Can we make guidelines better? An overview of the DECIDE project

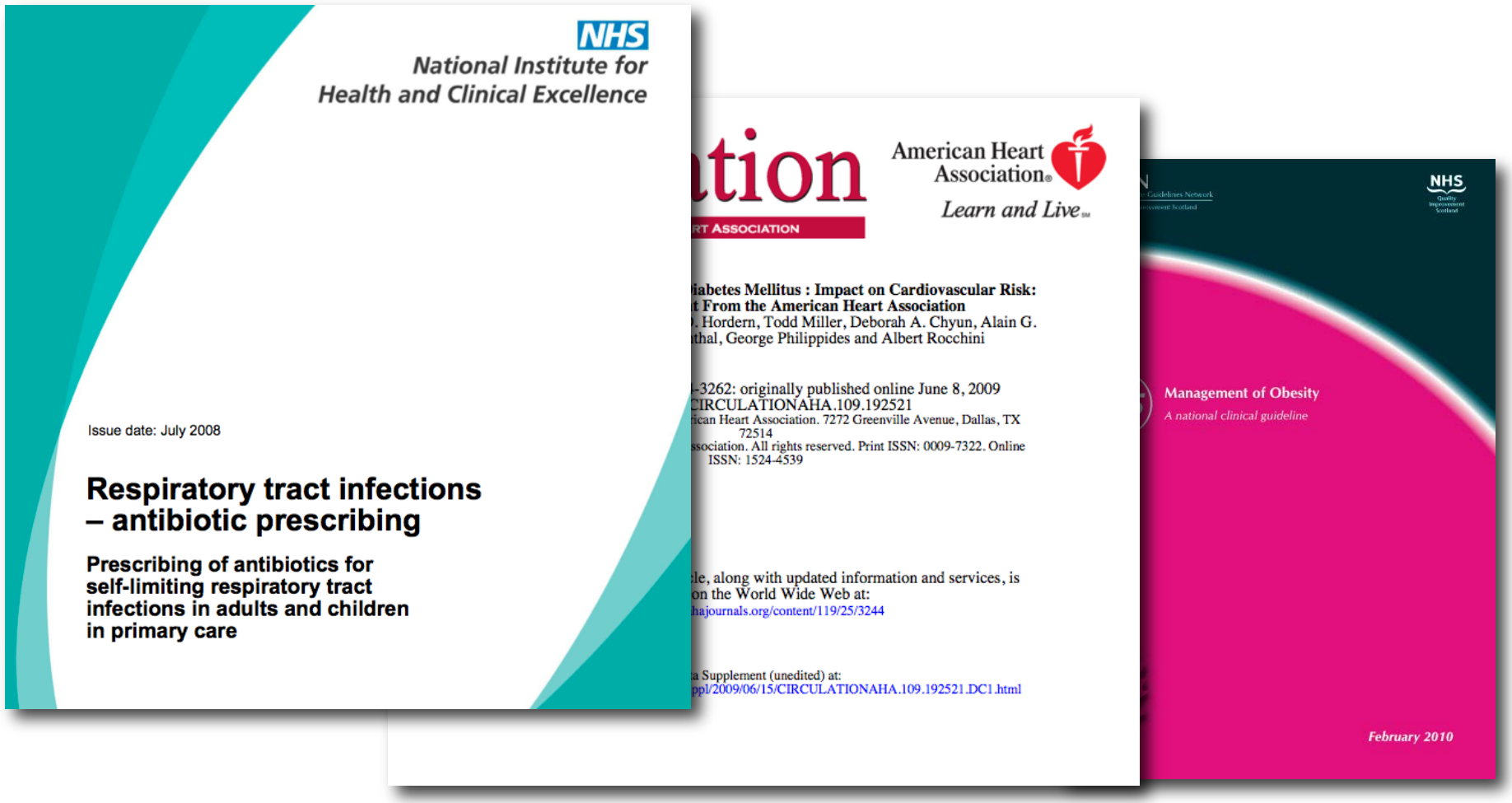
Shaun Treweek

University of Dundee, UK

streweek@mac.com

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

Guidelines - convenient



The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

Presentation is important

Providing information is good but the people you intend to use that information must be able to understand and use it.

From a family doctor -

'*You need to be able to do EBM at 2am.*'

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

DECIDE

GRADE

UNIVERSITY OF DUNDEE

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

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

G-I-N Conference
Berlin 2012

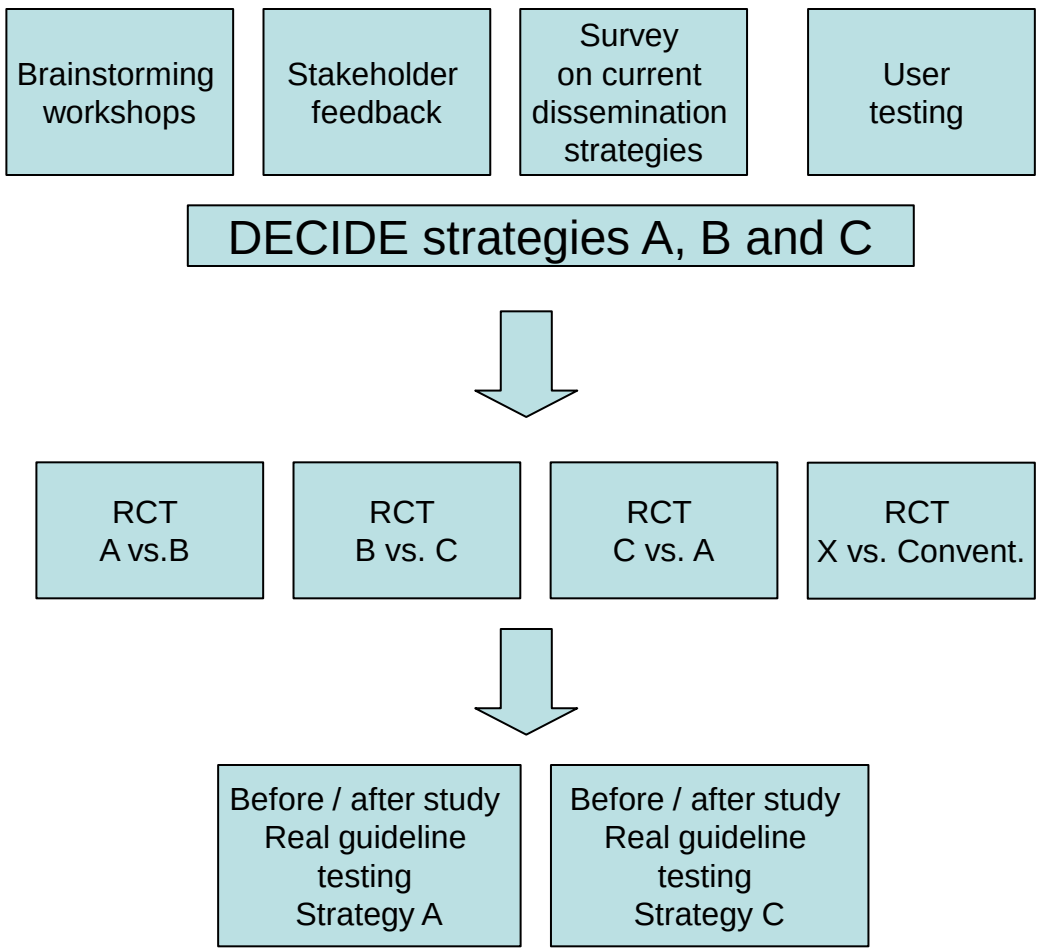
DECIDE: the ten partners

- University of Dundee, UK
- Norwegian Knowledge Centre for the Health Services, Norway
- Iberoamerican Cochrane Centre, Spain
- Azienda Sanitaria Locale Roma E, Italy
- University of Amsterdam, the Netherlands
- World Health Organisation (WHO), International
- German Cochrane Centre, Germany
- National Institute for Health and Clinical Excellence (NICE), UK
- Scottish Intercollegiate Guidelines Network (SIGN), UK
- Finnish Medical Society Duodecim, Finland

..and very strong links with the GRADE Working Group

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

DECIDE: a picture



Phase 1: **strategy development and user testing**

Phase 2: **Evaluation of strategies**

Phase 3: **Testing strategies with real guidelines**

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

DECIDE strategies

	WP1 health professionals	WP3 consumers	WP4 diagnostic tests	WP2 coverage decisions	WP5 health system decisions
Presentation of evidence and recommendations	Top Layer presentation				
	Explanations of key concepts				
	Interactive SoF tables/ videos				
Frameworks for going from evidence to recommendations	Evidence to recommendation frameworks				Evidence to recommendation framework
				Costing frameworks	
Decision support	Decision aids		Decision aids & Evidence to decision frameworks	Evidence to decision frameworks	
Communication strategies	Point of care applications	Point of care applications & Guidance and tools for guideline producers	Adaptation of point of care applications & Guidance and tools for guideline producers		

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

DECIDE strategies

	WP1 health professionals	WP3 consumers	WP4 diagnostic tests	WP2 coverage decisions	WP5 health system decisions
Presentation of evidence and recommendations	**Top Layer presentation**				
	Explanations of key concepts				
	Interactive SoF tables/ videos				
Frameworks for going from evidence to recommendations	Evidence to recommendation frameworks				Evidence to recommendation framework
				Costing frameworks	
Decision support	Decision aids		Decision aids & Evidence to decision frameworks	Evidence to decision frameworks	
Communication strategies	Point of care applications	Point of care applications & Guidance and tools for guideline producers	Adaptation of point of care applications & Guidance and tools for guideline producers		

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

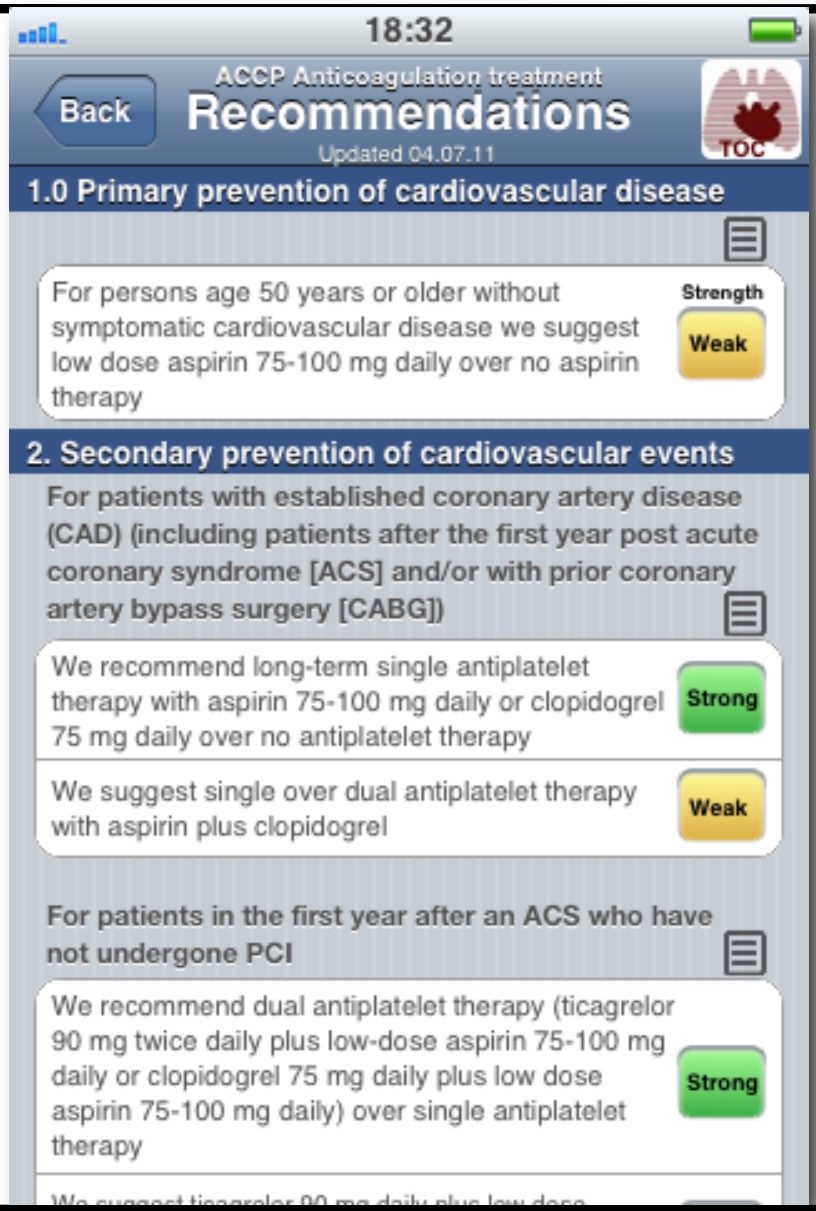
WP1: Top Layer presentation

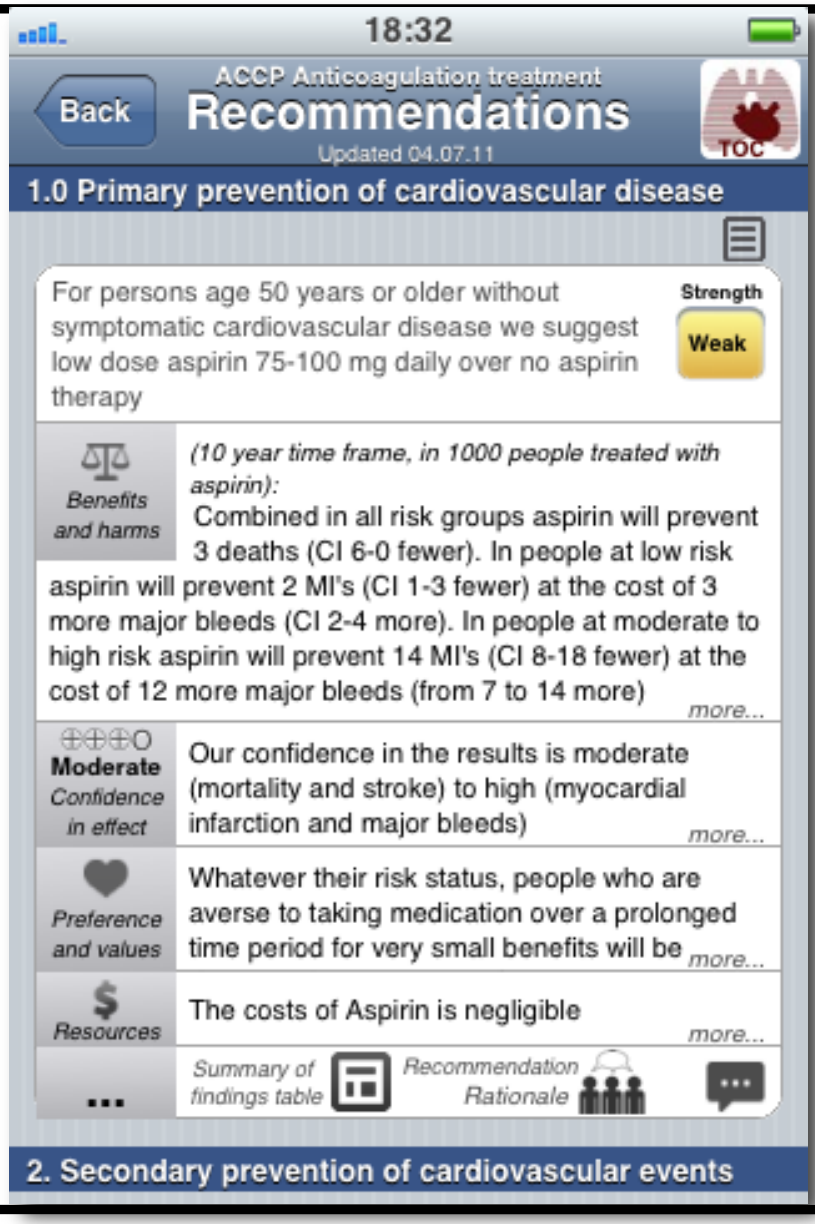
- The recommendation(s) and its strengthInformation on four key factors that influence the strength of recommendation:Confidence in the estimates of effectBalance between benefits and harmsValues and preferencesResource useThe rationale for the recommendation: the guideline panels' integration of the four factors above.

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

DECIDE GRADE

UNIVERSITY OF DUNDEE



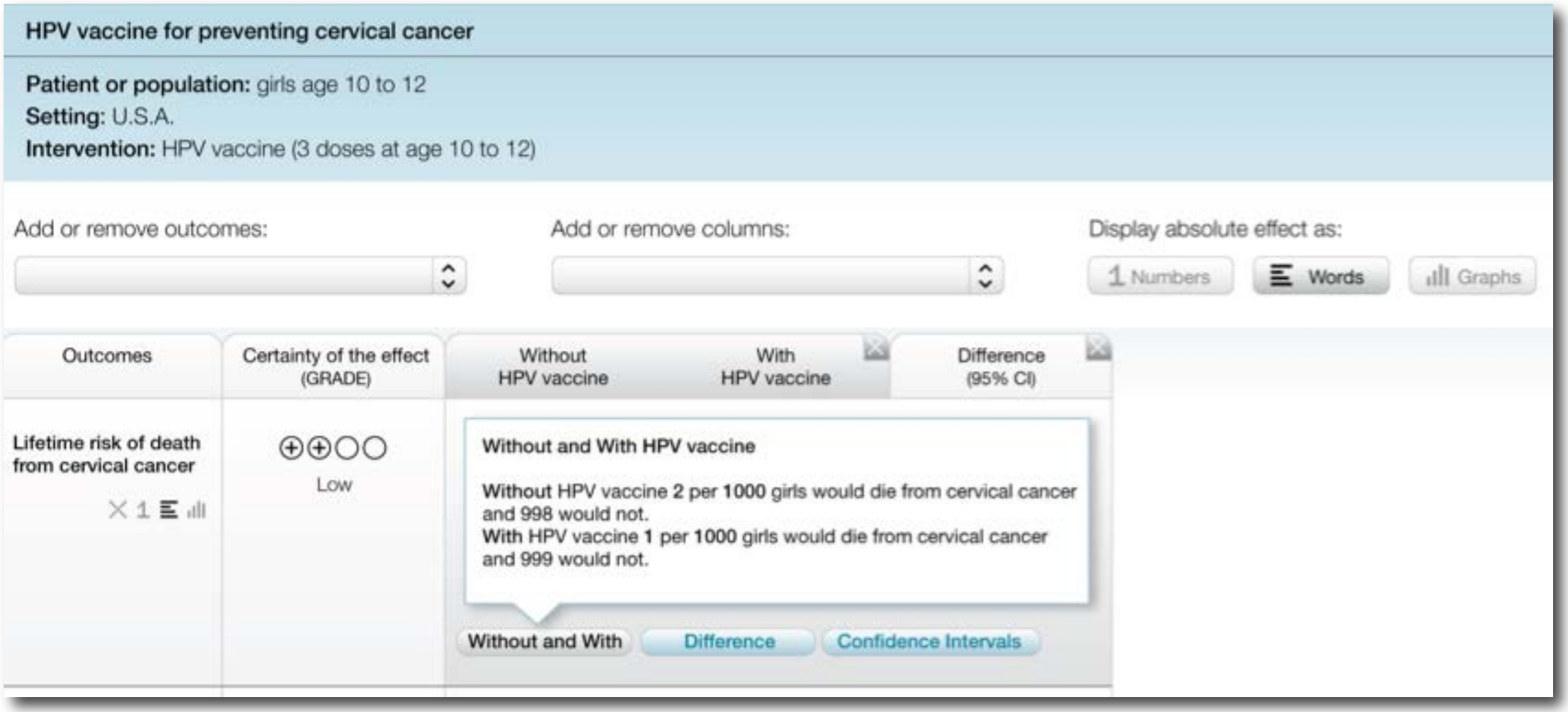


The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

SEVENTH FRAMEWORK PROGRAMME

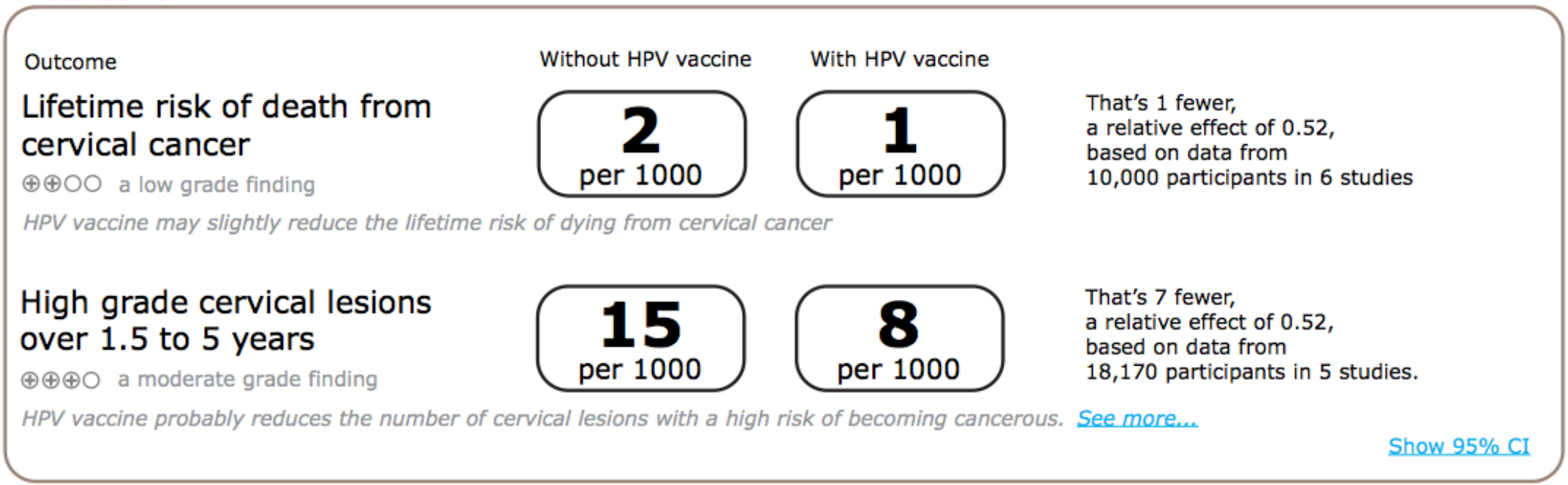
G-I-N Conference
Berlin 2012

Interactive Summary of Findings table



The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

Alternative, non-tabular presentations



Outcome	Without HPV vaccine	With HPV vaccine	
Lifetime risk of death from cervical cancer ⊕⊕◯◯ a low grade finding	2 per 1000	1 per 1000	That's 1 fewer, a relative effect of 0.52, based on data from 10,000 participants in 6 studies
HPV vaccine may slightly reduce the lifetime risk of dying from cervical cancer			
High grade cervical lesions over 1.5 to 5 years ⊕⊕⊕◯ a moderate grade finding	15 per 1000	8 per 1000	That's 7 fewer, a relative effect of 0.52, based on data from 18,170 participants in 5 studies.
HPV vaccine probably reduces the number of cervical lesions with a high risk of becoming cancerous. See more...			

Show 95% CI

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

Evidence to decision frameworks (WP2)

	CRITERIA	EVIDENCE	JUDGEMENT	COMMENTS
Severity	**What is the severity of the condition?**		Very low ☐ Low ☐ Uncertain ☐ Moderate ☐ High ☐	
Equity	**What would be the impact on health inequities?**		Increased ☐ Probably Increased ☐ Little or uncertain ☐ Probably reduced ☐ Reduced ☐	
Approriate use	**Is inappropriate use likely to be an important problem?**		Yes ☐ Probably ☐ Uncertain ☐ Probably not ☐ No ☐	

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

Evidence to decision frameworks (WP5 - health systems)

- Priority
- Lots of people affected
- Large effect
- Undesirable effects small
- Overall certainty
- Desirable effects large relative to undesirable effects
- ...

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

Should patients with acute stroke be treated in stroke units, stroke units with early discharge or general medical wards?

Balance of consequences	*Undesirable consequences* clearly outweigh *desirable consequences*	*Undesirable consequences* probably outweigh *desirable consequences*	*Desirable/undesirable consequences* closely balanced or uncertain	*Desirable consequences* probably outweigh *undesirable consequences*	*Desirable consequences* clearly outweigh *undesirable consequences*
	☐	☐	☐	☐	☑
Decision	***Do not implement the option***	***Postpone a decision***	***Do a pilot study***	***Implement with an impact evaluation***	***Implement the option***
	☐	☐	☐	☐	☑
	We conclude that patients with acute stroke should be cared for in stroke units with early discharge. All urban hospitals must, therefore, have a stroke unit and communities must have arrangements for early discharge from those units.				
Justification	Stroke units with early supported discharge probably will reduce mortality and dependency and save money. The cost-effectiveness analysis suggests that this conclusion is robust.				
Other implementation considerations	Implementing this option requires establishing responsibility and accountability for establishing and maintaining stroke units and early discharge, and aligning financial incentives for hospitals and communities; e.g. by compensating hospitals for the costs of establishing and maintaining a stroke unit.				
Monitoring	We suggest using the following indicators to monitor the implementation of this decision and inform decisions about the need for further action: establishment of stroke units at all urban hospitals, whether stroke patients are managed in stroke units and discharged early, survival, dependency, institutionalization, hospital costs and costs of community-based health and social services.				
Evaluation	Although further evaluation could increase the certainty of the anticipated effects, this is not likely to change the decision. Therefore evaluation of the impacts of this decision is not considered a priority.				

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

WP3: what do patients and the public want?

- Screened over 5000 abstracts, 41 included in a review
- Almost 2000 people surveyed about knowledge of guidelines
- Over 50 individuals (patients, the public, clinicians and journalists) involved in focus groups

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

WP3: what do patients and the public want?

- There is very poor awareness of guidelines (including that guidelines exist) among the public
- Less than 5% of those responding to NICE's survey thought guidelines were for patients/public
- Patients and the public want shared decision-making up to a point

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

WP3: what do patients and the public want?

'I don't know because … to a certain extent you do have to rely on professionals making judgements about the strength of evidence, and em you know I can't do everybody's job [m-mmm], at some point you have to trust them.'

(Dundee focus group participant (public))

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

Conclusion

- The presentation of guideline content can be improved
- DECIDE has proposals for how this might be done for different types of user
- These proposals are being tested and will be modified, improved and supplemented by others
- GRADE provides a solid foundation but how to present GRADE to users can be a challenge

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

Thanks for listening!

streweek@mac.com

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

Your view of the balance of desirable and undesirable consequences of the intervention	Yes	Probably	Don't know	Probably not	No
	Desirable consequences clearly outweigh undesirable consequences	Desirable consequences probably outweigh undesirable consequences	Consequences equally balanced or uncertain	Undesirable consequences probably outweigh desirable consequences	Undesirable consequences clearly outweigh desirable consequences
Decision	**Yes**	**Coverage with evidence development**		**No**	
Justification (reason for deciding the intervention should be covered, covered with evidence development or not covered)					
Implementation (details regarding the decision, including any restrictions on coverage and conditions for coverage with evidence development)					

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

Coverage decisions

Adverse effects
Are the undesirable effects of the option small?

Outcome	Results	GRADE
Any adverse event	Inconclusive compared to placebo	⊕⊕⊖⊖ LOW

These data come from a HTA document published in 2011 and a SR published in 2010.The documents include RCTs affected by several methodological flaws that leid their quality of evidence to be judge, using GRADE criteria, as LOW. That's why it is uncertain if the undesirable effects are small. These data are related to all of the populations considered in evaluating the estimate of beneficial effects

Yes	Uncertain	No
☐	■	☐

Resource use (costs)
Are the costs low/affordable?

Average costs in children without CLD (£)

	Palivizumab	No prophylaxis	Difference
Palivizumab	3437		
Drug administration	60		
Hospital	67	301	
Total cost (NHS)	3564	301	3263

Average costs in children with CLD (£)

	Palivizumab	No prophylaxis	Difference
Palivizumab	3437		
Drug administration	60		
Hospital	293	475	
Total cost (NHS)	3790	475	3315

Average costs in children with acyanotic CHD (£)

	Palivizumab	No prophylaxis	Difference
Palivizumab	3714		

Yes	Uncertain	No
☐	☐	■

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

Evidence to decision frameworks (WP2)

- How serious
- Quality of evidence
- Benefits
- Adverse events
- Costs and cost effectiveness
- Feasibility
- Equity

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

WP2: Policymakers

How to make evidence-informed policy decisions about coverage decisions? (ie. should we provide treatment X in our region?)

Key output to date: a framework for going from evidence to a coverage decision

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

But.. many grading systems

Evidence	Recommendation	Organisation
A to C	Class 1 to Class 3	American Heart Association
1++ to 4	?	NICE
A to C	1A to 2C	American College of Chest Physicians
1++ to 4	A to D	SIGN

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

Terminology: explaining common terms

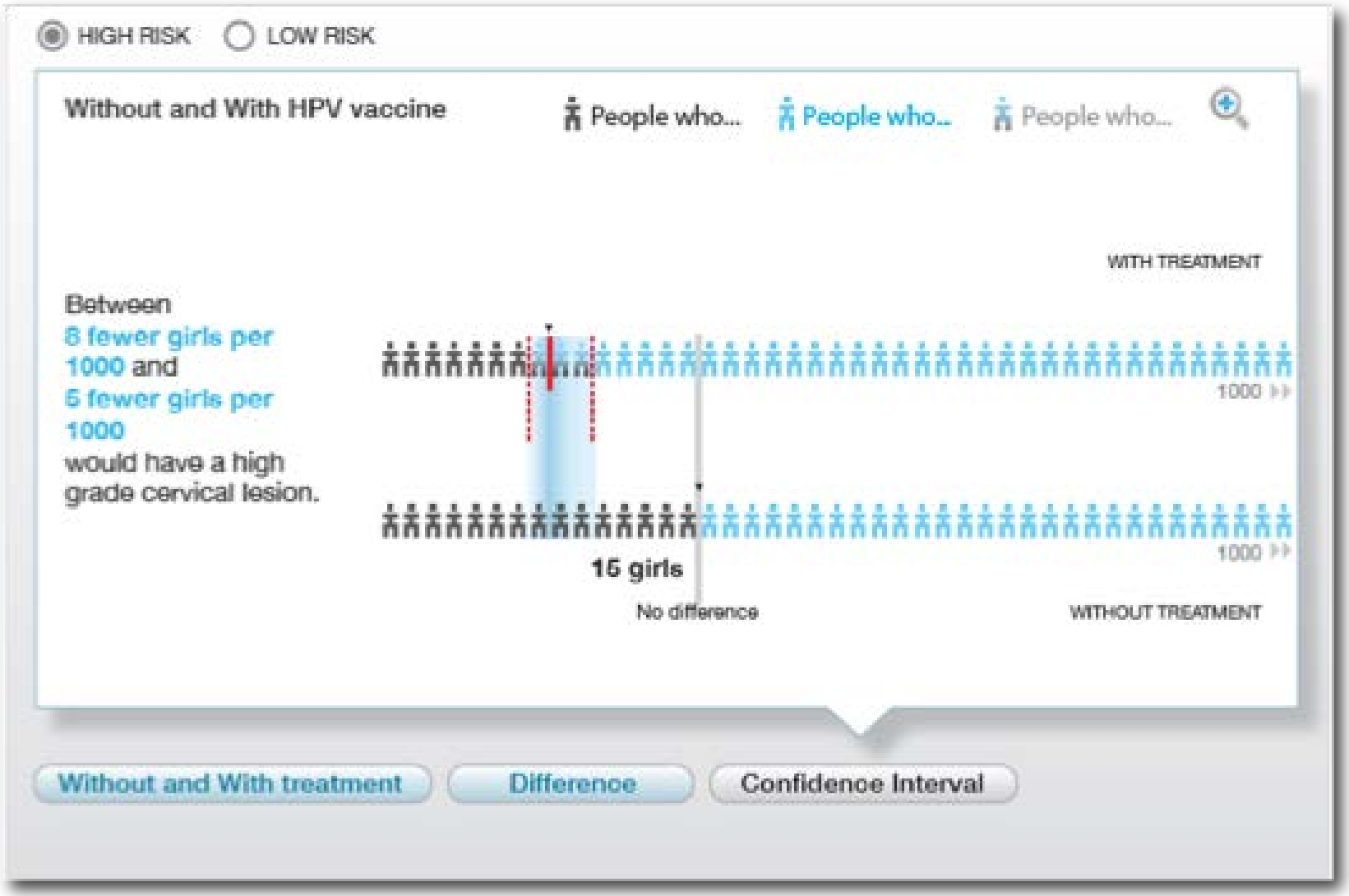
For example..

> S0: As far as .. this issue of uncertainty, we spent a lot of time talking about that, what do we think about that?S10: Don't duck it. If it is uncertain, say so …

(From a focus group with health journalists for WP3)

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

Terminology: CIs



The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583

	CRITERIA	JUDGEMENT	EVIDENCE	C
PROBLEM	Is the problem a priority?	No ☐ Probably not ☐ Uncertain ☐ Probably ☐ Yes ☑	Acute stroke patients cared for in general medical wards have a high risk of death (27%) and dependency (24%). 15% require institutional care following discharge. [1]	
	Are a large number of people affected?	No ☐ Probably not ☐ Uncertain ☐ Probably ☐ Yes ☑	15,000 strokes per year in Norway. 3rd most common cause of death. Most common cause of serious disability. [2]	

The DECIDE project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement no 258583