

TECHNOLOGY AND HEALTH INFORMATION PRIVACY: CONSUMERS AND THE IMPLEMENTATION OF DIGITAL MEDICAL RECORDS TECHNOLOGY

Final (Phase I & II) Report © May 24, 2005

**For a 20-slide summary powerpoint of this study, see
<http://www.comm.ucsb.edu/faculty/rrice/wallisrice.ppt>
For a one-hour online video presentation of this study, see
http://www.cits.ucsb.edu/video_fls_05-06.htm**

**Kier Wallis
kwallis [at] umail.ucsb.edu
Ronald E. Rice
rrice [at] comm.ucsb.edu**

**Department of Communication, University of California
Santa Barbara, CA 93106-4020**

**We thank Mike Skinner, Executive Director of the SBCCDE, for his guidance, contacts,
expertise, and support.**

Table of Contents

Problem Statement ... 3

- SBCCDE ... 3
- Electronic Health Records (Digital Medical Records) ... 3

Theory ... 5

- Technology Diffusion ... 5
- Privacy and Technology ... 7
- Health Information Privacy ... 8
- HIPAA: Evaluating the Legislation and its Effects ... 10
- Relationship between Technology and Health Information Privacy ... 13

Methods ... 14

- Stakeholder Interviews ... 15
- Focus Group Methodology ... 15
- Project Focus Groups ... 16

Results from Stakeholder Interviews ... 18

- Summary of Stakeholder Interviews ... 22
- Table 1. Summary of Responses to 12 Questions of Stakeholder Interviews ... 23

Results from Focus Groups ... 26

- Summary by Topics and Group Attributes ... 26
- Table 2. Focus Group Topics According to 15 Questions, by Type of Focus Group ... 34
- Most Frequently Occurring Words in Sets of Responses in Focus Groups ... 41
- Table 3. Focus Groups' Most Frequently Occurring Words: 5 or more times (number, and percentage of the specific word's occurrence within the top 160 words) ... 41

- Word Clusters ... 42

Integrated Summary of Stakeholder Interviews and Focus Groups ... 42

- Study Participants ... 42
- Expectations about Use ... 42
- Meanings of “Privacy” ... 43
- Awareness of Digital Medical Records and CDE ... 43

Development of and Results from Survey ... 43

- Measures ... 43
- Table 4. Descriptive Statistics for Individual Items, Scales and Subscales, with Reliabilities ... 47
- Figure 1. Hypothesized Relationships between the Explanatory Overall Scales and Subscales, and the Outcome Measures of Adoption and Reinvention ... 53

Descriptive Results ... 54

- Individual Characteristics: Demographics, Health, Self-Efficacy ... 54
- Technology Expertise: Internet Use, Web Expertise, Computer Use Location, Web Fluency ... 54
- Privacy and Rights: Need for Privacy, General Privacy Concerns, Organizational Privacy, Concerns about Computer Privacy, Accurate Perception of Legal Medical Rights ... 54
- Innovation Attributes: Relative Advantage, Compatibility, Complexity, Trialability, Observability ... 55
- Technology Evaluation: Adoption and Reinvention ... 55

Bivariate Results ... 56

- Personal Characteristics ... 56
- Internet Experience and Expertise ... 56
- Privacy Concerns and Medical Rights ... 56
- Innovation Attributes ... 56
- Table 5. Correlations of Items, Scales and Subscales (Personal Characteristics, Internet Experience and Usage, Privacy Concerns and Medical Rights, and Innovation Attributes, with Adoption and Reinvention ... 57

Multivariate Results ... 58

- Personal Characteristics ... 58
- Internet Experience and Expertise ... 58
- Privacy Concerns and Medical Rights ... 58
- Innovation Attributes ... 58
- Table 6. Final Summary Multiple Regressions Explaining Adoption and Reinvention ... 59

Discussion of Survey Results ... 60

- Personal Characteristics ... 60
- Internet Experience and Expertise ... 60
- Privacy Concerns and Medical Rights ... 61
- Innovation Attributes ... 62

References ... 63

- Appendix 1. Description of Individual Digital Medical Records Read to Focus Groups ... 66
- Appendix 2. Description of Implementation of Individual Digital Medical Records in the Santa Barbara County Care Data Exchange ... 67
- Appendix 3. Department of Communication Privacy and Medical Technology Survey ... 68
- Appendix 4. Factor Loadings, Correlations, Regressions ... 78

TECHNOLOGY AND HEALTH INFORMATION PRIVACY: CONSUMERS AND THE IMPLEMENTATION OF DIGITAL MEDICAL RECORDS TECHNOLOGY

Public opinion and research have demonstrated that “while organizations claim the right to use information technology to improve efficiency, consumers often exhibit the desire to control the flow and dissemination of their personal information” (Milberg, Smith, & Burke, 2000, p. 36). As a result, new technologies offering improvements to consumers’ daily lives are subject to scrutiny regarding the technologies’ ability to maintain information security and privacy, important values among today’s consumers (Alpert, 2003; Jeffords, 1999; Mandl, Szolovits, & Kohane, 2001). Medical information systems that combine digital technology with the highly personal and sensitive information contained in medical records, are increasingly examined as to their ability to achieve their stated medical function, while maintaining a level of privacy consistent with the government’s medical privacy legislation (Alpert, 2003).

Problem Statement

A new technology faces unique challenges upon its implementation within a community or organization, ultimately leading to its acceptance or rejection among its intended users (Aydin & Rice, 1991; Davis, 1993; Rice & Anderson, 1994; Rogers, 1983). The Santa Barbara County Care Data Exchange (SBCCDE), a major regional health infrastructure project is in the process of implementing digital medical records technology in Santa Barbara County, California, and is subsequently subject to evaluation by its consumers, composed of the general public and medical community. In preparing for the diffusion of digital medical records technology, it is appropriate to investigate those consumer perceptions and concerns that might determine the success or failure of the new system. Therefore, the current research is designed to investigate consumer concerns, knowledge, and level of awareness regarding several facets of individual medical records technology and privacy, including those existing concerns along with concerns prompted by the local implementation of the new technology. Ultimately, the research will also determine the likelihood that consumers will in fact adopt or reject the individual digital medical records technology, as well as an estimated level of patient participation following the implementation of the technology’s consumer portal.

SBCCDE

The Santa Barbara County Care Data Exchange (SBCCDE) cites its mission as “assisting all physicians, caregivers, and consumers in Santa Barbara County to locate and facilitate the sharing of patient data held by multiple health care organizations...thereby increasing the quality, safety, and efficiency of care delivery.” The SBCCDE, which began its task in 1998, is currently in the process of testing its technology known as the Care Data Exchange (CDE), and preparing for its diffusion into local hospitals, health care organizations, and the community at large (McGee, 2003). The SBCCDE project is a small-scale extension of a larger nation plan to institute a national electronic health information infrastructure (U.S. Dept. of Health and Human Service, 2004). The SBCCDE has received grants in excess of \$10 million from the California HealthCare Foundation, and the federal government. The efforts of the SBCCDE and similar concurrent projects in handful of cities, are intended to demonstrate the advantages of securely sharing health care information among providers, ultimately leading to the adoption of a similar system at the national level (McGee, 2003).

Electronic Health Records (Digital Medical Records)

The nature of health care in the US, largely HMO based, is driving the implementation of the electronic health record (EHR) in response to the demand for data transparency. Gunter and Terry (2005) describe the electronic health record (EHR) as ‘a longitudinal collection of

electronic health information and individual patients and populations' (p. 2). Recently, concerns over medical mistakes, some proving fatal, have spurred the desire for transparent data regarding physicians' track records of patient care. Also, as American patients are shifted among specialists, they are becoming more responsible for their care and demanding to possess a larger portion of their medical record, a phenomenon termed shared care. Also fueling the introduction of the EHR is the widespread occurrence of ambulatory care in which caregivers need immediate access to patients' medical information. In addition to the demand for the data available via an EHR, health care providers must also respond to patient demands for privacy, access, correction, and consent. As rapid technological progress has resulted in transferable and immediate data access, health care providers must evaluate their systems in terms of legal requirements and efficient patient care (Gunter & Terry, 2005).

The EHR is credited with reducing medical errors and subsequently improving health care through the elimination of handwritten clinical notes and the enabling of several error-reducing technologies. Advocates of electronic records emphasize the advantages of lowered costs, continuity and consistency of medical care and records, as well as providing data for research (Reynolds, 2003). Along with improving health care, the EHR provides for population-wide data collection and extensive research that may prove valuable to the further reduction of medical errors and efficient treatment of unique populations. For example, Wang et al. (2004) developed a web-based personal health record (PHR) for patients to collect and manage their health information (medical history, past surgeries, medications, and allergies), to request self-referrals, and to store a record of their consultations. The PHR also includes a messaging system that can be structured into the workflow of referral management as well as allowing more general communications. A preliminary study was conducted with 61 patients. Thirty-two patients completed a survey in which 85% of respondents were satisfied with the usability and 94% were satisfied with the overall online referral process. Joustra-Enquist and Eklund (2004) report on SUSTAINS, a web-based health care account in which the patient can login (with a login sent to their mobile phone) and review medical results and prescriptions and information, and exchange written information with physicians; participants reported that it is beneficial for both parties. According to Hassol et al. (2004), 65-85% of Americans in an experiment with electronic health records reported them easy to use, and that they understood all the information; a small minority reported confidentiality concerns. Using electronic medical records in hospital databases was demonstrated to help ensure consistent and correct coding by physicians, as well as context-sensitive treatment (Muller et al., 2003). Another study found benefits from physician use of electronic medical records (EMRs). Of the 30% of physicians who were using EMRs in 2003, 38% note that it has impacted overall time efficiency (25% major impact and 33% minor impact), 74% note that it saves money (32% major, 42% minor), 78% see an improvement in patient satisfaction (25% major, 53% minor), 87% say it allows them to deliver better care (53% major impact, 34% minor impact), and 89% see improved compliance with managed care (58% major, 31% minor) (Harris Interactive, 2003). So, the physician use of the Internet for health information and EMRs may well decrease time spent on patient care simply due to increased efficiency and better information and patient compliance; but it may also displace the time available for patient interaction.

EHR models in the United States and Australia have dealt with some key issues differently, the most apparent disparity between the two being patient control (Gunter & Terry, 2005). In the Australian model, the patient decides what information to 'push' into his or her EHR, resulting in only a partial rather than comprehensive medical record. In this model, patients work with their health care providers to choose which elements of their existing health record will be used for which purposes and who may view such information. The Australian model relies on voluntary participation on behalf of patients, but it is possible that this will

jeopardize the EHR's ability to collect a the necessary amount of information to be used for research and to make improvements to the quality of health care. In the United States, the national efforts at implementing an EHR system have primarily taken a technological focus in both building a national health information infrastructure and establishing data interoperability and comparability (Gunter & Terry, 2005). In contrast to Australia's model, it is proposed that American patients will be able to 'pull' or censor certain information in their records, however it is still unclear exactly what authority patients will have over their EHRs. While this U.S. system will maximize the flow of patient data, enabling valuable research, it may come at the cost of greater patient privacy and confidentiality. A third EHR option is the personal EHR in which individuals collect and manage their various health care records and may choose to make them available to health care providers through various subscription services. This model is not in place at a comparable scale to the push or pull systems of either Australia or the U.S., respectively.

All of the EHR models must still deal with questions of costs, politics, and patient privacy. There are anxieties about privacy and confidentiality; who would have access to the records, as well as how difficult would it be to delete information that may be disadvantageous to a person's current health treatment (Albisser, Albisser, & Parker, 2003). Computer and Internet breakdown could inhibit access to the records just at a time when access was vital. While initial implementation costs are expected to be high, it is unclear whether traditional 'brick and mortar' family practices will be able to afford such drastic technological changes. Australia and the U.S. again differ greatly in their legal requirements for providing patient privacy. Australian law is sensitive to patient protection and places strict limits on data collection and disclosure, whereas U.S. law only addresses disclosure, permitting information dissemination to a broad range of parties.

Theory

The current research is concerned with two facets of digital medical records technology, those technology characteristics influencing its diffusion, and those elements of privacy concern associated with the new information system. Two theories, Rogers's (1983) Diffusion of Innovations theory, and Smith et al.'s (1996) Information Privacy theory, will be used to frame the investigation and discussion of the relationship between technology and privacy, and the specific case of the implementation of individual digital medical records in Santa Barbara County.

Technology Diffusion

A new technology faces various challenges to successful diffusion within its potential community (Aydin & Rice, 1991; Davis, 1993; Rice and Anderson, 1994; Rogers, 1983). Different obstacles apply at each possible level, influencing the diffusion within organizations (Johnson & Rice, 1987; Rice & Anderson, 1994), and among prospective consumers (Davis, 1993; Demiris & Eysenbach, 2002; Mandl, Szolovits, & Kohane, 2001; Rogers, 1983). Of particular interest to this study are the characteristics of the diffusion process among consumers.

Rogers (1983) identifies five characteristics of innovations central to the effective diffusion of any new technology. Among these are relative advantage, compatibility, complexity, trialability, and observability. Consumers perceiving new technology to rate high on these characteristics are more likely to adopt the technology in comparison with consumers who perceive the technology as rating low (Rogers, 1983). While Rogers' (1983) diffusion of innovation theory has remained a staple in discussing the introduction of new technologies, similar models (Davis, 1993) also point to the importance of synonymous characteristics. For example, Davis' (1993) technology acceptance model (TAM) recognizes the importance of consumers' attitudes toward a technology as a main determinant of their actual use of that technology. Davis (1993) identifies two main technology components influencing consumers'

attitudes, perceived usefulness and perceived ease of use. These two components heavily correspond with Rogers' (1983) description of relative advantage and complexity, respectively. Also, Mandl et al. (2001) determine six desirable characteristics of electronic medical records: comprehensiveness, accessibility, interoperability, confidentiality, accountability, and flexibility. While these characteristics extend beyond the consumer to consider various health care organizations and systems as well, they are still very much reflective of those five characteristics identified by Rogers (1983). It is important to discuss these in further detail before moving on.

Relative Advantage. A technology's relative advantage corresponds to the "degree to which an innovation is perceived as better than the idea it supersedes" (Rogers, 1983, p. 15). In the case of individuals' digital shared electronic medical records, relative advantage may be conceptualized as the innovation's benefits in comparison to traditional paper records. Electronic medical records systems have been found to improve the quality of patient care and safety, reduce the occurrence of medical errors, and even provide a positive financial return to health care organizations (Chin, 2001; Wang et al., 2003). Such benefits may easily demonstrate relative advantage to physicians, organizations, and financial investors, but might not have an equal impact on the consumer.

Some of the qualities that might solidify relative advantage for consumers include accessibility, accountability, and flexibility (Mandl et al., 2001). Current patient access to personal medical records is often impeded by bureaucratic red tape (Finklestein, 2004), and the sheer difficulty of locating specific pieces of information amid masses of records (Chin, 2001). Dr. Bowers, director of student health at the University of California Santa Barbara, described the current retrieval system as "trying to find pieces of paper (health care providers) are supposed to have but don't" (Chin, 2001). Mandl et al. (2001) point out that secure universal access to medical records on the World Wide Web would be ideal, allowing authorized users patient data at the point of care. Also, where patients currently have no visible record of who has accessed or altered their records, an ideal electronic medical record system would allow patients to view any interaction with their record and subsequently hold any users accountable (Mandl et al., 2001). Finally flexibility is also identified as an ideal characteristic, explained by the patients' ability to "grant or deny access" to their medical records (Mandl et al., 2001, p. 285).

Compatibility. Rogers (1983) identifies compatibility as "the degree to which an innovation is perceived as being consistent with the existing values, past experiences, and needs of potential adopters" (p. 15). Innovations inconsistent with the value system of potential adopters will likely be rejected, as in a Peruvian village's rejection of water boiling or certain faiths' rejection of birth control methods (Rogers, 1983).

Values to be considered by consumers may include the value of their own personal health and health of loved ones, the ability to control their own health care (Mandl et al., 2001), and the value of privacy (Alpert, 2003; Jeffords, 1999; Mandl et al., 2001).

Complexity. Complexity is "the degree to which an innovation is perceived as difficult to understand and use" (Rogers, 1983, p. 15). Not all consumers are created equal in regard to their capacity to use, understand, and benefit from new technologies. The most recent US census cited 51% of American household as having a computer, 41.5% of households as having internet access, and 36% of Americans over 3 years old as using the internet at home (Newburger, 2001). Comparing these statistics to those of years past, internet use has continued to rise, demonstrating the innovation has not yet been fully adopted by the public.

An important consideration under complexity is that of self efficacy, or one's perceived ability to perform a specific task (Bandura, 1978). In light of self-efficacy theory, it is likely that those who have had experience with internet technology will be more comfortable with adapting a new internet-based technology because of previous experience. However, some health care recipients may not be as adept at using the internet, or have functional limitations preventing

them from access (Demiris & Eysenbach, 2002). For example, many elderly patients are to be inexperienced with internet use, and other individuals with disabilities or chronic illnesses may be physically or cognitively unable to use the internet in the same fashion as others in the population (Demiris & Eysenbach, 2002).

Trialability. Rogers (1983) defines trialability as “the degree to which an innovation may be experimented with on a limited basis” (p. 16). This may pertain to the extent of the commitment required of the consumer, visible by a monetary cost, or by the user’s ability to release and then later restrict access to an electronic medical record (Mandl et al., 2001).

Observability. Observability is “the degree to which the results of an innovation are visible to others” (Rogers, 1983, p. 16). In diffusing a new technology it is often beneficial if the positive consequences of the innovation are in the public’s view, as that is likely to reduce consumers’ uncertainty regarding the innovation. Although uncertainty is an inevitable companion to innovation (Rogers, 1983), consumers’ outcome expectations have been found to impact actual technology use (Compeau & Higgins, 1991).

Privacy and Technology

Public opinion has demonstrated the growing importance of privacy in today’s information saturated society (Udo, 2001). As competitors in the marketplace have harnessed information technology to collect and assemble data into usable and marketable forms, the general public is not convinced that the benefits of such information technology outweigh its costs (Culnan & Armstrong, 1999). For example, a 1999 IBM poll reported that 80% of consumers feel that they are no longer able to control how companies collect and subsequently use consumers’ information. Having lost the ability to control collection and use of personal information raises privacy concerns in accordance with Westin’s (1967) definition of privacy as the ability to control the collection and use of personal information.

The risks and benefits associated with information technology have resulted in a battle between the information-collecting organization and the consumer. As Milberg et al. (2000) recognize, “while organizations claim the right to use information technology to improve efficiency, consumers often exhibit the desire to control the flow and dissemination of their personal information” (p.36). The consumer is subsequently caught in a position of both victim and beneficiary. The organization-consumer struggle over information technology is affected by several factors that ultimately determine an individual’s level of privacy concern. Smith et al. (1996) identified four factors, in rank order of importance, to be (1) unauthorized secondary use, (2) improper access, (3) collection, and (4) errors.

Unauthorized secondary use, the use of an individual’s data for a purpose not authorized by the individual, may occur on 2 levels (Smith et al., 1996). Secondary use within the same organization that collected the data is an internal secondary use, whereas any use outside of the collecting organization is external. Although unauthorized secondary use is commonly met with a negative response, it is not unusual for an organization to invent and execute new internal uses for its stored data (Smith et al., 1996). A 2001 survey by the American Society of Newspaper Editors found the public to be concerned with such secondary uses, citing 52% of respondents reported that they had “very little” or “no confidence at all” that private companies only used personal information in exactly the manner the consumer had authorized. There are also frightening examples of external secondary use that contribute to its negative connotation. Among such examples include two pharmacies on the East coast that released information on customers purchasing HIV medication. Following the unauthorized transfer of their data to another company, customers received mailers for HIV products (Culnan & Armstrong, 1999).

The ability to control access to personal information is another important element of privacy that, when violated, heightens an individual’s privacy concerns (Smith et al., 1996). Often regarded by researchers as a security characteristic (Milberg et al., 2000), improper access

refers to the interpretation of who has the 'need to know' personal information and how much information he or she is authorized to access.

In a 2003 Harris poll (Harris Interactive, 2003), 69% of the American adults surveyed reported that the ability to control the collection of personal information is extremely important. Consistent with Westin's (1967) definition of privacy, Smith et al. (1996) recognizes the growing trends of personal information collection and public unrest over the quantity of data in the hands of private organizations.

Errors in data collection and data processing also provoke privacy concerns among the public. While deliberate errors have occurred and have received public attention, it is the accidental errors that people seem most concerned about (Milberg et al., 2000), and the desire to minimize errors to the greatest extent possible is the fourth component contributing to consumers' privacy concerns (Smith et al., 1996).

Having recognized the important factors in the formation of an individual's privacy concerns, previous studies have recommended that organizations follow Fair Information Principles (FIPs) to enhance the level of trust between the organization and the consumer (Culnan & Armstrong, 1999). FIPs emphasize the principles of notice and consent, paralleling Westin's (1967) definition of privacy, by acknowledging individuals' rights to be informed of the collection of any personal information, the level of confidentiality surrounding that information, all potential uses of that information, and also the right to seek redress against any improper or unauthorized uses of the individuals' personal information (Culnan & Armstrong, 1999, p. 107). Organizations following such fair information principles are said to engage in procedural fairness, and Culnan and Armstrong (1999) found that when consumers are informed of an organization's procedural fairness practices they are more likely to disclose personal information. The strong relationship between organizational practices and consumer awareness and perception of organizational practices is an important influence in determining an individual's level of privacy concern (Smith et al., 1996), and researchers have made corresponding recommendations that organizations' take their practices into consideration when developing trusting relationships with the consumer population.

Health Information Privacy

Westin's (1967) definition of privacy extends to the medical field in the degree to which an individual is able to control and limit others' access to his or her personal medical information, including the "storage, collection, use, maintenance, and disclosure of that personal information" (Alpert, 2003, p. 303). The traditional realm of information privacy has been affected by the rapid growth of computer and digital technology, leading to an increasing number of medical records stored in a digital or electronic format (Jeffords, 1999; Li & Shaw, 2004; Swartz, 2004). This transfer of data from the traditional paper to the new digital format has resulted in increased concerns among the patient population, and has prompted new legislation to establish privacy guidelines (Alpert, 2003; Ferdorowicz & Ray, 2004; Li & Shaw, 2004; Swartz, 2004). There are several major themes throughout medical privacy literature, including possible harms resulting from disclosure of medical information, present legislation and its implications for medical information, and the advantages and disadvantages accompanying the digitization of individual medical records (Alpert, 2003).

Possible Harms. Unauthorized use of personal information was identified by Smith et al. (1996) as a key component in the formation of individual's privacy concerns. The sensitive nature of medical information enhances patients' concerns if they suspect any chance that their information may be misused or inappropriately disclosed to a third party (Alpert, 2003). The confidentiality between a patient and health care provider is central to the delivery of sufficient treatment and promises that the patient's information will not be disclosed outside of the previously established patient-health care provider relationship (Nasser & Alpert, 1999). A public opinion survey conducted by the California HealthCare Foundation (CHCF) demonstrated the importance of a trusting relationship between patient and provider and its potential effects on the provider's ability to execute the appropriate or necessary patient care. The CHCF found that one in six adults reported having done something "out of the ordinary" to prevent the disclosure of their medical information, including avoiding care all together to (CHCF, 1999).

Advantages and Disadvantages. The possible disadvantages of implementing a digital medical records system are accompanied by several benefits, resulting in a close game between the proponents and opponents of such a system. Among the risks associated with the increasingly digital medical field is the possibility of improper access, as discussed by Alpert (2003) and Smith et al. (1996). The concern of improper access as previously discussed in relation to paper records is escalated with the added possibility of hackers gaining access to a medical records system (Shoesmith, 2001). While paper records are only accessible from their physical location, digital records are accessible from any computer with internet access, significantly broadening the number of people able to attempt access. There is a flip side to this risk, however, as proponents of digitization argue that there is an added security element in digital medical records, as all individuals must authorize their identity and need for access before gaining access to a patient's records (Shoesmith, 2001). Current paper records may sit exposed or in file cabinets, vulnerable to any doctor, office, or staff member that may come into their vicinity. While this threat of internal access violations has existed with paper records, the question of external improper access is now added with the introduction of information technology.

Another disadvantage present in the initial implementation of any new technology is the monetary cost required to purchase the hardware and set up a complex information system (Shoesmith, 2001). President Bush is among those proponents of electronic medical records, and has named a national health information technology coordinator to oversee the efforts of the federal government to establish standards to guide the development of new technology (Hawryluk, 2004). However, funding sources for the digital record systems have not been named, and it is inevitable that not all physicians will be financially able to adopt such a system, creating a possible problem of competitive advantage for those physicians or practices that are able to afford the initial \$15 to \$50 thousand cost per physician (CHCF). Likewise in this situation, there is a benefit to those physicians that are able to implement an electronic medical records system, as the system is estimated to save \$20 thousand per physician each year.

In addition to the potential savings and increased security that play alongside the risks associated with digital medical records, there is the benefit of increased health care quality as a result of comprehensive and easily transferable medical records (Alpert, 2003; Shoesmith, 2001). With the introduction of digital medical records, a patient's medical record may be shared between doctors, clinicians, lab technicians, and lab researchers, all at the simple click of a button (Shoesmith, 2001). Although most doctors and health care providers are excited at this benefit, the transferability of the records has also made some individuals uncomfortable and prompted questions about protection against unauthorized access. Also, the increasingly comprehensive nature that is characteristic of the digital medical records is credited with improving patient treatment, health research, the ability of doctors to make informed diagnoses, and the ability of the patient to make informed health care choices (Alpert, 2003).

HIPAA: Evaluating the Legislation and its Effects

Laws have a far-reaching presence in American society. Whether created by Congress, the President, the Judiciary, or a federally mandated regulatory agency, laws defining the rights of American citizens are subject to the scrutiny of policy experts, government officials, academics, researchers, theologians, and the public. The most notable legislation relevant to digital medical records is the Health Insurance Portability and Accountability Act (HIPAA) which is designed to ensure the integrity of patient information as it travels between health care providers, insurers, and data clearing houses (Ferdorowicz & Ray, 2004). HIPAA establishes requirements for health care organizations intended to maintain an acceptable level of privacy, to be enforced by severe punishments for the misuse of patient information. However, even with HIPAA active and in place, there are still looming concerns over data security and whether or not the benefits of such a digital medical system outweigh its costs. HIPAA has drawn both criticism and praise throughout its conception and implementation. This section examines the legislation more closely by first placing it in a historical and social context, and then considering its effectiveness on the basis of two publications, one government issued and the other created by a privately funded interest group.

HIPAA: History and Significance. In 1996 Congress created the Health Insurance Portability and Accountability Act (HIPAA) to fulfill a national need for patient record privacy standards (US Dept of Health and Human Services, 2001). The law was designed to safeguard the security and confidentiality of patient health information (PHI), as well as promote the development of a system that would allow for the electronic transfer of such information. Congress, as specified by HIPAA, had until August 21, 1999 to enact the corresponding health privacy legislation, but it failed to do so, requiring the Department of Health and Human Services (HHS) to create the medical privacy standards. HHS responded quickly and released its proposed regulations guaranteeing patients' rights and protections against the misuse or disclosure of their health records (US Dept of Health and Human Services, 2001), allowing for a public comment period. After reviewing the public's comments and criticisms, the HHS produced a final rule in December 2000, and upon review by President Bush and HHS Secretary Thompson, the rule took effect April 14, 2001. Health care entities, specifically health plans, health care clearinghouses, and health care providers who conduct transactions electronically, were required to achieve HIPAA compliance by April 14, 2003.

HIPAA's privacy rule, which establishes the national baseline for privacy standards, contains specific provisions pertaining to the privacy of medical records and other health information used or disclosed by a health care entity in any form, whether electronically, on paper, or orally (US Dept of Health and Human Services, 2001). The rule states that health care providers must obtain an individual's consent before using or disclosing PHI to carry out "treatment, payment, or health care operations" (US Dept of Health and Human Services, 2000). However, PHI may still be shared with public health authorities in the interest of protecting public health without obtaining consent. Therefore, while HIPAA attempts to satisfy the patient's need for privacy by requesting consent in certain situations, it allows for the additional disclosure of personal information without the consent of the patient.

A comprehensive and efficient evaluation of medical privacy legislation, specifically HIPAA, requires the researcher to consider those circumstances surrounding its implementation, and subsequently the intended and actual consequences of the legislation. Since HIPAA has only recently passed its first anniversary requiring all health care entities comply with its mandated standards, there is very little, if any, data documenting the direct effects of the legislation. However, government publications and public opinion offer an internal and external perspective on the legislation's progress, or lack thereof. Before examining such publications and data it is important to situate the legislation among the issue that mandated its creation, specifically

privacy and health information.

Privacy & Health Information. Public opinion has demonstrated the growing importance of privacy in today's information saturated society (Udo, 2001). The classic definition of privacy, according to Alan Westin, is the ability to control the collection and use of personal information (1967). Westin's definition of privacy extends to the medical field in the degree to which an individual is able to control and limit others' access to his or her personal medical information, including the "storage, collection, use, maintenance and disclosure of that personal information" (Alpert, 2003). Public opinion surveys have also documented the importance of privacy to patients. One such survey conducted by the California HealthCare Foundation (CHCF) demonstrated the importance of a trusting relationship between patient and health care provider, and its potential effects on the provider's ability to execute the appropriate or necessary patient care. The CHCF found that one in six adults reported having done something "out of the ordinary" to prevent the disclosure of their medical information, including avoiding medical care all together (California HealthCare Foundation, 1999).

Two important themes throughout medical privacy literature are the possible harms resulting from improper disclosure of medical information, and the present legislation's implications for medical information.

Present Legislation: Costs & Benefits. HIPAA's institution in 2001 signaled a change in the government's regulatory approach to the health care industry. Before HIPAA, patient privacy was protected under the umbrella of the Freedom of Information Act and various Medicare regulations, and improper behavior was addressed with criminal or civil action. Such an approach, in which sanctions are imposed following a violation, is common to many industries subject to government regulation, and is based on the idea that the thought of punishment will deter unlawful actions (Epstein, 2002). Following HIPAA's implementation, however, the medical industry became subject to a form of 'injunctive relief' in which requirements are imposed with the intention of preventing any harm, subsequently doing away with the need for post-sanctions. While ideally such a requirement would provide for large savings in the form of costs and time spent imposing sanctions and redressing injuries, there is also the concern that the requirement will produce a cessation in lawful activities, and even reduce the occurrence and benefits of lawful acts.

In the case of the health care industry, critics of HIPAA's privacy provisions assert that disclosure is a routine occurrence in the everyday lives of physicians, staff, and health care providers, and that mandating such professionals adhere to a minimum disclosure standard might hinder health care delivery (Epstein, 2000). HIPAA requires that only the minimum amount of personal health information, when not required for the immediate purpose of treatment, be shared or used by health care entities (US Dept of Health and Human Services, 2003). Whether or not this provision will increase or reduce the delivery of quality health care can only be hypothetically discussed at this point, as there is little, if any research that might suggest a correlation between the HIPAA provisions and quality of health care. However, since there is the possibility that health care might be adversely affected by the HIPAA requirements, it is logical to ask if the HIPAA provisions are in fact necessary and if they are the best way of providing sufficient protection of patients' medical information.

Public Opinion: The Formation of Consumers' Privacy Concerns. The sharing of PHI among health care organizations, clearinghouses, and providers, coupled with the increasing use of technology in the health care industry, has led to a struggle between the information-collecting or health care providing organization and its patients. As researchers have recognized, "while organizations claim the right to use information technology to improve efficiency, consumers often exhibit the desire to control the flow and dissemination of their personal information" (Milberg, Smith & Burke, 2000). Consumers and patients are subsequently caught

in the position of both victims and beneficiaries, simultaneously fighting for the best health care available and the best protection for their PHI. In response to this struggle, and to aid the health care industry in developing patient friendly policies, researchers have identified four factors that determine an individual's level of privacy concern. In rank order of importance, these factors are (1) unauthorized secondary use, (2) improper access, (3) collection, and (4) errors (Smith, Milberg & Burke, 1996). HIPAA's Privacy Rule attempts to address these four factors by mandating specific uses for PHI, enumerating those individuals and entities able to access PHI without patient's consent, setting standards for collection, and providing access to a process to correct errors. However, regardless of HIPAA's provisions for these consumer concerns, public opinion and consumer rights groups remain critical of the legislation and indicate that they are unsatisfied with its protections for PHI.

While acknowledging that Americans have been granted new rights with the implementation of HIPAA's Privacy Rule, consumer groups such as Washington D.C.-based Health Privacy Project (Health Privacy Project, 2004), criticize the government for failing to implement its policies properly, or provide sufficient guidance to consumers and the health care industry. The director of the Health Privacy Project asserts that one of HIPAA's biggest problems is that it is not consumer-friendly, and that many patient complaints stem from misunderstandings of the Privacy Rule, rather than blatant rule violations. Even the OCR's director has admitted that notices of privacy practices, distributed to patients in their doctor or hospital's waiting room, are cluttered with legal jargon and are not written with their patient audience in mind (Finklestein, 2004).

In a letter addressed to Congress shortly before the one-year anniversary of HIPAA's implementation, the Health Privacy Project pleaded with the government to reevaluate and improve its approach to its health privacy legislation, and finally grant patients' the rights they had legally been granted. As indicated earlier in CHCF's public opinion survey, one of the Health Privacy Project's greatest concern is that patients will continue to engage in 'privacy-protective behaviors,' out of fear of their information being disseminated to insurance companies, their employers, or commercial interests, and subsequently undermining their quality of care. Focus groups recently conducted at the University of California, Santa Barbara found that fears of information misuse, which constitutes one of those factors identified by researchers as contributing to privacy concerns, were prominent among its college age participants, a generation often credited as being fearless or even careless when disclosing personal information. Among the focus groups' concerns was improper access, achieved by hacking, and the unauthorized dissemination of patients' PHI to employers or insurance carriers.

Government Publications. Following the one-year anniversary of HIPAA's implementation, the Office for Civil Rights (OCR) sent a letter to all healthcare providers required to comply with HIPAA regulations. If the letter, dated May 17, 2004, is any indication of those challenges that health care providers have faced, it appears that there has been a significant amount of confusion surrounding many of the Privacy Rule's provisions. The letter advises hospitals and others charged with implementing the Privacy Rule to seek out the government's guidance through its website created by the Department of Health and Human Services (US Dept of Health and Human Services, 2004). Also, the letter, which shortly followed the Health Privacy Project's critical notice to Congress, addresses many of the specific issues raised by the Health Privacy Project, although it does not acknowledge any consumer groups or external organizations with which it is explicitly concerned. Whether or not the two letters have any direct relationship may only be speculated.

Within its letter, the OCR addressed important issues in response to healthcare providers' requests for clarification of HIPAA's Privacy Rule. The OCR first addresses the question of consent, clarifying that HIPAA allows doctors, hospitals, and ambulances to share information

for treatment purposes without requiring a patient's signature of consent. Whether or not providers had been withholding information in fear of violating HIPAA provisions, what the Health Privacy Project termed 'privacy-protective behavior,' is not stated, but it may be a serious concern that the OCR intended to alleviate with this letter. Second, the OCR writes about technology, with the statement that 'HIPAA is not anti-electronic,' and that doctors are free to use e-mail, the telephone, and the fax to communicate with patients and others, provided that the doctors use common sense to safeguard patient privacy. As the OCR indicates, precautions to uphold patient privacy standards were practiced long before HIPAA was implemented, and there is no reason for medical providers to change their means of communication as a result of the new legislation. Again, as with the issue of consent, it is difficult from a research standpoint to conclude whether or not these government-issued reminders are reflective of those complaints and questions expressed by healthcare providers. However, the website displaying Privacy Rule Frequently Asked Questions had received an impressive 2 million hits at the time the letter was issued.

Call for Research. While the government has indirectly acknowledged several problems that have accompanied its attempt to implement and enforce HIPAA's Privacy Rule through its letters to health care organizations, and numerous HHS publications on HIPAA Frequently Asked Questions, it remains unclear whether or not the quality of health care has been directly affected by this piece of legislation. The question remains as to how doctors in HMOs and private practices have adjusted their daily patient interactions or privacy procedures, and in doing so what effects such changes have had on their ability to provide sufficient health care. While complaints from consumers, voiced on behalf of patient rights advocacy groups, have appeared numerous, it remains to be seen if these complaints have been properly resolved and the pertinent parties provided redress for any injuries or errors. Therefore, as HIPAA's third anniversary approaches, it is important for researchers to examine any correlations between health care costs and quality, public privacy concerns, and the widespread implementation of the Privacy Rule. From there researchers may begin to speculate as to HIPAA's ability to provide patient privacy rights and simultaneously maintain or increase the previously held standard of quality health care, and if necessary make recommendations as to how the government may reform or adjust legislation to address those areas identified as most important and lacking by researchers.

Relationship between Technology and Health Information Privacy

Issues of technology and privacy are at the forefront of the debate surrounding individual digital medical records. As with any new information system, digital medical records technology will be, following its initial diffusion, subject to acceptance or rejection by its consumer population, largely composed of patients and health care professionals. According to research, the decision to adopt or reject a new technology is largely influenced by the consumer's evaluation of those characteristics identified by Rogers (1983), and in the case of digital medical records, the elements of privacy concern as determined by Smith et al. (1996).

Those characteristics identified by Rogers (1983) and Smith et al. (1996) are not mutually exclusive, but rather contain similar qualities and may interact or have dependent relationships with each other. Rogers' (1983) technology characteristics of relative advantage, compatibility, complexity, trialability, and observability, are not completely separable from Smith et al.'s (1986) privacy characteristics of unauthorized secondary use, improper access, collection, and error. In fact those factors contributing to privacy concern may be discussed as subsets of many of the technology diffusion characteristics, especially relative advantage and compatibility.

Relative advantage encompasses those aspects of a new technology that elevate it in comparison to previous or current technology (Rogers, 1983). In the case of digital medical records, several improvements over paper records have been cited, including increased security (Shoemith, 2001), and improved health care quality resulting from the ease of transfer and the

comprehensive nature of digital records (Alpert, 2003; Shoesmith, 2001). Privacy concerns corresponding to the proposed security of digital records are an important factor in evaluating the technology in terms of relative advantage. Critics of the digital records are concerned that the misuse of information (Alpert, 2003) might ultimately result in a compromised level of patient care, negating any advantage of the digital system in comparison to paper records. Therefore, improper access, unauthorized use, and error, whether system or human error, as discussed by Smith et al. (1996), may contribute to increased privacy concerns, and subsequently a lower evaluation of digital records in terms of relative advantage among consumers.

Similar to their influence on relative advantage, the same concerns over improper access, unauthorized secondary use, and error reverberate in terms of the technology's compatibility with the consumers' current value system and needs (Rogers, 1983). Research has determined that privacy is an important value to consumers (Alpert, 2003; Jeffords, 1999; Mandl et al., 2001), and it is likely that any privacy violation would reduce a consumer's belief that digital medical records are compatible with his or her value system. Also, the collection of information for digital records, depending on the level of communication between the collecting organization and individual, might also be linked to compatibility, as consumers have been found to prefer control over their personal information and its disclosure to third parties (Milberg et al., 2000).

Another instance of interaction between privacy concerns and technology characteristics occur when considering error and complexity. Complexity refers to the degree to which an individual is able to understand and use the new technology (Rogers, 1983), and error, as identified by Smith et al. (1996), would indicate that the system is overly complex for its intended users. Because of the sensitive nature of personal medical information, the possibility for error is extremely important in determining a consumer's adoption or rejection of digital medical records technology. If an individual is not convinced that the system will return reliable and accurate data, it is unlikely that he or she will spend time with the system, leading to rejection.

The intertwined nature of privacy and technology is demonstrated by those technology characteristics that are dependent on some aspect of privacy concern. It is those privacy concerns that, when evaluated by consumers relative to their own individual privacy values and the new technology system, will contribute to the consumers' decision to adopt or reject digital medical records.

Santa Barbara County consumers are currently facing the decision to adopt or reject the implementation of digital medical records by the SBCCDE. The current research is aimed at determining Santa Barbara consumers' concerns and perceptions regarding individual digital medical records. Important to this research are those underlying concerns consumers have in relation to privacy and electronically shared medical information.

Methods

The study used a variety of methods to summarize, integrate, and identify factors influencing potential users' responses toward individual digital medical records. The prior theory, legislative and technology overview resulted from literature reviews and personal interviews with the SBCCDE contact. Then, interviews were conducted with six prominent stakeholders associated with the SBCCDE. From the literature review and interviews, key questions and consumer concerns were identified, and used to develop a core set of topics to be discussed by focus groups. After pilot testing the topics and procedures in one focus group, they were revised and implemented in six focus groups, stratified by relevant influences. Central words, themes and semantic groups were identified from the focus group discussions, and summarized by topic and focus group attributes. The cumulative insights from the literature review, stakeholder interviews, and focus groups were then used to develop a comprehensive survey. A pilot survey was tested on a small sample and then revised. The revised survey was

then completed by over 400 respondents. Descriptive, bivariate and multivariate analyses of the survey data were summarized and interpreted. Finally, the overall results were summarized and discussed. The Appendices provide more detailed information on semantic analyses, the survey, and additional statistical analyses.

Stakeholder Interviews

Six interviews were conducted with individuals representing those institutions the executive director of the SBCCDE identified as major stakeholders in the CDE project. The stakeholders interviewed included Cottage Hospital, The Santa Barbara Regional Health Authority, Sansum Medical Foundation, Santa Barbara Public Health Authority, a community business professional, and a participating physician. The interviews lasted approximately 90 minutes, and were tape recorded to facilitate the later analysis. The following was the format used in all 6 interviews:

1. How long have you been involved with the organization you represent?
2. How long have you been involved in the medical field?

Throughout our conversation I will refer to the Care Data Exchange, or CDE. Care Science describes its CDE as “the first clinical results reporting solution that combines proven, state-of-the-art technology with the facilitation and support services that enable clinician information sharing from multiple systems....”

Please respond to the following questions on behalf of your organization:

3. What is your organization’s role in the CDE? (i.e. What does it stand to gain or lose; what actions has it taken?)
 4. How would your organization describe the CDE in terms of its purpose and function within the Santa Barbara community?
 5. How has your organization been involved with the development of the CDE?
 6. What does your organization view to be the potential advantages and disadvantages of instituting an infrastructure such as the CDE?
 7. What are your organization’s major concerns regarding the upcoming deployment of the CDE during its third phase of testing and certification?
- In a 10/25/2003 meeting regarding User Acceptance Testing (UAT), operability, security, and privacy were determined to be important characteristics of the CDE.
8. How would your organization define operability, security, and privacy?
 9. How would your organization rate the CDE in terms of operability, security, and privacy?
 10. What characteristics of the CDE does your organization perceive to be advantageous to its possible acceptance within the community? Disadvantageous characteristics?
 11. From your organization’s point of view, what rights do consumers have regarding the regulation and ability to access their medical records?
 12. How does your organization perceive consumers will participate in the CDE? Will they access their medical records, and if so, for what purpose?

Focus Group Methodology

Focus groups are a highly respected qualitative measure that researchers have employed both alone and in conjunction with quantitative measures in the research process (Fuller et al., 1993; Knodel, 1993; O’Brien, 1993; Wolff, Knodel, & Sittirari, 1993). Traditionally the focus group has served to answer research questions through the collection of qualitative data. Characterized by human interaction and communication (Morgan, 1993), the focus group offers a researcher advantages including insight into the most effective means of communicating with an unfamiliar target population (Fuller et al., 1993), developing questionnaire or survey content (Fuller et al., 1993; O’Brien, 1993; Wolff et al., 1993), and the exploration of categories that would be restricted by quantitative methods (Wolff et al., 1993).

The ability to design a focus group specific to a researcher's needs and interests is another great advantage to this qualitative method (Knodel, 1993). Knodel (1993) discusses a process specific to the design and analysis of focus groups, and outlines four major steps for researchers to follow. The first of these steps is to set the focus group's objectives and format the guidelines for discussion. Guidelines include the definition of concepts to be investigated, and furthermore the specific order of questions, topics, and comments for a moderator to follow. Depending on the project, there is usually not a pressing need for a professional moderator, as a member of the research team, if prepared and familiar with group work, is often able to moderate the group herself (Morgan, 1993). The second step in determining the focus group's design is to decide on the specific characteristics to be targeted within the population of interest. All groups will inevitably have some common characteristics, control characteristics, but it is those characteristics that differentiate the groups, break characteristics, that must be predetermined according to researchers' objectives. After determining such characteristics, conducting sessions with groups homogeneous relative to break characteristics is regarded as more productive than sessions with heterogeneous groups. After identifying important characteristics, researchers also must consider such practical issues as time and budget constraints, along with the complexity of their design, to decide how many sessions are needed. With complexity in mind, Knodel (1993) recommends that the "incorporation of break characteristics should be kept to as low a level as is consistent with examining major subgroups" (p. 41).

Once focus groups have been conducted, it is important to keep in mind that due to the qualitative nature of focus group generated data, subjective judgment will be required in any subsequent analysis (Knodel, 1993). Determining specific criteria to organize the data can maximize validity. Typically this is achieved by developing a coding system corresponding to the focus group guidelines. Throughout the coding process it is likely that additional codes for new topics or areas of special interest will be developed to address issues unforeseen by researchers. The generation of new concepts, hypotheses, and survey items is considered a major benefit to focus group research, especially when used as a precursor to quantitative methods (Fuller et al., 1993). Finally, constructing an overview grid among the research team to assess the reliability of coding measures is also a desirable aspect of data analysis.

Project Focus Groups

The current project used 6 focus groups during its initial phase to investigate the issues surrounding the diffusion of individual/shared digital medical records on both a conceptual and local level. An initial focus group with undergraduate students was conducted to identify any problems with the discussion guidelines previously developed by the researchers. The 5 remaining focus groups consisted of: 2 undergraduate groups, 1 graduate student group, 1 employee group, and 1 group of members of the UCSB Student Health Action Committee. Of the 2 undergraduate groups, 1 group consisted of students who identified themselves as having a chronic illness, such as diabetes or asthma, and the second group of students did not have a chronic illness. This distinction was made on the basis of literature demonstrating that patients' experiences with health technology may differ among healthy and unhealthy patients (Ralston et al., 2004; Ziebland et al., 2004). Past research has shown diabetes patients to reap important benefits from interaction with their electronic medical records (Ralston et al., 2004), and cancer patients have been found to utilize the internet to fulfill health information and support needs unavailable through traditional health care (Ziebland et al., 2004). The researchers were interested in identifying whether consumers' health status would influence their perceptions and concerns regarding their individual/shared digital medical records.

One method of testing new technologies is through small focus or discussion groups, in which a facilitator introduces the technology to a group of potential users and then gathers their feedback regarding the likelihood that the users will adopt the new technology, along with their

overall concerns and perceptions of the new medium (Williams, Rice, & Rogers, 1988). In the current study, each focus group had two main concepts for discussion. The first was a conceptual understanding of individual/digital shared medical records. The moderator read a short paragraph describing the concept and then opened discussion of the concept by asking questions about the participants' views and concerns regarding the new technology. The second stage of the focus group focused on the local implementation of such digital medical records, with the moderator again reading a paragraph to introduce the idea.

The following guidelines were used to moderate the focus groups:

General Introduction:

Thank you for participating in today's focus group. A focus group is a qualitative research tool consisting of in depth discussion among participants. Your feedback and input will serve to give the researchers a better understanding of the topic of interest, and we would like to encourage everyone's participation. Please take a look at the Consent form I have passed out.

It is possible that you may not have an opinion or knowledge regarding some issues that may arise, or it may be that you have a strong opinion and extensive knowledge. Whatever the case, we ask that everyone is respectful of each other and does not interrupt or criticize another individual's thoughts.

Because we would like to generate as much participation from each individual as possible, there may be times when the moderator will have to interrupt a participant; this is not due to the quality of the response, but simply due to our time constraints.

If possible we would also like to follow some basic ground rules: Only one person talks at a time, please turn off your cell phones, and feel free to utilize the name tags in responding to each others' comments or questions. You are not limited to answering the specific questions posed to you, but you are welcome to respond to the other participants.

Are there any questions?

Before we get started I'd like us all to quickly introduce ourselves...

Part I: Concept of individual digital medical records

A. Privacy

1. What information do you think your medical record contains? How would you use such information if you had access to it?
2. What rights do you think you have regarding your medical record?
3. What information from your medical record can doctors share with other health care providers or health institutions?
4. What concerns or questions do you have regarding the availability of your medical record?

B. Technology: Introduce concept: moderator will read a short description of individual digital medical records on the conceptual level

5. How do you think digital medical records would compare to current paper-based health care records?
6. What risks or disadvantages come with the implementation of this technology?
7. What benefits or advantages come with the implementation of this technology?
8. How would you feel about having your physician or health care provider implementing such digital records?

Part II: Local implementation of digital medical records

C. Local: Introduce SBCCDE: moderator will read a short description of the local implementations of CDE technology in Santa Barbara.

9. In the context of digital medical records' implementation in Santa Barbara County, what risks or disadvantages do the residents of Santa Barbara face following the implementation of this technology?

10. In the context of digital medical records' implementation in Santa Barbara County, what benefits or advantages will the residents of Santa Barbara encounter following the implementation of this technology?

11. Would you access your own medical record if given the opportunity? If so, for what purpose? If not, why? (Remember what they said medical records contained...Q1).

12. What do you think about other consumers accessing their medical records? For what purposes might they access their medical records?

13. What do you think about being able to see a list of individuals and institutions that have authorized access to your medical record?

14. What do you think about being able to see a log of individuals who have had authorized access to your medical record?

15. Would you be willing to sign a waiver allowing physicians and other authorized parties to view your medical record?

Results from Stakeholder Interviews

The Executive Director of the SBCCDE identified six major stakeholders in Santa Barbara's CDE and representatives of each stakeholder were contacted for an interview. The interviews are the statements and opinions of individuals on behalf of the organization or population they represent. Four organizations were represented: Cottage Hospital, Sansum Foundation Medical Clinic (SFMC), Santa Barbara Public Health Department (SBPHD), and Santa Barbara Regional Health Authority (SBRHA). Two populations were represented: the community-at-large and clinicians. These 6 stakeholders were then designated as Non-profit or Profit organizations with SBPHD, SBRHA, and the community-at-large as Non-profit stakeholders, and Cottage Hospital, SFMC, and clinicians as Profit stakeholders. All interviews were conducted in person between a researcher and the representative. Representatives were asked twelve questions, and the following sections summarize their answers.

Q1: Length of involvement with the organization represented. Individual representatives for the Non-profit stakeholder organizations averaged 7.1 years at their current organizations. Profit representatives averaged 9.3 years, demonstrating that both groups of individuals had an extended length of involvement with their organizations comparable to the age of the CDE (6 years).

Q2: Length of involvement with the medical field. The representatives of both the Non-profit and Profit stakeholders had considerable experience in the medical field, an average of 23.9 and 32.7 years, respectively. Such experience enhances the credibility of such individuals in their ability to speak both on behalf of a specific organization and in regard to the medical field.

Before continuing, the interviewer read each representative the following definition of the CDE found on Care Science's website: "Care Science describes its CDE as 'the first clinical results reporting solution that combines proven, state-of-the-art technology with the facilitation and support services that enable clinician information sharing from multiple systems....'"

Q3: Organizations' role in the CDE. Regardless of their Profit or Non-profit designation, all of the organizations had been involved with the development of the CDE through service on the CDE board. Also, members from both the Profit and Non-profit stakeholders reported contributing data, including lab, clinical, pharmacy, and eligibility data, to the CDE. Aside from one assertion regarding the lack of direct community involvement in the CDE, all interviewees described a significant investment, in terms of time, staff, and resources, to the development and implementation of the CDE. In accordance with such an investment, the representatives all acknowledged a potential gain associated with the CDE to be the efficient and timesaving access to patients' records.

The Non-profit and Profit representatives split slightly when expressing the potential gains and losses incurred from their organizations' participation in the CDE. Specifically, Profit

representatives explained they currently had an internal system similar to the CDE in place to manage their organization's transfer of data. Also, the potential loss of competitive advantage seemed to have been concern when the organizations initially decided to join the CDE, although the organizations' recognition of the CDE's benefits to the community and clinicians outweighed their own economic interests. The Non-profit representatives, when asked about any potential losses associated with the CDE, recognized that any security violation or inefficiently protected data would be seen as a loss on their organizations' part.

Both the Non-profit and Profit organizations have made considerable investments to the CDE since its inception in 1998. While there are equitable gains for each organization, Non-profit representatives differed from Profit representatives in their addition of a security violation to the potential resource or economic losses associated with the CDE.

Q4: Organizations' description of the CDE in terms of the CDE's purpose and function in the Santa Barbara community. Non-profit and Profit representatives described the CDE's purpose as the improvement of quality care and health outcomes throughout Santa Barbara County, made possible by the coordination of medical programs and patient care. Profit representatives especially emphasized their physicians' ability to access data provided from services outside of their local network, and Non-profit representatives acknowledged the community's gain in avoiding redundant medical testing or prescription duplication. The CDE's purpose might be summed up by one representative's comment that "It's a community based initiative to allow health care providers to obtain key medical information on their patients from a multitude of sources (at the patient's point of care)."

Q5: Organizations' involvement with the CDE's development. All of the stakeholders have had representatives on the CDE board. Also, the Profit stakeholders emphasized their organizations' contribution in terms of data, staff, resources, and funding throughout the CDE's conception and implementation. The Non-profit stakeholders recognized the lack of community involvement in the CDE, as they were unaware of any general community involvement prior to the CDE's establishment as a non-profit corporation, the SBCCDE, in March of 2004. All organizations have been active in the CDE's development, although there seems to be a consensus among the Non-profit stakeholders, that there has not been a sufficient amount of community involvement to date.

Q6a: Organizations' views on potential advantages of instituting CDE infrastructure. Non-profit and Profit stakeholders both recognized two advantages of instituting the CDE to be the improvement of quality care and the conservation of time through the consolidation of patients' medical information into digital records. Non-profit representatives also mentioned the possible reduced costs following the CDE's implementation resulting from the system's ability to accomplish some clerical labor tasks. Profit representatives added the importance of retrieving data from outside systems in a usable format.

Q6b: Organizations' views on potential disadvantages of instituting CDE infrastructure. The Non-profit and Profit representatives qualified disadvantages as being "things to think about" or "challenges," respectively, and recognized the infrastructure's ongoing development and maintenance costs as one such challenge. Also, both sets of stakeholders referenced technology as a hurdle to still be overcome, with the Non-profit stakeholders emphasizing their anxiety over the technology's unresolved security and privacy issues.

While one Non-profit representative saw no significant disadvantages to the CDE, the remaining representatives expressed concern regarding patients' reactions to the technology, and asserted that the CDE should in no means be a substitute for personal interaction. Profit representatives concentrated more on technology concerns, raising the issue of compatibility, as individual organizations' technologies will inevitably evolve separately from the CDE, and the future challenge of recalibrating and reevaluating systems that are part of the CDE.

Non-profit and Profit stakeholders alike anticipate many potential advantages of instituting CDE technology in terms of time, resources, and quality health care. It appears as if these advantages outweigh the potential disadvantages, as both groups reduced the word disadvantage to describe several side issues that are under consideration or in line to be resolved.

Q7: Organizations' major concerns regarding the CDE's upcoming third phase of testing and certification. The immediate concern that resonated with both Non-profit and Profit stakeholders was the adequacy and accuracy of data feeds into the CDE. There was a consensus among the representatives that the data's quality would determine the CDE's acceptance or rejection within the testing population. Furthermore, Non-profit representatives expressed the need for good planning and communication between CDE management and the participating organizations to ensure the success of the testing phase. It was also highlighted that at this point the community at large has no real concerns because it remains "out-of-the-loop."

From the perspective of Profit stakeholders, the success or failure of the CDE will be determined by the testing physicians' ability to see value in the CDE and its data. To achieve such success, all of the system's glitches must be worked out prior to the technology's deployment, especially in terms of accurate patient identification. Another concern expressed by the Profit stakeholders was the ambiguity regarding future funding of the CDE.

All representatives view data quality to be a concern in the CDE's testing phase, but aside from data Non-profit and Profit stakeholders split in their remaining concerns, with Non-profit representatives emphasizing communication over the Profit representatives' concerns about technology and funding.

Before proceeding, the interviewees were told that in a previous CDE board meeting in regard to User Acceptance Testing "operability, security, and privacy were determined to be important characteristics of the CDE."

Q8a: Organizations' definition of operability. Non-profit and Profit representatives defined operability to be whether or not the system works and consistently retrieves correct data. Profit stakeholders also indicated that operability included the CDE's accessibility and navigability to a user with standard technology.

Q8b: Organizations' definition of security. The stakeholders defined security to be the technological protection of data accomplished through user authorization. Non-profit representatives also asserted that the system must be able to resist any hacking attempts.

Q8c: Organizations' definition of privacy. Stakeholders' definitions of privacy and security overlapped as representatives repeated the need to protect medical records and authorize users. Non-profit and Profit representatives distinguished between privacy and security by establishing patient awareness as a privacy characteristic. Representatives acknowledged that patients must be informed that their data is being shared on the CDE system, with Profit stakeholders recalling their legal obligation to patients in maintaining HIPAA compliance.

Overall there was great consensus among all stakeholders when defining operability, security, and privacy.

Q9a: Organizations rate the CDE on operability. Non-profit and Profit stakeholders perceived the CDE to be working, but qualified their assertion by acknowledging that the CDE is still in its testing phase and a more accurate judgment would follow its implementation. A Non-profit representative seemed uncertain of whether or not the data was rich enough to allow CDE users to utilize all of the technology's potential functions.

Q9b: Organizations rate the CDE on security. Non-profit and Profit stakeholders agreed that in theory the CDE appears to be secure, and that security will remain a priority up to and following the CDE's implementation. Also, Non-profit representatives pointed to an outside evaluation of the CDE that gave the system passing marks on security.

Q9c: Organizations rate the CDE on privacy. Non-profit and Profit stakeholders agreed

that in theory the CDE seems to have achieved its privacy objectives, but that the technology's implementation would be the true test of privacy. Non-profit representatives said that privacy is continually being evaluated for improvements and that, like security, an outside evaluation passed the CDE in terms of privacy.

As with the definitions of operability, security, and privacy, both Non-profit and Profit stakeholders seem to be largely in agreement regarding the CDE's accomplishment of these three system attributes

Q10a: Characteristics of the CDE the organizations perceive to be advantageous to its possible acceptance within the community. Non-profit and Profit representatives perceived that the national attention the CDE has brought will continue to bring to Santa Barbara would foster the CDE's acceptance within the community. Also, stakeholders agreed that their organizations' ability to deliver better and safer treatment to patients through the CDE would place the new technology in a favorable light.

Following the implementation of the CDE, Non-profit representatives estimated that people would be able to avoid redundant testing and lab work, saving those patients time and money which will likely be received positively within the community. Also, a Non-profit representative thought that the elimination of paper records was advantageous.

Profit representatives also addressed the CDE's advantages for the patient community through the lightening of the patient's load or responsibility of coordinating their various physicians, specialists, and pharmacists' efforts. The Profit stakeholders also thought that the consumer portal, once implemented, would ensure the CDE's acceptance within the community.

Q10b: Characteristics of the CDE the organizations perceive to be disadvantageous to its possible acceptance within the community. Both Non-profit and Profit representatives acknowledged that not all patients in the community have adequate technology, internet access, or the skills necessary to use the CDE. While this will definitely influence patients' ability to use the CDE, the representatives also thought this might disadvantage the CDE during its initial community deployment. Also, both sets of stakeholders perceived that the concept of medical data housed on the internet rather than in health care facilities might create privacy concerns from the community.

Non-profit stakeholders thought that the lack of community involvement in the development of the CDE might create some resistance to the technology, while Profit stakeholders emphasized security and privacy issues prompting concerns in the community regarding insurance companies and employers' ability to access medical records via the internet.

The majority of stakeholders seemed to be in agreement over those characteristics that would likely be perceived as positive or negative attributes by the Santa Barbara community. However, as seen in previous questions, the Non-profit representatives reemphasized that lack of prior community involvement may disadvantage the CDE in terms of community acceptance. Profit representatives seemed to be more concerned with the community's reaction to privacy and security issues.

Q11: Organizations' view of consumers' rights to regulate and access their medical records. Non-profit and Profit representatives were quick to point to the law in determining patients' rights, and everyone acknowledged that by law patients have the right to access their medical records. A Profit representative referred specifically to the HIPAA policy allowing only those people managing a patient's care the have access to that patient's medical record, and a Non-profit representative also recognized the right for patients' to exclude their record from a system such as the CDE.

The Profit stakeholders raised an interesting side issue in response to this question regarding patients' ability to interpret their medical record. While consumers do have the right to obtain a copy of their records, what do they or what will they do with this information, and who

is responsible for aiding patients' interpretations of their records? This question of interpretation appears to be of great concern to those Profit stakeholders who may be confronted by patients with questions about their medical record or be held responsible for their patients' health care.

Both Profit and Non-profit representatives were in agreement that the law was the ultimate source of consumers' rights regarding access to their medical records, but Profit stakeholders would like to resolve the question of who is responsible for aiding patients' interpretation of their medical data.

Q12a: Organizations' perception of consumer participation in the CDE. There does not seem to be a clear consensus among stakeholders regarding consumer participation in the CDE. Within the Profit and Non-profit groups, representatives voiced contradictory perceptions, as some were very skeptical about patients' use, where others agreed that today's patients are becoming active in their health care and will use the CDE to view test results and retrieve up to date medical information. The common feature between the Non-profit and Profit representatives seems to be the acknowledgement that CDE use will vary according to the characteristics of the patient population in question (i.e., illness, income).

Non-profit representatives spoke on behalf of their low income and uninsured clientele who they see as unlikely users of the CDE. However, the representatives thought that once the consumer portal is implemented, those people with adequate technology will access the CDE to review the log of individuals having accessed their medical record, and to retrieve lab results, lists of medications, and other up to date medical data. Within both the Profit and Non-profit groups of stakeholders there seemed to be at least one dissenter who was skeptical of patient use. However, Profit representatives also acknowledged that patients would use the CDE to view test and lab results and request appointments and medicine, with chronically ill patients more likely to use the CDE in their practice of disease state management.

Summary of Stakeholder Interviews

Table 1 summarizes these answers, providing those responses that were common to both kinds of organizations, and those unique to each of the two types of organizations.

Table 1.
Summary of Responses to 12 Questions of Stakeholder Interviews

Question	Common Among Profit and Non Profit Stakeholders	Unique to Non Profit Stakeholders	Unique to Profit Stakeholders
1. Years at current org		Average 7.1 years	Average 9.3 years
2. Years in medical field		Average 23.9 years	Average 32.7 years
3. Role in CDE Possible Gains or Losses?	Active in CDE's development. Member on CDE board. Contribution of data, resources.	1 Organization serves as insurance company to the CDE. Community is unaware of CDE. Security violation would equal loss.	Recognize the benefit to community. Unclear direct benefits to orgs. Previous concern over competitive advantage. Initial implementation requires money and time.
4. CDE's purpose/function within SB community	Improved quality of care. Improved overall health outcomes. Coordination of care, medical programs.	Reduction of test and prescription duplication.	Clinicians will have a single access point to services outside of local network.
5. Involvement with CDE's development	Active participation on CDE board throughout CDE's conception and implementation.	Unaware of general community involvement in CDE (prior to estbl. as non-profit in 03/2004).	Contribution of staff, resources, funding, data.
6a. Advantages of instituting CDE	Improved quality of care. Save time by consolidating medical information into individual digital records.	Reduced labor costs with capabilities of electronic system.	Records available quickly and in a usable format.
6b. Disadvantages of instituting CDE	Disadvantages= "Challenges" or "Things to think about." Development and maintenance costs. Issues remain to be resolved.	CDE is not a substitute for personal interaction. Patients' reactions remain unknown. Anxiety over security and privacy issues.	CDE participants have separate and different technology systems. Getting started. Technology is a hurdle; "CDE is not proven state-of-the-art technology."
7. Concerns about	Adequacy and accuracy of CDE's	Good planning and	Source of future funding is

CDE's current testing	data.	communication between CDE management and testing clinicians is vital. Consumer doesn't have concerns because "out of the loop."	unclear. Physician must see value in the CDE. CDE needs to have all glitches resolved. CDE must accurately identify individual patients.
8a. Definition of operability	How the system works. System's ability to retrieve correct data.		Accessibility and navigability of CDE to user with standard technology.
8b. Definition of security	Technical protection of data via user authorization.	Can system be hacked into?	Access must have clear guidelines and procedures.
8c. Definition of privacy	Patients to be aware that their medical data is shared with CDE and aware of who has access.	Protection and confidentiality of medical records.	HIPAA compliance.
9a. Operability rating	Seems to be working, but CDE is still in testing phase.	Unsure if data is rich enough.	
9b. Security rating	In theory, CDE is secure, but technology has yet to be implemented.	Outside evaluation passed CDE.	Important to achieve security.
9c. Privacy rating	In theory, CDE seems to be private, but technology has yet to be implemented.	Outside evaluation passed CDE. CDE continuously working on privacy issues.	Important to achieve privacy.
10a. Characteristics advantageous to community acceptance	National attention for Santa Barbara. Improved and safer treatment of patients.	Patients can avoid redundant testing and blood work, saving time and money. Paper medical records eliminated.	Less effort for patient to coordinate different physicians and specialists. CDE consumer portal.
10b. Characteristics disadvantageous to	Not all patients have adequate technology, internet access, or the	CDE development has lacked community involvement and	Security and privacy concerns about insurance companies and

community acceptance	skills to use the CDE. Security and privacy concerns over data on internet.	input.	employers access to medical records.
11. Consumers' rights to regulate and access medical records	Law dictates consumers' rights. By law, patients have right to access their medical records.	Patients have right to request record be removed from system.	HIPAA provides for those people managing patient's care to have access to medical records. Question of consumers' abilities to interpret data in medical record.
12. Consumer participation in CDE	Consumer portal is on hold. Some orgs. are skeptical of consumer use. Patients to use CDE to view test results, get up do date medical information. Consumer use will vary according to characteristics of patient population. People are becoming increasingly active in health care.	Low income and uninsured patients won't be likely to access the CDE. People will review the log of users accessing their medical record.	Chronically ill patients are more likely to use CDE; may participate in disease state management. People to view test and lab results, request appointments and medicine.

Results from Focus Groups

Six focus groups were conducted to examine individuals' reactions to the implementation of individual digital medical records on both a conceptual and concrete level. 3 focus groups were conducted with undergraduate students who indicated on the sign-up survey that they had never had any chronic illness ("healthy" group), 1 focus group consisted of undergraduates who identified themselves as having been chronically ill ("illness" group), 1 focus group was made up of graduate students, and the final focus group was with university employees (administrative assistants). All 6 groups were asked the same 15 questions. The following sections summarize their answers, and Table 2 provides an overview of the answers, with common and unique responses, according to focus group demographics.

Summary by Topics and Group Attributes

Q1: What information do you think your medical record contains?

Healthy: The three healthy focus groups responded with the following list of information: Shots, current medications, past prescriptions, log of doctors visits, log of emergency room visits, insurance information, family medical history, doctor's name, height, weight, blood count, patient's reaction to medications, whether or not the individual is a smoker, major surgeries, symptoms the individual has reported, broken bones, and doctors' notes.

Illness: The students identified as chronically ill responded with the following list of information: X-rays, vaccinations, prescriptions, allergies, illnesses and diseases, current medications, individual's name, social security number, date of birth, insurance information, family history, blood type, cholesterol count, blood pressure, heart rate, vision and hearing information, weight, and height.

Graduate: The graduate students responded with the following list of information: Allergies, past medical history, family medical history, doctors' comments, lab tests, date of birth, immunizations, prescriptions, blood pressure, cholesterol, hospital stays, surgeries, medications with adverse effects, and patient's reported symptoms. The graduate students also thought that a patient began a new medical record with every new doctor, and one person admitted to being unaware of the medical record's contents.

Employee: The employee focus group responded with the following list of information: Date of birth, allergies to drugs, family medical history, surgeries, allergy shots, medical history, insurance information, dental records, heart rate, blood pressure, weight, height, treatments, doctors' comments. The employee group also asserted that the medical record's contents might depend on the doctor, and that any treatment from alternative medicine would not be recorded in the standard medical record. Also, the group acknowledged it was unlikely that the record would include childhood information.

Q2: What rights do you think you have regarding your medical record?

Healthy: The majority of students responded that they, as patients, have the right to access their medical record and to control the disclosure of their medical record to third parties outside of their doctor. Two of the three groups raised the issue of privacy and felt strongly that it was important for medical records to operate under some level of privacy and confidentiality. Also, two of the groups felt that parents have access to their children's medical records, but only up to a certain age. A smaller number of students felt that their records were not completely private and that their doctor had the right to disclose information and several people commented that if their records were not private they feared discriminatory hiring and insurance practices might occur.

Illness: Chronically ill students also raised the issue of privacy and thought a third party's ability to view a medical record was subject to the patient's consent and a reasonable need to view the specific record. However, the group also stated that a court is able to subpoena a record, a nurse can look at it, and that a patient has the right to transfer and make copies of her

record.

Graduate: The graduate students felt that patients have a right to complete access to their medical record, along with the ability to transfer the medical record to designated locations. Comments ranged from not desiring anyone but a doctor to access the medical record to believing the medical record was accessible to insurance companies.

Employee: The employees felt that patients have the right to access and obtain their medical records, but that there might be a cost to the patient. The employees were curious to know if they had the right to remove unwanted parts of their record or if their doctor had the right to disclose their medical record to others.

Q3: What information from your medical record can doctors share with other health care providers or health care institutions?

Healthy: Responses to the question varied among the healthy students, with one group strongly asserting that doctors were not able to share any information without the patient's consent, except for in the case of doctors working together on a patient's care. The other two groups felt that information could be shared with specialists, other doctors, and pharmacists. The information the groups thought might be shared included a patient's past medicines, allergies, and information on the patient's treatment.

Illness: The students did not feel that different levels of patient consent existed which designated, along with the urgency of the medical situation, the ability of doctors or health institutions to share a patient's information. One student stated that if a doctor or institution wanted information they would be able to obtain it, regardless of its legality. Also, a student stated that prescription information was shared with insurance companies.

Graduate: The majority of the graduate students felt that information relevant to a patient's treatment could be shared, but that they did not believe it was appropriate for insurance companies to have access to patients' medical records. One student felt that it would be advantageous if the patient's consent was requested before sharing information, empowering the patient as the gate keeper of her medical information.

Employee: The employees were unsure of what information doctors were able to share. One employee acknowledged recently signing a waiver release form without reading it.

Q4: What concerns or questions do you have regarding the availability of your medical record?

Healthy: While some of the students admitted that they hadn't considered many of the issues surrounding their medical record, many of the students were curious about the practical steps patients are required to take to obtain their medical records; the ability of third parties to view a patient's record, such as a child and parent; the ability of the patient to control the disclosure of her information, and to put that information into context if needed; whether or not medical records were in a format that could be understood by patients.

Illness: The students had few concerns or questions, but wanted to know if employers were able to access a record and subsequently discriminate based on an individual's illness. Also, the group raised the issue of parents' ability to access their children's medical records.

Graduate: The graduate students were concerned about medical records' availability to health insurance companies and employers. Also, they were unsure if medical records were transferred with a patient following a change in doctor. One person commented that a medical record was only dangerous if the patient's name was connected with it.

Employee: The employees were concerned about insurance companies' ability to access medical records and any possible relationship between the rising costs of medications and patients' illnesses.

After answering the initial four questions, the moderator passed out a brief description of individual digital medical records for the participants to read (included as Appendix 1). The

moderator read the description out loud before continuing with the following questions.

Q5: How do you think digital medical records would compare to current paper-based health care records?

Healthy: In comparison to paper-based health care records, the students felt that digital medical records would be more easily and quickly accessible, ideal in emergency situations, more readily transferable between doctors and insurance companies, more reliable and organized, able to store a greater amount of information, environmentally friendly, less susceptible to fire or physical damages, more complete as to facilitate better medical diagnoses, and digital medical records might also highlight those tests a patient has already completed, so as to avoid repeating unnecessary testing. Students also saw several downfalls to digital medical records in comparison to paper-based records, including decreased security and the threat of hackers, the ability for third parties to view the records without need for approval.

Illness: In comparison to paper-based records, the students thought that digital records would be more secure, easier to access, and less likely to be lost. However, the students acknowledged that some of the advantages of the digital records were coupled with possible disadvantages, such as hackers gaining access to the information, the downfall of complete reliance on computers, and the difficulty of retrieving lost information without any paper trail.

Graduate: The graduate students described the digital records as being centralized, easily accessible, facilitating more efficient diagnoses, compensating for human error, and allowing for the development of algorithms to diagnose patients. The graduate students also had several questions about the implementation of digital medical records, specifically regarding the standardization of the information and the quantity of information that would be transferred to a digital format.

Employee: The employees described digital medical records as being easily and widely accessible, ideal for emergency situations, and more complete, transferable, and readable in comparison to paper-based records. The employees also had questions regarding the designation of sensitive information and the possibility of hackers gaining access to the information.

Q6: What risks or disadvantages come with the implementation of this technology (individual digital medical records)?

Healthy: Among the students the most salient disadvantage appeared to be the potential for hackers to gain access to the medical records, along with problems inherent in computers, such as the speed of the data transfer, the computers' reliability, confusion of patients' files, human error with data entry, and computer viruses. Also, one group raised the issue that not all people or patients are computer literate or do not have access to a computer, thereby excluding them from accessing their digital medical record.

Illness: Students identified such disadvantages as the potential loss of information due to computer viruses, improper uses of records, the unauthorized alteration or deletion of information, and the political nature the digital records.

Graduate: The graduate students raised the question of access and control as creating possible disadvantages in terms of determining the limits of authorization and ultimate control over the data depository. Other disadvantages included the cost of the technology, the need to train the digital records' users, and the likelihood that patients will not be able to understand the records. The group also wanted to know if paper records would be maintained along with the new technology.

Employee: The employees identified discrimination and the possibility for medical information to be taken out of context as disadvantages accompanying the implementation of digital medical records. The employees felt the manner in which the information was presented as very important, and that the possibility for error was also a major risk.

Q7: What benefits or advantages come with the implementation of this technology?

Healthy: Among the advantages associated with the implementation of digital medical records, the students identified benefits specific to the doctor and patient. The medical records would be more convenient for doctors and promote accuracy in their diagnosis. For the patient, benefits include avoiding repeat paperwork during doctor visits, the ability to view who has accessed the medical record, the ability to access the record when traveling, and the accessibility of the record in emergency situations. Other advantages mentioned were the organization of digital records, and the fact that they're not susceptible to physical damage such as fire.

Illness: The students saw the implementation of digital medical records as contributing to the integrity of the medical field, and providing more accurate information on the general population, ultimately leading to the recognition and diagnosis of widespread problems. Also, the students thought the records would prevent people from overloading on medications and could also possibly contribute to research in the medical field.

Graduate: The graduate students designated consumer access as an important advantage of digital medical records, but they also questioned whether or not the patients would be able to comprehend the records. They also saw the records as creating efficiency for both the patient and the doctor, as a time saving mechanism that expedites paperwork and allows doctors to view prior diagnoses.

Employee: The employee group saw the digital medical records as being beneficial to travelers and as a helpful mechanism to recall previous medications and prescriptions. One employee also felt that the digital records were less bureaucratic.

Q8: How would you feel about having your physician or health care provider implementing such digital records?

Healthy: The majority of students responded that the implementation of digital medical records would not bother them. However, many students prefaced their answer by stating that they would want the system to be safe, subject to strict regulations, and require the patient's consent. Several questions were made regarding the definition of a third party, and who or what institutions would be granted access to the medical records.

Illness: The majority of the students were quick to state that they wouldn't mind if their physician or health care provider implemented digital records. However, the issue was raised regarding the ability of a child to keep information from her parents, specifically in the case of abortion.

Graduate: The graduate students were not immediately accepting of the implementation of digital medical records, and almost all of the students were not interested in utilizing the technology, unless their permission was requested and they were able to set parameter regarding parties able to access their records. There were two students that did not support the records implementation, but the others seemed to be interested in weighing the benefits and costs of the system before deciding whether or not they in fact were comfortable with the digital medical records.

Employee: The employees were largely supportive of the records' implementation, provided that they were able to give authorization to those users wishing to access their records. They felt it was important to be able to limit certain parties, such as drug companies and insurance companies from accessing their information.

Before continuing, the moderator passed out and read a short paragraph describing the implementation of individual digital medical records in the Santa Barbara County. Whereas the initial description of the medical records was on a conceptual level, this description focused on the records' local implementation by the Santa Barbara County Care Data Exchange.

Q9: In the context of digital medical records' implementation in Santa Barbara County, what risks or disadvantages do the residents of Santa Barbara face following the implementation of this technology?

Healthy: The students identified the local implementation of digital medical records to have limited benefits if the technology is only present in Santa Barbara County, and therefore students who receive most of the medical care outside of Santa Barbara, or those individuals who travel or move, would not be able to benefit from the technology. Other disadvantages included those risks discussed on the conceptual level, such as the system's susceptibility to hacking, the likelihood that not all residents of Santa Barbara do not have access to a computer, and the possibility of a computer virus destroying the records. Also, the students raised the issue of those hospitals in Santa Barbara not participating in the CDE, and they also felt that all patients should have been previously notified and asked for their consent in order to transfer their information to digital records. Finally, the students recognized that older generations might be particularly resistant to the new technology in comparison to their own generation which has grown up in a highly computer-centric time,

Illness: The students cited the initial cost of implementing the system to be a disadvantage, and also thought that improper use and access might be a problem. Some students felt that the system might not return accurate information consistently and that their privacy might be invaded.

Graduate: The graduate students found the finite list of CDE participating organizations to be a disadvantage as some private and local doctors were not included in the system. Other disadvantages included the cost to taxpayers, the limited health care options in Santa Barbara, and the fact that the patients had not been consulted earlier. Also, the group pointed out that if the records were only available in English that foreign-language speaking populations would be excluded from accessing their medical records.

Employee: The employees brought up the problem of a language barrier in dealing with patients who do not speak English, along with possible costs of the system being passed on to patient fees. Other risks the employees discussed included the possibility of doctors making a mistake and pulling up the wrong record, or doctors leaving computers unlocked with the system running so that third parties may gain access to the system. Finally, the employees recognized that there would be a great need for training for the system's users as many people are not completely comfortable with computers.

Q10: In the context of digital medical records implementation in Santa Barbara County, what benefits or advantages will the residents of Santa Barbara encounter following the implementation of this technology?

Healthy: The students identified several advantages of digital medical records' implementation in Santa Barbara County, including the ease of switching doctors and using the services at different local hospitals. Another advantage was that patients and health institutions would both save time by expediting much of the standard paperwork, and that ultimately money might also be saved by implementing the digital records. Other students thought that simply trying out the system in Santa Barbara was a great idea due to its small population, and that if the system was extended outside of Santa Barbara that it would benefit a greater amount of people. Also, students thought that visits to the emergency room would benefit from having immediate access to the patients' information.

Illness: The students with chronic illnesses thought that the implementation of digital records would ultimately benefit the Santa Barbara health community due to its efficiency and convenience. Also, they supported the eventual phasing out of paper records and thought that the elimination of paper storage costs would also save money. One student also brought up that typing would probably be easier to read than doctors' handwriting.

Graduate: The graduate students thought that the digital medical records would have benefits for the emergency room and would facilitate the doctors' patient referrals to specialists in the area. Also, the students anticipated that patients might prefer to patronize those hospitals

that participate in the CDE system, and thought that the implementation of the system might also influence health costs. The students were unsure if there were environmental or legal benefits from the system.

Employee: The employees named such advantages as the reduction of human error, the cost of paper, and the need for human time and labor as accompanying the implementation of digital medical records. The employees also felt that digital medical records would lead to more informed doctors and that the bureaucracy patients must currently deal with to obtain records would be reduced.

Q11: Would you access your own medical record if given the opportunity? If so, for what purpose? If not, why?

Healthy: Of the 29 healthy students that participated, 24 answered that they would access their medical records if given the opportunity. The most popular reason for accessing their record was the students' curiosity, along with the desire to verify information and inform themselves of their own medical history and past. The students were also interested in viewing their medical records to obtain family history, learn their blood type, see what third parties had accessed their medical record, monitor what medications had been effective in their treatment, and to obtain vaccination records. Those that said they would not access their medical records replied that they had no need to access their record, and one male student suggested that young adult males might be less interested than young adult females.

Illness: Almost all of the chronically ill students were interested in accessing their medical records, and cited their interest in learning about their previous illnesses and numerous doctors' visits. Also, the students thought that the records would compensate for their own forgetfulness and that the students would be interested in verifying their information and learning more details of their medical history.

Graduate: All of the graduate students responded that they would access their medical record if given the opportunity. Most students were curious to see what information their medical record holds, and were especially interested in the ability to view test results and the log of users accessing their record. Some students thought that having access to their medical record might motivate them to become more active in their health care, but that this could have both positive and negative consequences.

Employee: All of the employees were interested in accessing their medical records. The employees thought that having access to the records might influence their opinions on their doctor and the quality of the doctor's treatment. Also, the employees thought that creating a system to evaluate doctors, including those doctors providing alternative medicine services, would benefit the Santa Barbara community.

Q12: What do you think about other consumers accessing their medical records? For what purposes might they access their medical records?

Healthy: The students identified populations like the elderly and those with serious illnesses, such as diabetes, heart disease, and other chronic illnesses as being likely to access their medical records, especially if those patients are subject to frequent treatments such as dialysis or chemotherapy. Also, the students thought that spouses might be interested in accessing their husband or wife's record, parents would want access to their children's records, and that employers of highly active laborers might also want to have access to verify their employees fitness level. The students also raised that the records might provide for a research opportunity, or that marketers would have an interest in obtaining such detailed consumer information.

Illness: The chronically ill students felt that the majority of the general population would access their medical records, but that the elderly and those people with significant health problems might benefit the most from accessing their medical records. The students thought that

the records might aid people in obtaining insurance and compensate for individuals' forgetfulness. However, the students noted that those people without computer access or the skills to use a computer would not be able to access their medical records.

Graduate: The graduate student identified spouses, parents, the elderly, and adult children caring for parents as being especially interested in accessing their and their respective partner, parent, or children's medical records. The students thought that the records might benefit those older patients who are forgetful, along with the overall medical community, especially emergency responders. Finally, the graduate students thought that patients who become more educated due to the ability to access their medical records might be able to engage in self-treatment.

Employee: The employees responded that as individuals age it becomes increasingly important to be aware of family medical history, and that having access to medical records would benefit the adult community. Other populations that they anticipated would benefit from the records were those women considering becoming pregnant, as well as those individual who were adopted and had been previously unable to access their medical records. Also, the employees thought that patient access to the medical records might compensate for those doctors which are not always great at sending out their patients' results.

Q13: What do you think about being able to see a list of individuals and institutions that have authorized access to your medical record?

Healthy: The majority of students thought that the ability to view the list of those individuals and institutions with authorized access to their record was an essential component to the digital medical records system. The students were interested in known who and what was included as authorized users, but they were also curious as to whether or not the patient would be able to control or edit the list of users. Some students thought that not being able to do anything about the list was discouraging.

Illness: Most of the chronically ill students were interested in seeing the list of authorized users, but a few thought that it wasn't necessary and anticipated that the list would be too long to read and wouldn't be helpful unless there was some way for the patient to revise the list. The students were also curious to know if the patients would be able to see the list of users before the system was implemented.

Graduate: The graduate students were interested in the list of authorized users, but did not think it was useful unless the patients were able to change list of potential users. Some students were also concerned that some patients might be discouraged from seeking medical treatment based on those institutions or individuals that were named authorized users for fear of their information being released.

Employee: All of the employees were interested in viewing the list of authorized users, and were specifically interested in knowing the reasons for which those individuals and institutions would be accessing their records.

Q14: What do you think about being able to see a log of individuals who have had authorized access to your medical record?

Healthy: Almost all of the students thought that the ability to view the access log was an important aspect to the digital medical records system, and would create a sense of security for the patient. The students thought that it was a good feature to have, and that as patients they would be interested in viewing the log and also questioning it if they were uncertain as to why a particular user has accessed their information. Also, the students thought that the log would create a necessary accountability for those individuals or institutions accessing medical records.

Illness: Most of the chronically ill students stated that they would want to view the access log. Those who didn't express interest said that they didn't care who was accessing their record.

Graduate: All of the graduate students were interested in the access log, specifically to issue complaints if access was unwarranted.

Employee: All of the employees were interested in the access log, and they hoped that the log would provide a reason as to why the patient's information had been accessed. Also, the employees thought it would be interesting to see whether or not their doctor had actually checked and updated their medical record prior to and following doctor visits or treatments.

Q15: Would you be willing to sign a waiver allowing physicians and other authorized parties to view your medical record?

Healthy: All but three of the students said that they would be willing to sign the waiver. While some students expressed no reservations regarding the waiver, others said that they would sign the waiver, provided that the patient was able to maintain some control over those authorized parties able to view the medical record. However, most students reasoned that the pros of the digital records seemed to outweigh the cons. Those students who were not willing to sign the waiver cited the fact that the system was still in its testing phase, that they desired to maintain their privacy, and that they would prefer not to worry about who is accessing their information.

Illness: All of the chronically ill students said that they would sign the waiver. Some students said that they felt the records would have direct benefits for them, but one or two were also hesitant and wanted to see the list of authorized users before signing the waiver.

Graduate: The graduate students were split with about half of the students stating that they would not sign the waiver. Those students that said they would sign the waiver all did so on a very conditional basis, expressing a desire for the patient to control who and what has access. Also, the students wanted to have patient access before signing the waiver.

Employee: The employees seemed willing to sign the waiver, but only in a piece-by-piece fashion, authorizing specific doctors, clinics, and emergency room situations to have access to their records.

Table 2.

Focus Group Topics According to 15 Questions, by Type of Focus Group

** = Topics that are common across all four focus groups.

Q1: What information do you think your medical record contains?

Information	Healthy Students	Chronic Illness	Graduate Students	Employees
Allergies **	X	X	X	X
Blood Information	X	X		
Broken Bones	X			
Cholesterol		X	X	
Current Medications **	X	X	X	X
Doctor's name	X			
Doctor's notes	X		X	X
Doctors visits	X		X	
Emergency room visits	X		X	
Family Medical history	X	X		X
Gun in patient's house	X			
Heart Rate		X		X
Height	X	X		X
Illnesses & Diseases	X	X	X	
Insurance Information	X	X		X
Is Patient a Smoker?	X			
Lab Tests			X	
Past Prescriptions	X			
Patient's Address & Phone Number	X			
Patient's Date of Birth		X	X	X
Patient's name	X	X		
Patient's reactions	X			
Patient's SSN	X			
Patient's Symptoms	X	X		
Shots **	X	X	X	X
Surgeries	X		X	X
Vision & Hearing		X		
Weight	X	X		X
X-Rays		X		

Q2: What rights do you think you have regarding your medical record?

Right to...	Healthy Students	Chronic Illness	Graduate Students	Employees
Access **	X	X	X	X
Authorize 3 rd parties to access	X			
Confidentiality	X	X		
Doctor can disclose information/access	X		X	

Make copies of record		X		
Parents have access to children's records	X			
Privacy	X	X		
Signature required for confidentiality		X		
Transfer record		X	X	
Verify information	X			

Q3: What information from your medical record can doctors share with other health care providers or health institutions?

Shared information	Healthy Students	Chronic Illness	Graduate Students	Employees
Allergies	X			
Background information	X			
Emergency situations information is more freely shared	X	X		
Information is shared with insurance company			X	
Information may be shared illegally		X	X	
Information relevant to treatment			X	
None without patient's consent	X	X		
Past medications	X	X		
Unsure	X			X

Q4: What concerns or questions do you have regarding the availability of your medical record?

Concerns or questions	Healthy Students	Chronic Illness	Graduate Students	Employees
Are records transferred when a patient changes doctors?			X	
Are you allowed to have access to your records?	X			
Can a child look at her parents' records?	X			
Can parents' view their child's record?		X		
Can responsibility for an individual's record be transferred to a third party if the individual is incapable of caring for herself?	X			
Is medical information understandable to avg. person?	X			
Marketing				X
None		X		
Parties should only be able to access the information they need			X	
Patient should be able to put medical information in context	X			
Too young to have thought about it	X			
What information is available to insurance			X	X

companies?				
Who do you have to talk to get old records?	X			
Who has access?			X	

Q5: How do you think digital medical records would compare to current paper-based health care records?

In comparison to paper records, digital records would be...	Healthy Students	Chronic Illness	Graduate Students	Employees
Able to compensate for human error			X	
Centralized (more complete info.)			X	X
Develop algorithms for diagnosis			X	
Easier information retrieval	X			
Easily accessible **	X	X	X	X
Efficient for doctors	X	X	X	
Environmentally friendly	X			
Faster	X			
Harder to lose	X	X		
Ideal for travel	X			X
Ideal in emergency situations	X			X
Less bureaucratic				X
More bureaucratic		X		
More organized	X			
More reliable	X			
Paper records should coexist			X	
Potentially less secure (hackers)	X	X		X
Potentially more secure		X		
Require less storage space	X			
Would the records be standardized?			X	

Q6: What risks or disadvantages come with the implementation of this technology?

Risks and disadvantages of digital medical records	Healthy Students	Chronic Illness	Graduate Students	Employees
Computer viruses	X	X		
Computers aren't 100% reliable	X			
Confusion of records	X			X
Costs of technology			X	
Data transfer may take long	X			
Discrimination on medical info				X
Hackers may gain access	X	X		
Human error with data entry	X			X
Information may be altered or erased		X		
Patient might not understand record			X	
People are computer illiterate	X			
People don't have computer access	X			

Privacy risk	X			
Too political		X		
Users must be trained			X	
Who determines access?			X	

Q7: What benefits or advantages come with the implementation of this technology?

Benefits and advantages of digital medical records	Healthy Students	Chronic Illness	Graduate Students	Employees
Ability to view access log	X			
Accurate diagnoses	X	X		
Benefits patients with illnesses		X		
Brings integrity to medical field		X		
Convenience for doctors	X		X	
Easier to change doctors	X			
Easier to keep track of medication		X		X
Eliminates repeat paper work	X		X	
Ideal for emergency	X			
Ideal for travel	X	X		X
Information used for research		X		
No risk of losing files (in a fire, etc.)	X			
Patient access			X	
Quickly accessible	X			
Reliability	X			
Well organized	X			

Q8: How would you feel about having your physician or health care provider implementing such digital records?

Feeling about digital records' implementation	Healthy Students	Chronic Illness	Graduate Students	Employees
It wouldn't bother me	X	X	X	X
I would prefer the doctor have complete information	X			
Concerned over access to sensitive information				X
I trust my doctor	X			
I wouldn't want digital records			X	
I'm wary due to the costs and risks			X	
Minors or adult children might not want their parents to have access	X	X		
OK in an emergency		X		
Patients should control access			X	X
The doctor should ask for the patient's permission	X		X	X
The system must be secure	X			X
There should be strict regulations	X		X	

Those in the public eye might be bothered	X			
Women might want to keep an abortion private	X	X		

Q9: In the context of digital medical records' implementation in Santa Barbara County, what risks or disadvantages do the residents of Santa Barbara County face following the implementation of this technology?

Risks and disadvantages to residents of Santa Barbara County	Healthy Students	Chronic Illness	Graduate Students	Employees
Confusion of records		X		X
Hackers/ Improper use	X	X		X
High initial costs		X	X	X
If someone obtains health care outside of Santa Barbara they don't benefit from the records	X		X	
Invasion of privacy		X		
Not all hospitals participate in the SBCCDE	X		X	
Not yet accessible to the patient				X
Patients should have been notified	X		X	
Records are only in English			X	X
The system might fail (virus)	X			
There should still be a paper copy of the medical records	X			
Users must be trained				X

Q10: In the context of digital medical records' implementation in Santa Barbara County, what benefits or advantages will the residents of Santa Barbara encounter following the implementation of this technology?

Benefits and advantages to Santa Barbara County residents	Healthy Students	Chronic Illness	Graduate Students	Employees
Ability to compare paper and online records		X		
Convenience	X	X		
Doctors may compare notes	X			
Easier to switch doctors	X		X	
Easier to transfer medical record				X
Efficiency		X		
Eliminates paperwork	X			
Ideal in an emergency			X	
More informed doctors				X
Reduces human error				X
Santa Barbara is a good testing ground	X			
Saves money	X	X		X
Typing is easier to read (than handwriting)		X		

Q11: Would you access your own medical record if given the opportunity? If so, for what

purpose? If not, why?

Would you access your medical record and why	Healthy Students	Chronic Illness	Graduate Students	Employees
No, I have no need to	X	X		
No, I'm healthy	X			
Yes, because I am curious **	X	X	X	X
Yes, I've been to the doctor a lot		X		
Yes, it would be nice to have an additional system to evaluate the doctors				X
Yes, it would make the doctor more accountable	X			
Yes, to learn about my doctors	X			X
Yes, to learn about my past **	X	X	X	X
Yes, to learn my blood type	X	X		
Yes, to look up prescriptions	X			
Yes, to look up vaccination records	X			
Yes, to see how info is recorded	X			
Yes, to see test results			X	
Yes, to see who was accessing it	X		X	
Yes, to verify information	X	X	X	

Q12: What do you think about other consumers accessing their medical records? For what purposes might they access their medical records?

Other consumers accessing their medical records	Healthy Students	Chronic Illness	Graduate Students	Employees
Adopted individuals			X	X
Adult children caring for parents			X	
Athletes		X		
DMV may want access		X		
Employers might want access	X			
Facilitate insurance process		X		
Marketing agencies	X			
Medical research community	X		X	
Most of the general population		X		
Nursing homes want access			X	
Older people are forgetful	X	X	X	
Parents to look at children's records	X		X	
Patients can self-treat			X	
People are curious	X			
People don't trust their doctor	X			
People in a highly active work environment	X			
People in ongoing therapy	X			
People interested in family history	X			X
People want to see lab results	X			

People with serious and chronic illnesses	X	X		
People without computer access and skills can't access		X		
Spouse interested in partner's info			X	

Q13: What do you think about being able to see a list of individuals and institutions that have authorized access to your medical record?

List of authorized individuals and institutions	Healthy Students	Chronic Illness	Graduate Students	Employees
Adds security and comfort	X			
Can the patient do anything about it?	X		X	
I don't see it as necessary		X		
I want to see the list before the system is in place		X		
I would want the users contact info				X
It's essential **	X	X	X	X
Patients should have ability to block users	X	X	X	

Q14: What do you think about being able to see a log of individuals who have had authorized access to your medical record?

Risks and disadvantages of digital medical records	Healthy Students	Chronic Illness	Graduate Students	Employees
A log is much better than a list	X			
A log would enhance security	X			
Good to check that doctor has accessed record				X
I would want to see it **	X	X	X	X
It might make me paranoid	X			
The log is good to have	X			
Yes, the patient can question access	X		X	X

Q15: Would you be willing to sign a waiver allowing physicians and other authorized parties to view your medical record?

Would you sign a waiver?	Healthy Students	Chronic Illness	Graduate Students	Employees
It depends on who has access			X	
No, I want my privacy	X			
No, the system is still being tested	X			
No, there are too many components I dislike			X	
Yes **	X	X	X	X
Yes, after I see the list of users		X		X
Yes, but it might change in the future	X			
Yes, but only to allow limited access	X		X	X

Most Frequently Occurring Words in Sets of Responses in Focus Groups

Another way to indicate the main concerns of the focus participants is to note the most frequent words used in their responses. First, all responses to each respective question were combined across focus groups. Then, the 15 questions were combined into three categories of questions: (a) personal or individual concern, (b) others' concern, and (c) advantages and disadvantages of digital medical records. Questions 1, 2, 11, 12 were combined to form the personal or individual concern, questions 3, 8, 13, 14, 15 formed others' concern, and questions 4, 5, 6, 7, 9, 10, 11 were combined for the advantages and disadvantages category. "Stop words" (a and, the, etc.) were removed, and words were "stemmed" (all variants were converted to one form, such as "patients" and "patient", or "you're" and "you"). Then a computer program went through the text in each of the three sets of responses, identified each unique word, counted each time it occurred, and sorted the words alphabetically within decreasing frequency of words. Table 3 lists those words. The following tables list those remaining words occurring five or more times within each group of questions across the focus groups. The words included in the analysis were the note taker's notes, and it is possible that some bias may be present among the words – that is, that the one person who took notes for each separate focus group may have summarized participants' comments in ways that emphasized some words and meanings over other.

Table 3.

Focus Groups' Most Frequently Occurring Words: 5 or more times (number, and percentage of the specific word's occurrence within the top 160 words)

Personal:

I (77, 9.5%), doctor (37, 4.6%), yes 33 (4.1%), people (20, 2.5%), access, check, history (19, 2.3%), don't, might, record, want (17, 2.1%), curious, know (13, 1.6%), information (12, 1.5%), medication (11, 1.4%), need, right (10, 1.2%), family, insurance, look, stuff (9, 1.1%), blood, disease, go, medical (8, 1%), illness, parents, privacy, thing (7, .9%), allergies, ask, good, keep, maybe, visit (6, .7%), company, file, health, patients, think, type, vaccinations, whether, wouldn't (5, .6%)

Others:

I (106, 13.4%), yes (62, 7.9%), don't (39, 4.9%), access (29, 3.7%), doctor (25, 3.2%), want (23, 2.9%), people (17, 2.2%), know (16, 2%), long (15, 1.9%), care, information (13, 1.6%), look, record (12, 1.5%), think (11, 1.4%), might, wouldn't (9, 1.1%), good, health, need, thing (7, .9%), fine, interested, list, problem, share (6, .8%), asked, authorization, change, company, consent, definitely, insurance, maybe, permission, right (5, .6%)

Advantages and Disadvantages:

record (47, 4.9%), I, easy (42, 4.3%), access (41, 4.2%), people (40, 4.1%), doctor (38, 3.9%), don't (33, 3.4%), paper (27, 2.8%), information (21, 2.2%), computer (20, 2.1%), patient (17, 1.8%), thing (15, 1.6%), go (14, 1.4%), look (12, 1.2%), cost, hacker, health (10, 1%), change, file, know, might, think, wouldn't (9, .9%), ask, Santa Barbara, digital, having (8, .8%), better, good, help, history, lose, medical, problem, transfer (7, .7%), different, emergency, seems, system (6, .6%), advantage, allow, benefit, copy, diagnosis, hard, hospital, long, lot, older, online, outside, privacy, saves, time, want, wrong (5, .5%)

Word Clusters

Aside from reporting on word frequency within the focus group data, a semantic network analysis is used to uncover relationships among data, in this case among those words used most frequently together (here, according to the note taker). Those words occurring most frequently together (within each of the three categories above) are grouped through hierarchical cluster analysis, broken down into smaller clusters according to the strength of their relationship (here, the correlation among each word pair based on their frequency of co-occurrence). Much of a semantic network analysis relies on the subjective decisions of the researchers in determining specific clustering cutoffs and in interpreting the meaning of resulting word clusters.

Semantic network analysis provided insight as to the underlying concerns (represented by the word clusters) most salient among individuals and the information that individuals were interested in accessing through their digital medical records. Words such as ‘I don’t know information’ clustered together, as did words pertaining to the content of the individual’s medical records, including ‘allergies, disease, doctor, insurance, medication, visit, history, family, blood, and medical.’ Also, statements indicating curiosity and interest in viewing the digital medical record may be inferred from the word clusters, along with a concern for privacy rights.

Similarities between the data collected regarding personal and others’ concern include a strong relationship between words indicating that people believed others would want to access or view their individual medical records. Concerns regarding others’ access to medical records also arose, with a specific concern about insurance companies’ access to information and the need to require patients’ consent or authorization for specific purposes, including the alteration of their medical record’s contents. There was a recurrence of words such as permission, authorization, and consent, in reference to patients’ ability to control their personal information and access to that information, further indicating the salience of such concerns. Finally, some word clusters demonstrated that people thought others would find the medical records useful in medical emergencies and in maintaining a list of medications. However, there was also an indication that people were unsure of how others, including doctors and healthy individuals, would use the medical records.

The semantic network analysis also provided insight into those advantages and disadvantages that the focus group participants felt might accompany the implementation of digital medical records both locally and nationally. Among those benefits indicated by word clusters were the individual’s ability to access, look at, and transfer his or her record, the ability to learn history from a ‘better file,’ and easy information access for doctors. Drawbacks to the digital medical records included possible computer problems, the loss of digital data, costs of the system, and finally people were concerned that a strictly local implementation would not be extremely helpful.

Integrated Summary of Stakeholder Interviews and Focus Groups

Study Participants

The participating populations in each data collection were different; the six individuals interviewed were representatives of organizations participating in the Santa Barbara County Care Data Exchange (SBCCDE), and the focus group participants were undergraduate students, graduate students, and employees at the University of California, Santa Barbara. Therefore, it is important to examine the results of the data collections to identify similarities and contrasts between the two groups, most importantly in reference to the Care Data Exchange technology and concerns about privacy.

Expectations about Use

The prospect of digital medical records technology was exciting to both the stakeholders and focus groups, with both groups recognizing the technology’s advantages in comparison to current paper records and the improvements in health care that it made possible. There was some

disagreement among the stakeholders regarding consumer participation in the CDE. Stakeholders were not in complete agreement as to how consumers would participate in or use the CDE, and the non-profit stakeholders felt that their lower income and uninsured clientele would not reap the benefits of the CDE's consumer portal.

The focus group participants, when asked if they would access their digital medical records, were also not in agreement. The majority of participants said that they would, for reasons ranging from curiosity to self-treatment, access their record, but there were both healthy and ill students that stated they would not access their records. Whether or not this reflects the students' youth, in comparison to the graduate and employee groups, it may only be speculated; but it may also highlight a population that would require heavier marketing or intervention to successfully diffuse the CDE's technology.

Meanings of "Privacy"

The stakeholders were in agreement with their definition of privacy, including patient awareness as a requirement in fulfilling their organizations' obligations to its clients' privacy. In more general terms, the stakeholders tended to combine privacy and security, defined as the technological protection of data accomplished through user authorization. Although focus group participants were not asked to define privacy, privacy was identified as a specific concern accompanying the implementation of digital medical records, along with the participants' desire to be informed of and exercise discretion over their medical records' authorized users.

The general sentiment among the stakeholders was that, provided the CDE was in compliance with HIPAA regulations, privacy issues would not be a major problem. On the contrary, the focus group participants, the majority of whom held incorrect perceptions of their patients' rights, overestimated their ability to access and control their medical information, and perhaps subsequently were not completely willing to participate in the CDE.

Awareness of Digital Medical Records and CDE

While the stakeholders discussed patient awareness, the participants felt that, as of the present time, they had not been properly informed of the technology's implementation and would have appreciated communication between the SBCCDE and the community. This sentiment was also echoed by the community representative of the SBCCDE, in mentioning that the community was largely unaware of the CDE's presence in Santa Barbara County, but that community education would ideally play a large role at the time of the technology's implementation.

Development of and Results from Survey

Based upon the results from the stakeholder interviews and the focus groups, and central concepts from the literature review, a pilot survey was developed, tested with a small set of respondents, and revised for the formal survey. The final survey contained the following sections and items.

Measures

Individual Characteristics: Positive Health Status. Survey respondents were asked to rate their health in comparison to the health of other people of the same age and sex on a scale of 1 = very unhealthy to 7 = very healthy. Respondents were also asked to indicate whether or not they had ever had a chronic illness or health problem.

Individual Characteristics: Age. Age was measured by the number of years and months since the respondents' birth. Respondents' year in college was measured as 1=freshman to 4=senior.

Individual Characteristics: Health Insurance Responsibility. Respondents were asked to estimate how much of their annual expenses (tuition, housing, food, travel) they earn or pay for themselves on a scale of 1=none to 5= all, and whether they were responsible for their own health insurance or not.

Individual Characteristics: General Self Efficacy. A 10-item scale from Jerusalem and

Schwarzer (1992) was used to measure general self-efficacy (1=not at all true, 2=hardly true, 3=moderately true, 4=exactly true).

Privacy Attitudes: General Privacy Attitudes. 8 items measured respondents' *General Privacy* attitudes (from 1=very strongly disagree to 7=very strongly agree). The items, which measure the extent of an individual's general support for a right to privacy, were developed based on frequently cited definitions of privacy, including Warren and Brandies (1890), "people should have the right to be left alone," and Westin (1967), "people should have the right to control their personal information."

Privacy Attitudes: Need for Privacy. 19 items from Buss's (2001) *Need for Privacy* Scale measured three components of individuals' need for privacy (from 1=very strongly disagree to 7=very strongly agree). The *self-disclosure* factor consists of items about not divulging information about oneself, such as "it is hard for me to talk about myself." Individuals who score high on these items maintain a sharp psychological boundary between others and themselves. The *concealment* factor includes items about the desire to be free from intrusion and surveillance, such as "I hate being in a room when the people next door can overhear me." People who score high on these items desire a privacy space where they would not be seen or heard. The third factor, *personal space*, measures a person's need for personal space. Scoring high on these items indicates a preference for seclusion.

Privacy Attitudes: Organizational Privacy. Respondents' attitudes toward organizational privacy were measured using 11 items from the 15-item instrument developed by Smith et al. (1996). The instrument uses four subscales to measure individuals' concerns about collection, errors, unauthorized secondary use, and improper access. 3 items measured collection, errors, and unauthorized secondary use, and 2 items measured improper access (1=very strongly disagree to 7=very strongly agree).

Privacy Concerns. 9 items measured general concerns about computer privacy, such as monitoring and hacking (1=not concerned at all to 7=very strongly concerned).

Privacy Attitudes: Perception of Patients' Medical Rights. 12 items measured respondents' perception of patients' medical rights. These items were developed according to those rights discussed by the study's focus group participants in response to the question "What rights do you think you have regarding your medical record?" The items measure the extent to which respondents have a clear understanding of their rights as patients, as the focus group data suggested that most individuals have an incorrect perception of their rights (1=true, 2=false).

Technology Expertise: Internet Use. Respondents were asked to indicate the frequency of their internet use from their home, work, school (excluding the library), library, or other locations, each on a scale of 1 = never to 5= daily. They were also asked to indicate the number of years that they have been using the Internet (including email, web, chat, downloading, etc.)

Technology Expertise: Web Expertise and Fluency. Web fluency was measured using 2 scales, the first comprised of 12 questions taken from the Georgia Tech (1998) web survey that asked whether or not the respondent had performed a variety of activities (such as created a web page). The Georgia Tech survey calculated the total number of activities respondents had completed and grouped respondents according to four levels of expertise: 0-3 activities, novice; 4-6, intermediate; 7-9, experienced; and 10-12, expert.

17 items were taken from the computer-email-web fluency scale developed by Bunz (2004). The CEW fluency scale contains three subscales measuring respondents' technical and applied computer, e-mail, and web skills; the current study used only the web fluency scale. Fluency, as used in the development of the scale and as suggested by the Committee on Information Technology (1999), is defined by three concepts. That is, fluency (1) entails a lifelong learning process, (2) implies personalization of skills on levels of sophistication, and (3) is composed of three kinds of knowledge: contemporary skills, foundational concepts, and

intellectual capabilities.

Innovation Attributes. After the prior demographic and technology expertise sections on the questionnaire, survey respondents were asked to read a brief conceptual description of individual digital medical records, followed by a description of the system being implemented locally by the Santa Barbara County Care Data Exchange. Both descriptions were a paragraph in length and identical to those used in the focus groups. The conceptual description was derived from an article in PC Magazine (September 26, 2001), and the local description from the Care Science, Inc. website (www.Carescience.com). The scales used to measure the five primary innovation attributes identified by Rogers (1983) were developed based on the results of the focus groups conducted with undergraduates, graduate students, and employees at UCSB, as well as Rogers's research. Survey respondents were asked to indicate their agreement with statements on a scale of 1 = very strongly disagree to 7 = very strongly agree.

Relative Advantage. Relative advantage, or "the degree to which an innovation is perceived as better than the idea it supersedes," (Rogers, 1983, p. 15) was defined as the degree to which digital medical records are perceived to be better than paper-based medical records. Focus group participants were asked three questions pertaining to relative advantage: (1) How do you think digital medical records would compare to current paper-based health care records?, (2) What benefits or advantages come with the implementation of (digital medical records) technology?, and (3) In the context of digital medical records' implementation in Santa Barbara County, what risks or disadvantages to the residents of Santa Barbara County face following the implementation of this technology? Participants' responses to these questions were compiled and reviewed for frequency using a semantic network analysis, and those words and responses occurring most frequently were included in the 13 items in which respondents were asked to agree or disagree with statements comparing paper-based and digital medical records.

Compatibility. Compatibility, based on Rogers (1983), was defined as the degree to which digital medical records are perceived as being "consistent with the existing values, past experiences, and needs or potential adopters" (p. 15). The focus group data was reviewed for statements about the values and needs expressed by participants, most of which focused on access, privacy, security, and quality health care. 8 items represented these statements, and survey respondents were asked to agree or disagree with a statement of a value or need.

Complexity. 8 items measured complexity based on Rogers's (1983) definition as the degree to which digital medical records are "perceived as difficult to understand and use" (p. 15). Focus group questions pertaining to participants' concerns and questions, disadvantages of digital medical records, and the likelihood of their own individual use and others' use were reviewed for statements indicating participants' evaluation of the innovation's complexity. Survey respondents were asked to agree or disagree with those statements occurring most frequently among focus group participants.

Trialability. Trialability was measured using 3 items to determine the extent to which respondents desired the ability to experiment with digital medical records. Rogers (1983) defines trialability as "the degree to which an innovation may be experimented with on a limited basis" (p. 16), and the focus group data was reviewed for those statements indicating participants' desires to use the innovation while making modifications or reserving the ability withdraw their participation as well.

Observability. Observability was defined as the "degree to which the results of (digital medical records) are visible" (Rogers, 1983, p. 16). Researchers and the executive director of the SBCCDE identified several ways in which the public might observe or experience the results of digital medical record technology. 7 items were developed to measure observability; 2 statements focused on support for progress with the innovation and 5 items measured respondents' desire to obtain a physical representation of their participation in the new

technology or participate in its development.

Technology Evaluation: Adoption. Successful diffusion of an innovation, as described by Rogers (1983), results in its adoption by a significant amount of its potential audience. To measure survey respondents' likelihood of adoption or rejecting the digital medical records system, the executive director of the SBCCDE identified 9 consumer actions that would indicate adoption of the technology, such as whether respondent would be willing to sign a consent form releasing their information to the SBCCDE digital database (1 = very strongly disagree to 7 = very strongly disagree).

Technology Evaluation: Reinvention. Johnson and Rice (1987) and Rogers (1983) discuss reinvention as an important aspect in the diffusion of an innovation, as users often find or invent new uses for the innovation that were not directly intended by the innovation's creators. When reviewing the focus group data, researchers noticed a wide variety of statements describing previously unanticipated consumer and administrative uses of digital medical records. These statements were compiled along with statements about anticipated uses of the innovation, resulting in 14 items measuring the ways in which participants desired or anticipated they or others might reinvent or use the digital medical records system.

Table Four provides descriptive statistics on individual survey items, scales and subscales, with scale reliabilities.

Table 4.
Descriptive Statistics for Individual Items, Scales and Subscales, with Reliabilities

Demographics	Min	Max	Mean	S. D.	N
Q1 GenderM1F2	1	2	1.8	0.42	411
Q2Y AgeY	17	28	19.5	1.39	411
Q2M AgeM	0	12	5.6	3.30	404
Q2AGEM Age total months Q2Y*12+Q2M	212	337	239.8	16.3	403
Q4 Healthy	1	7	5.1	1.25	408
Q5 ChronicY1N2	1	2	1.8	0.39	408
Q6 AnnualExp	1	5	2.1	0.99	406
Q8 HealthInsY1N2	1	2	1.9	0.27	408
Q7 College1F4S	1	4	2.0	0.84	403
Q3 UseInternetYrs	2	15	7.3	1.91	403
Web Expertise (Georgia Tech, 1998)					
Q9A IntAct online order	0	1	0.9	0.34	413
Q9B IntAct order >\$100	0	1	0.6	0.49	413
Q9C IntAct create page	0	1	0.3	0.46	413
Q9D IntAct custom page	0	1	0.7	0.48	413
Q9E IntAct change browser homepage	0	1	0.8	0.43	413
Q9F IntAct change cookie pref	0	1	0.4	0.50	413
Q9G IntAct online chat/discussion	0	1	0.9	0.35	413
Q9H IntAct listen online radio	0	1	0.6	0.50	413
Q9I IntAct online phone call	0	1	0.2	0.37	413
Q9J IntAct online directory add/phone	0	1	0.6	0.50	413
Q9K IntAct class about Internet/web	0	1	0.2	0.35	413
Q9L IntAct bought book about Internet/web	0	1	0.1	0.28	413
Webexp (simple sum of the 12 items)	0	12	5.99	2.26	413
Webexpgt (grouped according to GT four levels of expertise: 0-3 activities, novice; 4-6, intermediate; 7-9, experienced; and 10-12, expert)	1	4	2.34	.79	413
Computer Use Location					
Q10A WebLoc live	1	5	4.9	0.45	410
Q10B WebLoc work	1	5	1.8	1.43	394
Q10C WebLoc school/notlibrary	1	5	2.2	1.27	413
Q10D WebLoc library	1	5	2.5	1.13	411
Q10E WebLoc other	1	5	2.4	1.05	407
Web Fluency (Bunz, 2001)					
Q12A ActDif using browser navigate	3	7	6.8	0.67	407
Q12B ActDif typing web address directly	3	7	6.8	0.54	407
Q12C ActDif identify host server from addr	1	7	5.4	1.56	348
Q12D ActDif use hypertext links	1	7	5.9	1.53	355
Q12E ActDif using back & forward in browser	4	7	6.9	0.42	408
Q12F ActDif add bookmarks in browser	1	7	6.4	1.24	401
Q12G ActDif editing bookmarks	1	7	5.9	1.60	389

Q12H ActDif using search engines	3	7	6.9	0.50	408
Q12I ActDif using advanced search techniques	1	7	6.0	1.27	394
Q12J ActDif save text of web pages to disk	1	7	5.4	1.76	397
Q12K ActDif save images web pages to disk	1	7	5.6	1.73	397
Q12L ActDif turn on/off auto load images	1	7	4.9	1.84	333
Q12M ActDif use dial-in account to log on	1	7	5.5	1.70	376
Q12N ActDif create website visual editor	1	7	3.3	1.90	354
Q12O ActDif use Internet email	1	7	6.8	0.82	405
Q12P ActDif set browser accept/reject cookies	1	7	4.5	2.02	349
Q12Q create website using html	1	7	3.0	1.79	357
Webflu Q12A-Q a=.88	2.9	7.0	5.7	.82	409
Wbasic Q12BEHO 4.4 36.7% a=.74	3.75	7.0	6.83	.45	409
Wmanip Q12FGJK 2.1 17.4% a=.85	1.25	7.0	5.82	1.32	408
Wconnect Q12CMNQ 1.1 9.1% a=.69	1.0	7.0	4.31	1.34	400
General self-efficacy (Jersualem & Schwarzer, 1992)					
Q11A Eff solve problems	2	4	3.3	0.51	408
Q11B Eff get what want	2	4	2.9	0.55	409
Q11C Eff stick to aims goals	1	4	3.1	0.62	407
Q11D Eff confident unexpected events	1	4	3.2	0.56	405
Q11E Eff resourceful unforeseen situations	1	4	3.1	0.62	409
Q11F Eff solve problems necessary effort	1	4	3.4	0.58	409
Q11G Eff calm problem coping abilities	1	4	3.0	0.68	408
Q11H Eff find several solutions	1	4	3.0	0.63	409
Q11I Eff in trouble think of solution	2	4	3.2	0.56	408
Q11J Eff usually handle whatever	2	4	3.2	0.55	406
Efficacy Q11A-Q11J 4.5 44.7% a=.86	2.1	4.0	3.16	.39	409
Need for Privacy (Buss, 2001)					
Q13A PPriv hard talk about myself	1	7	3.3	1.77	412
Q13B PPriv prefer others know little about me	1	7	3.4	1.55	413
Q13C PPriv never show diary to others	1	7	5.1	1.79	412
Q13D PPriv tell acq things about me (need r)	1	7	4.4	1.56	405
Q13DR	1	7	3.6	1.6	411
Q13E PPriv many things not talk about w/others	1	7	4.2	1.66	411
Q13F PPriv not talk personal unless others first	1	7	3.8	1.46	411
Q13G PPriv at home keep window shades closed	1	7	2.8	1.80	410
Q13H PPriv uncomfortable public restrooms	1	7	3.1	1.77	411
Q13I PPriv prefer car tinted windows	1	7	2.9	1.67	412
Q13J PPriv hate when people next door can hear	1	7	4.0	1.73	413
Q13K PPriv object bystander listening when telephone	1	7	4.2	1.68	413
Q13L PPriv don't like getting undressed locker room	1	7	3.6	1.69	413
Q13M PPriv rather study alone	1	7	4.4	1.76	411
Q13N PPriv difficult concentrate when others around	1	7	4.4	1.54	408
Q13O PPriv need lots room/space around me	1	7	4.3	1.53	413

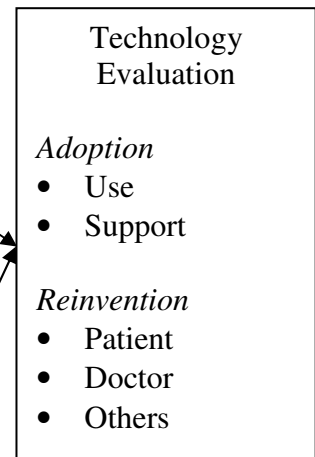
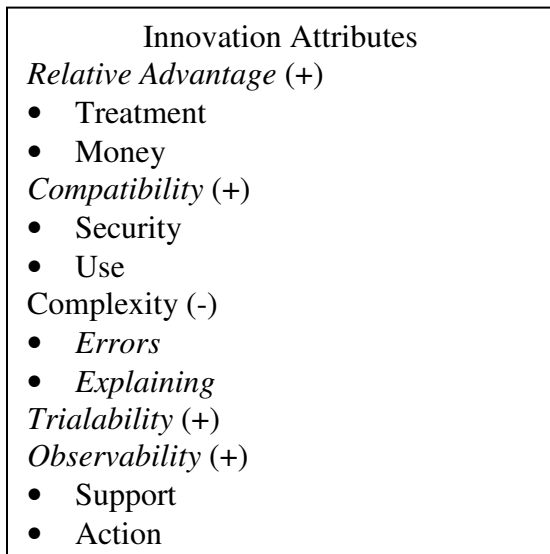
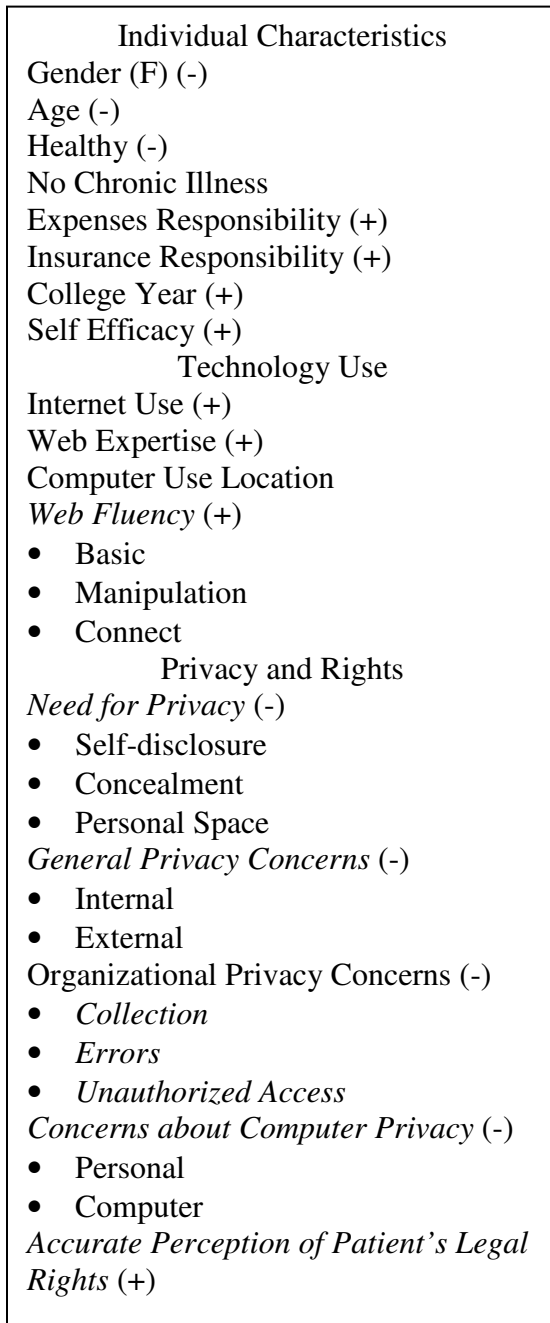
Q13P PPriv easier do many things if tune others out	1	7	4.6	1.42	412
Q13Q PPriv unwind -- get away from everybody	1	7	3.8	1.74	411
Q13R PPriv need time away from others	1	7	4.7	1.66	412
Q13S PPriv working studying need elbow room	1	7	5.1	1.51	412
PPall Q13A-S a=.81	1.6	6.8	4.0	.78	413
Self-disclosure: PPself Q13ABCEF 4.6 18.6% a=.56	1.0	7.0	3.96	1.04	413
Concealment: PPconcel Q13B-L 1.9 14.2%,a=.71	1.0	6.83	3.46	1.10	413
Personal space: PPperson Q13M-S 1.5 11.5% a=.80	1.0	7.0	4.47	1.07	413
General Privacy: individual's general support for a right to privacy. Based on definitions of privacy, including Warren & Brandies (1890), "people should have the right to be left alone," and Westin (1967), "people should have the right to control their personal information."					
Q14A GPriv people right to be left alone	1	7	6.3	1.00	411
Q14B GPriv people able use Internet anonymously	1	7	5.6	1.44	412
Q14C GPriv no gather disclose personal info w/out consent	2	7	6.5	1.00	412
Q14D GPriv people right control their personal info	2	7	6.5	0.90	412
Q14E GPriv govt never tap private lives w/out courts	1	7	5.9	1.39	410
Q14F GPriv businesses allowed personal info w/out consent	1	7	2.6	1.72	412
Q14FR	1	7	5.4	1.7	412
Q14G GPriv Internet cos track online activities w/out consent	1	7	2.1	1.38	412
Q14GR	1	7	5.9	1.4	412
Q14H GPriv govt able secretly monitor online activities natl sec	1	7	3.3	1.87	411
Q14HR	1	7	4.7	1.9	411
GPall Q14A-H a=.66	3.5	7.	5.8	.75	412
Internal: GPint Q14ABCD 2.3 33.5% a=.65	2.25	7	6.2	.77	410
External: GPext Q14FRGR 1.5 23.3% a=.67	1	7	5.7	1.4	410
Organizational Privacy (Smith et al., 1996)					
Q15A OPriv bother me cos ask for personal info	1	7	4.8	1.46	412
Q15B OPriv personal info database should be double-checked	1	7	4.3	1.32	411
Q15C OPriv cos not use personal info w/out authorization by ind	1	7	6.0	1.20	411
Q15D OPriv cos devote more time prevent unauthorized access	1	7	5.7	1.17	410
Q15E OPriv cos ask personal info think twice before providing	1	7	5.8	1.28	411
Q15F OPriv cos never use info for other reason	1	7	6.2	1.12	411
Q15G OPriv cos better procedures correct errors personal info	1	7	5.3	1.26	409
Q15H OPriv co databases protected from unauthorized access	2	7	5.8	1.18	410
Q15I OPriv cos never sell personal info in databases to other cos	1	7	6.4	1.08	410
Q15J OPriv cos devote mote time verify accuracy personal info	1	7	5.2	1.32	411
Q15K OPriv concerned cos collect too much personal info me	1	7	4.7	1.49	412
Opall Q15A-K a=.85	2.6	7	5.5	.79	412
Collection OPcoll Q15AEK 4.5 40.9% a=.67	2	7	5.1	1.1	412
Personal OPerr Q15BGJ 1.3 12.2% a=.74	1	7	4.9	1.0	412
Unauthorized Access OPunauth Q15CDFHI 1.2 10.5% a=.82	2.2	7	6.0	.87	412
Concerns about Computer Privacy (citations..Pew...Mike?)					
Q16A PCon hackers credit card number online	1	7	5.3	1.53	411
Q16B PCon computer virus attack	1	7	5.8	1.40	408

Q16C PCon email read by someone other than recipient	1	7	4.1	1.78	411
Q16D PCon other learning your personal info from online activities	1	7	4.6	1.73	412
Q16E PCon ISPs selling your personal info	1	7	4.7	1.79	412
Q16F PCon spam/junk emails	1	7	4.8	1.72	411
Q16G PCon ISPs monitoring emails other online activities	1	7	4.5	1.71	411
Q16H PCon employer/university monitoring emails other online act	1	7	4.6	1.86	409
Q16I PCon govt monitoring emails other online activities	1	7	4.4	1.95	411
GCcall Q16A-I a=.88	1.7	7	4.7	1.2	412
Personal GCpers Q16DEGHI 4.05 57.9% a=.89	1	7	4.6	1.5	412
Computer GCcomp Q16AB 1.06 15.1% a=.67	1	7	5.6	1.3	412
Accurate Perception of Patient's Legal Rights					
Q17A MR I obtain copy medical record T	1	2	1.1	0.22	410
Q17B MR I view medical record T	1	2	1.0	0.15	412
Q17C MR I change content medical record F	1	2	1.9	0.34	409
Q17CR	1	2	1.1	.3	409
Q17D MR I be informed med info used other purpose F	1	2	1.1	0.26	411
Q17DR	1	2	1.9	.3	411
Q17E MR physician share info med treatment w/o consent T	1	2	1.8	0.40	410
Q17F MR healthcare provider share info med treatment w/o consent T	1	2	1.7	0.47	412
Q17G MR physician share info med surgery w/o consent T	1	2	1.7	0.44	412
Q17H MR I can request med record sent to ind/inst my choice T	1	2	1.1	0.27	412
Q17I MR healthcare provider responsible safeguarding my health info T	1	2	1.2	0.38	409
Q17J MR parents right view their children's med records F	1	2	1.1	0.32	412
Q17JR	1	2	1.9	.3	412
Q17K MR adult children right view their parents' med records F	1	2	1.8	0.42	409
Q17KR	1	2	1.2	.4	409
Q17L MR ins cos right access my med records T	1	2	1.4	0.49	411
Sum of Correct Mrights Q17A-L #correct	0	11	6.8	1.4	413
Innovation Attribute: Relative Advantage					
Q18A IN accessible to patient	1	7	5.7	1.28	410
Q18B IN more secure	1	7	3.3	1.63	412
Q18C IN help doctors make better medical diagnoses	1	7	5.0	1.44	412
Q18D IN better in emergency situation	1	7	6.0	1.20	413
Q18E IN better treatment if needed while travelling	1	7	5.9	1.08	411
Q18F IN more convenient for doctors	1	7	6.0	1.14	412
Q18G IN patients more prescription-related info	1	7	5.0	1.33	412
Q18H IN easier transfer info between physicians clinics	1	7	6.1	1.03	413
Q18I IN easier change doctors	1	7	5.8	1.21	412
Q18J IN save you money	1	7	4.3	1.37	413
Q18K IN save your doctor money	1	7	4.5	1.37	412
Q18L IN save your hospital money	1	7	4.6	1.35	413
Q18M IN save your ins co money	1	7	4.5	1.32	411
IRall Q18A-M a=.88	1.7	7	5.1	.84	413

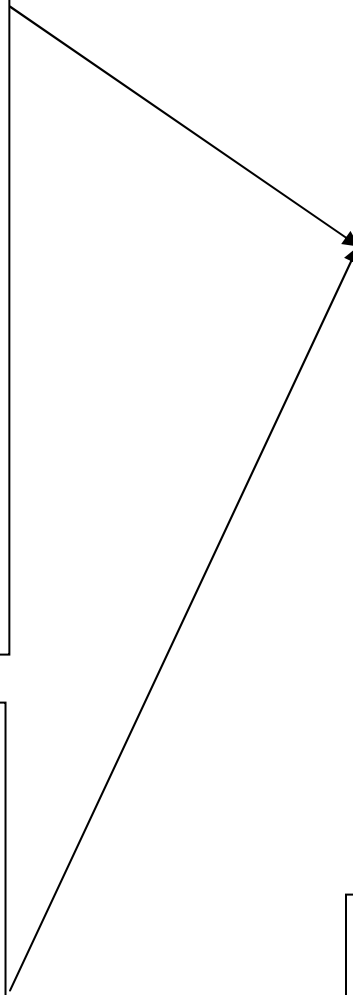
Relative Advantage – Treatment IR _{treat} Q18CDEFHI 4.99 49.9% a=.81	1	7	5.8	.91	411
Relative Advantage – Money IR _{money} Q18JKLM 2.06 20.6% a=.93	1	7	4.5	1.2	411
Innovation Attribute: Compatibility					
Q19A EXP allow me access my medical record	1	7	5.6	1.21	413
Q19B EXP confidentiality maintained by authorized third parties	1	7	4.0	1.52	409
Q19C EXP my digital med record remain private	1	7	3.6	1.60	411
Q19D EXP my digital med record info would be secure	1	7	3.6	1.56	410
Q19E EXP my digital med record improved health care for me	1	7	4.8	1.30	413
Q19F EXP my dig med record convenient source those who need it	1	7	5.3	1.24	413
Q19G EXP info my dig med record would be accurate	1	7	4.8	1.27	412
Q19H EXP patient decide who has authority view their med record info	1	7	5.9	1.31	412
IC _{all} Q19A-H a=.78	1.4	7	4.7	.86	413
Secure IC _{secur} Q19CB 2.8 40.6% a=.92	1	7	3.6	1.5	413
Use IC _{use} Q19AFGH 1.5 22.0% a=.62	1.25	7	5.4	.87	413
Innovation Attribute: Complexity					
Q20A CMP extensive training needed	1	7	4.5	1.40	410
Q20B CMP dig med records tech susceptible human error	1	7	5.6	1.13	411
Q20C CMP dig med records tech susceptible computer error	1	7	5.6	1.16	409
Q20D CMP I could explain dig med records tech to friend	1	7	4.6	1.40	411
Q20DR	1	7	3.4	1.4	411
Q20E CMP Dig med records tech seems straightforward	1	7	4.8	1.29	406
Q20ER	1	7	3.2	1.3	406
Q20F CMP Easy confuse patients medical records digital system (need r)	1	7	4.3	1.42	407
Q20G CMP I have many questions about the technology	1	7	4.8	1.52	408
Q20H CMP Entering data system will be difficult	1	7	3.9	1.36	408
IC _{Xall} a=.69	2.1	6.5	4.4	.75	411
Complexity – Errors IC _{Xerror} Q20BC 2.3 32.9% a=.86	1	7	5.6	1.1	411
Complexity – Explaining IC _{Xexpl} Q20DRER 1.8 25.3% a=.82	1	7	3.3	1.3	411
Innovation Attribute: Trialability					
Q21A LIKE to limit number authorized access med record	1	7	5.3	1.39	409
Q21B LIKE decide who family friends authorized access	1	7	6.0	1.28	409
Q21C LIKE option remove med record from systems in future	1	7	6.0	1.32	408
Trialability IT _{trial} Q21ABC 2.1 68.9% a=.77	1	7	5.8	1.1	408
Innovation Attribute: Observability					
Q22A PUB good move forward dig med rec tech	1	7	5.0	1.34	406
Q22B PUB exciting SB part national plan	1	7	4.9	1.33	405
Q22C PUB see list those authorized to view info in my med record	1	7	5.8	1.34	409
Q22D PUB wallet card indicating my agreement	1	7	5.0	1.56	408
Q22E PUB key chain containing computer chip med record	1	7	3.3	1.91	405
Q22F PUB more press coverage implementation in SB County	1	7	4.9	1.40	409
Q22G PUB participate community forum dig med records	1	7	3.4	1.46	407
IO _{all} a=.64	1.9	7	4.6	.85	409
Observability - Support IO _{supp} Q22AB 1.9 47.0% a=.87	1	7	5.0	1.3	409

Observability - Action IOAct Q22CD 1.3 31.7% a=.55	1	7	5.4	1.2	409
Adoption/Rejection					
Q23A BEH sign consent form included SBCCDE dig database	1	7	4.5	1.63	412
Q23B BEH access my dig med record given opportunity	1	7	5.4	1.33	411
Q23C BEH use info dig med record improve my health	1	7	4.9	1.44	409
Q23D BEH attend session doctor learn how use dig med record	1	7	4.7	1.59	410
Q23E BEH advise my family use their dig med record	1	7	4.5	1.46	410
Q23F BEH pay small fee use dig med records health care facility	1	7	3.3	1.55	412
Q23G BEH participate consumer oversight committee advise recommend	1	7	3.2	1.49	411
Q23H BEH sign petition support local funds support SBCCDE system	1	7	3.9	1.48	410
Q23I BEH sign form letter to physician requesting support SBCCDE	1	7	3.5	1.56	411
IAall a=.88	1	7	4.2	1.1	412
Adoption - Use IAUse Q23ABC 3.7 52.7% a=.81	1	7	5.0	1.3	405
Adoption – Support IASupp Q23FGHI 1.2 17.8% a=.82	1	7	3.5	1.2	405
Reinvention					
Q24A RE adults caring parents access parents records	1	7	5.2	1.20	412
Q24B RE medical community use records medical research	1	7	5.1	1.36	413
Q24C RE spouses use access partners record	1	7	4.7	1.41	413
Q24D RE people learn more about doctor	1	7	4.3	1.65	410
Q24E RE people see doctor updated their info after appt	1	7	5.3	1.27	411
Q24F RE people check doctor accessed record prior to appt	1	7	5.2	1.24	412
Q24G RE people learn personal medical history	1	7	5.7	1.15	411
Q24H RE people learn family medical history	1	7	5.5	1.26	413
Q24I RE people learn blood type	1	7	5.7	1.21	413
Q24J RE people look up prescriptions test results vaccination results	1	7	5.9	1.05	412
Q24K RE people verify medical info	1	7	5.9	1.11	413
Q24L RE people access childrens records	1	7	5.8	1.28	411
Q24M RE people help insurance processes	1	7	5.3	1.33	410
Q24N RE people diagnose and treat self	1	7	4.3	1.73	411
IREall a=.89	1.3	7	5.3	.84	413
Reinvention – Patients IREpat Q24GHIJKL 3.0 35.2% a=.91	1	7	5.7	1.0	412
Reinvention – Doctors IREdoc Q24EF 2.1 18.9% a=.86	1	7	5.3	1.2	412
Reinvention – Others IREoth Q24ABC 2.0 17.8% a=.70	1	7	5.0	1.05	412

Figure 1 summarizes the hypothesized relationships between the explanatory overall scales and subscales, and the outcome measures of adoption and reinvention.



Note: bulleted concepts are subscales of the primary concepts; italicized concepts are the scales or subscales used in the final regression analyses



Descriptive Results

Individual Characteristics: Demographics, Health, Self-Efficacy

The sample, composed of undergraduate students taking introductory communication courses at the University of California Santa Barbara, was 76.8% female and 22.8% male (these proportions are representative of communication students at UCSB). 29.8% of respondents were freshmen, 37.8% were sophomores, 26.9% were juniors, and 3.1% were seniors. The majority of the respondents described their health as at least average, with no more than 8.5% reporting to be below average, and 67.8% as above average. Only 17.9% of respondents had ever had a chronic illness. A small 7.7% of respondents were personally responsible for their own health insurance, and the remainder received health insurance through their parents or a third party. Similarly only 3.1% of respondents reported being responsible for all of their annual personal expenses, whereas 78.5% of respondents reported only being responsible for some or none of their expenses.

Self efficacy was measured using a 10 item scale (Cronbach's alpha= .86). On a scale of 1 to 4, with 4 indicating the highest level of self efficacy, respondents averaged 3.2, indicating a fairly high level of self efficacy within the sample. Respondents were most confident that "I can solve most problems if I invest the necessary effort," and least confident that "If someone opposes me, I can find the means and ways to get what I want."

Technology Expertise: Internet Use, Web Expertise, Computer Use Location, Web Fluency

Regarding *internet use*, respondents averaged 7.3 years internet experience, with the most experienced respondent reporting 15 years of use. Respondents were assigned a *web expertise* 'score' consisting of the sum up to 12 Internet tasks they had completed. On average, respondents had completed 6 tasks, with the least completed task being "Bought a book to learn more about the Web or Internet" and the most completed task being "Ordered a product/service by filling out an online form." Georgia Tech (1998) characterizes respondents having completed 4-6 tasks at the level of "intermediate expertise", and 7-9 tasks as "experienced".

Respondents were asked how frequently they used the internet from 5 different *locations*. By far the most popular place of use was respondents' homes, followed, respectively, by the library, school, other places, and work.

Web fluency was measured using a 17 item scale (Cronbach's alpha= .88). Respondents indicated how difficult various web-related tasks were (1=very difficult, 7=very easy), and on average respondents reported a score of 5.7, indicating that most people were at least comfortable in completing the majority of the described tasks. Respondents were most comfortable with such basic web skills as "Using search engines such as Google or Yahoo," "Using Internet email such as Yahoo, Hotmail, etc.," and "Using "back" and "forward" in your browser to return to pages." The tasks respondents were least comfortable with included "Creating a website using a visual editor," and "Creating a website using HTML."

Privacy and Rights: Need for Privacy, General Privacy Concerns, Organizational Privacy, Concerns about Computer Privacy, Accurate Perception of Legal Medical Rights

Respondents did not have a great *need for privacy*, averaging 4 on a scale of 1 to 7 (7 indicating greatest concern), although the area they were most concerned with was personal space. Respondents expressed greatest concern on the items "If I kept a diary, I would never show it to anyone," and "When working or studying, I need lots of elbow room." On the contrary, respondents were least concerned with issues of concealment, such as needing to tint car windows or keep shades closed while in their homes.

General privacy concerns had a mean of 5.8 (on a scale of 1 to 7, where 7 indicated the greatest concern) suggesting a fairly high level of concern. Respondents were in greatest agreement with the statement "No one should be able to gather or disclose my personal information without my consent." On the contrary, respondents were least in agreement with the

statement, “The government should be able to secretly monitor individuals’ online activities for national security.”

The mean of respondents’ *organizational privacy concerns* was 5.5, indicating a medium level of concern for organizational privacy, with greatest concern over unauthorized access. For example, respondents most strongly agreed with the statements “Companies should never sell the personal information in their computer databases to other companies. Following unauthorized access, respondents were also concerned with the collection of personal information and errors, respectively.

Overall, respondents’ concerns about *computer privacy* were not as great as their general or organizational privacy concerns, with a mean of 4.7, slightly above ‘somewhat concerned.’ Respondents were most concerned with “getting a computer virus attack” and least concerned with “your email will be read by someone besides the person you sent it to.”

The sum of respondents’ correct answers to 12 statements was used as a measure of their knowledge of *patients’ legal rights*. On average, respondents answered only 6.8 correctly, indicating that the majority of respondents did not accurately perceive their legal patients’ rights. The items respondents scored poorly on concerned physicians’ and healthcare providers’ ability to share medical information without consent, demonstrating that respondents believed they had greater control over their medical information than is actually true.

Innovation Attributes: Relative Advantage, Compatibility, Complexity, Trialability, Observability

The *relative advantage* of digital medical records (compared to paper medical records) had a mean of 5.1 (on a scale of 1 to 7, where 7 indicated the strongest level of agreement), somewhat favorable. Respondents felt that digital medical records’ most advantageous characteristics were the records’ availability in an emergency situation and the added convenience for doctors, both important aspects of treatment. The only statement which received, on average, below a neutral level of agreement was regarding digital medical records’ ability to save people money in comparison to paper records.

Compatibility had a mean of 4.7 on the 7 item scale, indicating that respondents at least somewhat agreed with the majority of statements. The statement receiving the highest scores was “The individual patient should decide who has the authority to view the information in his or her medical record,” while the lowest level of agreement was in response to the statement “My digital medical record would remain private.” The responses to these items indicate that respondents found digital medical records to be most compatible with their idea of use, and less compatible with their idea of security.

The *complexity* of digital medical records was perceived to be most complex in terms of their susceptibility to both human and computer error. Respondents seemed to feel slightly more comfortable in their ability to understand explain the technology.

Respondents tended to agree with statements indicating digital medical records’ *trialability*, averaging 5.8 on the 7 point scale. Respondents most agreed they would like the option to remove their medical record from the system in the future.

The mean *observability* was 4.6 on the 7 point scale, indicating basic recognition of digital medical records’ observability. Respondents agreed most strongly with statements of action, such as viewing a list of those authorized to view their medical record, and less strongly with statements of support, such as their willingness to participate in a community forum on digital medical records.

Technology Evaluation: Adoption and Reinvention

On average, respondents agreed with statements of *adoption* with a score of 4.2, only slightly above neutral. However, respondents agreed with statements concerning actual use of the system with a slightly higher score of 5.0. The statement with the highest level of agreement was

“I would access my digital medical record if given the opportunity,” and the lowest level of agreement was “I would participate in a consumer oversight committee to advise health administrators about recommendations for the SBCCDE.” Similar to the results for observability, respondents again indicated that they were more likely to use the system than to engage in activities to demonstrate their support for the system.

On average respondents scored 5.3 (1 to 7) on the *reinvention* scale, a moderate level of agreement with the statements describing various uses of digital medical records technology. Respondents were most likely to agree with instances concerning patient reinvention (for example, that they would use their medical records to learn their medical history) but with slightly less frequency about doctors’ and others’ uses of digital medical records, respectively.

Bivariate Results

A bivariate analysis was conducted to determine which variables significantly correlated with the adoption and reinvention outcome measures. The overall model proposed directional predictions regarding the influence of individual characteristics and innovation attributes on an individual’s likelihood to adopt, and reinvent, digital medical records technology. The bivariate analysis provided support for several of those predictions. Table 5 presents correlations between the variables – separate personal characteristics, and scales and subscales of technology experience and use, privacy and medical rights, and innovation attributes -- and the two outcome measures. The following sections summarize those measures/scales correlated at least $p < .05$ (one-tailed, as the predictions were directional) with adoption and with reinvention.

Personal Characteristics

Adoption of digital medical records technology was correlated with the percentage of annual expenses individuals were responsible for, responsibility for health insurance, and self efficacy. Reinvention was also correlated with the percentage of annual expenses individuals were responsible for.

Internet Experience and Expertise

Adoption and reinvention were both correlated with *Web expertise* and *Web fluency*.

Privacy Concerns and Medical Rights

Respondents who expressed lower levels of *concerns about computer privacy* and a more accurate knowledge of patients’ *medical rights* were more likely to adopt digital medical records technology. Privacy concerns, specifically *general privacy concerns*, *organizational privacy concerns*, and *concerns about computer privacy* were all significantly correlated with reinvention.

Innovation Attributes

Four of the five innovation attributes were correlated with adoption: relative advantage, compatibility, complexity, and observability. Four of the five innovation attributes (with one different attribute) also correlated with reinvention: relative advantage, compatibility, trialability, and observability.

Table 5.

Correlations of Items, Scales and Subscales (Personal Characteristics, Internet Experience and Usage, Privacy Concerns and Medical Rights, and Innovation Attributes, with Adoption and Reinvention

	IAall Q23A-I a=.88 Adoption	IREall Q24A-N a=.89 Reinvention
<i>Personal Characteristics</i>		
Q1 GenderM1F2	-.08	-.05
Q2AGEM Age total months Q2Y*12+Q2M	.01	.00
Q4 Healthy	-.056	.02
Q5 ChronicY1N2	.00	-.03
Q6 AnnualExp	.10*	.11*
Q7 College1F4S	-.00	.01
Q8 HealthInsY1N2	-.11*	.01
Efficacy Q11A-Q11J 44.7% a=.86	.06	.17**
<i>Internet Experience and Expertise</i>		
Internet Use	.04	-.02
Webexp sumQ9A-Q9L 0N1Y	.09*	.13**
Web Fluency	.18**	.19**
<i>Privacy Concerns and Medical Rights</i>		
PPall Q13A-S a=.81	-.02	-.02
GPall Q14a-H a=.66	-.01	.16**
OPall Q15A-K a=.85	.06	.22**
GCall a=.88	.14**	.16**
Mrights Q17A-L #correct	.08*	.04
<i>Innovation Attributes</i>		
IRall a=.88	.47**	.41**
ICall Q19A-H a=.78	.49**	.32**
ICXall Q20A-H a=.69	-.19**	-.01
ITrial Q21ABC 2.1 68.9% a=.77	-.07	.22**
IOall Q20A-G a=.64	.54**	.47**

* p<.05 level; ** p<.01 level (1-tailed).

N = 402 – 413

Multivariate Results

Multivariate analyses were conducted for the two outcomes of adoption and reinvention. Multiple regressions were run to identify unique variance explained by the explanatory variables, because of possible inter-correlations among those variables. All of the scales, subscales, and individual measures with significant bivariate correlations were first included in an overall regression, stepwise within blocks of personal, Internet experience and expertise, privacy concerns and medical rights, and innovation attributes. Table 6 reports the significant beta coefficients and overall results.

Those variables found to be most significant support the directional predictions proposed in the overall model regarding the influence of individual characteristics and innovation attributes on an individual's likelihood to adopt and reinvent digital medical records technology. The following sections summarize those scales or subscales with beta coefficients at least $p < .05$ (one-tailed, as the predictions were directional) with adoption, and with reinvention. About 40% of the variance in adoption of the SBCCDE system was explained, and about a third of the variance in reinvention of the SBCCDE was explained.

Personal Characteristics

Adoption of digital medical records technology was significantly influenced by the percentage of annual expenses that respondents were responsible for. Similarly, annual expenses remained a significant influence in both regressions for reinvention.

Internet Experience and Expertise

None of the variables were significant influences on adoption or reinvention.

Privacy Concerns and Medical Rights

The *collection* subscale of organizational privacy concerns and concerns about computer privacy were significant influences on adoption. The *unauthorized access* subscale of organizational privacy was a significant influence on reinvention.

Innovation Attributes

Observability, *compatibility*, *trialability*, and the *explanation* subscale of *complexity* were significant influences on adoption. *Relative advantage*, *observability*, and the *explanation* and *error* subscales of *complexity* were significant influences on reinvention.

Table 6.
Final Summary Multiple Regressions Explaining Adoption and Reinvention

	Adoption	Reinvention
<i>Personal Characteristics</i>		
Annual Expenses	.08 *	.10 **
<i>Privacy Concerns and Medical Rights</i>		
Organizational Privacy – Collection	-.12**	
Organizational Privacy – Unauthorized Access		.12 **
General Computer Concern	.10 *	
<i>Innovation Attributes</i>		
Relative Advantage		.17 ***
Observability	.44 ***	.32 ***
Compatibility	.25 ***	
Trialability	-.13 ***	
Complexity - Explanation	-.12 **	-.16 ***
Complexity – Error		.15 ***
Adjusted R2	.41	.33
F-ratio	40.5 ***	32.8 ***
N	393	394

* = p<.05; ** p<.01; *** p<.001

Discussion of Survey Results

Personal Characteristics

The percentage of *annual expenses* that individuals were responsible for was the most significant factor related to both adoption and reinvention of digital medical records technology. Other demographic characteristics, such as age and health status, did not significantly influence the respondents' likelihood to either adopt or reinvent the technology. In the case of adoption, responsibility for *health insurance* and *self efficacy* were also related to adoption, though their influence was not as prominent as annual expenses. The strong relationship between annual expenses and adoption may imply that those individuals with a heightened awareness of their financial obligations, such as health insurance, may be more likely to see benefits in digital medical records technology, and subsequently adopt the technology. Similarly, those more financially responsible respondents may also possess greater self efficacy as a result of their ability to maintain a sustainable income, and consequently may feel more confident in their personal ability to understand and use their individual digital medical records. Therefore, when introducing digital medical records technology to the public, it may prove useful to establish divisions among the community according to financial stability and independence, and develop programs to foster understanding of the new technology according to each group's specific needs. For example, the group that is more financially responsible, such as parents, may have a heightened awareness of the financial aspects of the technology, along with a curiosity about how health insurance companies will interact, if at all, with the new technology. In comparison, college students, a group that is largely not financially independent, might be more interested in learning about the technological aspects of the technology and how it will affect their personal privacy. Materials presenting and emphasizing different aspects of digital medical records should be developed in anticipation of a diverse consumer population.

Internet Experience and Expertise

Respondents who scored higher on measures of *web expertise* and *web fluency* were more supportive of digital medical records technology and their own ability to successfully use the application. While the current study's sample of respondents averaged 7.3 years of internet use, such a familiarity with the internet may not be the case in populations significantly different from a college educated community. For example, as focus group participants and SBCCDE stakeholders voiced, those community members who are not computer literate will not be able to take advantage of this new technology, and, as the survey results demonstrate, may be less likely to adopt digital medical records. To combat such a large obstacle as a deficit in computer skills among different segments of the population, whether they are senior citizens, minorities, or low-income families, regional health infrastructure organizations (RHIOs), such as the SBCCDE, may consider outreach programs to introduce people to the Internet and its proper use. Also, as many RHIOs are concerned with establishing stable funding for their projects, continued community outreach, in terms of education programs introducing increasingly sophisticated technology into the community, may further their ability to obtain grants, federal funding, and overall public support.

Disparities in computer skills should also be taken into consideration when developing materials or publications explaining digital medical records technology and the SBCCDE. Those consumer populations that have less computer or web skills will not benefit from discussion of peer to peer technology or firewalls; on the contrary, they are likely to be confused and turned off to the new technology. In comparison, discussing such technological issues with a group of knowledgeable computer technicians may solidify their belief that digital medical records are in fact secure and that precautions have been taken to ensure their personal privacy. Those groups whose fall toward the middle of the technologically savvy spectrum may benefit from a simple explanation of the technology that utilizes analogies of web terms and functions they are more

likely to be acquainted with.

Privacy Concerns and Medical Rights

Respondents with a more accurate perception of patients' *medical rights* were more likely to adopt digital medical records technology. Respondents averaged only 6.8 of 12 correct responses to statements regarding various patients' rights, demonstrating that the sample was largely misinformed about their medical rights. This may well be true of most population segments, so any implementation of digital medical records needs to take into account that consumers' concerns about their medical rights concerning new technologies may be falsely affected due to their inaccurate assumptions about traditional medical rights. As the current study showed an inaccurate perception of patients' rights to be related to the rejection of digital medical records, the SBCCDE should consider taking steps toward educating their potential consumers regarding their current medical rights as mandated under HIPAA, and the manner in which digital medical records technology strictly complies with those rights. It is likely that an inaccurate perception of medical rights, combined with the introduction of a new technology, may produce a heightened misunderstanding among patients; if a patient assumes that she has a right, which in fact she does not, that digital medical records appear to infringe on, the likelihood that she will be willing to adopt digital medical records may be significantly reduced. Therefore, informing consumers of their actual medical rights, before introducing digital medical records technology, would most likely be a useful strategy in encouraging consumer adoption. Such a strategy might be implemented by developing informative pamphlets, presentations, or videos for patients, constructed in a patient-friendly format that avoids legal and medical jargon. Also, as doctors are often seen as credible authority figures, it may be helpful to have doctors discuss medical rights with their patients, both individually in their medical offices and publicly in community forums, to reinforce the information and clarify any questions the patients may have. Finally, Santa Barbara County, as much of California, has a large Latino population, and it would be wise to have any patient education materials available in both English and Spanish.

Concerns about computer privacy and the *collection* aspect of organizational privacy concerns were also related to the adoption of digital medical records. Respondents with lower levels of privacy concerns were more likely to adopt the technology. Similarly, *general privacy concerns*, *concerns about computer privacy*, and the *unauthorized access* aspect of organizational privacy were related to reinvention. Such a significant presence of organizational privacy concerns in relation to both outcome measures points to the value of future efforts to establish stronger patient-organization relationships, whether it be through the organizations' outreach into the community through education programs, or various other means that simply increase the visibility and accountability of the organization within the community. In creating a consumer education program, it might be helpful to explicitly address those issues with which respondents were especially uncomfortable. For example, in terms of organizational privacy, respondents were most concerned that organizations might sell their information to other companies, use their personal information for reasons other than stated, or use their personal information without first obtaining the individual's consent. Addressing these specific concerns in a privacy pamphlet or video by describing exactly how and for what purpose patients' medical information will and will not be used, might reduce consumers' privacy concerns.

Also, in conjunction with efforts to increase consumers' web expertise and web fluency, it might be advantageous to inform consumers about how they may engage in 'safer web practices;' for example, learning to look for web sites' privacy policies and eliminating cookies from the hard drive. By educating consumers on how better to protect themselves from what they may consider to be privacy violations, overall privacy concerns may be reduced, leading to the greater likelihood of adoption of digital medical records technology.

Innovation Attributes

All of the innovation attributes were significantly related with at least one of the two outcome measures, demonstrating the importance of the consumers' evaluation of the technology in their ultimate decision to adopt or reinvent the technology. In fact, innovation attributes were, out of all variables, the most strongly related to both adoption and reinvention of digital medical records technology. In the case of *adoption*, *observability*, *compatibility*, *trialability*, and the *explanation* aspect of complexity were the most significant influences. Therefore, those respondents that were interested in some form of interaction with their digital medical record, such as viewing a list of users authorized to view their record, were more likely to adopt the technology. This implies that creating a variety of opportunities for individuals to participate in the introduction and development of their digital medical records will foster a positive attitude among consumers, permitting them to view the technology as compatible with their everyday needs and values. By simply engaging the patients with their digital medical records, it is possible that the SBCCDE may increase adoption among its potential consumers.

Relative advantage, *observability*, and the *explanation* and *error* aspects of complexity were significantly related to *reinvention*, confirming the directional predictions of the model that those respondents who evaluated the technology highly according to its innovation attributes were more likely to reinvent the technology. Whereas relative advantage did not play as significant a role in adoption, respondents who saw significant benefits of digital medical records in comparison to paper based medical records were more likely to acknowledge various reinventions of the new technology. Therefore, in developing consumer strategies, the SBCCDE would benefit from enumerating the differences between digital medical records technology and current paper-based systems, and by presenting the paper-based systems as outdated or inefficient. Specific advantages that respondents reacted to most positively focused on digital medical records' ability to enable better health care, especially by facilitating care in emergency situations, providing convenient information access for doctors, and by alleviating the pains of transferring paper records between physicians offices and medical clinics. Such a focus on treatment is a positive result for the SBCCDE, as it reaffirms its stated dedication of improving health care by facilitating access to medical records at the point of patient care. Also interestingly, respondents were less convinced that the implementation of digital medical records would save money, for any party involved, than they were that the records would improve patient treatment.

References

- Albisser, A., Albisser, J., & Parker, L. (2003). Patient confidentiality, data security, and provider liabilities in diabetes management. *Diabetes Technology and Therapeutics*, 5(4), 631-640.
- Alpert, S.A. (2003). Protecting medical privacy: Challenges in the age of genetic information. *Journal of Social Issues*, 59(2), 301-322.
- Aydin, C.E., & Rice, R.E. (1991). Social worlds, individual differences, and implementation: Predicting attitudes toward a medical information system. *Information & Management*, 20, 119-136.
- Bandura, A. (1978). On distinguishing between logical and empirical verification: A comment on Smedslund. *Journal of Scandinavian Psychology*, 19(2), 97-99.
- Bunz, U. (2004). The computer-email-web (CEW) fluency scale: Development and validation. *International Journal of Human-Computer Interaction*, 17(4), 477-504.
- Buss, A. (2001). *Psychological dimensions of the self*. Thousand Oaks, CA: Sage Publications.
- Care Science, Inc. Santa Barbara County Care Data Exchange. www.Carescience.com.
- Committee on Information Technology. (1999). *Being fluent with information technology*. Washington, DC: National Academy Press.
- California HealthCare Foundation. (1999). Medical privacy and confidentiality survey: Summary and overview. January 28. Available at <http://www.chcf.org/documents/ihealth/survey.pdf>. Accessed 10/14/2004.
- Chin, T. (12 March, 2001). Peer to peer: Sharing patient data online. *American Medical News*, 1-6.
- Compeau, D.R., & Higgins, C.A. (1995). Computer self-efficacy: Development of a measure and initial test. *MIS Quarterly*, 19(2), 189-212.
- Culnan, M.J., & Armstrong, P.K. (1999). Information privacy concerns, procedural fairness, and impersonal trust: An empirical investigation. *Organization Science*, 10(1), 104-115.
- Davis, F. (1993). User acceptance of information technology: System characteristics, use perceptions and behavioral impacts. *Int. J. Man- Machine Studies*, 38, 475-487.
- Demiris, G., & Eysenbach, G. (2002). *Journal of Medical Internet Research*, 4(2), 6-12.
- Epstein, R.A. (2002). HIPAA on privacy: Its unintended and intended consequences. *Cato Journal*, 22(1), 13-32.
- Fedorowicz, J., & Ray, A. W. (2004). Impact of HIPAA on the integrity of healthcare information. *International Journal of Healthcare Technology & Management*, 6(2), 142.
- Finkelstein, J.B. (9 August 2004). HHS outlines plan to increase national adoption of health information technology. *American Medical News*.
- Fuller, T.D., Edwards, J.N., Vorakitphokatorn, S., & Sermsri, S. (1993). Using focus groups to adapt survey instruments to new populations: Experience from a developing country. In D.L. Morgan (Ed.) *Successful focus groups: Advancing the state of the art* (pp. 89-104). Thousand Oaks, CA: Sage Publications.
- Georgia Tech's GVU's 10th WWW user survey (1998). Retrieved July 16, 2003, from http://www.gvu.gatech.edu/user_surveys/survey-1998-10/.
- Gunter, T.D., & Terry, N.P. (2005). The emergence of national electronic health record architectures in the United States and Australia: Models, costs, and questions. *Journal of Medical Internet Research*, 7(1):e3.
- Harris Interactive. (2003). eHealth's influence continues to grow as usage of the Internet by physicians and patients increases. *Health Care News*, 3(6), 1-7.
- Hassol, A., Walker, J. M., Kidder, D., Rokita, K., Young, D., Pierdon, S., Deitz, D., Kuck, S. & Ortiz, E. (2004). Patient experiences and attitudes about access to a patient electronic health care record and linked web messaging. *Journal of the American Medical*

- Informatics Association*, 11(6), 505-513.
- Hawryluk, M. (17 May 2004). President launches push for electronic records; funds for project still in question. *American Medical News*.
- Health Privacy Project. (2004). *HIPAA privacy check-up*. Washington D.C., April 12.
- Jeffords, M. J. (1999). Confidentiality of medical information: Protecting privacy in an electronic age. *Professional Psychology: Research and Practice*, 30(2), 115-116.
- Jerusalem, M. & Schwarzer, R. (1992). Self-efficacy as a resource factor in stress appraisal processes. In R. Schwarzer (Ed.), *Self-efficacy: Thought control of action* (pp. 195-213). Washington DC: Hemisphere.
- Johnson, B. & Rice, R. E. (1987). *Managing organizational innovation: The evolution from word processing to office information systems*. New York: Columbia University Press.
- Journal of Social Issues*, 59(2), 301-322.
- Joustra-Enquist, I. & Eklund, B. (2004). SUSTAINS: Direct access for the patient to the medical record over the Internet. *MEDINFO 2004*(CD): 1673.
- Knodel, J. (1993). The design and analysis of focus group studies: A practical approach. In D.L. Morgan (Ed.) *Successful focus groups: Advancing the state of the art* (pp. 35-50). Thousand Oaks, CA: Sage Publications.
- Krueger, R.A. (1993). Quality control in focus group research. In D.L. Morgan (Ed.) *Successful focus groups: Advancing the state of the art* (pp. 65-85). Thousand Oaks, CA: Sage Publications.
- Li, J., & Shaw, M.J. (2004). Protection of health information in data mining. *International Journal of Healthcare Technology & Management*, 6(2), 210.
- Mandl, K.D., Szolovits, P., & Kohane, I.S. (2001). Public standards and patients' control: How to keep electronic medical records accessible by private. *BMJ*, 322, 283-287.
- McGee, M.K. (3 November 2003). Collaborate and conquer. *InformationWeek*.
- Milberg, S.J., Smith, H.J., & Burke, S.J. (2000). Information privacy: Corporate management and national regulation. *Organization Science*, 11(1), 35.
- Morgan, D.L. (Ed.) (1993). *Successful focus groups: Advancing the state of the art*. Thousand Oaks, CA: Sage Publications.
- Muller, M. L, Burkle, T., Irps, S., Roeder, N. & Prokosch, H. U. (2003). The diagnosis related groups enhanced electronic medical record. *International Journal of Medical Informatics*, 70(2-3): 221-228.
- Nasser, C., & Alpert, S. (1999). *Protecting the privacy of medical records: An ethical analysis*. Lexington, MA: National Coalition for Patient Rights.
- Newburger, E. C. (September, 2001). *Home computers and Internet use in the United States: August 2000*. Washington D.C.: U.S. Census Bureau.
- O'Brien, K. (1993). Improving survey questionnaires through focus groups. In D.L. Morgan (Ed.) *Successful focus groups: Advancing the state of the art* (pp. 105-117). Thousand Oaks, CA: Sage Publications.
- PC Magazine*. (September 26, 2001). A healthier CHIN. Ziff Davis Publishing, Inc.
- Ralston, J.D., Revere, D., Robins, L.S., Goldberg, H.I. (2004). Patients' experience with a diabetes support programme based on an interactive electronic medical record: Qualitative study. *BMJ*, 328.
- Reynolds, S. (2003). Making sense of information technology. *British Journal of Midwifery*, 11(3), 178-183.
- Rice, R.E., & Anderson, J. G. (1994). Social networks and health care information systems: A structural approach to evaluation. In J. Anderson, C. Aydin, & S. Jay (Eds.) *Evaluating health care information systems: Methods and applications* (pp. 135-162). Newbury Park, CA: Sage.

- Rogers, E.M. (1983). *Diffusion of innovations (3rd Edition)*. New York: Free Press.
- Shoesmith, J. (2001). Privacy matters: As the healthcare sector and high-tech worlds converge, governments and service providers are scrambling to ensure that the benefits of ehealth don't come at the expense of personal privacy. *Canadian Healthcare Manager*, 8(2), 21.
- Smith, H.J., Milberg, S.J., & Burke, S.J. (1996). Information privacy: Measuring individuals' concerns about organizational practices. *MIS Quarterly*, 20(2), 167-196.
- Swartz, N. (2004). A prescription for electronic health records. *Information Management Journal*, 38(4), 20.
- U.S. Department of Health and Human Services. (2000). 45 CFR Parts 160 and 164. Standards for privacy of individually identifiable health information; Final rule. *Federal Register*, 65, 82462-82829.
- U.S. Department of Health and Human Services. (2001). Fact sheet: Protecting the privacy of patients' health information. July 6. (direct link available at <http://www.hhs.gov/news/press/21001pres/01fsprivacy.html>). Accessed 02/10/2005.
- U.S. Department of Health and Human Services. (2004). *OCR letter to healthcare providers*. May 17. Washington, D.C.: US DHHS Office for Civil Rights.
- Udo, G.J. (2001). Privacy and security concerns as major barriers for e-commerce: A survey study. *Information Management and Computer Security*, 9(4), 165-174.
- Wang, M., Lau, C., Matsen, F. A. 3rd & Kim, Y. (2004). Personal health information management system and its application in referral management. *IEEE Transactions on Information Technology in Biomedicine*, 8(3), 287.
- Wang, S.J., Middleton, C., Prosser, L.A., Bardon, C.G., Spurr, C.D., Carchidi, P.J., Kittler, A.F., Goldszer, R.C., Fairchild, D.G., Sussman, A.J., Kuperman, G.J., & Bates, D.W. (2003). A cost-benefit analysis of electronic medical records in primary care. *The American Journal of Medicine*, 114, 397-403.
- Warren, S., & Brandeis, L. (1890). The right to privacy. *Harvard Law Review*, 4, 193-220.
- Westin, A. (1967). *Privacy and freedom*. New York, NY: Atheneum.
- Williams, F., Rice, R.E., Rogers, E.M. (1988). *Research methods and the new media*. New York: The Free Press.
- Wolff, B., Knodel, J., Sittirari, W. (1993). Focus groups and surveys as complementary research methods: A case study. In D.L. Morgan (Ed.) *Successful focus groups: Advancing the state of the art* (pp. 118-136). Thousand Oaks, CA: Sage Publications.
- 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(564).

Appendix 1.

Description of Individual Digital Medical Records Read to Focus Groups

Imagine going to a new physician or medical clinic for the first time. During the examination, the doctor pulls up your entire medical history at his or her computer, even though he or she was not involved with your previous treatment. The medical record shows what other clinics you've visited, what tests you've had done with the corresponding lab results, a list of the medications you've been prescribed, and the doctor is even able to view your past x-rays. However, sensitive information, such as a patient's HIV diagnosis or psychotherapy notes are not shared on the record. Such a comprehensive medical record is available due to the technology of individual digital medical records. A central data depository manages and indexes every person's individual medical record, allowing it to be accessible to authorized users from their computers. Authorized users include those clinicians, specialists, and health care institutions charged with administering a patient's care. The patient also has access to his or her record, and is able to view a list of 3rd parties that have accessed the record, along with what changes have been made to the record.

Appendix 2.

Description of Implementation of Individual Digital Medical Records in the Santa Barbara County Care Data Exchange

The technology previously described to you is being locally instituted in Santa Barbara County. The Santa Barbara County Care Data Exchange is a community-wide initiative making patient-specific information more readily available at the point of patient care. Development of the Care Data Exchange (CDE) is in its sixth year, and a final test of the system is currently underway with Santa Barbara County physicians. The CDE allows authorized access to clinical results from multiple systems across health care organizations in Santa Barbara County, including Cottage Hospital, Sansum Medical Foundation, Santa Barbara County Regional Health Authority, and Santa Barbara County Public Health Department. These participating organizations can view data stored on another organization's database, via the CDE, without transferring ownership of the data. The available data includes a list of clinics a patient has visited, what tests the patient has had done and the corresponding lab results, a list of the patient's prescriptions and medications, and a patient's past x-rays. Ultimately patients will also have the opportunity to access their medical records from a computer via the internet.

Appendix 3.

Department of Communication Privacy and Medical Technology Survey

- The current project is aimed at determining consumers' perceptions about individual shared digital medical records, and developing a model of innovation diffusion and technology privacy concerns.
- Participation in this study is voluntary, and you may withdraw your consent to participate at any time without penalty.
- If upon looking over this survey, you wish to obtain an alternate research activity, please circle this sentence, complete this first page, and contact Kier Wallis.
- Completion of the survey will take between a half hour and 45 minutes. For each question, please simply enter the number or circle the number that best reflects your opinion. There are no right or wrong answers. The survey does not ask for any identifying information, so your responses are both anonymous and confidential. No individual information will be reported.
- There is no risk or discomfort associated with responding to this survey. Results from the survey will help regional policy-makers better understand people's perceptions and concerns about individual/shared digital medical records.
- In the event of a research-related injury, or if you have any questions about your rights as a research participant, you should contact the staff of the UCSB Human Subjects Committee in the Office of Research at 893-3807.
- For answers to questions about this research project, you may telephone the principal researcher, Kier Wallis, at 685-3397 anytime, or e-mail her at kwallis@umail.ucsb.edu

Student Name (please print clearly!): _____ Perm # _____

Your participation in this study will count toward **1 hr** of the research practicum requirement in one lower division communication course. Please indicate which course your participation should count toward. Also indicate your correct section/lab (day and time) and your TA for that course. NOTE: Even if you are enrolled in more than one of these courses, this study gives you credit toward the requirement in only one course.

Course: _____ TA name: _____
(Comm 1, 87 OR 89)

Section day and time: _____

We will remove this page from the survey before the survey is processed, so your responses will be anonymous, yet you will receive your research practicum credit.

Please contact Kier Wallis at [email] if you have any questions about this study.

Return the completed survey to the **box outside Ellison 5844 NO LATER THAN March 1, 2005.**

Please tell us a bit about yourself (circle the number or print a number in the space):

Are you male or female?	1 male	2 female		
How many years and months old are you?	____ years	____ months		
How long have you been using the Internet (including email, web, chat, downloading, etc.)?	____ years			
How healthy would you say you are, compared to other people your age and sex?	very unhealthy	aver -age	very healthy	
	1	2 3 4 5 6 7		
Do you, or have you ever had, a chronic illness or health problem (i.e., asthma, diabetes, heart problems?)	1 yes	2 no		
How much of your annual expenses (tuition, housing, food, travel) do you earn or pay for yourself?	1 none	2 some		
	3 about half	4 most 5 all		
What college year are you?	1 Fr	2 So	3 Jr	4 Sr
Do you pay for your own health insurance?	1 yes	2 no		

Please circle the “1” if you have ever done each of the following Internet-related activities:

	yes
Ordered a product/service by filling out an online form	1
Made a purchase online for more than \$100	1
Created a web page	1
Customized a web page for yourself (e.g., MyYahoo, CNN Custom News, TheFacebook, My Space, blog, etc.)	1
Changed your browser’s “startup” or “home” page	1
Changed your “cookie” preferences	1
Participated in an online chat or discussion (not including email)	1
Listened to a radio broadcast online	1
Made a telephone call online	1
Used a nationwide online directory to find an address or telephone number	1
Taken a seminar or class about the Web or Internet	1
Bought a book to learn more about the Web or Internet	1

How frequently do you access the Internet/World Wide Web from the following locations?

	never	less than once/mo	monthly	weekly	daily
From where you live?	1	2	3	4	5
From where you work?	1	2	3	4	5
From school other than at a terminal at the library?	1	2	3	4	5
From a terminal at the library?	1	2	3	4	5
From other locations?	1	2	3	4	5

To what extent do you disagree or agree with each of the following statements?

	very strongly disagree							very strongly agree
It is hard for me to talk about myself	1	2	3	4	5	6	7	
I prefer that people know only a little bit about me	1	2	3	4	5	6	7	
If I kept a diary, I would never show it to anyone	1	2	3	4	5	6	7	
I sometimes find myself telling casual acquaintances things about me	1	2	3	4	5	6	7	
There are many things about me that I would rather not talk about with other people	1	2	3	4	5	6	7	
I won't talk about personal matters unless someone else does so first	1	2	3	4	5	6	7	
When at home, I prefer to keep the window shades closed so that passersby cannot see in, even when I am dressed	1	2	3	4	5	6	7	
I feel very uncomfortable when using public restrooms	1	2	3	4	5	6	7	
I would much prefer a car with tinted windows so that other people could not see me	1	2	3	4	5	6	7	
I hate being in a room when the people next door can overhear you	1	2	3	4	5	6	7	
I strongly object to a bystander listening when I am on the telephone	1	2	3	4	5	6	7	
I do not like getting undressed in a locker room	1	2	3	4	5	6	7	
I would rather study alone than have others around	1	2	3	4	5	6	7	
It is difficult to really concentrate on a problem when other people are around	1	2	3	4	5	6	7	
In general, I need lots of room/space around me	1	2	3	4	5	6	7	
It is a lot easier to do many things if you just tune people out	1	2	3	4	5	6	7	
The only way I can really unwind is to get away from everybody	1	2	3	4	5	6	7	
I need time away from others so that I can get in touch with myself	1	2	3	4	5	6	7	
When working or studying, I need lots of elbow room	1	2	3	4	5	6	7	

To what extent do you disagree or agree with each of the following statements?

	very strongly disagree							very strongly agree
People should have the right to be left alone	1	2	3	4	5	6	7	
People should be able to use the Internet anonymously	1	2	3	4	5	6	7	
No one should be able to gather or disclose my personal information without my consent	1	2	3	4	5	6	7	
People should have the right to control their personal information	1	2	3	4	5	6	7	
The government should never tap into citizen's private lives without the permission of the courts	1	2	3	4	5	6	7	
Businesses should be allowed to get personal information from me and use it to better serve my needs as a consumer, without my explicit consent	1	2	3	4	5	6	7	
Internet companies should be able to track my online activities to better serve my needs as a consumer, without my explicit consent	1	2	3	4	5	6	7	
The government should be able to secretly monitor individuals' online activities for national security	1	2	3	4	5	6	7	

**To what extent do you disagree or agree
with each of the following statements:**

	very strongly disagree						neu- tral				very strongly agree
	1	2	3	4	5	6	7				
It usually bothers me when companies ask me for personal information	1	2	3	4	5	6	7				
All the personal information in any computer databases should be double-checked for accuracy – no matter how much this costs	1	2	3	4	5	6	7				
Companies should not use personal information for any purpose unless it has been authorized by the individuals who provided the information	1	2	3	4	5	6	7				
Companies should devote more time and effort to preventing unauthorized access to personal information	1	2	3	4	5	6	7				
When companies ask me for personal information, I sometimes think twice before providing it	1	2	3	4	5	6	7				
When people give personal information to a company for some reason, the company should never use the information for any other reason	1	2	3	4	5	6	7				
Companies should have better procedures to correct errors in personal information	1	2	3	4	5	6	7				
Computer databases that contain personal information should be protected from unauthorized access – no matter how much it costs	1	2	3	4	5	6	7				
Companies should never sell the personal information in their computer databases to other companies	1	2	3	4	5	6	7				
Companies should devote more time and effort to verifying the accuracy of the personal information in their databases	1	2	3	4	5	6	7				
I'm concerned that companies are collecting too much personal information about me	1	2	3	4	5	6	7				

Please indicate the extent to which you are concerned about each of these situations:

	not concerned at all							very strongly concerned
	1	2	3	4	5	6	7	
...computer hackers getting your credit care number online	1	2	3	4	5	6	7	
...getting a computer virus attack	1	2	3	4	5	6	7	
...your email will be read by someone besides the person you sent it to	1	2	3	4	5	6	7	
...someone learning personal information about you because of things you have done online	1	2	3	4	5	6	7	
...your Internet service providers (e.g., AOL, MSN, Yahoo!, Hotmail, etc.) selling your personal information	1	2	3	4	5	6	7	
...getting spam/junk emails from individuals and marketers	1	2	3	4	5	6	7	
...your Internet service providers monitoring your emails or other online activities	1	2	3	4	5	6	7	
...your employer and/or university monitoring your emails and other online activities	1	2	3	4	5	6	7	
...the government monitoring your emails and other online activities	1	2	3	4	5	6	7	

Please circle 1 or 2 for whether each of the following statements about your rights as a patient is true or false (i.e., not whether you prefer this or not, but whether it is a legal right or not):

I have the right to obtain a physical copy of my medical record from my physician's office	1	true	2	false
I have the right to view my medical record per my request	1	true	2	false
I have the right to change the content of my medical record	1	true	2	false
I have the right to be informed if my medical information is to be used for any purpose outside of my immediate care	1	true	2	false
My physician has the right to share information related to my medical treatment without my consent	1	true	2	false
My health care provider has the right to share information related to payment for my medical services without my consent	1	true	2	false
My physician has the right to share information related to my medical surgery without my consent	1	true	2	false
I have the right to request that my medical record be sent to an individual or institution of my choice	1	true	2	false
My health care provider is responsible for safeguarding my health information	1	true	2	false
Parents have the right to view their children's (under age 18) records	1	true	2	false
Adult children have the right to view their parents' medical records	1	true	2	false
Insurance companies have the right to access my medical records	1	true	2	false

This section briefly describes the concept of individual digital medical records, and a system being implemented in Santa Barbara regional health care facilities. Please carefully read the two paragraphs, and then answer the questions on the following three pages.

Imagine going to a new physician or medical clinic for the first time. During the examination, the doctor pulls up your entire medical history at his or her computer, even though he or she was not involved with your previous treatment. The medical record shows what other clinics you've visited, what tests you've had done with the corresponding lab results, a list of the medications you've been prescribed, and the doctor is even able to view your past x-rays. However, sensitive information, such as a patient's HIV diagnosis or psychotherapy notes, are not included in the record. Such a comprehensive medical record is available due to the technology of **individual digital medical records**. A central data depository manages and indexes every person's individual medical record, allowing it to be accessible to authorized users from their computers. Authorized users include those clinicians, specialists, and health care institutions charged with administering a patient's care. The patient also has access to his or her record, and is able to view a list of "third parties" – other medical personnel or organizations -- that have accessed the record, along with what changes have been made to the record.

This technology is being locally implemented in Santa Barbara County. The **Santa Barbara County Care Data Exchange (SBCCDE)** is a community-wide initiative making patient-specific information more readily available at the point of patient care. Development of the system is in its sixth year, and a final test of the system is currently underway with Santa Barbara County physicians. The SBCCDE allows authorized access to clinical results from multiple systems across health care organizations in Santa Barbara County. These participating organizations can view data stored on another organization's database, via the SBCCDE as a web page on the Internet, without transferring ownership of the data. The available data includes a list of clinics a patient has visited, what tests the patient has had done and the corresponding lab results, a list of the patient's prescriptions and medications, and a patient's past x-rays. Eventually, patients will also have the opportunity to access their own medical records from a computer via the Internet.

Using the above description of individual digital medical records and the SBCODE, please indicate the extent to which you agree with each of the following statements:

	very strongly disagree		neu- tral		very strongly agree
Compared to paper-based medical records, digital medical records would...					
... be more accessible to the patient	1	2	3	4	5 6 7
... be more secure	1	2	3	4	5 6 7
... help doctors to make better medical diagnoses	1	2	3	4	5 6 7
... be better in an emergency situation	1	2	3	4	5 6 7
... result in better treatment if you needed care while traveling	1	2	3	4	5 6 7
... be more convenient for doctors	1	2	3	4	5 6 7
... provide patients with more prescription-related information	1	2	3	4	5 6 7
... make it easier to transfer information between physicians or clinics	1	2	3	4	5 6 7
... make it easier for you to change to another doctor	1	2	3	4	5 6 7
... save you money	1	2	3	4	5 6 7
... save your doctor money	1	2	3	4	5 6 7
... save your hospital money	1	2	3	4	5 6 7
... save your insurance company money	1	2	3	4	5 6 7

To what extent do you agree with each of the following statements:

	very strongly disagree		neu- tral		very strongly agree
Digital medical records would allow me to access my medical record	1	2	3	4	5 6 7
The confidentiality of my digital medical records would be maintained by any third parties authorized to view my record	1	2	3	4	5 6 7
My digital medical record would remain private	1	2	3	4	5 6 7
The information in my digital medical record would be secure	1	2	3	4	5 6 7
My digital medical record would result in improved health care for me	1	2	3	4	5 6 7
My digital medical record would be a convenient source of my medical information for those who need to use it	1	2	3	4	5 6 7
The information in my digital medical record would be accurate	1	2	3	4	5 6 7
The individual patient should decide who has the authority to view the information in his or her medical record	1	2	3	4	5 6 7

To what extent do you agree with each of the following statements:

	very strongly disagree						neutral				very strongly agree
New users will need extensive training to use their individual digital medical records	1	2	3	4	5	6	7				
The digital medical records technology is susceptible to human error	1	2	3	4	5	6	7				
The digital medical records technology is susceptible to computer error	1	2	3	4	5	6	7				
I could explain the digital medical records technology to a friend	1	2	3	4	5	6	7				
The digital medical records technology seems straightforward	1	2	3	4	5	6	7				
It would be easy to confuse patients' medical records in the digital system	1	2	3	4	5	6	7				
I have many questions about the digital medical records technology	1	2	3	4	5	6	7				
Entering data into the digital medical records system will be difficult	1	2	3	4	5	6	7				

To what extent do you agree with each of the following statements:

	very strongly disagree						neutral				very strongly agree
I would like...											
... to be able to limit the number of medical practitioners authorized to access my medical record	1	2	3	4	5	6	7				
... to decide who of my family and friends has authorized access to my medical record	1	2	3	4	5	6	7				
... the option of deciding to remove my medical record from the web-based SBCCDE system if I should so decide in the future	1	2	3	4	5	6	7				

To what extent do you agree with each of the following statements:

	very strongly disagree						neutral				very strongly agree
I believe it is good to move forward with the digital medical record technology	1	2	3	4	5	6	7				
It is exciting that Santa Barbara is part of the national plan to improve health care, by implementing digital medical records	1	2	3	4	5	6	7				
I would like...											
... to see a list of medical practitioners and institutions who are authorized to view the information in my medical record	1	2	3	4	5	6	7				
... a wallet card indicating that I have agreed to be part of the digital medical records system	1	2	3	4	5	6	7				
... a key chain containing a computer chip with my medical record	1	2	3	4	5	6	7				
... to see more press coverage of the implementation of digital medical records in Santa Barbara County	1	2	3	4	5	6	7				
... to participate in a community forum on digital medical records	1	2	3	4	5	6	7				

To what extent do you agree with each of the following statements:

	very strongly disagree	neu- tral	very strongly agree
I would...			
...sign a consent form allowing my medical record to be included in the SBCCDE digital database	1	2 3 4 5 6 7	
...access my digital medical record if given the opportunity	1	2 3 4 5 6 7	
...use the information in my digital medical record to improve my health	1	2 3 4 5 6 7	
...attend a session with my doctor to learn about how to use my digital medical record	1	2 3 4 5 6 7	
...advise my family to use their digital medical records	1	2 3 4 5 6 7	
...be willing to pay a small fee to use digital medical records at my health care facility	1	2 3 4 5 6 7	
...participate in a consumer oversight committee to advise health administrators about recommendations for the SBCCDE	1	2 3 4 5 6 7	
...sign a petition to support the allocation of local (county or state) funds to support the SBCCDE system	1	2 3 4 5 6 7	
...sign a form letter and mail it to your physician requesting that s/he support and participate in the SBCCDE	1	2 3 4 5 6 7	

To what extent do you agree that people would use their digital medical records in the following ways:

	very strongly disagree	neu- tral	very strongly agree
Adults caring for their parents would use it to access their parents' records	1	2 3 4 5 6 7	
The medical community would use such records for medical research	1	2 3 4 5 6 7	
Spouses would use it to access their partner's record	1	2 3 4 5 6 7	
People would use their digital medical records to...			
... learn more about their doctor	1	2 3 4 5 6 7	
... see if their doctor updated their information after an appointment	1	2 3 4 5 6 7	
... check if their doctor accessed their record prior to an appointment	1	2 3 4 5 6 7	
... learn about their personal medical history	1	2 3 4 5 6 7	
... learn about their family medical history	1	2 3 4 5 6 7	
... learn their blood type	1	2 3 4 5 6 7	
... look up prescriptions, test results, vaccination results	1	2 3 4 5 6 7	
... verify medical information	1	2 3 4 5 6 7	
... access their children's records	1	2 3 4 5 6 7	
... help with insurance processes	1	2 3 4 5 6 7	
... diagnose and treat themselves	1	2 3 4 5 6 7	

Thanks!

Please return your survey to the box outside Ellison 5844 by March 1, 2005.

Appendix 4.
Factor Loadings, Correlations, Regressions

Efficacy

	Component
Q11A Eff solve problems	.610
Q11B Eff get what want	.467
Q11C Eff stick to aims goals	.592
Q11D Eff confident unexpected events	.745
Q11E Eff resourceful unforeseen situations	.710
Q11F Eff solve problems necessary effort	.655
Q11G Eff calm problem coping abilities	.646
Q11H Eff find several solutions	.708
Q11I Eff in trouble think of solution	.731
Q11J Eff usually handle whatever	.770

Eigenvalue 4.47, variance explained 44.7%

Web Fluency

	Component		
	1	2	3
Q12B ActDif typing web address directly	.725	.217	.060
Q12C ActDif identify host server from addr	.078	.260	.524
Q12E ActDif using back & forward in browser	.848	.127	.059
Q12H ActDif using search engines	.873	.056	.044
Q12J ActDif save text of web pages to disk	.209	.609	.447
Q12K ActDif save images web pages to disk	.196	.672	.440
Q12M ActDif use dial-in account to log on	.246	.133	.600
Q12N ActDif create website visual editor	-.075	.181	.836
Q12O ActDif use Internet email	.670	.253	.047
Q12Q create website using html	-.052	.037	.784
Q12F ActDif add bookmarks in browser	.204	.849	.053
Q12G ActDif editing bookmarks	.179	.844	.170

4.4, 2.1, 1.1; 36.7%, 17.4%, 9.1%

Basic; Transferring/Transforming; Connective Knowledge

Personal Privacy

	Component		
	1	2	3
Q13A PPriv hard talk about myself	-.094	.050	.671
Q13B PPriv prefer others know little about me	.094	.185	.676
Q13C PPriv never show diary to others	.085	.052	.479
Q13E PPriv many things not talk about w/others	.176	.094	.631
Q13F PPriv not talk personal unless others first	.207	.179	.574
Q13G PPriv at home keep window shades closed	.000	.529	.237
Q13H PPriv uncomfortable public restrooms	-.042	.556	-.007
Q13I PPriv prefer car tinted windows	.141	.651	.120
Q13J PPriv hate when pepole next door can hear	.287	.691	.120
Q13K PPriv object bystander listening when telephone	.327	.567	.102

Q13L PPriv don't like getting undressed locker room	.061	.618	.133
Q13M PPriv rather study alone	.550	.163	.019
Q13N PPriv difficult concentrate when others around	.620	.324	.000
Q13O PPriv need lots room/space around me	.700	.320	.063
Q13P PPriv easier do many things if tune others out	.620	.082	.164
Q13Q PPriv unwind -- get away from everybody	.688	-.042	.195
Q13R PPriv need time away from others	.704	-.159	.129
Q13S PPriv working studying need elbow room	.713	.133	.040

4.6, 18.6%; 1.9, 14.2%; 1.5, 11.5%

General Privacy

	Component	
	1	2
Q14A GPriv people right to be left alone	.649	-.069
Q14B GPriv people able use Internet anonymously	.611	.041
Q14C GPriv no gather disclose personal info w/out consent	.769	.168
Q14D GPriv people right control their personal info	.813	.171
Q14FR GPriv businesses NOT allowed personal info w/o consent	.032	.778
Q14GR GPriv Internet cos NOT track online act w/o consent	.110	.840
Q14HR GPriv gov NOT able secretly monitor online act natl sec	.061	.631

2.3, 1.5; 33.5%, 21.3%

Organizational Privacy

	Component		
	1	2	3
Q15A OPriv bother me cos ask for personal info	.213	.073	.796
Q15B OPriv personal info database should be double-checked	-.095	.696	.273
Q15C OPriv cos not use personal info w/out authorization by ind	.702	.007	.248
Q15D OPriv cos devote more time prevent unauthorized access	.603	.317	.339
Q15E OPriv cos ask personal info think twice before providing	.414	-.001	.661
Q15F OPriv cos never use info for other reason	.772	.164	.143
Q15G OPriv cos better procedures correct errors personal info	.331	.779	.072
Q15H OPriv co databases protected from unauthorized access	.601	.423	.217
Q15I OPriv cos never sell personal info in databases to other cos	.794	.133	.035
Q15J OPriv cos devote mote time verify accuracy personal info	.330	.821	.016
Q15K OPriv concerned cos collect too much personal info me	.033	.363	.697

4.5, 1.3, 1.2; 40.9%, 12.2%, 10.5%

Computer Privacy Concerns

	Component	
	1	2
Q16A PCon hackers credit card number online	.373	.762
Q16B PCon computer virus attack	.065	.890
Q16D PCon other learning your personal info from online activities	.641	.435
Q16E PCon ISPs selling your personal info	.726	.346
Q16G PCon ISPs monitoring emails other online activities	.834	.255
Q16H PCon employer/university monitoring emails other online act	.891	.137
Q16I PCon govt monitoring emails other online activities	.876	.082

4.05, 1.06; 57.9%, 15.1%

Relative Advantage

	Component	
	1	2
Q18C IN help doctors make better medical diagnoses	.655	.253
Q18D IN better in emergency situation	.805	.092
Q18E IN better treatment if needed while travelling	.812	.099
Q18F IN more convenient for doctors	.857	.156
Q18H IN easier transfer info between physicians clinics	.746	.166
Q18I IN easier change doctors	.724	.287
Q18J IN save you money	.163	.774
Q18K IN save your doctor money	.198	.926
Q18L IN save your hospital money	.188	.935
Q18M IN save your ins co money	.205	.902

4.99, 2.06; 49.9%, 20.6%

Compatibility

	Component	
	1	2
Q19A EXP allow me access my medical record	.076	.687
Q19B EXP confidentiality maintained by authorized third parties	.718	.183
Q19C EXP my digital med record remain private	.912	.019
Q19D EXP my digital med record info would be secure	.922	.028
Q19F EXP my dig med record convenient source those who need it	.249	.703
Q19G EXP info my dig med record would be accurate	.469	.611
Q19H EXP patient decide who has authority view their med record info	-.182	.699

2.8, 1.5; 40.6, 22.0; alpha = .92 (drop B), .62

Complexity

	Component		
	1	2	3
Q20B CMP dig med records tech susceptible human error	.927	.023	.096
Q20C CMP dig med records tech susceptible computer error	.920	-.033	.121
Q20DR CMP I could NOT explain dig med records tech to friend	.010	.912	.113
Q20ER CMP Dig med records tech NOT seem straightforward	-.013	.911	.116
Q20F CMP Easy confuse patients medical records digital system	.146	-.056	.738
Q20G CMP I have many questions about the technology	.270	.172	.683
Q20H CMP Entering data system will be difficult	-.114	.203	.752

2.3, 1.8, 1.1; 32.9, 25.3, 15.7; alpha=.86, .82, .58

Trialability

	Component
Q21A LIKE to limit number authorized access med record	.801
Q21B LIKE decide who family friends authorized access	.865
Q21C LIKE option remove med record from systems in future	.823

2.1, 68.9%

Observability

	Component	
	1	2
Q22A PUB good move forward dig med rec tech	.941	.033
Q22B PUB exciting SB part national plan	.931	.109
Q22C PUB see list those authorized to view info in my med record	.117	.815
Q22D PUB wallet card indicating my agreement	.010	.840

1.0, 1.3; 47%, 31.7%

Adoption/Rejection

	Component	
	1	2
Q23A BEH sign consent form included SBCCDE dig database	.320	.769
Q23B BEH access my dig med record given opportunity	.045	.907
Q23C BEH use info dig med record improve my health	.256	.800
Q23F BEH pay small fee use dig med records health care facility	.750	.222
Q23G BEH participate consumer oversight committee advise recommend	.782	.000
Q23H BEH sign petition support local funds support SBCCDE system	.721	.444
Q23I BEH sign form letter to physician requesting support SBCCDE	.827	.291

3.7, 1.2; 52.7%, 17.8%

Reinvention

	Component		
	1	2	3
Q24A RE adults caring parents access parents records	.273	.761	.138
Q24B RE medical community use records medical research	.246	.698	.113
Q24C RE spouses use access partners record	.045	.788	.180
Q24E RE people see doctor updated their info after appt	.231	.224	.871
Q24F RE people check doctor accessed record prior to appt	.275	.176	.870
Q24G RE people learn personal medical history	.721	.155	.438
Q24H RE people learn family medical history	.659	.352	.253
Q24I RE people learn blood type	.826	.160	.210
Q24J RE people look up prescriptions test results vaccination results	.865	.142	.226
Q24K RE people verify medical info	.837	.095	.157
Q24L RE people access childrens records	.720	.327	.040

3.9, 2.1, 2.0; 35.2%, 18.9%, 17.8%

Correlations

	IAall Q23A-I a=.88	IAuse Q23ABC 3.7, 52.7% a=.81	IASupp Q23FGHI 1.2 17.8% a=.82	IREall Q24A-N a=	IREpat Q24GHIJKL 3.0 35.2% a=.91	IREdoc Q24EF 2.1 18.9% a=.86	IREoth Q24ABC 2.0 17.8% a=.70
Wbasic Q12BEHO 4.4 36.7% a=.74	.10*	.15**	.02	.11*	.14**	.13**	.07
Wmanip Q12FGJK 2.1 17.4% a=.85	.19**	.19**	.14**	.18**	.16**	.13**	.11*
Wconnect Q12CMNQ 1.1, 9.1% a=.69	.15**	.12**	.13**	.18**	.16**	.13**	.08
PPself Q13ABCEF 4.6, 18.6% a=.56	-.01	.04	-.04	-.04	.01	-.06	-.06
PPconcel Q13B-L 1.9 14.2% a=.71	-.07	-.08	-.04	-.08*	-.10*	-.04	-.06
PPperson Q13M-S 1.5 11.5% a=.80	.06	.04	.05	.09*	.10*	.09*	.05
GPint Q14A-D 2.3 33.5% a=.65	.10*	.14**	.04	.18**	.23**	.04	.14**
GPext Q14FRGR 1.5, 23.3% a=.67	-.09*	.02	-.16**	.10*	.15**	.11*	.03
OPcoll Q15AEK 4.5 40.9% a=.67	-.04	.01	-.06	.09*	.07	.13**	.04
OPerr Q15BGJ 1.3 12.2% a=.74	.17**	.08*	.20**	.20**	.13**	.16**	.14**
OPunauth Q15CDFHI 1.2 10.5% a=.82	.02	.13**	-.07	.23**	.26**	.15**	.16**
GCcomp Q16AB 1.06 15.1% a=.67	.10*	.09*	.08*	.15**	.13**	.14**	.09*
GCpers Q16DEGHI 4.05 57.9% a=.89	.13**	.12**	.11*	.11*	.05	.12**	.03
IRtreat Q18CDEFHI 4.99 49.9% a=.81	.40**	.44**	.27**	.41**	.40**	.26**	.28**
IRmoney Q18JKLM 2.06 20.6% a=.93	.36**	.30**	.33**	.27**	.19**	.16**	.20**
ICsecur Q19CB 2.8 40.6% a=.92	.34**	.22**	.38**	.07	.05	-.02	-.05
ICuse Q19AFGH 1.5 22.0% a=.62	.34**	.34**	.22**	.43**	.48**	.22**	.34**
ICXerror Q20BC 2.3 32.9% a=.86	-.06	.03	-.14**	.21**	.23**	.22**	.13**
ICXexpl Q20DRER 1.8 25.3% a=.82	-.31**	-.35**	-.20**	-.32**	-.35**	-.16**	-.21**
IOSupp Q22AB 1.9 47.0% a=.87	.57**	.57**	.43**	.36**	.36**	.20**	.23**
IOact Q22CD 1.3 31.7% a=.55	.17**	.19**	.06	.35**	.32**	.35**	.22**

* p<.05; ** p<.01 (t-tailed)

Regressions

Explanatory Variables	Outcome Variables	
	Adoption	Reinvention
<i>All Stepwise</i>		
Relative Advantage		.24 ***
Compatibility	.27 ***	
Complexity	-.13 ***	
Triability		.15 ***
Observability	.46 ***	.32 ***
Annual Expenses Responsibility	.09 *	.12 **
Adjusted R2	.41	.29
F-ratio	70.2 ***	40.4 ***
<i>Stepwise by Blocks</i>		
<i>Block 1 (Individual)</i>		
Annual Expenses Responsibility		.11 *
Health Insurance (1Y2N)	.06	
Efficacy		.08
<i>Block 2 (Technology)</i>		
Web Fluency	.00	.03
<i>Block 3 (Privacy)</i>		
Organizational Privacy		.06
General Concern	.06	.06
Medical Rights (Correct)	.07	
<i>Block 4 (Innovation Attributes)</i>		
Relative Advantage		.23 ***
Compatibility	.27 ***	
Complexity	-.15 ***	
Triability		.12 **
Observability	.44 ***	.30 ***
Adjusted R2	.41	.29
F-ratio	40.3 ***	21.4 ***
N	392	394

* p<.05; ** p<.01; *** p<.001

Note: Adoption and Reinvention were correlated r=.44 ***

Explanatory Subscale Variables	Outcome Variables	
	Adoption	Reinvention
<i>All Stepwise</i>		
Annual Expense Responsibility		.11 *
General Privacy Concern Computer	.11 **	.11 **
Relative Advantage Treatment		.11 *
Relative Advantage Money	.13 **	
Compatibility Security	.12 **	
Compatibility Use		.16 **
Complexity Error		.11 *
Complexity Explanation	-.09 *	-.18 ***
Observability Support	.45 ***	.11 *
Observability Action		.24 ***
Adj R2	.37	.33
R-ratio	45.2 ***	24.9 ***
N	382	383
	Adoption	Reinvention
	Significant	Significant
Annual Expenses	All .08 *	All .10 **
Organizational Privacy – Collection	-.12**	
Organizational Privacy – Unauthorized Access		.12 **

General Computer Concern	.10 *			
Relative Advantage			.17 ***	.17 ***
Observability	.44 ***	.44 ***	.32 ***	.32 ***
Compatibility	.25 ***	.26 ***		
Trialability	-.13 ***	-.15 ***		
Complexity – Explanation	-.12 **	-.10 *	-.16 ***	-.16 ***
Complexity – Error			.15 ***	.14 ***
Adjusted R2	.41	.40	.33	.33
F-ratio	40.5 ***	66.6 ***	32.8 ***	34.1 ***
N	393	397	394	400

Note: Two regressions were run for each dependent variable. The first of the two regressions (“All”) included all the relevant scales or subscales and individual measures that had significant correlations, while the second regression (“Significant”) included only the significant influences from the first regression. Thus the second regression for each dependent variable is the most parsimonious multivariate result, while the first regression (in the case of the Adoption outcome) provides additional information useful for policy development.

* = $p < .05$; ** $p < .01$; *** $p < .001$