

DECIDE: health systems

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.
4. Users of diagnostic tests.
5. **People developing health system policies [covered by this summary].**

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 about health system policies

In common with other Work Packages, our work for people working on health system or public health policies used brainstorming, a survey, a literature review, its Advisory Group, prototyping and user testing to steer its direction. We did not find any published evaluations of strategies for disseminating health technology assessments or recommendations to policymakers and managers. As became clear from our work, recommendations and decisions depend on

This project has received funding from the European Union’s Seventh Framework Programme for research, technological development and demonstration under grant agreement no 258583

information and judgements that are beyond the scope of systematic reviews. Issues in need of consideration include the applicability of the evidence, costs, impacts on equity, acceptability and feasibility. Even when specific answers are not available; when the evidence is too uncertain to provide clear answers, or decision makers' settings vary greatly from those in the studies, policymakers still must make decisions. When there are important uncertainties, as is often the case, they may still decide to implement a change. Being clear about what those uncertainties are can help ensure appropriate monitoring and evaluation when changes are implemented, so that future decisions, such as whether to continue, modify or discontinue changes that were made, will be better informed.

DECIDE addressed the challenges that policymakers face by building on previous work, and developing and evaluating three strategies to communicate evidence-based health system and population (public) health recommendations effectively and efficiently:

- interactive Summary of Findings to facilitate understanding and use of the results of systematic reviews in health system and population health recommendations and decisions
- interactive Evidence to Decision frameworks to facilitate going from evidence to health system and population health recommendations and decisions
- explanations of terms relevant to health system and population health recommendations and decisions

The majority of this work had relevance to other Work Packages and was therefore done in collaboration with them.

Interactive summary of findings (iSoF)

A SoF table presents the key messages from a systematic review in a concise format. The table is an output from the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system. SoF tables include seven elements that have been judged to be most critical when making a health care decision (see Figure 2). These judgments are the cumulative result of efforts over the last decade of the GRADE working Group and the Cochrane Applicability and Recommendations Methods Group.

1. A list of the most important outcomes, both desirable and undesirable
2. A measure of the typical burden of these outcomes (e.g. control group, estimated risk)
3. A measure of the risk in the intervention group or, alternatively or in addition, a measure of the difference between the risks with and without intervention
4. The relative magnitude of effect
5. Numbers of participants and studies addressing these outcomes
6. A rating of the overall confidence in the effect estimate for each outcome (which may vary by outcome); and possibly
7. Comments

Figure 2: Seven elements of a Summary of Findings table

We have improved the SoF format by making it both simpler and more comprehensive, as well as more flexible. Our goal has been to make the table compatible with the needs of a wide range of users (e.g. health professionals, the public and policymakers with different levels of experience reading research results), as well as with different types of data and use contexts. To achieve this, we designed an electronic, interactive Summary of Findings table (iSoF) that allows table producers to tailor the presentation to their target audience by adjusting which outcomes and how much information about those outcomes are displayed. More importantly, the new solution allows users themselves to interact with the table by adding or hiding outcomes, by adding or hiding information about those outcomes, by viewing results as numbers, text or graphic representations, and by accessing explanations of standard concepts (such as confidence intervals) and topic specific explanations provided by the producer. For a more detailed list of specifications for development, see Figure 3.

The DECIDE project

Figure 6 is a screenshot of an iSoF for a health systems decision, showing all of the information for each outcome. Figure 7 is a screenshot of the same iSoF but now with some of the columns closed down. We developed the iSoF through iterative cycles of user-centred design, prototyping and user testing. We also gathered feedback from key stakeholders at several intervals.

<i>Features for users:</i>				
<ul style="list-style-type: none">– Simple, user-friendly interface– Layered presentation of information, allowing users to initially view a simple table with a minimum amount of information and (if desirable) drill down to more details, including links to reviews and full evidence profiles– Providing users with control over their viewing choices, including which outcomes to show in detail and how to view the results for these outcomes (as text, numbers or graphic representations)– Providing step-by-step visual presentation of the absolute effects and absolute differences, that includes an explanation of the confidence intervals in a way that makes them easy to grasp and see why they are important– Providing interactive explanations of generic terms (replacing legends and glossaries)– Providing interactive explanations of table-specific terms (replacing footnotes)– Responsive formatting for use on different size screens/devices– Availability in different languages				
<i>Features for producers:</i>				
<ul style="list-style-type: none">– Template flexibility that can accommodate data from different kinds of reviews, including those without meta-analysis– Ability to enter (and present) different levels of baseline (control group) risk for each outcome– Control over which information is expanded/displayed (and which is collapsed/hidden) in the initial (default) presentation, including:<ul style="list-style-type: none">○ Which outcomes○ What information about each outcome○ Which baseline risk (including more than one for outcomes when this is relevant)– Automatic reminders to include some information that is essential for understanding the findings of a systematic review, but is sometimes missing, including explanations about scales, about where the estimates of baseline risk came from, and about the reasons for downgrading or upgrading the certainty of evidence.– Allowing producers to tailor their own template, for instance to rearrange the order of the columns, create a custom default presentation, or add organization logos– Templates for table production in different languages				

Figure 3: New iSoF features

The iSoF was evaluated in a large online trial in Scotland using a register of members of the public who have expressed an interest in taking part in health research called SHARE (<http://www.registerforshare.org>). We emailed nearly 50,000 people to invite them to take part in the trial and a total of 2,194 people responded and when presented with standard patient information or a static SoF without the absolute effect, participants were, for the most part, not able to answer questions about the size of the benefits and harms or the certainty of the evidence correctly (Figure 4).

Outcome	SoF without absolute effect		Standard patient information	
	N	% correct	N	% correct
Understanding the benefits	73	1.4	32	0
Certainty of the benefits	437	20.8	238	10.5
Understanding the harms	78	1.3	33	0

This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 258583

Certainty of the harms	432	20.8	238	6.3
------------------------	-----	------	-----	-----

Figure 4: Understanding of participants who were not shown the absolute effect

Things improved when participants were shown absolute effects (Figure 5) although there was little difference between an iSoF and a static SoF that was showing absolute effects. However, nearly half did not answer questions about the size of the benefits correctly.

	iSoF		SoF with absolute effect	
Outcome	N	% correct	N	% correct
Understanding the benefits	761	51.8	574	50.2
Certainty of the benefits	1144	31	805	36.6
Understanding the harms	740	62.7	566	70
Certainty of the harms	1112	29.8	783	38.6

Figure 5: Understanding of participants who shown the absolute effect

Most participants were satisfied with the presentation to which they were allocated before seeing the other presentations. They were least satisfied with a static SoF without the absolute effect and most satisfied with the iSoF or static SoF with the absolute effect (difference 18.4 percentage points (95% CI -26.5 to -10.4)).

Interactive Evidence to Decision Frameworks

Healthcare decision-making is complex. Decision-making processes and the criteria that decision-makers should consider vary for different types of decisions, including clinical recommendations, coverage decisions, and health system decisions. However, some criteria are relevant for all of these decisions, including the anticipated effects of the options being considered, the certainty of the evidence for those effects (also referred to as quality of evidence or confidence in effect estimates), and the costs and feasibility of the options.

We have developed Evidence to Decision (EtD) frameworks to support the process of moving from evidence to decisions: for making clinical recommendations, coverage decisions, and health system or public health recommendations and decisions. Starting with the GRADE Working Group's approach for moving from evidence to clinical recommendations we iteratively developed the EtD frameworks based on reviews of relevant literature, a survey of policymakers, brainstorming, feedback from stakeholders, application of EtD frameworks to a variety of recommendations and decisions, and user-testing. A survey of stakeholders with health system decision experience from 15 countries and the World Health Organization provided us with 112 responses (70% response rate). Most respondents had healthcare (85%) and research (79%) experience. They (99%) indicated that systematic consideration of the available evidence would help to improve health system decision-making processes and supported the use of evidence from other countries (94%) and grading systems (81%). All ten criteria in the DECIDE framework were rated as important in the decision-making process. The survey results were published in 2013 (<http://www.health-policy-systems.com/content/11/1/19>).

EtD frameworks:

- Facilitate adaptation of recommendations and decisions to specific contexts.
- Inform panels about the relative pros and cons of the interventions or options being considered.
- Ensure that panels consider important criteria for making a decision.
- Provide panels with a concise summary of the best available evidence to inform their judgments about each criterion.
- Help panels structure discussion and identify reasons for disagreements, making the process and the basis for decisions structured and transparent.

EtD frameworks assist users of recommendations by:

This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 258583

The DECIDE project

- Enabling them to understand the judgments made by the panel and the evidence supporting those judgments.
- Helping them to decide whether recommendations can and should be implemented in their own settings.

Figure 8 shows the judgements that the EtD framework supports. The EtD framework was tested with real World Health Organisation guidelines on task shifting for maternal and newborn care, task shifting for contraception, and expanding training of health professionals. It was also tested with public health guidelines in Sweden and clinical practice guidelines produced by the Norwegian Directorate of Health. Another example of use was with a coverage decision about trans-catheter aortic valve implantation (TAVI) for patients with severe aortic stenosis in Lazio Regional Health Service, Italy. Two EtD frameworks were prepared comparing TAVI vs traditional surgery and vs medical therapy. They were presented and discussed with a panel of regional health system representatives that involved both regional decision makers as well as clinicians. The EtD frameworks were then included in the final regulatory document of Lazio Region. The EtD framework will now be used for future coverage decisions in Lazio Region. In addition, the EtD framework has been presented, tested and discussed at multiple international and national conferences, such as the Guidelines International Network, Cochrane Colloquium, and HTAI annual meetings.

Two publications describing the EtD are in-press at the BMJ.

Outcome	Plain language summary	Absolute Effect	Relative effect (95% CI) N° of participants & studies	Certainty of the evidence (GRADE)
		Without Stroke units	With Stroke units	
Death Follow-up: 1-12 months	Stroke units probably reduce the risk of death following acute stroke	265 per 1000	236 per 1000	RR 0.89 (0.80 to 0.99) Based on data from 3728 patients in 12 studies Moderate
Dependency Follow-up: 6-12 months	Stroke units probably reduce the risk of dependency following acute stroke	235 per 1000	223 per 1000	RR 0.95 (0.78 to 1.17) Based on data from 2748 patients in 9 studies Moderate
Institutionalized Follow-up: 1-12 months	Stroke units may reduce the risk of institutionalization following acute stroke	148 per 1000	117 per 1000	RR 0.79 (0.61 to 1.03) Based on data from 3659 patients in 11 studies Low

Figure 6 : iSoF showing all columns open

In order to facilitate flexibility both in preparation and use by groups, we developed the iEtD tool (interactive Evidence to Decision framework) through iterative cycles of brainstorming, design,

This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 258583

The DECIDE project

user-testing, piloting and stakeholder feedback. iEtD has functionality for administrating, creating, and using frameworks as well as disseminating results, including resources for:

- Managing templates
- Filling in and managing EtD frameworks
- Presenting EtD frameworks (e.g. at face-to-face or online panel meetings)
- Voting on judgements and decisions by panel members
- Creating reports and interactive summaries for end users

It also enables organisations to create tailored templates for:

- **EtD frameworks** adapted to specific types of decisions or recommendations and remits
- **Reports** generated from EtD frameworks for consultations or final reports of guidelines or decisions
- **Summaries for end-users**, including clinicians, patients and policymakers

iEtD end-user summaries can include interactive functions such as interactive Summary of Findings (iSoF) tables, layered information, scrollover explanations, hypertext links and the possibility of selecting or inserting specific information in decision aids. The iEtD tool has been released (<http://ietd.epistemonikos.org/#/login>), and further developed with feedback from use in public health and health system decisions and guideline processes by a number of organisations (including WHO, the Norwegian Knowledge Centre for Health Services and the Swedish National Institute of Public Health). WHO recommendations on antenatal care are using the iEtD website platform to provide both the guideline development panel with an online environment for deliberations on antenatal care recommendations, and also provide a public online forum for policymakers, clinicians and other stakeholders to navigate and utilise the recommendations. Figure 8 shows a summary of judgements screen from the iEtD for a guidelines developed by WHO.

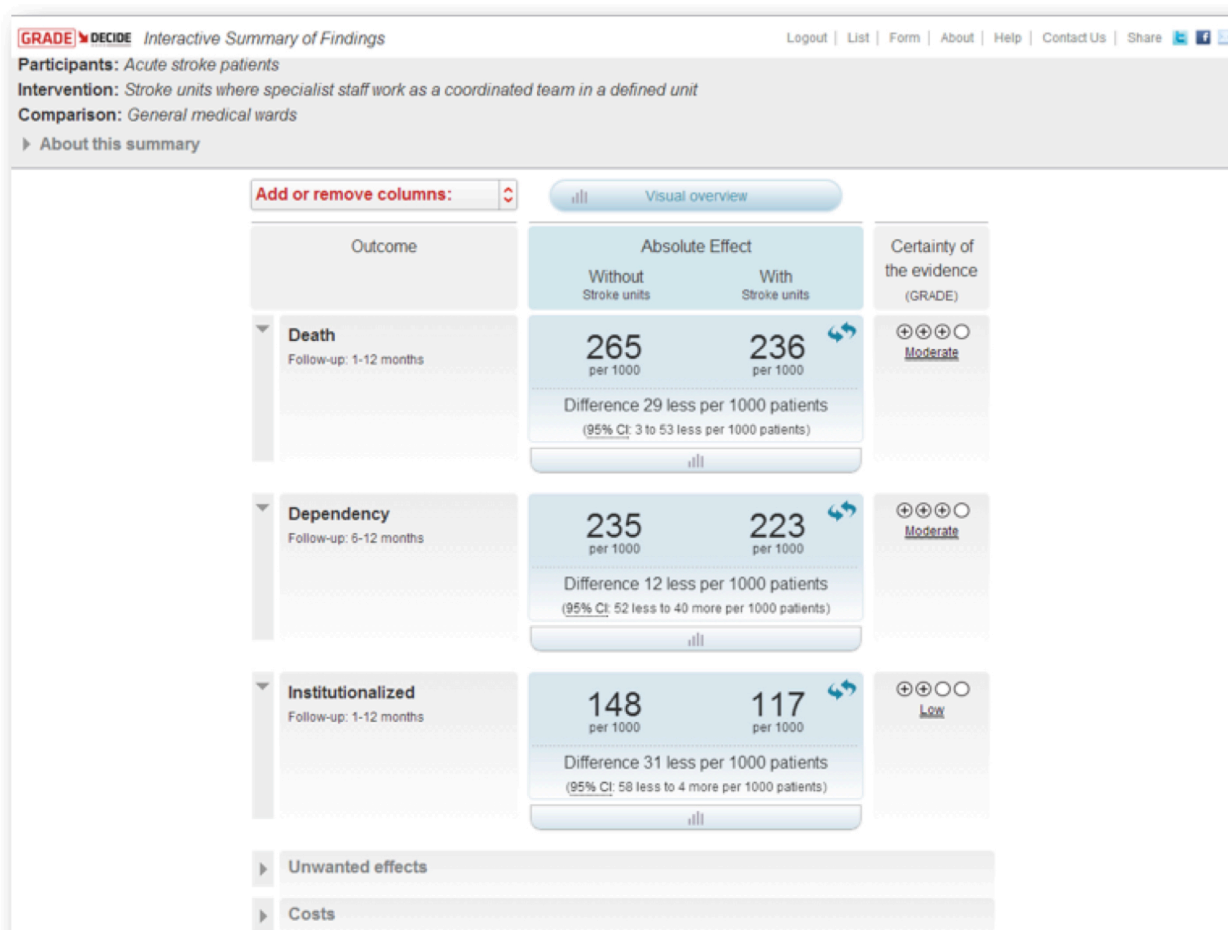


Figure 7: iSoF showing just a few columns selected by the user.

Explanations of terms: the GET IT glossary

Many people (not only the public, but health professionals and policymakers too) have problems understanding terminology linked to the evaluation of treatments. We have therefore developed a glossary to provide plain language explanations of terms such as '*certainty of the evidence*', '*false positive test result*' and '*P-value*'. Well-informed choices about how to intervene to improve health outcomes depend on access to good information, particularly research evidence. The use of jargon can be a barrier to people's understanding and use of research evidence to inform their choices. Inconsistent use of language also can cause confusion. The aim of this glossary is to facilitate informed healthcare choices by promoting consistent use of plain language and providing plain language explanations of concepts and terms that people might need to understand in order to assess claims about treatments. This includes claims arising from summaries of research evidence (systematic reviews) and evidence-informed recommendations that they find in guidelines.

The glossary includes:

- brief plain language definitions (that can be used as scroll over explanations)
- longer explanations
- links to resources such as illustrative examples, videos or interactive applications that help people to understand or apply the term or concept
- synonyms
- suggested plain language terms
- technical definitions

The glossary is available at <http://getitglossary.org> and can be used by guideline producers, health technology assessment agencies and others providing support for evidence-informed healthcare decisions, including health system decisions. Among other uses, it provides explanations for terms

This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 258583

The DECIDE project

used in interactive Summaries of Findings and interactive Evidence to Decision frameworks. Organisations can utilise some or all of those features and some or all of the terms that are included in the glossary. We have also developed technical tools that allow other organisations to embed the glossary on their own websites, as well as providing support for languages other than English. The glossary is currently being translated into Finnish and Spanish.

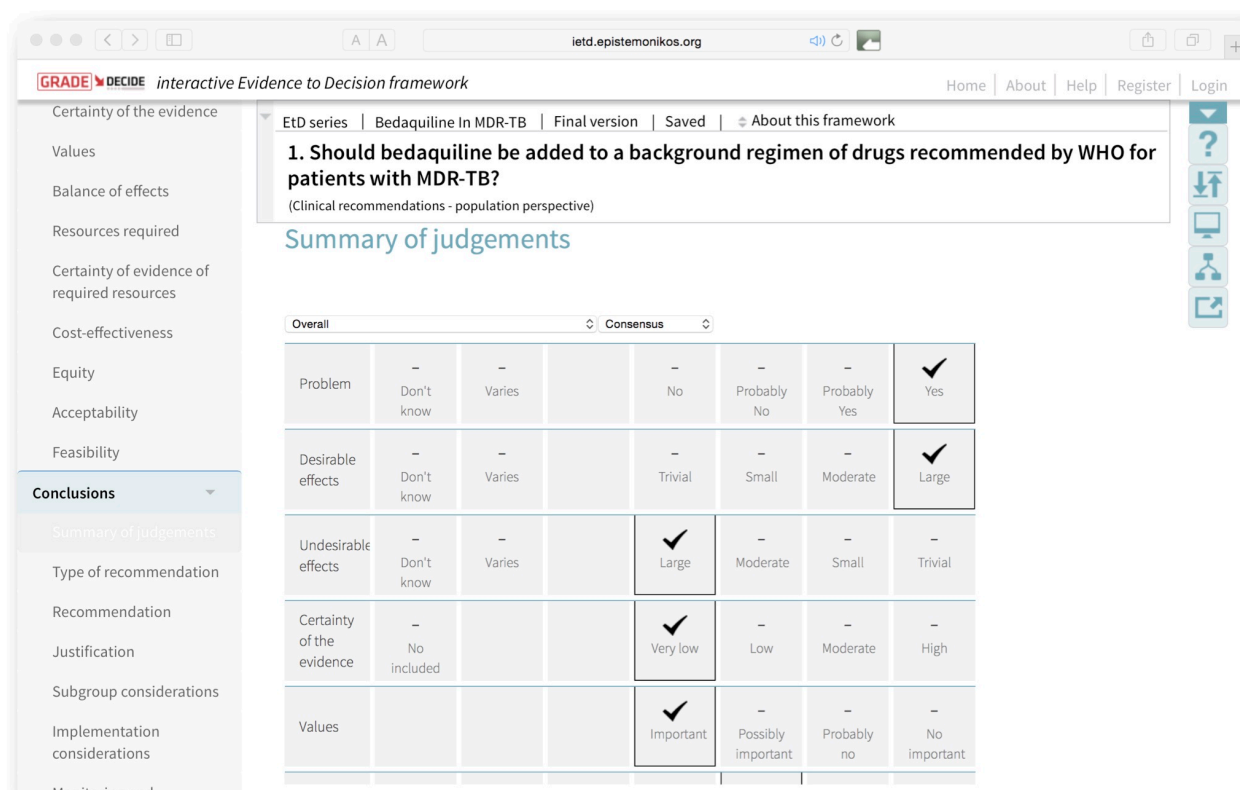


Figure 8: Summary of judgements screen from the iEtD for a guidelines developed by WHO.

Criterion	Detailed judgments
Is the problem a priority?	<ul style="list-style-type: none"> Are the consequences of the problem serious (i.e. severe or important in terms of the potential benefits or savings)? Is the problem urgent? [not relevant for coverage decisions] Is it a recognized priority (e.g. based on a political or policy decision)? [Not relevant when an individual patient perspective is taken]
How substantial are the desirable anticipated effects?	<ul style="list-style-type: none"> Judgments for each outcome for which there is a desirable effect
How substantial are the undesirable anticipated effects?	<ul style="list-style-type: none"> Judgments for each outcome for which there is an undesirable effect
What is the overall certainty of the evidence of effects?	<ul style="list-style-type: none"> See GRADE guidance regarding detailed judgments about the quality of evidence or certainty in estimates of effects.
Is there important uncertainty about or variability in how much people value the main outcomes?	<ul style="list-style-type: none"> Is there important uncertainty about how much people value each of the main outcomes? Is there important variability in how much people value each of the main outcomes? [not relevant for coverage decisions]

Criterion	Detailed judgments
Do the desirable effects outweigh the undesirable effects?	<ul style="list-style-type: none"> • Judgments regarding each of the four preceding criteria • To what extent do the following considerations influence the balance between the desirable and undesirable effects: <ul style="list-style-type: none"> • How much less people value outcomes that are in the future compared to outcomes that occur now (their discount rates)? • People's attitudes towards undesirable effects (how risk averse they are)? • People's attitudes towards desirable effects (how risk seeking they are)?
How large are the resource requirements?	<ul style="list-style-type: none"> • How large is the difference in each item of resource use for which fewer resources are required? • How large is the difference in each item of resource use for which more resources are required?
What is the certainty of the evidence of resource requirements?	<ul style="list-style-type: none"> • Have all-important items of resource use that may differ between the options being considered been identified? • How certain is the evidence of differences in resource use between the options being considered (See GRADE guidance regarding detailed judgments about the quality of evidence or certainty in estimates)? • How certain is the cost of the items of resource use that differ between the options being considered? • Is there important variability in the cost of the items of resource use that differ between the options being considered?

Figure 9: Detailed judgments in Evidence to Decision (EtD) frameworks.