STRATEGIC INNOVATIONS FOR AFFORDABLE, SUSTAINABLE HEALTH CARE:

A Model for Health System Reform

Environmental Scan

Social Networking and Consumer e-Health
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Social Networking and Consumer e-Health

Social Networking and Consumer e-Health – Social networking and e-Health include a variety of Internet-based communications, tools, and aids to help consumers and patients engage and empower themselves in their health and healthcare-related interactions. Recent research by The Pew Charitable Trusts and California Health Care Foundations shows that 74% of American adults go online, 61% of adults look online for health information—and these percentages are increasing for all age and ethnic groups.1

Social networking through the Internet facilitates interactions between people and groups who cannot easily meet in person, due to geographic distance or difficulty identifying needed skills, resources, or other information. In addition to the Internet, social networking can occur through the use of cell phones. Social Networking Web sites allow individuals to 1) construct a public or semipublic profile within a bounded system; 2) articulate a list of other users with whom they share a connection; and 3) view and traverse their list of connections and those made by others within the system.2 General social networking Web sites such as Facebook and My Space have open enrollment that is not based on specific characteristics, activities, or other common attributes of individuals; anyone can join. Health-specific sites typically direct content to specific health conditions and health care services. As a model of direct-to-consumer activity, social networking sites can enable people to use social networks to discuss and ask about health, and find others with the same conditions at the same stage of treatment.

Consumer e-Health refers to a broader set of online and electronic tools to help consumers and patients manage their health care. These tools can include consumer information sites, interactive games, tools for patient-provider connectivity, and others. E-Health approaches can be used for managing health choices, budgets, and care that normally is difficult because of the disparate systems, various health plans, different geographic locations, and incomplete information. E-health includes what is often referred to as Health 2.0, defined by the use of social software and its ability to promote collaboration between patients and the rest of the medical industry.3

Few studies have addressed specific intervention characteristics and linked these to impact or effectiveness of these approaches. Methods for defining and measuring effects are developmental though growing as researchers seek to evaluate electronic communication tools. Typically, social networking, media, and e-Health are seen to enhance, but not replace in-person medical interactions.

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<tr>
<td>General Social Networking Sites</td>
<td>General social networking sites provide channels for consumers and patients to share information about health and health care.</td>
<td>• While general sites are used by 39% of individuals who seek health information online, few use these sites to search for health care information.4 • Studies of impact and effectiveness are limited.</td>
<td>Social networking and health information sites expand traditional definitions of markets and communities to include virtual communities that cross geographic markets and other market configurations.</td>
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<td><strong>Other Comments</strong></td>
<td>Individuals of all ages and ethnicities are using general and health-specific social networking sites to search for health information.⁵</td>
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</table>
| **Health-specific social networking sites** | Health-specific social networking sites provide channels for consumers and patients to share information about health and healthcare. | • Most consumers/patients use health-specific sites to search for health information. In addition to seeking health information for themselves, individuals also seek information for family members and friends.  
• Little is known about the impact or effectiveness of online social networking or health information sites for health decision making, behavior change, or health outcomes. | Social networking and health information sites expand traditional definitions of markets and communities to include virtual communities that cross geographic markets and other market configurations. |
| **Other Comments**                  | Search engines are critical and are used frequently by consumers seeking health information. Exercise and fitness has become the most frequently searched for topic, followed by specific diseases; medical treatments and procedures; prescription and over-the-counter drugs; alternative treatments; depression, anxiety, and mental health; and experimental treatments.⁶ |                                                                  |                                           |
| **Case Example 1:** **Patientslikeme®** | This searchable site – www.patientslikeme.com/ allows individuals to record their symptoms and responses to treatment regimes and share these with other community members. The site includes up-to-date resources on conditions and treatments. | • Little quantitative data are available, as the PatientsLikeMe site recently launched.  
• Through PatientsLikeMe and the ALS community it has been “discovered” that ALS (known as Lou Gehrig’s disease or Amyotrophic Lateral Sclerosis) is a multi-system disorder which definitely affects cognition. Another measure of success is the period that PatientsLikeMe’s members stay active. Sixty percent of joiners from one year ago are still active members. | Social networking and health information sites expand traditional definitions of markets and communities to include virtual communities that cross geographic markets and other market configurations. |
| **Other Comments**                  | Patientslikeme® generates income not from advertising revenue, but from aggregating and selling of the data to life science companies for treatments (pharmaceuticals).⁷ The site has been labeled “a home for users for whom privacy does not matter.”⁸ |                                                                  |                                           |
### SOCIAL NETWORKING AND CONSUMER E-HEALTH

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| **Case Example 2: Patients Direct** | Patients Direct offers a web-based reporting system and seeks to provide naturalistic data on safety and efficacy captured directly from patients. It serves pharmaceutical companies and providers, and provides a way for patients to make their voices heard. The site also provides information on clinical trials that may be available to patients. | - This site offers an innovative recruitment tool that may facilitate recruitment across geographic areas.  
- Little is known about how use of the site impacts consumer decision making or health outcomes. | This site expands traditional markets and approaches for recruiting participants in studies and trials. Patients Direct notes that it “has developed partnership arrangements with community pharmacists both individual and across a range of local and national companies.” |

**Social Media and Health Information Sites**  
These sites provide consumers with a broad array of information and decision tools to help empower and inform health and health care choices.  
- Evidence regarding the effectiveness of social media and information sites is limited, and site-specific. However, media interventions are generally known to be more effective when combined with community and program interventions.  
- Internet access to community-specific and general health information can lead to increased empowerment and appreciation of information technology.  
- A recent study using 2005-2007 data for 10,000 participants showed that people who rely on print media for their health information and those who turn to community organizations tend to do better than web seekers at following a healthy lifestyle. The researchers note that changes in Internet access and telecommunications (e.g., smart phones) are occurring.  

Internet-based and other social media expand reach beyond traditional market or community areas.
### Social Networking and Consumer e-Health

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<td><strong>Other Comments</strong></td>
<td></td>
<td>rapidly, and this must be considered in assessing the comparative effectiveness of health communications.13</td>
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#### Case Example 1: Medscape

**www.medscape.com** is a health information and social network site for physicians and consumers/patients that includes discussions of recent medical research and case studies, and provides access to a network of medical and related resources, multi-media and slide shows, education, and interactive opportunities online.

This site aims to provide access to up-to-date information about medical research and findings as an information source for physicians, other health care professionals, and consumers/patients.

The effectiveness of specific programs and offerings through Medscape is often assessed in terms of use rates and user success completing CME/CE (Continuing Medical Education).

Internet-based and other social media expand reach beyond traditional market or community areas.

#### Case Example 2: The Mayo Clinic

**www.mayoclinic.com** is a comprehensive consumer health information site, searchable by condition, that serves as a consumer/patient information portal to assist with health knowledge, decision making, and empowerment. It includes a personal health manager using Microsoft Health Vault, which enables provision of individualized, actionable recommendations developed by

Downloads of Mayo Clinic podcasts have increased by more than 8,000% since 2005, because of using three free social channels.16

Internet-based and other social media expand reach beyond local market or community areas.
## Social Networking and Consumer E-Health

### Intervention Areas and Case Examples

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<td>includes decision tools and social media channels to promote and increase downloads of its podcasts. The clinic posts podcasts, with video and text, on its blogs. It also leverages a Facebook page, a Twitter account, and a YouTube channel.</td>
<td>Mayo Clinic experts.</td>
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<tr>
<td>Other Comments</td>
<td>The Mayo Clinic states: “More than 3,300 physicians, scientists, and researchers from Mayo Clinic share their expertise to empower you to manage your health.” Topics covered include: diseases and conditions, symptoms, drugs and supplements, tests and procedures, and healthy living.</td>
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### Consumer E-Health and Self Management Tools

#### Games

A wide range of interactive games have been developed to help inform patients about conditions such as diabetes, obesity, mental health, and others.

- Use of games as an approach to inform and educate patients and consumers builds on the popularity of online games and expands content to health and health care.

#### Case Examples

- Interactive online health promotion interventions overall are reported to be more effective in promoting health-related behavioral change outcomes (exercise, weight loss maintenance, knowledge of asthma treatment, etc.) than traditional offline approaches. Information regarding the efficacy of online approaches on long-term behavior outcomes is limited.

- Few studies have been conducted to assess the impact and effectiveness of online games as a specific health promotion tool. Most online health intervention studies are unable to determine causality and long-term impacts on health. However, many games that have been assessed do appear to be helpful and effective interventions.

- Online games expand reach beyond local market or community areas.

#### Other Comments

- [www.healthgames.org](http://www.healthgames.org) includes surveys and measures that can be used to evaluate games, including neighborhood population health questionnaires.

- The National Network of Libraries of Medicine includes a list of consumer health topics developed for children and teens at: [http://nnlm.gov/outreach/consumer/chforkids.html](http://nnlm.gov/outreach/consumer/chforkids.html)
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| Health Games Research—[www.healthgamesresearch.org](http://www.healthgamesresearch.org)—is a national program sponsored by the Robert Wood Johnson Foundation that funds research to advance the innovation and effectiveness of digital games and game technologies intended to improve health. This site includes a search feature to access games and related resources. | - There are many guides for consumers to select health care; however, research that tracks the application and related consequences of consumer decision support tools is limited.  
- Studies generally find report cards can positively influence consumer decision making when the information is easy to understand.  
  - Research shows conflicting results regarding the impact of report cards on quality topics on consumer behavior.  
  - Tools related to provider choice have shown improvements in users’ knowledge, satisfaction with decision making, likelihood of considering alternatives, and selection of plans that best meet consumers’ personal needs and preferences.  
  - Controlled trials have shown that decision aids improve knowledge regarding options, enhance realistic expectations about options, reduce patient frustration with decision making, and stimulate people to take an active role in decision making. | Decision support tools can be targeted to specific market areas, e.g., for provider choice options, and can expand reach beyond community market areas when options of care and treatment are considered. |

| Decision Support Tools  
These include online tools to assist with choice of providers, and tools related to specific care and treatment options. | Decision support tools aim to help patients/consumers frame questions, learn about treatment options, and clarify values and preferences.  
Internet Web site “calculators” are designed to match unique patient information with an underlying evidence-based knowledge repository and sources of potential feedback, e.g., tools for assessing an individual’s cardiovascular risk, potential drug interactions and drug dosing, and recommendations about appropriate screening interventions for a given patient.” | - Many payers have tools that provide consumers with pharmacy pricing:  
  - Pharmacy Price Quote – this tool drills down to the costs of drugs at a local pharmacy. Members can look at actual out-of-pocket prescription costs, the plan’s cost, and the total cost: Humana and RegenceRx enable members to access the estimated retail price of specific drugs.  
  - Subimo, based in Chicago, offers PharmaAdvisor, a Web-based tool that helps consumers make decisions about drug treatment options, both clinically and from a cost perspective, including possible interactions, efficacy, dosage, and how drugs work for certain conditions in side-by-side comparisons. |  
| | | | |
**Social Networking and Consumer e-Health**

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<td>Barriers to use include:</td>
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<tr>
<td>1. Lack of relevant content, e.g., comparative information;</td>
<td>Also:</td>
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<tr>
<td>2. Poor design and presentation; and</td>
<td>Low literacy levels;</td>
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<tr>
<td>3. Limited consumer awareness of</td>
<td>Lack of trust of information source;</td>
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<td>information.</td>
<td>Lack of online access;</td>
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<td></td>
<td>Lack of provider time and training to engage with patients; and</td>
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<td></td>
<td>Need for reimbursement incentives that reward practitioners for engaging in decision support.</td>
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The *Puget Sound Health Alliance* consists of employers, unions, doctors, hospitals, health plans, patients, and others who work on constructive ways to improve the value of local health care. The Community Checkup is a report to the public about health care quality and value.

**Case Example 1:**

**www.cancerfacts.com**

This online resource for cancer patients, their families, and caregivers provides personalized information via Cancer Profiler Tools that help people with cancer make informed treatment decisions for an optimal outcome. The site is developed by NexCura, and uses scientific evidence to populate the profilers.

Little is known about how use of the site impacts consumer decision making or health outcomes.

Decision support tools can be targeted to specific market areas, e.g., for provider choice options, and can expand reach beyond community market areas when options of care and treatment are considered.

**Other Comments**

Profilers are available for the following cancers:

- Bladder
- Hodgkin Lymphoma
- Lung - Non-Small Cell
- Ovarian
- Pancreatic

- Breast
- Kidney
- Lung - Small Cell
- Prostate

- Cervical
- Leukemia - Adult ALL
- Melanoma
- Testicular

- Colorectal
- Leukemia - Adult AML
- Multiple Myeloma

- Head and Neck
- Leukemia - Adult CML
- Non-Hodgkin's Lymphoma
- Uterine
### Interventions Areas and Case Examples

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<tr>
<td><strong>Case Example 1:</strong> Personal Health Records (PHRs)</td>
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<td><strong>Other Comments</strong></td>
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<tr>
<td><strong>Case Example 2:</strong> FONEMED®</td>
<td>FONEMED® uses communications technology to provide individuals with 24-hour telephone or Web-based access to medical advice, information, products, and services. They provide outsourced nurse triage services and qualified partners with tools, technology, protocols, and know-how to operate proprietary Medical Call Centers.²⁷</td>
<td>For $4 per month, Jitterbug LiveNurse uses FONEMED®, to provide 24-hour unlimited access to registered nurses; people can speak to an experienced, registered nurse 24 hours a day, 7 days a week; there is 24-hour access to a pre-recorded health library; and the personal health history is updated each time a call is made.²⁸</td>
<td>FONEMED® can be used in most if not all markets.</td>
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</table>

**Other Comments**

A Health Information Center is a powerful, proven strategy to lower costs, improve access, and leverage clinical service and marketing programs. Potential clients include government agencies, hospitals, clinics, insurance companies, and health maintenance organizations, as well as private companies and individuals.

### Mobile Health: Smart Phone Applications.

Smart phone applications are available to help people track weight loss, medication dosing, and manage conditions such as diabetes and others. Most use prompts and text message reminders.

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| Mobile Health: Smart Phone Applications. | Cell/smart phone applications aim to provide information to assist patients/consumers and providers in managing health conditions. These mobile devices and applications also facilitate in-the-moment feedback and information capture regarding symptoms and responses. | • Research, albeit limited and with small sample sizes, suggests that online systems are superior to traditional online interventions in their ability to influence health behaviors.²⁹  
• A systematic review of evidence regarding smart phone technologies shows:  
  o Frequency of prompts affects results;  
  o Medium used to communicate prompts did not matter;  
  o Tailoring prompts produced positive results; and  
  o More frequent prompts produced more positive results.³⁰ | Smart phone applications can be used in all market types and expand applications beyond convention local markets. |

**Other Comments**

These technologies present a cost effective way to implement behavior change.
## Social Networking and Consumer e-Health

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<td><strong>Case Example 1</strong>&lt;br&gt;STEALTH HEALTH</td>
<td>STEALTH HEALTH is designed to increase youth activity, reduce obesity, and increase learning of positive healthy behaviors. It is a social networking application designed around improving young people’s health. It is a project funded by the U.S. Department of Agriculture.</td>
<td>STEALTH HEALTH is in prototype design.</td>
<td>STEALTH HEALTH is designed for national application.</td>
</tr>
<tr>
<td>Other Comments</td>
<td>STEALTHHEALTH reports that is aim is to develop a simple, customizable software application (&quot;widget&quot;), integrating communication (MySpace, Facebook, instant messaging) and location-based (GPS, GIS, imagery) technologies with informal education (pop up nutrition and health messages), designed to promote increased physical activity and improved nutrition knowledge and behavior in youth.</td>
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<tr>
<td><strong>Case Example 1</strong>&lt;br&gt;AllOne Mobile™</td>
<td>This cell phone application allows access to consumers’ personal health and insurance information. It is used in conjunction with MedFlash™, a product offered by Connectyx, which stores personal health and lifestyle information on a portable flash drive and in an online personal health record. The MedFlash Web site allows users to maintain and update their information and upload it to the flash drive. MedFlash can be worn as a bracelet or used as a key chain. The combined MedFlash and AllOne Mobile tools allow customers’ health information to be viewed, managed, and shared with trusted health care partners using the owner’s cell phone.</td>
<td>AllOne Mobile™ is an application that can be used across and within markets with Internet connectivity.</td>
<td></td>
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<tr>
<td>Other Comments</td>
<td>AllOne Mobile™ was one of the highest profile mHealth services to date. The dissolution of its partnership with technology partner Diversinet became apparent as they began renegotiations in December 2009.</td>
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<td><strong>Case Example 2:</strong> LifeWIRE</td>
<td><em>LifeWIRE</em> is a mobile, two-way interactive e-health management solution that allows individuals and their providers to use text messaging, email or IVR-based interactions which are customized to track, monitor, and engage users to improve their health status or achieve other important health goals. <em>LifeWIRE</em>’s platform provides a tool for users to manage their own health, and for providers and care managers to manage patients through having them respond to personalized reminders and motivations.*&lt;sup&gt;33&lt;/sup&gt;</td>
<td>Studies are underway to test the impact and effectiveness of <em>LifeWIRE</em> as used with several clinical conditions.</td>
<td><em>LifeWIRE</em> is an application that can be used across and within markets with Internet connectivity.</td>
</tr>
<tr>
<td><strong>Other Comments</strong></td>
<td>Altarum Institute has adapted and is currently testing <em>LifeWIRE</em> as a behavioral health adjunct to therapy.</td>
<td></td>
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<tr>
<td><strong>Case Example 3:</strong> Applied Nanodetectors Phone Application</td>
<td><em>Applied Nanodetectors Phone Application</em> is a cell phone system that, when used in conjunction with a breathalyzer, detects health problems such as diabetes and cancer by reading the levels of gasses such as nitrogen, carbon dioxide, and ammonia.&lt;sup&gt;34&lt;/sup&gt;</td>
<td>The phone can also detect lung cancer, bad breath, types of food poisoning and blood-alcohol levels. The phone can inform its user’s doctor of its findings.</td>
<td><em>Applied Nanodetectors Phone Application</em> is an application that can be used across and within markets with Internet connectivity.</td>
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<tr>
<td><strong>Other Comments</strong></td>
<td>A growing number of organizations are researching or releasing modified mobile phones and mobile apps that diagnose serious health problems and disease patterns.</td>
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<td><strong>Case Example 4:</strong> BeWell Mobile Technology</td>
<td><em>BeWell Mobile Technology</em> was founded in 2004. It provides patient engagement software for the health care industry and medical research community. The software is used in cell phones, wireless data networks, and the Internet to collect valid data and to help patients manage their health. The software incorporates self-monitoring via cell phones. Asthma and diabetes are two of the most significant conditions being addressed by <em>BeWell Mobile Technology</em>. Patients have access to San Mateo Medical Center distributed mobile phones with customized disease management software to young asthma patients, allowing them to communicate with and receive real-time feedback from providers on at least a daily basis. The communication focuses on how to better manage asthma on an ongoing basis, with the goal of reducing exacerbations that might lead to costly acute episodes. The initiative enhanced compliance with the daily diary and with medication regimens, which, in turn, led to better patient outcomes, less use of rescue medications, and fewer emergency visits.</td>
<td><em>BeWell Mobile Technology</em> is an application that can be used across and within markets with Internet connectivity.</td>
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| **Case Example 1: mHealth Initiative** | to personalized information that helps them stay on track with their regimen.\(^{35}\) | department visits and missed school days.\(^{36}\)  
  The program received a patient satisfaction score of 3.8 out of 4.  
  - Program has reduced HbA1c by 0.91 points for patients with starting HbA1c between 8% and 9%;  
  - Program has reduced HbA1c by 2.22 points for patients with HbA1c >9%; and  
  - Blood sugar range (low to high) was lowered by 50 mg/dl between first month of service and the last month of service.\(^{37}\) | |

**Other Comments**  
Patient engagement is the key to self management and better medical outcomes, particularly for chronic conditions such as asthma and diabetes.

### Organizational Initiatives

**mHealth Initiative**  
*mHealth Initiative*, Inc. is a not-for-profit Massachusetts organization that uses cell phones and other mobile devices as health care clinician tools. mDevices allow access to the Internet, medical information, documentation systems, and decision support guidance for care. *Participatory Health* is a network of healthy people, patients, wellness and care providers, payers and researcher as active participants in a transparent health care system, allowing 24/7 communication patterns between healthcare participants, including observations of daily living.\(^{38}\)

**mHealth Initiative** is based in Massachusetts, but likely could be scaled to national distribution.

### ENDNOTES

10 Ibid., Patients Direct. (2010).
11 DeJong, William, PhD Lecturer, Harvard School of Public Health, Boston, MA.


ALTARUM INSTITUTE integrates objective research and client-centered consulting skills to deliver comprehensive, systems-based solutions that improve health and health care. A nonprofit serving clients in the public and private sectors, Altarum employs more than 350 individuals and is headquartered in Ann Arbor, Michigan with additional offices in the Washington, DC area; Sacramento, California; Atlanta, Georgia; Portland, Maine; and San Antonio, Texas.

Mission
Altarum serves the public good by solving complex systems problems to improve human health, integrating research, technology, analysis, and consulting skills.

Vision
Altarum Institute demonstrates and is sought for leadership in identifying, understanding, and solving critical systems issues that impact the health of diverse and changing populations. Altarum is acknowledged as a valued, collaborative, and collegial institute of the utmost competence and integrity.

Altarum Institute Systems Change Model

For more information: www.altarum.org or contact Gloria N. Eldridge, PhD, MSc at gloria.eldridge@altarum.org.