junk.</li> <li>• Most importantly, assess the needs of the audience, experiment, test, and iterate toward a final design.</li> </ul>
<b>US National Standards for the Certification of Patient Decision Aids</b> [54]	To provide criteria for a potential decision aid certification process in the U.S.	Although there is some overlap with our checklist, the criteria do not address how to present information about the effects of interventions other than “adopting risk communication principles”.

The Ensuring Quality Information for Patients (EQIP) tool [49] and the International Patient Decision Aid Standards (IPDAS) checklist [51,52] include specific recommendations related to using plain language (short sentences and a reading level not exceeding a reading age of 12). We have included key principles for plain language in our detailed guidance (Additional file 3).

The EQIP tool [49], the IPDAS checklist [51,52] as well as a systematic review on evidence-based risk communication by Zipkin and colleagues [50] recommend using visual aids. The last two recommend using graphs to show probabilities. We agree that information for people making decisions about interventions should be visually appealing and that well-designed visualisations can help some people to understand information about the effects of interventions. The DNEbM guidelines [55] recommend that “Graphics may be used to supplement numerical presentations in texts or tables” based on “low quality” evidence. They also recommend that “If graphics are used as a supplement, then either pictograms or bar charts should be used” based on “moderate quality” evidence.

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3 Spiegelhalter [53] recommends visualisations in communication about risk and uncertainty, which  
4 seems sensible. However, we do not think there currently is enough evidence to support  
5 recommendations about when to use visualisations or what type of visualisation to use  
6 [50,53,56,57].  
7

8  
9 The systematic review on evidence-based risk communication [50] suggests being aware that  
10 positive framing (stating benefits rather than harms) increases acceptance of therapies. The IPDAS  
11 checklist [52,53] recommends presenting probabilities using both positive and negative frames (e.g.  
12 showing both survival and death rates). We do not think there currently is enough evidence for  
13 either of these recommendations [58].  
14

15 Zipkin and colleagues [50] suggest placing a patient's risk in context by using comparative risks of  
16 other events. We do not think there is currently is enough evidence to support this recommendation  
17 and question its relevance for many decisions about interventions.  
18

19  
20 The DNEbM guidelines [55] suggest "Interactive elements may be used in health information" based  
21 on "moderate quality" evidence. Similarly, the IPDAS checklist [51,52] recommends allowing patients  
22 to select a way of viewing the probabilities (e.g. words, numbers, diagrams). We agree this is  
23 sensible and, in previous work, we have designed an interactive Summary of Findings with this in  
24 mind [45]. However, there is limited evidence to support this recommendation. We attempted to  
25 test this hypothesis in a randomised trial [59]. Because of technical problems (the interactive  
26 Summary of Findings and data collection did not work for some participants), we were not able to  
27 complete the trial. The qualitative data that we collected suggested that participants (people in  
28 Scotland with an interest in participating in randomised trials of interventions [60]) had mixed views  
29 about their preferences for an interactive versus a static presentation. They also had mixed views  
30 regarding which initial presentation they preferred in the interactive presentation.  
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34 Lastly, the DNEbM guidelines conclude that "Narratives cannot be recommended" based on "low  
35 quality" evidence. In contrast, the IPDAS checklist [51,52] recommends including stories of other  
36 patients' experiences and using audio and video to help users understand information. We agree  
37 that this may be helpful. However, it is also possible that stories that specifically describe patients'  
38 experiences of treatment effects and side effects can have unintended consequences. For example,  
39 people's perceptions of their own risks of experiencing a benefit or harm could be influenced by  
40 whether they identify with the person telling the story or not. We are not aware of evidence from  
41 randomised trials comparing information with and without patients' experiences, audio, or video; or  
42 comparing different types of presentations. A recent systematic review on the use of narratives to  
43 impact health policymaking did not find any trials [61].  
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## 49 **Strengths and weaknesses of our checklist**

50 We did not conduct a systematic review to inform our guidance, review non-English language  
51 literature, assess the certainty of the evidence supporting each recommendation, grade the strength  
52 of our recommendations, or use a formal consensus process. However, we have provided  
53 explanations of the basis for each recommendation and references to supporting research. Our  
54 approach to preparing this checklist has been pragmatic in terms of the methods we have used. We  
55 hope that others will find the checklist practical and helpful. To facilitate use of the checklist, we  
56 have prepared a flow chart with examples (Figure 1).  
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Implementation of the guidance can be facilitated by developing a template, specific guidance for those charged with using the template to prepare the information, and training for those people. Links to examples of these can be found in the flow chart. User testing can help to ensure that people in your target audience experience the information positively and as intended. We have provided links to examples of user tests of information about the effects of interventions and to resources for user testing in the flow chart.

### Implications for research

There remain many important uncertainties about how best to present evidence-based information about the effects of interventions to people making decisions about those interventions. There is a need for more primary research and more systematic reviews in this field. We have summarised key uncertainties that we identified while preparing this checklist in Table 2. In addition, there is a need for a methodological review and a consensus on appropriate outcomes for studies evaluating different ways of communicating evidence-based information about the effects of interventions [e.g. 62].

**Table 2. Important uncertainties about how to present evidence-based information about the effects of interventions to people making decisions**

Question	What is known	Research that is needed
<b>What are the effects of alternative visual displays of intervention effects on understanding and users' experience of the information?</b>	Not all visual displays are more intuitive than text or numbers, some visual displays can be misleading, some may require explanation in order for people to understand them, and people tend to prefer simplicity and familiarity, which may not be associated with accurate quantitative judgements [50,53,56,57,63,64].	Design and user testing of ways of visualising effects of multiple outcomes; randomised trials comparing different graphs or visualisations to each other and to information (tables and text) without visualisations; and a systematic review of those trials
<b>What are the effects of positive versus negative framing for different types of decisions on people's understanding and decisions?</b>	Low to moderate certainty evidence suggests that both attribute and goal framing may have little if any consistent effect on patients' behaviour [58]. Unexplained heterogeneity between studies suggests the possibility of a framing effect under specific conditions.	Randomised trials comparing positive to negative framing for different types of decisions; and a systematic review of those trials
<b>When should confidence intervals be reported and how should they be presented and explained?</b>	Although confidence intervals are more informative than p-values, confidence intervals can also be misinterpreted [43,65,66]. There are pros and cons to reporting confidence intervals and little evidence to support a recommendation either to include them or exclude them, or how to present and explain them, if they are included. Deciding whether and how to report confidence intervals may depend on the target audience.	User testing of ways of presenting and explaining confidence intervals; randomised trials comparing different ways of presenting and explaining confidence intervals to other ways and to not presenting confidence intervals; and a systematic review of those trials.

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Question	What is known	Research that is needed
<p><b>What are the effects of interactive presentations of information about the effects of interventions compared to static presentations, on comprehension, ease of use and usefulness in decision making for people across a broad range of target audiences?</b></p>	<p>Different people prefer different types of presentation formats, and access information for different reasons that require different amount of detail. Instead of offering multiple tailored static formats to different audiences, an alternative solution is making multiple types of presentations available to all viewers through an interactive solution. Unpublished qualitative data from a failed trial with patients and the public [59] suggests that there may be mixed preferences for an interactive versus a static presentation. There is also uncertainty about which initial presentation to use for interactive presentations.</p>	<p>Design and user testing of interactive presentations; randomised trials comparing interactive to static presentations in a heterogeneous group, comparing alternative initial presentations across different sub-groups; and a systematic review of this evidence</p>
<p><b>What are the effects of including stories of patients' experiences in patient information?</b></p>	<p>People want this information and value it [20].</p>	<p>Design and user testing of ways of incorporating patients' experiences, including the use of patients' stories to describe treatment benefits and harms, or to describe the treatment or condition; randomised trials comparing information with and without patients' experiences; and a systematic review of this evidence</p>
<p><b>What are the effects of audio and video presentations of information about the effects of interventions on peoples' understanding, decisions, and experience of the information?</b></p>	<p>Audio and video presentations are likely to be helpful for people with poor reading skills and some people may prefer these presentations either as an alternative or as a supplement to reading.</p>	<p>Design and user testing of audio and video presentations; randomised trials comparing information with and without audio and video presentations; and a systematic review of this evidence</p>

## Conclusions

The checklist that we have developed, which includes ten items, is the top layer of our recommendations for how to prepare evidence-based information on the effects of interventions that is intended to inform decisions by patients and the public, health professionals, or policymakers. These ten recommendations summarise the lessons that we have learned from our review of relevant research. The recommendations draw on our own experience over the past 20 to 30 years in developing and evaluating ways of helping people to make well-informed health choices by making research evidence more understandable and useful to them. We welcome feedback and suggestions for how to improve our advice.

## Contributors

ADO, CG, SF, SL and AF are health service researchers. SR is a designer and researcher. The authors have worked together for over two decades studying ways to help health professionals, policymakers, patients and the public make well-informed healthcare decisions. All the authors

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participated in discussions about the recommendations and this report, helped to review the literature and respond to external feedback on a draft report, and provided feedback on each draft of the report. ADO is the guarantor of the article.

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## Competing interests

We have no competing interests.

## Data availability statement

Data sharing not applicable as no datasets generate and/or analysed for this study.

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Make sure you know your audience

- Consider your target audience and their information needs.
- Consider establishing an advisory group with people from your target audience, if you have not already done this.
- Consider other ways of involving members of your target audience in preparing the information.

Design and user test your format template

- Develop a template and guidance for those responsible for preparing the information, if you do not have this.
- Take account of recommendations 1-9 in the template and guidance.
- Make sure it includes dates (recommendation 10).
- Prepare prototypes, get feedback from your advisory group, and user test prototypes.

Organise an editorial process and training

- Establish an editorial process including, for instance, peer review using content experts, assessment of language quality, and copy editing.
- Train the people who will be preparing the information.

Make it easy for your target audience to find information

- Make it easy for your target audience to recognise that the information is for them.
- Make it easy for your target audience to find information when they need it.

Tell your audience how you prepared the information

- Tell your audience how you prepared the information

Feedback, iteration, and evaluation

- Produce information iteratively by collecting feedback on each individual piece of information.
- Make changes, if needed to your template as well as to individual pieces of information.
- Evaluate again, if needed.
- Establish routines for updating, if this is planned.

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Summary of Findings tables for Cochrane reviews [22], SUPPORT Summaries [24,43], Plain language summaries [34, 44], Evidence-based policy briefs [45]

Summary of Findings tables for Cochrane reviews [22], SUPPORT Summaries [24,43], Interactive Summary of Findings [46], Plain language summaries [34, 44], Rapid responses [25], Evidence-based policy briefs [45], EPOC guidance [47]

SUPPORT Summaries [24,43], Rapid responses [25], Evidence-based policy briefs [45]

Review of websites that provide evidence-based information about treatment effects [19]

Summary of Findings tables for Cochrane reviews [22], Plain language summaries [34, 44], Rapid responses [25], Evidence-based policy briefs [45]

Summary of Findings tables for Cochrane reviews [22,23], SUPPORT Summaries [24,43], Plain language summaries [34, 44], Rapid responses [25]



**Additional file 1:****Feedback on the CIHC guidance for preparing evidence-based information about the effects of interventions****Name:****1. Are recommendations included that should not be?**

No

Uncertain

Yes

If yes or uncertain, which ones and why?

**2. Are there important recommendations that are missing?**

No

Uncertain

Yes

If yes or uncertain, which concepts are missing?

**3. Are the recommendations organised in a logical way?**

No

Uncertain

Yes

If no, what suggestions do you have for changes in how the concepts are organised?

**4. Are there systematic reviews or other research that we should consider, which are not referenced?**

No

Uncertain

Yes

If yes, can you list them?

**5. How might the checklist, flow chart and (planned) video be made more understandable/helpful for people preparing information?***Use next page if you need more space***6. Please include any other comments you have.***Use next page if you need more space*

**Additional file 2. Basis for the recommendations, caveats and risk mitigation**

Recommendation	Research evidence	How this can affect use of the information and decision-making	Caveats and risk mitigation
<b>Make it easy for your target audience to quickly determine the relevance of the information, and to find the key messages.</b>			
<p>1. Clearly state the problem and the options (interventions) that you address, using language that is familiar to your target audience – so that people can determine if the information is relevant to them.</p>	<p>People commonly use search engines to find health information, they often do not go beyond the first results page, and they examine and abandon pages quickly.<sup>1-4</sup> People quickly make judgments about the potential relevance of information before considering the quality of the information; and relevance and ease of access can affect judgements about the trustworthiness or credibility of information.<sup>2,5-7</sup></p>	<p>The harder it is to find information and the longer it takes people to assess its relevance, the less likely it is that it will be used. Making it possible to quickly determine whether the information addresses a problem (or risk) and options (interventions) that are relevant, can increase the likelihood that people in your target audience will use it. People are most likely to seek information that is relevant to specific problems or concerns that they have or specific interventions that they are considering.</p>	<p>The more likely it is that people will find and use your information, the more important it is to ensure that it is informed by the best available evidence and that it is usable and useful. Many decision-makers are unlikely to use Boolean operators when searching, and are likely to search using a single search term.<sup>1,8</sup> It may be important to consider how people in your target audience are likely to search for information and what terms they are likely to use; and to include multiple terms, when relevant. It may also be important to consider ways of increasing the ranking of your information by search engines, such as Google. For users who are directed to your website, it is important to ensure that information is easy to find using the website's search function.<sup>3,9</sup></p>
<p>2. Present key messages up front, using language that is appropriate for your audience and make it easy for those who are interested to dig deeper and find information that is more detailed.</p>	<p>Too much text contributes to the rejection and mistrust of websites, and reduces the likelihood that information will be used; people examine and abandon online information quickly; and much online health information has a readability level that is inappropriate for general public use.<sup>2,10,11</sup> Decision-makers want and are more likely to read short, clear summaries with brief key messages rather than large blocks of text, and layered information, beginning with a concise summary through to detailed information and links to systematic reviews, caters for varying needs, time demands, and expertise.<sup>5,12-25</sup></p>	<p>The more quickly that people find and understand the key messages, the more likely it is that they will use the information. Poor readability can reduce the likelihood of information being used and can result in misunderstanding and misinformation.</p>	<p>Repetition of information in more than one layer can be off-putting and should be minimised.</p>

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Recommendation	Research evidence	How this can affect use of the information and decision-making	Caveats and risk mitigation
<p>3. Report all potentially important benefits and harms, including outcomes for which no evidence was found – so that there is no ambiguity about what was found for each outcome that was considered.</p>	<p>It is frequently ambiguous whether unreported outcomes - particularly harms - were considered and no evidence was found or they were not considered; and outcomes are frequently reported selectively.<sup>26-36</sup></p>	<p>Reporting all of the potentially important benefits and harms that were considered, including ones for which little or no evidence was found, can reduce ambiguity and misleading reporting of key findings.</p>	<p>How important outcomes are to people varies. Patients, health professionals, policymakers, and researchers may have different views about which outcomes are important. It may be important to engage people in your target audience (or the people affected by a decision) in making judgements about the relative importance of outcomes. If there are many outcomes, this can be overwhelming. It may be desirable to report the most important outcomes in the top layer (summary information) and other important outcomes in other layers.</p>
<b>For each outcome, help your target audience to understand the size of the effect and how sure we can be about that; and avoid presentations that are misleading.</b>			
<p>4. Explicitly assess and report the certainty of the evidence.</p>	<p>Several factors affect the certainty (or quality) of the evidence for estimates of effect, and the certainty of the evidence can vary from very low to high.<sup>37-44</sup></p>	<p>The certainty of the evidence can affect the decisions that people make. Assuming the purpose is to inform people rather than to persuade them, it is necessary to include information about the certainty of the evidence. Not doing so can be misleading. Unsystematic and nonexplicit assessments of the certainty of the evidence also can be misleading.</p>	<p>Assessments of the certainty of the evidence requires judgements. The underlying judgements and the basis for those judgements should be available. Uncertainty might sometimes be misunderstood or misused as an excuse for not taking appropriate actions, particularly for health system and public health interventions.<sup>45</sup> Clear explanations of what is meant by different levels of certainty should be provided (e.g. as scroll-overs); and care should be taken not to imply that uncertainty about effects necessarily means that an intervention should not be used.</p>
<p>5. Use language and numerical formats that are consistent and easy to understand</p>	<p>Verbal expressions of uncertainty or probability often mean different things to different people and some verbal expressions may be easier to understand than others.<sup>46-52</sup> Inconsistent use of language increases the risk of spin and verbal descriptions that are inconsistent with the evidence.<sup>53,54</sup> Use of consistent language that has been tested can improve the understanding, usability, and usefulness of information about intervention effects.<sup>55,56</sup></p>	<p>Using consistent language with well-defined meanings can help reduce the risk of misunderstandings and misleading descriptions of the certainty of the evidence and the size of the effects.</p>	<p>Overly rigid application of consistent descriptions can result in awkward sentences that are difficult to understand. The language that is used to describe the certainty of the evidence and the size of the effects should be chosen carefully and, ideally, tested.</p>

Recommendation	Research evidence	How this can affect use of the information and decision-making	Caveats and risk mitigation
<p>6. Present both numbers and words, and include summary of findings tables.</p>	<p>Words may be easier to understand than numbers, and words used to express probabilities are often ordered consistently, but their interpretation is highly variable and may result in inappropriate perceptions and decisions.<sup>47-49,51,57</sup> Numbers are more accurate, but many people have poor numeracy skills and may have problems understanding effect estimates.<sup>50,51,58</sup> People differ in their preferences for words, numbers, or both.<sup>47</sup> Combinations of words and quantitative presentations are likely to have advantages over quantitative presentations alone as this can help to interpret and ensure understanding of numbers.<sup>51</sup> Summary of findings tables are perceived as understandable and useful, and they can improve how quickly people find key information, understanding, accurate perceptions of effects, and choices.<sup>13,56,59-61</sup></p>	<p>Presenting both numbers and words and including summary of findings tables can help to ensure correct understanding of effect estimates and may improve decision-making.</p>	<p>Words alone may be sufficient for communicating vague or very uncertain effects.<sup>48</sup> Some people may be put-off by numbers or overwhelmed by summary of findings tables. One strategy for mitigating this risk is to partially hide the tables (e.g. by only showing the top of the table or a thumbnail image), so that they can be quickly accessed by those who want that information, while not putting off those who do not. Another strategy is to use <a href="#">interactive summary of findings tables</a>, which enable users to modify what information is displayed.</p>
<p>7. Report absolute effects.</p>	<p>A relative effect may give readers the impression that a difference is more important than it actually is when the likelihood of the outcome is small to begin with.<sup>62,63</sup></p>	<p>Absolute effects generally are less likely to be misleading than relative effects and are easier to understand and use when making a decision.</p>	<p>For some target audiences it may be desirable to report both absolute and relative effects. Absolute effects may be difficult to calculate or interpret for some outcomes. In those cases, it may be best not to report an absolute effect. Consideration should be given to providing help with interpreting such effect estimates, when needed.</p>
<p>8. Avoid misleading presentations and interpretations of effects.</p> <ul style="list-style-type: none"> <li>Help your audience to avoid misinterpreting continuous outcome measures.</li> <li>Explicitly assess and report the credibility of subgroup effects.</li> </ul>	<p>Important continuous outcome measures, such as pain or quality of life, are easily misinterpreted and it is often difficult to make sense of them.<sup>29,64-66</sup></p> <p>Most differential effects suggested by subgroup results are likely to be due to the play of chance and are unlikely to reflect true differences.<sup>67</sup></p>	<p>Interpretation of continuous outcome measures is challenging. Careful reporting and explanations may help your target audience to make sense of them and to avoid misinterpreting them.</p> <p>Using explicit criteria to make judgements about the credibility of subgroup effects can help to avoid misleading presentations.<sup>68-71</sup></p>	<p>Although guidance is available for reporting continuous outcome measures,<sup>64</sup> alternative presentations all have merits and limitations.</p> <p>Assessments of the credibility of subgroup effects requires judgements. The underlying judgements and the basis for those judgements should be available.</p>

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Recommendation	Research evidence	How this can affect use of the information and decision-making	Caveats and risk mitigation
<ul style="list-style-type: none"> <li>Avoid confusing “statistically significant” with “important”, or a “lack of evidence” with a “lack of effect”.</li> </ul>	<p>Whether or not an effect is “statistically significant” is frequently confused with whether an effect is important.<sup>72-77</sup></p>	<p>Considering the precision of effect estimates when making judgements about the certainty of the evidence,<sup>78,79</sup> and not reporting effects as “statistically significant” or “statistically non-significant” can reduce the chances of misleading your target audience.</p>	<p>Although confidence intervals are more informative than p-values, confidence intervals can also be misinterpreted.<sup>80-83</sup> There are pros and cons to reporting confidence intervals and little evidence to support a recommendation either to include them or exclude them, or how to present and explain them, if they are included. Deciding whether and how to report confidence intervals may depend on the target audience.</p>
<b>Help your target audience to put information about the effects of interventions in context, and to understand why the information is trustworthy.</b>			
<p>9. Provide relevant background information, help people weigh the advantages against the disadvantages of interventions, and provide a sufficient description of the interventions.</p>	<p>Absolute effects may vary widely across subgroups with different baseline risks.<sup>84-87</sup> How much people value different outcomes also can vary widely.<sup>88-90</sup> Interventions are frequently inadequately described in trial reports and in systematic reviews.<sup>91,92</sup> Other factors besides treatment effects and the certainty of the evidence can affect people’s decisions.<sup>93-99</sup></p>	<p>Differences in baseline risk, differences in values, and other factors, including costs, acceptability, and feasibility can affect decisions. It may not be possible or appropriate to provide all this information outside of the context of guidelines or recommendations. Nonetheless, decision-makers may find it helpful to have potentially important considerations flagged,<sup>15</sup> and doing so may reduce the risk of other important factors not receiving appropriate consideration. If a decision is made to use an intervention, decision-makers cannot implement it if it is not adequately described.</p>	<p>When additional information is provided, care should be taken to ensure that it is trustworthy.</p>
<p>10. Tell your audience how the information was prepared, what it is based on, the last search date, who prepared it and whether the people who prepared the information had conflicts of interest.</p>	<p>This information is often lacking or difficult to find.<sup>100</sup> Information from reputable sources often is not based on systematic reviews, not clear, incomplete, and misleading.<sup>100-102</sup> Information may become out-of-date if new research evidence has been reported since it was prepared.<sup>103-110</sup> Conflicts of interest are common, frequently are not disclosed, and can lead to biased reporting.<sup>111-121</sup></p>	<p>The source of information about the effects of treatments does not alone provide a reliable basis for judging how reliable the information is. Empowering people to make well-informed decisions about interventions requires that they have access to trustworthy information and that they are able to assess the trustworthiness of information based on how it was prepared, when it was prepared, and the extent to which conflicts of interest may have distorted the information.</p>	<p>This information should be up-to-date, easy for the target audience to understand, and easy to find.</p>

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### Additional file 3. Detailed guidance

1. Clearly state the problem and the options (interventions) that you address, using language that is familiar to your target audience – so that people can determine if the information is relevant to them.

When searching for or considering information about the effects of interventions, people must decide whether the information is relevant to them. This requires a clear statement of the questions that you address, including the problem that you address. Unless an intervention is compared to something else, it is not possible to know what would happen without the intervention, so it is difficult to attribute outcomes to the intervention. Consequently, it is essential to specify at least two options (the intervention and a comparison intervention, which may be simply not adding the intervention to whatever else is done) whenever presenting information about the effects of interventions. Ideally, you should consider all the relevant options, since people making choices want to know what their options are.

2. Present key messages up front, using language that is appropriate for your audience and make it easy for those who are interested to dig deeper and find information that is more detailed.

Such a “layered” format is helpful to readers for several reasons:

- People tend to scan information first, to estimate its relevance and potential value, before deciding to read it. Short summaries can facilitate scanning.
- When people decide to start to read, many jump straight to the abstract and conclusions. Many people only read the abstract. Providing a short summary up front makes the parts readers are looking for easier to find.
- Different audiences have different needs regarding the amount of detail they want. When content is layered, readers can control the amount of detail presented to them according to their own needs, which may differ over time.
- A layered document structure encourages information providers to write clearly and succinctly, something they might not otherwise prioritize.

It is common to use three or four layers: the key messages, a brief summary, a full report, and appendices.

3. Report all potentially important benefits and harms, including outcomes for which no evidence was found – so that there is no ambiguity about what was found for each outcome that was considered.

Information about the effects of treatments should include information about both desirable and undesirable effects. When reliable evidence for potentially important harms or benefits is not available, you should clearly report this, rather than saying nothing about those outcomes.

Both short and long-term outcomes should be reported. Whenever possible, surrogates for important outcomes should be avoided. When the best available evidence only reports surrogate outcomes (e.g. hypertension) and not important outcomes (e.g. myocardial infarction and stroke), this should be made clear.

In order not to overwhelm the target audience with information when there are many potentially important outcomes, it may be desirable to omit less important outcomes [1]. Alternatively, less important outcomes can be omitted from the top layer but included in other layers. Decisions regarding which outcomes are more important require judgment and should be informed by how much people affected by the intervention value the outcomes of interest [2].

#### 4. Explicitly assess and report the certainty of the evidence.

The quality or certainty of the evidence (the extent to which research provides a good indication of the likely effects of interventions) can affect the healthcare decisions people make [3]. For example, someone might decide not to use or to pay for an intervention if the certainty of the evidence is low or very low. Information about the effects of interventions should include explicit judgements about the certainty of the evidence, based on the GRADE approach or similar approaches [4]. Consistent definitions of different levels of certainty should be used, such as those shown in Table 1. The definitions that are used should be easily accessible, for example using a pop-up or scroll-over for online information.

Table 1. Definitions of different levels of certainty of the evidence

Assessment	Definition
⊕⊕⊕⊕ High	This research provides a very good indication of the likely effect. The likelihood that the effect will be substantially different* is low.
⊕⊕⊕○ Moderate	This research provides a good indication of the likely effect. The likelihood that the effect will be substantially different* is moderate.
⊕⊕○○ Low	This research provides some indication of the likely effect. However, the likelihood that it will be substantially different* is high.
⊕○○○ Very low	This research does not provide a reliable indication of the likely effect. The likelihood that the effect will be substantially different* is very high.

\* Substantially different = a large enough difference that it might affect a decision

#### 5. Use language and numerical formats that are consistent and easy to understand.

The language that you use to report effects should reflect the importance of the effect and the certainty of the evidence, and it should be consistent. It is easy to cause confusion and misinterpretation by using words inconsistently or by using overly complicated phrases such as “a high likelihood of a somewhat small but possibly important effect”.

The importance of the effect depends on the size of the effect and how important the outcome is to people. For example, a small effect, say a difference of 5%, for an outcome that is not very important, such as mild discomfort, might be considered an unimportant effect. On the other hand, the same effect on an important outcome, such as strokes or death, is likely to be considered an important effect.

These can be difficult judgements to make. To help formulate clear, consistent expressions of the effects of interventions, we have developed standard expressions (Table 2) [3,5]. These describe effects in plain language, using similar words for similar combinations of importance and certainty.

Although these words can have different meanings to different people, consistent use of words such as these, and clear explanations of the meanings of the words that are used to express uncertainty, can reduce confusion, misunderstandings, and misleading presentations of how sure we can be about effects.

Table 2. Standard expressions for communicating effects

	Important benefit/harm	Less important benefit/harm	No important benefit/harm
<b>High quality / certainty<sup>1</sup> evidence</b>	<i>[Intervention]</i> improves/reduces <i>[outcome]</i> (high quality / certainty evidence)	<i>[Intervention]</i> slightly improves/reduces <i>[outcome]</i> (high quality / certainty evidence)	<i>[Intervention]</i> makes little or no difference to <i>[outcome]</i> (high quality / certainty evidence)
<b>Moderate quality / certainty<sup>1</sup> evidence</b>	<i>[Intervention]</i> probably improves/reduces <i>[outcome]</i> (moderate quality / certainty evidence)	<i>[Intervention]</i> probably slightly improves/reduces / probably leads to slightly better/worse <i>[outcome]</i> (moderate quality / certainty evidence)	<i>[Intervention]</i> probably makes little or no difference to <i>[outcome]</i> (moderate quality / certainty evidence)
<b>Low quality / certainty<sup>1</sup> evidence</b>	<i>[Intervention]</i> may improve/reduce <i>[outcome]</i> (low quality / certainty evidence)	<i>[Intervention]</i> may slightly improve/reduce <i>[outcome]</i> (low quality / certainty evidence)	<i>[Intervention]</i> may make little or no difference to <i>[outcome]</i> (low quality / certainty evidence)
<b>Very low quality / certainty<sup>1</sup> evidence</b>	We / The review authors are uncertain whether <i>[intervention]</i> improves/reduces <i>[outcome]</i> as the quality / certainty of the evidence has been assessed as very low		
<b>No studies</b>	None of the studies looked at <i>[outcome]</i>		

Using “plain language” means writing in a way that helps readers understand the content in a document the first time they read it. Although the use of plain language is commonly associated with information that is written for non-professionals, the principles underlying plain language [6] apply to any audience. This includes, for example, using:

- Words that are easily understood by the target audience
- Active verbs and personal pronouns
- Bullets, tables, and other design features that break up the text and add visual interest
- Short sentences and paragraphs

Terms that are unfamiliar to the target audience should be used only when necessary, and their meaning should be explained. Information about the effects of treatments should be as concise as possible. Extra or elaborate words reduce clarity and they should be avoided. Acronyms and abbreviations should also be avoided. Although they may be more concise, acronyms and abbreviations that are not familiar to the target audience make information more difficult to understand.



## 6. Present both numbers and words, and include summary of findings tables.

People's interpretations of the words used to describe treatment effects varies [7-9]. Patients' preferences for words, numbers, or both also vary [7]. More importantly, these different presentations can affect decisions. For example, women who received verbal information about disease-free survival for an experimental cancer treatment were more likely to select the treatment than those who received numerical information [7].

Words and numbers have different strengths and weaknesses for presenting the effects of interventions. The main argument for using numbers is that they are precise, whereas words can mean different things to different people. This can lead to misunderstanding. On the other hand, words are easier and more natural to use than numbers, allowing for fluidity in communication. They also may be easier to understand for people with poor numerical skills. In addition, words can quickly convey the "gist" of effects. This can be useful in situations where a precise understanding is not necessary and a rough understanding of the direction of effect is sufficient. Brief verbal summaries can also help people decide whether to continue on to more precise or detailed information [10]. Moreover, some people may not want numbers.

Because people have different preferences, and because numbers and words support different kinds of cognitive tasks (e.g. establishing gist, or determining precise effect differences), it is helpful to use both words and numbers to present the effects of interventions. The fact that some people may not be interested in numbers is not a reason not to provide them for those who can benefit from numerical information. This recommendation is supported by findings from user tests of various formats of Cochrane Review summaries using words, numbers, or both; which suggest that users prefer a combination [11]. Care must be taken to label numbers so that people can understand what they are referring to (e.g. "7 per 100 adults"). Standard expressions, such as those suggested above, presented alongside numerical results can help users feel more confident in their understanding of the numbers [3].

People's preference for words or numbers also depends on the way they are presented. For example, people may experience numbers inserted in text as off-putting and complicated, and therefore prefer numbers in tables. Summary of findings tables show size of the effect and the certainty of the evidence for each important outcome [10-14]. Other advantages of using summary of findings tables to present numerical information about the effects of treatments, include:

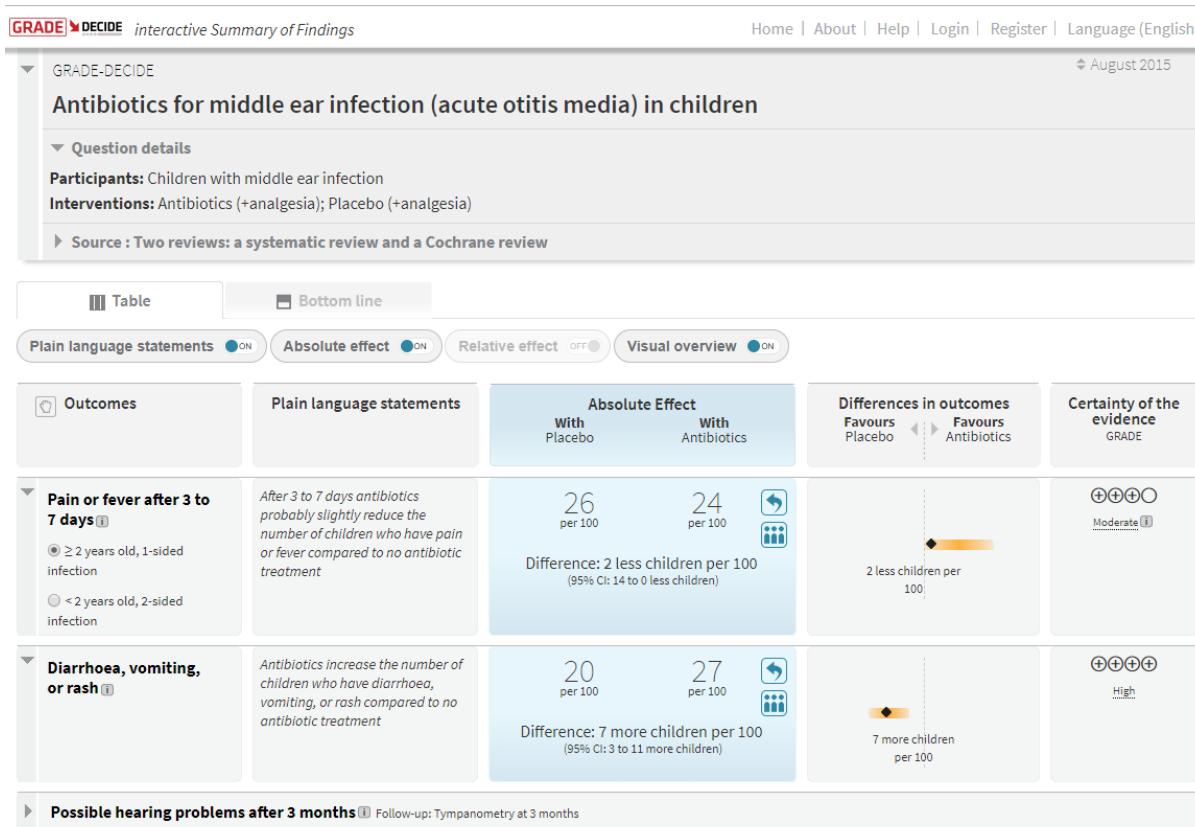
- Tables are more efficient for presenting numbers in the text, since the headings do not need to be repeated.
- Tables facilitate putting standard expressions alongside the numbers.
- People who are not interested or have difficulties with numbers can easily hop over tables or can just focus on selected information in tables, such as standard expressions.

Graphs or visual displays are appealing because they are visually interesting, and they take advantage of rapid visual perception skills. Visual displays of effects can help people to comprehend proportions and the size of effects. However, not all visual displays are more intuitive than text or numbers, some visual displays can be misleading, some may require explanation in order for people to understand them, and people tend to prefer simplicity and familiarity, which may not be associated with accurate quantitative judgements [8,9,15-17]. There is not sufficient evidence for us to recommend any specific visual display for presenting the effects of interventions, and people vary in their preferences. Thus, although well-designed visual displays can be used to supplement

numerical and verbal presentations of effects, they should not be considered as a substitute in most circumstances.

An illustration of these principles can be found in interactive Summary of Findings tables [18]. These tables enable the presentation of a visual display of effect sizes (Figure 1) and provide explanations of the visual displays, the size of the effects, and the confidence interval. Different columns in the tables can be turned on or off by the target audience, based on their needs.

Figure 1. Screen shot of an interactive Summary of Findings with a visual display of effects\*



\*[View an interactive version of this table](#)

## 7. Report absolute effects.

Three of the most used formats for presenting effects of interventions are relative risk reduction, absolute risk reduction and number needed to treat (NNT). The relative risk reduction is the risk in the intervention group relative to the risk in the control group. If the risk is 10% in the intervention group and 20% in the control group, the risk in the intervention group is halved, i.e. a 50% relative risk reduction. The absolute risk reduction is the difference in risk between the two groups, i.e. 10% (or 10 percentage points), using the same example. The NNT is the number of patients you need to treat in order to prevent one bad outcome. It corresponds to the inverse of the absolute risk reduction. With the same example, the NNT is 10 (1/0.1).

A relative effect may give readers the impression that a difference is more important than it is when the likelihood of the outcome is small to begin with [19,20]. On the other hand, the absolute effect of a treatment is likely to vary for people at different baseline risk. Therefore, when people with different baseline risks may make different decisions because of this, absolute effects should be

presented for people at different levels of risk. This should be done in such a way that the target audience can easily identify which information is relevant for them, either based on the description that is provided (see, for example, Figure 1), or by using a risk calculator.

Although it has been argued that natural frequencies (e.g. 26 per 100 or 3 per 1000) are preferable to percentages (26% or 0.3%), the evidence used to support this argument has come from studies of presenting information about diagnostic or screening tests [19]. Two randomised trials that compared using natural frequencies to percentages to present information about the effects of interventions found that understanding was slightly better when percentages were used for levels of risk that are high enough that whole numbers can be used when percentages are presented [20,21].

Considering this evidence, it may be appropriate to use either percentages or natural frequencies. When natural frequencies are used, the denominator should be kept constant across outcomes (typically per 1000) to avoid misleading numerators [16]. For very low levels of risk, natural frequencies may be preferable to percentages using decimal numbers (such as 0.26% or 0.026%).

The number needed to treat (NNT) is a popular alternative way of presenting absolute effects and is preferred over the risk difference by some health professionals. However, NNTs (and, for adverse effects, numbers needed to harm) are more difficult to understand than risk differences [19,22].

## 8. Avoid misleading presentations and interpretations of effects.

Three common mistakes in presenting and interpreting treatment effects are:

- Help your audience to avoid misinterpreting continuous outcome measures.
- Explicitly assess and report the credibility of subgroup effects.
- Avoid confusing “statistically significant” with “important”, or a “lack of evidence” with a “lack of effect”.

Help your audience to avoid misinterpreting continuous outcome measures.

Average effects do not apply to everyone. For outcomes that are assessed using scales (for example, measuring weight, or pain) the difference between the average among people in one treatment group and the average among those in a comparison group may not make it clear how many people experienced a big enough change for them to notice it, or that they would regard as important. Whenever possible, this information should be presented. When it is not possible, this should be explained.

In addition, many scales are difficult to interpret and are reported in ways that make them meaningless. This includes not reporting the lower and upper ‘anchor’, for example, if a scale goes from 1 to 10 or 1 to 100; whether higher numbers are good or bad; and whether someone experiencing an improvement of, say, 5 on the scale would barely notice the difference, would consider it a meaningful improvement, or would consider it a large improvement. It is also difficult to understand the meaning for standardised mean differences (the difference in standard deviations between two comparison groups) when these are reported. Several strategies have been suggested for helping people to understand differences on unfamiliar scales [23]. Because there are limitations for each alternative, we suggest using more than one presentation for these outcomes and providing comments to help with correct interpretation [23].

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3 Explicitly assess and report the credibility of subgroup effects.  
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5 Estimates of effects from studies or systematic reviews do not apply to everyone. Comparisons of  
6 treatments often report results for selected groups of participants to assess whether the effect of a  
7 treatment is different for different types of people (e.g. men and women or different age groups).  
8 These analyses are often poorly planned and reported. Most differential effects suggested by these  
9 “subgroup results” are likely to be due to the play of chance and are unlikely to reflect true  
10 differences [24]. Judgements about the credibility of the size of an effect being different for a  
11 subgroup should be assessed using explicit criteria [25], and an explicit judgement should be made  
12 about how credible such a difference is [26].  
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15 Avoid confusing “statistically significant” with “important”, or a “lack of evidence” with a “lack of  
16 effect”.  
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19 “Statistically significant” is so commonly misreported and misinterpreted that we recommend  
20 avoiding terms such as “not significant”, “not statistically significant”, “significant”, “statistically  
21 significant”, “trend towards [an effect]”, and “borderline significant” [27,28]. These terms are based  
22 on an arbitrary cut-off for statistical significance (typically 0.05). ‘Statistical significance’ (a ‘positive’  
23 study) is often confused with ‘clinical significance’ (importance), especially when ‘significant’ is used  
24 rather than ‘statistically significant’. People also often misinterpret it as meaning that the certainty  
25 of the evidence is high, when it might not be for other reasons, such as a high risk of bias.  
26 Conversely, ‘statistically non-significant’ is ambiguous. It is often misinterpreted as evidence of ‘no  
27 effect’ (a ‘negative’ study). However, results that are ‘not statistically significant’ can either be  
28 informative (if the confidence interval, and the certainty of the evidence, suggests that there is  
29 unlikely to be an important effect) or uninformative (inconclusive, if the confidence interval does not  
30 rule out an important effect). It is better to consider explicitly estimates of effect and confidence  
31 intervals, and to use plain language to describe effects based on the size of the effect and the  
32 certainty of the evidence, as suggested above.  
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36 Systematic reviews sometimes conclude that there is “no evidence of an effect” when there is  
37 uncertainty about the effect. This is often misinterpreted as meaning that there is “no effect” [29].  
38 However, lack of evidence of an effect is not the same as evidence of “no effect”. When there is a  
39 lack of evidence or very low certainty of the evidence (Table 1), we recommend using expressions  
40 such as the ones suggested in Table 2.  
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43 Although confidence intervals are more informative than p-values, confidence intervals can also be  
44 misinterpreted [3,30]. There are pros and cons to reporting confidence intervals and little evidence  
45 to support a recommendation either to include them or exclude them, or how to present and  
46 explain them, if they are included. Deciding whether and how to report confidence intervals may  
47 depend on the target audience.  
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## 50 51 9. Provide relevant background information, help people weigh the advantages against the 52 disadvantages of interventions, and provide a sufficient description of the interventions. 53

54 Information about the benefits and harms of interventions is essential but not sufficient for  
55 informed decisions. Decisions about whether or not to use an intervention depend on the balance  
56 between the potential benefits and the potential harms, costs, and other advantages and  
57 disadvantages of the intervention. This balance often depends on the baseline risk or severity of the  
58 symptoms. The balance between the advantages and disadvantages of a treatment is more likely to  
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favour the use of an intervention by people with a higher baseline risk, or more severe symptoms. The balance also depends on how much people value (how much weight they give to) the intervention's advantages and disadvantages. Different people may value outcomes differently and sometimes make different decisions because of this. In addition, people usually place more value on things that happen soon than on things that happen years into the future. In other words, the further into the future something is (for example, reducing the chance of heart disease or cancer after many years) the more people tend to "discount" its value or importance. The balance between the advantages and disadvantages of treatments may also depend on how much costs and events in the future are discounted.

If a recommendation is made, those making the recommendation should take all these factors into account. Ideally, the criteria that they use to make a decision should be explicit, the judgements that they made for each criterion should be explicit, the evidence to inform each judgement should be explicit, and the justification for the recommendation should be clearly spelled out. GRADE Evidence to Decision frameworks provide a tool for doing this [31]. When a recommendation is not made, Evidence to Decision frameworks can provide a useful framework for considering factors that may help your target audience to make a decision [32]. For difficult clinical or personal decisions, providing or linking to a decision aid can be helpful [33].

Interventions are frequently inadequately described in trial reports and in systematic reviews [34,35]. If a decision is made to use an intervention, decision-makers cannot implement it if it is not adequately described. Therefore, it is essential to provide a sufficient description of interventions.

Examples of other key types of information that can be helpful for patients and the public, health professionals, and policymakers are summarised in Table 3.

**Table 3. Additional information that can be helpful to different target audiences**

Patients and the public	Health professionals	Policymakers
What is (are) the intervention(s)?	Indications and contraindications	What are the policy options?
Who can use the intervention(s)?	Delivery of the intervention(s)	Equity considerations
What other options are there?	Cautions	Economic considerations
How do people experience the intervention(s)	Counselling patients	Monitoring and evaluation considerations
Is there anything else that someone should know before using the intervention(s)	Anything else that health professionals should know before using the intervention(s)	Anything else that policymakers should know before deciding on one of the policy options

## 10. Tell your audience how the information was prepared, what it is based on, the last search date, who prepared it and whether the people who prepared the information had conflicts of interest.

You should tell your audience when the information was last updated and when the last search for research evidence was done, so that they know how up-to-date the information is. If relevant, provide information about plans for updating the information.

Conflicts of interest are common, frequently are not disclosed, and can lead to biased reporting [36,37]. Therefore, it is important to tell your audience whether the people who prepared the information had conflicts of interest.

In order to earn their trust, and for transparency, you should tell them how the information was prepared, what evidence it is based on – and specifically whether the information about the effects of interventions is based on systematic reviews of fair comparisons. Lastly, you should tell them who prepared the information and who paid for it, disclose any conflicts of interest, and provide a contact address for feedback and questions. It is not necessary to repeat all of this information in each summary, but all of this information should be clearly identified in the summary as available elsewhere and easy to find via links or instructions. When we reviewed websites that provide information about the effects of treatments for patients and the public [38], we found that very few websites provided all of this information. It was frequently difficult to establish what information was available and seldom obvious where it was located.

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