Shared Decision Making

HELPING PATIENTS MAKE INFORMED AND PERSONALLY RELEVANT DECISIONS

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Outline

• What is shared decision making?
• When is it appropriate?
• What can commissioners do to promote it?
No Decision About Me Without Me?

"When we want your opinion, we'll give it to you"
Shared Decision Making

A process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient’s informed preferences.
<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Diagnosis</td>
<td>• Experience of illness</td>
</tr>
<tr>
<td>• Disease aetiology</td>
<td>• Social circumstances</td>
</tr>
<tr>
<td>• Prognosis</td>
<td>• Attitude to risk</td>
</tr>
<tr>
<td>• Treatment options</td>
<td>• Values</td>
</tr>
<tr>
<td>• Outcome probabilities</td>
<td>• Preferences</td>
</tr>
</tbody>
</table>
Who should make treatment decisions?

Telephone survey of 8,000 people in 8 countries, Coulter and Magee 2003
NHS Patients’ Experience

Wanted more involvement in treatment decisions

Source: NHS inpatient surveys
The Silent Misdiagnosis

Patients: unaware of treatment or management options and outcomes

Clinicians: unaware of patients’ circumstances and preferences

Poor decision quality
When to Use Shared Decision Making

- Selecting treatments for acute conditions
- Planning care for long term conditions
- Recovery and rehabilitation
- Advance care planning at end of life
Informed Consent: What Patients Need to Know

- What are my options?
- What are the benefits and possible harms?
- How likely are these benefits and harms?
Key Components

1. Reliable, balanced, evidence-based information outlining prevention, treatment, or management options, outcomes and uncertainties

2. Decision support with clinician or health coach to clarify options and preferences

3. System for recording, communicating and implementing patient’s preferences
Patient Decision Aids

Information on.....
• Condition
• Treatment options
• Outcomes with and without treatment
• Uncertainties
• Values clarification
• Balanced
• Evidence-based
### Types of Decision Support

<table>
<thead>
<tr>
<th>Clinical Guidelines</th>
<th>Patient Decision Aids</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Primarily for <strong>doctor</strong></td>
<td>• Primarily for <strong>patient</strong></td>
</tr>
<tr>
<td>• Evidence-based</td>
<td>• Evidence-based</td>
</tr>
<tr>
<td>• Describes likelihood of various outcomes</td>
<td>• Describes likelihood of various outcomes</td>
</tr>
<tr>
<td>• Outlines uncertainties</td>
<td>• Outlines uncertainties</td>
</tr>
<tr>
<td>• <strong>Recommendations based on values of clinical experts</strong></td>
<td>• <strong>Does not make recommendations</strong></td>
</tr>
<tr>
<td>• Assumes doctor makes the decisions</td>
<td>• Assumes shared decision making</td>
</tr>
</tbody>
</table>
Decision Aids: the Evidence

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
Breast Screening: A Difficult Decision

Peace of mind?
Best to catch it early so treatment is successful?
Less risk of dying from breast cancer?

Cancer might not be found?
Extra tests and worry from false alarms?
Unnecessary treatment due to overdiagnosis?
Right Care Patient Decision Aids
http://sdm.rightcare.nhs.uk/pda
Breast cancer surgery
Use this grid to help you and your clinician decide whether to have mastectomy or lumpectomy with radiotherapy.

<table>
<thead>
<tr>
<th>Frequently asked questions</th>
<th>Lumpectomy with Radiotherapy</th>
<th>Mastectomy</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Which surgery is best for long term survival?</strong></td>
<td>There is no difference between surgery options.</td>
<td>There is no difference between surgery options.</td>
</tr>
<tr>
<td><strong>What are the chances of cancer coming back in the breast?</strong></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><strong>What is removed?</strong></td>
<td>The cancer lump is removed with a margin of tissue.</td>
<td>The whole breast is removed.</td>
</tr>
<tr>
<td><strong>Will I need more than one operation on the breast?</strong></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><strong>How long will it take to recover?</strong></td>
<td>Most women are home 24 hours after surgery</td>
<td>Most women are home 2-3 days after surgery.</td>
</tr>
<tr>
<td><strong>Will I need radiotherapy?</strong></td>
<td>Yes, for up to 6 weeks after surgery.</td>
<td>Unlikely, radiotherapy is not routine after mastectomy.</td>
</tr>
<tr>
<td><strong>Will I need to have my lymph glands removed?</strong></td>
<td>Some or all of the lymph glands in the armpit are usually removed.</td>
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</tr>
<tr>
<td><strong>Will I need chemotherapy?</strong></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><strong>Will I lose my hair?</strong></td>
<td>Hair loss is common after chemotherapy.</td>
<td>Hair loss is common after chemotherapy.</td>
</tr>
</tbody>
</table>

More information can be found at [www.brcsex.com](http://www.brcsex.com)
Breast Cancer Decision Explorer
BresDex: www.bresdex.com

Here is a list of issues many women think about when choosing surgery
Click in the box next to the ones that are important to you. You do not have to click in every box

- Avoid looking lop sided
- Avoid mastectomy
- Avoid more unexpected surgery
- Remove the breast
- Less chance of cancer returning
- Avoid radiotherapy
- Smaller scar and less change to breast size
- Keep the breast

Ahmed H et al. BMJ 2012;344:bmj.e3996
Benign Prostatic Hyperplasia (BPH): Treatment Options

- **Surgery**
  - prostatectomy (TURP/TUIP/laparoscopic/stent)

- **Heat treatment**
  - laser, microwave, radiofrequency

- **Medication**
  - alpha blockers/5 alpha reductase inhibitors

- **Lifestyle changes, bladder training**

- **Watchful waiting**
BPH: appraising the options

Improvement in symptoms

- Reductase inhibitor
- Alpha blocker
- Heat treatment
- TURP

Risk of complications
Patient Decision Aid for Menorrhagia

- Three options – drugs, surgery, no treatment
- Decision aid – video + booklet
- Decision coaching
- Evaluated in 3-arm RCT
Decision Aid + Decision Support

- Helped patients form preferences
- Reduced hysterectomy rates
- Increased long-term satisfaction
- Information + preference elicitation was cost-effective

Kennedy et al. JAMA 2002; 288: 2701-8
Decision aid + coaching in gynaecology

Treatment costs ($) over 2 years

- Usual care: 2751
- Decision aid: 2026
- Decision aid + coaching: 1566
Personalised Care Planning for Managing Long-Term Conditions

- Share information
- Jointly develop care plan
- Discuss and agree goals
- Jointly review plan
- Agree follow-up schedule
- Record and share plan
- Agree follow-up schedule
Decision Support

- Clarify problem and goals
- Identify potential solutions
- Provide and discuss information
- Check comprehension and preferences
- Agree actions
- Motivate and encourage
- Implement and support
- Monitor outcomes
Risk Communication: What Works?

- Personalised information
- Quantification
- Balanced framing
- Natural frequencies (AR not RR or NNT)
- Common denominators and time periods
- Pictographs
Pictograph to explain reduction in cardiovascular risk from taking statins in people with a moderate risk of a cardiovascular event (20% over 10 years).

If 100 people each take a statin (such as simvastatin) for 10 years:
- About 5 people will be “saved” from having a cardiovascular event by taking the statin (the yellow faces above)
- About 80 people will not have a cardiovascular event but would not have done so even if they had not taken a statin (the green faces above)
- About 15 people will still have a cardiovascular event (the red faces above), even though they take a statin

Ahmed H et al. BMJ 2012;344:bmj.e3996
Risks for patient with atrial fibrillation before treatment
Risks for patient with atrial fibrillation following treatment with warfarin
Measuring Decision Quality

- **Knowledge**
  - Was the patient informed about the key things a person should know before embarking on a particular test, treatment, care management programme?

- **Match with preferences**
  - Was the decision personalised to reflect the patient’s goals? Did the treatment selected match their preferences?

- **Involvement in process**
  - Did the clinician inform and involve the patient in the decision process?
What are the barriers?

• Time/resources
• Inflexible systems
• Clinical culture
An Implementation Plan

Engage Clinicians
Identify decision points
Encourage Viewing
Provide Support for Clinicians
Map pathways
Distribute PtDAs
Provide Support for Patients
Measure Impact and Provide Feedback
What Can Commissioners Do?

• Map decision points
• Provide training for health professionals
• Promote information prescriptions
  • Information Standard certified
• Encourage use of patient decision aids
  • Detailed, short form
• Offer personal health budgets
• Commission non-traditional services
• Measure decision quality
What are the rewards?

- Better consultations
- Clearer risk communication
- Improved health literacy
- More appropriate evidence-based decisions
- Fewer unwanted treatments
- Improved confidence and self-efficacy
- Improved health behaviours
- Safer care and less litigation
- Greater compliance with ethical standards
- Reduced costs
- Better health outcomes