

Developing and using Brief Decision Aids (BDAs)

The MAGIC team – Newcastle

This case study describes how the team in Newcastle working on the Health Foundation's MAGIC programme to implement shared decision making developed 'Brief Decision Aids' as a tool that patients and clinicians can use to support people to play a more active role in decisions about their treatment and care.

The origins of Brief Decision Aids

The team in Newcastle originally developed a Brief Decision Aid as a teaching aid to support training for clinicians in shared decision making. The team took as a basis the 'comparing the pros and cons of treatment' grid that had been produced as part of the *NHS Booklet for patients: enlarged prostate*¹ and included some figures that had been taken with permission from patient information on 'Benign Prostatic Hyperplasia: Choosing your treatment'.²

In initial workshops the Brief Decision Aid proved very popular with clinicians when used as part of an exercise with a clinical scenario and actors. Over the first few months of the project the team therefore developed a number of other clinical scenarios and wrote corresponding 'pros and cons charts'. Local clinicians and others involved in the MAGIC programme were asked to help write the initial drafts and these were refined after comments from users.

At the same time the team in Cardiff working on the Health Foundation's MAGIC programme were developing Option Grids – an alternative brief decision support tool, derived from a table in the Bredex Patient Decision Aid for women diagnosed with early cancer³. One of the motivations for them was the realisation that long form tools were very expensive and time consuming to produce and not as widely used as expected. A brief tool was needed that aided the conversation during consultation and that could be taken home by the patient as hard copy.

Development of the two brief tools was initially parallel and separate. More recently, the format of Brief Decision Aids and Option Grids has been

adapted as part of the NHS Right Care Shared Decision Making programme's Patient Decision Aids (PDAs).⁴

Development process

After the initial success in workshops and the increasing use of these 'pros and cons tables' in primary care consultations, the team started to think more critically about the project that was emerging.

Key influences in the development process were:

- the International Patient Decision Aid Standards (IPDAS) criteria on quality Patient Decision Aids <http://ipdas.ohri.ca/>
- expertise in the MAGIC team, particularly on how to construct patient decision aids
- the evidence base around risk communication
- Cardiff MAGIC team's work on Option Grids
- other sources of data commonly used by primary care teams in the UK, particularly Patient UK / EMIS patient information leaflets (PILS)
- feedback from users of the early versions of brief decision aids.

The team already had some clear early criteria to help guide the development of Brief Decision Aids. Essentially each Brief Decision Aid needed to be a brief tool that:

- could be used within the consultation, but also used as an additional source of information for the patient to read outside the consultation
- could be accessed rapidly
- could be used online or printed with ease by front line clinicians
- fitted with the way clinicians and patients already talked in consultations
- would use high quality evidenced-based information
- provided up to date risk communication with common denominators, real numbers, absolute risk data, plain language.

¹ NHS Booklet for patients: enlarged prostate, 2009, Emberton et al. (Now out of print)

² Benign Prostatic Hyperplasia: Choosing your treatment, Informed Medical Decisions Foundation <http://www.informedmedicaldecisions.org/>

³ Breast cancer Decision Explorer: this website is being developed for women who have been diagnosed with early breast cancer - <http://www.bredex.com/>

⁴ The NHS Shared Decision Making website contains 36 condition-specific, online decision aids to help patients understand and consider the pros and cons of possible treatment options and to encourage communication between them and their healthcare professionals. <http://sdm.rightcare.nhs.uk/pda/>

One of the key decisions was about the layout of the grid format, with various arguments for and against the options available. A number of choices had to be made in design:

Arrange the content by option or by patient attribute?

The first choice was whether to organise the data by patient attribute (“what matters to me or frequently asked questions”) or to organise by option. The team in Cardiff had made the decision to organise by attribute and there are good theoretical reasons for doing this. At a later stage, NHS Right Care also opted for this format for the national NHS Patient Decision Aid tools. This method has one particular practical problem – it is very difficult to deal with more than 3 or 4 options running across a single A4 sheet.

Partly as a contrast in design, and partly because it allowed for an easier layout on printed A4 paper, we decided on a format that listed options. In later versions we have improved this by adding possible frequently asked questions in the introduction to the grid of pros and cons. This helps encourage both clinician and patient to continually focus on “what matters to me?” questions.

What terminology to use: ‘Pros and Cons’ / ‘Risks and benefits’?

There is always an issue about which words to use in producing patient information. It is common to talk about pros and cons but this does not seem appropriate for some situations when there are potential harms or risks. Patient representatives and some clinicians felt ‘harms’ to be somewhat alarming, and preferred ‘risks’. We settled for benefits, risks or consequences. ‘Consequences’ covers issues such as the need for hospital admission or not, impact on driving etc.

One of the critiques of this decision is the clear argument that ‘one man’s poison is another’s pleasure’: not everyone will regard a risk or a benefit equally. Some may regard a risk as a benefit. This happens rarely however, and many people are very familiar with a discussion about risks and benefits and are comfortable when they identify that something labelled a risk is “not much of an issue for me” or a benefit that “does not really apply to me”.

How brief is brief?

It is a constant challenge to balance brevity against having enough information to make the ‘decision that is right for me’. Some principles have emerged for us:

The information should be as brief as possible taking into account the following:

- The Brief Decision Aid must include the current evidenced-based options that are available in the UK
- Other options such as complementary therapies might be included if there is widespread use of them already and it would help to include the evidence base for them. For options NOT in widespread use and not recommended by NICE we omit them from the list of options
- Where there are ‘reliable numbers’ that add to the information for a particular option we have tried to include them
- Ideally the Brief Decision Aid should not run to more than 2-3 pages but some, such as contraception, inevitably run to more because of the number of legitimate options available
- The Brief Decision Aid is a tool to aid the quality of shared decision making in a conversation between patient and clinician and the information in the Brief Decision Aid is therefore designed to help both patients and clinicians

The development of a formal policy for construction of Brief Decision Aids

As the team started to develop more Brief Decision Aids, they felt that the process required greater clarity.

There was no doubt that involving clinicians from the teams currently implementing MAGIC helped with production, engagement, ownership and likelihood of adoption by clinicians and we realised that we needed to have specialist second authors where the primary author was a GP.

We wanted to involve patients and the public in the development of the product and negotiated with a local patient forum – VoiceNorth. Each emerging BDA was sent to a panel of 5 -10 VoiceNorth

members by email. All responses were taken into account during re-write. The lead author was editor for all these processes.

Comments were extremely helpful in ‘tweaking’ the format and style.

More recently we are using automatic feedback from the Patient UK website to provide a patient and user input into ongoing development of the BDA.

As the merits of the Brief Decision Aid emerged we decided to formalise the construction policy for the Brief Decision Aids.

Key components of this were:

- Having a first and second author
- Strict use of version control
- Input from patients and users of the BDAs
- To use the Patient UK Patient Information Leaflets (PILS - now called condition leaflets), which have their own quality assurance process, as the source material
- To supplement this with a rapid literature review if the PIL was relatively ‘old’ (not updated in last year) or lacking in detail that we felt might be available or useful to find

Partnership with Patient UK

A key challenge with any product is whether it is used! Members of the MAGIC teams were aware of, and were using the Brief Decision Aids, but we needed a delivery system that would ensure Brief Decision Aids were much more widely available. One of the implementation principles that has guided much of MAGIC is to use existing pathways and behaviours when at all possible. Patient UK is the second most used health website in the UK (NHS Choices is the first). Over 50 % of UK general practices use EMIS and this software has direct access to PILS. Many GPs have already got used to using PILS and printing these off for patients. It made good sense to piggy back onto the existing behaviour by entering into a partnership with Patient UK⁵. This proved extremely successful.

⁵ Decision Aids can be found on the Patient UK website here: <http://www.patient.co.uk/search.asp?searchterm=decision+aid&searchcoll=All&x=0&y=0>

In the first 5 months 22,000 Brief Decision Aids were downloaded (over 1,000 downloads per week).

More recently we have formalised our partnership with Patient UK who have clearly seen the benefits of our approach. They continue to redesign their website to make patient decision aids more available and now signpost not only to Brief Decision Aids but also to Cardiff’s Option Grids and to the national on-line Patient Decision Aids. We are working closely with them to maximise the ease with which the BDAs can be found and downloaded. There is clear evidence that when actively promoted on the site, downloads increase significantly.

Activity and Feedback from usage on Patient UK and with clinical teams

Activity

Event action	Total events
cramps.pdf	4782
ibs.pdf	4294
plantar-fasciitis.pdf	3373
warts-and-verrucae.pdf	2882
tennis-elbow.pdf	2708
carpal-tunnel-syndrome.pdf	2621
stopping-smoking.pdf	2588
heavy-periods.pdf	2447
prostate-enlargement.pdf	2382
contraception.pdf	2083
contraception.pdf.pdf	620
what-is-shared-decision-making.pdf	252
how-to-use-a-bda.pdf	227
	31259

Feedback

We gained feedback from a questionnaire that ‘pops’ up whenever you access the Brief Decision Aid as part of Patient UK. Only a small percentage of ‘total’ (patients and clinicians combined) users filled in the questionnaire, but this feedback gave us rich data about views:

Patient views of BDAs – a snapshot from April 2013

	1	2	3	4	5	Total responses
Clear?	17 (6%)	5 (2%)	20 (7%)	73 (26%)	161 (58%)	276
Accurate?	16 (6%)	4 (1%)	58 (21%)	72 (26%)	124 (45%)	274
Informative?	15 (5%)	7 (3%)	24 (9%)	75 (27%)	155 (56%)	276
Helpful?	15 (5%)	11 (4%)	23 (8%)	82 (30%)	142 (52%)	273
This would help me discuss options with my clinician	18 (7%)	10 (4%)	33 (12%)	71 (26%)	143 (53%)	275
I learnt something new using this BDA	27 (10%)	26 (9%)	37 (14%)	61 (22%)	123 (45%)	274
I would like to have BDAs for more conditions	17 (6%)	6 (2%)	43 (16%)	64 (23%)	147 (53%)	277

Patient comments:

- *“A much better document than provided previously by my GP. Less waffle than many other information sheets”*
- *“The clearest information on possible treatments and their effects I have found to date!”*
- *“Very good: for the first time I understand my condition”*
- *“The info was so clear; I could make a decision immediately”*
- *“Good to include web links to more detailed information”*
- *“Please check for English: not ‘less than’, but ‘FEWER THAN 4 PEOPLE...’”*

Clinician views of the quality of the BDAs

	1	2	3	4	5	Total responses
Clear?	8 (7%)	2 (2%)	4 (4%)	36 (32%)	62 (55%)	112
Accurate?	6 (5%)	3 (3%)	6 (5%)	34 (30%)	63 (56%)	112
Informative?	7 (6%)	4 (4%)	4 (4%)	28 (25%)	69 (62%)	112
Helpful?	7 (6%)	3 (3%)	6 (5%)	27 (24%)	69 (62%)	112
This would help me discuss options with patients	7 (6%)	3 (3%)	4 (4%)	31 (28%)	66 (59%)	111
I learnt something new using this BDA	15 (14%)	6 (5%)	14 (13%)	27 (24%)	49 (44%)	111
I would like to have BDAs for more conditions	8 (7%)	2 (2%)	4 (4%)	23 (21%)	74 (67%)	111

Comments from early adopters:

- *“I work for NHS Direct and the format of BDAs will make my advice to patients easy to deliver and allow discussion”*
- *“I particularly like the way the research figures are presented e.g. X in 100 people would/wouldn’t improve with certain intervention”*
- *“Really helped my patient decide what she needed. Helped me to help her”*
- *“Really useful. I’ve used the Smoking and Tennis Elbow documents with patients and found them very helpful. I have read and saved the others for future use too”*
- *“Very informative, especially for patients who may want some figures to inform their decisions”*
- *“More info would be good - a bit basic”*
- *“Much as all the management options would be options at some point in time, not all are appropriate or available for new presentations of carpal tunnel syndrome (i.e. surgery)”*

Conclusions from feedback after initial launch of BDA on Patient UK

- Well received
- Widely accessed by both patients and clinicians
- Used in consultations and given to patients to take away for further reflection
- Would help in discussions (87% clinicians; 78% patients)
- Demand for more (88% clinicians; 76% patients)
- Clinicians learned something new (68%)

The next phase of development

Developing additional BDAs

In recent months we have moved into a new phase in the development of Brief Decision Aids. Newcastle University has committed to an ongoing production of Brief Decision Aids and we have an agreement that Patient UK will host these, although Newcastle University has the right to offer the Brief Decision Aids to any other organisation that might wish to host and promote them.

We have completed a revision of the first 10 Brief Decision Aids and there is steady production of new ones, including anal fissure, knee arthritis, atrial fibrillation, shingles and gout. We are working closely with the author team at Patient UK to make sure that PILS and Brief Decision Aids are consistent and this has already proved mutually beneficial. We continue to engage with local clinicians interested in production of Brief Decision Aids as initial authors or contributors.

Quality assurance

We take as the basis for each Brief Decision Aid the relevant Patient Information Leaflet from Patient UK. These are highly valued leaflets with a strong history of usage. They have their own quality assurance process which includes regular searching of the literature and regular updates with a team of authors and an overall editor. In addition we have employed a research associate to review the literature, particularly for any numerical or risk benefit evidence.

Embedding in EMIS Web GP desktop system

One of the more encouraging recent developments is an agreement with EMIS to embed Brief Decision Aids into EMIS Web. The objective is to provide instant reminders to clinicians about the availability of Brief Decision Aids when they are working with a relevant patient condition. Pop ups on screen will alert the clinician to the availability of a Brief Decision Aids when a particular diagnosis is entered and a management plan coded. We think this will be the first attempt to bring decision aids to clinicians at scale (EMIS offers software to >50% of the GP practices in the UK).

Press launch

Patient UK and Newcastle University formally launched their partnership and the new Brief Decision Aids in September 2013.

Re-visit evaluation – possible link to patient data

The web-based pop up questionnaire (see above) which appears when you download a Brief Decision Aid has given us very useful feedback on the current Brief Decision Aids including usage, suggestions for improvement, errors, language and demographics. There is much more that could potentially be done to get greater clarity on a variety of questions e.g.

- Who uses Brief Decision Aids?
- With which patients?
- In what circumstances?

We are discussing with EMIS/ Patient UK ways in which we could capture anonymised patient specific data around Brief Decision Aid usage.

The possible risks of BDAs or any short form patient decision aid

Using a BDA or any other decision support material as part of a consultation is not an unalloyed good. There are risks and benefits to the use of BDAs which should be carefully considered.