1. Publishable summary

DECIDE: Developing and Evaluating Communication Strategies to Support Informed Decisions and Practice Based on Evidence

Coordinator
University of Aberdeen

Contact person
Professor Shaun Treweek
Tel.: +44 777 901 6955
E-mail: streweek@mac.com

Website
http://www.decide-collaboration.eu/

Partners
1. University of Aberdeen (UNIABDN)
2. Norwegian Knowledge Centre for the Health Services (KS)
3. Iberoamerican Cochrane Center-Biomedical Research Institute Sant Pau (IR-HSCSP)
4. Italian Cochrane Centre (CCI)
5. University of Amsterdam (AMC)
6. World Health Organisation (WHO)
7. University Hospital Freiburg (UHF)
8. National Institute for Health and Care Excellence (NICE)
9. Healthcare Improvement Scotland (HIS)
10. Finnish Medical Society Duodecim (FMS)
11. Azienda Sanitaria Locale Roma (ASL RME.DE)
12. University of Dundee (UNIVDUN)

Duration
January 2011 - December 2015

Total cost / EC funding
€3.8 million / €3.0 million

Aims and objectives

All of us - health professionals, patients, policymakers and the public - want to make healthcare decisions based on the best available research evidence. Experience shows, however, that this is complex for lots of reasons, including the overwhelming amount of (sometimes contradictory) research literature that is often presented in ways that are difficult for non-researchers to understand.

Our aims are to:

- **optimize the spread of knowledge and use of evidence-based interventions** in a sustainable way
- move **shared decision making forward** and **reduce the use of interventions where benefits are uncertain, particularly in relation to harms.**

DECIDE will develop and evaluate new ways of presenting research information in guidelines and tailor these to the information needs of patients, clinicians and policymakers - in other words to the key players who determine what happens in clinical practice. For this we will build on GRADE (http://www.gradeworkinggroup.org/), an internationally accepted approach to assessing and communicating the quality of evidence and the strength of recommendations.

Work performed and results so far

Strategy development and user testing

DECIDE has organised its empirical work around five work packages (WPs), each aimed at a different stakeholder group or type of recommendation:

- Health professionals (WP1)
- Policymakers and managers (WP2)
- Public, patients and carers (WP3)
- Diagnostic tests (WP4)
- Health systems policies (WP5)

Although these WPs may develop different presentation strategies, each focused on the needs of the particular stakeholder group, each will use a similar approach. This will comprise three phases:

- Phase 1: strategy development and user testing. This work will collect background information on what is known about

presentation strategies that might be helpful and through feedback from people in each of the targeted groups (e.g. health professionals), through user testing, workshops and surveys.
- Phase 2: evaluation, generally in randomised trials.
- Phase 3: testing our strategies with real guidelines.

Our work is iterative and we anticipate returning to, for example, Phase 1 in light of what we learn in Phase 2. DECIDE has now done work linked to all three phases. The DECIDE protocol has been published in the Open Access journal Implementation Science: http://www.implementationscience.com/content/8/1/6 and is flagged 'Highly Accessed' by the journal. It has also been translated into Japanese: http://homepage3.nifty.com/cont/41_2/p431-61.pdf

Literature reviews, brainstorming and surveys
Most WPs have looked to the literature to examine what is already known about research presentation methods for particular target groups. WP3, for example, reviewed the literature covering the evidence around the public's attitudes towards clinical practice guidelines and evidence-based recommendations, together with their general awareness of clinical guidelines. Overall, participants in these studies had mixed attitudes towards guidelines; some participants found them empowering but many saw them as a way of rationing care. Awareness that clinical guidelines exist at all ranged from 0% to 79%. Patients and members of the public questioned on their attitudes to guidelines revealed that guidelines are not always positively perceived compared to alternative sources of information. The review has been submitted to *BMC Health Services Research*.

WP4 has published a review of grading systems used to grade evidence on diagnostic tests, which informed work on how this process might be improved and how the results of the grading might best be presented. Twelve systems could be included, with only five addressing to any great degree issues such as describing how evidence was identified, what criteria were used to appraise the evidence and how decisions with regard to recommendations were arrived at. This information will be used to improve both GRADE (upon which much of DECIDE's work is based) and DECIDE itself. The review is available at http://www.implementationscience.com/content/8/1/78 and is 'Highly Accessed'.

Brainstorming is being used in all WPs as a rapid way to generate ideas that can then be tried out in user-testing. WP1 found for example that users found presentations to be too complex, wordy and crowded. End-users were confused by the methodology; the phrasing was unclear and repetitive. WP5 has done a large number of brainstorming sessions to develop and refine a framework for going from evidence to health policy decisions. The result is that feedback on the refined framework is very positive. Examples of the WP5 frameworks are available from the DECIDE website: http://www.decide-collaboration.eu/WP5/Strategies/Framework.

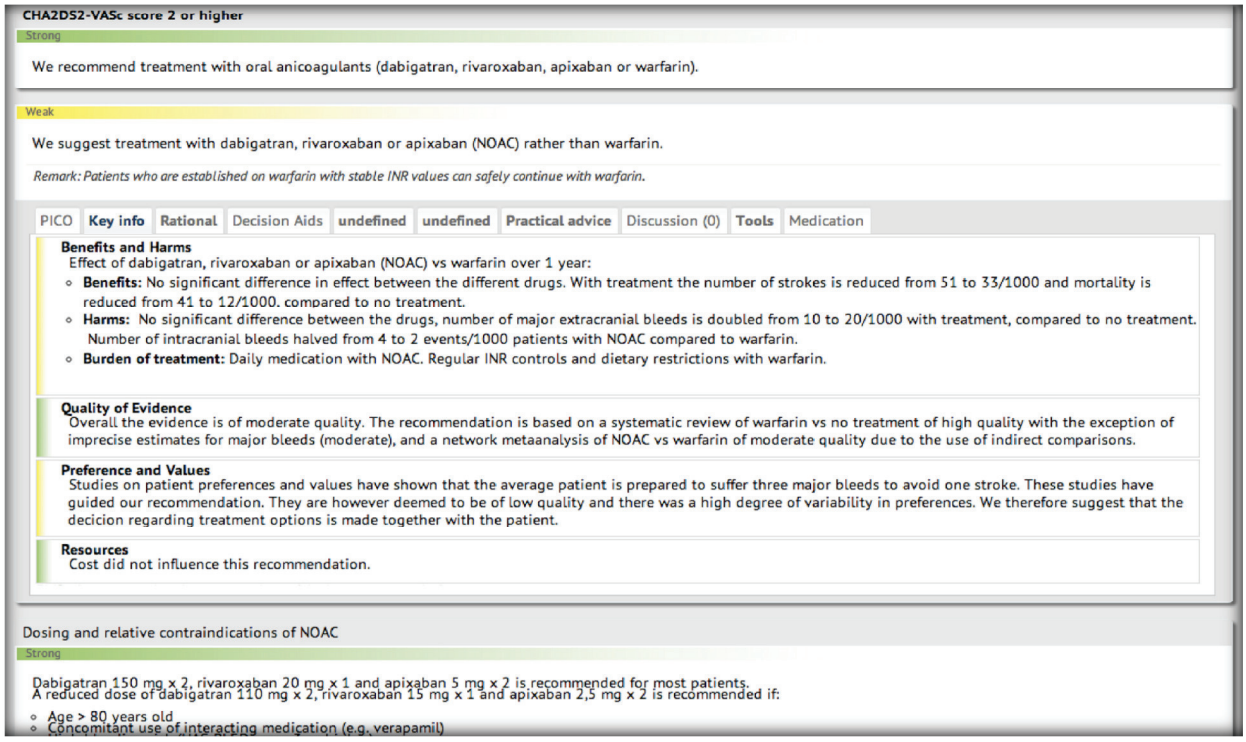
Surveys complement the information gathered from the literature and brainstorming. WP5 has run the biggest DECIDE-specific survey, with 150 people from 10 countries being invited to participate in a survey, of whom 112 responded (70% response rate). Most respondents had healthcare (85%) and research (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 (see previous paragraph) were rated as important in the decision-making process. The results are published in *Health Research Policy and Systems* (http://www.health-policy-systems.com/content/11/1/19) and is flagged as 'Highly Accessed' by the journal.

Finally, WPs 1-5 all have advisory groups, each with around 20 independent members who are able to provide feedback on ideas and approaches being suggested by the WP teams. Membership of the groups varies depending on the WP. WP1's group, for example, comprises health professionals, guideline developers as well as researchers with expertise in clinical epidemiology and statistics, implementation science, communication and psychology. WP2's and WP5's advisory groups contain more policymakers, WP3's has some journalists and patient representatives.

User-testing and focus groups

Once an idea for a presentation method or format has been developed, DECIDE gets the opinion of stakeholders through user-testing. Each user-test takes around one hour. Normally, with the participant or participants' written permission, we audio-record each test, and an observer takes notes. Using a semi-structured interview guide, we then explore both immediate first impressions as well as detailed descriptions of users' reactions to the presentation method or format. The format of user-testing has varied from one-on-one to small workshops with 8-10 participants.



The WP1 Top Layer presentation

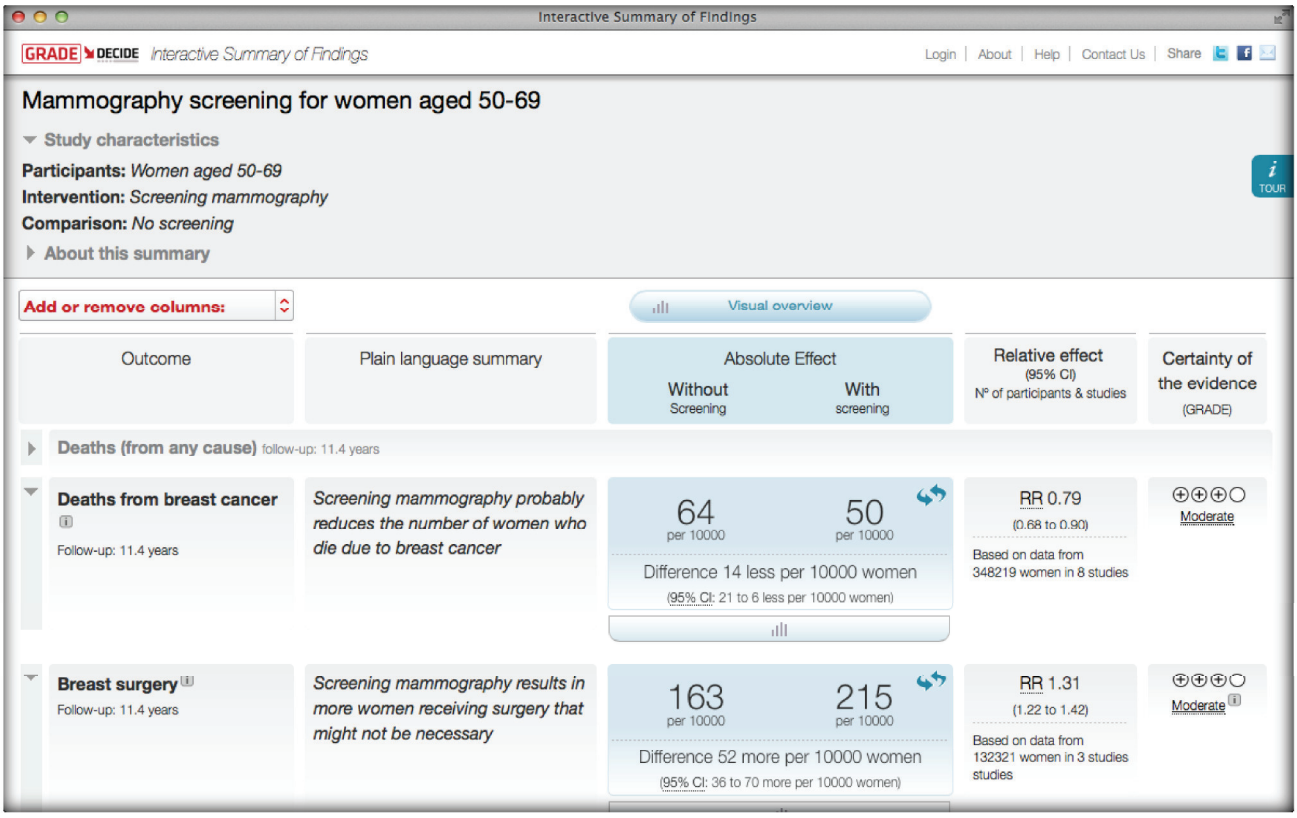
In WP1, for example, the tests have provided clear messages. First and most important users like our layered approach where information is presented in stages rather than all at once. The second round of user testing for WP1 involved seven countries, performing 16 individual sessions using a tablet computer, 24 individual sessions using a PowerPoint presentation and one group session. Feedback was more positive, reflecting the changes made after the first round. The current Top

Layer, which is the layer that presents the most important information to health professionals, is shown on the previous page.

Key information is presented first, users then select what else they want to see, if anything. WP2's user-testing found that policymakers needed better definitions of concepts such as inequity and desirable effects, as well as more information on costs. WP5 has led work developing new ways of presenting Summary of Findings tables and has developed an interactive Summary of Findings table tool, which allows users to select what they want to see, and how; a screenshot is shown below.

WP3 took a different approach and added focus groups with journalists, the public and patients as a stage between its literature review and user-testing. Key messages were that people wanted information on what they can do themselves (i.e. self-management), layering of information is essential and that harms need to be considered as well as benefits. WP3's user-testing has identified the need for context within the document (who is the document for, who has written it, will all the treatments be available etc.) and underlined the WP3 team's growing belief that guideline-derived documents need to be thought about right at the beginning of the guideline production process, not simply bolted on at the end, and need strong end-user involvement.

User-testing for all WPs is now moving to testing interactive Summary of Findings tables and interactive Evidence to Decision tables and the results of earlier user-testing will be submitted for publication during 2014. WP1, WP3 and WP4 will begin user-testing with shared decision tools, involving both health professionals and patients, during 2014.



An interactive Summary of Findings table

Testing DECIDE presentation strategies

WP1 has developed a protocol to evaluate the top layer presentation in an international randomized trial. The top layer will be compared with an alternative presentation from a real guideline or an electronic resource that physicians generally use (e.g. UptoDate). Outcomes measured during the trial, which is intended to start in March 2014, are likely to include understanding, preference, confidence and anticipated course of action. WPs 1 and 3 will use a tool developed by DECIDE's Finnish partner to randomly present users of the Finnish Medical Association guideline portal (>3 million hits a month on the public site) with alternative recommendation presentations, followed by short questionnaires asking their views. WP5 has tested its framework with real World Health Organisation guidelines on task shifting for maternal and newborn care, task shifting for contraception, and expanding training of health professionals. Some of the presentation ideas developed in this work are being used in other WPs (e.g. the symbols used for recommendation strength are being tested with the public in WP3). WP3 is working with the Scottish Dental Clinical Effectiveness Programme to produce a real document for patients linked to its forthcoming periodontal care guideline. The European Renal Best Practice association is also using DECIDE presentation strategies in the development of its live kidney donation guidelines.

The Guideline Development Tool

WP6 will provide a toolkit for preparing and communicating evidence-based recommendations. Two major developments in the second half of 2013 were the launch of the Guideline Development Tool (GDT) (http://www.guidelinedevelopment.org), which was initiated by DECIDE and will include the majority of DECIDE's outputs and deliverables (e.g. the frameworks and support for layered delivery). The GDT is the replacement for the GRADEprofiler (GRADEpro) software (http://www.ims.cochrane.org/revman/gradepro) developed by the GRADE Working Group. Unlike GRADEPro, the GDT supports the whole guideline production process as well as providing evidence profiles and Summary of Findings tables support as with GRADEPro. The second development was the publication of the Guideline Development Checklist (http://cebgrade.mcmaster.ca/guidecheck.html), which is a practical 'process' tool for guideline development groups and involved many of the DECIDE partners. Both the checklist and the GDT are likely to become global standards in the guideline production field.

Dissemination

We have given many presentations on DECIDE, including one at the European Commission's European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), Lisbon, Portugal. Indeed, DECIDE has greatly influenced the presentation of the EMCDDA portal (http://www.emcdda.europa.eu/best-practice). DECIDE is also working with the DG Joint Research Centre, Institute for Health and Consumer Protection, Ispra, Italy on the development of new EC-level guidance for the management of breast cancer. The World Health Organisation is using DECIDE work in some of its guidelines such as, for example, those on lay health workers in maternal health (http://optimizemnh.org/index.php). DECIDE had an extremely strong representation at the 2013 Guidelines International Network conference held in San Francisco with two plenary presentations, eleven oral presentations, four workshops and four posters. Preparation for the DECIDE international conference, to be held in Edinburgh, Scotland, in 2014 is well underway – as of 25/02/2014 we had 192 delegates registered. The opening address will be

given by Sir Harry Burns, the Chief Medical Officer for Scotland until January 2014.

Expected final results and potential impact

DECIDE is increasing our understanding of the many factors that affect whether a given intervention will be used by healthcare professionals, patients and policymakers by studying in a structured and consistent how to effectively present research evidence. We are building on the substantial experience and knowledge of the GRADE Working Group to directly address how information about health care interventions is created, packaged, transmitted, and interpreted among a variety of important stakeholder groups including healthcare professionals, healthcare managers, policymakers and patients.

By providing new understanding of stakeholders' needs for information on confidence as well as effect, the DECIDE consortium will provide a substantial body of new information to address the level to which health interventions can fit within real-world clinical systems. The outputs of the project are likely to have a high impact as there will be adaptations to specific settings and significant involvement of guideline users in all phases of DECIDE, recognising the very different needs not only of the various stakeholder groups but also the different clinical and healthcare fields and the cultural settings in which they operate. That these groups have different needs is clear from DECIDE's user-testing and other evaluations. Finally, because of DECIDE's links with producers of guidelines and systematic reviews, the potential for changing the way guidelines are created and presented is substantial.