Twitter Epidemic

By Jonathan Peck, IAF President

"Just coughed", Judy tweeted. Forty people across the nation paid immediate attention. "Couldn't stop for like 5 minutes." Right away, her boyfriend texted her back. "Probably Swine Flu. Stay in your room. Post a note telling your roommates to stay out. I'll bring Gatorade and Tylenol. I got a mask and gown from the clinic." Her father called Fedex to arrange a shipment of masks, gowns and a "care package" his wife put together. He then called Judy's college to notify them she had flu symptoms and would miss classes. He also got her name on the wait list for antiviral drugs. He and his wife then got on Skype so they could see how she looked while they talked.

The mutation of the H1N1 virus into a more lethal form could make it as deadly this fall as the Spanish Flu was in 1918 and 1919. But there was no Twitter or Skype during the Spanish Flu which killed tens of millions. During the Spanish Flu pandemic the population was only about a third of today’s. Now we have 6.8 billion people on the planet and more than half of us live in crowded cities. A New England Journal of Medicine article "Urbanization--An Emerging
Humanitarian Disaster” argues that this transition to urban living "threatens to create a humanitarian disaster". IAF pandemic simulations raise questions about how effective a public health strategy which relies largely on vaccines will really be. So finding other means, such as a modern day quarantine approach, is important.

Social networking tools could become an effective part of the public health strategy for fighting pandemics. The key to stopping epidemics from reaching the tipping point is isolating the virus and reducing transmission. People will spread the virus if they converge in hospitals, clinics, doctors' offices and waiting rooms. Yet if they stay home and have isolation kits to protect caregivers, it becomes much more difficult for the virus to leap from person to person. Social network tools like Twitter could provide an alternative means of communicating and arranging for care. A web-based public health strategy could allow people to be diagnosed and treated at home while the U.S. Post Office and private delivery vendors distributing masks, gowns and medicines.

Social networking can also be combined with other software tools to improve the knowledge, response times and research of caregivers and scientists. For example, Google is using the information gained through its search engine to track flu outbreaks through Google Flu Trends. The site has, on average, picked up outbreaks a couple weeks before the Centers for Disease Control and Prevention (CDC), the critical government organization tasked with tracking disease. Fast, knowledgeable tools like Google Flu Trends could dramatically improve the knowledge and response times of healthcare workers tasked with preventing and containing outbreaks. Social networking tools can also connect caregivers and scientists to help exchange vital information. IAF designed a conference with the National Heart, Lung and Blood Institute (NHLBI) to develop a networked approach that can speed knowledge discovered in basic research to the practice of medicine. The current lag is often twenty years and the toll patients pay for delay is already terrible. In a deadly pandemic, it could prove catastrophic.

We all hope that this fall will bring a milder flu. A new strain of H1N1 may be more lethal in younger populations than the older. However, this does not necessarily lead to an unusually high death toll. In that event, the typical response to flu season should be adequate. Signs suggest we'll have lots of people missing school and work, potentially setting the economy back but not leading to a terrible disaster. If that is the case, we will not need the highly creative adoption of social networking tools to address this pandemic.

However, in the long run a pandemic capable of killing tens of millions of humans is sufficiently likely, whether it's SARS, Avian, Swine or some other virus that makes the leap to humans. The growing human population, ecological changes and worldwide movement of people, plants and animals create more vulnerability.

We the people can be the most important actors in bringing change when longstanding practices endanger health. Perhaps most importantly, networks of citizens can become knowledgeable activists in protecting the public health. Our work with Consumers Advancing Patient Safety and the World Health Organization's World Alliance for Patient Safety has taught IAF that patients can do amazing things.

It takes organization and widespread sharing of knowledge, but that is what social networks offer, and they can bring it quickly. If H1N1 mutates into a deadly form this fall, people will need to learn quickly to keep the virus from spreading. That's why Twitter and other social networking tools may prove to be more than just short-lived fads.
**State of the Health Equity Movement**

The Disparities Reducing Advances (DRA) Project has recently released a detailed memo titled *Update: The State of the Health Equity Movement*. The memo identifies forty-two health equity conferences and eleven state and local health equity departments, commissions or related activities.

Several key themes have emerged across the health equity activities identified in this memo, including: the increasing awareness of health inequities and the social determinants of health; advocacy and leadership for health equity and social justice; emphasizing community empowerment; coordinating and utilizing research and outcome evaluations more effectively; increasing collaborative partnerships across all sectors; and providing culturally appropriate care.

You can learn more about the DRA Project and download the latest publications from the project at [www.altfutures.com/draproject](http://www.altfutures.com/draproject). The DRA Project is a multi-year, multi-stakeholder project developed by the Institute for Alternative Futures (IAF) to identify the most promising advances for bringing health gains to the poor and underserved and accelerating the development and deployment of these advances to reduce disparities.

**DRA Project and Partners Release National Patient Navigator Survey**

The American Cancer Society and the DRA Project have joined forces with academic partners at the University of Illinois at Chicago, Denver Health and the Colorado Patient Navigator Training Program to create a national survey of patient navigators.

The purpose of the survey is to 1) understand what types of activities patient navigators do in their daily work, 2) learn about the types of patient navigator programs that exist around the country, and 3) be able to better describe the scope and number of navigation programs in the country.

IAF would like to invite you to get involved in the survey! If you are a patient navigator, or know someone who works in the patient navigation field, we would like you to take a few moments to look at the survey at the link below. You will also find an informational sheet with contact information regarding this important national effort. The survey is intended for all navigators from around the nation working with any type of health condition (cancer, diabetes, cardiovascular disease, etc).

[www.patientnavigatorsurvey.org](http://www.patientnavigatorsurvey.org)

Any additional questions can be addressed to the Principal Investigator for the study, Dr. Elizabeth Calhoun, 312-355-1572 or via email at ecalhoun@uic.edu. You can also contact Craig Bettles, Futurist from the Institute for Alternative Futures, at 206-491-6205 or via email at cbettles@altfutures.com or Angelina Esparza, Director of the ACS Patient Navigator Program, at 404-329-7776 or via email at Angelina.Esparza@cancer.org.
IAF Co-authors Paper in the American Journal of Public Health

Clem Bezold from the Disparities Reducing Advances (DRA) Project, Ahmed Calvo of the Health Resources and Services Administration (HRSA) and former IAF intern Leah Calvo are in the process of publishing a paper on "The Expanded Care Model: Convergence of the Chronic Care Model, The Planned Care Model and The Patient-Centered Medical Home Model" in the American Journal of Public Health. The paper describes the framework of the "Expanded Care Model," and contrasts it with the "Chronic Care Model" and the "Planned Care Model." The recent parallel development of the "Patient Centered Medical Home Model" and other "Medical Home" Models are also discussed and the paper considers the opportunities for integrating the insights gained in order to use the lessons learned together to reduce health disparities.

The DRA Project has identified the Health Disparities Collaboratives, as it uses the "Expanded Care Model" framework, as an important disparity reducing advance. The Health Disparities Collaboratives (HDC) are an evidence-based quality improvement effort to increase the quality of health care being delivered by the U.S. safety net providers. The HDCs are also a strategic plan to reduce disparities of health outcomes.

Healthcare Reform Through the Reality of Rare Cancers

IAF, in partnership with the International Myeloma Foundation, is holding a Foresight Seminar on Capitol Hill on September 29th, 2009. Incurable but treatable cancers such as multiple myeloma point the way to potential innovations in treatment, necessary regulatory reform, and an improved payment system, all of which can be addressed through health care reform.

To be successful, health care reform must work for people with rare cancers. Diseases such as multiple myeloma, a cancer that affects cells in the bone marrow, are creating new models of disease and new paradigms of treatment that indicate how treatment of all diseases may evolve. Health care reform offers the opportunity to address issues that will someday affect not only myeloma patients but all Americans who suffer from cancer and other chronic diseases.

These issues include:

- A need for therapies that work better than today's medical products;
- Regulation that better meets the needs of patients; and
- A payment system that supports rather than distorts the best therapeutic options available.

If healthcare reform solves these problems, it will open the door to better treatments of cancer and all diseases. In this way, multiple myeloma provides a lens into the future of medicine in a way that highlights the reforms that are necessary to make today.

During this foresight seminar, presentations by a multiple myeloma patient, a leading physician-scientist, and a health policy expert will serve as the basis for discussions to identity ways to turn insurance reform into meaningful and cost-effective health reform.

You can register for the event [here](#). The meeting will be held on Tuesday, September 29th, 2009 from 12:00 pm to 2:00 pm in the Russell Senate Office Building, Room 325. Lunch will be served at 12:00 pm.

Upcoming October 20th Disparities Foresight Briefing on Capitol
The DRA Project will be hosting our fourth Disparities Foresight Briefing on Capitol Hill on October 20th. Cong. Donna Christensen and the Congressional Black Caucus Braintrust will co-host the Briefing. The Foresight Briefing is sponsored by Novo Nordisk. The noon-time discussion will focus on the state of the Health Equity movement, health equity in healthcare reform and the economic stimulus. Speakers will include Cong. Christensen, Larry Cohen of the Prevention Institute and Brian Smedley of the Joint Center Health Policy Institute. Clem Bezold will moderate. More details and online registration is available here.

**IAF Produces First Video Forecast, 2050: The End of the Future**

IAF has produced a video to convey a forecast that by 2050 humans will have fundamentally changed their view of time (The video can be seen here on IAF’s YouTube channel). This forecast was originally developed as part of IAF’s project to help the U.S. Army Medical Department look at military medicine in the year 2039; it also appeared in written form in the July issue of this newsletter. Kyle Gildea, IAF’s video intern, directed and edited the video with other contributions (even acting!) from IAF staff. This video shows how understanding of the future can be improved and conveyed through the use of video - a new device that IAF has added to its futures toolkit.

**Consumer Health World Conference**

The latest Consumer Health World Conference will be held on November 11th-13th in Miami, FL. The conference covers the efforts innovative employers are using to improve the bottom line by keeping employees healthy and by providing access to affordable quality care inside and outside their communities. The efforts of these forward thinking employers are vital to the national effort to control healthcare costs. IAF is a supporting sponsor of the Consumer Health World Conference. You can find out the full details on the Conference and register for the event at www.healthenomics.com.

**Upcoming Events**

- **Optimal Futures for Risk Evaluation and Mitigation Strategies (REMS)**, workshop organized by IAF for the Society for Women’s Health Research, September 22th, Washington D.C.

- **Healthcare Reform Through the Looking Glass of Myeloma**, IAF Foresight Seminar, September 29th, Washington D.C.

- **The Social Determinants of Health, and Health in All Policies**, Disparities Foresight Briefing, October 20th, Washington D.C.