"But I'm Not Sick":
Using Informatics to Make Health Relevant to the Well

This seminar will explore how informatics and information technology can be used to make healthcare relevant to the well. This will include a focus on defining what health is in the United States, who is healthy and how do people define health for themselves. The target audience for this seminar is informaticists who want to design tools to help people live healthier lives and clinicians who want to integrate these health-promoting tools into their practices.

Objectives:
By the end of this seminar, participants will be able to:
1. Explain their own views of what is and isn't health and how that might affect the tools they build
2. List ways in which cultural views of disease may influence how people view their own health
3. Discuss why healthcare technologies aren't seen as relevant by people who don't consider themselves unhealthy
4. Propose several ways in which informatics and information technology can play a role in helping people stay healthy

Outcomes:
As a result of meeting these objectives, participants will be able to:
1. Bring an understanding of cultural views of disease and health to designing information solutions
2. Design information solutions that support the pursuit of healthy behaviors
3. Create new technologies that are seen as relevant not only by people dealing with disease but those who consider themselves healthy

Structure:
Morning sessions:
1. Toward defining health, illness and disease. How do a person's background and experiences affect how they view their own health?
2. Health-related information behaviors. Do self-defined healthy and non-healthy people seek, use, manage and evaluate information the same way?
3. Promoting healthy behaviors. What are healthy behaviors and how do we encourage people to engage in them? What motivates people to engage in healthy behaviors? Why are Americans, in general, so unhealthy, even with so much health-related information available to them?
4. Does social marketing work? How can health plans use social marketing to increase patient health and decrease costs?
5. Health promotion through informatics solutions. What informatics tools currently exist, how effective are they and what could they do better?

6. Measuring effectiveness of tools. How do we know our health promotion tools are working? Can health plans use performance monitoring and statistics to measure the effectiveness of the systems?

Afternoon practica:
1. Analyzing mygrouphealth.com and webmd.com. What do they do? What should they do to encourage healthy behaviors? What could they do better?
2. Designing an informatics tools that helps people develop and maintain a healthy eating plan. Studies show that people who actively track their food intake and exercise lose weight and maintain that weight loss. This practicum will walk the participants through designing a system of tools that help people track and analyze their healthy eating and exercise plan with as little effort as possible. Possible tools include:
    a. Wireless bathroom scale that transmits data to the computer for analysis
    b. Wireless food scale in the kitchen that transmits portion data to the computer for analysis
    c. Pedometer that downloads workout data for analysis
    d. Software that analyzes all of this data and offers advice for improving fitness and nutrition
    e. Recipe generation based on what's in the user's pantry
    f. Email access to nutrition experts

Advance Preparation:

Evans, W.D. (20 May 2006). How social marketing works in health care, *BMJ*, Volume 332, p1207-1210.
Hastings, G., McDermott, L. (20 May 2006). Putting social marketing into practice, *BMJ*, Volume 332, p. 1210-1212.

Improving Health in the Community: A Role for Performance Monitoring
Jane S. Durch, Linda A. Bailey, and Michael A. Stoto, Editors; Committee on Using Performance Monitoring to Improve Community Health, Institute of Medicine
Free Executive Summary PDF version,

Resources:
People:
- Specialists in the cultural and biomedical definitions of health, illness and disease
- Public health officials to talk about measurement of outcomes
- Information behavior experts to talk about health-related information behaviors
- Information architects to talk about how to design UIs that compel people and how to integrate the systems into people's lives
- Clinicians to talk about the health behaviors that we should be encouraging in people
- Psychologists to talk about what motivates people

- Informaticists who currently design health-promoting tools to discuss what has worked for them and what hasn't, as well as to lead the design practica

Technology
- Various websites that current aim to bring health information to people and encourage healthy behaviors (for critiquing)

Worldview/Motivation:

When I recently interviewed James Hereford, executive vice president of Strategic Services and Quality at Group Health Cooperative, he said something I found very interesting. He said that GHC is very relevant to the sick, but not to the healthy. He said he believes that one of the greatest opportunities for GHC is to find ways to use informatics and information technologies to make health relevant to those who consider themselves healthy. This serves two main purposes. First, it gets members more involved in the governance of the coop by being relevant to them when they're healthy and not just when they're sick. Second, it helps GHC cut costs. He mentioned that about 13% of members, the chronically ill, account for 30% of GHC's costs. Simply helping those people understand and follow their care plans has been proven to cut costs dramatically. I think that helping people manage chronic diseases and helping healthy people stay healthy or get healthier are very related, but have chosen to focus only on the latter for this seminar. I assume that using information systems to help people be healthy would have a similar dramatic effect on the bottom life for health insurers, as many of the same behaviors that the chronically ill need to manage disease can also help healthy people stay health. These include weight management, good nutrition, physical activity, not smoking, drinking alcohol in moderation, getting sufficient sleep, minimizing stress, and many others.

The first problem encountered in trying to promote healthy behaviors is defining what health, illness and disease are. In *Medicine and Culture*, Payer writes about how culture affects not only how disease is treated, but also what is considered disease or illness. There are diseases that are widespread in some countries that aren't even acknowledged in others. These different views of what is and isn't disease or illness affect how the biomedical establishment treats patients. "Often, all one must do to acquire a disease is to enter a country where that disease is recognized – leaving the country will either cure the malady or turn it into something else" (Payer, 25).

Whitbeck defines health differently than simply the absence of disease. She claims that health is not merely a physical state of being, but that it consists of physical, emotional and mental states, as well. "Although medicine, in the broad sense, is the body of knowledge and practice concerned with the prevention of disease and the treatment of disease and injury (and, to some extent impairment), and diseases and injuries frequently *do* compromise the health of those who bar them, nonetheless, health promotion goes *beyond* the scope of medical care" (Whitbeck, 611). I completely agree with this, and

really believe that things that have the greatest impacts on people's health happen outside of the doctor's office.

Engel and Kleinman both talk about "folk models" of disease and how those differ significantly from the biomedical model of disease. Folk models are "culturally derived belief systems about disease" that as "efforts at social adaptation, … contrast with scientific models which are primarily designed to promote scientific investigation" (Engel, 592). Each culture has its own view of what constitutes health and what constitutes illness. Kleinman writes about the various cultural explanations for and experiences of disease among various ethnic groups in America, including "'soul loss' (*susto*) among working-class Mexican-Americans in Los Angeles, spirit possession among Puerto Ricans in New York, voodoo among Haitian immigrants in Boston…" (Kleinman, 25). That these views are not shared by the Western biomedical models does not make them less valid. More importantly, they have a significant effect on how people interact with the medical system.

And yet most of define our health simply in terms of what the biomedical model tell us health is and trust that our doctors always know best. I believe it is possible to use this trust to its full advantage by fully engaging doctors in the process of shifting the definition of health and healthy behaviors. Because most people do trust their doctors, they are more likely to engage in behaviors and utilize tools recommend by their caregivers. This is one of the keys to designing and implementing an informatics tool to encourage healthy behaviors.

This leads us to another key problem in designing such an informatics tool. What behaviors do we want to promote? Is there sufficient consensus in the American medical community to pick out those behaviors that will truly help people lead healthier lives? I believe there is a set of basic behaviors that most clinicians can agree are worth promoting. My personal interpretation of this generally-accepted list includes the following behaviors, many of them already mentioned above:
- weight management
- good nutrition
- frequent physical activity
- not smoking
- drinking alcohol in moderation, if at all
- getting sufficient sleep
- minimizing stress
- being engaged in some sort of community
- going to the doctor for appropriate screen exams in a timely manner, such as mammograms, colonoscopies, etc.

I would add a few more of my own:
- living a life with a small footprint
  - living in a smaller house
  - driving a smaller car only when other methods of transport are unavailable
  - purchasing locally grown food products, preferably organically grown

- o minimizing purchases of consumer goods
- o minimizing use and consumption of animal products
- avoiding processed foods of all sorts, focusing instead on whole foods, and minimizing sugar
- engaging in some sort of contemplative practice, be it yoga or mediation, attending spiritual services of some sort
- being constantly engaged in learning new things

This obviously extends the idea of living a healthy lifestyle to considering the impact of our lives on the health of the planet and our community.

The two ideas in the generally-accepted list that present the greatest issues are probably good nutrition and screenings. The medical community seems to be engaged in a somewhat crazy process of analyzing what foods are good for us and which aren't. It seems, however, that eating a simple diet of a wide variety of whole foods is the answer. Of course, this is easier said than done. As mentioned in the article on social marketing, junk food companies have decades of experience marketing their products to us. Convenience foods are popular for a reason. As Americans get busier and busier, few families find the time to cook healthy meals from scratch, instead relying on Hamburger Helper and take-out. While we may be convinced that a whole food diet is better for us and our kids, it can be daunting to face that each night at 5:00!

How, then, do we make the leap from knowing what we should do and actually doing it? How can we, as informaticists, encourage these behaviors?

I think before actually designing the tools to help people stay healthier, we need to engage in several activities. First, we need to better understand what motivates people, both in general, and more specifically in the area of health. Second, we need to design systems that will play on those motivations, utilizing what we know about social marketing. Finally, we need to engage both health practitioners and users of our systems in the design process.

There are fields that have studied motivation extensively. This seminar includes a session on what motivates people, because I think that we need to understand that before even starting to design a system. We need first to figure out if it's possible to encourage people to engage in healthy behaviors in "real-life." If not, there's no point in designing an informatics tool to try. Also, these motivations need to be designed into the system, so we need to be aware of them from the start.

I find that as a parent, I am living a healthier lifestyle than ever before, not only because I want to be a good role model for my child, but also because I want to make sure that I'm alive and physically able to actively participate in his life. These are very powerful motivators. They can lead us to do things, like extended breastfeeding, that are inconvenient in the short-term because of the long-term benefits. The statistics of childhood obesity show us that most children's parents are not teaching them to lead a healthy lifestyle. By not insisting children get regular exercise, allowing them to eat junk

food and watch hours of TV, parents are doing their children a huge disservice and setting them up for a lifetime of health problems. Is it possible for children to learn to life healthy lives if their parents don't? Should the focus of attacks on childhood obesity be aimed solely at children or do we first need to tackle the parents' issues? TLC has a new show called "Honey We're Killing the Kids!" where a medical nutritionist spends three weeks transforming the diets and exercise habits of an entire family. In each of the shows I've watched, the parents always express surprise that they're expected to transform their own eating habits in addition to those of their children. Clearly, there's a real lack of understand of how children learn their habits! This area presents an enormous opportunity to not only help adults live more healthfully, but to help an entire generation develop health habits from the beginning. Children are much more adaptable than adults.

Once we've identified the motivations we want to exploit, we need to design a plan based on what we know about social marketing. Marketers have known for decades how to manipulate people into doing things that are bad for their health. We need to take that information and use it to help people live healthily. Breastfeeding is one example of how this has been done. In many ways, it's simpler to bottle-feed, as babies who are fed formula eat less frequently and can be cared for by others for longer periods of time. Many women are uncomfortable nursing in public. Mothers who aren't breastfeeding have more flexibility in their schedules, and pumping is a drag. But as more and more benefits of breastfeeding are discovered and communicated to mothers, more women are breastfeeding. As more women breastfeed, including many celebrity mothers, breastfeeding is more common ad more socially acceptable. Recent laws that protect mothers' rights to nurse in public further support and promote a behavior that has enormous benefits for both babies and mothers.

This example includes many aspects that informaticists can bring to their tools. First, solid research that backed the behavior was communicated clearly via trusted sources (doctors, doulas, lactation consultants, birthing class instructors, trusted websites). Second, behavior shapers like celebrity mothers, made the behavior cool and desirable. Third, public policy protected the behavior and labeled it as desirable. And there are few stronger motivators than a mother's desire to give her child a better future.

Finally, medical informaticists developing tools really need to take advantage of established design methodologies, especially User-Centered Design. We need to involve both users and physicians to help us design systems that really meet the needs of our users. Tools that are simple and intuitive require usability testing and a real focus on giving the user what she wants and needs rather than on what the developer thinks is cool. The tools need to fit seamlessly into a person's life, taking advantage of existing patterns of behavior. For example, there are websites that use email to remind women to perform monthly breast self-exams. Rather than requiring a user to go to a website to figure out when and how to do a self-exam, the information is all emailed to her. Other options are using cell phones and text messaging to send motivational messages.

One assumption inherent in this worldview is that people really want to be healthy, and that, if given simple, easy steps to being healthier, people will take them. There is probably a segment of the population that doesn't value health highly. Clearly, since Americans as a whole are pretty unhealthy, I think there are some issues here to be explored. Another assumption is that, given an easy way to make it happen, people will at least put some amount of effort into following healthy behavior guidelines.

This seminar is important for informaticists and physicians because the areas of preventative medicine and health promotion are clearly on the mind of the public, as well as on the radar of health plans and public health officials. As healthcare costs skyrocket, limiting the amount of time people spend at the doctor is one way for everyone to help reduce costs. This area is a goldmine for tool providers, with huge market opportunities for tools that make a real contribution to improving people's health. Americans have shown repeatedly that they are willing to pay big money for the chance to be healthier, especially if it's easy and straightforward.

Physicians who integrate such tools into their practice create a new line of communication with their patients, enabling a more dynamic relationship and improving their customer service. These tools also present the possibility of reducing physician workloads if patients are able to email a quick question instead of coming in for an appointment or if the patient can search a vetted online reference source instead of contacting the physician directly.

Tools that are designed to promote healthy behaviors require different ways of thinking than that inherent in many current informatics tools. Rather than focusing exclusively on what has been valued by the traditional biomedical model, tools designed to help people become and stay healthy take into account psychological and social factors, as well. People's motivations are of paramount importance in designing these tools, in addition to a real understanding of what users need and want from a health-promotion tool. Informaticists are urged to think about ways to create tools that can make a real difference in the lives of healthy people, thus helping, to the extent possible, healthy people stay healthy.