Institute for Alternative Futures

THE DRA PROJECT

Accelerating Disparity Reducing Advances

Report of the Community and National Biomonitoring to Support Upstream Change Committee

September 2006 Report 06-07

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This paper is part of the DRA Project. The DRA Project is sponsored with funds from the National Cancer Institute, the Agency for Health Care Research and Quality, the Centers for Disease Control and Prevention, the American Cancer Society, the University of Texas Medical Branch, and Florida Hospital. The Federal Funds from the National Cancer Institute, National Institutes of Health, were under Contract No. NO1-CO-12400 and those from the Agency for Health Research and Quality, were under Contract No. GS-10F-0322R.

Report of the Community and National Biomonitoring to Support Upstream Change

INTRODUCTION

Today's surveillance and biomonitoring systems are providing an increasing awareness of risk factors, health conditions, and disease states in communities and among at-risk populations. As these systems evolve and improve, we will be able to target individuals and communities for "upstream" prevention. The DRA Partners at the April 6th meeting broadly conceived of the potential to use these emerging capacities to reduce disparities. This report explores aspects of our current and emerging tools to aggregate and use biomonitoring information to more effectively promote prevention. This is an initial review of emerging opportunities to connect these systems to disparity reduction.

We already have key components of a system for community and national biomonitoring in place, such as national surveys and emerging community and regional information systems. Over the next decade other major components will be added, such as ubiquitous electronic medical records. These surveillance and biomonitoring systems will become quite powerful as they are infused with greater knowledge of the causes and processes of disease and health. The evolution of these systems for upstream change could be delayed unless we can assure individuals there are effective safeguards for privacy, security and discrimination. It is also likely that these enhanced intelligence and monitoring capacities will expose the significance of the social determinants of health as the "upstream" factors most in need of change. (See the community health approaches described in the DRA Project Report 1 of 8, The Imperative of Reducing Health Disparities through Prevention: Challenges, Implications, and Opportunities).

CURRENT MONITORING SYSTEMS WITH POTENTIAL FOR UPSTREAM CHANGE

Several current national, state and local monitoring systems deal with personal data to develop trends and identify opportunities for disease prevention and health promotion. They generate useful information that can be used in disparity reduction.

BioSense: BioSense is the national program designed to improve the nation's capabilities for real-time biosurveillance and situational awareness. BioSense is a CDC initiative to support enhanced early

detection, quantification, and localization of possible biologic terrorism attacks and other events of public health concern on a national level. The goals of the BioSense initiative are to advance early detection by providing the standards, infrastructure, and data acquisition for near real-time reporting, analytic evaluation and implementation, and early event detection support for state and local public health officials. BioSense collects and analyzes Department of Defense and Department of Veterans Affairs ambulatory clinical diagnoses and procedures and Laboratory Corporation of America laboratory-test orders. The application summarizes and presents analytical results and data visualizations by source, day, and syndrome for each ZIP code, state, and metropolitan area through maps, graphs, and tables.

BioSense has been rolled out to pilot communities. An initial proof of a concept evaluation project was conducted before the system was made available to state and local users in April 2004. User recruitment involved identifying and training BioSense administrators and users from state and local health departments. User support has been an essential component of the implementation and enhancement process. CDC initiated the BioIntelligence Center (BIC) in June 2004 to conduct internal monitoring of BioSense national data daily. BIC staff has supported state and local system monitoring, conducted data anomaly inquiries, and communicated with state and local public health officials. Substantial investments will be made in providing regional, state, and local data for early event detection and situational awareness, test beds for data and algorithm evaluation, detection algorithm development, and data management technologies, while maintaining the focus on state and local public health needs. BioSense is connecting existing health information to public health in a way not previously possible. It is providing the immediate, constant, and comparable information needed to inform local, state, and national public health and to support national preparedness.
http://www.cdc.gov/mmwr/preview/mmwrhtml/su5401a4.htm

BRFSS (Behavioral Risk Factor Surveillance System): BRFSS monitors factors critical to serious health conditions, such as smoking, alcohol consumption, and failure to exercise. The BRFSS is the largest continuously conducted telephone health survey in the world. It uses a survey approach to sample patterns in personal behavior and life style. http://apps.nccd.cdc.gov/brfssdatasystems/overview.asp
With support from the CDC, BRFSS provides state-specific information about issues such as asthma, diabetes, health care access, alcohol use, hypertension, obesity, cancer screening, nutrition and physical activity, tobacco use, and more.

Federal, state, and local health officials and researchers use this information to track health risks, identify emerging problems, prevent disease, and improve treatment. The BRFSS system has been useful in identifying emerging health problems, developing public policy, and designing health programs. It has also been useful at the back end by allowing public health researchers to track trends in risk and evaluate the progress of public health and prevention programs. The system has allowed researchers to identify risks that might have gone unnoticed in underserved communities and to track the incidence of disparities in target populations and communities. For example, the system allows researchers to identify, map and track communities in Washington State such as Yakima and Spokane with abnormally high rates of diabetes.

BRFSS demographic data also includes information on education, race and income. States and many communities use it to target their areas of greatest need. BRFSS is challenged by its growing number of questions, by the fact that fewer households have landline telephones and are more reluctant to answer surveys, and the fact that CDC is prohibited at the moment from calling individuals via their cell phone.

National Health and Nutrition Examination Survey (NHANES): The NHANES conducted by CDC's National Center for Health Statistics, goes deeper than BRFSS by combining physical examinations with interviews. The NHANES detailed interview includes demographic, socioeconomic, dietary, and health-related questions. It includes medical and dental examinations, physiological measurements, and laboratory tests administered by medical personnel.

Findings from this survey are used to determine the prevalence of major diseases and risk factors for diseases. Information is used to assess nutritional status and its association with health promotion and disease prevention. NHANES findings are also the basis for national standards for such measurements as height, weight, and blood pressure. Data from this survey are routinely used in epidemiological studies and health sciences research, to develop public health policy, to direct and design health programs and services, and to expand health knowledge. Special emphasis in the current NHANES is on adolescent health and the health of older Americans. To produce reliable statistics for these groups, adolescents 15–19 and persons 60 and older are oversampled for the survey. African Americans and Mexican Americans are also over-sampled to enable accurate estimates for these groups. http://www.cdc.gov/nchs/data/nhanes/OverviewBrochureEnglish_May05.pdf

Other prominent monitoring systems include the Treatment Episode Data Set (TEDS), the National Program of Cancer Registries (NPCR) and Hospital Compare. The Substance Abuse and Mental Health Services Administration (SAMHSA) Treatment Episode Data Set provides information on about 1.5 million substance abuse treatment admissions annually. CDC's National Program of Cancer Registries together with data from the Surveillance, Epidemiology and End Results Program provides population-based cancer incidence data for the entire nation. CMS and the Hospital Quality Alliance's Hospital Compare provides audited, near real-time information from 4,200 hospitals on care for heart attack, heart failure, and pneumonia.

Electronic Medical Records: The Electronic Medical Record could become an important element in this biomonitoring system. Many community health centers have successfully implemented electronic medical records. Other health care provider groups have begun to take advantage of electronic medical records for community health uses.

PeaceHealth, a multistate provider network based in the Northwest, is a good example of a successful integration of health information systems into care delivery. PeaceHealth has expanded their medical records system to the community through its Community Health Record. For each of their patients, the Community Health Record provides a single, communitywide, longitudinal medical record (with security safeguards) to providers and patients associated with PeaceHealth. All health care providers and patients can access this. Since this program began, PeaceHealth reports adherence to care guidelines among diabetic patients has tripled.

An example today of using biomonitoring to effect upstream behavior change is the New York City Department of Health and Mental Hygiene's Electronic Clinical Laboratory Reporting System. All 127 laboratories in the city connected to the Electronic Clinical Laboratory Reporting System must inform the city government when they identify an individual with hemoglobin A1c blood sugar level above a certain level. The health department plans to use the lab results to develop a diabetic patient registry. Reports will go to both patients and their physicians with information on how to effectively manage the disease. This New York City plan makes diabetes a reportable and notifiable disease like sexually transmitted diseases, rubella, tuberculosis, tetanus, measures and food-borne illnesses. It immediately

invoked questions about privacy and discrimination and a much larger question of whether the city could be an effective partner in caring for the health of the individuals it identifies.

The Next Ten Years

These monitoring systems will grow in their scope and sophistication as they are coupled with other important advances over the next ten years. We will have greater knowledge of disease that will enable us to identify at-risk individuals at pre-disease stages. Personal biomonitoring will become easy and inexpensive. We will have a national health information network that connects personal health records and ubiquitous biomonitoring. We are rapidly developing knowledge technologies that turn biomonitoring data into usable knowledge for both care providers and individuals. We are turning to social marketing to create healthy behaviors in individuals and populations. And more communities and nations are tracking community health indicators that move upstream into the social determinants of health.

Greater Knowledge of Diseases: Over the next ten years, biomedical research will develop a greater knowledge of diseases. Biomedical research is working to understand disease at a genetic, molecular and cellular level. This emerging view can reveal fundamental processes in the pre-disease stage before symptoms appear. New interventions may be able to disrupt the disease processes early on the pathway, before they become manifest as illness. In these early stages it is likely that certain pathways could lead to many different forms of illness that have been historically diagnosed by symptoms or the part of the body that is most affected. The early indicators for pre-disease will likely be biomarkers based upon genetic, proteomic or other molecular markers. These early indicators will likely be stored in electronic medical records. The ability to aggregate data inside electronic medical records through a national or community health system will enable researchers to track pre-disease trends in large populations. They may also be able to compare this data to data from personal biomonitoring devices that monitor physical activity or with data from environmental monitoring on things like pollution levels. This will enable researchers to better understand the interaction of environmental factors and disease.

Personal Biomonitoring: We will have a variety of devices we wear, or carry (e.g. cell phones) or we set up in our homes. Personal biomonitoring devices will become quite common and increase the amount of data that can be used to determine individual risk factors for disease. For more information on

personal biomonitoring, see The Biomonitoring Futures Project: Preliminary Report & Recommendations.

National Health Information Network: Some form of national health information network will be in place by 2016 that will allow health information to be shared in secure, protected ways. It is likely that most individuals will have an electronic medical record stored with their health care provider. And they will have a personal health record that is under their control. Ubiquitous biomonitoring data from continuous, passive biomonitors in our clothing and in our house will be stored in our personal health record and with our health care provider.

Knowledge Technologies: Most individuals by 2016 will have some form of digital agent or electronic health coach. This expert agent program will take full advantage of the collected biomonitoring information. Our electronic health coach will also be able to use effective coaching, reinforcement, incentives, and/or games in helping us shape our health behaviors. In addition we can instruct our agents to appropriately share our data to enhance community and public health knowledge.

Social Marketing: The health communications field will benefit from combining advances in social marketing and biomonitoring. Social marketing uses the successful techniques from commercial marketing to "sell" communities on healthy behaviors such as good diet, exercise, screening tests and regular checkups. It is also an effective method for encouraging positive social change in communities. Social marketing listens to the needs and desires of the target audience and creates health education programs that are tailored to the unique cultures of communities. Information collected through monitoring systems can improve social marketing by providing more precise research on health trends in a community and developing real-time data on program effectiveness. These feedback systems can make it easier for social marketers to quickly evaluate and change programs to improve their effectiveness with communities and individuals.

Community Health Indicators: Policymakers are more interested in using indicators that look at the health of the community. The Leading Health Indicators developed by the Healthy People 2010 initiative have proven helpful in identifying disparities between different communities. Different states and communities have developed their own health indicators to track trends in population health. Most sustainable community initiatives include community health indicators as part of their public planning

process. The ability to track leading health indicators at the community level will be an important advance for community health advocates, sustainable community initiatives and policy-makers. At both the community and national level, the sustainability movement is including community health indicators as part of their larger visioning and strategic planning process. The Environmental Protection Agency includes human health indicators (e.g. asthma prevalence, cancer incidence, cardiovascular disease prevalence) as part of their state of the environment report. The European System of Social indicators include community health indicators as do the national initiatives of many EU member countries. Individual cities such as Baltimore, Cincinnati, Missoula, and Jacksonville have included community health indicators as part of their visioning processes, sustainability initiatives, and strategic planning processes. Connecting community health indicators with other indicators of social health will become an important counterweight to economic indicators in formulating public policy over the next ten years. The ability to monitor health more precisely through biomonitoring and to monitor environmental changes more precisely through advances in sensing technology will improve the ability to affect change upstream. Researchers will be able, over the next ten years, to make changes in the community and the built environment and monitor the changes through these indicators.

A Vision for the Future: The Health Advocate Avatar

The Institute for Alternative Futures recognized the promise of biomonitoring combined with knowledge technologies in its major study of the future of biomedical research (2029 Project: Achieving an Ethical Future in Biomedical R&D - See: http://www.altfutures.com/2029.asp). IAF imagined a Health Advocate Avatar as a knowledge interface that can mediate interactions between individuals and the world of medical knowledge. The Avatar is envisioned as a secure and discreet agent for the individual that also represents a highly ethical learning technology for collective knowledge for the community.

A variety of developments and new technologies will be required to provide components for the Avatar, including natural language search engines, truly effective voice recognition, haptic devices and high resolution displays. The Avatar is envisioned to be a coach, educator, and health manager that draws on the experience of large populations. The Avatar can provide individuals with control and personalized advice while serving health worldwide. More than just a technological wonder, the Avatar is an ethical development that can facilitate the health of both individuals and society.

Bringing It All Together

What will be the potential of community and national biomonitoring to support upstream change? We are definitely on track by 2016 for the affluent and the insured to routinely take advantage of biomonitoring technologies and personal health records. In-person and virtual health coaching will be an expected component of wellness programs. Insurance companies and employers will routinely monitor the health of their plan participants and target individuals for prevention and behavior change strategies. To the extent that we can overcome the concerns about privacy, security, and discrimination, we may be able to mine national and community monitoring systems and target individuals for prevention and treatment. If we do not also devise ways to provide these interventions for the poor and under-served, we will most certainly bifurcate into a healthcare system that prevents illness for the fortunate and only documents disease and death for the less fortunate. As these new capabilities to monitor health and preempt disease move us further upstream, we should see more clearly the strong correlation between these indicators of health and the social determinants of health (such as education, poverty, housing, work, personal meaning and access to health care.) The transparency that comes from meaningful intelligence about the health of individuals and communities could create a compelling and inescapable moral imperative for addressing these upstream factors.

Recommendations for the DRA Project to Pursue

1. **Biomonitoring & Surveillance Confidentiality**. The DRA Project could develop confidentiality agreements that the public and public health agencies are comfortable with by looking to the agreements used in other arenas, such as AIDS and STDs.

2. **Prevention Promotion Pathway**: The DRA Project could study and identify promising advances in social marketing for individual behavior change and community change to address the social determinants of health and disparity. Proven or promising practices could then be adapted and deployed through the DRA Project Network.

3. **Community Health Clinic Experiments with Information Integration.** The DRA Project could organize a users technical support group among community health clinics to accelerate the effective integration of the electronic medical record, the personal health record, biomonitoring and related communications devices for their patients.

4. **Leveraging Social Determinants.** A critical part of moving upstream is being able to affect the social determinants of health. The DRA Project should address how information from individual and population level monitoring can be used to promote improvement in the social determinants of health.