

ISOQOL

USING PROS IN CLINICAL PRACTICE CONFERENCE

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“A Non-visit Approach to Using PROs in Clinical Practice”

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HRQOL Discovery: Undertaking the Quest



Jason and the Argonauts. Pelias persuades Jason to undertake the quest; *Li livre des ansienes estoires*. c 1285, British Museum

HRQOL Development Phases



Jason and the Argonauts. The construction of the Argo. *Li livre des ansienes estoires*. c 1285, British Museum.

Prediction

“It is likely that in the early years of the 21st century, the completion of a quality of life questionnaire at a patient visit will be as routine as the taking of vital signs” (p. 65)

Ganz, PA. Impact of quality of life outcomes on clinical practice. *Oncology (Huntingt)* 1995; 9: 61-5.

*Four Stages of Acceptance for New Ideas or Methods**

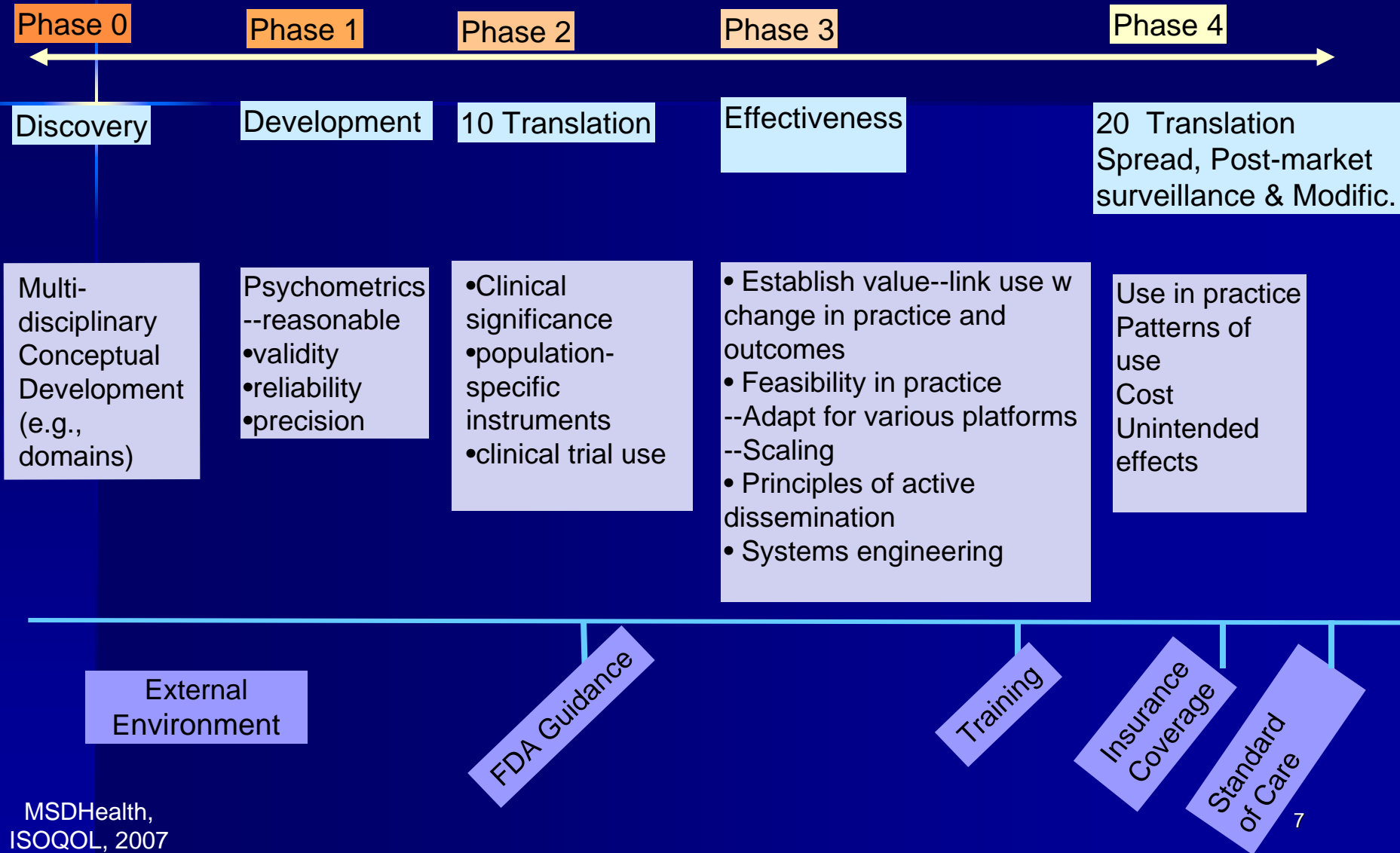
1. This is worthless nonsense;
2. This is an interesting, but perverse point of view;
3. This is true, but quite unimportant;
4. I always said so.

*Haldane JBS. The Truth About Death. *Journal of Genetics* 1963; 58: 463-4.

This Talk Covers Two Topics

- Where we are now and current thinking about dissemination of innovations
- Toward non-visit-based “patient-centered care”

HRQOL “Discovery–Development–Delivery Continuum”



Challenges to Using HRQOL in Practice*

Clinician Issues

- Knowledge
- Training
- Attitude
- Effect on clinic work flow (more, less efficient?)
- Reimbursement for time and effort,
- Liability--new standard of care, acting on information

* Donaldson, M.S. Using Patient-reported Outcomes in Clinical Oncology Practice: Benefits, Challenges and Next Steps. *Expert Review of Pharmacoeconomics & Outcomes Research* 6(1) 87-95, 2006.

Donaldson, M.S. Taking Stock of Health Related Quality of Life Measurement in Oncology Practice in the United States. *Journal of the National Cancer Institute Monograph*, 33: 155-167, 2004.

Or, in clinicians' words

- I already do this. I always ask my patients how they are doing.
- The patient tells me what is most important.
- Who's going to pay for it?
- I don't want to open a can of worms if I can't do anything about it.
- It's too complicated.
- Frankly, I'm interested in treatment, not fooling with referrals for mental health (my patients can't get them anyway).
- Is this going to increase the likelihood of being sued?
- I'm interested, but my partners aren't. We don't have time.
- I'm interested, but my staff would not be. They don't have time.

*Challenges to HRQOL Use in Practice**

Patient Issues

- Is it acceptable and how much response burden will I have over time?
- I expect that when I complete surveys, it will affect my care?
- Who will have access to my data? How will they be used? Can you promise me data confidentiality and security?
- Can I give my other doctors access to these data?
- Can I have access to and understand these data?
- Does the process meet my needs?

* **Donaldson, 2004, 2006**

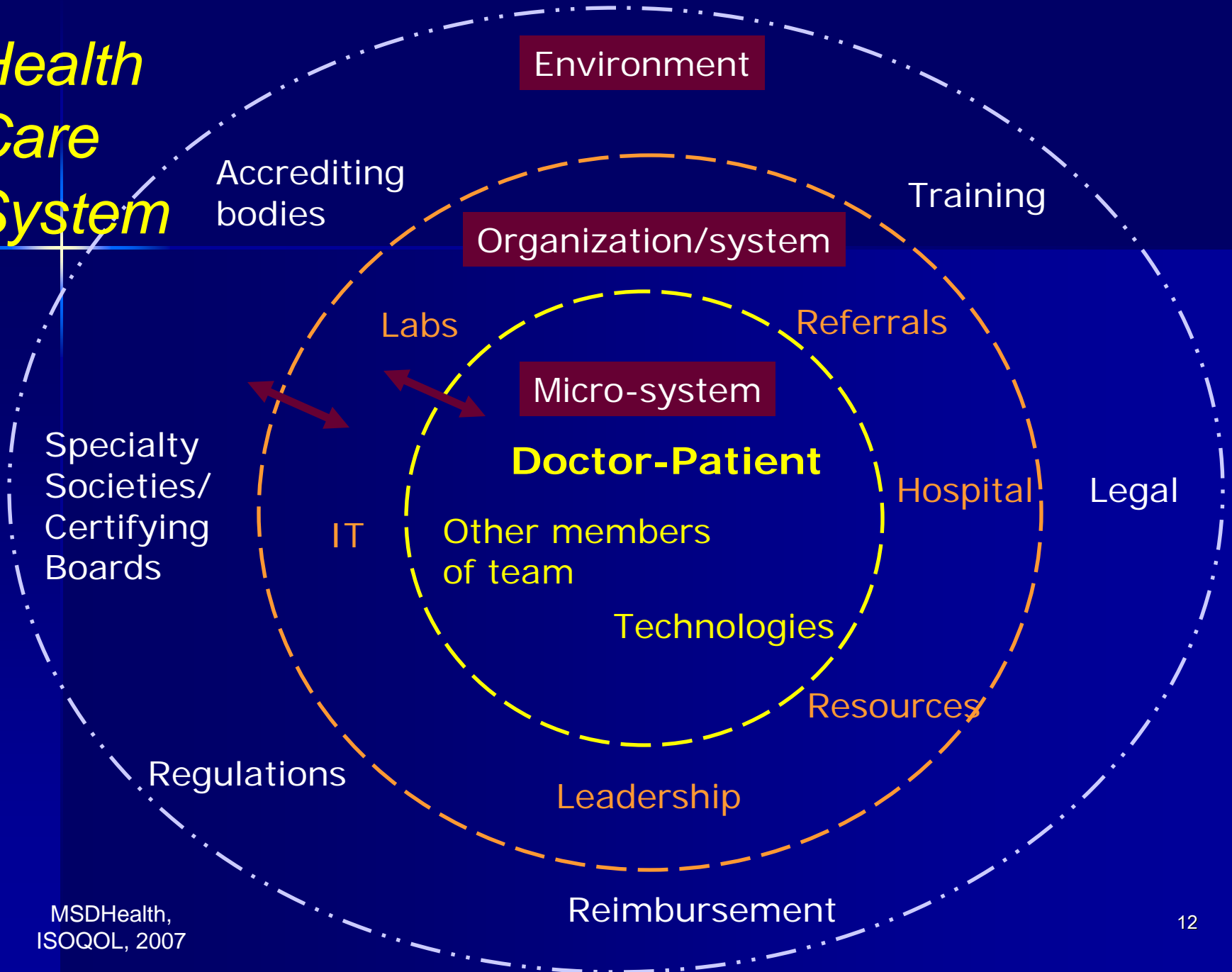
*Challenges to Use of PROs in Practice**

Health Care Organization Issues

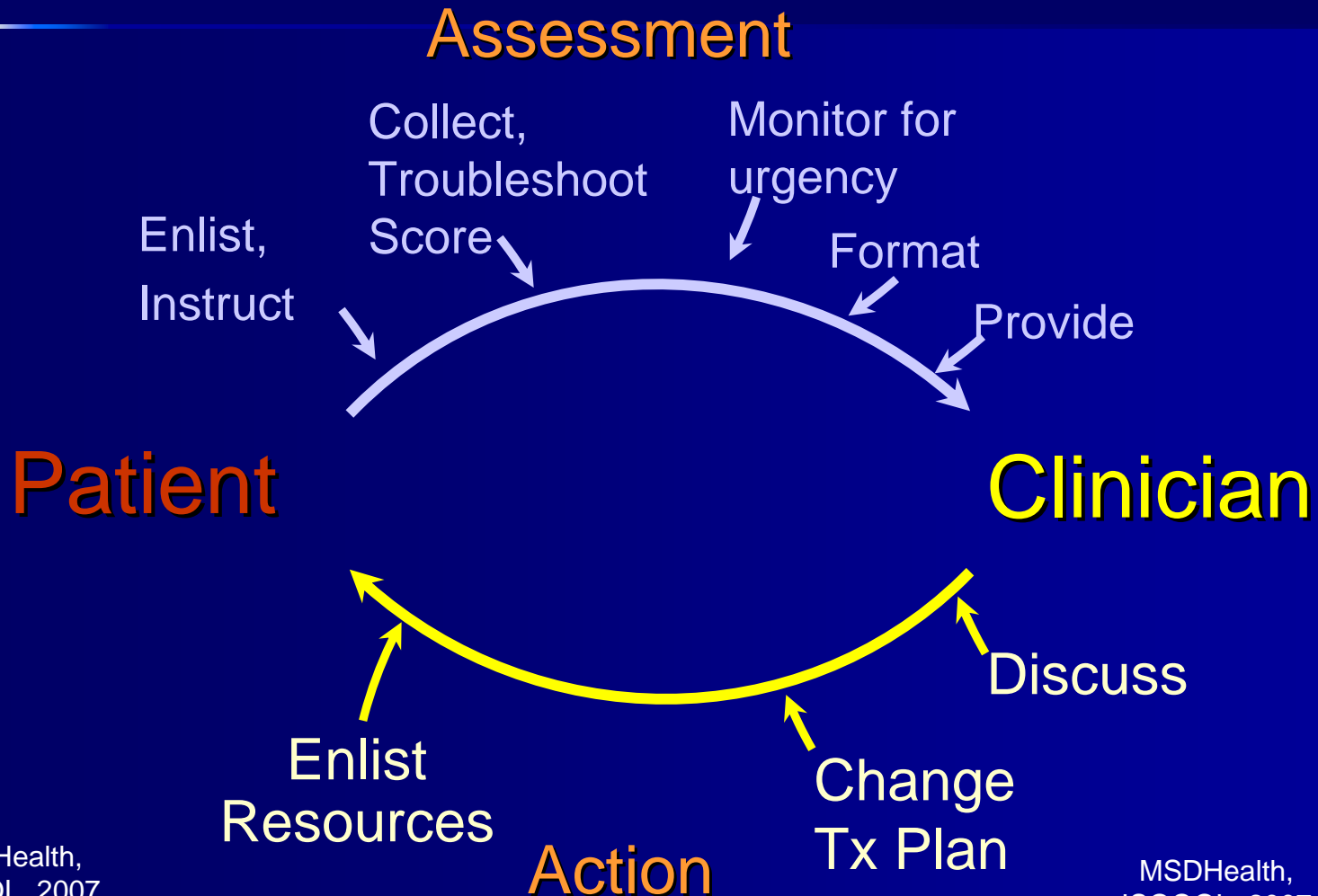
- Must deploy resources and staff for data management
- Must assure timely review of patient data
- Must respond to patient needs identified through quality-of-life measurement
- Complexity--must negotiate re coverage for measurement and services by many different payers

(Donaldson, 2004, 2006)

Health Care System



Using HRQOL During Clinical Interaction



Barriers to Effective Pain Management (NIH 2002)

Provider barriers to effective pain management:

- Lack of awareness of patient's pain
- Inadequate training and education on management of cancer pain
- Lack of time and resources to address pain
- A higher priority given to curing cancer than to treating symptoms
- Concern about legal or regulatory sanctions for overuse of opioids.

Barriers to Effective Pain Management, Continued (NIH 2002)

Patients and family

- Belief that pain is an inevitable part of cancer
- Belief that nothing can be done for cancer pain
- Fear of addiction and dependence
- Fear that the drugs will lose their effectiveness
- Fear that reporting symptoms will distract providers from cancer treatment or inclusion in treatment trial

Barriers to Effective Pain Management, Continued (NIH 2002)

Patients and family

- Cognitive impairment hindering symptom assessment
- The high cost of medications and treatments
- Failure to mention pain to providers
- Lack of adherence to treatment regimens

Barriers to Effective Pain Management Continued (NIH 2002)

System

- Lack of communication between specialists and primary care providers
- Lack of coordination of care, particularly during the transition from cure to hospice mode
- A priority on curing cancer over caring for cancer patients
- Regulatory barriers to effective pain management
- Lack of reimbursement for sx management

Lessons in Dissemination

- *Everett Rogers. Diffusion of Innovations. 4th ed. 1995. New York, NY: Free Press.*
- Jonathan Lomas. Diffusion, dissemination, and implementation: who should do what? 1993; *Ann N Y Acad Sci* 703:226-35.
- Donald Berwick. Disseminating Innovations in Health Care. 2003; *JAMA*, April 16; 289:1969-1975.
- Guus Schrijvers, Nico Oudendijk, Pety de Vries. In search of the quickest way to disseminate health care innovations. *International Journal of Integrated Care* 2003; 3:1568-4156.

Lessons in Dissemination (cont'd)

- Nico Pronk. Designing and Evaluating Health Promotion Programs: Simple Rules for a Complex Issue. *Disease Management and Health Outcomes*. 2003; 11:149-157.
- Margot Fleuren, Karin Wiefferink and Theo Paulussen. Determinants of innovation within health care organizations Literature review and Delphi study. 2004; *International Journal for Quality in Health Care*. 16:107-123.
- Others propose that innovation cannot be “managed” in complex systems--adoption may happen suddenly (see WL Miller, BF Crabtree, R McDaniel, KC Stange. Understanding change in primary care practice using complexity theory. 1998; *J Fam Pract* 46:369-76.

Effective Dissemination Strategies

(Lomas, 1993)

1. Synthesis of research by credible and influential body, provided in a user friendly format that justifies the need for change;
2. Explain how the change can be implemented by the intended users;
3. Communicate the existence and importance of the research findings in a variety of ways both locally and outside the local community;

Effective Dissemination Strategies *(cont'd)* (Lomas, 1993)

4. Highlight respected adopters;
5. Identify opportunities to meet with an influential local colleague or a respected outside authority; and
6. Ensure it is consistent with clinician's (or other's) economic or administrative incentives in the working environment or with the expectations of patients.

Three Basic Clusters of Influence that are believed to Correlate with the Rate of Spread of a Change (Rogers and Van De Ven):

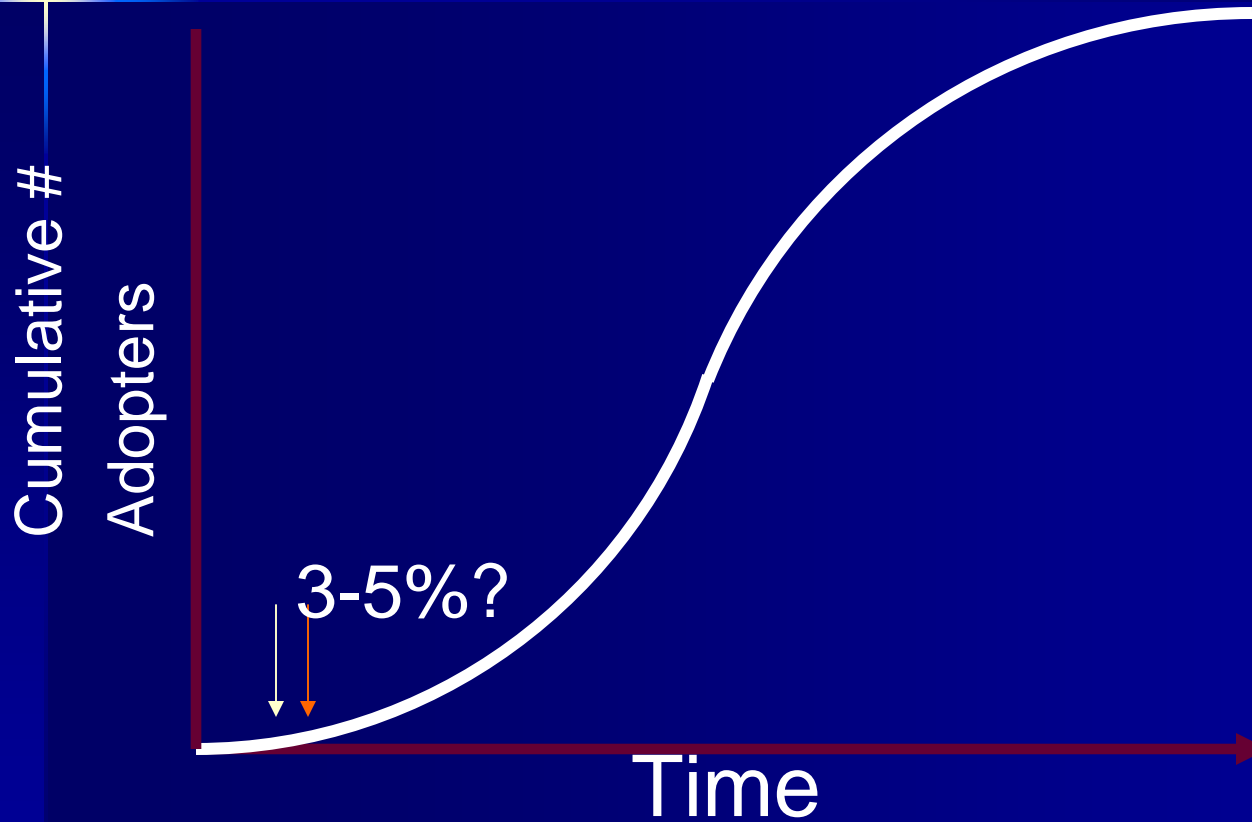
1. Perceptions of the innovation
2. Characteristics of the people who adopt the innovation, or fail to do so; and
3. **Contextual factors**, especially involving communication, incentives, leadership, and management.

Contextual Factors Believed to Correlate with the Rate of Spread of a Change

1. Whether [targets of change] see the change as beneficial Perceived (most powerful)
2. Whether the innovation is compatible with the values, beliefs, past history, and current needs of individuals who are implementing it.
3. How complex or simple it is – simpler is better
4. Whether they can try it out on a small scale
5. Whether they can see or learn what happens when others have tried it

Berwick, JAMA, April 16, 2003 – Vol. 289, No. 15: pp. 1969-1975

Adoption of Innovations*



Adapted from Rogers EM. *Diffusion of Innovations*.
4th ed. New York, NY: Free Press; 1995.

However,

- Goal should be to make it easy and useful; but most (increasingly stressed) delivery systems in US can't accommodate
- All such dissemination assumes that current ways of providing care can be made better incrementally
- This is a very tall order not only for health professionals but also for the microsystems – the other members of the practice, their information technologies, processes of care, and patients
- The way forward may not lie in urging clinicians to add patient-reported measurement to other tasks that are part of the patient encounter.

Will likely require:

- New attitudes about the function of medical records and patient encounters,
- New ways of organizing patient-clinician interactions and collecting data, and
- Redesigned systems of care that respond to patients' needs.

A Framework for Thinking About PRO Implementation

- Understand “micro” level of oncology practice
- Understand effect of larger organizations that enable or stymie change
- Understand the financial, legal, and regulatory environment that influences and constrains care
- Refocus interactions between clinicians and patients as outlined in The IOM report, *Crossing the Quality Chasm-- Aims, New Rules, and Organizational Change*

Framework for a New System: Institute of Medicine, Crossing the Quality Chasm

Aims (outcomes)

- Safety
- Effectiveness
- Patient-centered
- Efficiency
- Timeliness
- Equity

10 Simple Rules (process)

- The patient is the source of control
- Shared knowledge and the free flow of information
- Care based on a continuous healing relationship
- ...

Examples of New Rules

Now: Information is a record.

Information is retrospective, archival, passive, and inert.

New: Information is key to the healing relationship.

Information is interactive, real time, and prospective.

New Rules, continued

Now: Focus on visits

The unit of care is the patient visit. Organize and pay for health care by visits.

New: Focus on continuous interaction.

Organize and pay for health care so that patients receive care whenever they need it and in many forms; health care system is responsive “24-7.”

Rationale for New Rule: Patient care as a continuous healing relationship

- Can address needs when they occur or even anticipate, rather than at a visit
- Patient visit may not coincide with, or be well-suited to, responding to symptom and other quality-of-life issues
- Visit may be exhausting for cancer and other frail patients
- Clinician may not have needed information to act
- Time to address problems is very limited
- Using other approaches can free clinician time for visits that are needed

Continuous Interaction (compared with Patient Visits)

- The healing relationship is the core of health care, not something tacked on to a health care “encounter” or visit
- Does not preclude the face-to-face visit or the value of touch in such an interaction.
- Such relationships could be strengthened in interdisciplinary team practice
- Recognizes the value of other means of contact in improving information flow--such as new information technologies

Information Flow: Beyond Patient Visits

- Think beyond paper and pencil, tablets, waiting rooms
- Don't add another stand alone application if EHR is possible -- contribute to outcomes measurement!
- Health-system based QOL lab for all medical conditions?
- Requires timely review; timely response when urgent

Information Flow: Beyond Patient Visits (cont'd)

- Asynchronous applications to enter data off site, such as
 - Web-based (home or other personal computer)
 - PDA
 - Web-enabled cell phone
 - Web TV

- “Real-time data capture” can be in relation to treatment clinical event, when a problem occurs, at periodic intervals, etc. Tailor measurement intervals by patient and stage of disease

What if We Took Patient-centered Care So Seriously That

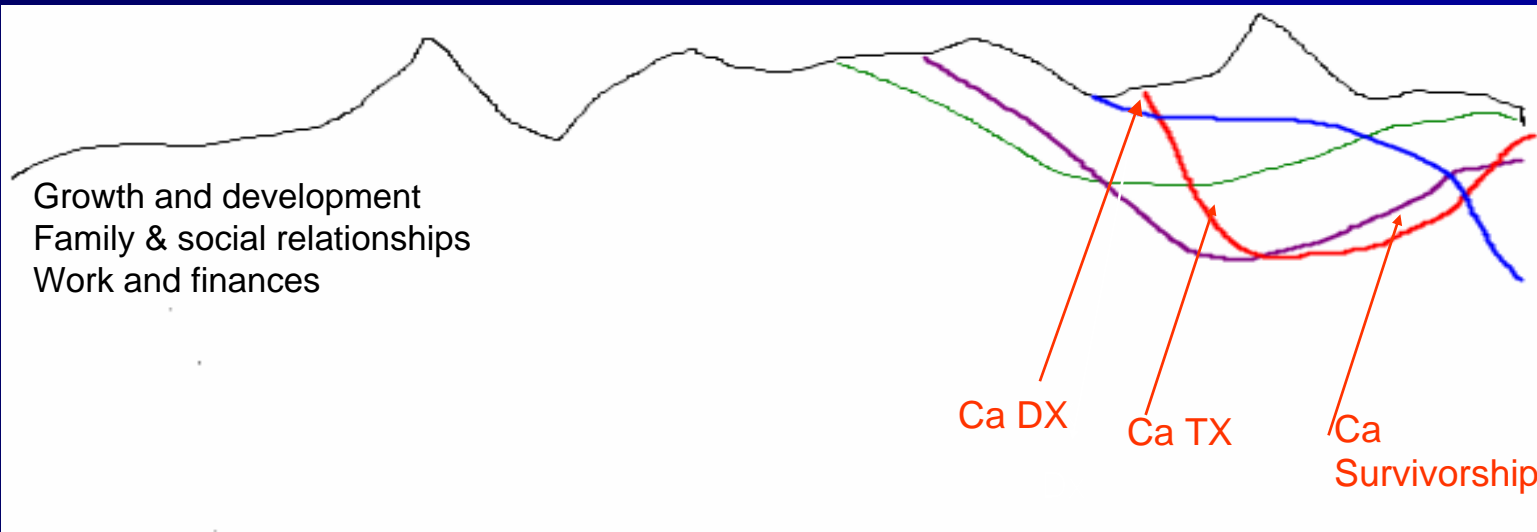
- It transformed the care delivery model
- PROs were at the center of and drove care rather than patient visits?
- PROs were patient-based, not tied to a specific specialty?
- Patients routinely accessed and completed PROs when well or sick and could choose what and where to send results?

If Cancer Were Viewed as One Condition in Complex Chronic Care

- View cancer survivorship as a new comorbidity
- Patient view of world – need drives care
- Perspective is patient who has disease rather than the disease the patient has. Of all the conditions a patient has, what are the 5 most important things to do? (Paul Wallace, Kaiser Permanente)
- Does HRQOL always trump all? Including family impoverishment, lost educational opportunities, caregiver burden?

Example: A Patient View of Cancer Diagnosis, Treatment, Survivorship

Birth

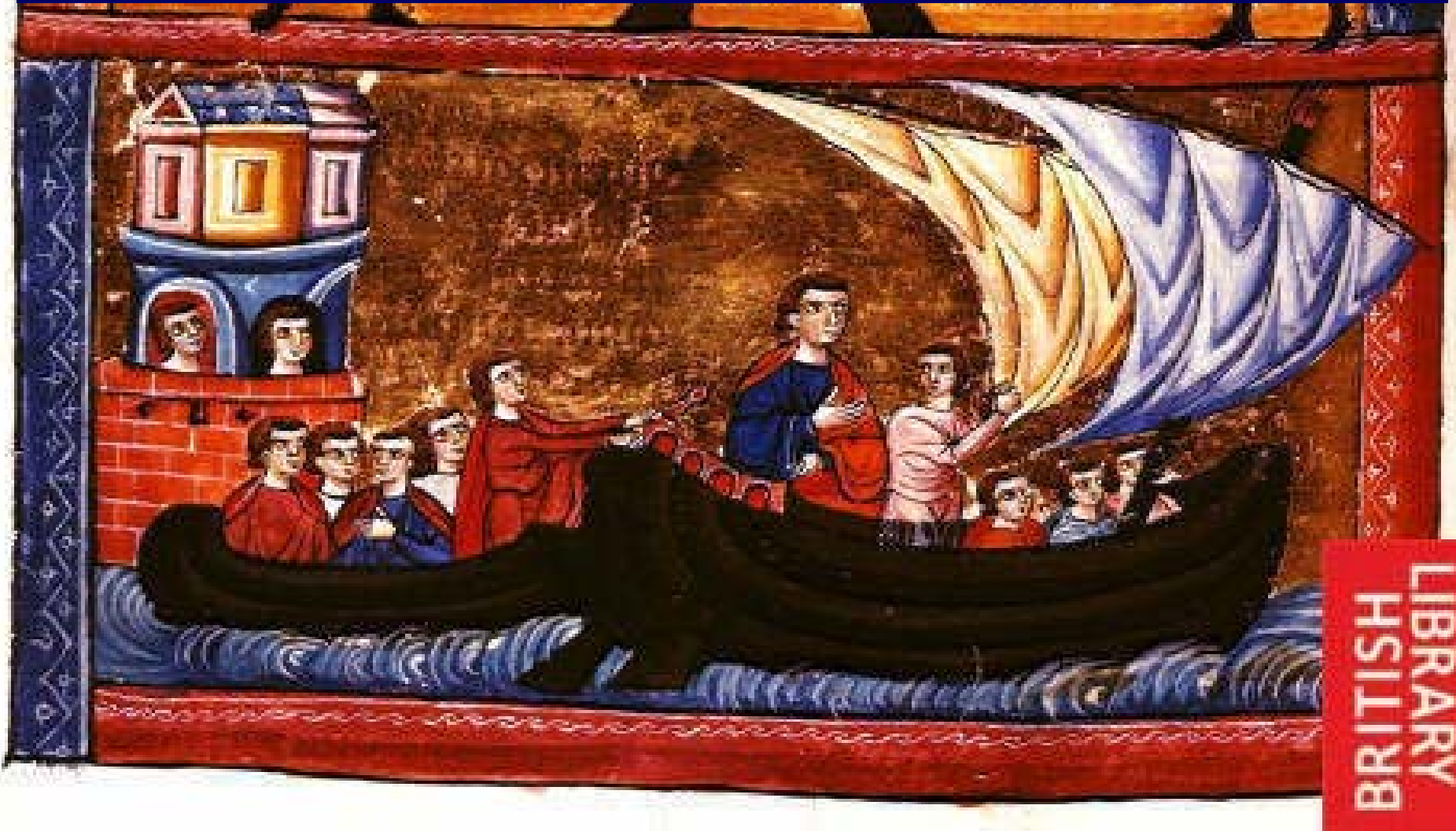


Oh, my gosh, this is really complicated.

Eric Green, Scientific Director, National Human
Genome Research Institute (USA)

Intricate Toiling Found in Nooks of DNA Once
Believed to Stand Idle. Washington Post, June
14, 2007, A1.

Implementing PROs in Clinical Practice



BRITISH LIBRARY

Jason and the Argonauts. the Argo and the Argonauts set out from Thessaly for Colchis. *Li livre des ansienes estoires*. c 1285, British Museum.