DECIDE: general public

The DECIDE project included six research Work Packages (WPs), the first five of which aimed to develop and evaluate strategies for presenting evidence-based recommendations in guidelines to different types of user:

1. Health professionals.
2. Policymakers and managers.
3. **General public [covered by this summary]**.
4. Users of diagnostic tests.
5. People developing health system policies.

The 6th Work Package was a toolkit that packaged much of the work coming from the first five Work Packages together. One of the key results of DECIDE was to deliver information in layers, most important first. So, in that spirit, the key findings of the whole DECIDE project are summarised in Figure 1. If you read no more, look at least at Figure 1.

Key findings:

- Guideline users – health professionals, patients and policymakers – want information delivered to them in layers, most important first.

- Guideline producers value structure when working through evidence to make recommendations and decisions.

- Numerical summaries of research findings can be understood by diverse audiences, including the public, but it is best if those summaries allowed users to interact with them so that they can choose the level of detail they require.

- Health professionals and their patients want materials that can be used in consultations to support their discussions.

- Guideline information about medical testing has to move beyond accuracy and precision and start talking about the effect on important patient outcomes.

Key tools:

- The Evidence to Decision framework to support guideline producers make evidence informed decisions.

- The interactive Summary of Findings tables to support interactive presentations of research findings to diverse types of user.

- The DECIDE/G-I-N public toolkit chapter for guideline producers on how to produce patient versions of guidelines.

- There are many ways information can be presented to users but we have not found a 'magic bullet' that always works for all users, especially members of the public. Guideline producers would be wise to do at least some testing of their materials with potential future users.

- The GRADEPro guideline development tool to package the bulk of DECIDE's work and to support guideline producers through the whole guideline process.

Figure 1: Key DECIDE findings and tools

Presenting evidence-based recommendations to the general public

A survey conducted by the UK National Institute for Health and Care Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN), both DECIDE partners, done at the start of the project demonstrated a demand for guidance on healthcare among members of the public. People were interested in using clinical guidelines in their care and treatment. However, many

respondents were unclear about the role and sources of information on guidelines. Many guideline producers are starting to produce versions of their guidelines meant for patients, carers and the public. However, it was clear that guideline producers were themselves not clear about how they intended these to be used, or why they chose to make them look the way they did. To address this problem, we began by doing a systematic review of the literature on patient and public attitudes to, and awareness of, guidelines. The search identified 26 studies that met all the inclusion criteria and involved a total of almost 25,000 individuals. Overall, participants in the included studies had mixed attitudes towards guidelines; some participants found them empowering but many saw them as a way of rationing care. Patients were also concerned that the information may not apply to their own health care situations. It is important that patient versions are clear about who the information is for so that potential users know what the information has to do with 'someone like me' and how it can be used to make healthcare improvements. With the exception of a survey conducted through a national guideline producer's website, awareness of guidelines amongst the public was extremely low to non-existent.   The full results were published in 2014 (http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-14-321).

We supplemented the literature review with a series of focus groups with patients and members of the public, plus one group with professional health care writers and communicators such as journalists and people who write content for health charities' websites. This allowed us to explore general issues around guidelines, as well as considering in more detail a few issues that are known to be problematic, such as how to present information about uncertainty to the public. A survey of international guideline producers also confirmed the need for guidance with regards to how patient versions of guidelines should be put together. For example, only 21 of 34 (62%) patient versions from 17 producers stated their purpose clearly (something patients and the public want) and none presented numerical information linked to the recommendations (which is known to increase understanding). Presenting information regarding uncertainty was also rare.

Using findings emerging from the reviews and survey, together with brainstorming and consultation with our Advisory Group, we developed a range of alternative presentation strategies that could be used in patient versions of guidelines. These strategies were discussed with focus group participants as well as in user-tests where we asked participants to provide feedback on particular elements of the presentations, as well as overall impressions. This work found that the following issues are considered important when using guidelines

- Context: who is the information for?
- Background information about the condition: What are the risk factors? How will the condition progress? How long will the condition last? What is the risk of other problems arising from the condition?
- Information about the treatments and interventions: What are the treatments, including the alternatives? What are the risks associated with treatments? What can I do for myself (i.e. self-management)?
- Where can I find more help (e.g. phone numbers and website for sources of support)?
- How are guidelines produced?

This information, together with the literature review and our survey, helped us to develop guidance for how a guideline producer should present patient versions of their guidelines. The DECIDE presentation strategies for patient versions of guidelines include changes to how information is organised, making it clearer who the information is for and what information is being provided, making it clear what the recommendations are and favouring self-management recommendations. We also developed different ways of presenting numerical information as well as information regarding uncertainty. Figure 3 is an example of one way of presenting recommendations; this presentation makes it clear what the recommendations are, as well as being a format that uses a structured 'words only' method to present the recommendation. The sentence structure and words used are linked to the size of effect and the quality of the underlying evidence. This presentation went on to be used in real patient version of guideline produced by the Scottish Dental Clinical Effectiveness Program (SDCEP) (http://www.sdcep.org.uk/published-guidance/periodontal-management/).

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A randomised comparison of two versions of the same real SDCEP patient version of a guideline on dental care and bisphosphonates, one produced before working with DECIDE, and one using DECIDE strategies, involving 90 people in Scotland found that using DECIDE strategies made the intended purpose of the information clearer (69% found the old version very clear or clear; this increased to 92% for the DECIDE version), increased confidence in picking out the most important information (increased from 55% to 67%) and was easier to understand (increased from 55% to 72%). It is important to note that the basic information remained the same in both versions; the crucial difference is that presenting that information according to DECIDE ideas helped make the information more useful.

These strategies have become a central part of the updated chapter on producing patient versions of guidelines in the Guidelines International Network (G-I-N) Public Toolkit. The new version was launched at the G-I-N 2015 conference held in Amsterdam in October 2015. The DECIDE innovation is to connect the advice in the Public Toolkit to research evidence generated by DECIDE and other research groups. The chapter is a template for guideline producers working on their own patient versions.

The new version of the Toolkit, including the new Chapter 7 on patient versions of guidelines is freely available at http://www.g-i-n.net/working-groups/gin-public/toolkit. A Scottish national glaucoma guideline, incorporating DECIDE strategies from the Toolkit, has also been published (http://sign.ac.uk/guidelines/fulltext/144/index.html) along with a publication describing the user-testing done to develop the guideline (http://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-016-1287-8).

Figure 2 shows the main findings from the user-testing. Following from this work, NICE is undertaking a major review of all presentation formats of guidelines and findings from DECIDE are being incorporated into revised information for patients.

Theme	Findings
Usefulness / Value	• Patient versions of guidelines can inform and empower people to ask questions. • They can help people to anticipate what to expect when seeing a healthcare professional or having an intervention. • They may be most useful to patients around the time of their diagnosis. • Information about risks is most useful if directly associated with information about self management or any form of action. • Simple diagrams and charts can communicate information clearly. • It is helpful to flag clearly any important areas not covered by the guideline. • Signposting to organisations that can provide help and further information is valued.
Usability	• Language should be kept as simple as possible • User testing may help to identify how much technical information to include. • Small font size, use of light/pale colours, and too much material on a page were major barriers to use of the guideline by this patient group. • Clear flagging of recommendations using headings/icons works well. • A risk of 2 in 100 was interpreted by some as very high and others as very low. • Icons for levels of recommendation worked best when kept recognisable, with a clear link to the intended message. • Vague or generic icons can cause confusion and be misinterpreted e.g. a blue circle can be interpreted as a zero. • Uncertainty was effectively communicated by the "?" icon but people may not know how to respond to this information.
Credibility	• Credibility arose from information on the guideline production process, and the involvement of qualified professionals. • The status of the guideline is important (do health services recognise the recommendations). • Credibility may be threatened by pathways or recommendations that do not fit with the patient's own experiences.
Desirability	• Participants were very positive about the look and feel of this patient version. • Aspects that increased desirability included a friendly tone, simple language, chunking of text, the use of colour, glossy "high quality" look, and use of icons/images. • A friendly feel is achieved by informal language, use of colour, and the inclusion of quotes and images/icons. • Negative language or images, and a bureaucratic/dogmatic tone were disliked. • Quotes can personalise the material, giving it an engaging and friendly tone, and emphasising a particular message.
Accessibility/ Findability	• The brief contents page, with simple question based headings was clear and facilitated flicking to relevant sections. • The participants were very concerned about the apparent lack of dissemination of patient versions of guidelines. • It is important for printed copies of the guideline to be available. • The patient version must be tailored to the intended audience's needs (e.g. font size, language/numerical information). • Information on how to access the services/interventions recommended is important. • Clear branding as a patient version is required. • Clear information on "who this booklet is for" encouraged people to read and share the guideline. • It is important to give telephone numbers and addresses as well as websites for signposted organisations.

Figure 2: *Summary of the main findings from the SIGN user-testing of their national glaucoma guideline. The full publication is at* http://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-016-1287-8

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Our work with patients, together with our work with health professionals, suggested that both patients and health professionals would appreciate resources to support their discussions during consultations. This led to the development of tools to support shared decision-making that are linked directly to guidelines. The reaction from patients to these materials has been very positive, with the very clear presentation of the numerical information (which is rarely presented in patient versions of guidelines) coming in for particular praise. More information about this work is presented in our summary of work with health professionals. Recent NICE guidelines often have accompanying tools to support decision making and again, findings from DECIDE may be incorporated.

Also of relevance to patients is DECIDE's work the interactive Summary of Findings (iSoF) table. The iSoF was evaluated in an online trial run in Scotland using the SHARE register (http://www.registerforshare.org). The trial involved a close collaboration with the SHARE team to email almost 50,000 members of the public in Scotland who had expressed an interest in taking part in health research. The trial was by far the biggest study done using the SHARE register to date. A total of 2,194 people responded during the one month trial: see the summary of our work with health systems policy for more information.

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.

Figure 3: *An example of one DECIDE strategy for how recommendations can be presented in a patient version of guideline.*