



ANALYSIS

SPOTLIGHT: PATIENT CENTRED CARE

Decision aids that really promote shared decision making: the pace quickens

Decision aids can help shared decision making, but most have been hard to produce, onerous to update, and are not being used widely. **Thomas Agoritsas and colleagues** explore why and describe a new electronic model that holds promise of being more useful for clinicians and patients to use together at the point of care

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Many, perhaps most, important decisions in medicine are not clear cut.^{1,2} Patients and clinicians need to discuss the options using the best available evidence and make informed joint decisions that take account of patients' context, values, and preferences.^{3,4} But implementing shared decision making is not easy. Doctors need the skills and tools to do it and to build trust; patients need information and support. Patients also need to have a greater role in developing strategies to improve the process.^{5,6}

Access to best evidence is another key ingredient. Until now the production and dissemination of clinical practice guidelines and summaries of evidence has largely been tailored to meet the educational needs of clinicians. They are seldom provided in a format that supports shared decision making.⁷ Patients meanwhile, struggle to find reliable and accessible summaries of evidence, although plain language summaries and patient versions of guidelines are being developed.⁸

In this article we highlight the limitations of current decision aids and discuss how the generic production of electronic

decision aids designed for use in the clinical encounter, linked directly to trustworthy summaries of evidence from systematic reviews and guidelines, may help in the long march to realising effective shared decision making.

Challenge of shared decision making

Shared decision making depends on a good conversation⁹ in which clinicians share information about the benefits, harms, and burden of alternative diagnostic and therapeutic options and patients explain what matters to them and their views on the choices they face.^{4,10} It should follow the principles of patient centred care, promote informed choice, and result in care that patients value.¹⁻¹¹ Many clinicians think they practice shared decision making, but evidence suggest a perception-reality gap³ because of misconceptions about the nature of shared decision making, the skills it requires, the time it takes, and the degree to which patients, families, and carers wish to share in decision making.¹²⁻¹⁴

Each clinical encounter is influenced by many factors. These include patients' circumstances and medical needs as well as

their beliefs, stemming from what they have read, personal experience, advice from family and friends, and the media. It is therefore important to provide patients with accurate, up to date evidence on the benefits and harms of alternative management strategies and their likely effect on outcomes that matter to them, although evidence may not always reflect the complexity and multimorbidity of individual patients and patients may choose to ignore the evidence. Good shared decision making requires clinicians to have access to detailed knowledge and ideally summaries of the latest evidence and the means to share it in a way that supports thoughtful deliberation, something that cannot be done on the fly.

Limitations of traditional decision aids

For the past two decades enthusiasts have advocated decision aids to facilitate shared decision making, and over 500 have been developed.^{15 16} A systematic review of 115 randomised trials showed that their use was associated with a 13% absolute increase in patients' knowledge scores and an 82% relative increase in accurate expectations of possible benefits and harms. Effects on clinical outcomes, adherence to treatment, and use of services have not, however, been consistent.^{15 17}

Most decision aids have been designed for patients to use independently outside the consultation, either in the waiting room or at home.¹⁰ Although these decision aids promote understanding of the issues, they cannot guarantee that decisions in the consultation are shared,^{3 18} and there is insufficient evidence to determine how their use influences the consultation.¹⁸ Another problem is that use of decision aids in routine care is low,¹³ mainly because of poor design and lack of ready access to them. Furthermore clinicians may find the format impractical to use in consultations and may be as unfamiliar as their patients with risk estimates and the inherent uncertainty associated with probabilities.¹⁹

Traditional decision aids are often not based on current evidence or rapidly outdated, at least in part because of limitations in funding after tool development—and may thus do more harm than good.²⁰ A rigorous systematic review is needed for each important outcome, and such reviews are often unavailable. A recent assessment found that although around two thirds of decision aids are based on systematic reviews or guidelines, many of these sources are of questionable quality, and only 5% of aids included an “expiry date” or a stated policy about updating.²⁰

Ensuring the quality and timeliness of decision aids is a daunting challenge. The work required to summarise evidence for a trustworthy decision aid is similar to that for producing a systematic review or a guideline, suggesting the potential for synergy between the worlds of evidence based practice and shared decision making.²⁰⁻²²

Harnessing the potential of recent developments

New decision aids

Some newer decision aids have been designed to facilitate collaborative deliberation in the course of the clinical encounter.^{3 10} Montori and colleagues pioneered a user centred approach to producing decision aids through iterative observations of discussions between doctors and patients.^{9 23} Their approach resulted in succinct, easy to use tools that provide graphic displays of the benefits and harms of different options organised around concerns that are important to patients (<http://shareddecisions.mayoclinic.org>). In contrast to traditional

aids, which patients use independently, they are not designed to be comprehensive and do not include explicit exercises to help patients clarify their values (such as the relative values of avoiding a stroke versus a gastrointestinal bleed)²⁴ Instead they rely on the unique conversations that take place between patients and clinicians, with clinicians providing just in time, tailored explanations and information.¹⁰ Direct observations in randomised trials have shown that these short tools (so far available for diabetes, statins, and antidepressants) promote dialogue and increase joint deliberation.²⁵ They also shift the “body language” as patients and clinicians sit together to review the data.^{23 26}

Other short point of care decision aids include Option Grids (www.optiongrid.co.uk).^{27 28} These are one page summaries that provide answers to patients' frequently asked questions, covering clinical outcomes and practical concerns faced in daily life. Their value in routine care is being evaluated.²⁷

Developments in appraisal and presentation of best evidence

The GRADE approach (Grading of Recommendations Assessment, Development and Evaluation) provides systematic, transparent, and explicit guidance for processing evidence from the medical literature, and has been widely adopted.⁷⁻³⁰ Use of the GRADE approach results in standardised and succinct evidence profiles or summary of findings tables, which specify the absolute effects of an intervention on outcomes important to patients rather than surrogate outcomes and provide a rating of the certainty in these estimates (high, moderate, low, or very low).³⁰ The recent international patient decision aids standards have emphasised the potential of GRADE for the production of decision aids²⁰, and it has been adopted by over 80 organisations (www.gradeworkinggroup.org).

Furthermore, clinical practice guidelines using GRADE now issue weak recommendations (in contrast to strong) when there is a close balance between desirable and undesirable outcomes among alternatives, low certainty in estimates of effect, or when there is large variability in patients' values and preferences. Weak recommendations, which dominate in recent high quality guidelines,² thus identify decisions where shared decision making is particularly important.^{20 22}

Use of new technologies

The not-for-profit MAGIC project (Making GRADE the Irresistible Choice www.magicproject.org) has developed an online “app” with potential to produce electronic decision aids for use in the clinical encounter.⁷ This MAGICapp (www.magicapp.org) allows authors of guidelines or systematic reviewers to write evidence summaries into a structured database and appraise them using GRADE criteria. The content can then be published on a web platform and presented in interactive formats on tablets, web portals, or electronic medical record systems.³¹

In the SHARE-IT project, we use this authoring and publication platform for the generic and semi-automated production of a large number of decision aids.⁷ The aids can be used with the corresponding systematic review or clinical practice guidelines and the format modified and tailored to specific contexts—for example, published in different languages or adapted to national guidelines.^{32 33} The electronic format facilitates continuous updating because the data in the decision aids will change automatically each time the underlying review is modified.⁷

Figure 1⇓ summarises the methods of the SHARE-IT project. In collaboration with DECIDE (www.decide-collaboration.eu),³⁴

we gathered an international team of experts in evidence based medicine and shared decision making, clinicians, guideline developers, and designers, and developed an initial framework and electronic prototype for the translation of GRADE summaries into decision aids. We then applied an iterative and user centred design, directly involving patients and clinicians facing real decisions. We built 10 decision aids on antithrombotic drugs and modified the generic prototype in light of observations of their use in practice and individual feedback from patients and clinicians.

The video illustrates how the prototype uses interactive formats to present evidence summaries at varying levels of detail. The prototype shows that the approach is feasible, and preliminary experience suggests it is appreciated by both patients and clinicians (box). Across 16 clinical encounters, patients consistently reported high levels of satisfaction with the prototype in understanding risks and benefits and in enhancing their confidence in decisions (mean scores of 88.7 and 90.9 respectively (maximum 100) as assessed by COMRADE.³⁵

Conclusion

No decision aid is sufficient to guarantee that clinical decision making is shared. Undergraduate, postgraduate, and continuing education programmes must teach health professionals about the importance of creating and fostering a culture of shared decision making and the skills needed to communicate evidence, and its limitations, in a way people can understand. Furthermore, the challenge of producing evidence summaries that deal optimally with complexity, multimorbidity, and potentially limited applicability to the patient remains.³⁶

We are, however, now in a position to construct, test, and refine electronic evidence summaries for use in the clinical encounter for a wide variety of patient groups and clinical settings. Our prototype, built in the MAGICapp, demonstrates the feasibility of semiautomated production of decision aids from a large number of electronically published evidence summaries. We also plan to implement these formats in another similar platform, the GRADEpro Guideline Development Tool (www.guidelinedevelopment.org). We invite patient organisations, research groups, guideline developers, patients, and clinicians to partner with us (www.magicproject.org) and help us advance the science and art of truly shared and well informed decision making.

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are affiliated. We also received numerous feedbacks from stakeholders at international meetings. TA led and coordinated the project, supervised by GHG and POV. TA, AFH, LB, and POV developed and implemented the prototype, and all contributors provided feedback at different stages. TA, AFH, and POV performed user-testing in clinical encounters. TA drafted the manuscript and all authors critically revised the manuscript. TA is guarantor.

Competing interests: All authors have read and understood BMJ policy on declaration of interests and declare the following interests: TA, AFH, LB, AK, PAC, EAA, IN, KAOT, VMM, GHG, POV are members of the GRADE working group (www.gradeworkinggroup.org), as well as coinvestigators in the DECIDE project (www.decide-collaboration.eu). TA, AFH, LB, AK, GHG, POV are members of the MAGIC research and innovation program. GE leads the Option Grid collaborative. VMM designs and tests shared decision making tools at the KER UNIT in Mayo Clinic. These tools are then made available for free with no income generated for him, his unit, or his institution.

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Reaction to the decision aid

A haematologist expressed surprise that one decision aid regarding long term anticoagulation treatment for patients with unprovoked venous thromboembolism begins by inviting patients to choose which outcome to discuss first. She usually started by discussing the risk of recurrence, then bleeding before inviting patients' questions, omitting mortality.

After we clarified she could use the tool as she wanted, she began with the six month follow-up of a 47 year old man taking rivaroxaban for an unprovoked pulmonary embolism. She explained that, although the treatment was indicated after the acute event, the decision to continue rivaroxaban depended on his preferences. She accessed the decision aid and moved to sit next to the patient. Revising her prior plan to use her accustomed order, she used the trigger sentence offered: "What aspect of your medication would you like to discuss first?" The patient chose "practical consequences." In the conversation that followed, they further discussed risk of bleeding, recurrence, and associated mortality. The patient decided to discontinue rivaroxaban.

After the encounter, the clinician pointed out that the patient focused on practical consequences first, and she reflected on how the tool resulted in positive changes to her usual communication strategy. The patient reported that the decision aid made it easier to "digest the information and get the bigger picture." He explained he was first interested by "day-to-day stuff" before exploring "more intimidating" but important issues.

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Figure

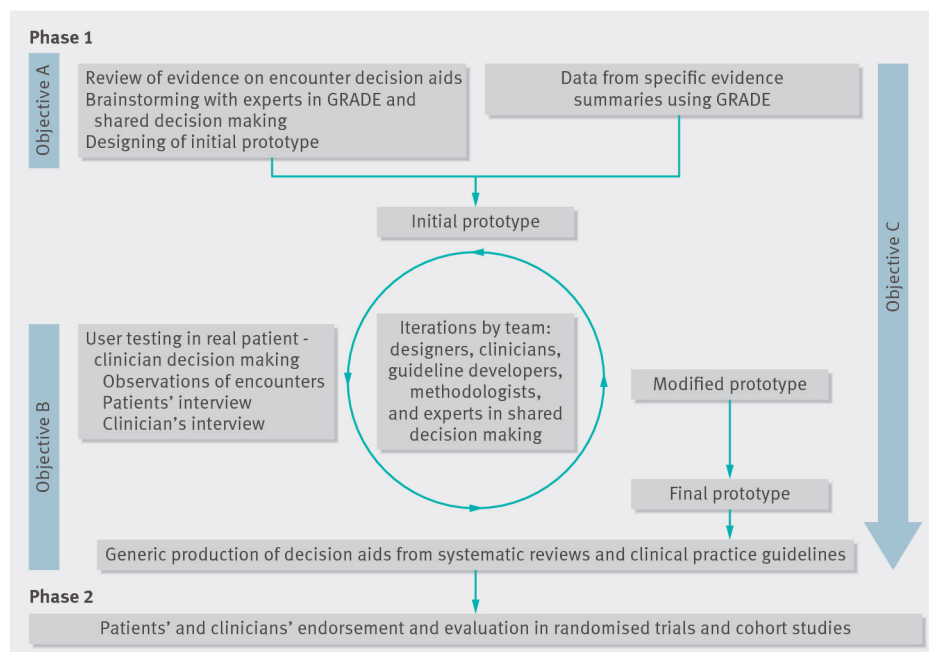


Fig 1 Outline of the methods and user-centred approach in the SHARE-IT project. Objective A=to develop a framework for the generic translation of GRADE evidence summaries into decision aids; Objective B=to design a set of interactive presentation formats for use in the clinical encounter; Objective C=to test the feasibility of an automated production of these decision aids from electronically published evidence summaries. Subsequent phases of the project involve the generic production of decision aids from real practice guidelines and their evaluation in randomised trials and cohort studies