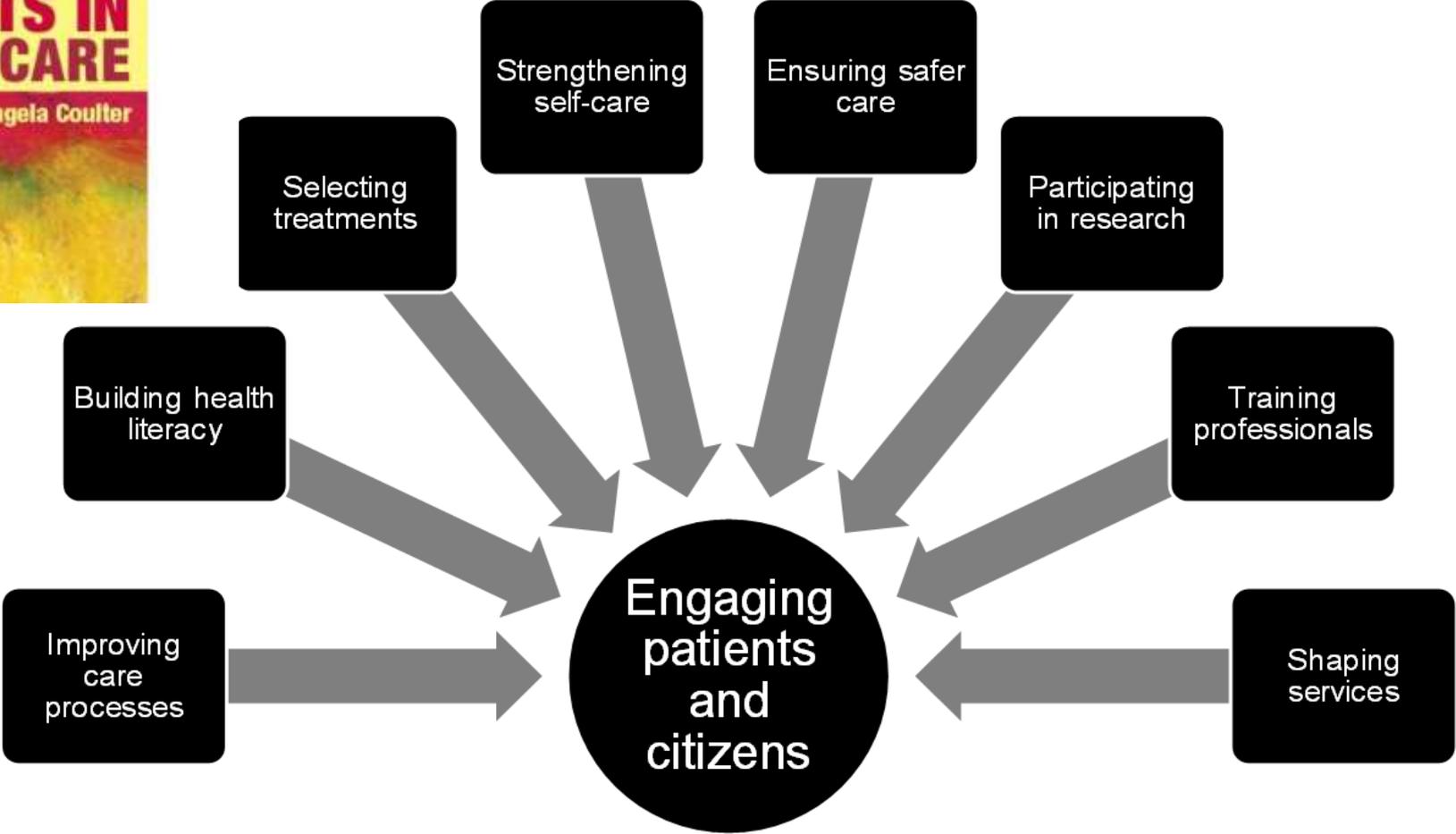
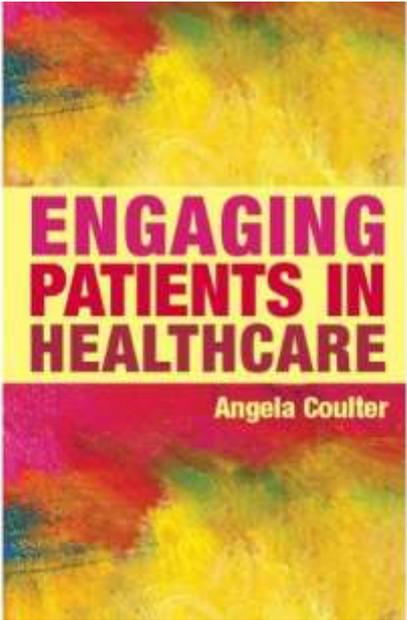
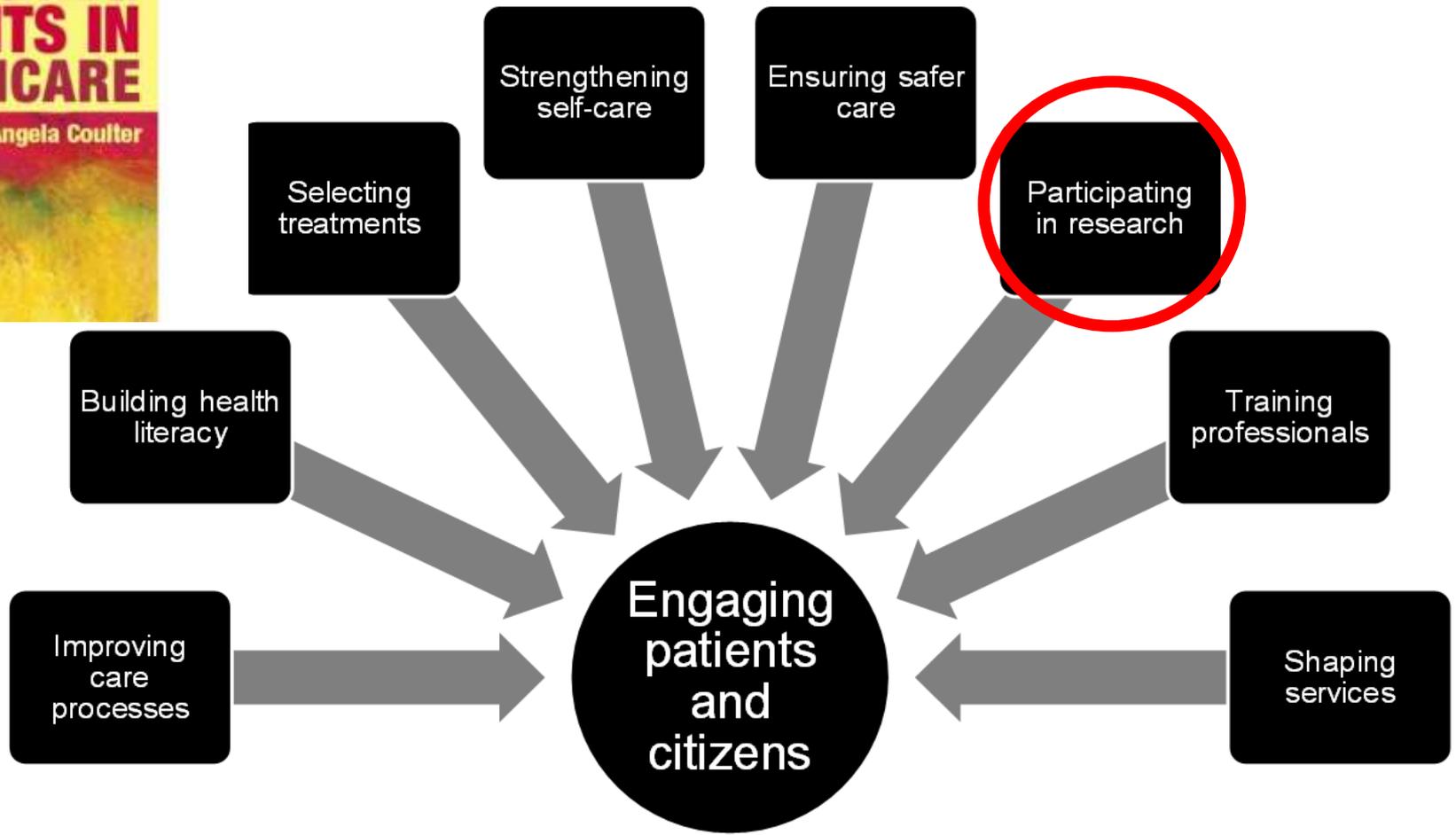
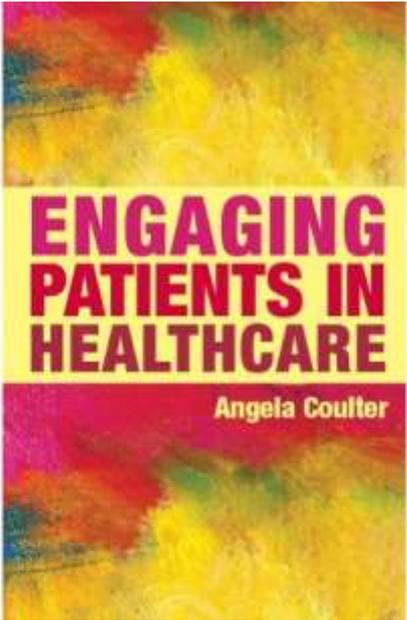


Patient and Public Involvement in Health Research

An introduction

Angela Coulter
HSRU, University of Oxford
Informed Medical Decisions Foundation
November 2014



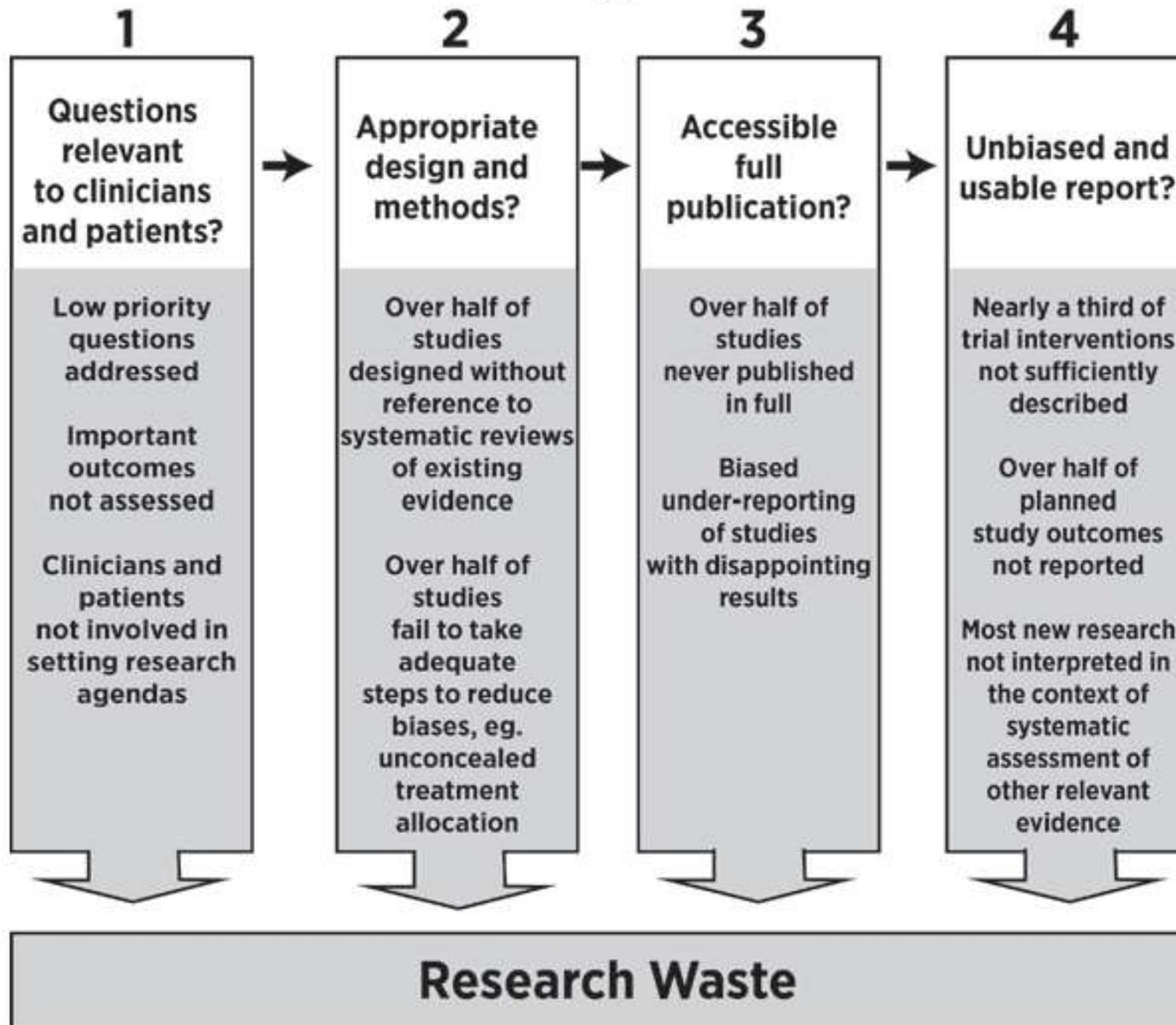


Patients' Research Roles

- Participating in studies
- Designing studies
- Specifying research questions
- Gathering and analysing data
- Supporting and funding research
- Ensuring accountability in research
- Using research findings



Waste at four stages of research





Research participants

NOT subjects!



Helping to Design Studies

- Specifying research questions
- Selecting outcome measures
- Advising on ethics and recruitment
- Writing plain language summaries



Goals and Concerns for Breast Cancer Decisions

Condition: Goal	Pat	Prov	p
Keep your breast?		71%	
Live as long as possible?		96%	
Look natural without clothes		80%	
Avoid using prosthesis		0%	



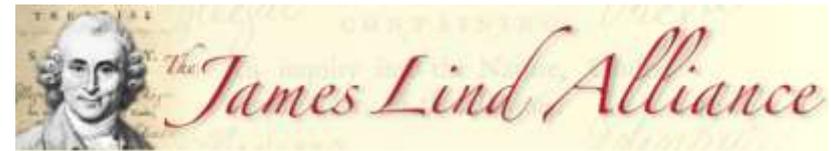
Goals and Concerns for Breast Cancer Decisions

Condition: Goal	Pat	Prov	p
Keep your breast?	7%	71%	P<0.01
Live as long as possible?	59%	96%	P=0.01
Look natural without clothes	33%	80%	P=0.05
Avoid using prosthesis	33%	0%	P<0.01



Ensuring Relevance

- Review evidence
- Identify uncertainties
- Determine priorities
- Commission studies



Priority-Setting Partnerships:

James Lind Alliance Top 6 for Schizophrenia

1. What is the best way to treat people with schizophrenia that is unresponsive to treatment?
2. What training is needed to recognize the early signs of recurrence?
3. Should there be compulsory community outpatient treatment for people with severe mental disorders?
4. How can sexual dysfunction due to anti-psychotic drug therapy be managed?
5. What are the benefits of supported employment for people with schizophrenia?
6. Do the adverse effects of antipsychotic drugs outweigh the benefits?



Gathering Data



- Peer interviewers may be able to collect richer data
- Training, support and supervision required



Communicating Research Findings

- Most research would be impossible without patients
- Their involvement can improve the quality and relevance of research
- Yet they aren't seen as a primary audience for research findings



Using Research Findings

- Understanding treatment options and outcomes
- Communicating risk
- Shared decision making
- Informed consent



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.



Personal Care Planning

One-time
Decisions for Tests
or Treatments

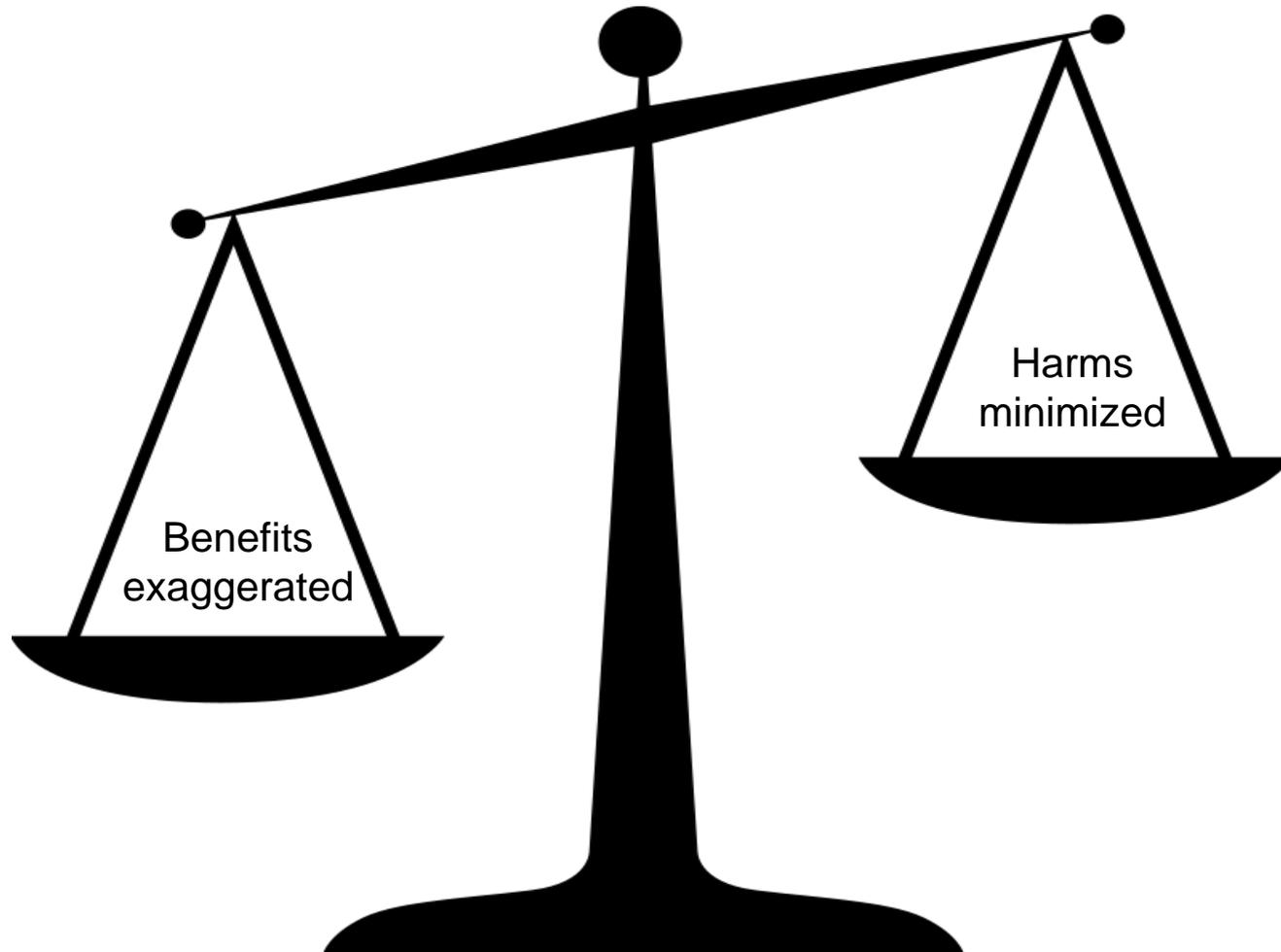
Chronic Care
Management
Decisions

Shared
Decision
Making

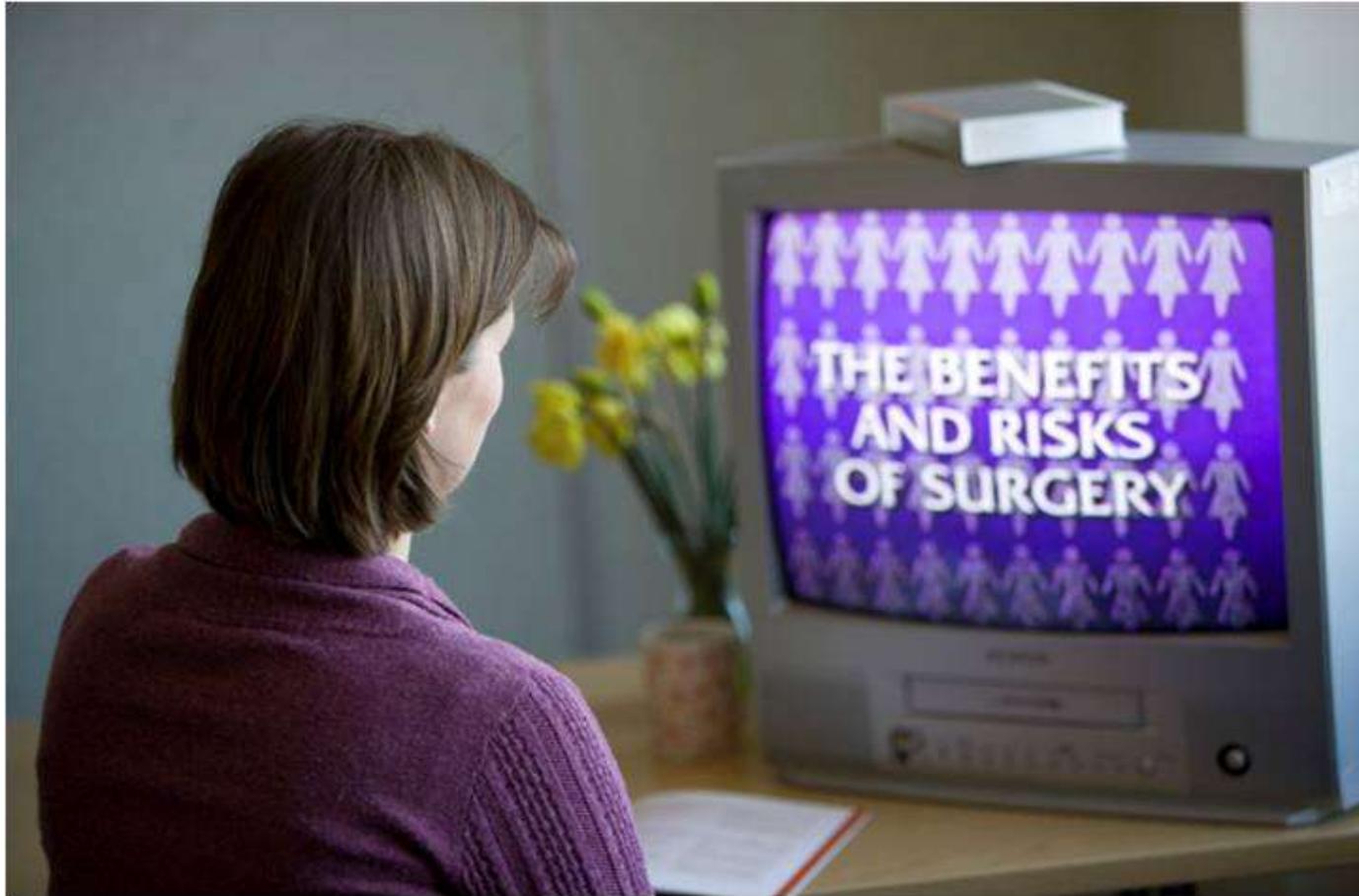
Wellness and
Health Promotion
Decisions



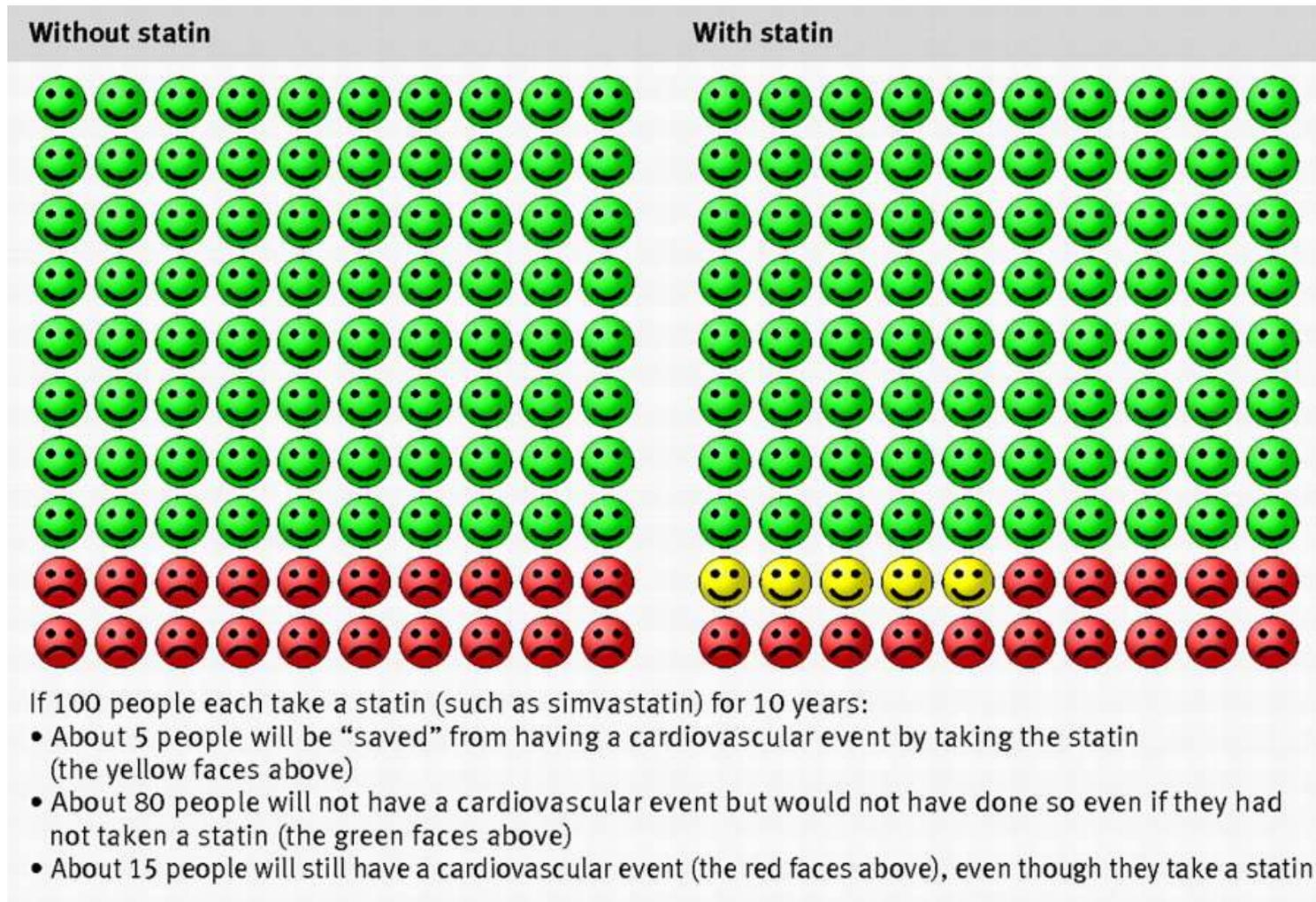
Information About Treatments is Often Unbalanced



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).



Ahmed H et al. *BMJ* 2012;344:bmj.e3996

BMJ

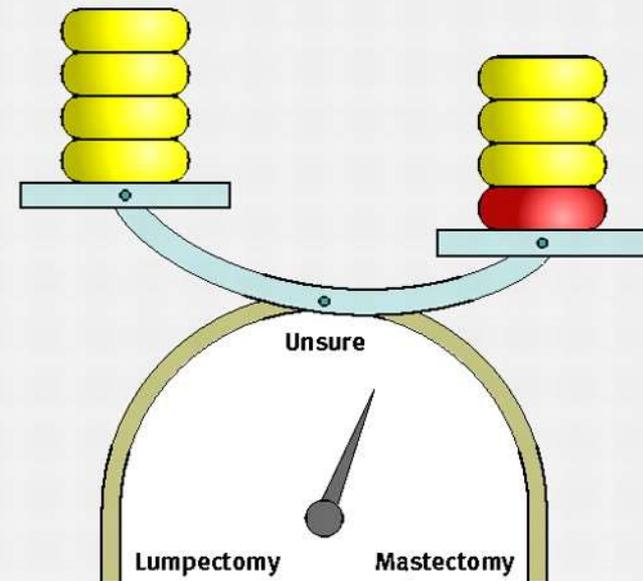


Breast Cancer Decision Explorer (BresDex; www.bresdex.com).

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	info	<input type="checkbox"/>
Avoid mastectomy	info	<input type="checkbox"/>
Avoid more unexpected surgery	info	<input type="checkbox"/>
Remove the breast	info	<input type="checkbox"/>
Less chance of cancer returning	info	<input checked="" type="checkbox"/>
Avoid radiotherapy	info	<input type="checkbox"/>
Smaller scar and less change to breast size	info	<input type="checkbox"/>
Keep the breast	info	<input type="checkbox"/>



Reset

Next >

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

BMJ

Decision Aids: the Evidence

- 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



Conclusions

- Most biomedical research would be impossible without patient participation or public funding.
- It is too important to leave to researchers alone.
- Patients have an important role to play in improving research quality and relevance.
- Patients and public are the intended beneficiaries of research, so the results must be communicated to them.

