

Quality of health information on the internet

achievements, lessons and the future

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What I want to talk about

- ? Trust
- ? What have we achieved so far
- ? Strengths and weaknesses of initiatives
- ? Current state of affairs
- ? What have we learnt
- ? What needs to be done

Trust

- ? Trust is fundamental in health care
- ? Trust is also fundamental in e-health care
- ? Trust is difficult to gain and sustain in a virtual environment:
 - Volume
 - Cross-border & cross-culture issues
 - Lack of evidence of quality
 - Fraud
 - Clinical constraints
 - Accessibility
 - Privacy & confidentiality issues
 - Lack of clarity and universality of standards

The eHealth Code of Ethics

- ? Its goal is to create a trustworthy environment for everybody
- ? Its Principles identify the fundamental values needed to create conditions of trust
- ? Extends ethical practices of face to face health care to the special challenges of virtual health care
- ? It reminds us of what matters. Of what is important

(Bette Crigger – 2001)

What have we achieved so far

1. Timeline

- 1969 ? Computers connect & exchange L & O
- 1993 ? CERN gives the Web free to the world
- 1993 ? First health information website (vh.org)
- 1996 ? HON Code
- 1996 ? BHIA Quality Standards
- 1998 ? HSWG- IQ Tool
- 2000 ? Hi-Ethics
- 2000 ? eHealth Code of Ethics
- 2000 ? AMA Guidelines
- 2000 ? MedCERTAIN/MedCIRCLE
- 2001 ? URAC accreditation programme
- 2002 ? EC Quality Criteria

What have we achieved

2. Mechanisms

1. Fundamental values	eHealth Code of Ethics
2. Codes of conduct	HON Code BHIA Quality Standards Hi-Ethics AMA Guidelines EC Quality Criteria
3. 3 rd party certification	URAC website accreditation
4. Technology I	HSWG-IQ Tool
5. Technology II	MedCIRCLE

Strength and weakness

Mechanism	Strength	Weakness
Codes of ethics/conduct	Broad-based participation Universality Synergy	Non-binding Misinterpretation Difficult to measure Non-specific change
3 rd party certification	Independent objective validation Forces change Easy to measure Consistency	High cost Labour intensive Indifference
Technology	Downstream filtering Machine dependent Consistency	Indifference Machine dependent Misunderstanding

Current state of affairs

1. eHealth Code of Ethics ? Updating & translating
2. HON Code ? 3000 sites - "live" link
3. URAC ? 40 sites (1 May)
4. Hi-Ethics ? 11 members (1 May)
5. MedCIRCLE ? 4 partners - ? Sites
6. EC ? ? sites

What have we learnt

1. Deep thinking & passion
2. Consensus is important
3. Collaboration and dissemination are crucial
4. The burden placed on people is too much
5. The cost of implementation is too high
6. The gap keeps getting bigger
7. User & provider indifference is real
8. Citizen education is a difficult task
9. Quality criteria are not enough
10. Technology and understanding need to catch up

What needs to be done

- ? Not to re-invent the flat tyre
- ? Develop thinking on the valour of ideas, chivalry, honour & fundamental universal values
- ? More research on:
 - value of reputation as a quality marker
 - how to measure reputation & make it machine dependent
 - consumer behaviour
 - relationship between poor information and health outcomes
- ? Better international collaboration & dissemination
- ? Think about the info-poor

Questions

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