The Biocitizen and New Media Technologies Conference (May 23-24, 2007)

BRIEFING
HEALTH HORIZONS PROGRAM

INTRODUCTION

In May 2007, IFTF’s Health Horizons Program held the Biocitizen and New Media Technologies conference to explore the convergence of trends around new media, health, and biocitizenship. We presented five video scenarios to illustrate our forecast of biocitizens’ usage of new media technologies in the coming decade. After the conference, we launched a new Web site (http://biocitzennewmedia.org) to demonstrate the participatory nature of new media. The Web site sought to encourage interactive communication with our clients around the potential implications of engaged biocitizens equipped with new media tools. In addition to the online dialogue, the Health Horizons team hosted four conference calls over the summer to enrich the discussion around new media technologies and the biocitizen.

WHO IS THE BIOCITIZEN?

Over the last decade, we’ve seen a number of citizen movements that have placed demands on governments or corporations to provide access to treatments, the health care system, or conditions conducive to good health. From post-Chernobyl Ukraine, to AIDS activists pressing for access to antiretroviral drugs in Africa, to the Abigail Alliance suing the FDA for access to developmental drugs, we’re witnessing a proliferation of claims and demands based on particular groups’ experiences with their own biologies.

These emergent forms of biosociality are early indicators of the development of a new participant in the world of health and health care—the biocitizen. The concept of the biocitizen captures how patient groups form social affinities based on biological data or status, create lobbying movements, and develop online communities around specific diseases and their experiences with their own or local biologies.
WHAT IS NEW MEDIA?

The ecosystem of media technologies is expanding to make room for old media, such as radio and TV, as well as new media (sometimes referred to as web 2.0 platforms), like YouTube, MySpace, blogs, and wikis. New media technologies have five dominant characteristics: they are participatory, networked, lightweight (tools and technologies are easily accessible, easy to use, and scalable), contain user-generated content, and exhibit collective intelligence.

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User participation in new media platforms is a fundamental difference that sets it apart from traditional media. These tools can be leveraged to generate solutions and add value for groups of five to groups of thousands. In the context of health, innovative applications will come not only from the top down as new business models emerge, but also from the bottom up as biocitizens find ways to use new media to further their own health and that of the communities they are part of. From platforms that create more transparency of government and corporations, to those for organizing and tracking environmental contaminants, these new media technologies will provide important tools and resources for citizens to make their voices heard.

WHAT IS DRIVING THIS CONVERGENCE OF BIOCITIZENSHIP, NEW MEDIA, AND HEALTH?

Five primary forces of change are driving this convergence of biocitizenship, new media, and health:

1) **Health as a central value**: Healthism reflects the constant barrage of imperative messages we endure directing us to maintain a certain diet or lifestyle—Lose weight! Stop smoking! Have safe sex! In this environment of health as a central value, our job security or insurance coverage may depend on our willingness to take personal responsibility for our health status.

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1 Definitions found on Wikipedia (http://en.wikipedia.org/wiki/Main_Page), a well-known wiki site.
Illustration 1—www.whoissick.org—an overlay of current reports of illnesses and location

Illustration 2—ITF’s www.biocitizennewmedia.org tag cloud
However, as a society, we may reach a tipping point when people will fight back and claim rights against these messages and the interference of health authorities in their lives; they may reject healthism as we now know it.

2) **Biotechnology**: How we relate to our bodies, our illnesses, and to one another is changing as we become more informed through biotechnological knowledge. In light of this knowledge and increasing susceptibility to future disease states, we must make new choices about how we live. New forms of care and professional roles may emerge to help us manage these understandings. Biotechnologies also come into play in how we think about controversies that arise from bioethics and its role in creating markets and political controversies over things such as stem cells, the end of life, and so on.

3) **Risk society**: Increasingly, our society is organized around how we think about risk. From terrorism, to pandemics, to risk pooling and its demise, risk assessment informs how we lead our everyday lives. Our economy is ever more risky and the inequities in who shoulders the burden of risk can rapidly become major political issues. For example, consider how the more than 47 million uninsured in the United States have now become a critical political problem over the last year.

4) **Sustainability**: Sustainability, which until several years ago was largely viewed as an issue that only a minority of people in the United States valued highly, has gone mainstream. Sustainability means different things to different people, but it often has a health filter. Green health practices are emerging in the form of LEED hospitals, green dentistry practices, concerns over hospital waste, etc.

5) **New Media Ecologies**: We now live in an ecosystem of media technologies that range from old media—such as radio and television—to web 2.0 platforms like YouTube, MySpace, blogs, and wikis. Citizen journalism and bottom-up social networking platforms have already demonstrated their utility to effect change. The juxtaposition of the driving forces outlined above with the pervasiveness of new media ecologies leads to the conclusion that the power of biocitizens is growing.
The trend toward biosociality and the trend toward new media are converging and changing people’s health information preferences and practices. As the information and media landscape continues to evolve over the next decade, we think it is important to keep in mind six ongoing shifts:

1. **From packaged to user-generated media**

   *biocitizens participate in creating the health information they use and rely on*

   Health information is no longer exclusively packaged and created from the top down by traditional sources like doctors, the media, and health care companies. Instead, it comes from users themselves, whether they are recently diagnosed cancer patients sharing their experiences with treatments or people exchanging strategies to “green” their homes. Indeed, people will no longer passively consume media but instead will actively participate in creating content from the bottom up in whatever form and on whatever scale suits them. Sometimes it will challenge, and other times it will complement, traditional health information authorities.
2. From searches to interactions

biocitizens interact and engage with each other to find, filter, and make sense of health information

Health information in this new context is less about searching for the right source as it is about participating and interacting with others to find, filter, and make sense of information. Contributing to a wiki, starting a blog, or opening a Google group to talk about symptoms, poor service experiences with health care providers, or the lack of differences among health plan choices will be the norm. Biocitizens will not fill out a comment card; they’ll start a blog. Searches won’t go away, however. Searching will become more social and contextualized as even search engines themselves become more specialized and integrate new social-filtering capabilities. It is through interactions with others that biocitizens will overcome the fragmented information environment and build for themselves the clarity and credibility they need to make informed health and health care decisions.

3. From experts to collective intelligence

biocitizens leverage and trust what the group knows rather than relying only on experts

The world in which health knowledge simply resides with individual experts is giving way to a collective intelligence that emerges from the collaboration and competition of many individuals creating and sharing information. Some will be formal experts, most will be engaged citizens. This is not surprising because trusted health information sources are few and far between. We are bombarded with health information on television, in print, online, on packaging and billboards, and even in grocery stores, and filtering and making sense of health information is no easy task. Knowing that resources for health are not found in just the health care industry, biocitizens will turn to new media to participate in a range of health communities and build for themselves channels to different kinds of collective intelligences—from politics and health care reform to food and sustainable living.

4. From segments to networks

biocitizens view themselves not as individual consumers but as citizens connected to larger networks

While consumers demand choice, biocitizens will demand rights to the conditions that enhance health, ultimately defining a new commons. In the new media ecology, we shift our focus from consumers to biocitizens, and organizations will shift their communications from individuals to small groups and larger networks. These networks are also markets in their own right. This new media ecology demands that we shift our thinking away from reaching
individual health care consumers (who may or may not fall into traditional segments) to engaging biocitizens who share similar health values or biological attributes. With networks as the unit of analysis, we can begin to see that biocitizens have different needs. Biocitizen networks need identity and purpose, they need infrastructure, activities and rituals, and they need exchanges to sustain them. New media's social computing platforms can help meet all of these needs.

5. From information to feedback
biocitizens engage with connected objects and spaces

The value of health information increases as it is accessed anytime, anywhere, in real time and in context—be it at the doctor’s office or in the aisle at the grocery store. As connectivity moves off the desktop and gets embedded in objects and spaces, opportunities for feedback will open up as a range of health-aware environments--from the office and home, to the car and mobile phone on-the-go—reinforce healthy behaviors and help us navigate around health risks. These connected objects and spaces will not only communicate with each other on our behalf, but also communicate with us as biocitizens—and we’ll turn to them as a resource for making better purchasing decisions, tools for personal health management, and as partners in citizen public health.

6. From readers to advocates
biocitizens consume information not simply out of interest but for collective action

New media are much more open to participation, and media practices of biocitizens are already evolving toward greater opportunities for collective action. Biocitizens are using new media tools to reveal new patterns in data, making what was once invisible visible. We can now map everything from hospital closures in poor neighborhoods to the lack of grocery stores that sell fresh fruits and vegetables in a given zip code. These are examples of a new health transparency that is driven by biocitizens' use of new media. What's important here is the potential to turn readers of health information into advocates focused on health commons. As health transparency from the bottom up reveals new and shared health risks, new health commons will be created. These new health commons will reinforce our identities as biocitizens, compelling us to advocate on our own behalf.
At the Spring Conference, the Health Horizons team presented five forecasts in the form of video scenarios to illustrate the ways in which biocitizens may leverage the tools and technologies of new media to engage in new health and wellness practices. We then used the Biocitizens and New Media Technologies Web site (http://biocitizennewmedia.org), as well as the four conference calls over the summer, to develop and explore the potential implications of these forecasts.

The first two scenarios—Moms Like Me and Patientology—emphasize the role that social networking technologies will play in empowering biocitizens. Already, research shows that the sources people turn to for health information have shifted significantly in the last few years, with medical authorities like doctors, nurses, and health web sites losing favor, and new sources of information exchange—such as retailers and online social networks—gaining favor (see Graph 1).

Digital Health Native illustrates how young people will see themselves as part of health collectives and will use new media to define new health commons around shared risks or needs. And possible uses of mobile technologies are highlighted in Eco-Health and In the Hands of Users.

These video scenarios can be viewed on the Biocitizens and New Media Technologies Web site. Draft transcripts of the scenarios are attached as Addendum A.

Our use of new media tools to amass and categorize implications resulted in the “implications tag cloud” seen in Illustration 2, above.
Forecast: Moms Like Me

Consider a big-box retailer that recognizes the importance of online social networks and shifts its communication target from individuals to small groups that share similar health or lifestyle decisions. In Moms Like Me, the local “Bullseye” store offers a program that enables shoppers to use Web 2.0 and mobile technologies to get together for support, for information, and for community.

This scenario recognizes that retail social support networks may become one element of retailers’ comprehensive health strategies for the care and management of health and wellness that has moved from clinical settings to the community, home, and on the go. With the rise of new social-networking technologies, these small groups scale up to form large networks, and have the ability to identify others with similar experiences, organize and advocate for change in policy or health systems, or engage with scientific research.

Forecast: Patientology:
In this video scenario, Dr. Osborne, a family physician, realizes that she must embrace the tools and leverage the attributes of new media in order to connect with—and meet the needs of—her patients. So she regularly contributes to the user-generated content within an online social network dedicated to her patients’ health interests.

To promote greater shared knowledge and increased collaborative efforts, physicians like Dr. Osborne will participate in new media platforms such as blogs, wikis, and social networks. Successful physicians in the future will recognize that biocitizens are emerging as information authorities (sometimes challenging, sometimes complementing existing or traditional sources of information), and will engage with them in meaningful ways.

**Implications of Social Networking and the Biocitizen**

These scenarios highlight that, from food companies to big-box retailers to traditional health care professionals, new opportunities to become purveyors of relied-upon health information will abound. With easy access to information online and new affinities forming around health, biocitizens will also emerge as leading health authorities themselves. Corporate communications strategies will need to meet the challenges created by this wealth of bottom-up information.

New health affinities, facilitated by the proliferation of new media technologies, range from people with chronic disease to those with particular diets (such as locavores); they also include new communities (such as body hackers or the better-than-well crowd) and those who share similar health values (such as natural and ecological health). Each of these represents a unique potential market and serves as a channel for communications and products. The everyday person might belong to multiple health affinities, placing her in a range of markets in the global health economy.

As health information generated by social networks and “people like me” becomes part of the ecology of the global health economy, companies will need to reevaluate not only their assumptions about information channels, but also (and perhaps more importantly) how trust and credibility are negotiated. User-centric groups will be immensely rich sources of valuable information for organizations seeking to understand their markets and their customers.

However, the proliferation of health media and the increasing availability of biological data, medical information, and social data may create bottlenecks due to the lack of capacity to handle and process all of the information generated through new platforms and channels. A valuable skill—or service—will be the ability to make sense of the flood of inputs, turning data into useful/usable information. Filtering and making sense of large amounts of
data in order to identify trends and patterns that invite action may be an opportunity space for companies, but fostering trust will be essential to success in this role.

Traditional models of consumer decision-making and behavior change will need to be re-evaluated in light of the burden of risk shifting from institutions and governments to consumers. This shift creates a sense of empowerment that is evident in the increasing responsibility consumers face for decision-making and financing related to their health care. While biocitizens and social networks help mitigate the risks we collectively face, new practices for decision making, chronic disease management, and citizen involvement will emerge and spread widely.

**Forecast: DigiHealth Native (DHN)**

![Image](image)

The term “digital natives” refers to individuals who have grown up immersed in technology. DigiHealth Natives (DHNs) are young people who will have had their formative health experiences occur in a global health economy; as a result, they will look to a broader spectrum of stakeholders as potential resources for health.

In this scenario, we hear from a DHN who points out that she doesn’t make any health decisions—from what to eat to how to de-stress to ways of avoiding illnesses—as a lone individual because she is always connected via technology to her closest friends, who provide her with instant feedback and support. They all rely on new devices to help them manage their health, on new sources of information about nutrition, sustainability, and health care decisions, and on new collectives to manage risk.

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Implications of the emergence of DigiHealth Natives

While older cohorts are used to accessing health care in a physician-centric paradigm, DigiHealth Natives will come of age at a time when the role of physicians as supreme authority has begun to change (see Graph 1). DHNs will view clinicians as merely one of several inputs into their health decision-making process. They will pioneer new ways to leverage the collective intelligence of their social networks, communicating their health states and identities across different channels, and defining new peer-to-peer health approaches that emphasize group metrics, group feedback, and group decision-making. The challenge for all players in the global health economy will be to recognize the differences among cohorts and to develop strategies for responding to each group accordingly.

One key difference will be found in how DHNs (whose use of social networking technologies is a ubiquitous part of their lives) think about privacy and their health information. Bottom-up sharing of health information may be the norm for DHNs, and they will likely want to have their electronic health records integrated into their networked lives. This desire for ready access to what many would consider to be private information will create potential conflicts and disruptions for health plans constrained by regulatory standards. This tension will open up new opportunities to leverage the integration of health information into people’s daily lives.

For example, regular status reports from a DHN that indicate sad or hopeless feelings may aggregate into a warning flag that tips off her electronic health record service to notify a mental health provider to check in on the DHN. By combining DHN real-time status reports with electronic health records, specific warning signs could provide an extraordinary business opportunity to enhance health screening models.

4. In the Hands of Users:
Mobile health platforms are emerging as important personal health technologies that encourage and facilitate “anytime/anyplace” self-care, self-diagnosis, and environmental sensing. As the first generation of “health-aware” mobile phones (phones with sensors that can detect some data about users’ bodies or their immediate environment) become available, people will start using these phones in unexpected new ways.

In the Hands of Users presents two newsmagazine-style reports on news uses of mobile phones. In the first story, a community’s residents use their phones’ built-in sensing technology to monitor location, air quality, and heart rate; this data is continually aggregated to build a map of their city—a “mashup”—based on biology and risk. In the second story, a company requires its employees to carry mobile phones that can track their whereabouts and levels of activity. Their health coverage depends on whether they visit donut shops or health food stores, maintain an active lifestyle or are “couch potatoes.” “Mobile phone walkers” help game the system by providing false data.

5. Eco-health:

Our protagonist in this scenario sees his world through an entirely new lens. He is equipped with augmented-reality mobile technology that constantly feeds him information about his environs—the healthfulness of a restaurant’s menu, the sustainability practices of a store, the risk of infection from a pandemic flu.

**Implications of mobile technology on health**

The burgeoning deployment of health-aware mobile technologies will allow biocitizens to expect greater transparency, which will lead them to new framings of risk. Making previously invisible risks visible will empower biocitizens to demand conditions conducive to good health than go far beyond the traditional health care delivery system. The health narratives that
emerge will blur boundaries at the intersections of industries. This blurring of traditional boundaries will open up new business models and disrupt old ones; new value propositions will be defined to form new markets.

For example, as people begin to include environmental and sustainability concerns in their broad definition of health, addressing these factors as health issues will create opportunities to become stakeholders in the emergence of “green health.” Also, the impact of the built environment on health outcomes will be enhanced by the use of mobile technologies, in conjunction with the proliferation of geocoded data. This will mean that collaboration across urban design and health will grow in importance and firms will have opportunities to join smart growth coalitions and find cost-effective ways to approach chronic diseases outside of the traditional health paradigm.

However, in an age of transparency, trust will become a critical issue. Companies will need to develop sophisticated strategies for responding to and managing bottom-up reviews of their products and services. People will no longer rely exclusively on information presented by retailers or manufacturers; instead they will use customized filters to gather eco-health data from trusted sources in their communities (whether an individual or user-generated content on a social networking platform). In order to develop and maintain health-related branding, companies will need to embrace and manage demands for transparency, and find ways to become trusted members of these communities.

Trust also becomes an issue when health care payers (whether employers, plans, or government) use mobile technology to monitor individuals’ behaviors through a health filter. This top-down surveillance may have some success, particularly for those who use the technology as part of a feedback loop that supports positive health behaviors. For others, this “big brother” approach may offer new opportunities for providing products and services to help those who want to cheat the system. Also, an assumption of ubiquitous connectivity at all times may encounter significant challenges as people choose to value privacy over accessibility. Strategies that rely on persuasion rather than surveillance may be more effective at changing behaviors in the long run.

Mobile technology will serve as a key feedback tool for personal health management. People will use the information to make on-the-go decisions about what they eat, what products they buy, or what neighborhoods they visit. For some, access to such location-based dietary, biological, and/or environmental information may help overcome current systemic barriers to health. When employer health plans place an emphasis on results over mere participation in health promotion programs; collaborative approaches between payers, plans, and even drug companies, may emerge.
Biocitizens will also repurpose these mobile tools to support their own collective interests, like group formation or data aggregation. Community public health may be reframed, reprioritized, and redefined when groups use the data collected by their members to develop their own narratives about network and community health and safety. These biocitizens will be empowered to gather on-the-ground data about outbreaks (or threats) of illnesses faster than public health agencies can, making them early advocates for action. This citizen-army of information-gatherers may be a powerful group to tap into.

CONCLUSION

Our exploration of the evolution of biocitizenship and how the health and health care landscape will be transformed in the coming decade by new media technologies reveals the power of the tapping into the collective intelligence of social networks for health. This collective intelligence will introduce new health information authorities and will redefine the health care consumer in the future. Indeed, signs of what lies beyond the current consumer paradigm can be found in the increasingly complex ways that social affinities are being created on the basis of biological factors and the role these media and technologies play in enhancing the market power and force of biocitizens. By considering the implication of our forecast scenarios, we hope we have painted a picture of the quickly emerging landscape of biocitizenship and new media technologies and provided insights into how players in the global health economy might innovate around them.
Moms Like Me

[voice 1]: When we first moved to town, I didn’t know anyone. New mom, new town...a real recipe for loneliness. I remember going to the local Bullseye and I saw a kiosk about a new program, groups of local shoppers getting together...for support, for information, for community. They were called Bullseye Groups. A lot of these were around health: there were groups for diabetes, beauty, weight loss, you name it, but there were also groups about balancing careers, or good parenting, or the environment. I took a flyer and when I got home I went online and signed up for the local MomsLikeMe group, not having any idea what to expect...

Fast forward a few months and, just, wow! These women have become...

[voice 2]:...a real part of my daily life. I just can’t imagine shopping without the help and support of MomsLikeMe. With all the green labels, the socially responsible labels, the personal health index labels, and then all the advertising in the store—shopping nowadays is like running a marathon!

So I turn to the MomsLikeMe group to help make sense of it. We’re all thinking about these issues and we’re all buying the same products in the store. Sometimes I post a question in the MomsLikeMe forums online before I go shopping, but a lot of times I’ll send a message from my cell phone in the store when I’m standing in front of a product and want to know what the group thinks about it. I trust these women—they’re just like me, and they’re out there each day trying to keep themselves and their families healthy. Why not tap into that?

But MomsLikeMe isn’t just shopping advice about the products in Bullseye. It’s about...
[voice 3]:...community. I’ve made so many contacts through MomsLikeMe recommendations—we found our doctor, a dentist, good restaurants, even financial planners. We have to do so much more ourselves these days, especially around health. Everyone is scared to get sick anymore, and we have to pay so much more ourselves, so we help each other as much as we can to stay well. The MomsLikeMe group is an important part of that—heck, we talk to each other online or in the store a lot more than we talk to our doctors.

When my dad was diagnosed with heart disease, I basically turned to the group first—for ideas about what he should eat, meals in town he could still, questions like that. I got so many replies from other women in town going through the exact same thing. We ended up creating a new group for us that meets once a month and a group for our parents so they can exercise and go out to eat together.

The heart of MomsLikeMe is online, in the discussions, the questions, the advice in our community forums. But we also meet in the “real world”, in the Bullseye store, in these new spaces just for groups like ours to meet. Just yesterday I went to my women’s healthy heart meeting there. I had stuff to pick up in the store anyway so it worked out great, and the meeting space is right next to the little drop-in clinic in the store. We did talk about heart health, but we always drift topics...husbands, kids, the town...many of these women have become real friends.

But, they’re more than that, too. These women are my...

[voice 1]:...my comrades in arms. I don’t know if Bullseye ever intended for this to happen, but our local MomsLikeMe group has become a real...political force I’d almost call it. Someone posted a petition one day, in the forums, to improve the quality of lunches in our elementary schools, and in a couple of hours it was far and away our most active discussion. Bullseye even let us set up canvassing tables outside the local store. After that petition, we now talk a lot in the forums about making real
change, mostly about health issues in town. But now we’re even teaming with other MomsLikeMe groups at other Bullseye stores to changes rules about personal health savings accounts, to get more environmentally-friendly products included. It’s almost like the MomsLikeMe forums are our campaign headquarters. Honestly, it’s exciting to be a part of this.

Most of us from MomsLikeMe are in at least a couple of Bullseye Groups, and there are new ones waiting as we need them. I about ready to graduate from the new mom’s group, and that’s going to mean new questions and new parts of the store to consider. It’s a little scary, but c’mon, I have MomsLikeMe helping me the whole time. Together we can do anything.
**Patientology**

REPORTER: Not that long ago, when 47-year-old Doctor Jill Osborn wanted to know how her patients were managing their Type-2 diabetes, she did the only thing she knew how.

DOCTOR: I asked them. But I had only 15 minutes with each patient, and that was barely enough time to evaluate their vitals, review their test results, and then try to spend a few minutes talking about how they were dealing with the daily challenges of their illness.

REPORTER: Often, Doctor Osborn would get the standard response.

DOCTOR: Most of my patients would tell me that things were fine. When I pressed them about compliance, they would admit that sometimes they weren’t very good about watching what they ate or checking their blood-sugar levels—they’re tough subjects with no easy answers, and we never had enough time to think through them together.

REPORTER: All of that began to change with one patient and one consultation.

DOCTOR: When one of my patients casually mentioned the support and advice she got from her online diabetes community, I had no idea they used these forums for so much.”

REPORTER: Doctor Osborn has come a long way since that conversation. Last week, she won the award for “Best Interactive Physician Group” at the 2009 Online Health Community Awards, which recognizes outstanding health-related social networking Web sites. So how did she do it? And why?
DOCTOR: When I first started to visit these patient-centered online sites, it became clear that patients had many more questions about diabetes than the ones they asked during office visits. Recently diagnosed members of one community wanted to know about drinking champagne and eating cake at their weddings. They wanted to know about pregnancy. They asked about qualifying for medical research or clinical studies. I realized...if I really wanted to make a difference, to practice medicine the way every doctor hopes they canI needed a better way of reaching my patients than limited office consultations.

REPORTER: So in late 2007, Doctor Osborn launched osbornodiabetesfamily.com, a place for her patients to talk to each other but also a place for Dr. Osborn to offer advice and respond to questions when patient-to-patient support alone didn’t have the answers. The site now includes traditional diabetes information, along with patient-generated video tutorials and health diaries, and links to new research studies relating to diabetes. Many of these links come from Dr. Osborne, but many more come from patients themselves, and the site has become a place for them to pool their collective knowledge and latest discoveries. Dr. Osborne’s patients immediately responded, and she soon began prescribing membership in the site right along with pharmaceuticals. But Doctor Osborn soon realized that she had created more than just a community of interest.

DOCTOR: Patients began linking to things like Google map “mash-ups” that overlay childhood obesity rates on top of easily searchable local maps or videos on YouTube about getting insurance companies to cover all their diabetes supplies.

REPORTER: Osborn’s patients started to connect online and then offline through informal meet-ups in town; some even initiated group fitness sessions. In response to a patient-led initiative, Doctor Osborn linked her site
to other providers' blogs in the area to increase the size of the local diabetes community, or “D-communities” as they’re known.

DOCTOR: I was frankly a little surprised when my patients began to self-organize. But because of the Web site, they came to realize that many people in our area’s D-community had similar health plans. Once they found each other and discovered their shared situations they united to demand that their health plans cover more medical supplies and even new drugs. I’m thrilled to have been a part of this movement.

REPORTER: While Doctor Osborn is getting recognition for her efforts, that’s far from the only way this has affected her. The patient community has had an impact on how she practices medicine.

DOCTOR: Doctors always think they have all the answers. I’m sure I did too. But we don’t. We can’t. We can’t keep up to date on everything no matter how much we read. We won’t be treated like peers by our patients, nor should we expect to. They need more support than one doctor, one resource can offer. We need to tap into these peer communities they’re building—not as oracles on high but as peers who have as much to learn as we do to teach. I now frequently host group appointments, but my one-on-one sessions have improved too, even when we only get a few minutes. It’s a strange new world that we sure as hell didn't learn about in medical school, and it’s a big step in the right direction.

REPORTER: Sarah Maston, NPR News, Des Moines, Iowa.
**DigiHealthNative**

OK, so you asked me to think about how I talk about my health during the course of a typical week. I jotted down some notes so I wouldn't forget anything.

The first thing you have to know about me is that even though I look like just one person, I'm really not.

I'm always connected to my 6 best friends. We all met our first year in college, and health-wise we've helped each other with everything, day after day...eating decently, stress, depression, sleep, power studying, and most of all how not to get sick.

Even though we're not all in the same city anymore--it's been almost 2 years since graduation and most of us have "real" jobs now all over the country--we're still connected...and now we're almost closer than when we were all in the same place.

We send each other dozens of little 'nano-updates' each day, like random thoughts or what we had for lunch or what kind of mood we're in, and I get them on my computer and my phone. Most of these updates are public, and they go up on our online profiles right away, but there are some private ones we write just for the 6 of us. I know when a private message comes through that I really need to read it.

These updates are the messages we choose to send to each other but we're also using technology that sends health info automatically, like the Nike-Ipod-X which I love love love.

So you probably heard of it, it automatically streams my heart-rate and data about my workout to wherever I want it to--to my personal profile if I want it public, or just to my friends if I want it private. 5 of us got one to help stay motivated, and it works soo well. When I see that one of my friends had a great workout, I'll send her a
message or give her some extra karma points. I love getting those kinds of daily messages myself—even when they’re short, they actually do help—so I try and send them whenever I can.

So, between the messages we send ourselves and the messages our gadgets are sending, I always know how my girls are doing. Like last week, Yasmeen didn’t send a lot of messages, and her mood on her profile was set to bummed, and I saw she hadn’t gone for a run in 2 days, so I staged a mini-intervention and made her take the early train home from work and go for a run.

I realized all of that stuff so far is mostly about my 6 best friends. They are the people that affect my health the most, but, I also don’t have to actually know people to get useful information from them.

Like whenever I have to make a decision, big or small, I look up something about it—a product, a company, a name—to see what other people are saying and how they’re rating it. I do this for almost every decision—too much, my boyfriend says—but I especially do it for anything about health. I’ll look up an ingredient if I haven’t heard of it, or if I doubt a store’s label about some product being healthy or being sustainably manufactured I’ll look up ratings from other sources, right there in the store. I love to add this kind of information too, and give my own ratings. In a way it only seems fair, since I use them so myself so often. I even got that new phone that makes it easy to get and post these ratings right there in the store.

Those are all small decisions, but it just so happens a big one hit last week. Something changed at work and now they’re giving us money to pick our own health plan. Even though I barely used our old one since I never really get sick, I know this is a major decision. I’m asking everyone for advice—my girls, and my larger go-to list of around 200 people, and I'm posting questions in a lot of online forums.

There’s one I’m really leaning towards, a new experimental collective-type-thing
called YouHealth. It's not actually a health plan, but a group of people at similar companies that were in the same boat and wanted to pool their power to negotiate cheaper prices and more focused services. Unlike a traditional plan, I won't be lumped in with other people that don't care about their health, so essentially I'm not paying for their donuts.

To join the collective you have to be public about how you manage your health—you have to have a profile, update regularly, join online groups—so, basically, it sounds like they reward you for a lot of behaviors that I already do, and they even use devices like the Nike-iPod-X.

So I think that's it. I hope this was helpful for your research. I gotta run, literally, cause if I don't I'll get a message from Yasmeen ASAP. Bye!
In the Hands of Users

Tonight on Our American Life, we hear two stories from the frontlines of place and space, of technologies designed to watch our bodies that are being used in some unexpected ways.

First, a community that's writing its own map of their city, based not on topology but rather biology. Many residents in Richmond, California already had cell phones with built-in sensors—location, but even air quality or heartrate or even stress—without their owners even realizing their phones could do this. Some came from insurance companies or health plans, but many others were just the whizzbang new features of ever-advancing phones.

But it took a Richmond community organizer, Yasmeen Richards, to see new potential in all this unused technology. She worked with a local community college to create a piece of software for these types of phones that continually uploads sensor data as people move about the city.

The data may be street-by-street levels of smog or quantified stress from galvanic skin response or heartrate, but day-by-day, data point by data point, the residents of Richmond are creating a map of their community that can't be bought in a gas station. It's a map of risk, of emotion, sometimes even fear. A map that tells the hidden stories cartographers don't capture, and a map that rewrites itself a bit each time someone's heart beats a little faster. Already this data has helped divert funds earmarked for an area of town that most felt didn't need it, when the risk map clearly showed there were other places that stirred emotions more, quite literally.

Yasmeen's next step is to bring more people into the conversation and capture more voices. She's using off-the-shelf mobile services—the ones generally designed for your teenager to share his life with his hundred closest friends—to create a virtual town meeting. So far she’s finding that people who wouldn’t ordinarily talk about
Richmond on the internet, and definitely not attend a community meeting in person, will actually share photos or record a video opinion on their cell phones.

Now, If that first story can be said to highlight the participatory nature of our always-connected world, well, this next one might just drive you into one of those new wireless-blocking coffeshops.

For this story, we were sworn to secrecy and promised not to tell you where it takes place. Recently, employees of the largest employer in this town were given cell phones that watch where they go and how much they move, and report this information back to the company. "Given" may actually be too euphemistic. They were in fact told their health coverage depended on using them. A slightly different story you'll agree.

Now of course many would call it surveillance, but this company claims it isn't looking at the exact locations employees travel, but rather the higher-level patterns produced, as a way to control spiraling health care costs.

So, if you don't move around enough at night, or you hit the donut shop on the weekend, you're gonna pay more, or suffer an even worse fate.

But, a growing group of these employees isn’t just sitting around, pun intended. They've joined together in a new homegrown service to trick the system, to beat quote-unquote The Man at his own game. It was started by a guy named “Bob”—probably not his real name, but we couldn't be sure—a fellow between jobs who felt he could spend his down time helping those who were being monitored. Altruistic, yes, and he also charges 2 bucks a day.

They give their phones over to Bob as they're leaving work, and Bob will run around town, do a couple of laps around the park, even linger in health food stores. The next morning, subscribers of this service, if they can be called that, meet him to pick the
phones up at, well, where else but at a local vegetarian restaurant near company headquarters.

Two stories, two very different takes on the same tools. And we’ll probably see a lot more of both.
**In the Hands of Users**

*Intro:*

"Welcome to anyone tuning into my channel for the first time, and a big yo! to everyone coming back.

This is Day 4 of what some are calling the next pandemic, and in California we're seeing signs all over the place--dead birds, people sick. But officials haven't done anything yet—they even just announced there isn't enough "conclusive evidence".

Those of us in the New Audubon Society are taking matters into our own hands...we're not going to let another official delay cost us as much as the first time.

So right now I'm taking a break from work, heading out to run some errands but also record what's going on, on the ground."

*Pizza store:*

"Hey pizza does sound good..."

"Yeah I know, I know"

*Global Mobiles:*

"Oh yeah I heard about this new store. Ok, so they got an 'official' rating of GOOD, but what are people really saying......? That's what I thought. Man you just can't trust labels anymore."

*Newspaper stand:*

"Wow, people out there really don't know what's happening out here..."

"Hell yeah it could be like last time. That's why we're mobilizing."
Woman passing by:

"Awesome, another New Audubon member. I should bookmark her."

Red gov’t poster:

[angry]: "Aww c’mon this is out-rag-eous. People are wearing masks for a reason, and every extra day that people are outside means this thing is only going to get bigger. We have to fight this with hard data and then get the word out."

Ye Olde Coffeeshop:

"We finally have a coffeeshop in town that makes the community healthier by being here."

Glucose message:

"Johnny just started streaming his data to the group. 'Hey Johnny you doin ok? Go grab something to eat man'"

Crossing the street:

"OK, so so far today I've counted 6 sick people and I saw one dead bird earlier on the walk to work. I geo-coded it all, adding that data now..."

White poster on the tree:

"So this other group, similar to us, has already declared a warning. I'm gonna call for a vote tonight, for New Audubon to do the same. It's time to take our own action. Going offline for a bit, I'll check in later."