



**Health Literacy in  
Action:** Improving  
Measurement by  
Analyzing Online  
Discussion of Cancer  
Screening  
Recommendations

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# Using the Internet for health information

80% of US adults use the Internet  
60% have searched for health information

## Previous work focuses on health-specific online communities

Various cancers  
Diabetes management



# Health Literacy, “In Action”

How are people actively communicating about health topics on general message boards?

Need for information about *general* online communities

## Health Literacy Measurement: + An Ongoing Issue

*Healthy People 2020*

The need to improve current measures





# Health Literacy, “In Action”



Two stories from New York Times Online

Mammogram recommendations (2009)

PSA recommendations (2011)

Codebook created to examine reader comments

631 reader comments

448 reader comments

**1 079 reader comments total**



A number of  
themes  
emerged from  
the data:

Mammogram and PSA Tests

Cultural Differences in  
Health Beliefs

Gender as a Factor in Health  
Recommendations

Public vs. Private Health

Referencing Outside  
Information

Health Status

Costs



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# Mammogram and PSA tests

- Specific details about the preventive measures/treatment and alternatives
- Understanding of the scientific process and potential for contradictory results over time
- Talking about other health issues/procedures that might be unnecessary
- The line between overtreatment and prevention
- Questioning how accurately the article conveys the actual panel recommendations

“Calm down. Get a PSA if you must. But don't make the mistake of thinking that an elevated PSA won't lead to a whole host of interventions, all of which are plagued with false positives and false negatives.”





# Public vs. Private Health

- Difference between personal health and public health
- Referencing stats/population-level data in favor of the procedure
- Referencing stats/population-level data against the procedure
- Personal stories in favor of the procedure
- Personal stories against the procedure
- Perception that people “saved” by screening “don’t matter”

“I just hope I'm not the one in 1900 whose life wasn't worth the effort and expense to save. I'm guessing I speak for several million women under the age of 50.”





# + Referencing Outside Information

- Research results referenced without any kind of link/specific information
- Mass media sources referenced for more info
- Nonprofit/organizations references for more info
- Government agencies referenced for more info
- Research studies referenced for more info
- Personal expertise (doctor, nurse, etc.) claimed
- Comments on credentials/expertise of panel members (GPs vs. different specialties, etc.)
- Doctors should have a choice, regardless of data/recommendations

“I do urge anyone reading this to heed the recommendations of groups like the Young Survival Coalition, [breastcancer.org](https://www.breastcancer.org) (Dr. Marisa Weiss's organization), and cancer groups in the US and Canada.”

# Conclusion & Implications

Qualitative analysis of comments on a general message board about health is a way of understanding health literacy and improving its measurement

Importance of considering other areas contributing to health literacy

Zarcadoolas, C., Pleasant, A., & Greer, D. (2005). Understanding health literacy: An expanded model. *Health Promotion International*, 20(2), 195-203.

rather than focusing on patient's literacy and numeracy capacities

Future research:

Continue to further improvements in health literacy measurement

Determine how these factors play a role in health literacy and the strength of this impact



Thank you.

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# Cultural differences in health beliefs

- Comparisons of US vs. other countries
- Cultural/ethnic differences in health – belief, trends, etc.

“The Task Force is ignoring international evidence that bears on the efficacy of PSA testing. A much higher proportion of men in the United States have been given the PSA test than in other wealthy countries. And the United States has had a much more rapid decline in mortality from prostate cancer than other rich countries.”





# Gender as a Factor in Health Recommendations



- Comparing recommendations/screenings between men vs. women
- Role of gender of the panel/recommenders in influencing the decision
- Research dollars spent varying by gender
- Deaths varying by gender
- Spouses who said the test got their non-preventive health oriented partner into the doctor
- Men can get breast cancer too

“Wow, first I read the ECONOMIX column how women are being paid less than men (DUH, not news to women!), and now in this article, the men are trying to kill us off (I guess this is going to be an approach to controlling health care costs -- minimize mammograms AND stop teaching women to examine their breasts). Turning the hands of time backwards, backwards, backwards, all to the detriment of women's pay & health. Ugh.”



# Impact on Healthcare Costs



- Impact of recommendations on insurance status/system
- Healthcare as a business, more money to be made by providers in treatment vs. prevention
- Recommendations are related to healthcare reform

“Is this a precursor of what Obamacare will look like? Next we will be hearing that men do not need a prostate exam until they turn 65.”



# Health Status

- Talking about personal emotions (anger, fear, sadness, etc.) these recommendations inspire
- Family history as a factor in effective prevention/treatment
- Equating lack of screening with ignorance of health status
- Patients should have a choice, regardless of data/recommendations

“I had my breasts examined in May and everything was okay, I have no family history of breast cancer so I didn't think much of it. By September I already had a lump sized about two and a half centimeters and had spread to one lymph node.”

