Option Grids: tools that make shared decision making easier for clinicians and patients

Professor Glyn Elwyn
Institute of Public Health and Primary Care
MAGIC
Implementing shared decision making into practice in the UK
Acknowledgements: The Health Foundation, Cardiff and Vale Health Board, Newcastle upon Tyne Hospitals NHS Foundation Trust, and most importantly all staff and patients involved across both sites.
Background:

The Health Foundation - An independent charity working to improve the quality of healthcare in the UK

- Leadership and organisations
- Patient safety
- Changing relationships between people and health services
- Engaging healthcare professionals

18 months project: started August 2010
Further 18 months funding agreed February 2012
Are patients involved?

Wanted more involvement in treatment decisions
Source: NHS inpatient surveys
I prefer this option ...
Shared decision making

Shared decision making occurs when clinicians and patients communicate together using the best available evidence when faced with the task of making decisions.
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Shared decision making occurs when clinicians and patients communicate together using the best available evidence when faced with the task of making decisions, where patients are supported to deliberate about the possible attributes and consequences of options, to arrive at informed preferences in making a determination about the best action and which respects patient autonomy, where this is desired, ethical and legal.
In 86 trials addressing 35 different screening or treatment decisions, use has led to:

- greater knowledge
- more accurate risk perceptions
- greater comfort with decisions
- greater participation in decision-making
- Fewer people remaining undecided
- Fewer patients choosing major surgery.

Stacey et al. Cochrane Database of Systematic Reviews, 2011
MAGIC Making Good Decisions in Collaboration

The MAGIC Framework: Action learning with indicator feedback, located in a social marketing context and supported by organisational level leadership.
• Evidence-based patient decision support

• Social marketing

• Clinical skills development

• Organisation and clinical team engagement

• Measurement with rapid feedback, Plan Study Do Act cycles.

• Patient and public engagement
Early learning from MAGIC
Challenges of implementing shared decision making

- Response to change
- Clinical complexity
- Medical culture
  - Paternalism
  - Clinical care pathway
- Time and resources
Identifying challenges

We practice in a vacuum of evidence. We can’t expect patients to decide. Giving patients too much choice is completely damaging to their ability to cope. Surgeons and oncologists get into detailed and sometimes argumentative discussions.

Collectively we’ve got 200 years worth of experience. There is always a best option. I am more likely to be right. We are there to steer the patient in the right direction. The team are already doing SDM. It’s impossible for patients to decide.
Shared decision making: a model for clinical practice

DELIBERATION

Initial

Preference Construction

Informed preferences

Choice Talk

Option Talk

Decision Talk

Patient Decision Support

Brief as well as Extensive
BresDex is for women recently diagnosed with breast cancer and who have been given a choice between:

Lumpectomy* with Radiotherapy or Mastectomy

*also known as Wide Local Excision or Breast Conserving Surgery

In many cases women will have been offered this choice if the cancer is less than 5 centimetres wide.

In some cases, women may have chemotherapy to try and make the cancer smaller to allow the possibility of lumpectomy.

Many women diagnosed with DCIS (Ductal Carcinoma in Situ or pre-invasive cancer) also have the choice between lumpectomy and mastectomy and can use this website.

BresDex is not for you if you have two or more cancers in the breast, or if you are a man with breast cancer.
Lumpectomy with Radiotherapy | Mastectomy
--- | ---
**Which surgery is best for long term survival?** | There is no difference between surgery options. | There is no difference between surgery options.
**What are the chances of cancer coming back?** | Breast cancer will come back in the breast in about 10 in 100 women in the 10 years after a lumpectomy. | Breast cancer will come back in the area of the scar in about 5 in 100 women in the 10 years after a mastectomy.
**What is removed?** | The cancer lump is removed with a margin of tissue. | The whole breast is removed.
**Will I need more than one operation?** | Possibly, if cancer cells remain in the breast after the lumpectomy. This can occur in up to 5 in 100 women. | No, unless you choose breast reconstruction.
**How long will it take to recover?** | Most women are home 24 hours after surgery. | Most women spend a few nights in hospital.
**Will I need radiotherapy?** | Yes, for up to 6 weeks after surgery. | Unlikely, radiotherapy is not routine after mastectomy.
**Will I need to have my lymph glands removed?** | Some or all of the lymph glands in the armpit are usually removed. | Some or all of the lymph glands in the armpit are usually removed.
**Will I need chemotherapy?** | Yes, you may be offered chemotherapy as well, usually given after surgery and before radiotherapy. | Yes, you may be offered chemotherapy as well, usually given after surgery and before radiotherapy.
**Will I lose any hair?** | Hair loss is common after chemotherapy. | Hair loss is common after chemotherapy.
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Section of Epidemiology and State Medicine
President—Sir Arthur MacNalty, K.C.B., M.D.

[May 27, 1938]

The Incidence of Tonsillectomy in School Children
J. Alison Glover, O.B.E., M.D., F.R.C.P., D.P.H.

The rise in the incidence of tonsillectomy is one of the major phenomena of modern surgery, for it has been estimated that 200,000 of these operations are performed annually in this country and that tonsillectomies form one-third of the number of operations performed under general anaesthesia in the United States. There are, moreover, features in the age, geographical and social distribution of the incidence, so unusual as to justify the decision of the Section of Epidemiology to devote an evening to its discussion.

HISTORY

It seems unnecessary to review the history of operative treatment of the tonsil, and I will confine myself to pointing out that while it was natural that, in pre-anæsthetic and pre-Listerian days, the incidence of operation should be very small, it is astonishing to find how recent is the great vogue of the operation. For many years after the introduction of anaesthetic and antisepic surgery the incidence remained low. In 1885 that great physician Goodhart [14] said, “It is comparatively seldom that an operation is necessary, and fortunately so, for parents manifest great repugnance to it. Children grow out of it, and at 14 or 15 years of age the condition ceases to be a disease of any importance.” These words were repeated in several subsequent editions.

In 1888 I went to a preparatory boarding school of 50 boys, and then, in 1890, to a public school of 650 boys. Though, as the son of a doctor and destined for the profession myself, I took some interest in medical matters even then, I cannot recall a single boy in either school who had undergone the operation. Both schools still flourish, but the percentage of tonsillectomized boys is now in both alike about 50%, and, as we shall see later, even this is nowadays a low figure for schools of these types.

Old photographs reveal little difference in appearance between the untonsillectomized fathers and the tonsillectomized sons, and although the latter seem to grow taller and heavier than we did, memory suggests that we were at least as resistant to infection.

EARLY ESTIMATES OF THE NEED FOR OPERATION

It is difficult to estimate the number of operations previous to the introduction of the School Medical Service. Any such estimate is derived either from estimates of the number of children whose tonsils are said to “require immediate operation” or from hospital records.

In 1903 the Report of the Royal Commission on Physical Training (Scotland) gave the age-and-sex grouped results of the examination of 600 Edinburgh and 600 Aberdeen school children, in tables, which showed well the two periods of physiological
J Allison Glover, 1938 Report to Royal Academy of Medicine

10-fold variation in tonsillectomy
8-fold risk of death with surgical treatment

“…these strange bare facts of incidence…”

“… tendency for the operation to be performed for no particular reason and no particular result.”

“…sad to reflect that many of the anesthetic deaths… were due to unnecessary operations.”
**Variation 2009 – 80 Years Later**

Even for some operations whose effectiveness has been questioned, variations in treatment between PCTs are widespread.

The removal of tonsils in children has been queried since the 1930s, yet the rate of tonsillectomies in Coventry PCT in 2009/10 was ten times higher than the rate in Kingston PCT for example.
Meet Jennifer...
JENNIFER’S TONSILS

You are Tracy / Terry Collins, 36 - mother / father of Jennifer, aged 10. You work as a technician at a busy dental practice and rely on your mother for after school care.

Jennifer was doing well at school. However, over the last two years she has had what seem like endless colds and tonsillitis. She has an episode every few months.

She does not sleep well. She has missed a lot of school and you are worried that she will do badly in her tests.

Your mother struggles when she is ill. She also, believes that Jennifer needs to have her tonsils out.

You are not quite so sure. But you are beginning to wonder if your mother isn’t right. You have booked an appointment to discuss your daughter and you are going without her.

When you left Jennifer at your mothers’ place on the way to the doctors, she told you not to take no for an answer.
Decision Quality Measure

- Knowledge
- Readiness to decide “DelibeRATE”
- Preference
- Intention
Decision Quality Measure

Knowledge at diagnosis
N=28

Knowledge at home visit
N=20
DelibeRATE Scale “readiness to decide”

At diagnosis (DQM1)

<table>
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<tr>
<th>Question Number</th>
<th>Know options</th>
<th>Understand options</th>
<th>Aware of pros</th>
<th>Aware of cons</th>
<th>Can judge best</th>
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At home visit (DQM2)

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Strong preference for mastectomy
Leaning towards mastectomy
Not sure
Leaning towards lumpectomy
Strong preference for lumpectomy

Intention at diagnosis (DQM1)

Intention at home visit (DQM2)
“Decision Quality – it’s nothing to do with MAGIC any more – it’s what we do in the breast care team...”

Helen McGarrigle
Breast Care Nurse
Cardiff.
Social Marketing

- Social marketing to patients
- Shift from implementation team to clinical teams
- Clinicians and managers - awareness raising and profile
Three simple questions to increase information about treatment options and patient involvement in healthcare consultations.

Shepherd, HL; Barratt, A; Trevena, LJ; McGeechan, K; Carey, K; Epstein, RM; Butow, PN; Del Mar, CB; Entwistle, V; Tattersall, MHN

Patient Education and Counseling 2011.
Ask three Questions
Ask 3 Questions

Sometimes there will be choices to make about your healthcare. If you are asked to make a choice, make sure you get the answers to these 3 questions:

1. What are my options?
2. What are the possible benefits and risks of those options?
3. How likely are the benefits and risks of each option to occur?

We want to know what’s important to you.
Implementation into practice - Lessons learnt so far

• Needs multi-faceted, multi-level, sustained strategy

• Most important learning to date:
  • Simple tools Option Grids act as catalysts
  • DQM: measurement that has clinical relevance
  • Quality Improvement methods are helpful but not well understood
  • Importance of policy drivers and incentives