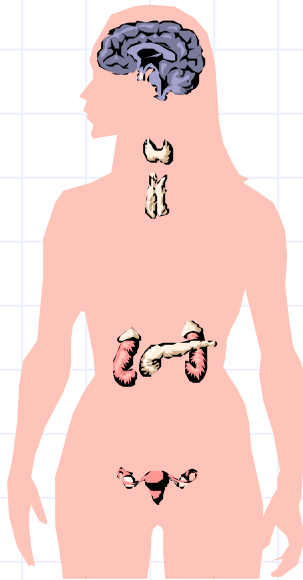


Informative activities for medical consumers



view of public understanding of science

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INFORMATIVE ACTIVITIES FOR MEDICAL CONSUMERS: VIEW OF PUBLIC UNDERSTANDING OF SCIENCE

<http://www.knt-ec.com/event/icim/abstract/11-PO-9.html>

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PURPOSE: Reflecting the use and value of medical information, particularly ones for profession, from the viewpoint of public understanding of science(PUS).

DESIGN and METHOD: narrative, non-systematic review of literature including both medical and social sciences with regard to PUS.

RESULTS: PUS is a concept in the sociology of science. As is well known, conflicts between professionals and lay persons over dissemination of scientific knowledge often induce severe social issues. The same problem over knowledge stands in front of medicine. Medical knowledge including ones for professionals should be freely accessible to lay public.

CONCLUSION: Medicine is no occult sciences, but derived from collaborative works of professionals and the public over disease. Lay opinions are not superstitions or irrational beliefs. It's just common or sound sense.

Summary

1. PUS(Public Understanding of Science) is a key concept of democratization of scientific feature of modern societies.
2. Lay-experts are playing important roles in PUS.
3. Consensus conferences(CCs) not only coordinate complicated interests of stakeholders but also make things right for societies.
4. In CCs, stakeholders are witnesses, lay persons are juries.
5. To be known medical knowledge profoundly by lay persons, we've hold some meeting to instruct evidence-based way of reading medical literatures; CASP method.

What is PUS?(1)

Public Understanding of Science:PUS

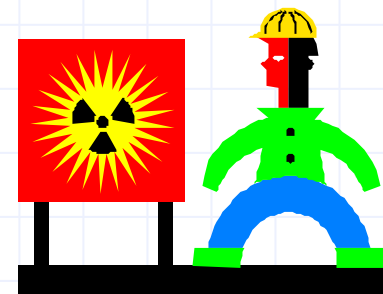
1. Top-down movement

- Improving scientific literacy (enlighten people, technocratic aspect)
- 1980s ; administrative authorities and foundations for scientific research of Anglo-American countries originated this movement
- The purpose of them is to promote scientific research and to enlighten people on scientific knowledge.

What is PUS?(2)

2. Bottom-up movement (*or grass roots activities*)

- Chernobyl disaster, Nagara-river dam of JAPAN, Celafeld disaster
- To determine acceptance or rejection of public policy on scientific technology
- Sociological aspect (rediscovery of local knowledge or “common sense” of lay persons)
- Local self-governance by inhabitants



Are lay persons idiot on science?

1. Of course, the ignorants should be enlightened.
2. Yes, that's why experts keep silent on scientific knowledge. Lay person should be obedient to expert opinion.
3. Absolutely No. Lay persons have common sense. Experts often have deviated opinions

Democratization of modern societies

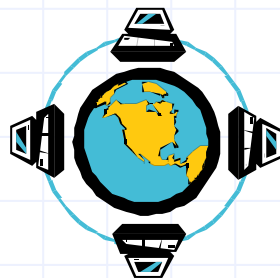
Empowerment of consumers

- Knowledge is power.
- Every citizen has their own specialities.

Era of information technology

- Horizontal relationships between citizens
- Globalization
- Accelerated delivery of information

Transparency, accountability, accessibility



Networking !

Everybody is an expert!

Lay experts



- **Highly educated societies**
 - High school teachers often are strong opinion leaders.
 - Knowledge of lay person sometimes overwhelm expertise.
- **To learn specialized knowledge is NOT so difficult.**
 - Paradigms and basic concept of modern thoughts are mostly understandable by cultivated people.
 - The way of recognizing special knowledge is rather common between different specialties.
- **Consensus conference and policy making process**
 - Social epistemology

Dominant stakeholder views about public responses to GMOs

Myth 1: The primordial cause of the problem is that lay people are ignorant about scientific facts

Myth 2: People are either 'for' or 'against' GMOs

Myth 3: Consumers accept medical GMOs but refuse GMOs used in food and agriculture

Myth 4: European consumers are behaving selfishly towards the poor in the Third World

Myth 5: Consumers want labelling in order to exercise their freedom of choice

Myth 6: The public thinks - wrongly - that GMOs are unnatural

Myth 7: It's the fault of the BSE crisis: since then, citizens no longer trust regulatory institutions

Myth 8: The public demands "zero risk" - and this is not reasonable

Myth 9: Public opposition to GMOs is due to "other" - ethical or political - factors

Myth 10: The public is a malleable victim of distorting sensationalist media

<http://www.lancs.ac.uk/depts/ieppp/pabe/docs/summary.doc>

Consensus Conference

Let's think together!

- Originated 1980s in Denmark
- 1988~ , Japan
 - GMOs
 - Gene therapy
 - IT and society
 - Human genom
- Resemblance or analogue of jury system
 - Stakeholders are witnesses, lay persons are juries.
 - Expert panel vs. public panel(recruit from lay persons)
 - Discussion and consensus making between both panels : advocating guidelines



Social epistemology

Among the STS, an intellectual movement of broad cross-disciplinary provenance that attempts to reconstruct the problems of epistemology once knowledge is regarded as intrinsically social.

1. Normative issues ought to be discussed from the view point of how to organize societies.
2. Is the position of science and technology worth its relative highness?
3. What is the implication of high position of science upon politics ?

***STS: Science Technology Social study**

PUS around medical circumstances(1)

Doctor-patient relationships

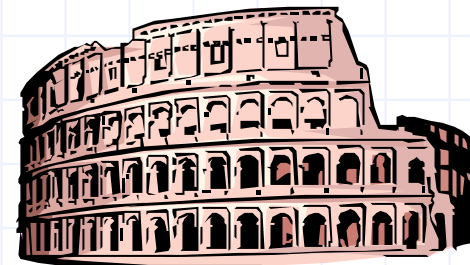


- Medical consumers' awareness of self-defence over increasing medical errors
- Transparency and accountability of medical practice
- Informed decision or shared decision making (Let me decide my own treatment strategy!)
- From paternalism to patient-participation
- Movie; **“Lorenzo’s Oil”** - consumers learning medical knowledge
- Patients who diagnose their own disease from the information on the web
- Patients who criticize the ability of doctors precisely

PUS around medical circumstances(2)

Medical policy making

- Participation of lay persons to committees and councils of government
- Guideline making
- Cochrane Collaboration
- IRB(Institutional Review Board) and intra-hospital ethical review board
- BSE issue, drug-disaster-AIDS, CJD etc...
- Claim of “ Trust us , we’re experts” won’t make sense.



How to teach medical knowledge to lay persons

1. Critical Appraisals Skills Program(CASP)

- To teach refined EBM methodology to consumers, policy makers or co-medical workers with friendly way
- We hold some meeting of CASP.



2. DISCERN

- Guideline of discerning medical information to medical consumers based upon their reliability of sources.
- We introduced Japan the DISCERN instrument.

Digging even deeper clinical knowledge

1. Learn from local knowledge of patients
2. Knowledge management: from implicit knowledge to explicit knowledge
3. Democratize medicine by teaching EBM methodology toward consumers; CASP
4. To be a citizen of insight is vital for each medical workers
5. Proceed shared decision making
6. Evaluation of every treatment option by each person
7. Consensus conferences for medical policy making shall be held