Engaging patients and citizens

- Strengthening self-care
- Ensuring safer care
- Participating in research
- Building health literacy
- Improving care processes
- Training professionals
- Shaping services
What is Good, Safe Medical Care?

✓ Doing things *right*

✓ Doing the *right thing*
Doing Things Right

• Giving the right dose of the medicine

• Operating on the knee with the problem

• Washing hands to prevent infections

• Removing all the sponges from the surgical patient
Doing the Right Thing

• Not giving a medicine to a patient who, if informed, would not want to take it

• Not doing a screening test on a patient who, if informed, would think the risks outweighed the possible benefits

• Not assuming a patient’s goals, preferences and priorities are the same as yours
Medical Errors

“If operating on the wrong leg is a medical error, what would you call operating on the wrong patient*?”

* A patient who would say NO to surgery (or other type of treatment) if they understood the pros and cons

Jack Wennberg, epidemiologist, Dartmouth College NH
<table>
<thead>
<tr>
<th>Condition: Goal</th>
<th>Pat</th>
<th>Prov</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep your breast?</td>
<td></td>
<td>71%</td>
<td></td>
</tr>
<tr>
<td>Live as long as possible?</td>
<td></td>
<td>96%</td>
<td></td>
</tr>
<tr>
<td>Look natural without clothes</td>
<td></td>
<td>80%</td>
<td></td>
</tr>
<tr>
<td>Avoid using prosthesis</td>
<td></td>
<td>0%</td>
<td></td>
</tr>
</tbody>
</table>

### Goals and Concerns for Breast Cancer Decisions

<table>
<thead>
<tr>
<th>Condition: Goal</th>
<th>Pat</th>
<th>Prov</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep your breast?</td>
<td>7%</td>
<td>71%</td>
<td>P&lt;0.01</td>
</tr>
<tr>
<td>Live as long as possible?</td>
<td>59%</td>
<td>96%</td>
<td>P=0.01</td>
</tr>
<tr>
<td>Look natural without clothes</td>
<td>33%</td>
<td>80%</td>
<td>P=0.05</td>
</tr>
<tr>
<td>Avoid using prosthesis</td>
<td>33%</td>
<td>0%</td>
<td>P&lt;0.01</td>
</tr>
</tbody>
</table>
The Silent Misdiagnosis

Patients: unaware of treatment or management options and outcomes

Clinicians: unaware of patients’ circumstances and preferences

Poor decision quality

Mulley et al, King’s Fund, 2012
The Silent Misdiagnosis

“Many doctors aspire to excellence in diagnosing disease. Far fewer, unfortunately, aspire to the same standards of excellence in diagnosing what patients want.”

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?
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.
## Sharing Expertise

<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>Management options</td>
<td>Values and preferences</td>
</tr>
<tr>
<td>Outcome probabilities</td>
<td>Goals</td>
</tr>
</tbody>
</table>
Personal Care Planning

One-time Decisions for Tests or Treatments

Chronic Care Management Decisions

Wellness and Health Promotion Decisions

Shared Decision Making
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, preferences, goals and action plan (personalised care planning)

3. System for recording, communicating and implementing patient’s preferences
Information About Treatments is Often Unbalanced
Evidence-Based Patient Decision Aid
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
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.

<table>
<thead>
<tr>
<th>Issue</th>
<th>Info</th>
<th>Selected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid looking lop sided</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoid mastectomy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoid more unexpected surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remove the breast</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less chance of cancer returning</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Avoid radiotherapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smaller scar and less change to breast size</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keep the breast</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ahmed H et al. BMJ 2012;344:bmj.e3996
BPH: Treatment Options

- Surgery: prostatectomy (open/TURP)
- Heat: laser, microwave, radiofrequency
- Medication: alpha blockers/reductase inhibitors
- Plant extracts
- Watchful waiting
BPH: appraising the options

Improvement in symptoms

- Reductase inhibitor
- Alpha blocker
- Heat treatment
- TURP

Risk of complications
THINKING ABOUT TRADE-OFFS

How troublesome is urinary dysfunction?

How troublesome will retrograde ejaculation be?
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
Menorrhagia Decision Aid + Decision Support

Treatment costs ($) over 2 years

- Usual care: $2751
- Decision aid: $2026
- Decision aid + coaching: $1566
In 118 trials involving 35,163 participants, 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, 2013
Managing Long Term Conditions

Professional care – 5 hours per year

Self-care – 8,755 hours per year
Personal Care Planning

Personalised care planning aims to ensure that individuals’ values and concerns shape the way in which they are supported to live with and self-manage their long-term condition(s)
Care Planning Consultation

- Patient’s issues
- Professional’s issues

- Information gathering
- Information sharing
- Goal setting and action planning
- Agreed and shared care plan
Engaged, informed patients

Organisational processes

Responsive commissioning

HCPs committed to partnership working

Personalised care planning

Coulter, Roberts, Dixon: Delivering better services for people with long-term conditions – building the House of Care, King’s Fund, October 2013
Patient and provider working together to co-produce health

Information sharing

Goal setting, action planning

Coordinated treatment/care

Shared records

Follow-up and review

Supporting behaviour change

Patient and provider working together to co-produce health

Information sharing

Goal setting, action planning

Coordinated treatment/care

Shared records

Follow-up and review

Supporting behaviour change
Effects of Personal Care Planning

• Physical health: blood glucose control improved
• Psychological health: depression symptoms improved
• Self-management capabilities: self-efficacy improved
• No evidence of adverse effects

Coulter et al. Systematic review of 19 RCTS
What We Have Learnt

Traditional practice styles....

- Create dependency
- Discourage self-care
- Ignore preferences
- Undermine confidence
- Do not encourage healthy behaviours
- Lead to fragmented care
Informed, Empowered Patients

Have the knowledge, skills and confidence to manage their own health and healthcare,

And they……

• Make healthy lifestyle choices
• Make informed and personally relevant decisions about their treatment and care
• Adhere to treatment regimes
• Experience fewer adverse events
• Use less costly healthcare

Health Affairs Feb 2013