

DOWNLOAD PDF INTO THE FUTURE : ACTION RESEARCH FOR HEALTH CARE INFORMATION.

Chapter 1 : Health informatics - Wikipedia

the stated aims considered by the Department of Health Strategy for Research (Department of Health, a). In addition, the Strategy for Nursing document 'Vision for the Future' (Department of Health, b).

BOX Research Priorities for Transforming Nursing Leadership Identification of the personal and professional characteristics most critical to leadership of health care organizations, such as accountable care organizations, health care homes, medical homes, and clinics. Identification of the skills and knowledge most critical to leaders of health care organizations, such as accountable care organizations, health care homes, medical homes, and clinics. Identification of the personal and professional characteristics most important to leaders of quality improvement initiatives in hospitals and other settings. Identification of the characteristics of mentors that have been or could be most successful in recruiting and training diverse nurses and nurse faculty. Identification of the influence of nursing on important health care decisions at all levels. Identification of the unique contributions of nurses to health care committees or boards. Learning from barriers to diffuse evidence-based health care interventions within health systems, Naylor and colleagues identified several ingredients crucial to successful diffusion. First, the model or innovation should be a good fit in response to a critical need, either within an organization or nationwide. Second, without strong champions, especially those with decision-making power, there is very little chance of widespread adoption. The researchers learned the hard way the cost of failure to engage all stakeholders in a project—early, continually, and throughout. Engagement with the media is especially important. An understanding of the landscape is necessary as well and should guide efforts to market the innovation to others. Milestones and measures of success are important to all team members and throughout the entire diffusion process. Finally, flexibility, or the willingness to adapt the model or innovation to meet environmental or organizational demands, increases the probability of success Naylor et al. However, the committee urges health care providers, organizations, and policy makers to carry out the eight recommendations presented below to enable nurses to lead in the transformation of the health care system and advance the health of patients and communities throughout the nation. The Future of Nursing: Leading Change, Advancing Health. The National Academies Press. The committee sees its recommendations as the building blocks required to expand innovative models of care, as well as to improve the quality, accessibility, and value of care, through nursing. Advanced practice registered nurses should be able to practice to the full extent of their education and training. To achieve this goal, the committee recommends the following actions. Expand the Medicare program to include coverage of advanced practice registered nurse services that are within the scope of practice under applicable state law, just as physician services are now covered. Amend the Medicare program to authorize advanced practice registered nurses to perform admission assessments, as well as certification of patients for home health care services and for admission to hospice and skilled nursing facilities. Extend the increase in Medicaid reimbursement rates for primary care physicians included in the ACA to advanced practice registered nurses providing similar primary care services. Require third-party payers that participate in fee-for-service payment arrangements to provide direct reimbursement to advanced practice registered nurses who are practicing within their scope of practice under state law. Page Share Cite Suggested Citation: Amend or clarify the requirements for hospital participation in the Medicare program to ensure that advanced practice registered nurses are eligible for clinical privileges, admitting privileges, and membership on medical staff. For the Office of Personnel Management: Require insurers participating in the Federal Employees Health Benefits Program to include coverage of those services of advanced practice registered nurses that are within their scope of practice under applicable state law. Review existing and proposed state regulations concerning advanced practice registered nurses to identify those that have anticompetitive effects without contributing to the health and safety of the public. States with unduly restrictive regulations should be urged to amend them to allow advanced practice registered nurses to provide care to patients in all circumstances in which they are qualified to do so. Expand

opportunities for nurses to lead and diffuse collaborative improvement efforts. Private and public funders, health care organizations, nursing education programs, and nursing associations should expand opportunities for nurses to lead and manage collaborative efforts with physicians and other members of the health care team to conduct research and to redesign and improve practice environments and health systems. These entities should also provide opportunities for nurses to diffuse successful practices. The Center for Medicare and Medicaid Innovation should support the development and evaluation of models of payment and care delivery that use nurses in an expanded and leadership capacity to improve health outcomes and reduce costs. Performance measures should be developed and implemented expeditiously where best practices are evident to reflect the contributions of nurses and ensure better-quality care. Private and public funders should collaborate, and when possible pool funds, to advance research on models of care and innovative solutions, Page Share Cite Suggested Citation: Health care organizations should support and help nurses in taking the lead in developing and adopting innovative, patient-centered care models. Health care organizations should engage nurses and other front-line staff to work with developers and manufacturers in the design, development, purchase, implementation, and evaluation of medical and health devices and health information technology products. Nursing education programs and nursing associations should provide entrepreneurial professional development that will enable nurses to initiate programs and businesses that will contribute to improved health and health care. Implement nurse residency programs. The following actions should be taken to implement and support nurse residency programs: The Secretary of Health and Human Services should redirect all graduate medical education funding from diploma nursing programs to support the implementation of nurse residency programs in rural and critical access areas. Health care organizations, the Health Resources and Services Administration and Centers for Medicare and Medicaid Services, and philanthropic organizations should fund the development and implementation of nurse residency programs across all practice settings. Health care organizations that offer nurse residency programs and foundations should evaluate the effectiveness of the residency programs in improving the retention of nurses, expanding competencies, and improving patient outcomes. Increase the proportion of nurses with a baccalaureate degree to 80 percent by Academic nurse leaders across all schools of nursing should work together to increase the proportion of nurses with a baccalaureate degree from 50 to 80 percent by These leaders should partner with education accrediting bodies, private and public funders, and employers to ensure funding, monitor progress, and increase the diversity of students to create a workforce prepared to meet the demands of diverse populations across the lifespan. The Commission on Collegiate Nursing Education, working in collaboration with the National League for Nursing Accrediting Commission, should require all nursing schools to offer defined academic pathways, beyond articulation agreements, that promote seamless access for nurses to higher levels of education. Private and public funders should collaborate, and when possible pool funds, to expand baccalaureate programs to enroll more students by offering scholarships and loan forgiveness, hiring more faculty, expanding clinical instruction through new clinical partnerships, and using technology to augment instruction. Secretary of Education, other federal agencies including the Health Resources and Services Administration, and state and private funders should expand loans and grants for second-degree nursing students. Schools of nursing, in collaboration with other health professional schools, should design and implement early and continuous interprofessional collaboration through joint classroom and clinical training opportunities. Academic nurse leaders should partner with health care organizations, leaders from primary and secondary school systems, and other community organizations to recruit and advance diverse nursing students. Double the number of nurses with a doctorate by Schools of nursing, with support from private and public funders, academic administrators and university trustees, and accrediting bodies, should double the number of nurses with a doctorate by to add to the cadre of nurse faculty and researchers, with attention to increasing diversity. Academic administrators and university trustees should create salary and benefit packages that are market competitive to recruit and retain highly qualified academic and clinical nurse faculty. Ensure that nurses engage in lifelong learning. Accrediting bodies, schools of nursing, health care organizations, and

continuing competency educators from multiple health professions should collaborate to ensure that nurses and nursing students and faculty continue their education and engage in lifelong learning to gain the competencies needed to provide care for diverse populations across the lifespan. Faculty should partner with health care organizations to develop and prioritize competencies so curricula can be updated regularly to ensure that graduates at all levels are prepared to meet the current and future health needs of the population. The Commission on Collegiate Nursing Education and the National League for Nursing Accrediting Commission should require that all nursing students demonstrate a comprehensive set of clinical performance competencies that encompass the knowledge and skills needed to provide care across settings and the lifespan. Academic administrators should require all faculty to participate in continuing professional development and to perform with cutting-edge competence in practice, teaching, and research. All health care organizations and schools of nursing should foster a culture of lifelong learning and provide resources for interprofessional continuing competency programs. Health care organizations and other organizations that offer continuing competency programs should regularly evaluate their programs for adaptability, flexibility, accessibility, and impact on clinical outcomes and update the programs accordingly. Prepare and enable nurses to lead change to advance health. Nurses, nursing education programs, and nursing associations should Page Share Cite Suggested Citation: Nurses should take responsibility for their personal and professional growth by continuing their education and seeking opportunities to develop and exercise their leadership skills. Nursing associations should provide leadership development, mentoring programs, and opportunities to lead for all their members. Nursing education programs should integrate leadership theory and business practices across the curriculum, including clinical practice. Public, private, and governmental health care decision makers at every level should include representation from nursing on boards, on executive management teams, and in other key leadership positions. Build an infrastructure for the collection and analysis of interprofessional health care workforce data. The National Health Care Workforce Commission, with oversight from the Government Accountability Office and the Health Resources and Services Administration, should lead a collaborative effort to improve research and the collection and analysis of data on health care workforce requirements. The Workforce Commission and the Health Resources and Services Administration should collaborate with state licensing boards, state nursing workforce centers, and the Department of Labor in this effort to ensure that the data are timely and publicly accessible. The Workforce Commission and the Health Resources and Services Administration should coordinate with state licensing boards, including those for nursing, medicine, dentistry, and pharmacy, to develop and promulgate a standardized minimum data set across states and professions that can be used to assess health care workforce needs by demographics, numbers, skill mix, and geographic distribution. The Workforce Commission and the Health Resources and Services Administration should set standards for the collection of the minimum data set by state licensing boards; oversee, coordinate, and house the data; and make the data publicly accessible. The Workforce Commission and the Health Resources and Services Administration should coordinate workforce research efforts with the Department of Labor, state and regional educators, employers, and state nursing workforce centers to identify regional health care workforce needs, and establish regional targets and plans for appropriately increasing the supply of health professionals. The Government Accountability Office should ensure that the Workforce Commission membership includes adequate nursing expertise. Disseminating innovations in health care. Translating research into practice: Transitional care for older adults. *Journal of Evaluation in Clinical Practice* 15 6:

Chapter 2 : HIPAA: An Overview of Impacts and Actions by States

Add. Download As healthcare information systems become increasingly critical to clinical care and hospital operations, CIOs are under significant pressure to prioritize their resources appropriately.

Advanced Search Abstract Objective. Data sources and study design. An analysis of the successful applications for the TRIP I and II requests for applications in and was produced from the data collected. The following items were abstracted from each of the successful applications: A wide variety of health care providers, settings, and patients were the target of the grants. The most common study design was a randomized controlled trial. The most common TRIP interventions were educational and the most common frameworks were either adult learning theory or organizational theory. More than half of the projects planned to use information technology and half the projects had a focus on reducing errors. The TRIP projects encompass a broad range of providers, environments, patients, and interventions. The field of applied research and quality improvements should be considerably enhanced by these research projects. A definition of quality health care is often elusive, but the key components are health care that is effective, efficient, up to date, and timely [1 , 2]. In order to achieve at least some of these goals, it is necessary to use the findings of well designed research studies and translate them into everyday practice. Despite these best efforts to improve access to research information, the impact on clinician behavior or patient outcomes has been limited. In most of these conditions, research evidence of effective strategies exists that could help improve health outcomes if it could be implemented successfully. Although a number of strategies for implementing change have been proposed, research evidence to guide this phase of the process is lacking [4]. These strategies include continuing medical education, self-instructed learning, academic detailing, audit and feedback, provider reminder systems, incentives, local opinion leaders, outreach visits, continuous quality improvement initiatives, clinical information systems, and computer decision support systems. Despite a number of randomized controlled trials of quality improvement and implementation initiatives, considerable gaps in the research evidence remain [2 , 5 - 8]. Fortunately, some research has already demonstrated that implementation of available research evidence is worthwhile, as significant improvements in health outcomes will accrue [9 - 12]. Although no one successful strategy currently exists, a combination of different strategies may be effective in achieving behavior change. The impact of implementation strategies will depend on the context in which they are applied, and will be influenced by factors including incentives, health care settings, practitioner and patient perceptions, and the desired behavior change [13]. However, too little is known about which combinations of implementation strategies are effective in which clinical contexts and for which clinical conditions. These realities compound the problem of getting evidence into practice. A second goal was to demonstrate that the translation of research into practice leads to measurable and sustainable improvements in health care. Broadly, these RFAs encouraged research related to innovative strategies for implementing evidence-based tools and information among practitioners caring for diverse populations in a variety of health care settings. A range of interventions was suggested, including: In addition, the RFAs encouraged applications from studies addressing how organizational research could be translated into practice, the impact of organizational variables on clinical translation, and the organizational and structural context of successful interventions needed to facilitate replication. Of particular interest were interventions that used the strengths of information systems for implementing evidence-based strategies for health care improvement. Methodologies that were sought included qualitative studies, quantitative research, and empirical work. In order to monitor and account for secular changes in practice patterns, studies employing control group designs were strongly encouraged. It was emphasized that to ensure internal and external validity, reliability and transferability, the evidence needs of organizations that might eventually implement similar interventions should be considered. Strategies to reduce bias such as use of randomization or concurrent comparisons were recommended. Applicants were further asked to consider the potential of evidence-based tools. They were also

encouraged to consider the effect of local circumstances such as specific populations, diverse health settings, resources constraints, and political context on both the implementation process and the outcomes of care. The following items were abstracted by one author C. The applications were categorized by C. Categories for the conceptual frameworks included adult learning, social influence, marketing and social marketing, organizational theory, and behavioral theory [17]. Adult learning theory and health education theory focus on personal motivation to change and active participation of the learner [18 , 19]. Social influence theories focus on the role of social support, peer approval, and role models in promoting behavior change [20]. Marketing and social marketing theory together provide a framework for identifying factors that drive change and meet the needs of the target group [21]. Organizational theory focuses on the environmental context within which clinicians function as a key determinant of whether innovations are utilized, and the emphasis is on organizational and structural factors that may hinder or facilitate changes in practice [22]. Behavior theory, which focuses on environmental cues and reinforcement such as audit and feedback, is seen to be central in encouraging and maintaining behavioral change [19]. To learn more about the TRIP I and II research projects and to promote exchange of ideas among the TRIP researchers, the AHRQ designed a series of activities to take advantage of the similarities and differences among projects both in research design and execution of the studies. Previous experience had led the AHRQ to believe it was likely that recruitment problems, contamination issues, and problems concerning stability of delivery systems were challenging for implementation research. Since many of these obstacles can be difficult to overcome, it was thought that the investigators, the AHRQ, and eventually the research community could benefit by promoting formal venues for discussion among the investigators. In addition, all of the TRIP projects were limited to 3 years, so it was important that study problems be addressed early and effectively. Grantees were asked to give a brief overview of their methods, problems anticipated or experienced, and the importance of their research. The major goals for the steering committee are to continue to develop the science base for implementation, provide leadership to the field, advance methods for the study of TRIP, lead the dissemination of TRIP II results, advise the AHRQ on future TRIP initiatives and on development of an agency toolbox of implementation tools and research aids, and conduct external evaluation. The steering committee meets at least twice a year with ongoing communication via conference call, Email, and ad hoc meetings of subcommittees. A description of each of the grants is given in Table 1.

Chapter 3 : Center for Collaborative Action Research

The article builds upon the themes that arose at an Institute of Medicine (IOM) and National Research Council (NRC) workshop on the "Future of Home Health Care," which was held on September 30 and October 1, 1 The research and discussion in this article are intended to be a call for action among home health agencies and home-based.

Back to Top Emerging Issues in Access to Health Services Over the first half of this decade, as a result of the Patient Protection and Affordable Care Act of , 20 million adults have gained health insurance coverage. In addition, data from the Healthy People Midcourse Review demonstrate that there are significant disparities in access to care by sex, age, race, ethnicity, education, and family income. These disparities exist with all levels of access to care, including health and dental insurance, having an ongoing source of care, and access to primary care. Disparities also exist by geography, as millions of Americans living in rural areas lack access to primary care services due to workforce shortages. Future efforts will need to focus on the deployment of a primary care workforce that is better geographically distributed and trained to provide culturally competent care to diverse populations. Specific issues that should be monitored over the next decade include: Increasing and measuring insurance coverage and access to the entire care continuum from clinical preventive services to oral health care to long-term and palliative care Addressing disparities that affect access to health care e. Access to Health Care in America. National Academies Press; Agency for Healthcare Research and Quality; May Insurance coverage, medical care use, and short-term health changes following an unintentional injury or the onset of a chronic condition. Self-assessed health status and selected behavioral risk factors among persons with and without healthcare coverageâ€”United States, The medical home, access to care, and insurance. Provider continuity in family medicine: Does it make a difference for total health care costs? The importance of having health insurance and a usual source of care. The timing of preventive services for women and children; the effect of having a usual source of care. Am J Pub Health. Evidence from primary care in the United States and the United Kingdom. Balancing health needs, services and technology. Oxford University Press; Contribution of primary care to health systems and health. A national profile on use, disparities, and health benefits. Partnership for Prevention; Aug. Data needed to assess use of high-value preventive care: A brief report from the National Commission on Prevention Priorities. Future of emergency care series: Agency for Healthcare Research and Quality; April The increasing weight of increasing waits. Trends Affecting Hospitals and Health Systems. American Heart Association; Department of Health and Human Services; Mar 3.

Chapter 4 : Health Communication and Health Information Technology | Healthy People

Patient Safety in Action: TeamSTEPPS® Now and a Look into the Future Team Strategies and Tools to Enhance Performance and Patient Safety (TeamSTEPPS) is a teamwork system designed to improve the quality, safety and efficiency of health care.

This is a short overview of action research for new action researchers which is revised yearly current version is October, It serves as an initial orientation to action research for students in the online Masters of Arts in Learning Technologies program at Pepperdine University. Each year a cadre of students engage in action research. Please feel free to share this document. An interactive guide, resources and tutorials can be accessed here or by using the "interact" icon in the menu. Thanks to those who have translated this article into these languages: For other languages please use google translator. Margaret Riel Action research is not a single approach but rather represents a tension between a number of forces that lead to personal, professional and social change. However it is also a collaborative process as it is done WITH people in a social context and understanding the change means probing multiple understanding of complex social systems. And finally as research it implies a commitment to data sharing. We use collaborative action research to highlight the different ways in which action research is a social process. Action researchers examine their interactions and relationships in social setting seeking opportunities for improvement. As designers and stakeholders, they work with their colleagues to propose new courses of action that help their community improve work practices. As researchers, they seek evidence from multiple sources to help them analyze reactions to the action taken. They recognize their own view as subjective, and seek to develop their understanding of the events from multiple perspectives. The action researcher uses data collected from interactions with others to characterize the forces in ways that can be shared with other practitioners. This leads to a reflective phase in which the action researchers formulates new plans for action during the next cycle. Over time, action researchers develop a deep understanding of the ways in which a variety of social and environmental forces interact to create complex patterns. This diagram illustrates the process of action research through time. The iterative process of action research The subjects of action research are the actions taken, the resulting change, and the transformation thinking, acting and feeling by the persons enacting the change. While the design of action research may originate with an individual, the process of change is always social. Over time, the action researcher often extends the arena of change to a widening group of stakeholders. The goal is a deeper understanding of the factors of change which result in positive personal and professional change. This form of research then is an iterative, cyclical process of reflecting on practice, taking an action, reflecting, and taking further action. Therefore, the research takes shape while it is being performed. Greater understanding from each cycle points the way to improved practice Riel and Rowell, Action researchers differ in the weight that they put on different factors or dimensions of action research for more discussion and examples, see Rowell, Riel and Polush, Each action researcher evolves his or her approach to doing action research as the conditions and support structures are unique. To understand how action research varies, I describe two points, A, and B, along six dimensions. When someone engages in action research, they or others make choices that place them at some point along the continuum for each dimension. Some will argue that side A, or B, or a perfect balance between them, is ideal, or even necessary, to call the process action research. Most will have very convincing arguments for why all action research should be done in the way they advocate. The dialogue is healthy and helps us each understand the value of the positions we take. By understanding the boundaries we develop a deeper understanding of the process. If you click on the bar graphic, you can make your own choices and compare them with others. Practice- Emphasis on creating a transformative change in a social setting by taking purposeful action B. Inquiry - Emphasis on rigorous methodology and methods for validating assumptions about what changed A. Theory from Practice - Using practices to generate theories beginning with values, needs and knowledge of human interaction B. Theory into Practice - Using social science findings to inform

patterns of change A. Inside Expertise- Action researchers are empowered to locate problems of practice and develop methods to improve them B. Outside Expertise - Action researchers form partnerships with outside experts to guide the process A. Individual Process - Action researchers select their own questions to investigate B. Group Process - A group of action researchers select a common question or set of questions to investigate A. Problem-Based Approach- Action Researchers locate problems and engage in progressive problem solving in cycles B. Inquiry-Based Approach - Action Researchers explore effective practices to better understand and perfect them through multiple cycles A. Identity Transformation - The primary outcome of action research is change to the way the action researcher thinks, acts and feels B. Social Change -The primary outcomes of action research is the shift in the social context where people collectively change how they act, think and feel A. Shared Practices - Action Researchers share what they have learned informally at their site B. Shared Knowledge- Action Researchers share their findings in more formal contexts Authors and professors as well as practitioners often have very strong views about what are the essential and non essential characteristics of action research. Movement to one or the other side of each continuum represents shifts in the action research approach. I like to think of action research as a disposition of mind as well as a research approach. It is a commitment to cycles of collective inquiry with shared reflections on the outcomes leading to new ideas. Action research forms a path towards a professional "adaptive" expertise. Hatona and Ingaki set out a contrast between efficiency expertise and adaptive expertise. I have added innovative expertise and created this chart. The path to expertise The yellow path can also be applied to the activist who is singled minded without researching the outcomes and consequences of action, The blue panel might be the path of researchers who do not apply their theories to change contexts. The green combines inquiry and activism to engage in action research. When you balance these two very different learning approaches you follow the green path of action research leading to adaptive expertise and the acquisition of a deeper understanding of yourself and others. Goals of Action Research include: Action research involves a systematic process of examining the evidence. The results of this type of research are practical, relevant, and can inform theory. Action research is different than other forms of research as there is less concern for universality of findings, and more value is placed on the relevance of the findings to the researcher and the local collaborators. It can be the process through which an organization learns. We conceptualize action research as having three outcomesâ€”on the personal, organizational and scholarly levels. Action research is often located in schools and done by teachers, but it can also be carried out in museums, medical organizations, corporations, churches and clubsâ€”any setting where people are engaged in collective, goal directed activity. Equally important, not all teacher research is action research. Teachers can do ethnographic, evaluative or experimental research that is NOT action research. At the organizational level, action research is about understanding the system of interactions that define a social context. Kurt Lewin proposed action research as a method of understanding social systems or organizational learning. He claimed that the best way to test understanding was to try to effect change. Action research goes beyond self-study because actions, outcomes, goals and assumptions are located in complex social systems. The action researcher begins with a theory of action focused on the intentional introduction of change into a social system with assumptions about the outcomes. This theory testing requires a careful attention to data, and skill in interpretation and analysis. Activity theory, social network theory, system theories, and tools of evaluation such as surveys, interviews and focus groups can help the action researcher acquire a deep understanding of change in social contexts within organizations. Many people acquire expertise in their workplace, but researchers value the process of building knowledge through ongoing dialogue about the nature of their findings. Engaging in this dialogue, through writing or presenting at conferences, is part of the process of action research. Action Research and Learning Circles Action research is conducted in the workplace with others. It is a collaborative process. But, also, the doing of action research is more effective when action researchers can benefit from the help of a community of action researchers. The Center for Collaborative Action Research is part of a process of developing the community of action researchers for each cadre. In our program, action researchers carry out their work in learning circles â€”a

structure for organizing group interaction. Combining this collaborative structure with the action research process is an effective way to provide high levels of support for action researchers as they design their action and engage in the process of studying the outcomes. *Developing Action Research Questions: A Guide to Progressive Inquiry* The questions asked by action researchers guide their process. A good question will inspire one to look closely and collect evidence that will help find possible answers. What are good examples of action research questions? What are questions that are less likely to promote the process of deep sustained inquiry? The best question is the one that will inspire the researcher to look at their practice deeply and to engage in cycles of continuous learning from the everyday practice of their craft. These questions come from a desire to have practice align with values and beliefs. Exploring these questions helps the researcher to be progressively more effective in attaining their personal goals and developing professional expertise. Good questions often arise from visions of improved practice and emerging theories about the change that will move the researcher closer to the ideal state of working practices. If I [insert the action to be taken], how will it affect [describe one or more possible consequences of the action]? We will look at two examples, one from education and one from a business setting. *Development of Action Research Questions in an Educational Context* Suppose the researcher is worried about designing the learning context to meet the needs of students who are currently not doing well in the classroom. The general question might be: How can I personalize instruction to match the diverse needs of my students?? This forms a good overall goal which can then lead to a number of possible cycles of action research, each with a separate question. I find that a help research question has two parts. If I listen to students, will I have better understanding of them?

Chapter 5 : Current Issues in Research Ethics : Privacy and Confidentiality

The role of the primary-care physician will evolve into that of team leader “the hub of the care management team, coordinating with a number of midlevels and specialists for each patient. Or the primary care physician will go the way of the dodo.

Vehicle identifiers and serial numbers, including license plate numbers Device identifiers and serial numbers Web Universal Resource Locators URLs Internet Protocol IP address numbers Biometric identifiers, including finger and voice prints Full-face photographic images and any comparable images Any other unique identifying number, characteristic, or code, unless otherwise permitted by the Privacy Rule for re-identification. A Limited Data Set is similar to the de-identified data set but has fewer of the 18 identifiers removed. The Limited Data Set is health information that may include city, state, zip code, elements of date, and other numbers, characteristics, or codes not listed as direct identifiers. Limited data sets are often utilized in multi-center studies when using fully de-identified data is not useful. The use of a Limited Data Set allows a researcher and others to have access to dates of admission and discharge, birth and death, and five-digit zip codes or other geographic subdivisions other than street address. It requires that the researcher neither re-identify the data nor contact the research participant and contains assurances that appropriate safeguards will be used to prevent improper use or disclosure of the Limited Data Set. It may, therefore, be necessary for covered entities to properly use and disclose individually identifiable health information in compliance with both sets of regulations. It is mandatory to report positive HIV test data to state health departments. Depending on the state where the research is conducted, Waivers of Authorization may not be permitted with fully identified HIV data. However, different institutions vary in their policies concerning decedent research. To use or disclose PHI of deceased persons for research, covered entities are not required to obtain an Authorization, a Waiver, an Alteration of the Authorization, or a Data Use Agreement from the personal representative or next of kin. Department of Health and Human Services Obviously, Public Health services provide important essential public health protections. Consequently, various federal and state laws, as well as the policies of various medical and healthcare professional organizations and institutions, provide confidentiality protections for adolescents. Some institutions have developed policies that would require disclosing information to parents in certain circumstances, such as in suicide research if there are threats of suicide by children, adolescents, or college students. Civil penalties usually involve monetary fines. Covered entities and individuals e. Research participants must be given fair, clear, honest explanations of what will be done with information that has been gathered about them and the extent to which confidentiality of records will be maintained. However, the promise of confidentiality cannot be absolute. Under court order or subpoena for example, there may be legal reasons for compelling a researcher to disclose the identity of, or information about, a research participant. In some instances, a researcher may be mandated to report information to government agencies as in cases of child abuse or elder abuse, certain communicable diseases, illegal drug use, and other situations such as gunshot wounds. When research is conducted across multiple sites, review how the information is being protected. Identify and limit the number of people having access to the data, particularly when data are being transferred across locations, and be aware of when data are reproduced in other formats, such as faxes or computer files. Make sure that duplicated information is properly destroyed when transferring data. Review confidentiality procedures during the continuing review of protocols by reexamining the protection of sensitive information and the success of the protection efforts. Educate researchers, research coordinators, and IRB staff on data management and data protection. Also perplexing, are situations in which the IRB must determine which safeguards should be in place to protect past participants who need to be contacted to sign a new Informed Consent Form. Behavioral and social sciences research conducted at a university that is not a covered entity may not fall under the HIPAA regulations. Protections could include the encryption of the data, authentication, and authorization of passwords for those who have access to the data, software security, and

electronic and physical security of data storage devices and networks. Designing study-specific protections for confidentiality requires planning, diligence, time, and knowledge of privacy and confidentiality strategies and procedures. It is important to develop a specific Data Protection Plan. A plan would include: A key that deciphers the code allows re-associating or linking the coded information with the identity of the participant. If applicable, codes may need to be protected by an outside agency or third party. It is important that a clear policy be defined for re-identification. Generally researchers themselves should not be able to re-identify the data but might ask a third party to trace identifiers back to the individual. Various states have laws governing the privacy of such information. Generally, state laws that provide additional privacy protections in a specific area will supercede the HIPAA regulations in those areas. State laws that require reporting of disease or injury, child abuse, elder abuse, birth, death, or public health surveillance, are not overridden by the Privacy Rule.

The Uniqueness of Genetic Information There are differences of opinion about the significance of genetic information for individuals and their families. What makes genetic information unique is that it reveals information not just about the individual from whom it was collected, but also about his or her family members who may not even be aware that genetic information was gathered. It may also reveal information about the larger population of which the individual is a member. Genetic information also can be revealed about individuals and their families and populations simply from a tissue sample or database. Consequently, the decoding of the human genome makes privacy and confidentiality issues extremely acute. Medical research centers and other health care organizations will need to revise current protection procedures to avoid dignitary harms, such as stigmatization and discrimination associated with violations of genetic privacy. Policies must address challenging questions such as: This will present a significant challenge to protecting privacy and maintaining confidentiality in the collection and storage of DNA samples for pharmacogenomic research. Participants in genetic studies may not want family members to know that they carry a specific trait fearing that they will be ostracized or blamed. Furthermore, they may not want to disclose to family members the results of their genetics tests because of potential discrimination by insurance companies and concerns that test results may make the family uninsurable. Many have encouraged the U. Congress to pass a Genetic Information Nondiscrimination Bill. Researchers interested in the possibility of studying genetic markers for diseases or treatments need to learn how to plan appropriately to collect data and how to contact participants for future research and follow-up. Other considerations should include: What length of time is specified for protecting data that include linkages with names and other identifiers? What are the risks to individuals who contribute their DNA to a data repository? Who has access to a data repository? How will the genetic information be used? What are the issues in association studies and how meaningful are they? What are the appropriate safeguards for genetic information? What are the implications of state laws? How will unexpected findings e. The authors of the study concluded that genetic privacy concerns present strong deterrents to genetic counseling and testing research. Include in the Informed Consent Form any possible commercial application resulting from their genetic material for which they will not realize any profit. Protect the interlinking of databases that could reveal personal identities. Establish confidentiality and data security safeguards. Devise sound data access, ownership, and intellectual property policies. Be clear about whether and how study participants will be informed of findings that might be medically helpful to them. Arrange review and oversight by research ethics and privacy protection bodies. Many states have passed genetic privacy laws that provide protections in addition to the protections provided by federal privacy laws. Some states require informed consent and the offer of genetic counseling before performing a genetic test. Some states explicitly define genetic information as personal property; some consider DNA samples as personal property, and some states have penalties for violating genetic privacy laws. The National Conference of State Legislatures publishes information on the specific laws passed by each state. In addition, many states have passed genetic and health discrimination laws. Ethical issues in pedigree research are complicated because there can be potential conflicts between the rights and responsibilities of an individual and of a group. The privacy and autonomy of one family member can conflict with the privacy and autonomy of another individual

or a family. Pedigree research relies on an accurate determination of family history, therefore, it is important to get full family participation. When publishing the family pedigree, care must be taken to protect families, especially in instances of rare diseases because these families are uniquely identifiable by the nature of their branches. There are strategies to protect identities in published pedigree diagrams such as omitting gender information in unaffected family members, collapsing unaffected children into a single icon, and including only a portion of the family. Accessing DNA data banks and the medical histories of many people will be required to determine how genetic variation affects disease incidence, and to determine pharmacologic effects of various treatments. Finding the appropriate balance between privacy and genetic research should be continually considered as genomic medicine progresses. Ethical or IRB review of the circumstances is needed to ensure that the risks are minimized and that proper safeguards for confidentiality will be used. Researchers should consider getting informed consent in advance if there is any possibility of future use of the genetic sample. There may be instances in which prior consent for future studies is advantageous because the risk level of the future study precludes a waiver of informed consent. A brief review of some of these additional challenges is presented below to provide a more comprehensive picture of considerations needed to protect research participants. The types of mandatory reporting, and the agencies that must be reported to, vary by locality. Social and behavioral research may present dilemmas for researchers when data resulting from a behavioral study such as the use of a personality scale or depression inventory suggest that a participant might be at risk of harming himself or herself. There may be an obligation to provide ancillary care when certain diagnostic insights are realized during research. The researcher should consider that participants entrust only specific aspects of their health to the researcher, not necessarily their health in general. The researcher should consider the scope of what is entrusted to him or her by the participants, and what is his or her duty to care for their well-being. Especially in epidemiological studies, researchers often collect data from the proband the affected individual who led to the research done on their family about family members even though informed consent is provided only by the proband. When this occurs, the Common Rule applies and requires the informed consent of the third party. Generally in these situations, whenever informed consent can be sought, it is best to obtain it from the third party, depending on the urgency, practicability, and cost of obtaining it. In designing protocols, researchers must consider whether any third party may be adversely affected by the research. Several specific populations have been defined as vulnerable e. However, it is important to remember that vulnerability may apply to populations that are otherwise not viewed as vulnerable but are considered vulnerable depending on the particular research conditions. Sensitivity to being vulnerable is relative. Data considered sensitive by one person or group may not be considered sensitive by another. In addition, attitudes and vulnerabilities change over time. Many African-Americans are less trusting of medical research, given their fears of discrimination based in part on past experiences e. Gay men and lesbians also may be particularly concerned about their privacy and wary of medical research.

Chapter 6 : The Future of Nursing: Focus on Education : Health and Medicine Division

The integration of health information technology (IT) into primary care includes a variety of electronic methods that are used to manage information about people's health and health care, for both individual patients and groups of patients.

Transforming the health care system to provide safe, quality, patient-centered, accessible, and affordable care will require a comprehensive rethinking of the roles of many health care professionals, nurses chief among them. To realize this vision, nursing education must be fundamentally improved both before and after nurses receive their licenses. As part of its report, *The Future of Nursing: Leading Change, Advancing Health*, the committee considered many challenges that face the nursing education system and some of the solutions that will be required to advance the system. It determined that nurses should achieve higher levels of education and training through an improved education system that promotes seamless academic progression. **The Need for Highly-Educated Nurses** In the 21st century, the health challenges facing the nation have shifted dramatically. The American population is older—Americans 65 and older will be nearly 20 percent of the population by 2020—as well as more diverse with respect not only to race and ethnicity but also other cultural and socioeconomic factors. While chronic conditions account for most of the care needed today, the U. The ways in which nurses were educated during the 20th century are no longer adequate for dealing with the realities of health care in the 21st century. As patient needs and care environments have become more complex, nurses need to attain requisite competencies to deliver high-quality care. These competencies include leadership, health policy, system improvement, research and evidence-based practice, and teamwork and collaboration, as well as competency in specific content areas such as community and public health and geriatrics. Nurses also are being called upon to fill expanding roles and to master technological tools and information management systems while collaborating and coordinating care across teams of health professionals. To respond to these increasing demands, the IOM committee calls for nurses to achieve higher levels of education and suggests that they be educated in new ways that better prepare them to meet the needs of the population. **An Improved Education System** Much of nursing education revolves around acute care rather than community settings that include aspects of primary care, public health, and long-term care. Nursing education frequently does not incorporate the intricacies of care coordination and transitions. Many nursing schools have dealt with the rapid growth of health research and knowledge by compressing available information into the curriculum and adding layers of content that require more instruction. New approaches and educational models must be developed to respond to burgeoning information in the field. For example, fundamental concepts that can be applied across all settings and in different situations need to be taught, rather than requiring rote memorization. Competencies also must move from task-based proficiencies to higher-level competencies that provide a foundation for care management knowledge and decision-making skills under a variety of clinical situations and care settings. **Entering the Profession** Nursing is unique among the health care professions in the United States in that it has multiple educational pathways leading to an entry-level license to practice. Nursing students are able to pursue three different educational pathways to become registered nurses RNs: These various pathways provide numerous opportunities for women and men of modest means and diverse backgrounds to access careers in an economically stable field. The qualifications and level of education required for entry into the nursing profession have been widely debated by nurses, nursing organizations, academics, and a host of other stakeholders for more than 40 years. Although a BSN education is not a panacea for all that is expected of nurses in the future, it does, relative to other educational pathways, introduce students to a wider range of competencies in such arenas as health policy and health care financing, community and public health, leadership, quality improvement, and systems thinking. Care within the hospital continues to grow more complex, with nurses having to make critical decisions associated with care for sicker, frailer patients and having to use more sophisticated, life-saving technology coupled with information management systems that require skills in analysis and synthesis. Care outside the hospital is becoming more

complex as well. Nurses are being called on to coordinate care among a variety of clinicians and community agencies; to help patients manage chronic illnesses, thereby preventing acute care episodes and disease progression; and to use a variety of technological tools to improve the quality and effectiveness of care. A more educated nursing workforce would be better equipped to meet the demands of an evolving health care system, and this need could be met by increasing the percentage of nurses with a BSN. The committee recommends that the proportion of nurses with baccalaureate degrees be increased to 80 percent by 2025. While it anticipates that it will take a few years to build the educational capacity needed to achieve this goal, the committee maintains that it is bold, achievable, and necessary to move the nursing workforce to an expanded set of competencies, especially in the domains of community and public health, leadership, systems improvement and change, research, and health policy. Improving the education system and achieving a more educated workforce—specifically increasing the number of nurses with baccalaureate degrees—can be accomplished through a number of different programs and educational models, including: In addition to increased numbers of BSN-educated nurses, schools of nursing must build their capacities to prepare more students at the graduate level who can assume roles in advanced practice, leadership, teaching, and research. While 13 percent of nurses hold a graduate degree, fewer than one percent have a doctoral degree. Nurses with doctorates are needed to teach future generations of nurses and to conduct research that becomes the basis for improvements in nursing science and practice. The committee recommends doubling the number of nurses with a doctorate by 2025.

Chapter 7 : Update to Congress on the Adoption of Health Information Technology

Thanks to the efforts of the Health Care Payment Learning and Action Network to track this progress, we know that plans and states that cover approximately million Americans are now spending.

Describes the specific actions that have been taken by the federal government and private entities to facilitate the adoption of a nationwide system for the electronic use and exchange of health information 2. Describes barriers to the adoption of such a nationwide system 3. Contains recommendations to achieve full implementation of such a nationwide system The Secretary of Health and Human Services HHS submitted the first report required by section a on January 17, with subsequent submissions on June 21, , October 9, , and February 29, This report is the annual update to the previous submissions. Complete, accurate, and actionable information enables patients to obtain the care they need and to manage their health, providers to make timely and accurate diagnoses, public health entities to conduct electronic immunization reporting and disease surveillance, and researchers to advance science by finding effective treatments for cancer or pursuing precision medicine. Clinicians, care teams, and researchers needed to undertake time-consuming retrospective medical record abstractions to understand whether specific treatments or interventions improved health outcomes. Sharing information with public health officials or measuring health outcomes at the practice level or community level was complex. Recognizing that the delivery and the efficiency of health care could be improved through stronger integration of an electronic health information infrastructure, Congress passed the Health Information Technology for Economic and Clinical Health HITECH Act as part of the American Recovery and Reinvestment Act of ARRA , launching an unprecedented effort to spur the adoption and use of information technology IT throughout the health system. Hospitals and health care providers are using health IT at unprecedented levels. Health IT Quick-Stat Non-Federal Acute Care Hospitals: ONC Data Brief In , 96 percent of hospitals 2 Henry, J. Possession means that the provider has a legal agreement with the EHR vendor, but is not equivalent to adoption. This rapid digitization of the health system was the result of many factors, including extensive collaboration among clinicians, hospitals, technologists, patient and consumer advocates, and experts from all over the country, as well as extensive financial support from the Medicare and Medicaid EHR Incentive Programs. The Regional Extension Center program provided technical assistance to more than , health care providers, helping them adopt and meaningfully use certified health IT. HITECH funding, including awards made under the State Health Information Exchange HIE Program , created and expanded HIE-related infrastructure—both in the technical sense of services and infrastructure, and in the legal sense of governance, consent, and policy structures to support it. Achieving an Interoperable Health System This progress, where an extraordinary amount of electronic health information and infrastructure now exist that the country lacked merely a decade ago, has set the stage for a transition in focus to the seamless and secure flow of this health information — also known as interoperability — to improve the health and care of individuals and communities. Specifically, these advancements have laid the groundwork for progress on a range of national health priorities, including delivery system reform, the Cancer Moonshot, combating the opioid epidemic, the Precision Medicine Initiative, clinical innovation, and protecting and advancing public health. To achieve these and other health priorities, HHS is focused on three priority areas: Open APIs are published and accessible in a way that makes them easy for interested developers to find and use without a program host system intervention and for which there are no fees or other intellectual property restrictions that limit their availability to any competent and interested programmer. Changing the culture around access to information through: In , HHS and other federal agencies have implemented a wide range of actions in these priority areas to bolster the person-centered foundation for a learning, interoperable health system that has developed over the past seven years. HHS will continue to work with public and private sector partners in the months and years to come to ensure that people, organizations, and communities can easily access actionable electronic health information when and where it matters most. Introduction A variety of sources, platforms,

and settings generate electronic health information that can inform health goals, behaviors, and decisions. The secure and seamless flow of this information is foundational to many national priorities: Making usable electronic health information readily available and easily transferable for patients, health care providers, and researchers is fundamental to successfully assembling a research cohort of over a million participants, effectively analyzing that data, and returning results to individuals. The flow of electronic health information using the latest technology is critical to accelerating efforts to cure cancer by, for example, providing access to millions of cancer pathologies, genomic sequences, family histories, and treatment outcomes at once. Prescription drug monitoring programs—state and municipal databases that help clinicians and pharmacists track controlled substances issued to their patients—must communicate more seamlessly and securely with the health IT systems used in clinical care to more effectively address the opioid epidemic. Interoperability is critical to modernizing public health practice to emphasize actions across sectors—environmental, policy, and systems—that directly affect all of the determinants of health. It is also instrumental for detecting, tracking, managing, and preventing communicable diseases. Interoperability is critical to creating an effective learning health care system in which the latest research and clinical trials inform clinical care and patient encounters; in turn, the results of clinical care and patient encounters inform subsequent research and scientific inquiry as well as the future of health and patient care. The rapid adoption of health IT has facilitated increased use of functionalities that have real-world clinical impacts. For example, clinical decision support CDS can alert health care providers to evidence-based clinical guidelines at the point of care, facilitate an enhanced diagnosis or treatment path, and alert providers to potentially harmful drug interactions. Automated identification of antibiotic overdoses and adverse drug events via analysis of prescribing alerts and medication administration records. *Journal of the American Medical Informatics Association*. Effect of Clinical Decision-Support Systems: *Annals of Internal Medicine*. Increased Flow of Health Information Hospitals and physicians are now exchanging more electronic health information than ever before. In 2014, 41 percent of all hospitals electronically exchanged health information with outside health care providers. These rates have since doubled. In 2015, more than eight in ten 82 percent non-federal acute care hospitals electronically exchanged laboratory results, radiology reports, clinical summaries or medication lists. *Non-federal Acute Care Hospitals in 2015*. Percent of non-federal acute care hospitals that electronically exchanged clinical information with ambulatory care providers or hospitals outside their organization: Exchange was assessed using survey questions asking respondents whether their hospital electronically exchanged or shared the following four types of clinical information: Electronic health record systems have also transformed one of the most fundamental elements of health care: Prior to 2010, virtually all prescriptions were handwritten by health care professionals. These paper prescriptions could get lost or misread. With electronic prescribing e-prescribing, health care professionals communicate clearly and directly with pharmacies. In the past 10 years, the number of e-prescriptions transmitted on the Surescripts network rapidly increased. Since 2010, e-prescriptions have nearly doubled to 1. Prescribers can be authenticated before prescribing a controlled substance and prescriptions may be transmitted to pharmacies securely without risk of alteration or diversion. By June 2015, 87 percent of retail pharmacies and 18 percent of e-prescribing providers were enabled for EPCS. This access is vital to their health. Research demonstrates that when individuals have access to, and use, their electronic health information, they feel a greater sense of trust in how their health information is being managed and in how providers are protecting their rights as a patient. Individuals with electronic access to their health information can monitor chronic conditions, better adhere to treatment plans, find and fix errors in their records, and directly contribute their information to research. In 2010, only one-quarter of hospitals provided patients with the ability to electronically view their information; today, 95 percent of hospitals have this capability. The ability of patients to download their information increased from 14 percent in 2010 to 87 percent in 2015; and the ability to transmit information has increased from 12 percent in 2010 to 71 percent in 2015. *Electronic Capabilities for Patients among U.S. Hospitals*. Percent of non-Federal acute care hospitals that provide patients with the capability to electronically view, download, and transmit their health information, SOURCE: Data regarding "Transmit" and "View,

DOWNLOAD PDF INTO THE FUTURE : ACTION RESEARCH FOR HEALTH CARE INFORMATION.

Download, and Transmit" were not collected in Moving Forward The digital health infrastructure and huge volume of electronic health information that now exists provide ever-increasing new opportunities to empower individuals, improve care delivery, modernize public health, and advance research and scientific discovery. To plan for this next era in health IT, the Office of the National Coordinator for Health Information Technology (ONC), in consultation with partners across the federal government, developed the Federal Health IT Strategic Plan, which outlines the commitments of agencies that use or influence the use of health IT to expedite the availability of high-quality, accurate, secure, and relevant electronic health information for stakeholders across the nation. ONC also initiated a complementary planning effort with public and private partners to set a clear path for seamless and secure data flow with A Shared Nationwide Interoperability Roadmap. These plans recognize the important shift from adoption and use of EHRs through the Medicare and Medicaid EHR Incentive Programs as the focus, to a focus on using health IT as a tool to our ultimate goal of supporting individuals and their health outcomes. Federal agencies will also apply a more comprehensive and integrated use of federal payment, procurement, and policy levers to make electronic health information easily accessible and usable across the care continuum. While this report primarily focuses on the actions taken by HHS, there are many examples of progress throughout the federal government. MHS Genesis will utilize certified health IT and common, federally-recognized interoperability standards. Additionally, the VA has begun health IT modernization efforts that focus on assisting clinicians in providing more comprehensive, patient-centered care using modern technological tools. These are just a few of the many examples of federal efforts beyond HHS to advance the seamless and secure flow of electronic health information across the country. This year HHS announced interoperability pledges from the broad communities most affected by electronic health information exchange. These stakeholders include companies that provide 90 percent of hospitals their EHRs, large health systems including the top five largest private health systems in the country with facilities in 47 states and more than two dozen professional associations and stakeholder groups. To help consumers easily and securely access their electronic health information, direct it to any desired location, learn how their information can be shared and used, and be assured that this information will be effectively and safely used to benefit their health and that of their community. Implement federally recognized, national interoperability standards, policies, guidance, and practices for electronic health information, and adopt best practices including those related to privacy and security. Critical Actions to Advance Health IT Use and Information Flow Public and private sector efforts should together drive toward a health system where electronic health information flows seamlessly through easy-to-use technology solutions that present actionable information when it is needed most. This section describes actions undertaken by HHS in building on work throughout the HITECH era to achieve seamless and secure data flow by promoting common, federally-recognized standards, building the business case for interoperability, and changing the culture around access to information. Promoting Common, Federally-Recognized Standards Standards help individuals, health care entities, public health agencies, health IT products, and medical devices consistently and accurately find, send, receive, and integrate electronic health information. Use of common technical standards and specifications are necessary for electronic health information to move seamlessly and securely. Much of the content of clinical records including laboratory test results, clinical measurements e. Using data elements consistently and reliably allows for collecting information for individual health needs as well as for reuse of that information to drive decision support, quality measurement and reporting, population health management, public health, and research. Pilot testing and aligning standards activities with clinical care delivery and business needs can help accelerate their widespread adoption, allowing health IT to be more usable and efficient. ONC has initiated key actions to accelerate the use of common standards, such as publishing the Interoperability Standards Advisory (ISA) a single resource for those looking for federally recognized, national interoperability standards and guidance. The ISA provides the industry with a single list of the standards and implementation specifications that can fulfill specific clinical health information interoperability needs. It reflects the results of ongoing dialogue,

debate, and consensus among industry stakeholders when more than one standard or implementation specification could be used. The ISA also documents known limitations, preconditions, dependencies, and security patterns among referenced standards and implementation specifications when they are used to fulfill specific clinical health IT interoperability needs. The Edition final rule also advances the movement toward common standards and the criteria needed for their certified use in health IT products. It builds on past rulemakings to facilitate greater interoperability for several clinical health information purposes and enables health information exchange through new and enhanced certification criteria, standards, and implementation specifications. These updates will improve access for health care providers across the care continuum to the technical standards that form an essential foundation for interoperability and help ensure that key information is consistently available to the right person, at the right place, and at the right time. The Edition final rule has a strong focus on the interoperable exchange of data, including through the use APIs such as those built using Fast Healthcare Interoperability Resources FHIR see text box and new transparency and accountability provisions. The final rule also enhances the ONC Health IT Certification Program by including provisions for more rigorous testing of health IT exchange capabilities, establishing explicit requirements for in-the-field surveillance and transparency of health IT, and by making granular information about certified health IT publicly available through an open data certified health IT product list CHPL. An API is a software application function that can be invoked or controlled through interactions with other software applications apps. APIs are the means by which apps communicate and exchange information across systems. FHIR API access seeks to provide seamless transmission of electronic health information from a health system to consumers or the app that the consumer chooses. FHIR is suitable for use in a wide variety of contexts “ mobile phone apps, cloud communications, EHR-based data sharing, and server communication in large institutional health care provider organizations. ONC also encourages community-driven, user-focused innovation to allow individuals and health care providers to access, easily and securely, electronic information and direct it to any desired location. Additionally, ONC promotes collaboration on these efforts through the Interoperability Proving Ground , a dynamic user-generated platform of health-related interoperability projects across the nation and around the world. For example, in March , ONC launched a three-part strategy to connect and accelerate a FHIR-app ecosystem that will spur the development of market-ready, user-friendly software apps for consumers and health care providers. The strategy seeks to leverage the growing interest in an industry-wide approach to open, standardized APIs. The strategy has three goals:

Chapter 8 : Embracing the Future: New Times, New Opportunities for Health Information Managers

In the near future, require timely information and action, and sometimes have life or death consequences. many attempts to bring data analytics or other information technology into health.

Insurance companies and HMOs; and Consulting firms. Within this variety of settings HIM professionals fulfill a wide range of job positions, and increasingly work in critical and influential positions. Healthcare providers and HIM employers are increasingly utilizing health information for a variety of decisions and benchmarking measurements, increasing their reliance on HIM professionals to provide data management and analysis and ensure quality and security of information. This growing demand for HIM services in a variety of functions has resulted in the profession embracing a broader set of roles. As a result, HIM professionals often specialize in a particular area of expertise, in addition to being trained in a core set of HIM skills. HIM professionals are becoming: Professional Development Specialized Advanced Certificates. To ensure the value of credentials, AHIMA is updating certification exams to ensure they reflect current and future practice. As the field becomes more advanced, certifications for specific areas such as the EHR, HIM system design and classification systems will be increasingly available. AHIMA is working toward a future in which health information is electronic, patient-centered, comprehensive, longitudinal, accessible, and credible. In addition, AHIMA publishes practice guidelines and other materials that reflect how HIM practice evolves and enables members to continue to move it forward. Credentialing and continued educational and advancement opportunities are critical to the future success and growth of HIM. Education and Preparation Meeting Workforce Needs. Education is a key part of this process, as the best and the brightest will pursue the HIM profession if the field is viewed as recruiting top performers and offers advancement opportunities. Ensure Students Are Prepared for the Future. Educational programs must ensure that their curricula reflect what students need to know for careers in electronic environments. Their progress will be reflected in accreditation by the Commission on Accreditation for Health Informatics and Information Management Education, created in as an accrediting body for degree-granting programs in HIM and health informatics. And the Association is making sure that HIM educators are up to date on the latest developments in HIM practice and providing new learning tools, such as a virtual learning lab to provide students experience in the electronic environment. All these ensure that HIM graduates have practical, hands-on experience and a curriculum reflecting the evolution of the profession. Build on the Strengths of Increasing Diversity. HIM professionals are increasingly employed in nontraditional settings. AHIMA seeks to help members meet the needs of a growing variety of employers and to broaden the influence of the profession throughout healthcare. Raise the Profile of the Profession. Patients need to become more aware of the services and advocacy provided by HIM professionals, and HIM professionals want the public and the places they work to know more about them, too. In addition, HIM tasks are becoming increasingly decentralized-so an HIM professional might conceivably work in many different areas of an organization. AHIMA is committed to supporting its members as they work to raise their professional profiles. AHIMA is committed to advancing the profession by supporting its members and using its influence to make strong HIM practices pervasive throughout the industry. With the national focus on health information and the need for information technology that is comprehensive and interoperable across the country, AHIMA is in a unique position to help shape the national agenda. Change is happening on four fronts: Privacy and security; Standards for data interchange and system interoperability; The EHR; and The overall national health information infrastructure. With the overriding goal of HIM always in mind-ensuring the availability of health information to facilitate real-time healthcare delivery-AHIMA is involved in initiatives designed to advance the role of HIM in informing clinical practice, developing standards to improve data quality and facilitate information exchange, and helping healthcare organizations migrate to the electronic health record EHR.

The Importance of Health Research. Like privacy, health research has high value to society. It can provide important information about disease trends and risk factors, outcomes of treatment or public health interventions, functional abilities, patterns of care, and health care costs and use.

As noted in the introduction to Chapter 2 , the committee views privacy and health research as complementary values. Ideally, society should strive to facilitate both for the benefit of individuals as well as the public. In addition to defining health research and delineating its value to individuals and society, this chapter provides an overview and historical perspective of federal research regulations that were in place long before the Privacy Rule was implemented. Because a great deal of medical research falls under the purview of multiple federal regulations, it is important to understand how the various rules overlap or diverge. The chapter also explains how the definition of research has become quite complex under the various federal regulations, which make a distinction between research and some closely related health practice activities that also use health data, such as quality improvement initiatives. The chapter also reviews the available survey data regarding public perceptions of health research and describes the importance of effective communication about health research with patients and the public. Perhaps the most familiar form of health research is the clinical trial, in which patients volunteer to participate in studies to test the efficacy and safety of new medical interventions. But an increasingly large portion of health research is now information based. A great deal of research entails the analysis of data and biological samples that were initially collected for diagnostic, treatment, or billing purposes, or that were collected as part of other research projects, and are now being used for new research purposes. This secondary use of data is a common research approach in fields such as epidemiology, health services research, and public health research, and includes analysis of patterns of occurrences, determinants, and natural history of disease; evaluation of health care interventions and services; drug safety surveillance; and some genetic and social studies Lowrance, ; Lowrance and Collins, *The Importance of Health Research* Like privacy, health research has high value to society. It can provide important information about disease trends and risk factors, outcomes of treatment or public health interventions, functional abilities, patterns of care, and health care costs and use. The different approaches to research provide complementary insights. Clinical trials can provide important information about the efficacy and adverse effects of medical interventions by controlling the variables that could impact the results of the study, but feedback from real-world clinical experience is also crucial for comparing and improving the use of drugs, vaccines, medical devices, and diagnostics. For example, Food and Drug Administration FDA approval of a drug for a particular indication is based on a series of controlled clinical trials, often with a few hundred to a few thousand patients, but after approval it may be used by millions of people in many different contexts. Therefore, tracking clinical experience with the drug is important for identifying relatively rare adverse effects and for determining the effectiveness in different populations or in various circumstances. It is also vital to record and assess experience in clinical practice in order to develop guidelines for best practices and to ensure high-quality patient care. Collectively, these forms of health research have led to significant discoveries, the development of new therapies, and a remarkable improvement in health care and public health. If the research enterprise is impeded, or if it is less robust, important societal interests are affected. The development of Herceptin as a treatment for breast cancer is a prime example of the benefits of research using biological samples and patient records Box Slamon et al. Many other examples of findings from medical records research have changed the practice of medicine as well. Such research underlies the estimate that tens of thousands of Americans die each year from medical errors in the hospital, and research has provided valuable information for reducing these medical errors by implementing health information technology, such as e-prescribing Bates et al. This type of research also has documented that disparities in health care and lack of access to care in inner cities and rural areas result in poorer health outcomes Mick et al. Furthermore, medical records research has

demonstrated that preventive services e. These findings have all informed and influenced policy decisions at the national level. As the use of electronic medical records increases, the pace of this form of research is accelerating, and the opportunities to generate new knowledge about what works in health care are expanding

CHSR, Herceptin and breast cancer: Data were collected from a cohort of more than 9, breast cancer patients whose tumor specimens were consecutively received at the University more Advances in health information technology are enabling a transformation in health research that could facilitate studies that were not feasible in the past, and thus lead to new insights regarding health and disease. The informatics grid recently developed with support from the National Cancer Institute Cancer Biomedical Informatics Grid, or caBIG is an example of a how information technologies can facilitate health research by enabling broader sharing of health data while still ensuring regulatory compliance and protecting patient privacy

Box Science today is also changing rapidly and becoming more complex, so no single researcher or single site can bring all the expertise to develop and validate medical innovations or to ensure their safety. Thus, efficient sharing of information between institutions has become even more important than in previous eras, when there were fewer new therapies introduced. The expansion of treatment options, as well as the escalating expense of new therapies, mandates greater scrutiny of true effectiveness, 5 once efficacy has been demonstrated. This requires registries of patient characteristics, outcomes, and adverse events. Analysis of the data collected is expected to facilitate improved patient evaluation and management while aiding in better device development. Registry results are also expected to influence future research and facilitate appropriate regulation and reimbursement of such devices. Similarly, the Extracorporeal Life Support Organization ELSO , 7 an international consortium of health care professionals and scientists who focus on the development and evaluation of novel therapies for support of failing organ systems, maintains a registry of extracorporeal membrane oxygenation and other novel forms of organ system support. Registry data are used to support clinical practice and research, as well as regulatory agencies. Another example is the database developed by the United Network for Organ Sharing UNOS for the collection, storage, analysis and publication of data pertaining to the patient waiting list, organ matching, and transplants. Information-based research, such as research using health information databases has many advantages reviewed by Lowrance, It is often faster and less expensive than experimental studies; it can analyze very large sets of data and may detect unexpected phenomena or differences among subpopulations that might not be included in a controlled experimental study; it can often be undertaken when controlled trials are simply not possible for ethical, technical, or other reasons, and it can be used to study effectiveness of a specific test or intervention in clinical practice, rather than just the efficacy as determined by a controlled experimental study. It can also reexamine data accrued in other research studies, such as clinical trials, to answer new questions quickly and inexpensively. However, information-based research does have limitations. Often it has less statistical rigor than controlled clinical studies because it lacks scientific control over the original data collection, quality, and format that prospective experimental research can dictate from the start. In addition to these scientific limitations, because of its relational and often distant physical separation from the data subjects, and the sheer volume of the records involved, obtaining individual consent for the research can be difficult or impossible. Advances in information-based medical research could also facilitate the movement toward personalized medicine, which will make health research more meaningful to individuals. In spite of the strides made in improving health through new treatments, it is widely known that most drugs are effective in only a fraction of patients who have the condition for which the drug is indicated. Moreover, a small percentage of patients are likely to have adverse reactions to drugs that are found to be safe for the majority of the population at the recommended dose. Both of these phenomena are due to variability in the patient population. The surveys reviewed in this chapter focus on interventional clinical trials. A review of survey questions to gauge the public willingness to allow their medical records to be used in research can be found in Chapter 2. The Public Values Health Research A number of studies suggest that most Americans have a positive view of medical research and believe that research is beneficial to society. A recent Harris poll found that nearly 80 percent of respondents were interested in health research findings, consistent with

previous survey results Westin, A study in compiled data from 70 state surveys and 18 national surveys and found that the majority of Americans believe maintaining world leadership in health-related research is important. Seventy-eight percent of respondents said that it is very important, and 17 percent said that it is somewhat important. Only 4 percent of Americans reported that maintaining world leadership in health-related research is not important Woolley and Propst, Similar results were found in a survey—76 percent of respondents reported that science plays a very important role in our health, and 78 percent reported that science plays a very important role in our competitiveness Research! Overall Experience When Participating in Research Little is known about the attitudes of individuals who have actually participated in medical research. However, the available evidence suggests that most research participants have positive experiences. A recent Harris Poll found that 13 percent of respondents had participated in some form of health research, and 87 percent of those felt comfortable about their experience Westin, In a study focused on cancer, 93 percent of respondents who participated in research reported it as a very positive experience; 76 percent said they would recommend participation in a clinical trial to someone with cancer. Most physicians surveyed in this study stated that they believe clinical trial participants receive the best possible care, and have outcomes at least as good as patients receiving standard cancer treatment Comis et al. Another study found that 55 percent of individuals who participated in a research study would be willing to participate again in a future research study Trauth et al. Willingness to Participate in Research Public opinion surveys indicate that a majority of Americans are willing to participate in clinical research studies. In , a compilation of studies commissioned by Research! America found that 63 percent of Americans would be willing to participate in a clinical research study Woolley and Propst, This percentage has remained stable over time. America survey also found that 63 percent of Americans would be very likely to participate in a clinical research study if asked Research! America, ; 68 percent of respondents reported that their desire to improve their own health or the health of others was a major factor in deciding whether to participate in a clinical research project Research! Other surveys also suggest that willingness to participate in research focused on specific diseases is quite high. In one survey, the percentage of respondents indicating a willingness to participate in a medical research study was 88 percent for cancer, 86 percent for heart disease, 83 percent for a noncurable fatal disease, 79 percent for addiction, 78 percent for depression, and 76 percent for schizophrenia Trauth et al. Respondents with greater knowledge of how research is conducted were more willing to participate Trauth et al. Another study found that 8 of 10 Americans would consider participating in a clinical trial if faced with cancer. More than two-thirds of respondents said they would be willing to participate in a clinical trial designed to prevent cancer Comis et al. Americans also seem to be very supportive of medical research that relies on genetic data. The Trauth survey found that individuals with higher income levels, with a college or graduate degree, or with children were more likely to participate in research. Age affected willingness to participate: It is well documented that minorities participate in health research at a much lower percentage than white Americans. Many cultural, linguistic, and socioeconomic barriers could be responsible for this difference Giuliano et al. Several studies suggest that the low participation rates by racial and ethnic minority groups are due to their strong distrust of the medical research community compared to the general population Braunstein et al. Thus, it is likely that the low number of minority individuals participating in medical research is at least partly due to recruitment techniques that are ineffective for minority populations. The survey that focused on cancer research suggests that one of the main reasons why individuals do not participate in research is lack of knowledge about the availability of clinical trials. In a survey of nearly 6, cancer patients, 85 percent said they were unaware of the opportunity to participate in a clinical trial. Respondents who did participate said they did so because of one of the following beliefs: A recommendation from a physician can also impact participation. Twenty percent of respondents in an Italian public survey indicated that the presence of a physician as a reference during a research study influenced their willingness to participate Mosconi et al. In sum, surveys indicate that the vast majority of Americans have a positive view of medical research, believe that research is beneficial to society, and are interested in health research findings. Although little is known about the attitudes

of individuals who have actually participated in medical research, the available evidence suggests that most research participants have positive experiences. Surveys also suggest that a majority of Americans are willing to participate in clinical research studies. Notably, respondents with greater knowledge of how research is conducted were more willing to participate in research. The most well-known examples included 1 reported abuses of concentration camp prisoners in Nazi experiments during World War II, and 2 the Tuskegee syphilis study begun in , in which researchers withheld effective treatment from affected African American men long after a cure for syphilis was found. Most of the current principles and standards for conducting human subjects research were developed primarily to protect against the physical and mental harms that can result from these types of biomedical experiments. Therefore, they focus on the principles of autonomy and consent. Although the standards apply to research that uses identifiable health information, research based solely on information is not their primary focus. Nuremberg Code The Nuremberg Code, created by the international community after the Nazi War Crimes Trials, is generally seen as the first codification more In the United States, perhaps the most influential inquiry into the protection of human subjects in research was the Belmont Report. The Belmont principles have been elaborated on in many settings, and served as the basis for formal regulation of human subjects research in the United States. In general, states do not directly regulate the activity of most researchers Burris et al. The committee agreed that uniformity of federal regulations on human subjects protection is desirable to eliminate unnecessary regulations and to promote increased understanding by institutions that conduct federally supported or regulated research.