



*Crowdsourcing for quality improvement?  
Questioning the rise of rating and  
recommendation sites in healthcare*

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# Today's talk

Quotes

Changing trends and related techno-promises

Project Background and Critical Analytical Themes

Quotes revisited

FAQs

Trying to transform experience into evidence

Less frequently asked... but still important!

# Transparency and healthcare

“The black box of health care is being opened. There is an entire industry built around transparency. Transparency via indicators is one of the central mechanisms through which evaluative relationships in health care are being structured. Transparency is expected to contribute to improving health care, increasing care options for patients and facilitating citizen trust in governance structures.” (Robben, 2010)

“When patients share their experiences publicly, they help others make good choices. It is important that you, as a patient – and thus as an experiential expert – have a public voice. ... This is how your opinion will become visible for other patients, and also for the physician who treated you.” (Website)

“Physicians serve a public service and therefore should be able to withstand a little critique.” (Social Media Advocate)

# Changing trends & related techno-promises

+/- 2007: Web applications increasingly easy to use ('web 2.0')

Point and click applications enable more people to participate

Less text, more interactive/social

'More direct' lines of communication → removal of traditional (human) mediators

The disclosure imperative and 'writing the self'

Increase in publicness among individuals, institutions and groups

Sharing opinions and experiences online

The 'wisdom of the crowd'

Leads to quality improvement: better products and services

# Translated to healthcare

Easy-to-use information platforms with different types of information resources

Important for reaching special needs populations

Can lead to more transparency and patient-centeredness

‘The [miracle cure](#) for Dutch healthcare’ ([Dutch Social Media Conference, 2012](#))

Concurrent with increased disease self-management & personal health information management

Institution-based Personal Health Records & Portals

Online (commercial) health information spaces

Development of health-related web ‘communities’

Active [solicitation and publication](#) of patient experiences

# Project Background (2007-2012)

Sites where patients **rate** and/or **review** various aspects related to their care

## 1. Web review:

Personal stories (n= 100)

Reviews of institutions, physicians (n = 350)

Reviews of pharmaceuticals (n = 467)

NL: **TNO Digital Experiences Record**, **Patient Opinion Pilot**, **Consumer and Care/Health Map**, **Search Doctor/Independence Health**, **My medicine ('mea medica')**

USA: Utah Story Bank, **Stories for America**

UK: NHS Choices, Patient Opinion

## 2. Dutch 'stakeholder' interviews (n=17)

## 3. Website end-user (patient) interviews (n=18)

# Critical analytical themes

Neoliberalism, **reflexivity** & the medical encounter

Voice/choice in healthcare & the transparency imperative

Post-panoptic '**veillance**' & **techno-governance**

Role of sites as **knowledge brokers**

(Proposed) institutional uses & hierarchies of knowledge

# Transparency and healthcare

“The black box of health care is being opened. There is an entire industry built around transparency. Transparency via indicators is one of the central mechanisms through which evaluative relationships in health care are being structured. Transparency is expected to contribute to improving health care, increasing care options for patients and facilitating citizen trust in governance structures.”

(Robben, 2010)

“The experiences you have with a hospital, that you want to share with the hospital, should be resolved and handled *with the hospital*. Reviews on the internet? That’s not the best way to handle concerns.”

(Quality Controller)



# Let the people speak?

“When patients share their experiences publicly, they help others make good choices. It is important that you, as a patient – and thus as an experiential expert – have a public voice. Therefore, let your opinion be heard. This is how your opinion will become visible for other patients, and also for the physician who treated you.”  
(Search Doctor Website)

“Then you have four reactions. We have more than 100,000 patients per year. What does that mean? And, what’s it about? Coffee, communication, and their emotional experience. I can’t use that type of information.”  
(Quality Controller)

# Patients and professionals

“Physicians serve a public service and therefore should be able to withstand a little critique.”

(Social Media Advocate)

“If I don’t know that a site even exists, how can I defend myself against what is written there?”

(Dermatologist)

“The funny thing is that the only way to control the information is to make sure you do a good job. Or you ask your good patients to please write a review. That’s always a possibility, I guess.”

(Health Consultant)

# About the reviews – FAQ's

Are the reviews...

Mostly negative? **NO!**

About the 'softer' aspects of care? **Often**

Representative for the patient population? **Depends on definition of "representative"**

Useful? **Yes, but...**

Do site administrators...

Edit reviews? **Depends on the site**

Guard against 'naming and shaming' and 'gaming the system'? **Somewhat**

# Trying to transform experience into evidence

Who establishes

Reasons for establishing

Monitoring and improving **quality** and patient **safety**

Improving **representation**

Providing **legitimacy** for health policies and budgets

Bridging an **information gap**, facilitating **collaborative learning** and improving **health promotion**

Structuring information

Quantitative rating with free text space

24-48 hour delay: Postings are actively monitored (and adjusted)

Protect **institutions** and **physicians**

Protect **patients**

Protect **quality** of information

'Repackaging' in reports

# Which means...

## Various **hierarchies** at play

Scientific versus non-scientific knowledge

Assumptions about importance of quantification and for whom

## Sites emphasizes the importance of patients' own words and stories

But edit and alter these where necessary

Edits by the site often carry a strong **medicalized** discourse

## Secondary reasons for establishing sites

Improving **compliance** with medication use

Ensuring individual **participation** in order to fulfill policy goals

# Less frequently asked, yet still important! (1/2)

## A relatively new phenomenon

- What is the place of sites on the health information landscape?
- Do they provide an ‘appropriate’ avenue for collecting information?
- Does their hidden top-down structure actually contradict the ideology of social media?
- Do sites deliver information that other actors can/will actually use?

## Institutional and professional transparency considered positive

- What are possible consequences of opening out the protected space of the medical encounter?
- How are (online) personae and reputations affected?
- Do current structures to vet information sufficiently protect against “worst case scenarios”?
- Is a site administrator “liable” if reviews reveal a pattern about possible risks or quality issues in care?
- How can governing bodies use these sites – if desired?

# Less frequently asked, yet still important! (2/2)

Patients must also be transparent about their choices and behavior

- Does this reflect an unethical turn in 'patient-centered care'?
- What assumptions are made about access, ability, willingness and use?
- Is this shift in the burden of work an appropriate use of patient time and knowledge?
- Or are we just merely collecting information that sits in an online database?

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