1. Publishable summary

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. 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 has developed and is evaluating new ways of presenting research information in guidelines that are tailored to the information needs of patients, clinicians and policymakers - in other words to the key players who determine what happens in clinical practice. In this we 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 the WPs have in some cases developed different presentation strategies, each has focused on the needs of the particular stakeholder group and each has used a similar approach. 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 and has been accessed over 14,500 times.

Literature reviews and brainstorming

Most WPs have looked to the literature to examine what is already known about research presentation methods for particular target groups and this work is now largely complete. DECIDE publications include a review summarizing the public's attitudes towards clinical practice guidelines and evidence-based recommendations, together

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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)

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with their general awareness of clinical guidelines (http://www.biomedcentral.com/1472-6963/14/321 and is 'Highly Accessed' having been accessed over 6500 times). A WP3 review of published patent versions of guidelines is currently under review. WP4 has also 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 (http://www.implementationscience.com/content/8/1/78 and is 'Highly Accessed').

Brainstorming continues to be used in all WPs as a rapid way to generate ideas that can then be tried out in user-testing and other evaluations. WP1 has discovered that users found presentations to be too complex, wordy and crowded. End-users were confused by the methodology; the phrasing was unclear and repetitive. WPs 2 and 5 have 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 has been very positive. A series of five papers describing the Evidence to Decision framework (covering issues relevant for WPs 1, 2, 4 and 5) is currently under review.

Testing DECIDE presentation strategies
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 although we have found that one-to-one works best.

In WP1 and WP3, 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 current Top Layer, which is the layer that presents the most important information to health professionals (i.e. WP1), is shown in Figure 1. Key information is presented first, users then select what else they want to see, if anything. The Top Layer format is described further in the journal CHEST (http://journal.publications.chestnet.org/article.aspx?articleid=1916306). 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 (iSoFs) table tool, which allows users to select what they want to see, and how. These iSoFs are part of the interactive Evidence to Decision frameworks, which all WPs have contributed to (see Figure 2). Finally, WP1, WP3 and WP4 began user-testing with shared decision tools, involving both health professionals and patients, during 2014 and this will continue through 2015. A paper describing the general approach was published in the BMJ early in 2015 (http://www.bmj.com/content/350/bmj.g7624.long).

WP1 has - together with the MAGIC research and innovation program (www.magicproject.org) as a major collaborator and contributor in the DECIDE project - moved from user-testing multilayered guideline presentation formats to implementing these as web-based digitally structured guidelines in several countries. WPs 1 and 3 have an ongoing trial that uses a tool developed by DECIDE's Finnish partner to present members of the public using the Finnish Medical Association guideline portal with alternative recommendation presentations, followed by a short questionnaire. 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. WP3 has worked with the Scottish Dental Clinical Effectiveness Programme (SDCEP) to produce a real document for patients linked to its periodontal care guideline; the patient version is available at http://www.sdcep.org.uk/published-guidance/periodontal-

management/. WPs 5 and 3 will work together in late summer 2015 to run a large trial of alternative iSoF presentations to the public.

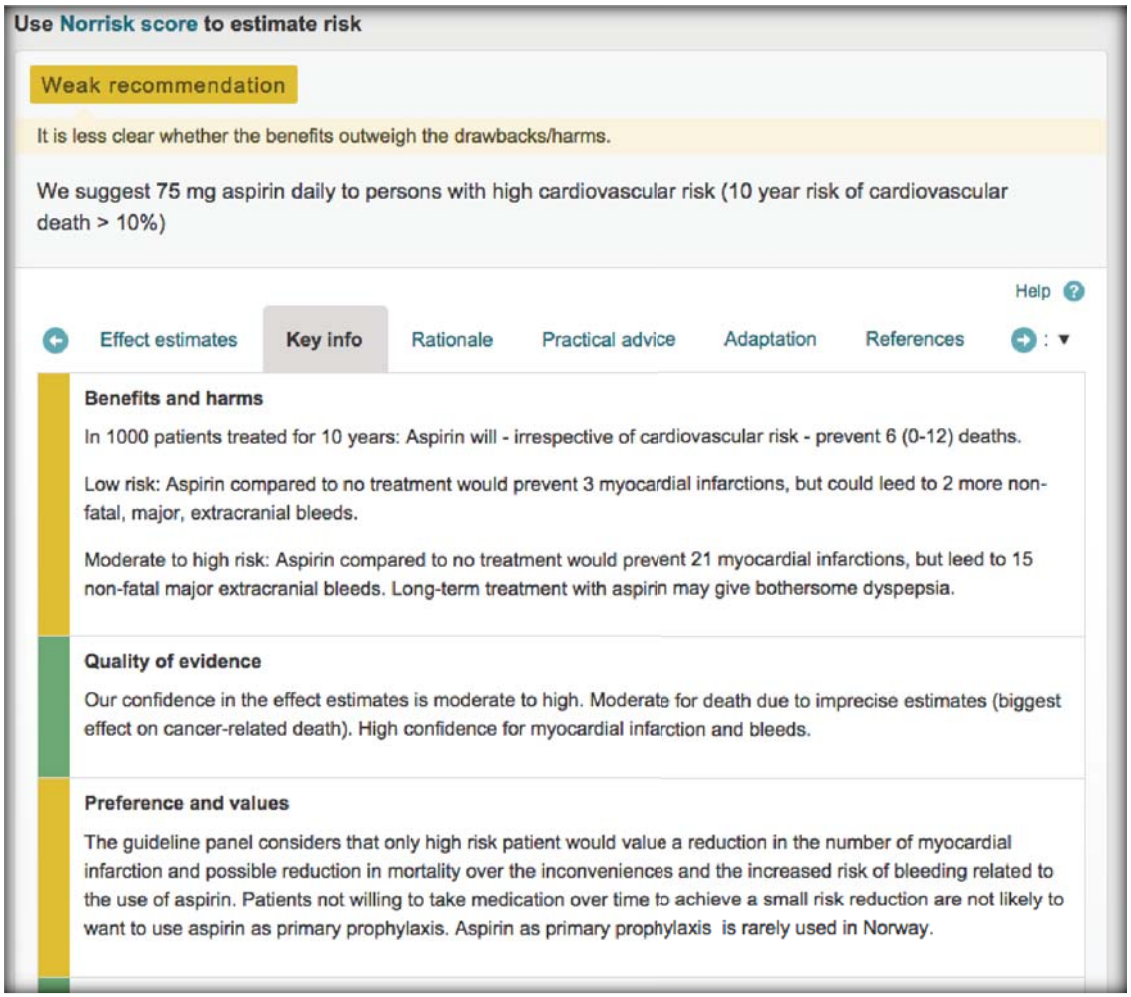

Figure 1 *The WP1 Top Layer presentation*

The Guideline Development Tool
WP6 has developed DECIDE's primary tool for packaging its work: the GRADEPro Guideline Development Tool (GRADEProGDT) (http://www.guidelinedevelopment.org). The tool has been substantially improved during 2014/2015 and now includes the majority of DECIDE's outputs and deliverables. The GRADEProGDT is the replacement for the GRADEprofiler software developed by the GRADE Working Group but unlike the old software, GRADEProGDT supports the whole guideline production process as well as providing evidence profiles and Summary of Findings tables support.

Dissemination
We have given many presentations on DECIDE, especially through the 3-day DECIDE conference held 2-4 June 2014 in Edinburgh, Scotland. Two-hundred and seventy delegates from 20 countries came to discuss DECIDE work and provide feedback on its direction. Feedback at the conference contributed to all WPs. For example, some concerns were raised about the usability of the Evidence to Decision framework with regard to equity and feasibility, which led to changes in our guidance and became a focus for WP2 work, which is still ongoing. DECIDE is also working with the DG Joint Research Centre, Institute for Health and Consumer Protection, and the CanCon project (http://www.cancercontrol.eu/index.php) 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 extremely strong representation at the 2014 Guidelines International Network (G-I-N) conference held in Melbourne with 13 oral presentations. DECIDE ideas were discussed in two plenary presentations at the 2014 Cochrane Colloquium in Hyderabad, as well as at meetings in Colombia, the Netherlands, Norway and the UK.

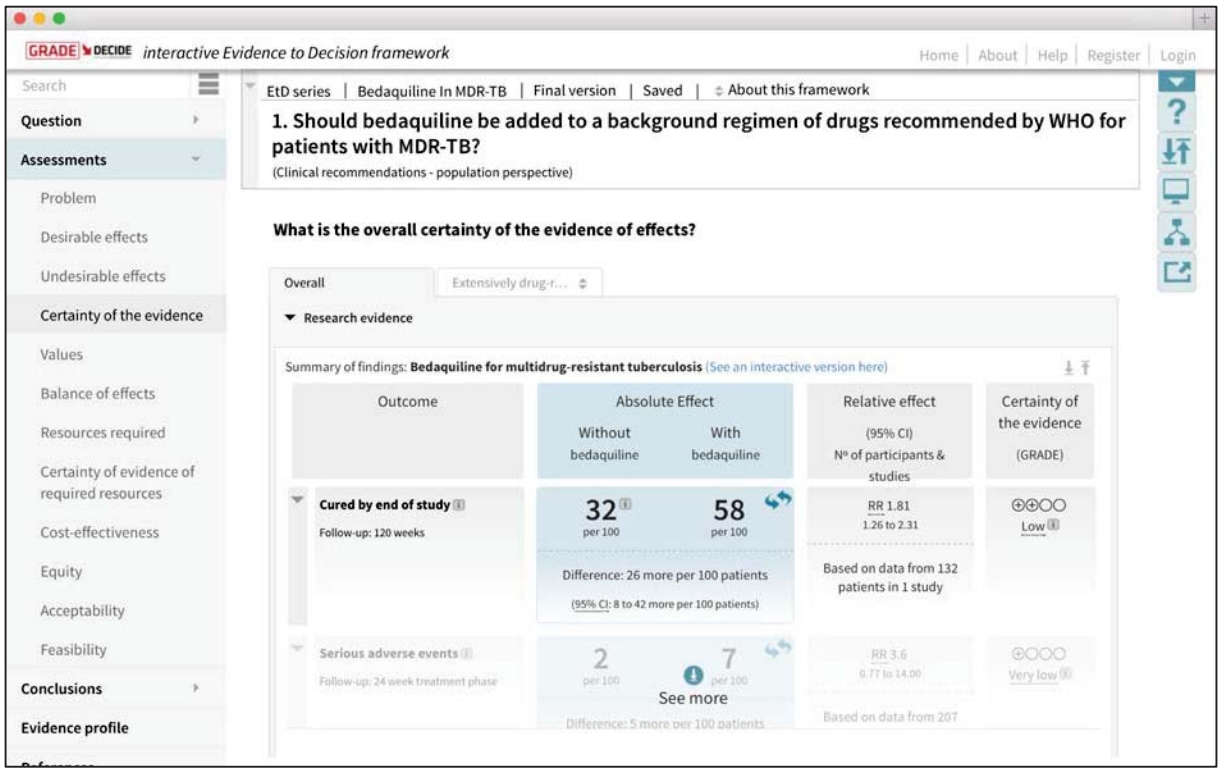

Figure 2 *An interactive Evidence to Decision framework.*

Expected final results and potential impact

DECIDE is increasing our understanding of the many factors that affect whether a given healthcare innovation 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 is providing a substantial body of new information to help guideline producers tailor their guidelines to meet the needs of their users. The outputs of the project are likely to have a high impact as guideline producers have had an active role from starts, ensuring relevance, and some of the DECIDE strategies and ideas are already starting to be used by guideline producers around the world. Because of these links with producers of guidelines (and systematic reviews, which underpin guidelines), the potential for changing the way guidelines are created and presented is substantial.