



How to measure patient empowerment

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The GROWTH INDUSTRY OF
THE NEXT MILLENNIUM:

HMO DEPOT
DO-IT-YOURSELF HEALTH CARE!

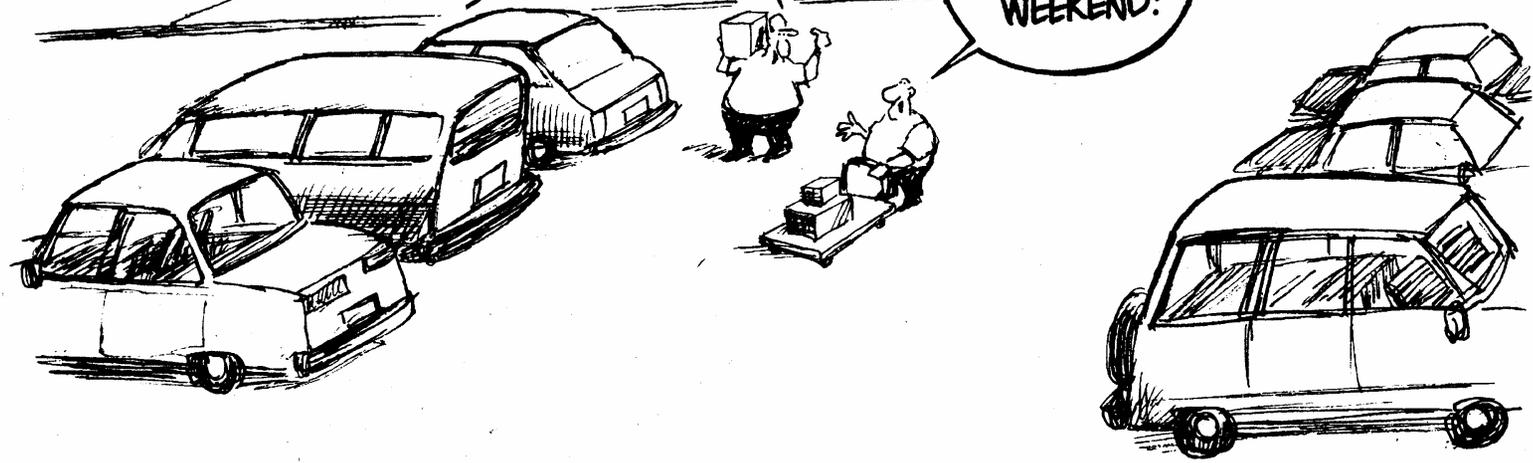
SALE
SURGICAL
SUPPLIES

TV's
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002

HOW-TO
BOOKS
LARGEST
SELECTION!

I PICKED UP
EVERYTHING I
NEED TO DO
MY OWN
APPENDECTOMY!

...I'M PUTTIN'
IN A NEW
HIP THIS
WEEKEND!





Aims

At the end of this session the participant will be able to:

- discuss the diverse concepts of patient empowerment
- outline different reasons to measure patient empowerment
- identify methods of measuring patient empowerment
- consider ways in which the results of patient empowerment research can be used in PHC practice



Summary



- Patient empowerment and patient enablement
- Elements of empowerment
- Levels of empowerment
- Measuring patient empowerment
- Research on patient empowerment

● ● ● | Patient empowerment and patient enablement





Patient Independence

Patient Autonomy / Self-determination

Definition from ethics - refers to the capability and right of patients to control the course of their own medical treatment and participate in the treatment decision-making process without their health care provider trying to influence the decision.



Patient Independence

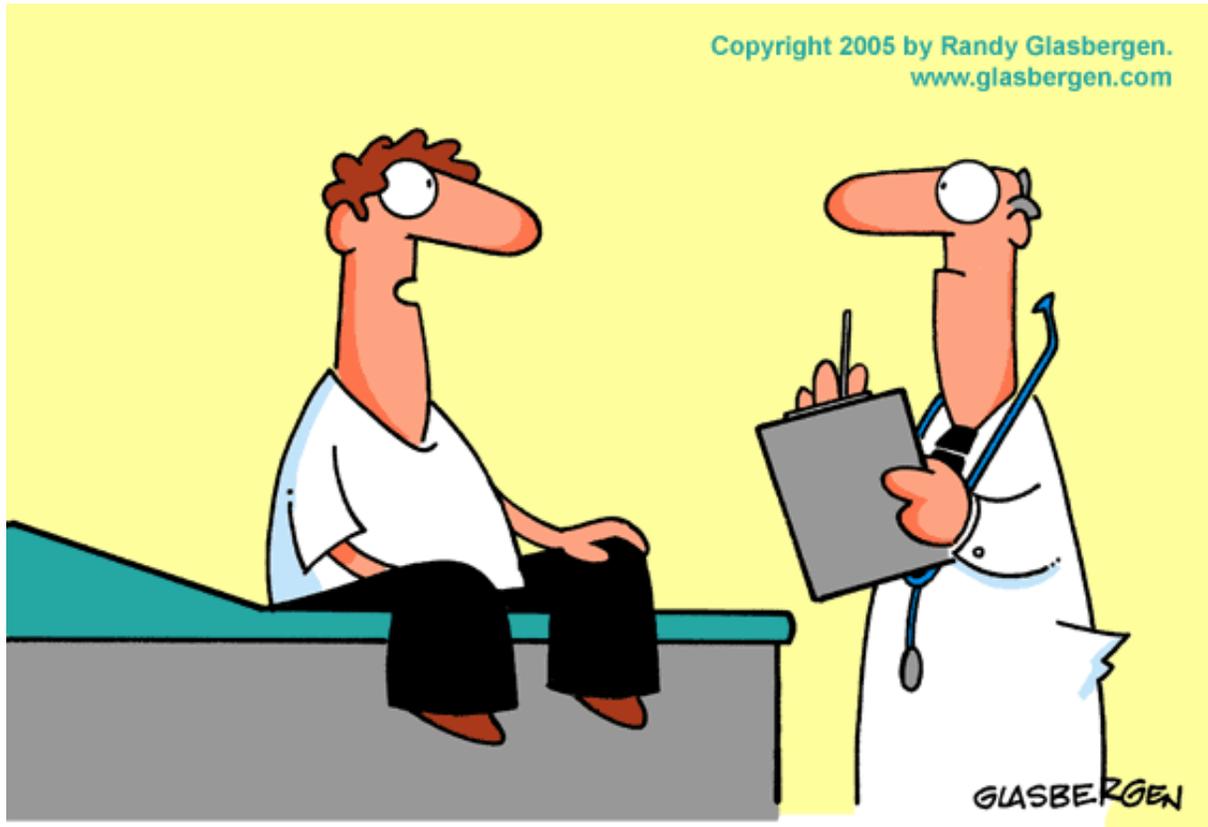
- Deciding when to or not to see a doctor
- Using CAM
- Choosing a physician
- Seeking a second opinion
- Deciding to accept / reject a treatment
- Self-medication
- OTC medication

- Informed choice
- The expert patient





Patient Independence



**“I already diagnosed myself on the Internet.
I’m only here for a second opinion.”**



Patient Enablement

- It describes the effect of the clinical encounter to a patient's ability to cope with and understand his/her illness
- Encouraging and enabling the patient to realize his/her autonomy.





Patient Enablement

- Enablement is conceptualised as an indicator of the self-efficacy benefits of consulting a GP, and is expected to be associated with behaviours like treatment adherence and self-care.
- This is in contrast to satisfaction, which is conceived as a consultation outcome in and of itself.

The impact of general practitioners' patient-centredness on patients' post-consultation satisfaction and enablement. (Mead et al. 2002)

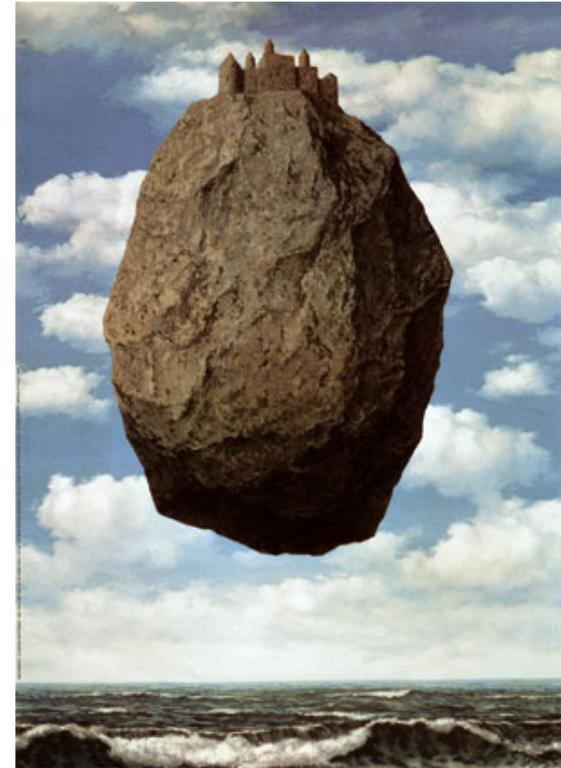


Patient Empowerment

Different definitions

- From social sciences
- From medicine

- Individual
- Group





Patient Empowerment

- It is a multi-dimensional social process that helps people gain control over their own lives.
- It is a process that fosters power in people, for use in their own lives, their communities, and in their society, by acting on issues that they define as important.



Patient Empowerment

Empowerment is multi-dimensional, social, and a process.

- Multi-dimensional
 - it occurs within sociological, psychological, economic, and other dimensions.
 - It also occurs at various levels, such as individual, group, and community.
- It is a social process, since it occurs in relationship to others.
- It is a process that is similar to a path or journey, one that develops as we work through it. The individual and community are fundamentally connected.



Elements of empowerment

1. Having decision-making power
2. Having access to information and resources
3. Having a range of options from which to make choices
4. Assertiveness.
5. A feeling that the individual can make a difference



Elements of empowerment

6. Learning to think critically; unlearning the conditioning; seeing things differently
7. Learning about and expressing anger.
8. Not feeling alone; feeling part of a group.
9. Understanding that people have rights.
10. Effecting change in one's life and one's community.



Elements of empowerment

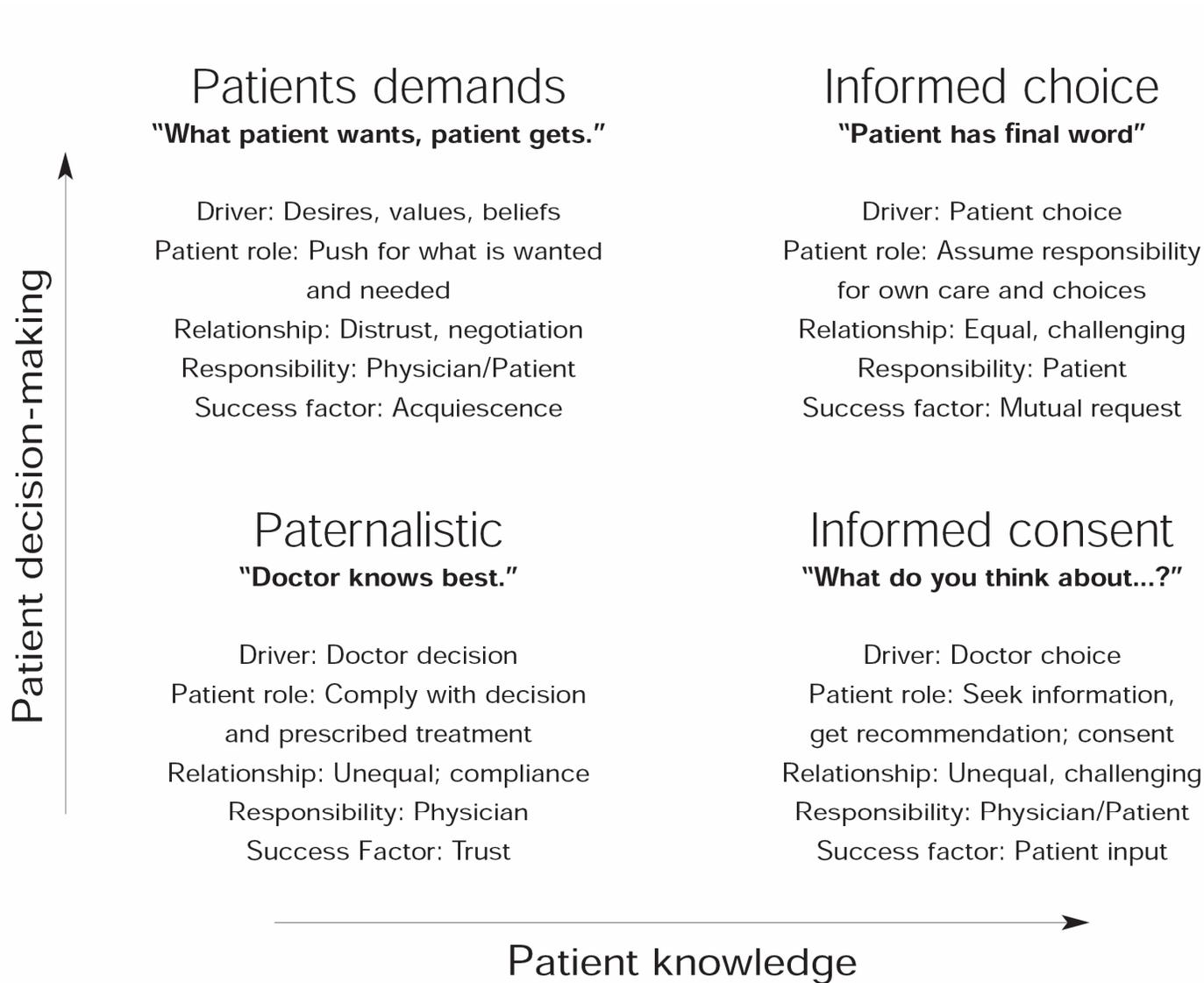
11. Learning skills that the individual defines as important.
12. Changing others' perceptions of one's competency and capacity to act.
13. Coming out of the closet.
14. Growth and change that is never ending and self-initiated.
15. Increasing one's positive self-image and overcoming stigma.

Levels of individual empowerment

- Paternalistic
- Patients demands
- Informed consent
- Informed choice



Levels of individual empowerment

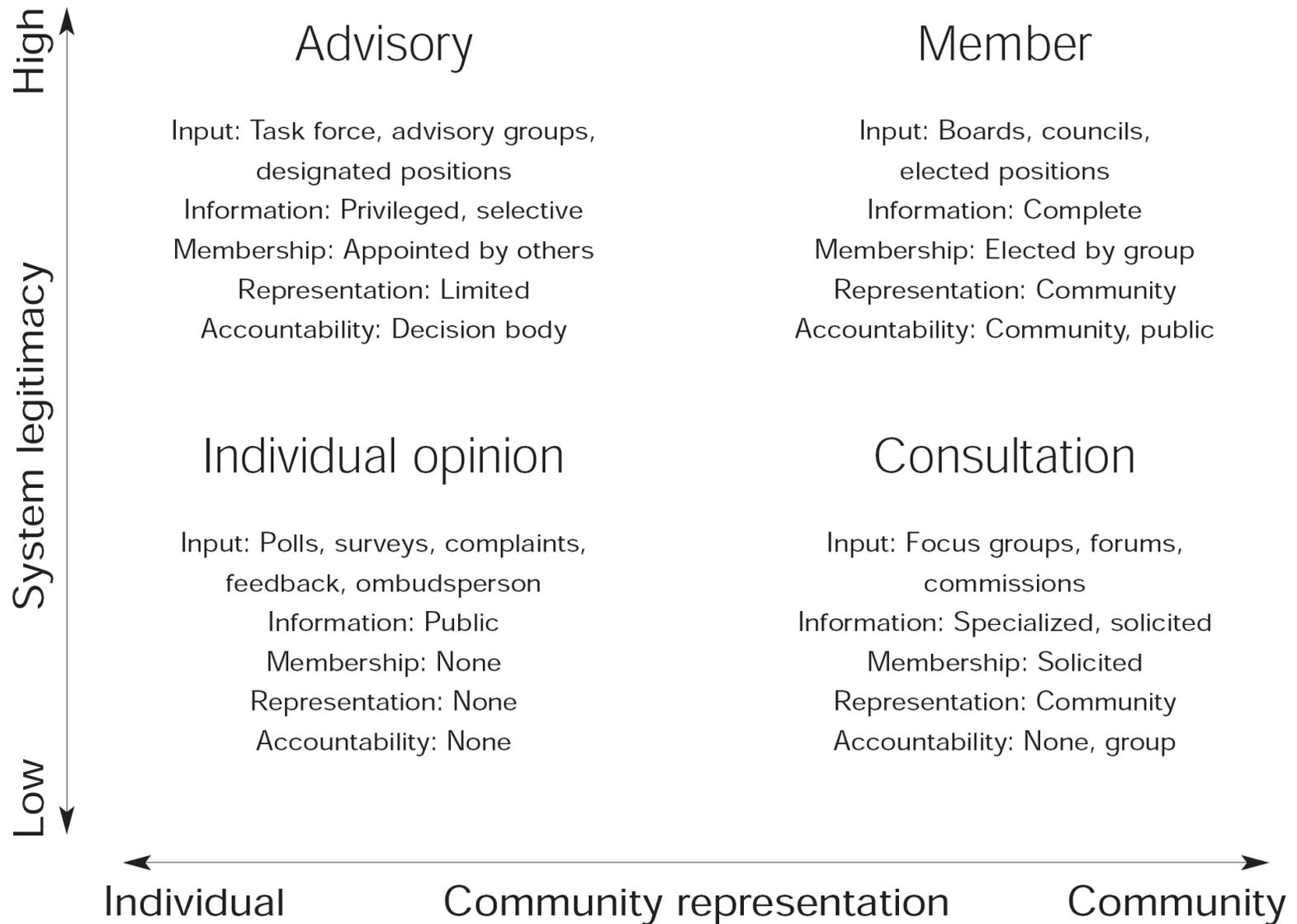




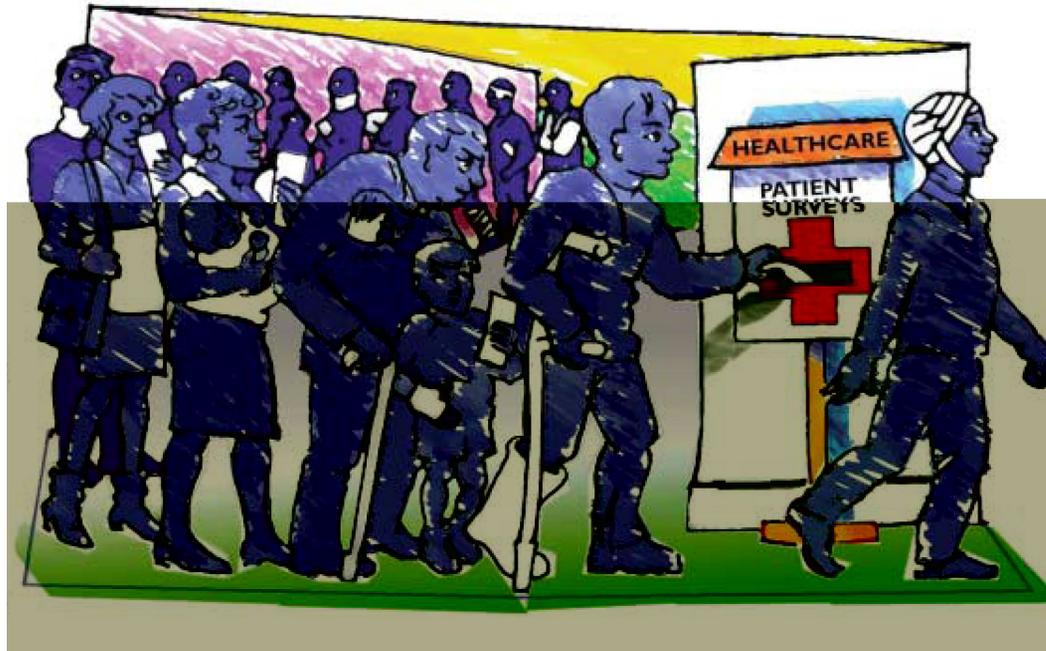
Patient Empowerment

- There is an important difference between information and knowledge
- Empowerment involves the ability to translate information into meaningful knowledge
 - There is a difference between knowledge and the right to make decisions.

Levels of group empowerment

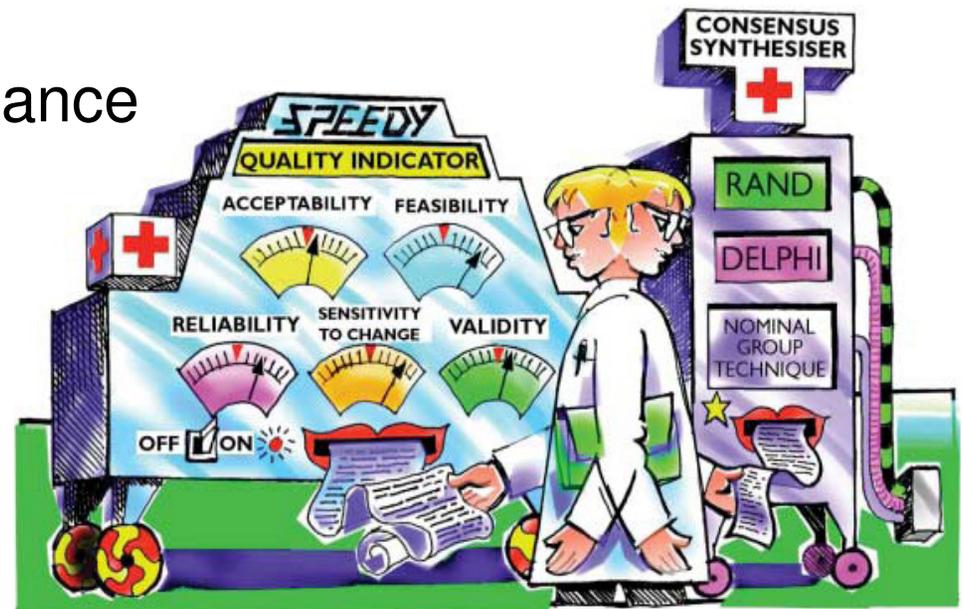


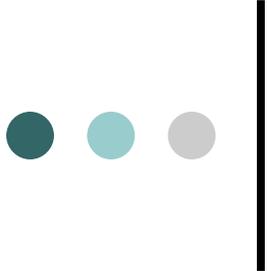
Measuring patient empowerment



Why measuring?

- Ethical reasons
- The importance of the views of users in developing services
- Contractual / payment system reasons
 - Audit
 - Clinical governance





Objectives of patient involvement and relevant measures

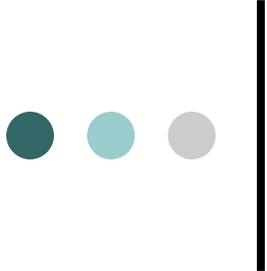
Objectives	Relevant measures
Adhere to ethical principles	Assess the impact of the processes of involvement at different levels (service design, clinical interactions, feedback systems) with criteria derived from ethical principles
Meet patients' preferences	Same as above, but with patient-based criteria
Provide improved care process	Assess doctor-patient communication, medical care, organisation of care, etc.
Provide improved patient outcomes	Assess patient compliance, health status, anxiety, coping, satisfaction with care, etc.
Achieve political or strategic aims	Assess the position on healthcare market, democratic organisation, etc.

Research on patients' views in the evaluation and improvement of quality of care. (Wensing, Elwyn, 2002)



What to measure?

- Patient's views on the quality of health care
 - Measures of preferences,
 - Evaluations by users
 - Reports of health care
- Patient involvement and satisfaction
- Patients' views on the doctors' performance



Classification of measures of patients' views

	Reports	Ratings
Health status	Functional status measures, measures for disability and handicap; measures of beliefs related to health status (e.g. health locus of control)	Quality of life measures, measures for coping with health problems
Health care	Reports on the use of health care, health care received, and treatment adherence; measures of beliefs related to health care (e.g. efficacy of care providers)	Expectations, needs, preferences, priorities, attitudes, evaluations, complaints and satisfaction related to health care

Research on patients' views in the evaluation and improvement of quality of care. (Wensing, Elwyn, 2002)



What to measure?

Patient's views on the quality of health care

- **Preferences**
- **Evaluations**
- **Reports of health care**



What to measure?

Patient's views on the quality of health care

- **Preferences** are ideas about what should occur in healthcare systems.
 - Preference is often used to refer to individual patients' views about their clinical treatment,
 - The term priorities is used to describe the preferences of a population

Methods for incorporating patients' views in health care (Wensing, Elwyn, 2003)



How to measure?

Preferences

- Qualitative research methods
 - individual interviews
 - focus groups
- Quantitative methods
 - surveys
 - consensus methods
 - Delphi
 - nominal group techniques



*Methods for incorporating patients' views
in health care (Wensing, Elwyn, 2003)*



How to measure?

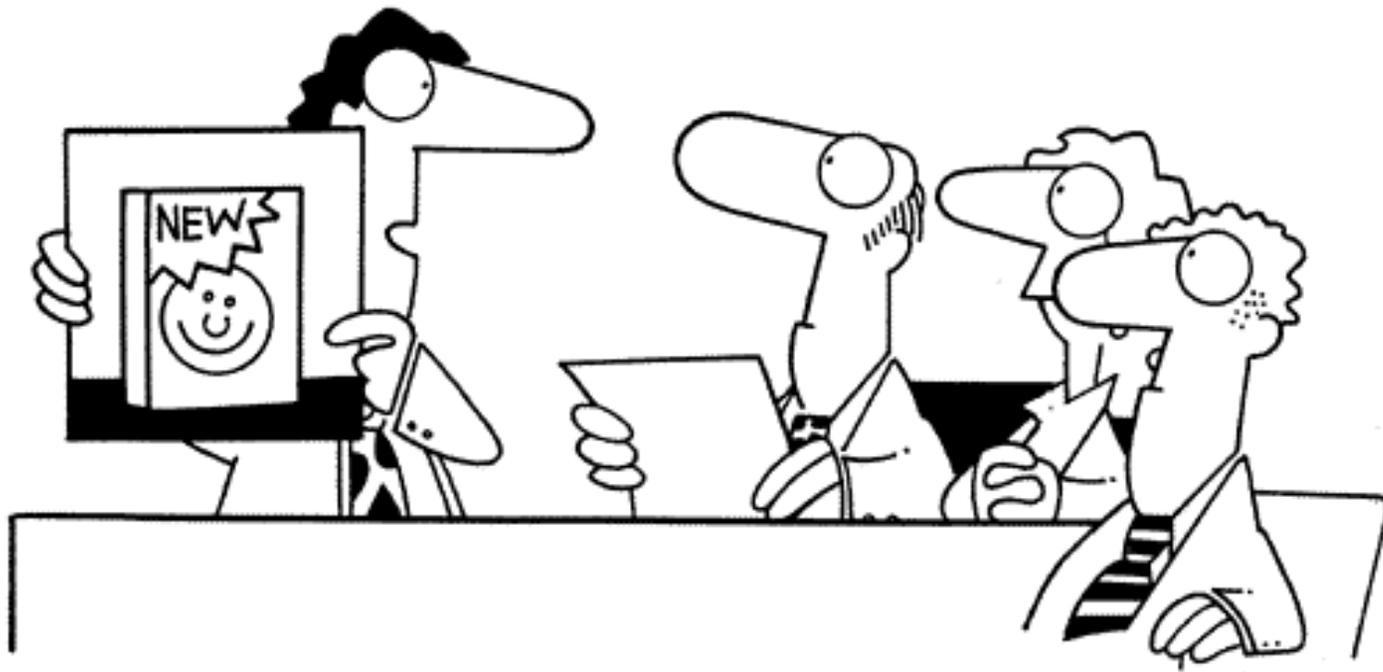
Preferences

- Literature on preferences spans a wide range of disciplines including medicine, epidemiology, ethics, psychology, sociology, economics and policy areas
- The knowledge base in this area of work is very diffuse
- It is difficult for those with unidisciplinary approaches to become aware of all relevant research.

*Methods for incorporating patients' views
in health care (Wensing, Elwyn, 2003)*



Preferences



**“Our new product has no fat, no cholesterol,
no calories, no sugar, no salt and no preservatives.
The box is empty, but it has exactly what everyone wants!”**



What to measure?

Patient's views on the quality of health care

- **Evaluations** are patients reactions to their experience of health care
 - for example, whether the process or outcome of their care was good or bad



How to measure?

Evaluations

- Written questionnaires (structured questions / rating scales)
 - both preferences and experiences should be measured
 - no validated framework for deriving evaluations from preferences and experiences
- Qualitative methods
 - data analysis of qualitative material is time consuming
 - the reliability and validity have not been assessed

*Methods for incorporating patients' views
in health care (Wensing, Elwyn, 2003)*



What to measure?

Patient's views on the quality of health care

- **Reports** of health care represent objective observations of organisation or process of care by patients, regardless of their preferences or evaluations.
 - patients can register how long they had to wait in the waiting room, irrespective of whether this was too long



How to measure?

Patients' reports of health care

- Represent objective observations of organisation or process of care by patients
- Can be used for quality improvement

Use of patients' views for quality improvement

- Provision of data to those who seek health care:
 - Health education
 - Internet communication
 - Public reports
- Eliciting patient preferences in episodes of care:
 - Needs assessment
 - Tailored patient education
 - Shared decision making
 - Patient-held records
- Patients' feedback on medical care:
 - Written surveys
 - Complaint procedures
 - Patient participation groups
- Patient involvement in healthcare systems:
 - Assessment of priorities
 - Involvement in guidelines
 - Patient organisations



Research on patients' views in the evaluation and improvement of quality of care. (Wensing, Elwyn, 2002)



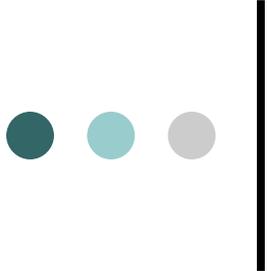
Patient involvement and satisfaction

- patient surveys
- patients' feedback on individual doctors



What are we measuring?

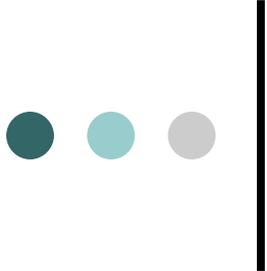
- communication skills?
- technical skills?



Patients' views on the doctors' performance

1. A cross sectional population based study using the general practice assessment survey in 18 general practices in south east England; *for an overall assessment both patient based and records based measures are required.*

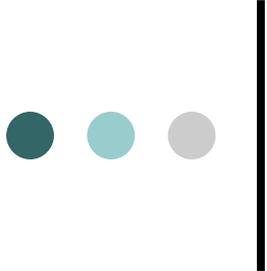
Rao, Clarke, et al. Patients' own assessments of quality of primary care compared with objective records based measures of technical quality of care: cross sectional study. BMJ. 2006



Patients' views on the doctors' performance

2. An internationally-validated questionnaire was distributed to and completed by patients in 10 European countries; *patients in Europe are positive about general practice but improvements in practice management in some countries are requested.*

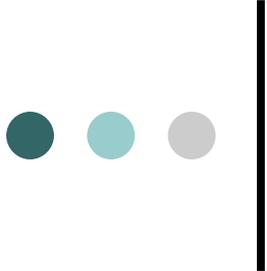
Grol, Wensing, Mainz et al. Patients in Europe evaluate general practice care: an international comparison. Br J Gen Pract. 2000



Patients' views on the doctors' performance

3. A written survey in general practices in Europe; *the study provides information on what patients expect of and value in general practice care.*

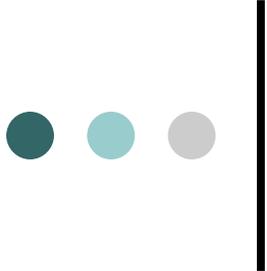
Grol R, Wensing M, Mainz J, et al. Patients' priorities with respect to general practice care: an international comparison. Family Pract 1999



Patients' views on the doctors' performance

4. An extensive literature review was conducted to explore presumptions and definitions reported by previous studies; *what the patient hopes to gain from the consultation was incorporated, as opposed to their 'expectations of the most likely outcome'*

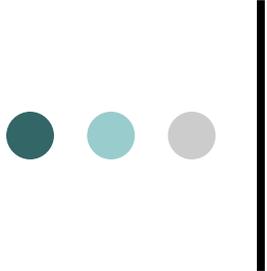
Thorsen H, Witt K, Hollnagel H, Malterud K. The purpose of the general practice consultation from the patient's perspective-theoretical aspects. Fam. Pract. 2001



Patients' views on the doctors' performance

5. A sensitivity study, using generalisibility theory and real data from surveys of patients with chronic illness from 23 GP's in The Netherlands; *surveys of patients can only provide reliable information if the samples of questions and patients are large enough.*

Wensing M, Van der Vleuten C, Grol R, et al. The reliability of patients' judgements of general practice care: how many questions and patients are needed? Quality in Health Care 1997



Patients' views on the doctors' performance

Top ten of priorities of patients in Europe with respect to general practice care

1. enough time to listen, talk and explain
2. quick service
3. confidentiality
4. GP should tell me all I want to know
5. freedom to tell the doctor about my problems.
6. appointment at short notice.
7. up-to-date GP.
8. prevention
9. critical evaluation of the usefulness of medicine and advice
10. explain the purpose of tests and treatment

Patients' priorities with respect to general practice care: an international comparison. (Grol et al, 1999)



Measuring Enablement

- **The Patient Enablement Instrument (PEI)** - the Objective was to compare the Patient Enablement Instrument (PEI) against two established satisfaction measures (MISS) and (CSQ), to test whether enablement and satisfaction are related or separate concepts and to assess whether the internal consistency of the PEI might be enhanced by the inclusion of items from the satisfaction instruments. *The study shows that 'enablement' is a primary care outcome measure which is related to but is different from general satisfaction.*

A comparison of a Patient Enablement Instrument (PEI) against two established satisfaction scales as an outcome measure of primary care consultations. (Howie et al, 1998)



The Patient Enablement Instrument (PEI)

As a result of your visit to the doctor today, do you feel you are...	MUCH BETTER	BETTER	SAME OR LESS	NOT APPLICABLE
able to cope with life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
able to understand your illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
able to cope with your illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
able to keep yourself healthy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	MUCH MORE	MORE	SAME OR LESS	NOT APPLICABLE
confident about your health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
able to help yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Scoring of the PEI

“same or less” – score 0

“better” or “more” – score 1

“much better” or “much more” – score 2

A comparison of a Patient Enablement Instrument (PEI) against two established satisfaction scales as an outcome measure of primary care consultations. (Howie et al, 1998)



Research problems

- Methods to include patients' views must be shown to affect the processes and outcomes of health care
- Possible negative consequences should also be considered



Instrument validation

- Measures of patients' views should be assessed for validity by rigorous qualitative studies
- The instrument used should be compared with a criterion measure - that is, a measure with established validity.
- Qualitative studies are particularly suitable for this purpose.
- **Europep**, an international instrument for obtaining patients' evaluations of general practice care, was based on systematic literature studies and qualitative and quantitative studies of patients' priorities



Sampling

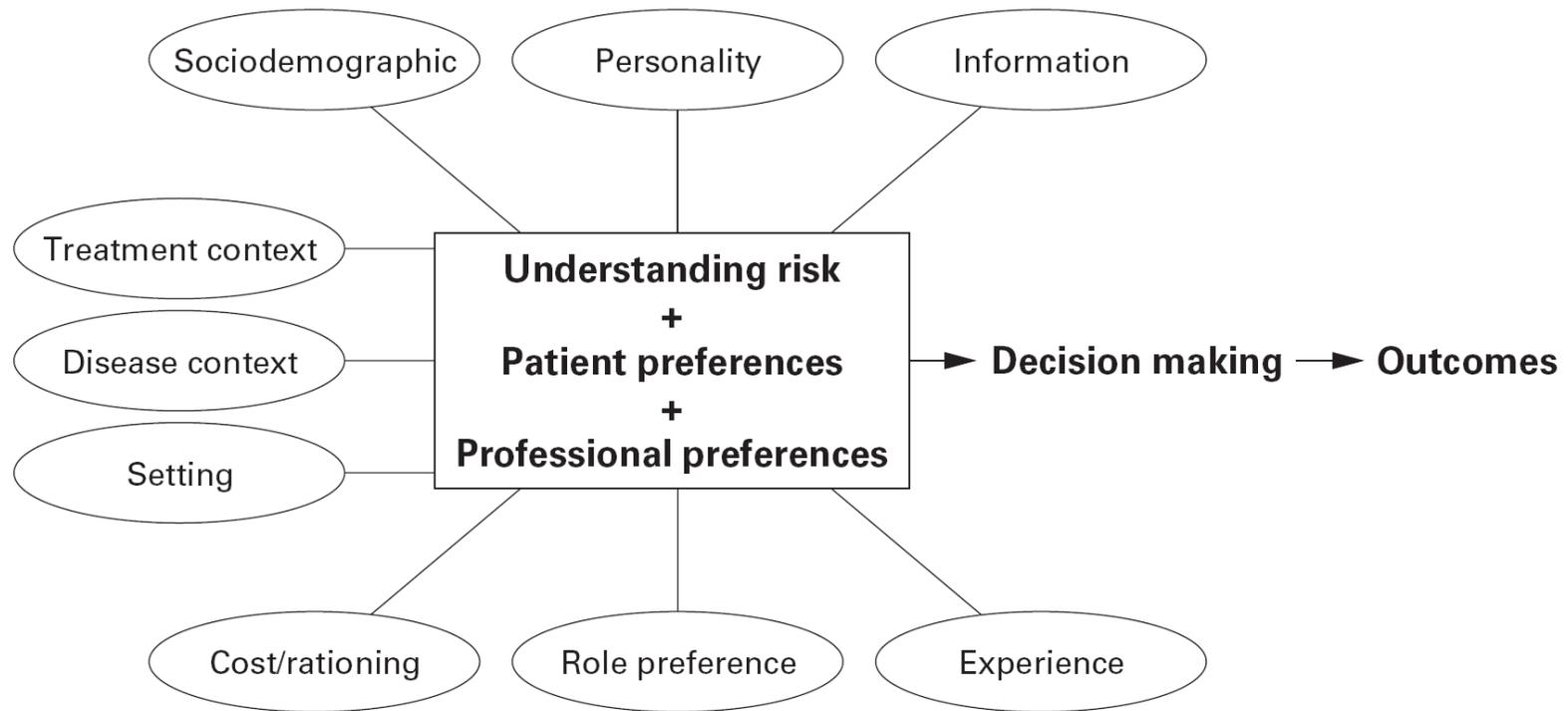
- Non-responders are more likely to be
 - ill
 - less satisfied with care provided
 - less frequent users of health care
- Factors that can influence the response rate:
 - motivation of the clinician to recruit patients
 - attractiveness of the layout of a questionnaire
 - method of administering the questionnaire to patients
 - use of monetary incentives
 - use of information technology for administering questionnaires



Effectiveness

- Methods to identify and use patient views to improve health care need to be shown to be effective.
- The best way to show this is by randomised trials.
- It is important that the outcomes chosen are relevant

Proposed areas of research on patients' preferences



Measuring patients' preferences for treatment and perceptions of risk (Bowling ,Ebrahim, 2003)





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