PRE-DIABETES
An Informatics Research Agenda

Barbara M. Hayes

School of Informatics, Indiana University, 535 W. Michigan Street, Indianapolis, IN, USA

William Aspray

School of Informatics, Indiana University, 901 E. 10th Street, Bloomington, IN, USA

Abstract: The paper sets out a research agenda for practitioners of the relatively new, interdisciplinary field of informatics who wish to improve the health experience for people who have susceptibility to diabetes – a condition known as pre-diabetes. Using information technology tools and methods, but with sensitivity to the social and organizational complexities of the health care system, the article suggests addressing a set of problems that will improve the lives of patients and their friends and families, as well as making the provision of pre-diabetes care more effective and cost-efficient. Topics include public health and community informatics, knowledge dissemination, information alerts, decision support, clinical guidelines, health literacy, patient, pharmacy, and laboratory feedback systems, interface design, reminder systems, consumer informatics, and privacy and security issues.

1 INTRODUCTION

The healthcare industry is one of the last to heed the call of the information revolution. Its relationship with information technology is deeply conflicted. Healthcare leaders recognize that transformational IT will decrease the risk of many common errors, streamline workflow and, in some instances, save money. Advanced computational techniques may uncover genetic predispositions to disease and identify new and more targeted pharmacologic agents. Despite these promises, the healthcare industry faces tremendous challenges as it integrates information technology into healthcare delivery. The cost of the transformation is high. Patient privacy is in jeopardy. And, by its very nature, IT threatens to disrupt the treasured, traditional relationship between physician and patient.

Healthcare is shaped strongly by the interaction of human need, economics, social demographics, and the complex organization of the healthcare community. These interacting variables make healthcare a subject well suited to study by the relatively new academic discipline of social and organizational informatics. This field of study, which is pursued in approximately twenty universities in the United States and a few other universities (including the University of Edinburgh, City University in London, National University of Singapore, Singapore Management University, and the IT University of Copenhagen) is not to be confused with the similarly named programs in Europe that are focused primarily on computer hardware and software. The practitioners of this new informatics discipline are faculty members with an interdisciplinary mindset, a social science methodology, and a familiarity with IT and its applications.

It is difficult for a healthcare practitioner to find out about research in social and organizational informatics not only because the literature is scattered, but also because it often appears in places where the healthcare community might not typically look. Nevertheless, healthcare information system

designers, healthcare policy makers, Medical and Nursing Informatics researchers, and teachers need to know about the discipline because it can improve technological solutions in healthcare and quality of life for patients. Since IT development and deployment are becoming important adjuncts in the treatment of chronic diseases such as diabetes, awareness of social and organizational informatics research is especially important to those who develop, deploy, and assess those technologies. Examples of these technologies include e-mail and Internet-based support, consumer-centered personal electronic health records, home monitoring systems, telemedicine, decision support aids, and online interventions.

Healthcare insurers and providers have made substantial investments in IT in order to make their care more effective and cost-efficient. Less attention has been given to using IT to improve the lives of patients and their families. This paper uses one stage of a widespread and expensive illness, Type 2 diabetes, as a means of examining ways in which IT can be used to improve the lives of patients when social and organizational factors are considered in the design and delivery of care.

Pre-diabetes lends itself to social and organizational informatics study because tools for managing that syndrome may be found in several areas of IT: public health and community informatics, knowledge dissemination and management, decision support, health literacy and technological literacy, feedback systems, interface design, information quality, consumer informatics, and security. There is a particular need to disseminate research on IT design and management that takes into full consideration the way IT affects individuals and organizations. IT designers often lack an understanding of the environments in which their work will be deployed, particularly in the multifaceted world of healthcare.

In an ongoing research program, the authors are looking at the social and organizational informatics issues related to every stage of diabetes, from the public health issues, to the diagnosis of the disease, to the self-care issues that face most diabetes patients as they live with the disease, to complications of the disease such as loss of eyesight or heart or kidney problems, to end-of life issues for the diabetes patient.

We have chosen pre-diabetes, a syndrome associated with Type 2 diabetes, as the focus of this paper. Individuals with pre-diabetes have blood glucose levels that are higher than normal, but not high enough to qualify for a diagnosis of diabetes.

The American Diabetes Association (ADA) now estimates that there are 54 million people in the United States who have pre-diabetes (American Diabetes Association, 2007c) We will examine several information and IT challenges associated with identifying pre-diabetes to allow informatics researchers who are unfamiliar with health care to "witness" the social and organizational factors in the ebb and flow of information around this syndrome.

To that end, the first part of this paper is organized in sections, each of which is preceded by a question. The body of the section then provides information about the topic, some examples of how the question has been addressed, and some examples of current challenges to date. The authors hope that this format will stimulate informatics researchers to create innovative research agendas that can provide ever-improving answers to these critical questions relating information to pre-diabetes. In the last portion of the paper, we offer our own suggestions for new research.

2 PUBLIC HEALTH AND COMMUNITY INFORMATICS

How do researchers educate and persuade the public to act on important new information about a syndrome -- in this case, pre-diabetes, in which higher than normal glucose levels and insulin resistance are present but do not qualify for a diagnosis of diabetes?

New information about diabetes is frequently incorporated into the medical literature. The general public may read about new medical studies in the newspaper, hear about them on the evening news or encounter them on web sites, but the vast majority of those studies are of interest only to the provider community and then only as background information. Occasionally, however, a major shift in thinking occurs. In 2002, the Department of Health and Human Services and the ADA issued position statements to the press on two conditions linked to an increased risk for developing diabetes. The term pre-diabetes was used to describe these conditions.

Patients with pre-diabetes have either impaired fasting glucose (IFG) or impaired glucose tolerance (IGT) (American Diabetes Association, 2007b). Research shows that some long term cardiac and circulatory damage may already be occurring during pre-diabetes (American Diabetes Association, 2007c). While healthcare providers had known about IFG and IGT for some time, the results of three major randomized controlled studies in different countries with different populations had concluded

at nearly the same time that individuals could prevent or delay diabetes with changes in diet and exercise (Narayan, Imperatore, Benjamin, & Engelgau, 2002). On that basis, the ADA recommended screening overweight people 45 years of age or older to detect those with impaired glucose tolerance or impaired fasting glucose (American Diabetes Association & National Institute of Diabetes and Digestive and Kidney Diseases, 2003). Those with pre-diabetes became candidates for diabetes prevention interventions.

A risk test for pre-diabetes is available on the Association's web site at http://www.diabetes.org/risk-test.jsp (American Diabetes Association, 2007a). People with pre-diabetes are slowly becoming insulin resistant. Medications exist to reduce insulin resistance, but more emphasis is put on weight loss, healthy diet, and exercise, which also reduce insulin resistance (Diabetes Prevention Research Group, 2002).

The identification of a new condition, syndrome or infectious agent triggers an effort to educate the public about (1) the existence of the condition (2) its symptoms (3) screening tools (4) treatments, if they exist and (5) prevention, if prevention is possible. The identification and "naming" of pre-diabetes signalled a shift from identifying people with diabetes to identifying people with pre-diabetes. The public policy ramifications of such a shift are substantial. Every time a new syndrome is identified and a recommendation is made for screening, new costs are added to the nation's healthcare bill.

The ADA and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) discussed five conditions that should be met before attempting to prevent a disease. They are (1) that the disease to be prevented is an important public health problem and affects a significant population (2) that the early history of the disease is understood well enough to measure its progression (3) that safe, predictable, acceptable tests exist to identify the pre-disease state (4) that safe and reliable methods exist to help prevent or delay the disease and (5) that it is cost effective to find individuals at high risk and treat them. The ADA and NIDDK argued that all five conditions had been met by cumulative research (Diabetes Prevention Research Group, 2002).

National and state public health agencies, along with diabetes advocacy groups, began to communicate the shift in emphasis and information to the public. They employed traditional media (television, radio and print) and websites to engage the public in learning about this pre-cursor to diabetes. The shift was important because it conveyed hope. Lifestyle changes really do reduce risk. For example, the Diabetes Prevention Program study concluded that individuals with pre-diabetes who lost 5% to 10% of their total body weight and exercised could lower their risk substantially (58%) (Diabetes Prevention Research Group, 2002)

3 KNOWLEDGE DISSEMINATION AND MANAGEMENT/INFORMATION ALERTS

How do researchers undertake informing an entire community of healthcare providers who are already in practice about a new diagnostic entity and the appropriate screening and treatment of that entity?

When the discussion about screening for pre-diabetes intensified, multiple avenues were already in place to educate providers who routinely came into contact with diabetic patients. Providers were asked to screen individuals (1) who are overweight and at least 45 years of age and (2) who are under 45 and have one of several other risk factors, such as membership in high risk ethnic groups, high blood pressure, a close relative with diabetes, and others factors. Lifestyle recommendations were fairly simple: increase physical activity and achieve weight loss.

In the United States, primary care physicians (usually internal medicine specialists or family physicians) see the majority of patients before a diagnosis of diabetes is established. All physicians have a sizeable information burden, but primary care physicians bear the additional burden of having to stay aware of medical research in nearly every area of medicine since they are the first line diagnosticians. They need tools with which to screen, organize, absorb, and implement the substantial amounts of new medical information created each year.

Physicians receive information from a variety of resources, including colleagues, conferences, medical journals available in print or on the Internet, online texts and repositories such as UpToDate, handheld decision support tools such as Epocrates, web-based decision support tools such as Isabel, online databases such as PubMed, and alerts from Federal and state public health agencies. Many physicians receive information from pharmaceutical representatives who come to discuss products, although there is concern about this practice in the

United States on the presumption that such information is biased toward increasing sales.

State licensure boards and most professional societies require physicians to complete a certain number of mandatory continuing medical education hours each year. In addition, most medical specialties require re-certification. For example, family practitioners recertifying through the American Board of Family Medicine (ABFM) interact with online clinical simulations that may include content about diabetes.

There is often considerable lag time between the introduction of new information or recommendations and the subsequent formation of clinical guidelines, the necessary adaptation of paper or electronic record systems, and the adoption of new practice patterns in the office and clinic. While some physicians see patients in large group practices or hospital settings with information infrastructures that support the rapid transmission of information, others are solo or small group practitioners with severe time constraints and paper record keeping systems that are not easily updated.

4 DECISION SUPPORT AND CLINICAL GUIDELINES

How can new information be reviewed and inserted into existing information systems to help providers identify those patients who are at risk for developing pre-diabetes?

With the identification of a new diagnostic entity or clinical recommendation, existing information systems must be revised to prompt providers to screen and treat those patients at risk. Procedures must exist to vet new clinical information and determine whether and how it will be integrated into routine data collection, treatment activity, and quality measures. As in the case of screening people who may pre-diabetic, a general consensus about *what* should occur emerged after the results of several large clinical trials became public. In the United States, *how* to implement those recommendations is usually left to individual health systems and individual physicians.

While all physicians make claim to expertise in medical care, there will be "experts among experts" (in this case, those with recognized expertise in diabetes) who step forward to provide authoritative guidance in implementing new information. Many healthcare information systems, both paper and electronic, include some component of expert

guidance. Clinical advisory committees assemble to work with technical staff to approve changes for the paper or electronic health record. These groups may adopt existing clinical guidelines or develop their own guidelines. Such guidelines always have cost implications, so administrators and financial staff may also be found on advisory committees. The National Guideline Clearinghouse of the Agency for Healthcare Research and Quality (AHRQ) provides a searchable database of evidence-based guidelines at http://www.guideline.gov/.

After new guidelines and procedures are agreed upon, the designated experts must educate their colleagues about new forms or procedures and persuade them that new behavior is in order. That often presents a challenge, since practicing physicians are very busy and their practice patterns are difficult to change. Large groups can provide incentives to change by capturing compliance data and feeding it back to providers. Solo practitioners may find it easier to change their own behavior, but face a greater burden of staying up to date on their own.

5 HEALTH LITERACY AND TECHNOLOGICAL LITERACY

Patients have different degrees of health literacy and computer and technological literacy. If digital tools become important ways to communicate with patient and prompt them to action, what factors must be considered in the design and delivery of those health messages?

Health literacy has been defined in various ways. Practically speaking, it is the ability of a patient to take in health information, comprehend it, and take appropriate action to protect and preserve his or her health. In 2007, the Joint Commission published a white paper on improving health literacy in order to protect patient safety. It recommended raising awareness across organizations of the impact of health literacy and English proficiency on patient safety and emphasizing patient-centered communication across the entire span of care (Joint Commission, 2007). The report noted that many individuals with chronic medical conditions also have low health literacy. It recommended specific techniques, such as "teach back" and "show back" techniques to assess patient understanding; limiting information provided to two or three important points at one time; using drawings, models and devices; and giving patients information about all of

their diagnoses, medications, test result, and plans for follow-up care. Studies have shown that diabetic patients with low health literacy were less likely to achieve good control over their blood sugars and more likely to have vision impairment (Schillinger et al., 2002).

Computer literacy or technological literacy is a topic more often discussed in traditional academic circles. There are active, ongoing debates in education about what students need to learn about computing, technology, and strategies for acquiring information in the digital world in order to become informed and effective adults. Providers, insurers, and hospitals are interested in using digital tools to communicate with patients because they present opportunities to target information, reinforce it, and reduce costs. However, patients have very different degrees of computer or technological literacy as well as health literacy. There will be no "one-size-fits-all" disease information. It is far more likely that patients' comfort with technology will need to be assessed in the same way that their health literacy will need to be assessed, before they can simply be referred, for example, to web-based education materials or cell phone reminder systems.

6 PATIENT, PHARMACY, AND LABORATORY FEEDBACK SYSTEMS

How can IT systems develop patient, pharmacy and laboratory feedback systems that might assist in the treatment of patients with pre-diabetes?

Healthcare providers may prescribe smoking cessation, diet, exercise, medications, and laboratory tests for pre-diabetic patients. However, there is a significant body of literature on non-adherence to medical recommendations. Relatively few patients are successful at making substantive change, particularly when those changes involve ingrained habits. In the case of weight loss, adherence to recommendations can be measured by a decrease in the patient's weight, but it is still difficult to determine if the patient is following a healthy diet, exercising regularly, and using medication appropriately.

There is great interest in extending communication and a sense of connection between the diabetes provider and the patient with pre-diabetes or diabetes outside the walls of the exam room. Web-based tools such as interactive risk assessments, exercise diaries, and diet planners are widely available for patients. Virtual health coaches are being developed to help patients adhere to medication and exercise recommendations. A few providers and systems have established two-way communication through the Internet on password-protected sites so that risk scores and patients' exercise and food plans can be integrated into reporting mechanisms that give feedback to providers on patients' actions. This type of communication has not been universally implemented for two reasons: (1) concerns about protecting patient privacy and complying with Health Insurance Portability and Accountability Act (HIPAA) regulations and (2) concerns about overwhelming the provider with information that he or she will not have time to read. If a physician has information and doesn't act upon it, his or her legal liability may increase.

There is also interest in mobile communication devices for extending the relationship. Patients and providers, who move from room to room, are both mobile. The portability of cell phones and Personal Digital Assistants (PDAs) offer many advantages. For example, if the patient is recording diet choices, he or she may record and transmit them via cell phone application while at the dinner table rather than waiting to access a desktop or laptop computer. The assumption is that such information will be more accurate since it is reported so close to the event.

Compliance with medication is a particular concern. In a recent study of heart attack patients, researchers were surprised to find that one out of eight patients quit taking important medications – aspirin, beta blockers, and statins – within one month of discharge from the hospital. Those same patients were three times more likely to die during the next year than those who adhered to recommended medications (Ho et al., 2006). Pharmacy benefits manager Medco Health Solutions predicts that spending on diabetes therapies will increase up to 20% each year between 2007 and 2009 (Medco Health Solutions, 2007). One recent study found that physicians discussed cost, coverage, or purchase logistics of medications in just one-third of interviews when prescribing new medications (Tarn et al., 2006). Many patients are embarrassed to admit to their physician that they cannot afford to pay for medication.

Physicians need to know whether patients are actually filling prescriptions as directed or showing up for laboratory tests. If the patient is filling prescriptions at an in-house pharmacy (one owned by the clinic, hospital, or health plan) that information may be captured and fed back into the

record fairly easily. It will not be added to the record easily if the patient fills the prescription at an "outside" pharmacy. The physician's only recourse is asking the patient directly. Self-report is not the best way to gather that information, since many patients have difficulty facing a physician if they have not complied entirely with his or her recommendations. At present, the capacity to give providers feedback on whether a patient actually filled or refilled a prescription exists, but it exists with some risk to the patient's privacy.

It is somewhat easier to know if the patient has completed a laboratory test. The convention is that the results are sent directly to the physician. The patient must ask the physician to interpret the test results. The fact that a patient actually reported for a laboratory test is most easily added to the record if the patient is sent to a laboratory owned by the clinic, hospital, or health system.

7 INTERFACE DESIGN ISSUES AND REMINDER SYSTEMS

Can easy-to-use, inexpensive, reliable reminder systems be devised that will assist patients with a variety of lifestyles to remember office visits and medication?

Patients who are pre-diabetic need regular visits to assess their progress. If the initial treatment interventions do not produce the desired weight loss and increase in exercise, other recommendations may be made. In most cases, results from routine laboratory tests, which are private medical information, will stay in the medical record until the patient's next visit. If the patient wants the results, the patient needs to return to the office.

Physician offices employ a number of strategies for reminding patients about the time of their next visit. Most patients leave the office with a printed reminder of the date of their next visit. Some offices provide a telephone prompt a few days before the visit, although such calls add to office overhead. Some offices charge a fee for missed appointments to motivate patients to keep appointments.

The Veterans Administration and a few private insurers are beginning to "push" information out to patients on their appointment times and lab tests (Ferris, 2007). Some private medical providers and facilities also see the Internet as a way for patients to view their information on line. Authentication technologies will make it easier to assure that only the patient can see his or her own personal medical information.

Information may be captured about whether a patient filled a prescription, but it will still be difficult for physicians to assess if patients are actually taking medication or using it as prescribed. One company has produced a pill bottle that uses Short Message Service (SMS) to track how often pills are taken and send a reminder to the patient's phone if a dose is missed (www.simpill.com).

8 INFORMATION QUALITY AND CONSUMER INFORMATICS

What tools can be developed to assure consumers that they are accessing the highest quality health information as they interact with the Internet and other information resources? How can search engine results lead patients to reputable information? How can patients avoid "health mythology" propagated by participatory tools such as chat rooms and blogs that may transmit information with little basis in fact?

The Internet affords patients with access to a computer an incredible number of tools with which to research their risk factors and conditions. The amount of information can be overwhelming. On a single day in April 2007, a Google search using the word "diabetes" returned 92,500,000 "hits." Yahoo returned 78,900,000 results. Microsoft's search engine, MSN, returned 18,462,447 results.

An increasing number of U.S. citizens research their medical conditions online. The major search companies are well aware of that fact. Steve Case, the founder of AOL, has launched Revolution Health, a health web site that will coach subscribers on their health, store their health information, match them with doctors, and help them with insurance claims (Freudenheim, 2007). Google introduced a health information subscription service in 2006 (Modern Healthcare, 2006). Microsoft bought a health information search engine in 2007 (Lohr, 2007). Most of the major search engines are actively engaged in a race to produce more relevant, focused results. Google, Microsoft, and Yahoo all have test sites that collect and display large amounts of information in intuitive ways. Some return definitions first and then categorize results. For the search term "diabetes," one search engine grouped clusters of information into these categories: care, research, management, control, risk, centers, types, drugs, and supplies. Video search engine

Blinkx.com retrieved over 14,000 videos with diabetes content.

Unfortunately, there is no consensus on how to evaluate the quality of the information cited (Eysenbach, Powell, Kuss, & Sa, 2002). Online health information varies in quality; patients are vulnerable to misinformation and fraud if they are unable to evaluate the quality of the material accessed. Information gained through participatory tools such as chat rooms or blogs may be inaccurate information, giving patients false hope or diverting them from evidence based treatment. Websites may expose them to worthless or even harmful diet pills and exercise equipment for which unreasonable claims are made.

Operational definitions of quality are still needed, although rating tools are beginning to emerge. The Health on the Net Foundation offers the HONcode designation for health web sites that follow its standards of quality. The Foundation has a policing system that is designed to help developers monitor their own compliance to the code, as well as remain responsive to user concerns. The policing procedures can be initiated by individual site users or by the Foundation itself.

Reputable organizations try to provide quality information on the Internet. Some of these include the American Diabetes Association, The National Diabetes Educational Program, The National Diabetes Information Clearinghouse, and the National Institute of Diabetes and Digestive and Kidney Diseases.

There is a growing body of research on information seeking behavior. Researchers are beginning to build a set of tools and techniques with which to examine patient interaction with healthcare materials available on the Internet. Several studies have shown that online health information has a positive influence on patients' ability to cope with serious illness (Mills & Davidson, 2002; Ziebland et al., 2004). Access to disease information online has also been linked to reduced anxiety and increased perceptions of self-efficacy (Ybarra & Suman, 2006). There is still much to be learned about search strategies, information retrieval, demographic differences, and subsequent actions over the course of a chronic illness.

While information available on the Internet has helped to equalize the power in physician-patient relationships, it has two consequences that are less positive. One is the annoyance some physicians feel when patients question their judgment and recommendations. The other is the time that must be spent evaluating and responding to the patient's attempt to gather information and participate in his or her healthcare.

9   SECURITY AND PRIVACY

How can systems be designed to secure patients' confidential information? How can stigmatizing information be kept private so that patients feel they can confide in their physicians? How can patients be persuaded to allow their treatment information to be collected and be assured it will not be used to penalize them at a later date, for example, by cutting off care for those with pre-existing conditions?

In the past two years, there have been literally millions of accidental and intentional breaches of patient privacy through lost laptops, inadequate storage procedures, and outright fraud. Some recent news stories provide examples: hackers accessed personal data for 14,000 Pentagon employees through health insurance records (Pulliam, 2006); the loss of 130,000 Aetna records by Aetna when backup tapes were stolen in a burglary (Zeller Jr, 2006).

Few incentives exist to encourage insurers, hospitals, and providers to tighten their security. Although mandatory notification of data loss and financial penalties are being considered by several states, there are few real penalties for compromising or losing medical information. Further, the Health Information Portability and Accountability Act (HIPAA), which was the impetus for spending millions of dollars to redesign systems to achieve compliance with governmental privacy directives, has had little impact. "*In the three years since Americans gained federal protection for their private medical information (through HIPAA), the Bush administration has received thousands of complaints alleging violations yet not imposed a single civil fine and has prosecuted just two criminal case*"(Stein, 2006).

The Healthcare Information Management and Systems Society and Phoenix Health Systems published a survey on HIPAA compliance in the summer of 2006. The survey noted that only 56% of providers had implemented the security standards and that a substantial portion of providers (22%) and payers (13%) remained non-compliant with the privacy regulations. The report further suggested that even those who were compliant had significant implementation gaps and that there may be a core group of entities covered by the law that cannot or will not implement the privacy standards at all

(Healthcare Information and Management Systems and Society 2006).

Many people disagree about whether business or government presents a bigger threat to privacy. While it might be assumed that government-sponsored healthcare programs have stricter privacy standards, when data from millions of U.S. veterans were contained on a stolen disk in May of 2006, the VA waited two weeks before reporting the loss. Several weeks went by before all the details of the situation came to light (Stout & Zeller Jr., 2006).

Medical privacy is also important because some diseases are stigmatizing. At different times in history, different diseases have had greater or lesser amounts of stigma attached to them. At one time, cancer was a stigmatizing illness. Some people thought cancer was contagious and that people who had it were to be avoided. Others thought death was inevitable and stopped visiting those afflicted because it was "too depressing." Even today, individuals with lung cancer may be blamed for their disease on the assumption that they must have been smokers.

Diabetes has been relatively free of stigma, although that is starting to change as the association between obesity and diabetes becomes clearer. Many people in the United States see the condition of being overweight or obese as a sign of lack of discipline or laziness. Corporate wellness programs are beginning to reward people for losing weight and maintaining the reduced weight.

Patients with pre-diabetes or diabetes have to provide information to their physician in order to receive treatment. Courts in the United States have guarded doctor-patient privilege as essential to the greater societal good. Many people find it difficult to confide in a physician. In order to encourage open and honest exchanges, patients have been assured that information about their medical records would be kept confidential. The assumption is that society benefits when patients are treated, because the potential spread of the disease and cost of its treatment have been kept in check.

There are times when all the information and power in the relationship resides with the physician. An example is the treatment of an unconscious patient in the emergency room. Society accords the physician the responsibility of gathering information and making decisions on the patient's behalf. There are also situations of shared information and power. An example is an acute illness during which the patient consults the physician but is unlikely to argue or negotiate about the prescribed treatment, such as a dosage of an antibiotic over a certain number of days. In pre-diabetes, the power resides with the patient and the physician is in a consulting role. The physician, diabetes nurse, or dietician recommends lifestyle management techniques, but the patient has to implement them on a daily basis.

Unfortunately, healthcare providers are no longer able to guarantee privacy when they act for the unconscious patient, advise the acutely ill patient, or consult with the chronically ill patient. The worst case scenario is that the patient's own medical data cause his or her insurance company to drop insurance coverage. Patients who have chronic illness fear losing their healthcare coverage. Some stay at jobs they dislike because they would lose coverage for pre-existing conditions if they changed jobs and had to obtain new insurance. If self-employed, they run the risk that their insurance company declares them "uninsurable" and terminates their policy. If insured by government program, they may lose access to the latest treatments or experimental treatments.

In a very real sense, the information patients give to their providers for treatment and their insurance company for reimbursement may well be used against them. In the United States, the courts do not compel a defendant to testify against himself, but healthcare information systems are used to do exactly that. If patients choose to lie about their conditions, they also run the risk of losing coverage. At present, there is no way for healthcare providers to guarantee that patients will not be penalized for their honesty in providing information to the medical record.

Of course, a patient is not required to use his or her insurance benefits, but most cannot cover the cost of treating a chronic illness without doing so. If a patient wants to use insurance benefits, he or she allow information about the diagnosis to be shared with the insurance company. The insurer then decides whether or not to reimburse for care based on the terms of the policy. Insurance companies battling rising healthcare costs may use data analysis to limit access to care. They employ information systems to control costs and increase profitability. They review data to forestall unnecessary spending.

Some companies put burdensome procedures in place, deny care, or insist on lesser care in the time period before sustained evidence of efficacy can be added to the medical research. For example, insulin pumps became available in 1979. They are useful for some patients, but expensive. Some insurance companies would not cover them at first; others required providers to provide written justification of the need for an insulin pump.

10 CONCLUSIONS

Throughout the United States, medical and nursing practitioners are rapidly becoming interested in solving some of the information challenges described here, as they exist specifically for pre-diabetes and generally for every other disease and syndrome. Healthcare professionals are integrating technology into the everyday delivery of care. As their familiarity and level of comfort increase, they will seek IT support for their patients as well.

Clinicians, often led by early adopters of technology, are commissioning IT applications from commercial providers and academic research teams to solve day to day medical problems. The application developers are often unfamiliar with the realities of healthcare. These applications tend to be stand-alone; they rarely generalize well to wider use.

Individual public health, medical and nursing researchers are seeking major grant funding for large scale development of IT solutions to healthcare conundrums. In "Toward an Informatics Research Agenda: Key People and Organizational Issues," Kaplan et al. present a research agenda model that addresses individual, institutional, trans-organizational, and transnational concerns, aligning them with the social science disciplines that may be brought to bear on their exploration. Those disciplines include cognitive psychology, social psychology, sociology, and cultural anthropology (Kaplan, Brennan, Dowling, Friedman, & Peel, 2001). In this context, and with these observations of pre-diabetes, in Table 1 we suggest some areas of productive research.

At present, many healthcare IT solutions fall short of their intentions because patients and providers do not respond to those solutions as anticipated. Social and organizational factors are often at the core of those unanticipated, unsatisfactory responses. Money is being spent that does not result in real human benefit. The emphasis needs to shift from the construction of specific technologies to human and organizational behavior in interaction with those technologies. Informatics researchers should lead the way toward incorporating a respect for and expectation of social science research in IT development.

Table 1: Pre-Diabetes Informatics Research.

Public health and community informatics
- Identify effective tools, such as community dashboards, to educate individuals and communities about pre-diabetes and the importance of life change styles to reduce the risk of diabetes; develop those tools in ways that help communities set priorities for spending on such activities as screening.
- Design and fund public health and community information systems that allow data about pre-diabetes to flow between and among Federal, state, and local agencies, as well as advocacy groups, clinicians, and individuals.
- Explore and evaluate information gathering patterns in individual communities; design reliable, predictable information pathways for publicizing new information in the domain of public health.
- Find ways for important public health messages to rise above the "noise" of a media-saturated environment; develop and place screening tools in the media that healthcare consumers already use, rather than trying to train them to use new technologies; develop the ability to target individuals with personalized messages about their specific risk for pre-diabetes.

Knowledge dissemination and management/information alerts
- Identify tools for primary care physicians with which they can effectively screen, organize, absorb, and implement the substantial amounts of new medical information created each year; consider ways to effectively manage the information burden placed on busy clinicians.
- Study search strategies and patterns of information seeking in domain experts such as physicians and nurses; develop knowledge dissemination patterns that fit into the existing work flow rather than disrupting it.
- Identify ways to reduce the lag time between the introduction of new information or recommendations about pre-diabetes and diabetes, and the subsequent formation of clinical guidelines, the necessary adaptation of paper or electronic record systems, and the adoption of new practice patterns in the office and clinic.
- When presenting clinicians with new information, assist them with clear information on how to implement screening and treatment recommendations at the point of care.

Decision support and clinical guidelines

- Study existing processes for the institutional adoption of new standards of care; develop models for identifying the social and organizational barriers that slow the implementation of new expert knowledge; develop systems that will alert organizations and institutions to new evidence-based medical research and assist them in implementing it, rather than relying solely on practitioners to come into contact with and absorb that new knowledge on a clinician by clinician basis.
- Identify effective ways to marshal current expert knowledge about diabetes and pre-diabetes, update existing medical information systems to reflect that knowledge, and provide communication technologies, strategies, and incentives for busy primary care physicians to pay attention to these recommended changes in practice.

Health literacy and technological literacy

- Identify effective means to test the health literacy and technology literacy of pre-diabetes and diabetes patients and match them with web sites and other communication means that are suited to their particular health and technology literacy.
- Develop rubrics for measuring whether best practices in promoting health literacy are being incorporated into healthcare technologies.
- Understand the ways in which healthcare consumers gather information about their health and the health of their families, the ways they use technology to support that process, and the thresholds or decision points that prompt them to take action, such as scheduling an appointment or attempting to change a habit or behavior.

Patient, pharmacy and laboratory feedback systems

- Identify technologies and procedures that will extend communication and a sense of connection between the diabetes provider and the patient with pre-diabetes or diabetes outside the walls of the exam room. These might include, for example, web-based tools such as interactive risk assessments, exercise diaries, and diet planners, virtual health coaches, or two-way communication systems using PDAs between patients and providers that allow that patient to record and report data and ask questions.
- Design systems to provide feedback to providers about how well patients are adhering to the prescribed treatment (medications, diet, exercise, further tests or medical consultations); those systems should be sensitive to patient privacy issues and avoid overwhelming providers with data that does not contribute to decision-making or increases their legal liability.
- Create and evaluate systems that optimize the capture of patient adherence data even if that data exists across multiple organizations.

Interface design issues and reminder systems

- Develop and evaluate treatment support systems that "follow" the patient into his or her work and home environments; patients should be able to choose from among a number of support systems based on their individual profiles and preferences.
- Design inexpensive, reliable reminder systems that are patient-specific; avoid generic applications that require the patient to wade through information or reminders that are not specific to his or her situation.

Information quality and consumer informatics

- Develop tools to assure consumers that they are accessing the highest quality health information as they interact with the Internet and other information resources.
- Develop operational standards of quality of information and tools that allow both website developers and users to rate the quality of their information on the site.
- Redesign search engines to lead patients to reputable information and away from "health mythology" propagated by participatory tools such as chat rooms and blogs that may transmit information with little basis in fact.

Security and privacy

- Develop legal, economic, technological, and social means to increase the privacy of patients' confidential information; develop technologies and protocols that protect the trust and tradition of the doctor-patient relationship.
- Design systems that ensure that stigmatizing information is kept private so that patients feel they can confide in their physicians; allow treatment information can be collected without fear it will be used to penalize patients at a later date, for example, by cutting off care for those with pre-existing conditions.

REFERENCES

American Diabetes Association. (2007a). Diabetes Risk Test [Electronic Version] from http://www.diabetes.org/risk-test.jsp.

American Diabetes Association. (2007b). How to Tell If You Have Pre-Diabetes [Electronic Version] from http://www.diabetes.org/pre-diabetes/pre-diabetes-symptoms.jsp.

American Diabetes Association. (2007c). Pre-Diabetes [Electronic Version]. Retrieved June 14, 2007 from http://www.diabetes.org/pre-diabetes.jsp.

American Diabetes Association, & National Institute of Diabetes and Digestive and Kidney Diseases. (2003). The Prevention or Delay of Type 2 Diabetes. *Diabetes Care, 26 Supplement*(1), S62-S69.

Diabetes Prevention Research Group. (2002). Reduction in the evidence of type 2 diabetes with life-style intervention or metformin. *N Engl J Med, 346*(6), 393-403.

Eysenbach, G., Powell, J., Kuss, O., & Sa, E. (2002). Empirical studies assessing the quality of health information for consumers on the World Wide Web: a systematic review. *JAMA: Journal of the American Medical Association, 287*(20), 2691-2700, 2723-2694.

Ferris, N. (2007, January 24). Vets can see EMR data. *Government Health IT News*.

Freudenheim, M. (2007, April 17, 2007). AOL Founder Hopes to Build New Giant Among a Bevy of Health Care Web Sites. *New York Times*.

Healthcare Information and Management Systems and Society , P. H. S. (2006). *US Healthcare Industry HIPAA Compliance Survey Results: Summer 2006*.

Ho, P. M., Spertus, J. A., Masoudi, F. A., Reid, K. J., Peterson, E. D., Magid, D. J., et al. (2006). Impact of Medication Therapy Discontinuation on Mortality After Myocardial Infarction. *Arch Intern Med, 166*(17), 1842-1847.

Joint Commission. (2007). *"What Did the Doctor Say?": Improving Health Literacy to Protect Patient Safety* (White Paper).

Kaplan, B., Brennan, P. F., Dowling, A. F., Friedman, C. P., & Peel, V. (2001). Toward an Informatics Research Agenda: Key People and Organizational Issues. *J Am Med Inform Assoc, 8*(3), 235-241.

Lohr, S. (2007, February 27, 2007). Microsoft to Buy Health Information Search Engine. *New York Times*.

Medco Health Solutions. (2007, May 17). Unmanaged, diabetes drug costs could surge nearly 70 percent within three years. *Drug Trends Extra*.

Mills, M. E., & Davidson, R. (2002). Cancer Patients' Sources of Information: Use and Quality Issues *Psycho-Oncology, 11*, 371–378.

Modern Healthcare. (2006). Google introduces health-info subscription service [Electronic Version]. Retrieved May 14.

Narayan, K. M. V. a. p., Imperatore, G. m. e., Benjamin, S. M. e., & Engelgau, M. M. c. e. a. s. b. (2002). Targeting people with pre-diabetes: Lifestyle interventions should also be aimed at people with pre-diabetes. *BMJ, 325*(7361), 403-404.

Pulliam, D. (2006, May 1). Hackers access personal information on TRICARE servers. *Government Executive*.

Schillinger, D., Grumbach, K., Piette, J., Wang, F., Osmond, D., Daher, C., et al. (2002). Association of health literacy with diabetes outcomes. *JAMA: Journal of the American Medical Association, 288*(4), 475-482.

Stein, R. (2006, June 5). Medical Privacy Law Nets No Fines. *Washington Post*.

Stout, D., & Zeller Jr., T. (2006, March 24). Agency Delayed Reporting Theft of Veterans' Data. *New York Times*.

Tarn, D. M., Paterniti, D. A., Heritage, J., Hays, R. D., Kravitz, R. L., & Wenger, N. S. (2006). Physician communication about the cost and acquisition of newly prescribed medications. *American Journal of Managed Care, 12*(11), 657-664.

Ybarra, M. L., & Suman, M. (2006). Help seeking behavior and the Internet: A national survey. *International Journal of Medical Informatics, 75*(1), 29-41.

Zeller Jr, T. (2006, December 18). An Ominous Milestone: 100 Million Data Leaks. *New York Times*.

Ziebland, S., Chapple, A., Dumelow, C., Evans, J., Prinjha, S., & Rozmovits, L. (2004). How the internet affects patients' experience of cancer: a qualitative study. *BMJ, 328*(7439), 564.