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 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's objectives are to develop and evaluate strategies that address the **targeted dissemination** of information and intervention materials to the key stakeholders who determine what happens in clinical practice. We will develop and evaluate strategies for effectively and efficiently communicating and supporting the uptake of evidence-based recommendations to:

- healthcare professionals
- policymakers and managers
- patients and the general public

In addition to addressing recommendations about prevention, treatment and rehabilitation, we will develop strategies for recommendations about:

- diagnostic tests
- health system policies that enable or inhibit evidence-based clinical practice

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.

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

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Partners
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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. Freiburg University Hospital (UHF)
8. National Institute for Health and Clinical Excellence (NICE)
9. Scottish Intercollegiate Guidelines Network (SIGN)
10. Finnish Medical Society Duodecim (FMS)

Duration
Jan 2011 - December 2015

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

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:

1. 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.
2. Phase 2: evaluation, generally in randomised trials.
3. Phase 3: testing our strategies with real guidelines.

Although our work is iterative and we anticipate returning to, for example, Phase 1 in light of what we learn in Phase 2, the bulk of our effort to date has been spent on Phase 1.

Literature reviews, brainstorming and surveys

Most WPs are doing a review of the literature to collate what is already known about research presentation methods for particular target groups. WP3, for example, is reviewing the literature covering the evidence around patient (lay, public, citizen, consumer) understanding and knowledge, expectation and perception of healthcare guidelines and to collate knowledge on methods of communicating guideline recommendations to this audience. The search identified 5415 articles, of which 41 met all the inclusion criteria. Initial results suggest generally poor awareness of healthcare guidelines; even if individuals are aware they are not likely to follow them. Ideas from commercial advertisers are suggested as a way of raising awareness, for example using personal stories or celebrities.

WP4 is reviewing the systems used to develop and disseminate evidence-based recommendations about diagnostic tests, which will inform work on how this might be improved and how the results of the grading might best be presented. Thirteen systems have been identified, with GRADE being most explicit and systematic in rating the evidence.

WP1 is doing two rapid systematic reviews, one looking at how guidelines and secondary resources (e.g. UptoDate) present recommendations and evidence summaries, the other looking for what has been studied about the different aspects around presentation of recommendations and evidence summaries. The results of these reviews will both inform DECIDE's work and advance knowledge around presenting guideline information to a wide range of stakeholders.

Brainstorming is being used in all WPs as a rapid way to generate ideas that can then be

tried out in user-testing. WP1 has held six brainstorming meetings to identify problems and ways of improving its presentation formats, which have led to the development of presentations that aim to directly support shared decision-making between healthcare professionals and patients. This has led to a close collaboration between WPs 1 and 3, with WP4 increasingly being involved.

WP5 has had over 20 brainstorming meetings to develop and refine a framework for going from evidence to health policy decisions.

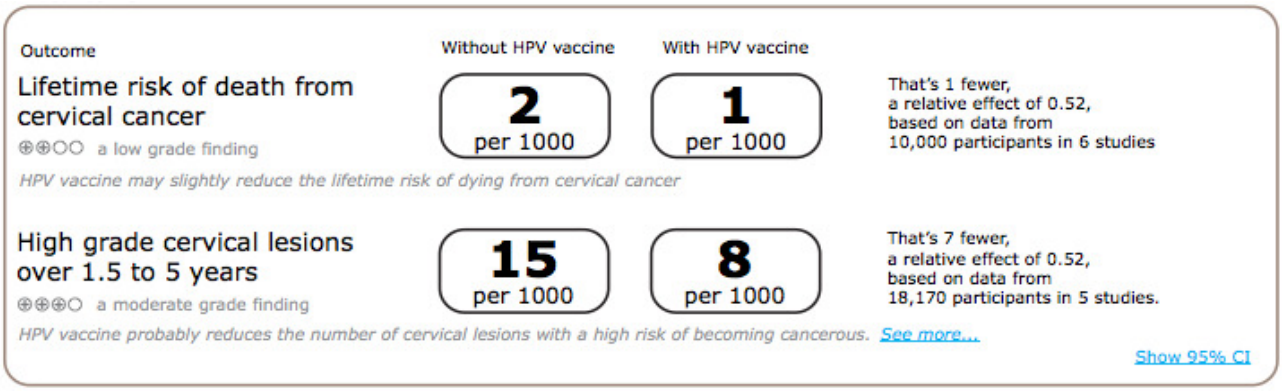
WP2 has gone through a similar process to develop a framework for going from evidence to coverage decisions.

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 109 responded. These responses are currently being analysed. Two of our partners, NICE and SIGN, were running surveys which were modified for DECIDE and together they received nearly 2000 responses. Key messages from these are that a significant minority of respondents were not aware of guidelines at all. Most of those who were aware of them thought guidelines were for only for healthcare professionals and that guideline producers have a substantial job to do to improve how they reach out to the public and patients.

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 needs to see what its users think of it, which is the purpose of 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.

In WP1, for example, the tests have provided some clear messages. First and most important users like our layered approach where we present information in stages rather than all at once. Users like this because they have different needs with regard to additional information, which vary with the type of use, clinical circumstances, specialty or time. Conversely, some users had difficulties understanding the GRADE approach and the terminology used was sometimes not well understood or liked. One general practitioner participating in a user-test said '*We need EBM [evidence-based medicine] at 2am*', in other words they need a presentation and interface that is so clear that they can use it in the early hours of the morning on patient call-outs when they are half-asleep. 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; an example of one of the suggested new presentations is shown on the next page.



WP3 has taken a different approach and has added focus groups with journalists, the public and patients as a stage between its literature review and user-testing. To date it has had one meeting with 11 UK-based journalists, including participants from the BMJ Group, the BBC, *The Sun* newspaper and several large charities, one with seven members of the public, two groups involving a total of nine doctors and five focus groups involving a total of 28 patients. More are planned to build a picture, when combined with the WP3 literature review and surveys, of what the public and patients know about, and want from, guideline information. Key messages so far are that people want 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. Public and patients want shared decision-making but within limits; one participant in the focus group with members of the public summed this up well:

> *'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.'*

WP3's user-testing will start in late summer/early autumn of 2012.

Evidence-to-Recommendation frameworks

WP6 will provide a toolkit for preparing and communicating evidence-based recommendations that will be based on the GRADEprofiler (GRADEpro) software (http://www.ims.cochrane.org/revman/gradepro). This is being developed by members of the GRADE Working Group and used by a wide variety of organisations, including the DECIDE partners. An important part of this work is the inclusion in GRADEPro of Evidence-to-Recommendation (EtR) frameworks, which will support guideline producers decision-makers to consider the research evidence and other relevant issues (e.g. cost and patient values and preferences) when making judgements leading to a recommendation. WP5, for example, has tested its framework with World Health Organisation guidelines on task shifting for maternal and newborn care, task shifting for contraception, and expanding training of health professionals WP2 is about to get widespread feedback on its framework, which focuses on coverage decisions.

Dissemination

We have given many presentations on DECIDE, including two at the European Commission's European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), Lisbon, Portugal. DECIDE will be well represented at the 2012 Guidelines International Network conference to be held in Berlin in August with one plenary presentation, two workshops and four posters. Work has already started on DECIDE's international conference, to be held in Edinburgh, Scotland, in 2014. We have invited the Scottish Deputy First Minister and Cabinet Secretary for Health, Wellbeing and Cities Strategy, to open the meeting.

Expected final results and potential impact

DECIDE will increase 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 way the effect of how research evidence is presented. We will build 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 (and needed) 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 higher 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. Finally, because of DECIDE's links with real guideline producers, the potential for changing the way guidelines are created and presented is substantial. The GRADE Working Group, our key external collaborator, has already done this and there is no reason to expect that DECIDE's work will not do the same.