A National Web Conference on the Use of Health Information Technology to Enhance Patient Understanding of Health Concerns

June 5, 2014
1:30 pm–3:00 pm ET
Moderator:
Angela Nunley, M.S.Ed.*
Agency for Healthcare Research and Quality

Presenters:
Kathleen McTigue, M.D., M.P.H.*
Sara Czaja, Ph.D.*
Jason Glanz, Ph.D.*

*Have no financial, personal, or professional conflicts of interest to disclose.
The Effectiveness of Delivering an Online Version of the Diabetes Prevention Program (DPP) Lifestyle Counseling Intervention

Kathleen McTigue, M.D., M.P.H.
University of Pittsburgh
June 2014
Acknowledgements

• Collaborators:
  ▶ Laurey R. Simkin-Silverman, Ph.D.
  ▶ Molly B. Conroy, M.D.
  ▶ Dana L. Tudorascu, Ph.D.
  ▶ Rachel Hess, M.D.
  ▶ Gary Fischer, M.D.
  ▶ Cindy L. Bryce, Ph.D.

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Over one-third of U.S. adults are obese.

The U.S. Preventive Services Task Force (USPSTF) recommends that primary care providers (PCPs) screen for obesity and offer or refer obese patients to intensive, multicomponent behavioral interventions.

- The Diabetes Prevention Program (DPP) lifestyle intervention is one of the best established intensive lifestyle programs.

Such treatment is rarely accessible in the primary care setting; multiple barriers exist (insufficient time, lack of training).
Study Goals

• Facilitate the delivery of preventive counseling by using information technology (IT) to translate an evidence-based intensive lifestyle intervention into diverse primary care settings.

• Conduct a randomized clinical trial (RCT) comparing the effectiveness of three online approaches for integrating behavioral lifestyle treatment with primary care.
Methods

• Obese patients from six primary care practices referred by their PCPs for an online lifestyle program

• Participants were randomized to one of three arms:
  ▶ An in-person lifestyle counseling session
    o Fat, calories, and physical activity goals
    o Instructions on self-monitoring
    o Safety advice
  ▶ Plus 1 year of access to an online intervention
Implementation

- PCPs referred patients using normal electronic health record (EHR) referral procedures.
- Quarterly feedback was to be provided via routine consultant feedback channels.
- When applicable, a lifestyle coach notified other members of the health care team if health issues arose.
Virtual Lifestyle Management Resources

VLM Handouts:
- Beat the Heat
- Calculating Fat from a Recipe
- Cheat Sheet for Portion Sizes
- How to Take your Heart Rate or Pulse
- Keep it Safe: Stretch those Muscles
- Keep Warm in the Cold

Helpful websites:
- AHA Delicious Recipes
- Heart Healthy African American Dishes
- Heart Healthy Latino Dishes
- Heart Healthy Recipes
- Keystone Active Zone
- Local Farmers Markets

Online Goals & Resources Arm (OGR; minimal intervention): the online intervention was a static web-page including lifestyle handouts & reputable Internet links
The other two arms received comprehensive online lifestyle support (CLS) based on the DPP Lifestyle intervention including the same resources page;
Audio: “Welcome to the first lesson of the Virtual Lifestyle Management Program. The program is designed to help you establish a healthier eating and physical activity routine, to lose weight, and to help you prevent or better manage diabetes. We hope you enjoy the course, and that participating in the program helps you improve your health.”

Virtual Lifestyle Management (VLM) Lesson 1

Getting started losing weight!
self-monitoring tools, with automated graphic feedback;
Hi Brenda,

From your notes and tracking this past week, it sounds like your business trip made it challenging to stick to your regular routine. It’s great, however, that you got right back to tracking on Friday! I’m posting a hand-out for you with tips on healthy lifestyles while traveling — let me know if you want help planning around your next trip.

Your next lesson will help you learn ways to handle problem foods and add activity cues to your day.

Have a great week!

Coach Sue

and regular, brief advice from a lifestyle coach who was considered an extended member of the health care team.
Coaching Protocols Varied Between the Two CLS Arms

• **Standard coaching**: scheduled coaching notes (weekly x 16 weeks, biweekly)

• **As-needed coaching**:
  - coaches modified their counseling intensity to reflect participant need
  - an electronic tool helped identify patients in need of counseling
Measurement and Analyses

- **Patient data:** We measured weight change and used electronic surveys to assess covariates and potential confounders at baseline, 6 months, and 12 months.

- **Provider data:** After the intervention ended, providers were e-mailed survey links on multiple occasions, and paper surveys were distributed at practice meetings and seminars.

- Fisher exact and Chi-square tests were used for comparisons.
Referrals: 1,282

- Eligible: 473
  - Enrolled: 377
    - Screening Failures: 4
      - CLS-S: 126
        - 1-yr data: 88
      - CLS-AN: 129
        - 1-yr data: 85
      - OGR: 118
        - 1-yr data: 90

Over 1,200 referrals from 6 PCPs over 8 months
Referrals: 1,282

Eligible: 473

Enrolled 377

Screening Failures: 4

CLS-S 126

1-yr data: 88

CLS-AN 129

1-yr data: 85

OGR: 118

1-yr data: 90

4 screening failures (no intervention)
Referrals: 1,282

Eligible: 473

Enrolled 377

Screening Failures: 4

CLS-S
126
1-yr data: 88

CLS-AN
129
1-yr data: 85

OGR: 118
1-yr data: 90

373 participants fairly evenly distributed across 3 arms
Referrals: 1,282

Eligible: 473

Enrolled: 377

Screening Failures: 4

Primary outcome collected for 71% of the sample

CLS-S: 126
CLS-AN: 129
OGR: 118

1-yr data: 88
1-yr data: 85
1-yr data: 90
Results: Recruitment and Sample Description

- On average, participants were aged 49.4 (SD 12.6) and weighed 106.1 kg (SD 20.7)
- 76% female
- 20% African American
- Weight-related comorbidities were common
# CLS Groups: Longer Duration of Website Use

<table>
<thead>
<tr>
<th></th>
<th>CLS-S</th>
<th>CLS-AS</th>
<th>OG&amp;R</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Days enrolled at last login</td>
<td>Median (IQR)</td>
<td>Median (IQR)</td>
<td>Median (IQR)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td>185.5 (51.0,359.0)</td>
<td>199.5 (49.00,362.0)</td>
<td>6.00 (0.00,45.00)</td>
<td>&lt;0.001¹</td>
</tr>
<tr>
<td>Last login w/in 30 days of study end</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>33</td>
<td>38</td>
<td>4</td>
<td>&lt;0.0001³</td>
</tr>
</tbody>
</table>

¹Kruskal-Wallis test; ²Wilcoxon test³
<table>
<thead>
<tr>
<th>Last lesson completed</th>
<th>CLS-S</th>
<th>CLS-M</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Last lesson completed</td>
<td>Median (IQR)</td>
<td>Median (IQR)</td>
<td>0.7142</td>
</tr>
<tr>
<td></td>
<td>8.50 (3.00,16.00)</td>
<td>7.00 (3.00,17.00)</td>
<td></td>
</tr>
<tr>
<td>Completed lesson 16</td>
<td>%</td>
<td>%</td>
<td>0.40043</td>
</tr>
<tr>
<td>Completed lesson 24</td>
<td>18</td>
<td>20</td>
<td>0.58213</td>
</tr>
</tbody>
</table>
Lesson Completion in CLS Arms:
~1/3 Finished Core Lessons

<table>
<thead>
<tr>
<th># of lessons completed</th>
<th>CLS-S Median (IQR)</th>
<th>CLS-M Median (IQR)</th>
<th>p-value</th>
</tr>
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<tbody>
<tr>
<td>8.50 (3.00,16.00)</td>
<td>7.00 (3.00,17.00)</td>
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<td>18</td>
<td>20</td>
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</table>

No difference between CLS groups
Average 6-month Weight Loss in Each Arm: 2-3 kg
Weight Loss was Sustained at 12 Months: No Difference Between Arms
Weight Loss was Sustained at 12 Months: No Difference Between Arms
Weight Loss was Sustained at 12 Months: No Difference Between Arms

Month of Enrollment

Weight Change (kg)

OGR  CLS-M  CLS-S

A little more than expected
Weight Loss was Sustained at 12 Months: No Difference Between Arms

Month of Enrollment

Weight Change (kg)

OGR  CLS-M  CLS-S

Quite a lot less than expected

-2.5

-3.0

-4.0

-6.0
Potentially Relevant Factors

• Survey data on the use of non-study resources for weight loss differed by study arm at 6 months of enrollment:
  ▶ 14.4% OGR
  ▶ 6.3% CLS-M
  ▶ 3.4% CLS-S (p=0.015)

• CLS participants experienced considerable technical malfunctions:
  ▶ 46 “site-wide” errors
  ▶ Average resolution time: 44 days each
### PCP Data: Sample Description

<table>
<thead>
<tr>
<th>Category</th>
<th>Non-Adopters N=17</th>
<th>Adopters N=50</th>
<th>Total</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Female</td>
<td>29%</td>
<td>52%</td>
<td>46%</td>
<td>0.1066</td>
</tr>
<tr>
<td>% Latino</td>
<td>6%</td>
<td>4%</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>59%</td>
<td>76%</td>
<td>72%</td>
<td>0.1032</td>
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<tr>
<td>Black</td>
<td>6%</td>
<td>0%</td>
<td>1%</td>
<td></td>
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<tr>
<td>Asian</td>
<td>24%</td>
<td>22%</td>
<td>22%</td>
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<tr>
<td>Other</td>
<td>12%</td>
<td>2%</td>
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<tr>
<td>Status</td>
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<tr>
<td>Resident</td>
<td>71%</td>
<td>12%</td>
<td>27%</td>
<td>&lt;0.0001</td>
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<tr>
<td>Fellow</td>
<td>12%</td>
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<td>5%</td>
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<tr>
<td>Attending</td>
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Of 185 providers, 67 (36%) completed surveys.
## Results: Integration with Primary Care

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</table>

Adopters differed from non-adopters in training status.
### Implementation and PCP Engagement (% Agreeing)

<table>
<thead>
<tr>
<th>Questions</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>The enrollment process integrated smoothly with my normal workflow.</td>
<td>94</td>
</tr>
<tr>
<td>The process for providing me with my patients’ 1-year follow-up reports integrated smoothly with my normal workflow.</td>
<td>80</td>
</tr>
<tr>
<td>I found the physician reports detailing my patients’ study findings [e.g., every-6-month body weight, blood pressure, quality of life] useful.</td>
<td>73</td>
</tr>
<tr>
<td>Did you typically provide your patients with feedback regarding their efforts to change their lifestyles or body weight through the OCELOT-PC study?</td>
<td>53</td>
</tr>
<tr>
<td>Item</td>
<td>Non-adopt (n=17)</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>I prefer to counsel on healthy eating and physical activity myself, without referring [patients] for additional counseling.</td>
<td>29</td>
</tr>
<tr>
<td>There is typically sufficient time during my appointments to counsel patients adequately on diet, physical activity, and obesity.</td>
<td>29</td>
</tr>
<tr>
<td>I find it useful to refer patients to community …resources for promoting healthy lifestyles.</td>
<td>71</td>
</tr>
<tr>
<td>There is typically sufficient time during my appointments to refer patients for counseling on diet, physical activity, and obesity.</td>
<td>88</td>
</tr>
<tr>
<td>My patients are generally not interested in receiving counseling for diet, physical activity, and weight loss.</td>
<td>24</td>
</tr>
</tbody>
</table>
## Predictors of Adoption: Access or Interest in Internet (% Agreeing)

<table>
<thead>
<tr>
<th></th>
<th>Non-adopt (n=17)</th>
<th>Adopt (n=49)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>My patients are generally not interested in using the Internet to access counseling for diet, physical activity, and weight loss.</td>
<td>47</td>
<td>22</td>
<td>0.007</td>
</tr>
<tr>
<td>Many of my patients are likely to have minimal computer skills.</td>
<td>76</td>
<td>35</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Many of my patients are unlikely to have Internet access.</td>
<td>65</td>
<td>33</td>
<td>0.042</td>
</tr>
</tbody>
</table>
### Predictors of Adoption: Patient Need and PCP Workflow (% Agreeing)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Adopt (n=17)</th>
<th>Non-adopt (n=49)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most of my patients would not benefit from advice to lose weight through exercise and a low-fat diet.</td>
<td>12</td>
<td>20</td>
<td>0.470</td>
</tr>
<tr>
<td>Obesity should be managed outside the clinical setting.</td>
<td>24</td>
<td>18</td>
<td>0.528</td>
</tr>
<tr>
<td>Referring patients to the OCELOT-PC study [would have] interfered with my normal workflow.</td>
<td>12</td>
<td>6</td>
<td>0.178</td>
</tr>
</tbody>
</table>
Limitations

- Single geographic region and health care system
- Technical malfunctions limited CLS intervention fidelity and were difficult to assess
- Potential for contamination?
Conclusions

• All interventions led to weight loss over 1 year and weight regain was not seen in any group.
• No statistically significant difference was observed in the estimated differences between the three groups.
  ▶ Group-specific estimated weight change suggests that the CLS with as-needed coaching had the most clinically relevant results.
• Greater weight loss in the OGR group than anticipated from the literature may reflect participants’ greater use of personal resources for lifestyle management.
Conclusions (Continued)

• The combination of a referral model and an online health care team member can smoothly integrate online self-management support for obesity into the workflow of routine primary care.
  ► Only about half of PCPs provided patients with feedback.

• The adoption of online self-management support tools may be most likely among PCPs who:
  ► have limited available time for counseling,
  ► do not have a strong preference for personally delivering preventive behavioral counseling, and
  ► have completed residency training.

• PCPs’ perception that their patients lack Internet access, skills, or interest can inhibit adoption of online counseling.
Implications

- Online lifestyle support generates a lot of interest among patients and providers, and can result in clinically significant weight loss.
- Intervention fidelity can be difficult to assure in IT interventions.
- "Low-cost" self-management support programs may result in higher out-of-pocket patient costs.
- Choice of control group is a challenge in pragmatic trials.
• Extending the health care team to deliver virtual self-management support is a feasible method for delivering convenient, intensive preventive counseling.

• Although the referral model worked well from a workflow perspective, its promotion of ongoing lifestyle dialogue was suboptimal, and more attention is needed in this area.

• An understanding of clinicians’ time constraints, counseling preferences, and perceptions of their patients’ technical capabilities can provide insight into the adoption of technology for self-management support.
Contact Info

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University of Pittsburgh
Cognitive Aiding Tools to Enhance the Usability of Internet-based Health Applications for Older Adult Consumers

Sara J. Czaja, Ph.D.
Leonard M. Miller Professor
Department of Psychiatry and Behavioral Sciences
Scientific Director
Center on Aging
University of Miami Miller School of Medicine
• Increase in the elderly population especially “oldest old” who require more care and long-term assistance
Number of people age 65 and over, by age group, selected years 1900-2000 and projected 2010-2050

Note: Data for 2010-2050 are projections of the population.
Reference population: These data refer to the resident population.
Source: U.S. Census Bureau, Decennial Census and Projections.
Dramatic increases in health care expenditures have occurred in the United States and most other countries.

Trends: move from inpatient to outpatient care; and an increased reliance on family members to provide needed care and support.

Consumers are expected to take more active role in health self-management.

Increased use of technology within the health care arena has expanded the realm of health-related tasks performed by consumers.
• The Internet is increasingly being used as a source of health information.

• In 2012, 85% of adults in the United States used the Internet and 72% searched for health information online (Pew Internet and American Life Project, 2013).

• Information searched:
  ▶ Specific disease/medical problems
  ▶ Diagnoses
  ▶ Medical treatments, medications

• The majority of health information seekers (77%) begin with a search engine.
Potential Advantages of Technology

- Eliminates the need for patients and health care professionals to travel.
- Permits more flexible appointment scheduling.
- Permits easier access to a wider array of information and services especially for rural and underserved patients.
- Permits increased access to specialists.
- Fosters patient empowerment (e.g., well-informed questions; information on treatment options).
Potential Disadvantages of Technology

- Proliferation of incorrect or inappropriate information.
- Proliferation of too much information.
- Potential disruptions in physician/patient relationships.
- Privacy issues.
- Promotion of false sense of security.
- Potential for increasing health care disparities.
Google search engine, May 2014:

- “Depression”: 985,000,000
- “Anxiety”: 47,900,000
- “Dementia”: 14,300,000
- “Diabetes”: 77,400,000
- “Caregiving”: 2,410,000,000
Access to Internet health information has an influence on:

- Decisions about seeking care,
- Treatment choices,
- Adherence and patient/physician interactions

In 2012 35% of online “health seekers” looked for diagnoses and only 53% followed up with their physicians.
• **Domain expertise:** Basic knowledge of the problem domain (e.g., depression) and credible sources of information

• **System expertise:** Basic facility with the physical interface to the search system (basic computer/Internet skills)

• **Information-seeking expertise:** Knowledge concerning the configuration of information and of information-seeking methods (e.g., use of links, search boxes, knowledge of reliable sites)
Basic Requirements of Using Online Health Applications

• Enter the appropriate search term.
• Select a credible Web site
  ► Accurate
  ► Current
  ► Reliable source
• Comprehend the information.
• Integrate the information from numerous Web sites and other information sources.
• Use the information appropriately.
Issues

• These skill requirements are challenging for:
  ► People with cognitive declines
    o Older adults
    o Patients with mental illness
    o Individuals with traumatic brain injury
    o People with low literacy, low health literacy, or low numeracy
  ► People with limited Internet/computer experience
Age-related Differences in Crystallized Ability

• Different developmental trends for two higher order human abilities are termed *crystallized* and *fluid* abilities (Horn, 1982; Li et al., 2004).

• Crystallized abilities refer to the end products of information processing; namely, the common knowledge base that people usually acquire at a particular sociocultural time period.

• That type of ability tends to show a rise into adulthood and then a peak in the 50s or 60s followed by slow decline. It is measured by tests such as vocabulary and information.
CREATE Crystallized Ability
(n=1197)
• Fluid abilities are thought to represent cognitive operations important in being able to solve novel problems efficiently.

• Fluid abilities typically involve inference tasks with novel materials: abstract problem-solving ability.
CREATE Fluid Ability
(n=1174)

R Sq Linear = 0.375
Improving Meaningful Access of Internet Health Information for Older Adults

Study aims:

- To refine, through a user-centered iterative design process, a set of software aiding tools that can be used by older adults in the performance of Internet-based health management tasks.

- To evaluate the feasibility, acceptability, and usability of these tools among adult health consumers and the impact of the use of these tools on the performance of Internet-based health management tasks.

The study is a collaborative initiative between the Palo Alto Research Corporation (PARC) and the University of Miami Miller School of Medicine (UM).
• **Phase 1:** Focus groups and a usability analysis where the tools were tailored for health information-seeking and older health consumers through a user-centered iterative design process.

• **Phase 2:** A randomized trial where a sample of users used the tools to find and “make sense” of Internet-based health information to solve “ecologically valid” health problems.
Brief Description of Tools

• **Mr. Taggy Search Engine:** allows users to identify content relevant to their search problem as well as associated Web sites by providing a list of search results together with a side list of search tags.

• **SparTag.us Notebook:** allows a user to build a “notebook” of information related to a topic, which can be used to collect, organize, and save material of interest within Web pages, including the source Web site, and build a collective knowledge space on a particular topic.

• **Automated Highlighting:** highlights words and phrases that are related to the information interests of the user.

• **Pop-Up Glossary:** helps to enhance comprehension of technical language by providing simple common language translations of medical terminology.
Mr. Taggy Search Browser

Not sure where to start? Try clicking on a word below...

- best
- cheap
- cool
- crazy
- daily
- helpful
- interesting
- mobile
- social
- useful

and

...then click on a second word here to begin exploring.

- books
- business
- economy
- entertainment
- environment
- fashion
- finance
- fitness
- health
- internet
- jobs
- lifestyle
- politics
- sports
- technology
- travel
- weather

About MrTaggy ~ Blog ~ Terms ~ Privacy ~ Copyright 2009 Palo Alto Research Center, Inc. ~ This site uses Thumbshots previews
Thumbs Up/Thumbs Down Buttons
Each gold medal is made up of 92.5 percent silver and 1.34 percent gold, with the remainder copper. The silver medal (which represents second place) is made up of 92.5 percent silver, with the remainder copper. The bronze medal is made up of 97 percent copper, 2.5 percent zinc and 0.5 percent tin. The value of the materials in the gold medal is about £410 (US $644), the silver about £210 (US $330), and the bronze about £3 (US $4.71) as of 30 July 2012.
Vatican City

Vatican City is an independent state within the city of Rome, Italy. It is the smallest independent state in the world, with an area of approximately 44 hectares (110 acres) and a population of just over 800. It is landlocked and its territory consists of a walled enclave within the city of Rome.

Vatican City State was established in 1929 by the Lateran Treaty, signed by Cardinal Secretary of State Pietro Gasparri, on behalf of Pope Pius XI and by Prime Minister and Head of Government Benito Mussolini on behalf of King Victor Emmanuel III of Italy.

Vatican City State is distinct from the Holy See, which dates back to early Christianity and is the main ecclesiastical see of a billion Latin and Eastern Catholic adherents around the globe. Ordinaries of Vatican City are published in Italian; official documents of the Holy See are issued mainly in Latin. The two entities have distinct passports: the Holy See, not being a country, issues only diplomatic and service passports, whereas Vatican City State issues normal passports. In each case very few passports are issued.

The Lateran Treaty in 1929, which brought the city-state into existence, spoke of it as a new creation (Preamble and Article III), not as a vestige of the much larger Papal States (756–1870) that had previously encompassed much of central Italy. Most of this territory was ceded to the Kingdom of Italy in the late 19th century and was occupied by Rome in 1929.
Much of what is known about the human health effects of trichloroethylene is based on occupational exposures. Beyond the effects to the central nervous system, workplace exposure to trichloroethylene has been associated with toxic effects in the liver and kidney.[9] Over time, occupational exposure limits on trichloroethylene have tightened, resulting in more stringent ventilation controls and personal protective equipment use by workers.

**P22081JA: TCE effects**

My notes: Liver and kidneys may be impacted. It may have an effect on the central nervous system.

http://en.wikipedia.org/wiki/Trichloroethylene

Some are exposed to TCE through contaminated drinking water. With a specific gravity greater than 1, trichloroethylene can be present as a dense nonaqueous phase liquid if sufficient quantities are spilled in the environment. Another significant source of vapor exposure in Superfund sites that had contaminated groundwater, such as the Twin Cities Army Ammunition Plant, was by showering. TCE readily volatilizes out of hot water and into the air. Long, hot showers would then volatilize more TCE into the air. In a home closed tightly to conserve the cost of heating and cooling, these vapors would then recirculate.

**P22081JA: TCE exposure**

My notes: TCE exposure not good at all.

http://en.wikipedia.org/wiki/Trichloroethylene

The chemical compound trichloroethylene (C₂H₃Cl₃) is a chlorinated hydrocarbon commonly used as an industrial solvent. It is a clear non-flammable liquid with a sweet smell. It should not be confused with the similar 1,1,1-trichloroethane, which is commonly known as chloroform.
Phase 1 Sample Characteristics

- Twenty-three older adults, all English speaking, participated.
- They were 65+ years of age and with computer and Internet experience; participated in three separate focus groups (consisting of eight, eight, and seven people, respectively).
- Each was paid $30 for participating.
- The total sample consisted of nine males and 14 females with a mean age of 73.1 years (SD = 8.1).
- Two participants had completed high school, nine had completed some college, and 12 had a college degree or higher.
- Thirteen participants reported their health to be very good, eight reported their health to be good, and two reported their health to be fair.
From the Health Information-Seeking questionnaire, of 11 sources of health information considered (e.g., popular books, friends, or family, newspapers): participants indicated the two sources that they used most of the time or always were the Internet \((n = 13)\) and their doctors or other providers \((n = 14)\).

In response to the question, “In general, how difficult is it for you to find the health information that you need?” only one participant indicated that it was not difficult or was just a little difficult; five participants indicated it was moderately difficult and 17 participants indicated that it was quite or extremely difficult.
Data were derived from the transcriptions of the group and individual discussions.

- The initial focus group discussion revealed a number of problems participants encountered that particularly related to searching and making sense of health information.

- One participant noted, “I was researching a while ago on shingles, and if you research that [topic] you get all kinds of ambivalent information which doesn’t necessarily equal with each other [sic].”
Positive Comments:

- “It would give you a variety of options of what to zero in on what you are looking for.”
- “It’s helpful because of the thumbs up and thumbs down mechanism.”
- “It’s more specific; subject can be found faster than Yahoo or Google.”
- “It gives you words (tags)—that I liked.”
• Positive Comments:
  ► “It would enable me to integrate information.”
  ► “You can grab all the information at once and then go back leisurely to read it.”
  ► “I look at a dozen sites. Often, there are a few items of interest in each Web site (and) the idea of putting that all into one place is good.”
  ► “It organizes all the information I’m interested in.”
• Negative Comments:
  ► “I have never needed to save information in this way.”
  ► “I prefer printing information.”
  ► “I don’t quite understand how to get started using it.”
# One-on-One Interview Results (N = 23)

<table>
<thead>
<tr>
<th>Individual Discussion Questions</th>
<th>M</th>
<th>S</th>
<th>A</th>
<th>G</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would you find the tool useful?</td>
<td>Yes</td>
<td>18</td>
<td>17</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>3</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Would you use this tool?</td>
<td>Y</td>
<td>19</td>
<td>16</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>4</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Do you think this tool would be</td>
<td>Y</td>
<td>19</td>
<td>20</td>
<td>19</td>
</tr>
<tr>
<td>easy to use?</td>
<td>N</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Do you think it would be hard to</td>
<td>Y</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>use this tool?</td>
<td>N</td>
<td>19</td>
<td>22</td>
<td>23</td>
</tr>
<tr>
<td>Do you think this tool would</td>
<td>Y</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>make searching/finding health</td>
<td>N</td>
<td>21</td>
<td>22</td>
<td>22</td>
</tr>
<tr>
<td>information more difficult?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you concerned that you would</td>
<td>Y</td>
<td>2</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>forget to use this tool or how</td>
<td>N</td>
<td>21</td>
<td>19</td>
<td>21</td>
</tr>
<tr>
<td>to use it?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
• A sample of 80 adults was randomized into one of four conditions:
  1. Diabetes scenario aided (Mr. Taggy)
  2. Diabetes scenario unaided
  3. MS scenario aided (Spartagus notebook)
  4. MS scenario unaided

• Participants were asked to use the tools to solve “ecologically valid” health problem scenarios.
Diabetes Scenario Task: developed to examine participants’ use of the Mr. Taggy search engine and the automated glossary:

- A story was developed in which the central character, Daniel, was introduced along with a description of his lifestyle, eating habits, and family history of diabetes. After reading the story, the participant was asked to explore each aspect of Daniel’s lifestyle and to decide whether or not he was at risk of developing diabetes. The participant was then asked to write a summary that explained this risk in the context of his (Daniel’s) family history and lifestyle and to provide specific steps that he should take with regard to eating sugar, pasta, exercise, taking vitamin and mineral supplements, etc.

- Using the Mr. Taggy search engine, participants then had to complete three more questions that dealt with blood glucose levels and the glycemic index (GI).
**MS Scenario Task:** developed to examine participants’ use of the Spartag.us Notebook tool and the automated glossary:

- The central character was a woman named Jennifer who might or might not have multiple sclerosis (MS). Participants were asked to cast themselves in the role of a doctor’s special medical assistant charged with reading Jennifer’s medical history, in narrative form, that described her current state of health, mother’s medical history, and a chronology of medical and life events dating back to 2006 through to the present day. The chronology detailed a series of attacks of weakness and numbness in her extremities, a rock-climbing accident, a blood test, and her employment history.

- Instructions stressed the two main participant goals: (1) to copy all relevant information from the Internet to the Spartag.us Notebook using Google as their search engine and (2) to write a complete detailed summary using information they copied to the notebook.

- Participants were also asked to write a summary examining all of the relevant parts of the medical history, how they were related to Jennifer’s current medical state, and provide a diagnosis, to whatever degree they were capable of, of her medical condition (i.e., whether she had MS or not or what other event, exposure, etc., could explain her current medical condition).
## Sample Characteristics for Phase 2 (N=80)

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Diabetes Scenario</th>
<th>MS Scenario</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unaided (N=20)</td>
<td>Aided (N=20)</td>
</tr>
<tr>
<td>Age (M, SD)</td>
<td>58.25  10.62</td>
<td>55.75  10.16</td>
</tr>
<tr>
<td>Computer Proficiency (M, SD)***</td>
<td>138.4  21.05</td>
<td>131.1  22.91</td>
</tr>
<tr>
<td>Health Literacy (M, SD)**</td>
<td>4.65   1.309</td>
<td>3.70   1.342</td>
</tr>
<tr>
<td>Gender, Male, n,%</td>
<td>8     40</td>
<td>3     15</td>
</tr>
<tr>
<td>Gender, Female, n,%</td>
<td>12    60</td>
<td>17    85</td>
</tr>
<tr>
<td>Ethnicity, n,%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>3     15</td>
<td>4     20</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>10    50</td>
<td>10    50</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>6     30</td>
<td>5     25</td>
</tr>
<tr>
<td>Education, n,%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School or Less</td>
<td>4     20</td>
<td>4     20</td>
</tr>
<tr>
<td>Some College</td>
<td>9     45</td>
<td>9     45</td>
</tr>
<tr>
<td>College Graduate/Postgraduate</td>
<td>7     35</td>
<td>7     35</td>
</tr>
<tr>
<td>Yearly Household Income n,%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $20,000</td>
<td>8     40</td>
<td>11    55</td>
</tr>
<tr>
<td>$20,000 to $49,999</td>
<td>7     35</td>
<td>8     40</td>
</tr>
<tr>
<td>More than $49,999</td>
<td>4     20</td>
<td>0     0</td>
</tr>
<tr>
<td>Occupational Status n,%</td>
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<td></td>
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<tr>
<td>Work Full Time</td>
<td>0     0</td>
<td>2     10</td>
</tr>
<tr>
<td>Work Part Time</td>
<td>1     5</td>
<td>2     10</td>
</tr>
<tr>
<td>Seeking Employment, Laid off</td>
<td>7     35</td>
<td>4     20</td>
</tr>
<tr>
<td>Retired</td>
<td>9     45</td>
<td>5     25</td>
</tr>
</tbody>
</table>
Sample Characteristics for Phase 2 (N=80)

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Diabetes Scenario</th>
<th>MS Scenario</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unaided (N=20)</td>
<td>Aided (N=20)</td>
</tr>
<tr>
<td>General Health Status n, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Fair</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Good</td>
<td>9</td>
<td>45</td>
</tr>
<tr>
<td>Very Good</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>Excellent</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Length of time using Internet n, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 6 months</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Between 6 months and 1 year</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>More than 1 year, but less than 5 years</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>5 years or more</td>
<td>18</td>
<td>90</td>
</tr>
<tr>
<td>Hours/week using Internet n, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 1 h</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Between 1 h and 5 h</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>More than 5 h, but less than 10 h</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>10 h or more</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>Reported diabetes lifetime/now n, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Reported MS lifetime/now n, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Cognitive Measures*</td>
<td>Diabetes Scenario</td>
<td>Multiple Sclerosis Scenario</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td></td>
<td>Unaided</td>
<td>Aided</td>
</tr>
<tr>
<td>CVLT (M, SD)</td>
<td>27.15</td>
<td>5.659</td>
</tr>
<tr>
<td>Paper Folding (M, SD)</td>
<td>6.55</td>
<td>2.743</td>
</tr>
<tr>
<td>Reading Comprehension (M, SD)</td>
<td>21.30</td>
<td>9.985</td>
</tr>
<tr>
<td>Digit Symbol (M, SD)</td>
<td>54.95</td>
<td>10.15</td>
</tr>
<tr>
<td>Digit Symbol Recall (M, SD)</td>
<td>5.20</td>
<td>2.546</td>
</tr>
<tr>
<td>Shipley (M, SD)</td>
<td>31.75</td>
<td>3.370</td>
</tr>
<tr>
<td>Inference Test (M, SD)</td>
<td>10.00</td>
<td>4.155</td>
</tr>
<tr>
<td>Task Performance Scores (M, SD)*</td>
<td>8.10</td>
<td>2.453</td>
</tr>
</tbody>
</table>

*CVLT measures memory span. Paper Folding measures Spatial/Visualization Ability. Reading Comprehension and Shipley measure Verbal Ability. Digit Symbol measures Perceptual Speed. Digit Symbol Recall measures Working/Incidental Memory. Inference Test measures Reasoning and Inductive Ability** Diabetes Scenario Score Range (0-12), Multiple Sclerosis Scenario Score Range (0-21).
# Correlations of Various Cognitive Measures with Task Performance Scores

## Cognitive Test Aided (n=20) | Unaided (n=20) | Overall (n=40) | Aided (n=20) | Unaided (n=20) | Overall (n=40)
---|---|---|---|---|---
**CVLT - Immediate** | .632*** | .195 | .403*** | .384* | .216 | .363**
**Paper Folding** | .180 | .265 | .185 | .384* | .057 | .099
**Reading Comprehension** | .454** | .374 | .444*** | .482** | .046 | .323**
**Digit Symbol Substitution** | .333 | .462** | .427*** | .508** | .228 | .360**
**Digit Symbol Recall** | -.251 | .102 | -.038 | -.226 | -.115 | -.073
**Shipley Vocabulary** | .701*** | .230 | .516*** | .458** | .189 | .344**
**Inference Test** | .499** | .328 | .462*** | .653*** | .062 | .387**

Note: Significance levels are 2-tailed, *p < = .1, **p < = .05, ***p < = .01.
# Usability Measures for the Mr. Taggy Search Browser

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree/Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Disagree/Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home Page</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>…. was easy to learn.</td>
<td>17 85</td>
<td>0 0</td>
<td>3 15</td>
</tr>
<tr>
<td>…. was hard to use.</td>
<td>2 10</td>
<td>2 10</td>
<td>16 80</td>
</tr>
<tr>
<td>…. helped me find the information I needed.</td>
<td>15 75</td>
<td>5 25</td>
<td>0 0</td>
</tr>
<tr>
<td><strong>Tag Clouds</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>…. were easy to learn.</td>
<td>17 85</td>
<td>1 5</td>
<td>2 10</td>
</tr>
<tr>
<td>…. were hard to use.</td>
<td>1 5</td>
<td>2 10</td>
<td>17 85</td>
</tr>
<tr>
<td>…. helped me find the information I needed.</td>
<td>13 65</td>
<td>4 20</td>
<td>3 15</td>
</tr>
<tr>
<td><strong>Search Results Page</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>…. was hard to learn.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>…. was easy to use.</td>
<td>15 75</td>
<td>3 15</td>
<td>2 10</td>
</tr>
<tr>
<td>…. helped me find the information I needed.</td>
<td>15 75</td>
<td>2 10</td>
<td>3 15</td>
</tr>
<tr>
<td>…. was well organized.</td>
<td>16 80</td>
<td>4 20</td>
<td>0 0</td>
</tr>
<tr>
<td><strong>Thumbs Up / Thumbs Down Buttons</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>…. were easy to learn.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>…. was easy to use.</td>
<td>17 85</td>
<td>2 10</td>
<td>1 5</td>
</tr>
<tr>
<td>…. did not help me find the information I needed.</td>
<td>4 20</td>
<td>7 35</td>
<td>9 45</td>
</tr>
<tr>
<td>The sizes of the buttons were too small.</td>
<td>0 0</td>
<td>10 50</td>
<td>10 50</td>
</tr>
</tbody>
</table>
# Usability Measures for the Mr. Taggy Search Browser

<table>
<thead>
<tr>
<th>Feature</th>
<th>Strongly Agree/ Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Disagree/ Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tag Sidebar</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>……. was hard to learn.</td>
<td>3 (15%)</td>
<td>3 (15%)</td>
<td>14 (70%)</td>
</tr>
<tr>
<td>……. was easy to use.</td>
<td>16 (80%)</td>
<td>2 (10%)</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>……. helped me find the information I needed.</td>
<td>12 (60%)</td>
<td>5 (25%)</td>
<td>3 (15%)</td>
</tr>
<tr>
<td><strong>Search Engine, Overall</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>……. was easy to learn.</td>
<td>16 (80%)</td>
<td>2 (10%)</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>……. was hard to use.</td>
<td>3 (15%)</td>
<td>3 (15%)</td>
<td>14 (70%)</td>
</tr>
<tr>
<td>……. helped me find the information I needed.</td>
<td>13 (65%)</td>
<td>7 (35%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>Find Tool</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>……. was easy to learn.</td>
<td>16 (80%)</td>
<td>1 (5%)</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>……. was easy to use.</td>
<td>15 (75%)</td>
<td>2 (10%)</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>……. helped me find the information I needed.</td>
<td>10 (50%)</td>
<td>8 (40%)</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>….features and results were hard to read.</td>
<td>3 (15%)</td>
<td>6 (30%)</td>
<td>11 (55%)</td>
</tr>
<tr>
<td><strong>Automated Glossary Feature, Overall</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>…. were easy to learn.</td>
<td>16 (80%)</td>
<td>3 (15%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>…. were easy to use.</td>
<td>16 (80%)</td>
<td>3 (15%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>…. helped me find the information I needed.</td>
<td>9 (45%)</td>
<td>11 (55%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Definitions were hard to read.</td>
<td>2 (10%)</td>
<td>8 (40%)</td>
<td>10 (50%)</td>
</tr>
</tbody>
</table>
## Usability Measures for the Spartagus Notebook

<table>
<thead>
<tr>
<th>Feature</th>
<th>Strongly Agree/Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Disagree/Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tag Tool Feature</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>.... was hard to learn.</td>
<td>1 5</td>
<td>2 10</td>
<td>17 85</td>
</tr>
<tr>
<td>.... was easy to use.</td>
<td>19 95</td>
<td>0 0</td>
<td>1 5</td>
</tr>
<tr>
<td>.... helped me collect and organize the info. I needed.</td>
<td>19 95</td>
<td>0 0</td>
<td>1 5</td>
</tr>
<tr>
<td><strong>Note Box Feature</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>.... were easy to learn.</td>
<td>20 100</td>
<td>0 0</td>
<td>0 0</td>
</tr>
<tr>
<td>.... were easy to use.</td>
<td>20 100</td>
<td>0 0</td>
<td>0 0</td>
</tr>
<tr>
<td>.... helped me write notes for each clipping.</td>
<td>18 90</td>
<td>2 10</td>
<td>0 0</td>
</tr>
<tr>
<td><strong>Notebook Search Tool</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>.... was hard to learn.</td>
<td>2 10</td>
<td>0 0</td>
<td>18 90</td>
</tr>
<tr>
<td>.... was easy to use.</td>
<td>20 100</td>
<td>0 0</td>
<td>0 0</td>
</tr>
<tr>
<td>.... helped me find clippings and info, in Notebook.</td>
<td>18 90</td>
<td>2 0</td>
<td>0 0</td>
</tr>
<tr>
<td><strong>Notebook Tag Area Feature</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>.... was hard to learn.</td>
<td>3 15</td>
<td>0 0</td>
<td>17 85</td>
</tr>
<tr>
<td>.... was easy to use.</td>
<td>19 95</td>
<td>0 0</td>
<td>1 5</td>
</tr>
<tr>
<td>.... helped me find clippings and info, in Notebook.</td>
<td>19 95</td>
<td>1 5</td>
<td>0 0</td>
</tr>
<tr>
<td></td>
<td>Strongly Agree/Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree/Strongly Disagree</td>
</tr>
<tr>
<td>-----------------------------------------------------------------</td>
<td>----------------------</td>
<td>-----------------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td><strong>Notebook, Overall</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>.... was easy to learn.</td>
<td>19 95</td>
<td>1 5</td>
<td>0 0</td>
</tr>
<tr>
<td>.... was easy to use.</td>
<td>18 90</td>
<td>1 5</td>
<td>1 5</td>
</tr>
<tr>
<td>.... helped me find the information I wanted.</td>
<td>19 95</td>
<td>1 5</td>
<td>0 0</td>
</tr>
<tr>
<td>.... was hard to read.</td>
<td>0 0</td>
<td>1 5</td>
<td>19 95</td>
</tr>
<tr>
<td>Notebook and features were well organized.</td>
<td>18 90</td>
<td>1 5</td>
<td>1 5</td>
</tr>
<tr>
<td><strong>Find Tool</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>.... was easy to learn.</td>
<td>18 90</td>
<td>2 10</td>
<td>0 0</td>
</tr>
<tr>
<td>.... was easy to use.</td>
<td>18 90</td>
<td>2 10</td>
<td>0 0</td>
</tr>
<tr>
<td>.... helped me find the information I wanted.</td>
<td>14 70</td>
<td>6 30</td>
<td>0 0</td>
</tr>
<tr>
<td><strong>Automated Glossary Feature, Overall</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>.... were easy to learn.</td>
<td>19 95</td>
<td>1 5</td>
<td>0 0</td>
</tr>
<tr>
<td>.... were easy to use.</td>
<td>19 95</td>
<td>1 5</td>
<td>0 0</td>
</tr>
<tr>
<td>.... helped me find the information I wanted.</td>
<td>12 60</td>
<td>6 30</td>
<td>2 10</td>
</tr>
<tr>
<td>Definitions were hard to read.</td>
<td>0 0</td>
<td>5 25</td>
<td>15 75</td>
</tr>
</tbody>
</table>
Conclusions and Lessons Learned

• Cognitive-aiding tools have the potential to help older consumers find and use Internet-based health information.

• Although the tools did not enhance performance, all of our participants were able to use the tools after one training session.

• These tools are feasible and acceptable to older adult consumers.

• These tools need to be tested with diverse user groups using a user-centered design approach.

• It is important to ensure that sufficient training, opportunities for practice, and instructional support are available.

• The currently available tools are still too complex and cognitively demanding.
Sara Czaja
SCzaja@med.miami.edu
University of Miami Miller School of Medicine
Overview

- Epidemiological studies
- Focus groups / Survey study
  - Parents
  - Physicians
- Pilot study to build social media Web site
- Randomized trial to evaluate social media Web site
Epidemiology of Vaccine Refusal

- Compared to vaccinated children, children of parents who refused immunizations were:
  - 23 times more likely to become infected with pertussis
  - 9 times more likely to contract varicella
  - 7 times more likely to be hospitalized for pneumococcal disease or lobar pneumonia
Mixed Methods Study: Focus Groups and Survey

- Parents enrolled in KPCO
  - Pregnancy
  - Internet
  - Balance
  - Not enough time with pediatrician
  - Constantly reevaluate decisions
  - Overall trust pediatricians’ advice, but do not trust their advice on vaccines
Mixed Methods Study: Focus Groups and Survey

- Pediatricians
  - Important issue
  - Not enough time
  - Hard to keep up with latest concerns
  - Establishing trust can be difficult
  - Would welcome additional resources to address issue
Using Social Media to Address Parental Vaccination Concerns
• E-patient
  ► Americans tend to choose the Internet over their physician for health information.
  ► 60% of adults look online for health information (Pew 2011, 2013).
    o A 2.5-fold increase from 2000
  ► Average user is female, < 50 years, college educated, and HHI >$50,000
• E-patient
  ▶ Using second generation of Internet applications: Web 2.0 and social media
  ▶ 46% of adults and 62% of e-patients report using social media to find health information.
What are Web 2.0 and Social Media?
Web 2.0: A Multi-Directional Communication Model

- Website Developers
  - Content
- User Population
  - Information
  - Messages
• Online discussion and support groups
  - Cancer, diabetes, MS

• Blogs
  - Mommy and women’s health blogs
  - Diet, fitness
  - Natural holistic
  - Diabetes
  - Mayo Clinic
• Twitter
  ◀ CDC and WHO during the H1N1 pandemic
H1N1 Social Media Response

Social Media at Kaiser Permanente
Media Coverage

- Print circulation: 731,000
- Online subscribers: 1.3 million
- #3 most emailed story for 3 days on nytimes.com

The Face of Future Health Care

OAKLAND, Calif. — When people talk about the future of health care, Kaiser Permanente is often the model they have in mind.

The organization, which combines a nonprofit insurance plan with its own hospitals and clinics, is the kind of holistic health system that President Obama’s health care law encourages.

Kaiser has sophisticated electronic records and computer systems that — after 10 years and $30 billion in technology spending — have led to better-coordinated patient care, another goal of the president. And because the plan is paid a fixed amount for medical care per member, there is a strong financial incentive to keep people healthy and out of the hospital, the same goal of the hundreds of accountable care organizations now being erected.
...With Social Media Amplification

The Face of Future Health Care

OAKLAND, Calif. — When people talk about the future of health care, Kaiser Permanente is often the model they have in mind.

The organization, which combines a nonprofit insurance plan with its own hospitals and clinics, is the kind of holistic health system that President Obama's health care law encourages. Kaiser has sophisticated electronic records and computer systems that...

Twitter: 7.8M Twitter accounts, 10.8M impressions
Facebook: 28,352 views, 551 likes, 70 shares, 46 comments
LinkedIn: 91 likes, 4 comments
Sharing Our Expert Medicine Via TweetChats

TweetReach Report for #abcDRBchat

estimated reach: 1,981,452 accounts reached

exposure:

- 14,048,035 impressions
- 405 < 100
- 491 < 1k
- 528 < 10k
- 152 < 100k
- 22 

activity:

- 1,598 tweets
- 374 contributors
- 7 days

top contributors:
- @MayoClinic
- @kpthrive

most retweeted tweets:
- "kpthrive: KP oncologist Joanne Schottinger gives tips to prevent colon cancer in this short video: bit.ly/198gxs9 #abcDRBchat"
- "kpthrive: T5: Dr. Schottinger - Very important part of rehab is making lifestyle changes - quit smoking, healthy body weight, exercise. #abcDRBchat"

CDC Cancer: Learn how your family health history may affect your risk for breast & ovarian cancer: abcDRBchat go.usa.gov/pjcy

SUZU: T4 abcDRBchat HPV vaccine infographic w/ @theNCI data. http://bit.ly/copeF7Te6

CDC Cancer: T5 #Cancer survivors are living longer due to earlier diagnosis, better treatments, more access to care abcDRBchat go.usa.gov/pjcy

Joanne Schottinger, MD Discusses Colon Cancer Prevention

Approximately 150,000 cases of colon cancer are diagnosed every year in the United States alone. Kaiser Permanente medical oncologist Joanne Schottinger, MD, aims to stress the importance of screening for the disease.

"About one in 20 [Americans] will be diagnosed with colon cancer," she says. And while the statistic is ominous, colon cancer is also one of the most preventable forms of cancer. "Polyps and early-stage malignant growths can be taken out and removed at the time of screening so that you never actually develop cancer."
Potential for Research

• Lots of data: quantitative and qualitative
• Surveillance
• Social network analyses
Limitations and Unanswered Questions

- Prone to misinformation and vandalism
- Forums often not moderated by experts
- Sources of health information often anonymous
- Privacy issues
Limitations and Unanswered Questions for Research

- Lack of denominator
- Self-reported outcomes
- Little evidence that participating in social media influences health behavior
Social Media Research in an Integrated Health Care Setting

- Denominator
- Follow-up
- Linkage with electronic health record
  - Capture clinical outcomes
- Privacy
- Behavioral interventions
Research Overview

• Epidemiological studies
• Focus groups
  ► Parents
  ► Physicians
• Pilot study to build social media Web site
• Randomized trial to evaluate social media Web site
### Hep A (Hepatitis A)

Two brands of Hep A vaccine are given at Kaiser Permanente Colorado. Below you'll find an overview of each vaccine and its ingredients. To see the full list of vaccines given at Kaiser Permanente Colorado and their ingredients, visit the Vaccine Ingredient Table.

**Brand Name:** Havrix (Hep A)  
**Manufacturer:** Glaxo Smith Kline  
**Given as:** Shot, Intramuscular

**Havrix - Hep A**

<table>
<thead>
<tr>
<th>Ingredients</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adjuvants</td>
<td>Yes</td>
</tr>
<tr>
<td>Albumin</td>
<td>None</td>
</tr>
<tr>
<td>Aluminum</td>
<td>25 mg</td>
</tr>
<tr>
<td>Animal Serum</td>
<td>None</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>Trace</td>
</tr>
<tr>
<td>Chicken Egg Protein</td>
<td>None</td>
</tr>
<tr>
<td>Formaldehyde</td>
<td>&lt; 0.5 mg</td>
</tr>
<tr>
<td>Gelatin</td>
<td>None</td>
</tr>
<tr>
<td>Virus Grown in Human Fetal Cells</td>
<td>Yes</td>
</tr>
<tr>
<td>Lactose</td>
<td>None</td>
</tr>
</tbody>
</table>

**Vaqla - Hep A**

<table>
<thead>
<tr>
<th>Ingredients</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adjuvants</td>
<td>Yes</td>
</tr>
<tr>
<td>Albumin</td>
<td>None</td>
</tr>
<tr>
<td>Aluminum</td>
<td>225 mg</td>
</tr>
<tr>
<td>Animal Serum</td>
<td>Trace (cow)</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>Trace</td>
</tr>
<tr>
<td>Chicken Egg Protein</td>
<td>None</td>
</tr>
<tr>
<td>Formaldehyde</td>
<td>&lt; 0.0008 mg</td>
</tr>
<tr>
<td>Gelatin</td>
<td>None</td>
</tr>
<tr>
<td>Virus Grown in Human Fetal Cells</td>
<td>Yes</td>
</tr>
<tr>
<td>Lactose</td>
<td>None</td>
</tr>
</tbody>
</table>

**Edit**
Welcome to the Vaccine Resource Center

Researchers at Kaiser Permanente Colorado are conducting a study with pregnant moms and parents of young children. We want to see if a vaccine social media website is a good source of information for parents as they are making vaccine decisions for their children. To see if you’re eligible to participate in the Vaccine Social Media Website Study, we need you to give us some information and answer a few quick questions.

1) Please enter your Last Name followed by the Last 4 Digits of your Kaiser medical record number "smith1345" or your last name and your child’s Kaiser medical record number. Data Protection Details

Last Name\HRN (smith1345)*

2) Please answer the following questions with a Yes or No response:

Do you intend to use Kaiser insurance for your child? *

I am 18 years or older.*

Submit Form
Thank you for joining the Vaccine Resource Center!

Thank you for joining the Vaccine Resource Center! We are so glad you agreed to participate in our project and look forward to being your source for honest and accurate vaccine information. The Vaccine Resource Center isn't meant to replace the care you receive from your doctor, but rather to complement the information you already receive. Each month we will be sending out a newsletter with the very latest updates to our blog along with any new information we've added to the website.

For this first newsletter we wanted to start out by showing you around the site. You'll find blog posts on our site features, blog series to come and a welcome video from two Kaiser Pediatricians. Bookmark the site, check out our "About Us" page to get to know the VRC team, feel free to leave your comments on the blog posts and send our experts your questions. We can't wait to hear from you!

Welcome to the Vaccine Resource Center

Welcome to the Vaccine Resource Center website. As you might have seen on our "About Us" page, we are public health researchers at the Institute for Health Research at Kaiser Permanente Colorado. We have been studying vaccines for the last 12+ years. But before I go on and on about who we are and what we do, ... 

Read online.

Pediatricians: Parents just like you

Kaiser Permanente Colorado Pediatricians, Elizabeth and Neil DeSouza, would like to welcome you to the Vaccine Resource Center. As pediatricians and parents of a young child themselves, we understand the concerns you may have about vaccines. In the coming issue, we will be discussing the importance of vaccines and how they can help protect your child. Stay tuned for more updates on the latest vaccine news.
Topics

- Vaccine 101
- Vaccines in the news
- The doctor is in
- Vaccines around the world
- Personal vaccine stories (open mic)
- Day in the life / From the research bench
Vaccine Research: A Cash Cow?

Maybe for some, but not for us.

We hear from a lot of parents that they are suspicious of research. We’ve heard that research is funded by pharma, that it is purely driven by profit, and that results are hidden from the public. Well, we agree some research is funded by pharma, some researchers are purely driven by profit, and some results are hidden.

But we do things a little differently around here. For example, all of our vaccine research is paid for by federal grants. We don’t take any money from pharmaceutical companies – not even crummy pens or paperweights. In fact, pharmaceutical sales reps are not allowed in any of Kaiser clinics or our research offices. Just take a look at the photo.
Study Procedures

• Recruit all pregnant women and parents with children ≤6 months
  ➤ Letter, e-mail, phone calls, posters, flyers

• Online consenting

• Randomization

• Need login and password (not publically accessible)
**Intervention Trial**

**Figure 5. Study Arms and Follow-up**

- **Study Arm 1**: Social media website + UC
- **Study Arm 2**: Traditional website + UC
- **Usual Care**: (Study Arm 3)

**KAB**: Assess Knowledge, Attitudes, Beliefs about Vaccines

**Outcomes**:
1) Days underimmunized
2) Immunization Rates
3) Change in KAB

-3 0 4 6 12

Calculated in Months since birth of child

---

**Study Arm 1**: Social media website + UC
**Study Arm 2**: Traditional website + UC
**Usual care**: (Study Arm 3)

KAB: Assess Knowledge, Attitudes, Beliefs about Vaccines

**Figure 5. Study Arms and Follow-up**
Administering the Intervention

- Web site monitoring
  - Updating content
  - Responding to questions (≤ 48 hours)
  - Creating/sending newsletters
  - Moderating the forums
  - Screening comments
  - Tracking usage
Establishing Trust and Credibility

• Present both sides – risks and benefits
• Provide detailed “About Me” page
• Respond to questions quickly – tailored, personalized responses
• Acknowledge parents’ concerns
• Try not to exaggerate risks or benefits
• Incorporate personal experiences into our posts and response
Establishing Trust and Credibility

- Craft messages that are easy to understand – avoid jargon
- Establish an ongoing discourse
- Promote transparency
  - Funding source
  - Reference all material
  - Vaccination stance
Risk Communication Messages

• Use simple short sentences

• Include one to three messages per block of information

• Present information using an array of media: text, video, audio, images

• Use active voice

• Avoid scare tactics
Preliminary Results

• 706 recruited (20.1%)
  ► 241 pregnant (34.1%)
  ► 465 parents with children 0-9 months (65.9%)
  ► 17.8% hesitant (126/706)

• Study arms
  ► Social media (n=356)
  ► Information only (n=234)
  ► Usual care (n=116)
Preliminary Usage Results (Quantitative)

- Usage
  - 960 page views
  - 169 unique visitors
  - Most frequently visited pages
    - Vaccine Schedule (137 page views)
    - Childhood Vaccination (85 page views)
    - Your Vaccine Visit (67 page views)
## Preliminary Usage Results: Interaction

<table>
<thead>
<tr>
<th>Topic</th>
<th>Blog Comment</th>
<th>Ask a Question</th>
<th>Forum Posts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hepatitis B at Birth</td>
<td>3</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Safety of Rotavirus</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Travel</td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Vaccine Schedule</td>
<td></td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Exemption Law</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vaccine Reactions</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Flu Vaccine</td>
<td></td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>
Two New Studies Look at the Safety of Rotavirus Vaccines

<table>
<thead>
<tr>
<th>Rotavirus Vaccine Studied</th>
<th>Our Study Results</th>
<th>FDA Study Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rotarix (RV1)</td>
<td>Increased risk for intussusception</td>
<td>The FDA did not look at this</td>
</tr>
<tr>
<td>RotaTeq* (RV5)</td>
<td>No risk for intussusception</td>
<td>Small increased risk for intussusception</td>
</tr>
<tr>
<td>Rotarix (RV1) vs RotaTeq (RV5)</td>
<td>Rotarix (RV1) is more risky than RotaTeq* (RV5)</td>
<td>The FDA did not look at this</td>
</tr>
</tbody>
</table>
Participant Comment # 1
Within seconds of reading this, I was put off. The fact that it discussed how to publish results regardless of outcome makes me wonder: are you really telling us the truth? It says the rotavirus causes diarrhea, and you want me to inject my kid with all the additives, preservatives and who knows what else to ‘protect’ them from something the CDC says most kids under 3 contact [sic] at least once. Then a side effect could be diarrhea, or worse and the vax is not even 100% effective. Um, no thanks.
Staff Response #1

This is a topic many parents feel passionately about, and we appreciate that you took the time to bring up these points. We encourage all parents to share their comments, questions and concerns about vaccines.

To your first point, maybe we weren’t clear about what we meant by publishing results regardless of the outcome. Our goal is to be open and transparent. We want to give you as much available information as possible on the risks and benefits of vaccination. For this blog post, our intent was to explain the results from two different studies showing that the rotavirus vaccines have some risks.

You also brought up some really good points about weighing the risks and benefits of vaccines. We agree that it sounds odd that the vaccine could both prevent and cause diarrhea at the same time. The difference is in the severity of the diarrhea. In other words, clinical studies have shown that the rotavirus vaccine can cause mild diarrhea in healthy babies. These studies also show that the rotavirus vaccine prevents severe diarrhea that can lead to hospitalization. So based on this research, it appears as though the benefits of the vaccine greatly outweigh the risks. This is the type of information that we in the public health field use to make our vaccine recommendations.

Thanks again for your comments. If anyone wants to explore this further, you can find more information about the effectiveness of the vaccine and other safety concerns on the rotavirus page: http://www.vaccineresourcecenter.com/all-about-vaccines/vaccines-and-vaccine-preventable-diseases/rv-rotavirus/

We also have an ingredients page where we list all of the ingredients in all of the vaccines given at Kaiser, including for rotavirus: http://www.vaccineresourcecenter.com/all-about-vaccines/vaccine-ingredients-table/
Respect All Opinions: “We encourage all parents to share their comments, questions, and concerns about vaccines.”

Balanced Information: “Our goal is to be open and transparent. We want to give you as much available information as possible on the risks and benefits of vaccination.”

Acknowledge Concerns: “You also brought up some really good points about weighing the risks and benefits of vaccines. We agree that it sounds odd that the vaccine could both prevent and cause diarrhea at the same time.”

Sources Referenced: “If anyone wants to explore this further, you can find more information about the effectiveness of the vaccine and other safety concerns on the rotavirus page: http://www.vaccineresourcecenter.com/all-about-vaccines/vaccines-and-vaccine-preventable-diseases/rv-rotavirus/”
Project Funding Page:

“This Web site is solely funded by the Agency for Healthcare Research and Quality (grant #1R21HS01960-01). No funding from private companies or institutions was used to develop this Web site or influence the content provided.”

On the aluminum ingredients information page:

References:


Challenges and Barriers

• IRB concerns
• Provider concerns
• Recruitment challenges
• Cost
Next Steps

• Complete recruitment and follow-up
• Analyze Web site usage data
• Analyze knowledge, attitudes, and beliefs
• Measure efficacy
• Assess costs
Final Thoughts

• Vaccine hesitancy continues to be an important public health challenge.
• We need better ways to inform and communicate with parents about benefits and risks of vaccines.
• Social media / interactive Web technologies have potential.
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<td>Kristin Goddard</td>
<td>Kate Burniece</td>
<td>Matt Daley</td>
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<td>Jo Ann Shoup</td>
<td>Marilyn Pearson</td>
<td>Jason Glanz</td>
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<td>Cap Luckett</td>
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Contact Info

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Please submit your questions by using the Q&A box to the right of the screen.
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