



Gathering Evidence & Improving Research *Workgroup 4 results*

Facilitator: Joan Dzenowagis
Expert Resource: Earl Steinberg



History of Health: for Web2.0

<http://youtube.com/watch?v=eAUH1IX54z8>

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11 participants' profile

- Researchers
- Information providers
- Website providers/owners
- Consultant/analyst
- Academics (professors & students)

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Focus of discussion

1. *What do consumers consider to be evidence?*
2. *Does culture trump science?*
3. *How can we improve the health research enterprise (related to internet)?*
4. *What can health research contribute to transparency & decision making?*
5. *How can consumers help researchers?*

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1. Evidence

- Assumption: “Consumers are general public, not necessarily scientific background, diverse”
- Knowing source & bias is important
- Credibility is function of trust of source
- Trust has shifted → less centralized
- Role of peer networks increasing

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1. Evidence (2)

- Personal acceptance of “evidence” – everyone has their own threshold (eBay)
- Infomediaries: how to use to better advantage, what is their role & how to enhance it?

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1. Evidence (3)

- Medium/mechanism is important for using & understanding information
- Generational & SES gaps: “expert” is different
- Health literacy (broadly defined) – how will it play role in access & use of info? How to enhance?

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2. Consumers

- Global consumer/ context is changing
- Relationships changing: patients – providers, expectations are different
- Internet & consumer role → improve accountability, transparency, personal awareness

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2. Consumers (2)

- Given impact of marketing, mass media...
(negative effect)
- How to improve collaboration between
consumers, clinicians, & others? (Balance &
informed choices)
- Quality, safety, satisfaction are drivers

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3. Culture vs science

- Culture is CONTEXT in which
 - Science happens
 - Is communicated
 - Is understood & used
- Multidimensional factors – vital in health literacy
& care
- Research: how can we better understand & use
this diversity? When is it meaningful?
(disaggregation of data)

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4. Decision dilemmas

- Context is proliferation of information
- New tools to sort info & to make sense of it? (info availability, is it enough, how to interpret?)
- How to get tools out there & used, & actually transforming care?
- Consumers as owners/drivers of care (advocacy, transparency, relevant/peer info)

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5. Research enterprise

- How can we use internet more effectively in research participation/ interpretation to improve results & process:
 - To include other populations'/ groups' participation
 - To increase dissemination
- Complex, dynamic process of research

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5. Research enterprise (2)

- How can we link to research policy & funding so this is done? (i.e., more inclusive)
- How can internet be used to engage, inform and learn from consumers at all levels of process?

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- C U in 2017!

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