



# How to develop patient versions of guidelines: updating the G-I-N PUBLIC Toolkit

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# DECIDE



Developing and Evaluating  
Communication strategies to support  
Informed Decisions and practice based  
on Evidence



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# G-I-N PUBLIC Toolkit

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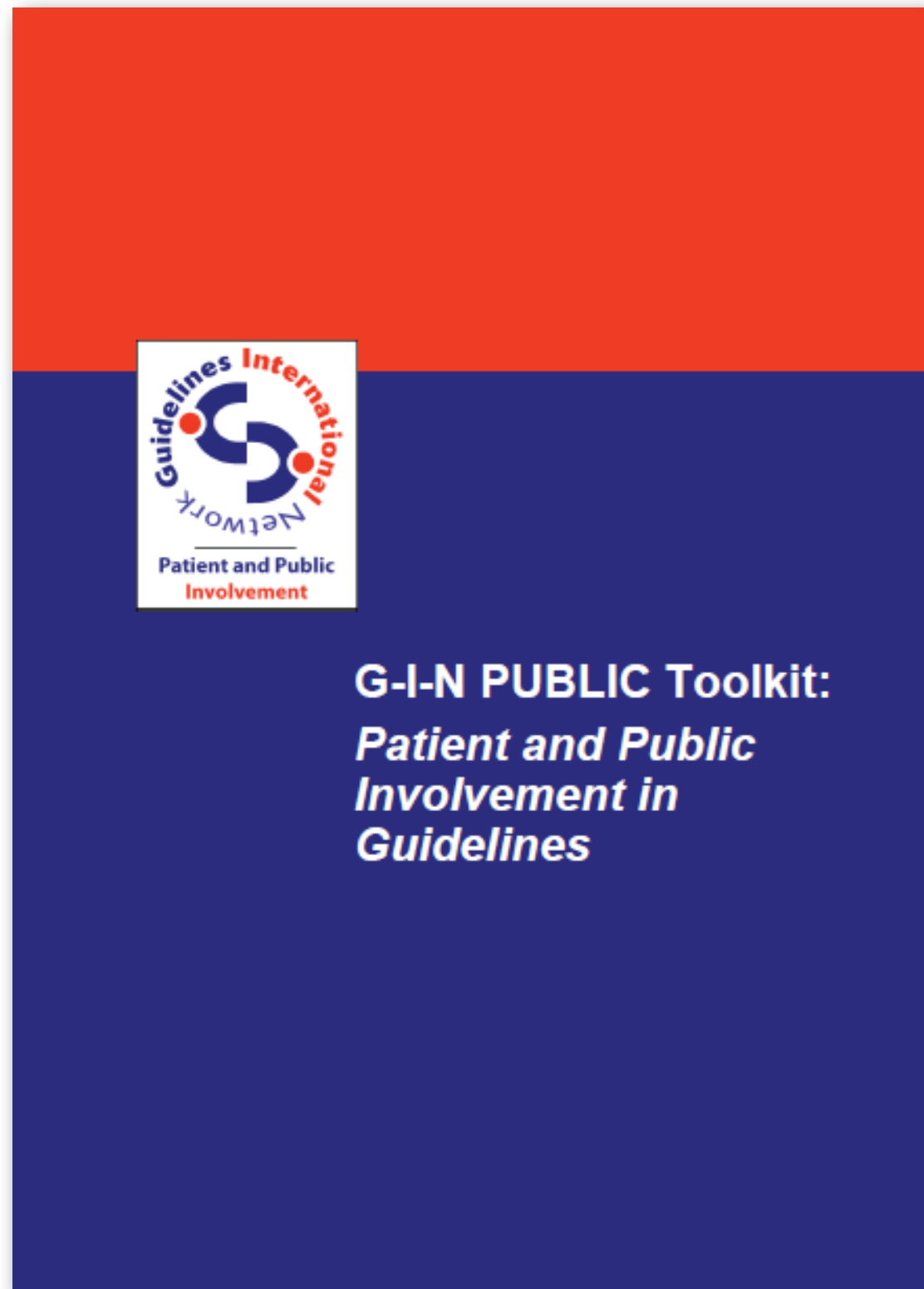


**G-I-N PUBLIC Toolkit:**  
*Patient and Public  
Involvement in  
Guidelines*

**Aims to support guideline  
developers considering  
involving patients in  
guideline development or  
dissemination**

# Chapter 4

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**'How to develop patient versions of guidelines'**

**By Corinna Schaefer**

# So, why update Chapter 4?

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- **Time passes, always good to update**
- **Is the information in patient versions useful to patients and public?**
- **Evidence from the DECIDE project**

# **DECIDE work that informs GIN PUBLIC**

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- **Review of public/patient attitudes and awareness of guidelines**
- **Review of existing patient versions**
- **Focus group and user-testing work with patients and public**
- **General knowledge of literature, brainstorming and discussion**

# Some highlights

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- **Most people have no idea that guidelines exist**
- **Who is the patient version for?**
- **People want information that often isn't in guidelines**
- **Opinion is divided about numerical information**
- **Deliver information in small doses**

# Chapter 4

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**G-I-N PUBLIC Toolkit:**  
*Patient and Public  
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**The new Chapter 4 will  
include these findings.**



guidelines as one of the purposes of patient versions<sup>3</sup>. Relatively few patient versions currently meet this need<sup>5</sup>.

Presenting recommendations linked to self-management are therefore ones to prioritise when deciding which recommendations to cover in a patient version of a guideline. The Scottish Dental Clinical Effectiveness programme chose to present three recommendations in its patient version, all linked to self-management (Figure 4). More information on selection of recommendations is given in section 5.2.

## References

### Recommendation 1

#### Brush your teeth regularly and effectively

Improving your oral hygiene reverses the early stages of gum disease. Your dentist or hygienist can help by showing you how to brush your teeth in the most effective way.

### Recommendation 2

#### Have a plan of when you will brush your teeth

Having a firm plan will help you remember to brush your teeth. For example, you could plan to always brush first thing in the morning when you get up and last thing at night when getting ready for bed.

### Recommendation 3

#### Use an ordinary toothbrush or a rechargeable powered toothbrush and fluoride toothpaste

Rechargeable powered toothbrushes may remove more plaque than ordinary toothbrushes. However, both types of toothbrush are good for removing plaque if they are used properly.

## An example

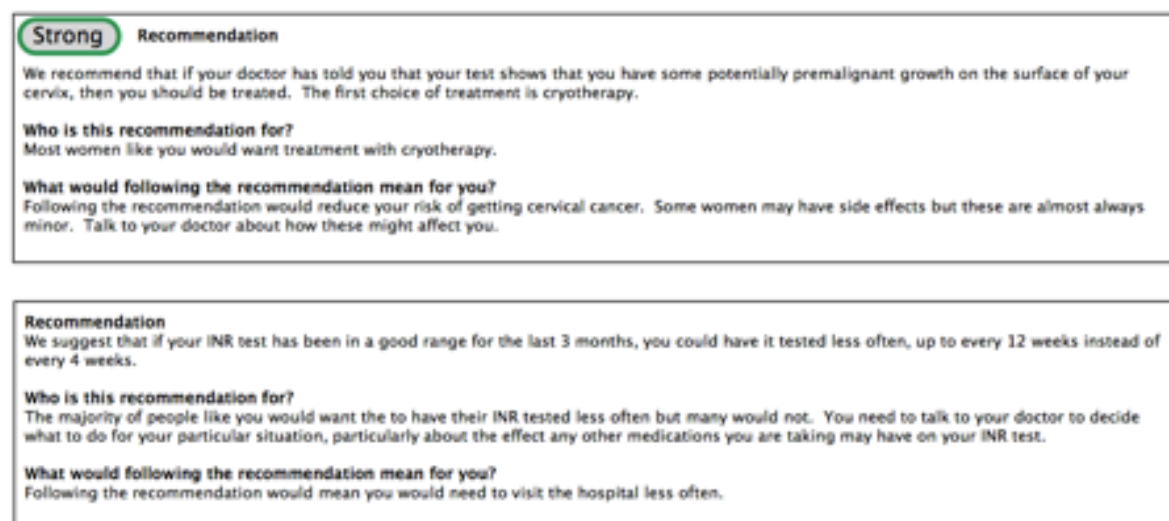
**Figure 4** The three recommendations presented in the patient version of the Scottish Dental Clinical Effectiveness Programme's periodontal guideline.

cardiovascular risk<sup>7</sup>. Making the strength of a recommendation more explicit was one of the key drivers behind the development of the GRADE system for grading the quality of evidence and strength of recommendations (see <http://www.gradeworkinggroup.org>).

It seems reasonable then that patient versions should also provide an indication of the strength of a recommendation to avoid similar misunderstandings. How to do this is challenging and is best done together with patients and/or public when developing the patient version. Some general guidance can be given though:

*1. Using the GRADE terms 'Strong' and 'Weak' to label recommendations is likely to be confusing*

This is because of how 'Weak' is interpreted ('Why are you presenting a recommendation if it is weak?')<sup>8</sup>. One alternative option may be to label 'Strong' recommendations but not 'Weak' recommendations (see figure 8). This is being evaluated in the DECIDE project but results are not yet available.



**Figure 8** Labelling strong recommendations as 'Strong' but not labelling weak as 'Weak' (the lower example is a weak recommendation, the upper strong). This is currently being evaluated as part of the DECIDE project.

*2. Symbols may help although these have to be intuitive (and tested with your audience)*

Symbols were used with a WHO guideline on health worker roles in maternal and newborn health (<http://optimizemnh.org/intervention.php>), which was aimed at a range of stakeholders (though not the public) and the symbols were well received (see figure 9). The solid green ticks are strong recommendations in favour of the intervention; solid red crosses are strong recommendations against the intervention. The dotted ticks and crosses are weak recommendations for and against

**An example, but  
one still under  
development**



### Antibiotics for a sore throat

Use this Grid to help you and your healthcare professional talk about how to best treat your sore throat.

The likelihood of having a bacterial infection increases if you have pus on the tonsils, tender neck glands, a fever, and do not have a cough. If you have 3 or more of these 4 issues (pus, tender neck, fever, no cough), it is moderately likely that you have a bacterial infection. If you have 2 or fewer of these issues, it is unlikely that you have a bacterial infection.

Frequently asked questions	Treatment with antibiotics	Treatment without antibiotics
It is moderately likely that my sore throat is bacterial.  Will I get better faster with this treatment?	Roughly 50 in every 100 people (50%) who take antibiotics will feel better about 1 day earlier than they would without antibiotics. They may not feel better for the first day or two. Roughly 50 in every 100 people will not benefit.	No, the symptoms are usually a problem for about 3-7 days.
It is unlikely that my sore throat is bacterial.  Will I get better faster with this treatment?	Roughly 20 in every 100 people (20%) will feel better about 1 day earlier than they would without antibiotics. Roughly 80 in every 100 people (80%) will not benefit.	No, the symptoms are usually a problem for about 3-7 days.
What does this treatment consist of?	Taking antibiotics, as well as taking over-the-counter pain relievers, drinking fluids, eating ice cubes or other cold foods.	Taking over-the-counter pain relievers, drinking fluids, eating ice cubes or other cold foods.
What problems might this treatment cause?	About 16 in every 100 people (16%) will have one or more of the following problems: upset stomach, rash, or diarrhea. Using antibiotics can lead to bacteria becoming resistant to the treatment.	You avoid any problems antibiotics might cause.
Will this treatment lower my chance of having other infections?	Depending on the type of infection you have, you are slightly less likely to develop an ear or sinus infection.	No.

Editors: Roshan John, Nick Francis, Andy Carson-Stevens, Adrian Edwards, Richard Lehman, Glyn Elwyn.  
Evidence document: [http://www.optiongrid.org/resources/sorethroat\\_evidence.pdf](http://www.optiongrid.org/resources/sorethroat_evidence.pdf)  
Publication date: 14 July 2014 Expiry: 14 July 2015 ISBN: 978-0-9575461-6-5 License: CC BY-NC-ND 3.0  
Download the most current version from: <http://www.optiongrid.org>

**An example from  
the literature  
beyond DECIDE**

Figure 12 Option Grid for use of antibiotics for sore throat (<http://www.optiongrid.org>).



# Antibiotics for a sore throat

Use this Grid to help you and your healthcare professional talk about how to best treat your sore throat.

The likelihood of having a bacterial infection increases if you have pus on the tonsils, tender neck and do not have a cough. If you have 3 or more of these 4 issues (pus, tender neck, fever, no cough), it is likely that you have a bacterial infection. If you have 2 or fewer of these issues, it is unlikely that you have a bacterial infection.

Frequently asked questions	Treatment with antibiotics	Treatment without antibiotics
It is moderately likely that my sore throat is bacterial.  Will I get better faster with this treatment?	Roughly 50 in every 100 people (50%) who take antibiotics will feel better about 1 day earlier than they would without antibiotics. They may not feel better for the first day or two. Roughly 50 in every 100 people will not benefit.	No, the symptoms are unlikely to improve for about 3-7 days.
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the intervention, respectively. Use of symbols to express strength of evidence would need to be tested with your target audience.

## 3. Standard qualitative text statements can be used to present strength of a recommendation

The example shown in Figure 4 from the Scottish Dental Effectiveness Programme (SDEP) uses standard text phrases based on those used by the Cochrane Collaboration to present information on the magnitude of effect in words (see Table 5)<sup>12</sup>. In the SDEP example, recommendations 1 and 2 are strong, recommendation 3 is weak

	Important benefit/harm	Less important benefit/harm	No important benefit/harm or null effect
<b>High quality evidence</b>	Will improve/ decrease/ prevent/ lead to fewer (more) [outcome]	will improve slightly/ decrease slightly/ lead to slightly fewer (more) [outcome]	will not improve/ will lead to little or no difference in [outcome]
<b>Moderate quality evidence</b>	probably improves/ decreases/ prevents/ leads to fewer (more) [outcome]	probably improves slightly/ probably decreases slightly/ probably leads to slightly fewer (more) [outcome]	probably will not improve/ probably leads to little or no difference in [outcome]
<b>Low quality evidence</b>	may improve/ decrease/ prevent/ lead to fewer (more) [outcome]	may improve slightly/ may decrease slightly/ may lead to slightly fewer (more) [outcome]	may not improve/ may not lead to any difference in [outcome]
<b>Very low quality evidence</b>	We are very uncertain whether [intervention] improves [outcome]		
<b>No events or rare events</b>	Use comments in SoF in a plainer language or summarise results		
<b>No studies found or reported</b>	No studies found/reported [outcome]		

**Table 5** Structured text statements used by the Cochrane Collaboration to present uncertainty information in a consistent way<sup>12, 13</sup>.

## Why have I been given this leaflet?

You may have told the dentist that you taste and see blood when you clean your teeth, or that you feel that some of your teeth may be loose. Your dentist may have noticed that your gums bleed or that you need to improve your oral hygiene. Bleeding is a sign of gum disease.

## What is gum disease?

Gum disease, also known as periodontal disease, is caused by a build up of plaque on the teeth. If plaque is not regularly removed by brushing, the gums can become irritated and inflamed. Plaque which is not removed eventually hardens into a substance called calculus which is also irritating to the gums. Calculus has to be removed by your dentist or hygienist.

### Gingivitis

The early stage of gum disease is called gingivitis. The symptoms are swollen, red gums which bleed easily when you brush, floss or eat hard foods, such as apples. You may also notice an unpleasant or metallic taste in your mouth. A relative or friend may complain that you have bad breath. Gingivitis is reversible with good oral hygiene.

### Periodontitis

If gingivitis is left untreated, it can develop into a more advanced stage of periodontal disease called periodontitis. If left untreated, periodontitis can lead to receding gums, loose teeth and eventual tooth loss.

## Can I prevent gum disease?

Most people can prevent gum disease with good oral hygiene. The table lists some key things you can do to improve your oral hygiene and prevent gum disease.

### Recommendation 1

#### Brush your teeth regularly and effectively

Improving your oral hygiene reverses the early stages of gum disease. Your dentist or hygienist can help by showing you how to brush your teeth in the most effective way.

### Recommendation 2

#### Have a plan of when you will brush your teeth

Having a firm plan will help you remember to brush your teeth. For example, you could plan to always brush first thing in the morning when you get up and last thing at night when getting ready for bed.

### Recommendation 3

#### Use an ordinary toothbrush or a rechargeable powered toothbrush and fluoride toothpaste

Rechargeable powered toothbrushes may remove more plaque than ordinary toothbrushes. However, both types of toothbrush are good for removing plaque if they are used properly.

## What else can I do?

- **Stop smoking**

Stopping smoking reduces your chance of getting gum disease.

- **Clean between your teeth using floss or interdental brushes**

Flossing in addition to toothbrushing may make gums less likely to bleed. Using interdental brushes in addition to toothbrushing may remove even more plaque.



## What will the dental team do?

- If you need to improve your oral hygiene, your dentist or hygienist can show you the best ways to remove plaque from your teeth. They can also help you plan when you will do this at home.
- If you have periodontitis, your dentist will show you how to improve your oral hygiene and will recommend that you have treatment to remove the build-up of plaque and calculus on your teeth. You may need intensive treatment that will take place over several weeks.
- If you smoke, your dentist will advise that you consider stopping.
- If you have diabetes, your dentist will recommend that you ensure it is well-controlled, as uncontrolled diabetes increases your risk of developing gum disease.

## Why has this leaflet been developed?

SDCEP has recently provided guidance for dental healthcare staff on the best ways to prevent and treat gum disease. SDCEP guidance is developed by groups that contain clinical experts, researchers and patients. This leaflet explains how patients can also make a difference to the health of their gums.



### Scottish Dental Clinical Effectiveness Programme

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Phone: 01382 425751  
Website: [www.sdcep.org.uk](http://www.sdcep.org.uk)

Scottish Dental  
Clinical Effectiveness Programme



## Your Oral Health Prevention of Gum Disease

This leaflet includes information on

- The causes of gum disease
- How you can prevent gum disease
- How the dental team treats gum disease
- How SDCEP produces guidance to improve dental health

# Conclusions

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- **We know a lot about how to make patient versions**
- **We want to put this knowledge into Chapter 4, highlighting uncertainty where it exists**
- **We hope this will help guideline producers to produce their patient versions**
- **Everything is draft; it still needs G-I-N approval.**

# Thank you!

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