IMPLEMENTATION OF SHARED DECISION MAKING IN PRACTICE

Emerging learning from MAGIC, a UK implementation study.
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
Are patients involved?

Source: NHS inpatient surveys

Wanted more involvement in treatment decisions

<table>
<thead>
<tr>
<th>Year</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>2002</td>
<td>46</td>
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<td>2003</td>
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<td>2004</td>
<td>47</td>
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<td>2005</td>
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<td>2007</td>
<td>49</td>
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<td>2008</td>
<td>48</td>
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<td>2009</td>
<td>48</td>
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</table>
So why aren’t we doing it?

• Multiple barriers

  - “We’re doing it already”
  - “It’s too difficult” (time constraints)
  - Accessible knowledge
  - Skills & Experience
  - Decision support for patients / professionals
  - Fit into clinical systems and pathways

• Lack of implementation strategy
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

2009 call for “SDM Design Team”

18 months project: started August 2010
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.
Focusing on implementation

• Evidence-based patient decision support

PLUS

• Social marketing
• Clinical skills development
• Organisation and clinical team engagement
• Measurement and rapid feedback, action learning, quality improvement cycles
• Patient & public engagement

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.
Early learning from MAGIC
Evidence-based decision support

- Timely access for clinicians and patients
  - Internet and intranet
  - Desk folders in primary care
  - Patient access to internet?

- In consultation or outside?
  - Complex PDAs and gist based in-consultation tools

- Fit to clinical pathways
  - Adapt pathway or tools?
Clinical skills development

- Interactive, advanced skills-based

- Eye opening and valued – moving from “we do this already” to “I think we do this, but we could do it better”
  - “I thought I knew a lot about the best ways to communicate during informed consent…this has made me completely re-think…” (Cardiff)
  - 95% of attendees in Newcastle agreed that “I will be able to use what I have learned in this workshop”

- Challenge of getting senior clinicians to attend

- Utilise a range of opportunities

- Role of the model of the consultation
### Standard pathway

Women attend antenatal clinic (ANC) ‘s@ 20 weeks gestation

Review case notes. Discussion with obstetrician

If decision VBAC return to Community Midwife

If decision elective repeat caesarean or uncertain, ANC review @ 36 weeks

### Adapted pathway (women with 1 previous CS)

Information leaflet and adapted ODG sent out @18 weeks

SDM consultation with midwife @ 20 weeks

If uncertain, asked to think further about discussion and further ANC @36 weeks

If decision elective repeat caesarean or uncertain, ANC review @ 36 weeks

**Vaginal birth after previous caesarean section**

Ninety one per cent read the information before attending the clinic and 81% used the adapted Ottawa Decision Guide
Shared decision making: a model for clinical practice
### Option Grid

<table>
<thead>
<tr>
<th>Question</th>
<th>Lumpectomy with Radiotherapy</th>
<th>Mastectomy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Which surgery is best for long term survival?</td>
<td>There is no difference between surgery options.</td>
<td>There is no difference between surgery options.</td>
</tr>
<tr>
<td>What are the chances of cancer coming back?</td>
<td>Breast cancer will come back in the breast in about 10 in 100 women in the 10 years after a lumpectomy.</td>
<td>Breast cancer will come back in the area of the scar in about 5 in 100 women in the 10 years after a mastectomy.</td>
</tr>
<tr>
<td>What is removed?</td>
<td>The cancer lump is removed with a margin of tissue.</td>
<td>The whole breast is removed.</td>
</tr>
<tr>
<td>Will I need more than one operation</td>
<td>Possibly, if cancer cells remain in the breast after the lumpectomy. This can occur in up to 5 in 100 women.</td>
<td>No, unless you choose breast reconstruction.</td>
</tr>
<tr>
<td>How long will it take to recover?</td>
<td>Most women are home 24 hours after surgery</td>
<td>Most women spend a few nights in hospital.</td>
</tr>
<tr>
<td>Will I need radiotherapy?</td>
<td>Yes, for up to 6 weeks after surgery.</td>
<td>Unlikely, radiotherapy is not routine after mastectomy.</td>
</tr>
<tr>
<td>Will I need to have my lymph glands removed?</td>
<td>Some or all of the lymph glands in the armpit are usually removed.</td>
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</tr>
<tr>
<td>Will I need chemotherapy?</td>
<td>Yes, you may be offered chemotherapy as well, usually given after surgery and before radiotherapy.</td>
<td>Yes, you may be offered chemotherapy as well, usually given after surgery and before radiotherapy.</td>
</tr>
<tr>
<td>Will I lose my hair?</td>
<td>Hair loss is common after chemotherapy.</td>
<td>Hair loss is common after chemotherapy.</td>
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<td>Mastectomy</td>
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<td>There is no difference</td>
<td>There is no difference</td>
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<td></td>
<td>between surgery options.</td>
<td>between surgery options.</td>
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<tr>
<td>What are the chances of cancer coming back?</td>
<td>Breast cancer will come</td>
<td>Breast cancer will come</td>
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<td></td>
<td>back in the breast in</td>
<td>back in the area of the scar</td>
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<td>about 10 in 100 women in</td>
<td>in about 5 in 100 women in</td>
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<td>the 10 years after a mastectomy.</td>
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<td>removed with a margin of</td>
<td>removed.</td>
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<td>tissue.</td>
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<td>No, unless you choose</td>
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<td>remain in the breast after</td>
<td>breast reconstruction.</td>
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<td>the lumpectomy. This can</td>
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<td>occur in up to 5 in 100</td>
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<td>women.</td>
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Clinical team engagement

• Leadership and champions
  • Team of champions
  • Learning sets
  • Importance of medical leadership & role of nurse specialists
  • Grand rounds and external expertise

• Transfer of leadership

• Different facilitators for different teams
  • Patent experience – decision quality
  • Support new developments (place of birth)
  • Support for model of delivery (MDT in head and neck cancer)
Social marketing

• Awareness raising or social marketing?
  • Clinicians and managers = awareness raising and profile
  • Shift from implementation team to clinical teams
  • Social marketing to patients
Measurement & rapid feedback

• Action learning model
  • Regular meetings to share good practice and experiences

• Measurement for monitoring, research or QI?
  • Language
  • QI champion
  • Skills – rapid QI/PDSA, early
  • Role of rapid testing locally and ownership
  • PDSA framework
  • Patient experience data a challenge
About this questionnaire
This brief confidential questionnaire will help us find out how well we are doing at involving patients in choices and decisions about their own care. It focuses on how things went in your consultation today. We will repeat the questionnaire regularly to see whether you think we are improving!

Completing the questionnaire
Please complete this voluntary questionnaire after your appointment. Whether you answer the questions or not, this will not affect your care in any way. Once completed, please place in the box marked ‘MAGIC – Strictly Confidential’ at the reception desk or in the waiting area.

Part A. How was your consultation today? (Please only consider today’s appointment)

Please answer the following questions by placing a tick clearly inside one box.

1. In my consultation today, I was told that there was more than one choice for my care and treatment.
   - [ ] Strongly agree
   - [ ] Agree
   - [ ] Neither agree nor disagree
   - [ ] Disagree
   - [ ] Strongly disagree
   - [ ] Does not apply

2. In my consultation today, we talked about the pros and cons of each choice for my care and treatment.

3. In my consultation today, I was asked what was important to me in making a decision on my care and treatment.
   - [ ] Strongly agree
   - [ ] Agree
   - [ ] Neither agree nor disagree
   - [ ] Disagree
   - [ ] Strongly disagree
   - [ ] Does not apply

4. In my consultation today, I was involved in decisions about my care and treatment.
The clinician asked what was important to me

- Practice A: 45 (Strongly agree), 27 (Agree), 4 (Neutral), 3 (Strongly disagree), 3 (Disagree), 2 (Does not apply), 1 (No response)
- Practice B: 138 (Strongly agree), 119 (Agree), 38 (Neutral), 21 (Strongly disagree), 3 (Disagree), 1 (Does not apply), 2 (No response)
- Practice C: 64 (Strongly agree), 73 (Agree), 31 (Neutral), 6 (Strongly disagree), 5 (Disagree), 1 (Does not apply), 2 (No response)
- Practice D: 7 (Strongly agree), 8 (Agree), 2 (Neutral), 1 (Strongly disagree), 1 (Disagree), 1 (Does not apply), 2 (No response)
Sepucha K, Ozanne E, Silvia K, Partridge A, Mulley AG.

An approach to measuring the quality of breast cancer decisions.

**Decision Quality Measure:**
Alignment of informed preference with intention

<table>
<thead>
<tr>
<th>Knowledge Level</th>
<th>Preference Alignment</th>
<th>Intention</th>
<th>Decision Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Knowledge</td>
<td>aligned to</td>
<td>Intention</td>
<td>High</td>
</tr>
<tr>
<td>High Knowledge</td>
<td>not aligned to</td>
<td>Intention</td>
<td>Poor</td>
</tr>
<tr>
<td>Low Knowledge</td>
<td>aligned to</td>
<td>Intention</td>
<td>Poor</td>
</tr>
<tr>
<td>Low Knowledge</td>
<td>not aligned to</td>
<td>Intention</td>
<td>Poor</td>
</tr>
</tbody>
</table>
Decision Quality Measure

Knowledge at diagnosis
N=28

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

At diagnosis (DQM1)

At home visit (DQM2)
Decision Quality Measure

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 our clinic”

Helen McGarrigle
Breast Care Nurse
Cardiff.
Patient and public involvement

• Start early
  • True engagement

• Role of patient narratives/stories

• Social marketing to patients: PPI role
  • Patient materials design and content – MAGIC or SDM
  • Three questions campaign
  • Timing of switch from clinicians to patients
Who decides about your healthcare?
There is often more than one way to improve or treat health problems. We want to help you to understand your choices, and support you to make better decisions about your healthcare.

What is shared decision making?
Shared decision making is a process where you can expect:

- Support to understand the choices available.
- That your clinician will understand what is important to you.
- That your clinical team will work with you to decide which treatment option is best for you.

What is the MAGIC Programme?
Through shared decision making, MAGIC is working to find the best ways of making sure that patients are involved as much as they would like to be in decisions about their healthcare. For more information, ask a member of the team looking after you.

www.magicsdm.co.uk

The MAGIC Programme is funded by the Health Foundation.

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

Three simple questions to increase information about treatment options and patient involvement in healthcare consultations.

In Press 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.
Did you get answers to the 3 questions?

We want to find out how much you were involved in decisions about your care and treatment so we can do a better job for our patients. This survey will take around 3 minutes to complete and is entirely voluntary. Your answers will be completely anonymous. If you need help completing the survey, please ask a receptionist.

Please complete this survey **after your appointment**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Unsure</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Was there a decision to make about your healthcare or treatment?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>For example, did you decide whether or not to have treatment, or did you choose which treatment to have?</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>2. Were you told about your different options?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Were you told about the benefits and risks of each option?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Were you told how likely the benefits and risks are?</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>5. Were you asked about what matters to you?</td>
<td></td>
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</tr>
</tbody>
</table>

Thank you for completing this survey

**Please post back in the ‘MAGIC’ box at reception**
Organisation and policy support

• Mixed response to national policy

• Board level and middle management roles – evidence not “lip service”

• Competing incentives
  • Waiting and treatment time targets
  • What is measured gets done
  • Cost effectiveness and efficiency pressures

• Link to existing initiatives
  • Wales - 1000 lives campaign; Newcastle - CNST
Conclusions

• Implementation hugely challenging!

• Needs multi-faceted strategy with flexibility and fleet of foot

• Most important learning to date:
  • Skills as important (if not more so) than tools
  • Key barriers at clinical team are “we are already doing it” and “It’s too hard (time)”
  • Skills of rapid QI/implementation lacking or underdeveloped
  • Meaningful, immediate measurement and feedback of patient experience and decision quality problematic, but a “big prize”
  • Importance of policy drivers and incentives
THANK YOU

richard.thomson@newcastle.ac.uk
glynelwyn@googlemail.com