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## Chapter 1 : Occupational Therapy - calendrierdelascience.com

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Many people seek medical information on the Internet but may encounter requests for registration or fees, or? National Library of Medicine NLM , a component of the National Institutes of Health, provides web-based resources that address the challenges of newborn screening education. These resources include MedlinePlus? NLM websites are not commercial, do not require registration or fees, and provide varied levels of information for a continuum of audiences from low-literacy consumers to health professionals. Using phenylketonuria as an example, this study describes the information that parents and their medical providers can? NLM has embraced the digital age and provides the public with reliable, accurate, and up-to-date educational materials. Published Wiley-Liss, Inc.? National Institutes of Health NIH , provides resources that address the challenges of newborn screening education. As a consequence of free access, this resourceâ€” once used almost exclusively by medical librarians, scientists, and health professionalsâ€”was discovered by the public [Lacroix and Mehnert, ]. Internet users have searched the Web for health information [Fox, ], including information about genetic disorders [Guttmacher, ; Taylor et al. Consumers, however, assert that web sites with genetic information are often hard to understand and dif? Patient education web sites that are user-friendly and provide lay-language materials often focus on a narrow range of disorders or charge a fee for these materials. With the growing public use of the Internet, NLM recognized that consumers wanted a broad spectrum of health information in easy-to-understand language. Beginning in , NLM introduced new resources designed to help the general public and professionals? In small increments, states expanded testing for additional disorders. By , most states screened for fewer than 8 genetic disorders [National Newborn Screening and Genetics Resource Center, ]. The introduction of tandem mass spectrometry for newborn screening in the s, however, allowed detection of 30 or more metabolic disorders from a single specimen [Chace et al. This technological advance, coupled with recommendations for expanded newborn screening [Newborn Screening Task Force, ; Health Resources and Services Administration, ], accelerated the increase in the number of disorders that are included in state newborn screening programs. By , half the states screened for 25 or more disorders [Therrell, ]. The challenge of educating healthcare providers and parents has intensi? Many of the disorders included in expanded screening programs are rare and may not be well understood by medical professionals who provide treatment and educate parents [Newborn Screening. N levels of information for a continuum of audiences from low-literacy consumers to health professionals. MedlinePlus Introduced in , MedlinePlus [http: MedlinePlus Quality Guidelines for Selecting Online Resources](http://www.nlm.nih.gov/medlineplus/) Quality, authority and accuracy of content Sites must provide the names of their advisory board members or be published by a government agency. Intrusive or content-linked advertisements disqualify pages from inclusion. Most of the content must be free and not require registration. Maintenance The site must be consistently available, without broken links, and provide a Webmaster address. Pages must display dates. Quality, nonredundant content Because MedlinePlus is selective, not comprehensive, links on Health Topic should have minimal redundancy. Each linked document provides unique information to the consumer using that Health Topic page. Some links bring users a clear summary of an entire disease or condition, while others bring unique features, such as different reading levels, clear diagrams, illustrations, or interactive programs. MedlinePlus also has extensive information about drugs, an illustrated medical encyclopedia, interactive patient tutorials, and the latest health news. Health Topic pages are the core of MedlinePlus. These topic pages provide highly selective collections of links to Web documents, not comprehensive lists of everything on the Web. They point consumers to the best Web resources and minimize redundant listings. As of August , health topics were available on MedlinePlus. Many of these topics are also available in Spanish. MedlinePlus updates the Health Topic pages

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daily with press announcements from government organizations and with news stories from Reuters and HealthDay. Images illustrate how to? They also include the source of online resources and identify easy-to-read materials and other special features such as pictures, diagrams, and? The Health Topic pages function like a table of contents to chapters in an Internet book. This arrangement helps consumers easily scan the pages and provides them with a refuge from the overwhelming amounts or varying quality of Internet health information. NLM uses established guidelines Table 1 to identify and select high-quality information produced by other NLM has several web-based resources that provide information about newborn screening and rare disorders detected through screening efforts. NIH Institutes, government organizations, and nongovernmental health information providers. MedlinePlus publishes these guidelines <http://www.nlm.nih.gov/medlineplus/>: These guidelines assure users that the information they? MedlinePlus does not use cookies and does not request any personal information. Licensed content supplements the Health Topic pages in areas where authoritative Web content is not available. MedlinePlus licenses drug information, herbal and dietary supplement information, an illustrated medical encyclopedia, health news, a medical Fig. The left hand side of the topic page serves as a table of contents for phenylalanine-speci? Using Flash technology, audio narration, and animated graphics, each tutorial explains a procedure or condition in easy-to-read language. A printed summary is available for each tutorial. The tutorials also include quizzes to reinforce major points of the presentation. They are an invaluable information source for patients, including those with low vision or low-literacy skills. For a wide range of diseases and conditions, ClinicalTrials. In , more than a dozen major medical journals began requiring registry in ClinicalTrials. As of August , the ClinicalTrials. For each study in the database, ClinicalTrials. The interactive health tutorial provides a multimedia presentation on several facets of phenylketonuria reproduced with permission from the Patient Education Institute x-plain. Learning aids are also available and include a glossary of terms used in clinical trials and a series of frequently asked questions that provide introductory information about clinical trials. Using a question-and-answer format, GHR provides short summaries of genetic disorders and the genetic variations responsible for these disorders. As of August , summaries were available for conditions, genes, and all the human chromosomes. GHR provides information for the 29 conditions included in the core screening panel recommended in the draft report by the Health Resources and Services Administration []. The summaries are written on a high-school level in lay-friendly language. Each condition summary provides a concise description of the disorder and an explanation of its incidence or prevalence, inheritance pattern, and genetic etiology. Chromosome summaries describe the basic characteristics of each chromosome, and some summaries include a discussion of related chromosomal disorders. Each type of summary links to a wide spectrum of online resources to accommodate the varied needs of GHR users. MEDLINE contains bibliographic citations and author abstracts from more than 4,000 biomedical journals published in the United States and 70 other countries. The database contains more than 16 million citations dating back to the mid 1950s. Coverage is worldwide, but most records are from English-language sources or have English abstracts. Users may have to register, or there may be a fee or subscription required to access the full text. PubMed is an indispensable tool for users who want to read the latest research from professional medical journals. The NLM web sites described earlier are crosslinked to one another. In this case study, a search will begin on the MedlinePlus web site and will illustrate connections to the other NLM resources and the authoritative information available to patients and health professionals. Beginning with the MedlinePlus homepage <http://www.nlm.nih.gov/medlineplus/>: Once on the topic page for phenylketonuria, the user can scan the contents of the page from the box in the left margin Fig. Each topic page is like a table of contents that allows the user to go quickly to a speci? For example, the link for Newborn Screening takes the user to a Health Topic page that covers the general aspects of newborn screening and provides resources describing disorders that are detected through screening programs. Clicking on the link to the interactive tutorial provides users with a multimedia presentation Fig. A search of the ClinicalTrials database reveals several studies related to phenylketonuria. If the user prefers to scroll through the Health Topic page, the? Scrolling further down the page, users? The link to ClinicalTrials. Clicking on a link to any of these trials will bring the user to an information page about the

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study. Genetics Home Reference condition summaries provide learning aids such as relevant information in the tutorial Handbook and links to glossary terms. The left margin of each summary page offers quick links to the related genes and additional resources such as PubMed. A search using PubMed? The LinkOut feature can be used to? The summary describes signs and symptoms and explains the concept of autosomal recessive inheritance. The condition summary includes links to glossary terms and sections of the Handbook to help users with unfamiliar terminology or concepts. The left margin of the page offers links to the related gene and additional resources from NIH, NLM, and other organizations. These resources range in complexity from lay-level overviews to the genetics database Online Mendelian Inheritance of Man [Hamosh et al. This case study highlights the network of NLM resources that provides valuable information for parents and health providers. SUMMARY Expanded newborn screening and subsequent detection of rare genetic disorders challenges medical providers and parents to understand the consequences of these disorders. In , NLM began to introduce web-based educational resources that are designed for the general public and are also suitable for healthcare professionals. These NLM web sites address dozens of disorders detected through newborn screening and provide users with a continuum of medical information ranging from easy-to-understand information about genetic etiology, inheritance, and incidence to available clinical trials and relevant biomedical literature. NLM web sites also direct users to additional online resources that meet quality standards. These government web sites are freely accessible and offer information that is reliable, accurate, and up to date. Perceived barriers to Internet-based health communication on human genetics.

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## Chapter 2 : THE ROLE OF NATIONAL LIBRARY OF MEDICINE WEB SITES IN NEWBORN SCREENING

*The National Library of Medicine Reaches Out to Consumers In ,NLM partnered with the Patient Education Institute (PEI),Iowa City,Iowa, for a pilot test to customize its X-Plain interactive tutorials to NLM's speciifcations for.*

Advanced Search Abstract Increasingly, consumers engage in health information seeking via the Internet. Taking a communication perspective, this review argues why public health professionals should be concerned about the topic, considers potential benefits, synthesizes quality concerns, identifies criteria for evaluating online health information and critiques the literature. More than 70 websites disseminate health information; in excess of 50 million people seek health information online, with likely consequences for the health care system. The Internet offers widespread access to health information, and the advantages of interactivity, information tailoring and anonymity. However, access is inequitable and use is hindered further by navigational challenges due to numerous design features e. Increasingly, critics question the quality of online health information; limited research indicates that much is inaccurate. Future research needs to address the Internet as part of the larger health communication system and take advantage of incorporating extant communication concepts. Both interpersonal and mass communication concepts open avenues for investigation and understanding the influence of the Internet on health beliefs and behaviors, health care, medical outcomes, and the health care system. Introduction Increasingly, professionals and consumers engage in interactive health communication. Perhaps the most common and influential function of interactive health communication today is health-information seeking by consumers. This state-of-the-art review focuses on consumer online health-information seeking. Public health interest in consumer health-information seeking via the Internet Public health professionals need to focus on health-information seeking via the Internet for a variety of reasons. These include magnitude and diversity of use; diversity of users; and, ultimately, implications for the health care system, in terms of structure, health care interaction and quality of medical outcomes. Magnitude of use As the Internet has grown, so too have health-related purposes. Perhaps most common is consumer health-information seeking. Although only computers were linked to the Internet in , by , 4 million were Eng et al. Consumers seeking health information Consumer use of the Internet for health information is large and growing; more than 70 websites provide health information Grandinetti, Expressed in raw numbers, an estimated 18 million adults in the US sought health information online in Cyber Dialogue, An example illustrates the growth. Searches increased from 7 million in to more than million in ; more than one-third of the latter were consumers Louis Harris and Associates, In addition, consumers report convenience, anonymity and diversity of information sources as attractions Pew Internet and American Life Project, c. Consumers access online health information in three primary ways: Health web pages Consumers can access online health information directly from credible scientific and institutional sources e. Medline, Healthfinder as well as unreviewed sources of unknown credibility e. Searches often are triggered by a diagnosis and desire for treatment information Boyer et al. In turn, information found may influence medical decision making and help consumers to manage their own care Wilkins, ; Pew Internet and American Life Project, c. Consumers also use the Internet to access performance reports regarding providers and hospitals Green ; Anonymous, , and information about managed care organizations Williams, Information may be used to select providers Coile and Howe, , identify specialists Williams, and make decisions regarding employment-related health care benefits Cronin, In addition, the Internet may be used to complement school health education Roffman et al. Online support groups An estimated one in four health-information seekers joins a support group Anonymous, ; Cyber Dialogue, Social support groups abound offline and online for an array of reasons Cline, Like face-to-face groups, online groups offer an alternative to professional care; provide social support, information, shared experiences and behavioral models; and empower participants, fulfilling the functions of a community Sharf, ; King and Moreggi, ; Nochi, One study found that users rated online support groups more helpful than physicians in numerous ways e. Relative advantages of online groups

are their h availability, anonymity, selectivity in responding, capacity for immediate and time-delayed reactions, unlimited volume of participants including professionals , and exposure to an increased number of opinions, expertise and experience Sharf, ; Haythornwaite et al. The lack of non-verbal cues and potential for anonymity create a level playing field with regard to status King and Moreggi, Online interaction with health professionals Increasingly, consumers use the Internet to consult with health professionals. About one in five physicians E-mail patients Cyber Dialogue, b and 3. A more controversial development is fee-based psychotherapy via E-mail. Online therapy raises ethical questions and legal concerns King and Moreggi, related to diagnosis by E-mail alone Buhle, , given the potential for misrepresentation and deception McLellan, , and unclear care standards with regard to record keeping, outcome expectations, billing and confidentiality Shapiro and Schulman, Diverse users Early Internet users were likely to be white male professionals. Women, more than men, tend to prefer health sites, in part because of care-taking roles. Internet use spans generational lines. Izenberg and Lieberman identified health websites specifically designed for children Izenberg and Lieberman, Many of the latter were ill or had ill spouses. Collaborations or collisions ahead? Implications for the health care system Increased consumer participation in interactive health communication is likely to influence the health care system due to its information dissemination, health promotion, social support and health services functions Robinson et al. A PricewaterhouseCoopers PricewaterhouseCoopers, global survey of health industry thought leaders yielded the expectation that the Internet will create massive changes in health care. However, critics disagree about the valence of consequences. Optimists anticipate better-informed decisions by consumers, better and more tailored treatment decisions, stronger providerâ€”client relationships, and increased patient compliance and satisfaction Ayonride, ; Wilkins, , resulting in better medical outcomes Bader and Braude, ; Wilkins, and more efficient service PricewaterhouseCoopers, Pessimists contend that interactive health communication will not enhance physicianâ€”patient communication, with physicians likely to balk at the added responsibilities Appleby, ; Baur, Among the ways that interactive health communication is forecast to affect health care include: As consumers increasingly use the Internet to more actively and independently manage their health care, they are likely to take this active role into encounters with providers. This emerging consumer role has implications for health care relationships. Consumers may confront providers who are unprepared to deal with the magnitude of available information Coiera, , with patients sometimes having greater information access than their providers. Providers may be stressed by added responsibilities for information seeking and clarification, and become frustrated and resistant due to time costs in correcting inaccuracies Ayonride, ; Appleby, ; Lincoln and Builder, Many providers are threatened by their loss of power and fear damage to physicianâ€”patient communication Anonymous, Anticipated changes highlight the need to integrate interactive health communication into medical and health professional curricula Aschenbrener, ; Kaufman et al. Potential benefits to consumers are many. Breaking the space and time barriers of traditional information-seeking processes, the Internet offers widespread dissemination, high volume and currency Eng and Gustafson, ; Gregory-Head, ; McKinley et al. As a result, the Internet offers the potential for greater equity in access to health information Morris et al. In some cases, websites are developed specifically for otherwise hard-to-reach audiences e. NetWellness, a consumer health library, developed for a rural population Guard et al. Interactivity A major potential benefit of the Internet is its capacity for interactivity, emphasizing transactional rather than linear communication processes Pereria and Bruera, ; McMillan, Interactivity is reflected in complexity of choice, responsiveness or conversationality and interpersonal communication McMillan, Interactivity further promotes tailoring of messages and facilitates interpersonal interaction. Tailoring of information In contrast to traditional sources of health information e. Consumers can select sites, links and specific messages based on knowledge, educational or language level, need, and preferences for format and learning style, often at lower cost than conventional methods Pereira and Bruera, At the same time, traditional health information and patient education materials and messages can be placed on the Internet inexpensively Richards, et al. Potential to facilitate interpersonal interaction and social support The Internet offers opportunities for consumers to

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interact interpersonally with health professionals and peers. Research consistently indicates that health behavior change typically results more from interpersonal than mass communication [e.

Chapter 3 : calendrierdelascience.com: Sitemap

*The National Library of Medicine reaches out to consumers / J.E.B. Backus, E.M. Lacroix. Baby CareLink: collaborative tools to support families / C. Safran, D. Goldsmith. CHOICES: patients as participants in shared care planning at the point of care / C.M. Ruland.*

My intention was to find authors from a wide range of countries. But the occupational therapy interventions included here are largely from Australia, Europe, and the United States. The chapters in this handbook provide evidence-based interventions that can be clinically applied. It is hoped that this handbook will contribute to the future development of occupational therapy worldwide. References American Occupational Therapy Foundation. Thesaurus of occupational therapy subject headings. A subject guide to OT search. American Occupational Therapy Foundation. Educational intervention toward preventive home visitors reduced functional decline in community-living older women. *J Clin Epidemiol*, 60 9 , " Spastic paralysis treatment of by the use of reflex inhibition. *Br J Phys Med*, 13 6 , " Occupational therapy after hip fracture: A pilot study of the clients, the care and the costs. *Clin Rehabil*, 8 2 , 52" Early individualized postoperative occupational therapy training in patients improves ADL after hip fracture: *Acta Orthop Scand*, 75 2 , " *Acta Orthop*, 77 1 , " Effects of Bobath-based therapy on depression, shoulder pain and health-related quality of life in patients after stroke. *J Rehabil Med*, 39 8 , " Hospital discharge among frail elderly people: *Occup Ther Int*, 15 1 , 18" *Clinical Research in Occupational Therapy*, 4th ed. Chapter 2 Occupational Therapy: Clients1 are diagnosed with medical conditions causing functional limitations and restrictions in activities of daily living, such as selfcare, and in home, work, and leisure activities. Occupational therapy core contents, purposes, and goals are defined. Statements of Definitions of Occupational Therapy Core Contents Occupation is the core content and the most basic concept of occupational therapy. Occupations is everything people do to occupy themselves, including looking after themselves"enjoying life"and contributing to the social and economic fabric of their communities". Levine and Brayley, 1 Client is the chosen term throughout the Handbook. However, it is interchangeable with the term patient. McNary, In occupational therapy, occupation is thus both the mediator and the goal of the intervening process Royeen, These factors deeply influence how the OT conducts an intervention. This facts are illustrated: In his presentation, my colleague explained how to adapt the knobs on an electric stove if the patient has weak handgrips, and how to arrange for a person in a wheelchair to be able to reach the knob when cooking. This is not relevant, possible, or appropriate in my country: Emphasis on Clinical Practice 15 Fig. A wall at the Temple of Karnak, Luxor, Egypt. Students may participate in occupational therapy at their schools WFOT, a. Classification systems are used to define and describe strengths and deficits of people who may need occupational therapy. The following are used alone or in combination: The ICF also includes a list of environmental factors. According to the ICF, people may be helped by occupational therapy if they meet the following criteria: They seldom have impairments due to 1 voice and speech functions; or 2 functions of the cardiovascular, hematologic, immunologic, and respiratory systems. To manage internal, temporal, occupational, and environmental adaptations that affect occupational behavior and performance and that influence patterns of daily occupation. To teach activities of daily living so that that clients learn to accomplish desired and expected tasks at home, at work, at school, in leisure time, and in the community. To enable the client to perform meaningful and purposeful occupations, which then promotes his or her recovery and well-being. To promote health and wellness, i. The figures are stylized Ankh signs see page 3. According to the Framework, candidates for occupational therapy have performance limitations when conducting needed or desired occupations see, for example, Chapter For children, see Chapters 35 and 42; for adults, older adults, and frail elderly, see Chapters 18 and The diagnoses represented in this handbook are classified according to the ICD, and are presented in Table 2. They correspond relatively well to those in occupational therapy textbooks, such as that by Pedretti and Early While the ICD might not be considered the most appropriate system for describing strengths and deficits among occupational therapy

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clients, it has the overwhelming advantage of being well known among health professions and stakeholders internationally, for which reason it is used here. As long as there is no consensus among OTs worldwide regarding what classification system has the desired validity for identifying people needing therapy, it is of less significance what system is used—either one of those mentioned above, or a locally used system. Consequently, epidemiologic knowledge of which people need and participate in occupational therapy should be further developed by conducting research on needs assessment Soriano, The Occupational Therapist An occupational therapist is a health care practitioner who analyzes the impact of occupation on health and quality of life in order to restore a functional interaction between the person and the environment.

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### Chapter 4 : Handbook of Public Communication of Science and Technology - PDF Free Download

*The National Library of Medicine (NLM) has a history dating back more than a century and a half. From its beginnings as the Library of the Army Surgeon General's Office, it grew to the Army.*

The meeting was open to the public from 9: On September 10, the meeting was reopened to the public from 9: Eugenie Prime [Chair] Dr. Department of the Navy Dr. Deanna Marcum, Library of Congress Dr. Department of the Army Dr. Department of Veterans Affairs Ms. Mary Ann Tatman, U. Department of Veterans Affairs Mr. Department of Agriculture Dr. Marion Ball, Healthlink, Inc. Morris Collen, Kaiser Permanente Mr. Steven Phillips, Public Dr. Eugenie Prime welcomed the Regents, alternates, and guests to the th meeting of the Board of Regents of the National Library of Medicine. She noted the presence of two new Regents, Dr. Buchanan of the University of New Mexico and Dr. Deanna Marcum from the Library of Congress. She welcomed also consultants Dr. Marion Ball and Dr. Kenneth Walker and Dr. Public Health Service, reported to the Regents about the priorities and activities of his office. Connected to all three is the issue of health literacy. Carmona said he has had conversations with Dr. Lindberg and other Institute directors about this. There is also a health literacy gap with peers, e. Carmona discussed the state of the Public Health Service Commissioned Corps; he believes that it must be transformed as a uniformed service. We also need a more robust reserve component for the Commissioned Corps this may require legislative action. A training academy and other educational 3 September , - Board of Regents components are also being planned for the Corps. Finally, the Surgeon General reported on a number of reports in the pipeline: Carmona said he is sensitive to the needs of NIH researchers. Perhaps there should be two parallel tracks of professionalism at NIH, allowing flexibility between Corps members and regular civil service. The Board is meeting next spring on May The dates of September , , were adopted for the meeting next fall. Donald Lindberg reported that there is as yet no final budget for FY At the level put forward by the President, NLM would receive about a 3 percent increase. There are comments in the bills that are helpful to NLM, for example, about a backup computer facility, bioethics research, clinical vocabulary standards, the Visible Human Project, an expanded physical facility, outreach to minority communities, PubMedCentral, and outreach to senior citizens. Betsy Humphreys introduced new staff members in Library Operations: Loo, Nancy Pulsipher, and Andrea N. Alexa McCray introduced Dr. Aaron Navarro and Mr. David Lipman introduced several new members of the staff of the National Center for Biotechnology Information: Lindberg next reported briefly on legislation of interest to the NLM, including HIPAA and bills dealing with medical privacy and with the national health information infrastructure. The bill will be much discussed in the coming weeks, especially issues about ensuring that government-produced information remains openly available to the public. The NLM Director mentioned that there were several recently introduced bills on homeland security, an area where NLM would like to be useful. That bill would not allow copyright for the results of federally supported research and development. Lindberg said he would report further on this legislation if Congress acts on it. The Board has heard progress reports in the past, and the agreement is now a reality. The Regents are invited to attend. On another subject, Dr. The goal of the Listening Circle is to promote open dialog between NLM and tribal leaders with a view to identifying collaborative projects that can benefit both, especially in the areas of improving the information resources of tribal colleges and lessening the unemployment rate on the reservations. Thirty-four informatics trainees presented their research projects. Another meeting in July was the Planning Meeting for the National Center for Biotechnology Information at which program priorities, staffing levels, and funding for the next 3 to 5 years were discussed. A summary of the meeting is in the agenda book. A training program aimed at mid-career medical librarians is being funded by NLM in cooperation with the Association of Academic Health Sciences Libraries: Five fellows are being funded each year for a 3-year trial period. The purpose is to lay out a direction roadmap for the NIH in the aftermath of the doubling of the budget over 5 years. Two areas are worthy of note: The Regents will see the exhibit at their next meeting. Bates presented some data about the

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rates of adverse events in several states and in other countries. In all of those studies medications were the leading cause of injuries. We should do a better job of tracking patient allergies to medications and warning physicians about these allergies. One source of error is poor handwriting on the part of the physician that is misinterpreted by other staff. Computerizing the ordering of drugs can improve safety by streamlining and structuring the order process, by giving information at the time needed, and by performing a variety of checks in the background, for example drug-drug interactions and dose ceilings. The key features of their system: He showed the allergy and reaction entry screen. The goal of the current study was to find out why so many drug-allergy alerts were being overridden and the consequences and to make recommendations to refine and improve the system. Bates discussed the problem of overridingâ€”in what circumstances the physician overrode the warnings, and why. There were 23 adverse drug events on occasions in which the warning had been overridden. Completeness of the drug-allergy documentation on patient charts ranged from fair to poor. There are several future directions for the study: Specific recommendations include the need for consistent decision support across applications, reduce unnecessary alerting, adjust notification based on severity, improve allergy documentation, and include drug-food allergies. Bates said that the use of information technology in this area has the potential to dramatically improve safety and quality of health care, but we still have a lot to learn about how best to deliver decision support. Bates said they had seen some experiments where that was done; a substantial proportion of physicians then elect not to see the alerts at all. However, if the slider bar were sensitive enough, that might be an option to look into. Richard Dean said that physician order entry is a very high priority subject. Bates agreed that there is a question about data validityâ€”having incorrect allergies in the application is a problem. An initial decision not to let physicians delete allergies turned out to be a mistake and was reversed, he added. William Stead asked whether anyone was creating a database that had clinically relevant actual occurrence data that could be used to drive a sliding bar. Bates said he did not know of such a system. Robert Roswell said that at the Department of Veterans Affairs, which treats 5 million patients a year, they have been using CPOE for years with results similar to what Dr. Donald King commented that there are also errors and lack of compliance on the part of the patient. He asked whether anyone was attacking the problem of multiple drug interactionâ€”the synergistic or antagonistic effects of many drugs in a patient. Bates said that to his knowledge this was not being done; in their ICU the average patient is receiving 25 different drugs and predicting the consequences is uncertain. Lindberg presented the Frank B. Rogers Award to Christa F. Hoffmann, Head of the Cataloging Section, Technical Services Division for leadership and vision in reinventing the NLM Classification as a system that can be kept constantly up to date. He praised the teamwork of the NLM staff, especially Mr. Ron Stewart, the architects, engineers, and the NIH construction managers. He briefly reviewed the timeline for the design from its earliest stages to the present. If funds are made available, the building could be constructed in three years. Following this introduction, Mr. William Stead said that the Board of Regents has been behind this initiative from its beginning. Stead will undertake to draft such a document. The two test states are Iowa and Georgia. Prime said that special outreach materials were produced for the projectâ€”prescription pads, posters, etc. She briefly described some of the preliminary data reported by Dr. A full report will be made at a future Board meeting. Bioethics Working Group Dr. Thomas Detre, who chairs the Working Group, said that it met for the first time on May

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### Chapter 5 : Search Results | The Online Books Page

*MEDLINEplus is a Web-based consumer health information resource, made available by the National Library of Medicine (NLM). MEDLINEplus has been designed to provide consumers with a well-organized, selective Web site facilitating access to reliable full-text health information.*

New Methods for Randomized Clinical Trials: Point-of-Care Clinical Trial One new method for conducting experimental research is the point-of-care clinical trial. These trials currently are being conducted at the Boston Veterans Affairs Health Care System, with similar trials being proposed or conducted at other locations Vickers and Scardino, The method entails using an electronic health records system to conduct randomized controlled trials by automatically flagging patients who have a choice between competing treatments. If patients do not express a preference, they are asked whether they would be willing to participate in a trial and if so, are randomly assigned to a treatment protocol. The electronic health record system records outcome data and automatically calculates the effectiveness of the treatment protocols. Disadvantages of such trials are that they do not allow for a control group and can be used only for treatments that are already approved for standard care. This type of trial has started being applied to consideration of competing methods for insulin administration a sliding scale versus a weight-based regimen for blood sugar control Fiore et al. In addition to new research methods, advances in statistical analysis, simulation, and modeling have supplemented traditional methods for conducting trials. Given that even the most tightly controlled trials show a distribution in patient responses to a given treatment or intervention, new statistical techniques can help segment results for different populations. Further, new Bayesian techniques for data analysis can separate out the effects of different clinical interventions on overall population health Berry et al. With the growth in computational power, new models have been developed that can replicate physiological pathways and disease states Eddy and Schlessinger, ; Stern et al. As computational power grows, the potential applications of these simulation and modeling tools will continue to increase. Despite the opportunities afforded by new research methods, several challenges must be addressed as these methods are improved. One such challenge for the clinical research enterprise is keeping pace with the introduction of new procedures, Page Share Cite Suggested Citation: Best Care at Lower Cost: The National Academies Press. As currently structured, clinical trials often are not comparable, so that a new trial must be conducted to compare the effectiveness of new treatments, diagnostics, or care delivery models with that of existing ones. One solution to this problem is to create standard comparators for a given disease or clinical condition, which would allow new innovations to be compared easily using existing data for current treatments or diagnostic technologies. Additionally, as the research enterprise is expanded, additional emphasis may be required in fields that are underserved by the current clinical research paradigm, such as pediatrics Cohen et al. One exception to this observation is pediatric cancer care. Virtually all of the treatment provided in pediatric oncology is recorded and applied to registries or active clinical trials, which then inform future care for children undergoing treatment IOM, b; Pawlson, These questions have important ramifications for the design and operation of the overall data system. With respect to the first question, stakeholders in the health care system are interested in comparing the effectiveness of different treatments and interventions, monitoring the current safety of medical products through surveillance, undertaking quality improvement activities, and understanding the quality and performance of different providers and health care organizations. Achieving these goals will require capturing data on the care that is delivered to patients, such as processes and structures of care delivery, and the outcomes of that care, such as longitudinal health outcomes and other outcomes important to patients. With respect to how these data will be used to generate new health care knowledge, uses will include comparing the effects of different treatments, interventions, or care protocols; establishing guidelines and best practices; and searching for unexpected effects of treatments or interventions. Finally, the new knowledge generated will have little impact if not shared broadly with all involved in delivering care for a given patient or, for research

cases, all those involved in research. Each of these three questions is explored in further detail below. Page Share Cite Suggested Citation: Data on how patients respond to diagnostic technologies, treatments, interventions, or care delivery methods are the raw material for generating new clinical knowledge. However, gathering this raw material currently requires significant effort through specialized research protocols. Substantial quantities of clinical data are generated every day in the regular process of care. Unfortunately, most of this information remains locked inside paper records, which are difficult to access, transfer, and query. As of , only about percent of office-based physicians were using a basic electronic health record EHR system Decker et al. The anticipated growth in the adoption of digital records presents an unprecedented opportunity to improve the supply of data available for learning, particularly as data sources are designed to capture information generated during the delivery of care. Examples of such sources include larger clinical and administrative databases, clinical registries, personal electronic devices such as smartphones and mobile sensors , clinical trials for regulatory purposes such as new drug applications , and advanced EHR systems. Just as the information revolution has transformed many other fields, growing stores of data hold the same promise for improving clinical research, clinical practice, and clinical decision making. Health care providers play a critical role in supplying clinical data for research and ensuring the quality of the data. In addition, professional and specialty societies might be engaged to increase the number of providers willing to participate in the clinical research enterprise. Finally, aligning financial incentives and reimbursement can encourage providers and health care organizations to gather, store, and manage clinical data. Currently, many individuals and organizations donate their time when collecting data for research, which limits the amount of effort they can expend on these initiatives. Specific incentives for generating clinical data could increase the supply of data available for research and the quality of the overall enterprise. New sources of health care data, combined with existing resources, offer unprecedented opportunities to learn from health care delivery and patient care. These sources include, for example, EHR systems; registries on diseases, treatments, or specific populations; claims databases from insurers and payers; and mobile devices and sensors that capture local data. In addition to the capacity these sources bring to the collection of clinical data, they also support clinical effectiveness research; surveillance for safety, public health, and other purposes; quality improvement initiatives; population health management; cost and quality reporting; and tools for patient education. As noted above, EHR systems provide a substantial opportunity for learning by unlocking information currently stored in paper medical records. In considering how to maximize the clinical knowledge gained from EHR systems, a tension exists between the data needs of research studies and the resources required to collect and store clinical data on care processes and patient outcomes. Given the range of health care research studies, it is likely to be infeasible for every system to capture the full amount of data needed to fulfill all potential research needs. A compromise solution to this tension is to identify those core pieces of information that are needed for many research questions and ensure that this limited set of information is captured faithfully by most digital health record systems. This method of identifying a core dataset that satisfies both research and clinical care needs has been used by several organizations. As EHR systems become more widespread, it will be necessary to provide flexibility to address new and unforeseen research questions. The sheer scale and complexity of the digital utility, its use by a variety of individuals with conflicting needs, and its constant evolution will require new ways to set standards, develop applications, and interact with the users of clinical data. One technological solution is to ensure that these digital systems are designed in the modular fashion popular in other industries, as with smartphone applications and computer software. This modular approach could also provide additional capacity for meeting new research needs without necessitating an overhaul of the central structure of the digital system. Registries, which are distinguished by their focus on a specific disease, procedure, treatment, intervention, or resource use, are another important tool for developing new knowledge Robert Wood Johnson Foundation, see Box A registry collects uniform clinical data using observational methods to evaluate specified outcomes for a specific population and for a specific purpose AHRQ, By collecting detailed data not contained in other sources, registries have been able to determine the clinical effectiveness of a variety of

health care interventions and treatments Akhter et al. Further, the clinical and financial payoffs of this method of aggregating and generating knowledge can be substantial. In addition to EHRs and registries, mobile technologies for providers and patients will play an increasingly important role in capturing and storing health care data. These technologies include a wide range of patient-focused devices that monitor patient health, with the potential to support improved diagnosis or treatment. Provider-focused tools include applications that are built into existing personal digital assistants, smartphones, and tablet computers to store patient health information or access clinical databases. Growing computational capabilities to generate, communicate, and apply new knowledge create the potential to build a clinical data infrastructure to support continuous learning and improvement in health care. The application of computing capacity and new analytic approaches enables the development of real-time research insights from existing patient populations. One study found that real-time analysis of clinical data from electronic health records could have identified the increased risk of heart attack associated with rosiglitazone, a diabetes drug, within 18 months of its introduction. Computational capabilities offer the prospect of speeding the delivery of important new insights from the care experience. For example, a comprehensive disease registry in Sweden has helped facilitate a 65 percent reduction in day mortality and a 49 percent decrease in 1-year mortality for heart attack patients. Computational capabilities present promising, as yet unrealized, opportunities for care improvement. For example, mining data BOX Registries: An Important Source for Developing Knowledge Registries that are well designed and well managed can promote continuous learning and improvement. In , the Register created a publicly reported quality index that ranked hospitals on their adherence to clinical guidelines, and by , the average hospital quality index score was growing at an annual rate of 22 percent, with the lowest-performing hospitals improving at a rate of 40 percent per year. By , the Register had helped facilitate a 65 percent reduction in the average day mortality rate for patients who had suffered an acute heart attack, as well as a 49 percent decrease in the 1-year mortality rate from heart attacks.