# Patient-Centered Care Systems

# 15

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After reading this chapter, you should know the answers to these questions:

- What is patient-centered care? How does it differ from traditional, clinician-centric care?
- What are the information management challenges in patient-centered care?
- What are the roles of electronic health records and other informatics applications in supporting patient-centered care?
- What forces and developments have led to the emergence of patient-centered care systems?
- What collaborative processes are required to design patient-centered care systems and the electronic health records to support such care?
- How is current informatics research advancing progress toward collaborative, interdisciplinary, patient-centered care?

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## 15.1 Information Management in Patient-Centered Care

Patient care is the focus of many clinical disciplines—medicine, nursing, pharmacy, nutrition, therapies such as respiratory, physical, and occupational, and others. Although the work of the various disciplines sometimes overlaps, each has its own primary focus, emphasis, and methods of care delivery. Each discipline's work is complex in itself, and collaboration among disciplines, an essential component of patient-centered care, adds another level of complexity. In all disciplines, the quality of clinical decisions depends in part on the quality of information available to the decision-maker. The systems that manage information for patient-centered care are therefore a critical tool. Their fitness for the job varies, and the systems enhance or detract from patient-centered care accordingly. This chapter describes information management issues in patient-centered care, the emergence of patient-centered care systems in relation to these issues, the interdisciplinary collaboration required to develop patient-centered care systems, and current research. In so doing, it will demonstrate the necessity of a patient-centered perspective in the design of electronic health records.

As described later in this chapter, reports of the National Academy of Sciences, Federal Government mandates, and a variety of social forces have called for transformation in the organization, delivery, financing, and quality of health care. The demand is for evidence-based,

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cost-effective, **patient-centered care**. Informatics is seen as essential to the provision, monitoring, and improvement of such care.

### 15.1.1 From Patient Care to Patient-Centered Care

Patient-centered care is a collaborative, interdisciplinary process focused on the care recipient in the context of the family, significant others, and community. A distinguishing feature of patient-centered care is the patient's active collaboration in shared decision-making, as contrasted to traditional clinician-centered care where the clinician holds the preponderance of power and authority. Patient-centered care empowers patients to actively participate in care by presenting treatment options that are consistent with patient values and preferences and in a format or context that is understandable and actionable (Krist and Woolf 2011; Payton et al. 2011). Typically, patient care includes the services of physicians, nurses, and members of other health disciplines according to patient needs: physical, occupational, and respiratory therapists; nutritionists; psychologists; social workers; and many others. Each of these disciplines brings specialized perspectives and expertise. Specific cognitive processes and therapeutic techniques vary by discipline, but all disciplines share certain commonalities in the provision of care.

In its simplest terms, the process of patient-centered care begins with collecting data and assessing the patient's current status and expressed concerns in comparison to criteria or expectations of normality. Through cognitive processes specific to the discipline, diagnostic labels are applied, therapeutic goals are identified with timelines for evaluation, and therapeutic interventions are selected and implemented. The patient participates, as he or she is able, in determining therapeutic goals and selecting personally acceptable interventions from the options and their potential consequences as described by the clinician. At specified intervals, the patient is reassessed, the effectiveness of care is evaluated, and therapeutic goals and interventions are continued or adjusted as needed. If the reassessment shows that the patient no longer needs care, services are terminated. This process was illustrated for nursing in 1975 (Goodwin and Edwards 1975) and was updated and made more general in 1984 (Ozbolt et al. 1984). The flowchart reproduced in Fig. 15.1 could apply equally well to other patient-care disciplines.

Although this linear flowchart helps to explain some aspects of the process of care, it is, like the solar-system model of the atom, a gross simplification. Frequently, for example, in the process of collecting data for an initial patient assessment, the nurse may recognize (diagnose) that the patient is anxious about her health condition. Simultaneously with continuing the data collection, the nurse sets a therapeutic goal that the patient's anxiety will be reduced to a level that increases the patient's comfort and ability to participate in care. The nurse selects and implements therapeutic actions of modulating the tone of voice, limiting environmental stimuli, maintaining eye contact, using gentle touch, asking about the patient's concerns, and providing information. All the while, the nurse observes the effects on the patient's anxiety and adjusts his behavior accordingly. Thus, the complete care process can occur in a microcosm while one step of the care process—data collection—is underway. This simultaneous, nonlinear quality of patient care poses challenges to informatics in the support of patient care and the capture of clinical data.

Each caregiver's simultaneous attention to multiple aspects of the patient is not the only complicating factor. Just as atoms become molecules by sharing electrons, the care provided by each discipline becomes part of a complex molecule of interdisciplinary, patient-centered care. Caregivers and developers of informatics applications to support care must recognize that true patient-centered care is as different from the separate contributions of the various disciplines as an organic molecule is from the elements that go into it. The contributions of the various disciplines are not merely additive; as a therapeutic force acting upon and with the patient, the work of each discipline is transformed by its interaction with the patient and the other disciplines in the larger unity of patient-centered care.

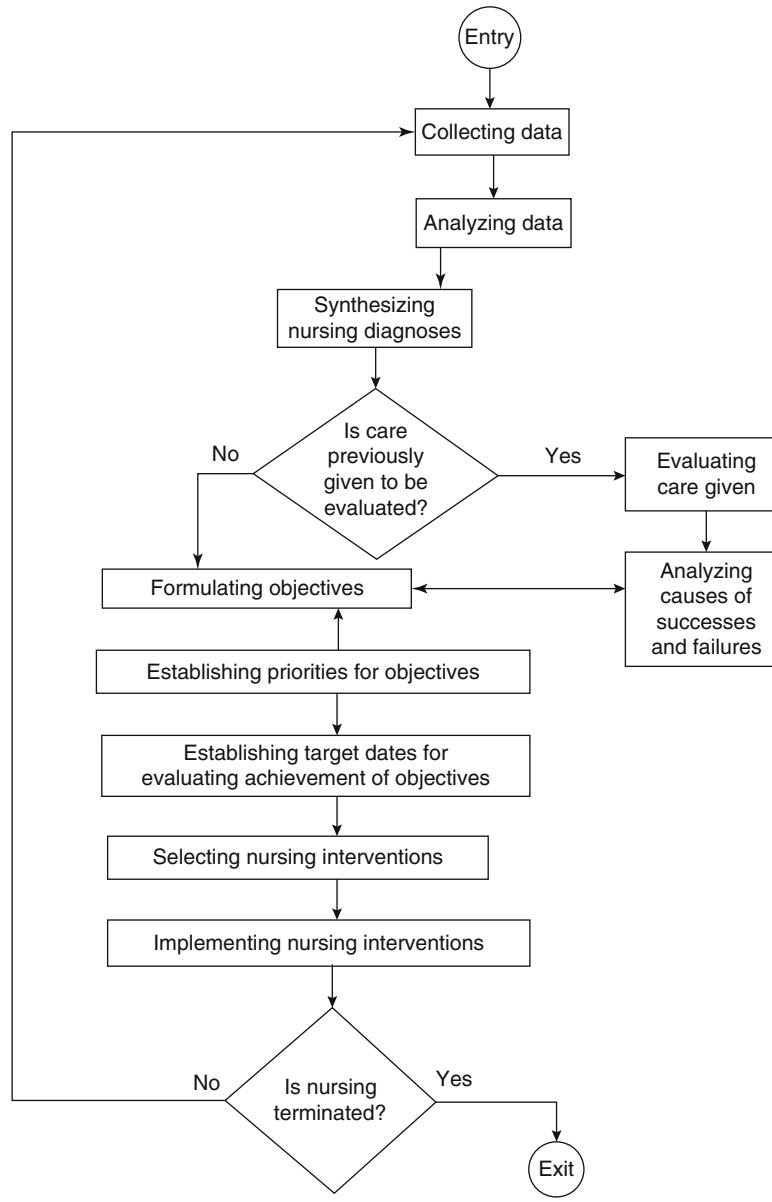


**Fig. 15.1** The provision of nursing care is an iterative process that consists of steps to collect and analyze data, to plan and implement interventions, and to evaluate the results of interventions (Source: Adapted with permission from Ozbolt, J.G. et al. (1985). A proposed expert system for nursing practice. *Journal of Medical Systems*, *9*:57–68)

### 15.1.2 Patient-Centered Care in Action

A 75-year-old woman with osteoarthritis, high blood pressure, and urinary incontinence is receiving care from a physician, a home-care nurse, a nutritionist, a physical therapist, and an occupational therapist. From a clinician-centered, additive perspective, each discipline could be said to perform the following functions:

1. Physician: diagnose diseases, prescribe appropriate medications, authorize other care services
2. Nurse: assess patient's understanding of her condition and treatment and her self-care abilities and practices; assess patient's concerns, values, and preferences regarding the management of her health; teach and counsel as needed; help patient to perform exercises at home; report findings to physician and other caregivers

3. Nutritionist: assess patient's nutritional status and eating patterns; prescribe and teach appropriate diet to control blood pressure and build physical strength
4. Physical therapist: prescribe and teach appropriate exercises to improve strength and flexibility and to enhance cardiovascular health, within limitations of arthritis
5. Occupational therapist: assess abilities and limitations for performing activities of daily living; prescribe exercises to improve strength and flexibility of hands and arms; teach adaptive techniques and provide assistive devices as needed

In a collaborative, interdisciplinary, patient-centered practice, the nurse discovers that the patient is not taking walks each day as prescribed because her urinary incontinence is exacerbated by the diuretic prescribed to treat hypertension, and the patient is embarrassed to go out. The nurse reports this to the physician and the other clinicians so that they can understand why the patient is not carrying out the prescribed regime. The physician then changes the strategy for treating hypertension while initiating treatment for urinary incontinence. The nurse helps the patient to understand the interaction of the various treatment regimes, provides practical advice and assistance in dealing with incontinence, and helps the patient to find personally acceptable ways to follow the prescribed treatments. The nutritionist works with the patient on the timing of meals and fluid intake so that the patient can exercise and sleep with less risk of urinary incontinence. The physical and occupational therapists adjust their recommendations to accommodate the patient's personal needs and preferences while moving toward the therapeutic goals. Finally, the patient, rather than being assailed with the sometimes conflicting demands of multiple clinicians, is supported by an ensemble of services that meet shared therapeutic goals in ways consistent with her preferences and values.

This kind of patient-centered collaboration requires exquisite communication and feedback. The potential for information systems to support or sabotage patient-centered care is obvious.

### 15.1.3 Coordination of Patient-Centered Care

When patients receive services from multiple clinicians, patient-centeredness requires coordinating those services. Coordination includes seeing that patients receive all the services they need in logical sequence without scheduling conflicts and ensuring that each clinician communicates as needed with the others. Sometimes, a **caseman-ager** or **care coordinator** is designated to do this coordination. In other situations, a physician or a nurse assumes the role by default. Sometimes, coordination is left to chance, and both the processes and the outcomes of care are put at risk. In recognition of this, the Institute of Medicine designated coordination of care as 1 of 14 priorities for national action to transform health care quality (Adams and Corrigan 2003). The Health Information Technology for Economic and Clinical Health Act (HITECH Programs 2009[1]) calls for patients to have a **medical home**, a primary care practice that will maintain a comprehensive problem list to make fully informed decisions in coordinating their care. Well-designed information systems with patient facing-technologies (e.g., personal health records and patient portals) enable care coordination as they ensure that patients and providers have immediate access to accurate health information at home and across care settings (Ahern et al. 2011).

### 15.1.4 Patient-Centered Care Across Multiple Patients

Delivering and managing interdisciplinary patient-centered care for an individual is challenging enough, but patient care has yet another level of complexity. Each clinician is responsible for the care of multiple patients. In planning and executing the work of patient-centered care, each professional must consider the competing demands of all the patients for whom she is responsible, as well as the exigencies of all the

[1] http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__hitech_programs/1487 (Accessed: 4/26/13).

other professionals involved in each patient's care. Thus, the nurse on a post-operative unit must plan for scheduled treatments for each of her patients to occur near the optimal time for that patient. She must take into account that several patients may require treatments at nearly the same time and that some of them may be receiving other services, such as imaging or physician's visits, at the time when it might be most convenient for the nurse to administer the treatment. When unexpected needs arise, as they often do—an emergency, an unscheduled patient, observations that could signal an incipient complication—the nurse must set priorities, organize, and delegate to be sure that at least the critical needs are met. Similarly, the physician must balance the needs of various patients who may be widely dispersed throughout an institution. Decision-support systems have the potential to provide important assistance for both the care of individual patients and the organization of the clinician's workload.

### 15.1.5 Integrating Indirect-Care Activities

Finally, clinicians not only deliver services to patients, with all the planning, documenting, collaborating, referring, and consulting attendant on direct care; they are also responsible for **indirect-care** activities, such as teaching and supervising students, attending staff meetings, participating in continuing education, and serving on committees. Each clinician's plan of work must allow for both the direct-care and the indirect-care activities. Because the clinicians work in concert, these plans must be coordinated.

In summary, patient care is an extremely complex undertaking with multiple levels. To achieve patient-centered care, each clinician's contributions to the care of every patient must take into account not only that patient's values, preferences, and concerns, but also the ensemble of contributions of all clinicians involved in the patient's care and the interactions among them, and this entire suite of care must be coordinated to optimize effectiveness and efficiency. These very complex considerations are multiplied by the number of patients for whom each clinician is responsible. Patient care is further complicated by the indirect-care activities that caregivers must intersperse among the direct-care responsibilities and coordinate with other caregivers. The resulting cognitive workload frequently overwhelms human capacity. Systems that effectively assist clinicians to manage, process, and communicate the data, information, and knowledge essential to patient-centered care are critical to the quality and safety of that care.

### 15.1.6 Information to Support Patient-Centered Care

As complex as patient care is, the essential information for direct, patient-centered care is defined in the answers to the following questions:

- What are the patient's needs, concerns, preferences, and values?
- Who is involved in the care of the patient?
- What information does each clinician require to make decisions in his or her professional domain?
- From where, when, and in what form does the information come?
- What information does each clinician generate? Where, when, and in what form is it needed?

The framework described by Zielstorff, Hudgings, and Grobe (1993) provides a useful heuristic for understanding the varied types of information required to answer each of these questions. As listed in Table 15.1, this framework delineates three information categories: (1) patient-specific data about a particular patient acquired from a variety of data sources; (2) agency-specific data relevant to the specific organization under whose auspices the health care is provided; and (3) domain information and knowledge specific to the health care disciplines.

The framework further identifies four types of information processes that information systems may apply to each of the three information categories. *Data acquisition* entails the methods

**Table 15.1** Framework for design characteristics of a patient-care information system with examples of patient-specific data, agency-specific data, and domain information and knowledge for patient care

| Types of data | System processes | | | |
|---|---|---|---|---|
| | Acquiring | Storing | Transforming | Presenting |
| Domain-specific | Downloading relevant scientific or clinical literature or practice guidelines | Maintaining information in electronic journals or files, searchable by key words | Linking related literature or published findings; updating guidelines based on research | Displaying relevant literature or guidelines in response to queries |
| Agency-specific | Scanning, downloading, or keying in agency policies and procedures; keying in personnel, financial, and administrative records | Maintaining information in electronic directories, files, and databases | Editing and updating information; linking related information in response to queries; analyzing information | Displaying on request continuously current policies and procedures; sharing relevant policies and procedures in response to queries; generating management reports |
| Patient-specific | Point-of-care entry of data about patient assessment, diagnoses, treatments planned and delivered, therapeutic goals, and patient outcomes | Moving patient data into a current electronic record or an aggregate data repository | Combining relevant data on a single patient into a cue for action in a decision-support system; performing statistical analyses on data from many patients | Displaying reminders, alerts, probable diagnoses, or suggested treatments; displaying vital signs graphically; displaying statistical results |

*Source*: Framework adapted with permission from *Next Generation Nursing Information Systems*, 1993, American Nurses Association, Washington, DC

by which data become available to the information system. It may include data entry by the care provider or acquisition from a medical device or from another computer-based system. *Data storage* includes the methods, programs, and structures used to organize data for subsequent use. Standardized coding and classification systems useful in representing patient-centered care concepts are discussed in greater detail in Chaps. 2, 7, and 12. *Data transformation* (or *data processing*) comprises the methods by which stored data or information are acted on according to the needs of the end-user—for example, calculation of a pressure ulcer risk-assessment score at admission or calculation of critically ill patients' acute physiology and chronic health evaluation (APACHE) scores. Figure 15.2 illustrates the transformation (abstraction, summarization, aggregation) of patient-specific data for multiple uses. *Presentation* encompasses the forms in which information is delivered to the end-user after processing.

Transformed patient-specific data can be presented in a variety of ways. Numeric data may be best presented in chart or graph form to allow the user to examine trends, whereas the compilation of potential diagnoses generated from patient-assessment data is better presented in an alphanumeric-list. Different types of agency-specific data lend themselves to a variety of presentation formats. Common among all, however, is the need for presentation at the point of patient care. For example, the integration of up-to-the-minute patient-specific data with agency-specific guidelines or parameters can produce alerts, reminders, or other types of notifications for immediate action. See Chap. 19, on patient-monitoring systems, for an overview of this topic. Presentation of domain information and knowledge related to patient care is most frequently accomplished through interaction with databases and knowledge bases, such as Medline or Micromedex (see Chap. 21). Commercial applications such as UpToDate™ are popular among

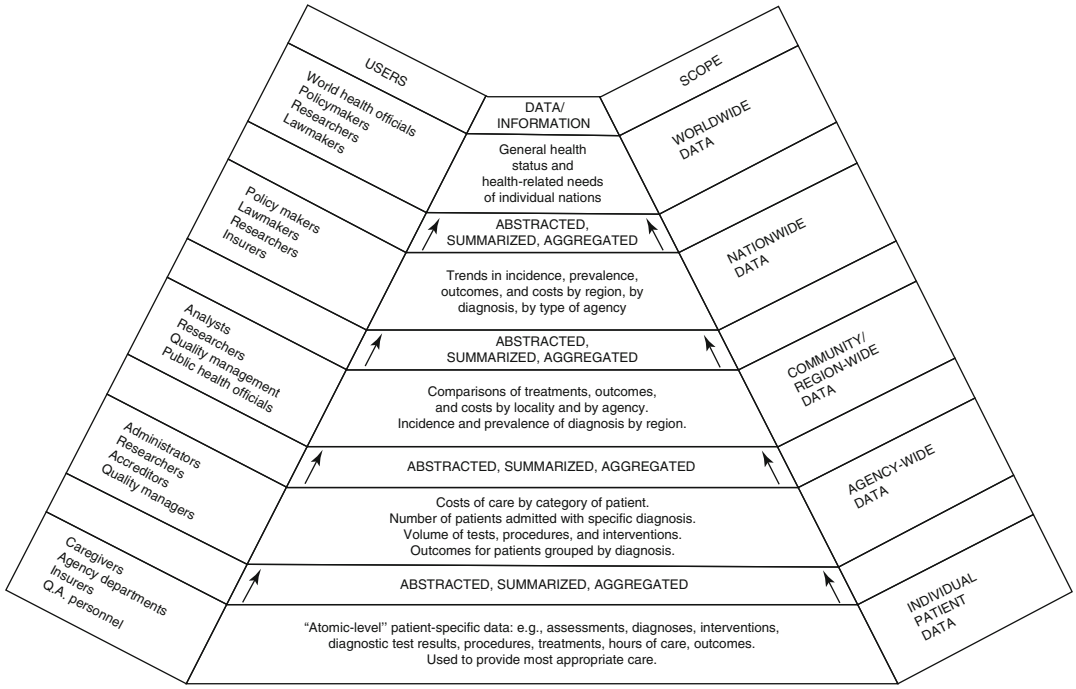


**Fig. 15.2** Examples of uses for atomic-level patient data collected once but used many times (Source: Reprinted with permission from Zielstorff, R. D., Hudgings, C. I., Grobe S. J. & The National Commission on Nursing Implementation Project Task Force on Nursing Information Systems. Next-Generation Nursing Information Systems, © 1993 American Nurses Publishing, American Nurses Foundation/American Nurses Association, Washington, DC. Reproduced with permission of the publisher)

clinicians because they provide easy access to knowledge resources at the point of care. The Infobutton, developed at New York-Presbyterian Hospital, is in the public domain. Incorporated into electronic health records, Infobuttons can integrate data about the patient and the clinical context to provide immediate, point-of-care access to relevant knowledge resources (Cimino et al. 2002a).

To support patient-centered care, information systems must be geared to the needs of all the clinicians involved in care. The systems should acquire, store, process, and present each type of information (patient-, agency-, and domain-specific) where, when, and how the information is needed by each clinician in the context of his or her professional domain. Systems designed for patient-centered care have the potential to go beyond supporting the collaborative, interdisciplinary care of individual patients. Through appropriate use of patient-specific information (care requirements), agency-specific information (clinicians and their responsibilities and agency policies and procedures), and domain information (guidelines), such systems can greatly aid the coordination of interdisciplinary services for individual patients and the planning and scheduling of each caregiver's work activities. Patient acuity is taken into account in scheduling nursing personnel, but historically has most often been entered into a separate system rather than derived directly from care requirements as recorded in the electronic health record. Fully integrated, patient-centered systems—still an ideal today—would enhance our understanding of each patient's situation, needs, and values, improve decision-making, facilitate communications, aid coordination, and use clinical data to provide feedback for improving clinical processes.

Clearly, when electronic health records and other information systems designed to support patient-centered care fulfill their potential, they

will not merely replace oral and paper-based methods of recording and communicating. They will be an integral and essential part of the transformation of health care to apply evidence-based interventions in accordance with patient needs and values. How far have we come toward the ideal? What must we do to continue our progress?

## 15.2 The Emergence of Patient-Centered Care Systems

Events in the first decade of the Twenty-first Century planted the seeds of transformative change in patient care and clinical informatics. Over 10 years, the shared ideal of health care began to move from the Twentieth Century "doctor knows best" model toward a new vision of health care based on interdisciplinary teams drawing on a variety of knowledge and information resources to collaborate with one another and with patients and families to resolve or alleviate health problems and to achieve health goals. Recursive and iterative developments grew from reports of the National Research Council and the Institute of Medicine (components of the National Academy of Sciences); from government policies and initiatives; from changes in organizational and financial structures for health care delivery; and from advances in the informatics methods and technologies that have become integral to the provision, management, reimbursement, and improvement of health care. During the second decade, much remains to be done to nurture continuing development, but with care and patience, before this decade ends we can begin to harvest the benefits of better health care and better health for individuals and populations.

### 15.2.1 Publications of the National Academy of Sciences

With its seminal publication, *To Err is Human*: *Building a Safer Health System* (Kohn et al. 2000), the Institute of Medicine startled the world by estimating that clinical errors were killing up to 98,000 hospitalized Americans each year. The report called for a national focus to advance knowledge about safety, reporting efforts to identify and learn from errors, higher standards and expectations for safety, and implementation of safe practices and systems within health care organizations.

The follow-on report, *Crossing the Quality Chasm*: *A New Health System for the 21st Century* (Committee on Quality of Health Care in America 2001), addressed the need for fundamental change in the health care delivery system. The report noted that the provision of health care had not kept pace with advances in science and technology and did not make the best use of resources. Moreover, health systems had not been restructured to raise quality, control costs, and employ information technologies to improve clinical and administrative processes. Nor had clinical infrastructures been developed to provide the full range of services needed by persons with chronic conditions, the leading causes of illness. Significantly, the report placed the blame for these shortcomings not on individual health care professionals, but on inadequate and broken systems of care.

*Crossing the Quality Chasm* outlined a call for action by government, payers, providers, and the public to embrace a statement of purpose for the health care system as a whole—to reduce illness and improve health and functioning—and to adopt a shared agenda to achieve health care that would be safe, effective, patient-centered, timely, efficient, and equitable. The report recommended Federal Government funding and initiatives to track progress toward these aims. It also advised the redesign of care processes to achieve continuity in care relationships; customization in accordance with patient needs and values; the sharing of knowledge, information, and decision-making with patients; evidence-based decision-making; safety as a system property; transparency of information to facilitate informed decision-making by patients and families; anticipation of patient needs; continuous decrease in waste; and cooperation among clinicians. Since achievement of these aims could be predicted to improve health and thereby reduce fee-for-service revenues, the report urged government and private payers to devise approaches to health care financing that would support quality.

The report gave considerable attention to informatics as an essential methodology to achieve these aims and called for a renewed national commitment to a national health information infrastructure, with the elimination of most hand-written clinical information by 2010. Finally, the report noted that the changes in practice it recommended would require new approaches to the education of clinicians.

The following year, the Institute of Medicine produced a set of *Priority Areas for National Action* (Adams and Corrigan 2003) to transform the quality of health care. In addition to identifying a number of diseases and health conditions as foci, the report recommended efforts to advance three cross-cutting strategies: care coordination, self-management/health literacy, and medication management. It saw these strategies as essential to ensuring that care be evidence-based, adequate, appropriate, and patient-centered.

In *Patient Safety*: *Achieving a New Standard for Care* (Committee on Data Standards for Patient Safety 2004), the Committee highlighted the fact that a national health information infrastructure – a foundation of systems, technology, applications, standards, and policies - is required for error prevention and capture of data that facilitate local and global learning from adverse events, near misses, and hazards. The need for data interchange standards as an essential building block was emphasized.

The National Academy of Sciences followed these four reports with a number of others that explored in greater depth aspects of the problems and recommendations described within them and made further recommendations for public and private actions to improve health care and its costs and outcomes. In 2009, The National Research Council published *Computational Technology for Effective Health Care*: *Immediate Steps and Strategic Directions* (Stead & Lin, Eds.). This report noted that many health information technologies in the current marketplace lacked the functionality to achieve the goals of improving health care. It addressed the challenges of implementing the best of today's health information technologies to achieve short-term gains and of identifying advances in those technologies needed to reach the ultimate aims of health care as described in the other reports cited. The central finding was that computer scientists, experts in health and biomedical informatics, and clinicians would need to collaborate to create technologies that would provide cognitive support to clinicians, patients, and family members as they sought to understand, resolve, or alleviate health challenges. The report recommended that Federal and state governments and clinicians join forces to require vendors to provide systems that offer such "meaningful" support.

### 15.2.2 Federal Government Initiatives

The Health Information Technology for Economic and Clinical Health (HITECH) Act provided an unprecedented federal investment in HIT through a series of initiatives aimed at ensuring that all Americans benefit from EHR-supported patient-centered care. Administered by the Office of the National Coordinator for Health Information Technology, the activities are designed:

- To support the health care workforce through Regional Extension Centers for technical assistance for implementation of EHRs and training initiatives to ensure meaningful use of EHRs
- To enable coordination and alignment within and among states (State Health Information Exchange Cooperative Agreement Program)
- To establish connectivity to the public health community in case of emergencies (Beacon Community Program)
- To achieve breakthrough advances, overcoming factors that have hindered EHR adoption (Strategic Health IT Research Projects (SHARP) Program[2]; "HITECH Programs").

In addition, two federal rules support meaningful use of EHRs. The Incentive Programs for Electronic Health Records rule from the Centers

[2] http://healthit.hhs.gov/portal/server.pt/community/strategic_health_it_advanced_research_projects/1436/home/16979. (Accessed: 4/26/13).

for Medicare & Medicaid Services (CMS) defines minimum requirements that hospitals and eligible professionals must meet through their use of certified technology to qualify for incentive payments. Criteria related to providing patients with an electronic copy of their own health information and ability to electronically exchange key clinical information are particularly important to patient-centered care. The complementary Standards and Certification Criteria for Electronic Health Records rule defines the criteria for certification of the technology. Also relevant to patient-centered care are NHIN Direct and NHIN CONNECT, which support health information exchange to enable patient-centered care. These are described in more detail in Chap. 13.

The Agency for Health care Research and Quality (AHRQ) has also invested in advancing patient-centered care through investments in health information technology. A particular focus is the re-use of EHR data for comparative effectiveness research with an emphasis on underserved populations. This in reflected in the AHRQ PROSPECT (Prospective Outcome Systems using Patient-specific Electronic Data to Compare Tests and Therapies) grant portfolio. For example, the Washington Heights/Inwood Informatics Infrastructure for Comparative Effectiveness Research (WICER) integrates EHR data with data from home health care, long-term care, and a community household survey to examine research questions related to hypertension management.

Given these major investments in promoting EHR adoption and use for patient-centered care and research, the vision of every American reaping the benefits of EHRs is moving closer to reality. However, this will be heavily influenced by associated changes in health care financial and organizational structures.

### 15.2.3 Financial and Organizational Structures in Health Care

The historical evolution of information systems that support patient care, and eventually patient-centered care, is not solely a reflection of the available technologies (e.g. Web 2.0, cloud computing). Societal forces—including delivery-system structure, practice model, payer model, and quality focus—have influenced the design and implementation of patient-care systems (Table 15.2).

#### 15.2.3.1 Delivery-System Structure

Authors have noted the significant influence of the organization and its people on the success or failure of informatics innovations (Massaro 1993; Campbell et al. 2006; Ash et al. 2007). Others have documented unintended consequences of implementation of health information technology and called for applications of models of processes, such as Iterative Sociotechnical Analysis, that take into account, health care organizations' workflow, social interactions, culture, etc. to further elucidate the relationship between organizations and technology (Harrison et al. 2007; Koppel et al. 2005). As delivery systems shifted from the predominant single-institution structure of the 1970s to the **integrated delivery networks** of the 1990s to the complex linkages of the twenty-first century, the information needs changed, and the challenges of meeting those information needs increased in complexity. The **patient centered medical home** (PCMH)[3] (also known as primary care medical home, advanced primary care, and health care home) is a model of primary care that delivers care that is patient-centered, comprehensive, coordinated, accessible, and continuously improved through a systems-based approach to quality and safety ("Patient Centered Medical Home Resource Center" 2011).[4] AHRQ and others (Bates and Bitton 2010) have noted the seminal role of health information technology (e.g., health information exchange, disease registries, alerts and reminders) to support tasks related to NCQA PCMH standards for enhancing access and continuity, identifying and managing patient populations, planning and managing care, providing self-care and community support, tracking and coordinating care, and measuring and improving performance ("Patient Centered Medical

[3] http://www.ncqa.org/ (Accessed: 4/26/13).

[4] http://www.pcmh.ahrq.gov/portal/server.pt/community/pcmh__home/1483 (Accessed 4.26.13).

**Table 15.2** Societal forces that have influenced the design and implementation of patient-centered systems

| | 1970s | 1980s | 1990s | 2000s | 2010s |
|---|---|---|---|---|---|
| Delivery-system structure | Single institution | Single organization | Integrated delivery systems | | Patient-centered medical home |
| Professional-practice model | Team nursing | Primary nursing | Patient-focused care, multi-disciplinary care, case management | Patient-centered care | Expansion of nurse and advanced practice nurse roles to legal scope of practice |
| | Single or small group physician practice | Group models for physicians | Variety of constellations of physician group practice models | | |
| Payer model | Fee for service | Fee for service | Capitation | CMS P4P hospital initiative | Affordable Care Act of 2010 |
| | | Prospective payment | Managed care | | Accountable Care Organizations |
| | | Diagnosis-related groups | | | |
| Quality focus | Professional Standards Review Organizations (PSROs) | Continuous quality improvement | Risk-adjusted outcomes | Patient safety | Value-driven health care |
| | Retrospective chart audit | Joint Commission on Accreditation of Health Care Organization (JCAHO) 's Agenda for Change | Benchmarking | Learning organizations | Patient-centered outcomes |
| | | | Practice guidelines | | |
| | | | Critical paths/care maps | Consumer-driven | |
| | | | Health Employer Data and Information Set ((HEDIS) | | |
| General technology trends | | | World Wide Web (Web 1.0) | Web 2.0 | Cloud computing |
| | | | | Social media | |
| | | | | "Smart" mobile devices | |

Home 2011"). See Chaps. 14, 15, and 16 for discussions of managing clinical information in integrated delivery systems, in consumer-provider partnerships in care, and in the public health information infrastructure.

#### 15.2.3.2 Professional Practice Models

Professional practice models have also evolved for nurses and physicians. In the 1970s, team nursing was the typical practice model for the hospital, and the nursing care plan—a document for communicating the plan of care among nursing team members—was most frequently the initial computer-based application designed for use by nurses. The 1990s were characterized by a shift to interdisciplinary-care approaches necessitating computer-based applications such as critical paths to support case management of aggregates of patients, usually with a common medical diagnosis, across the **continuum of care**. The twenty-first century sees advanced practice nurses increasingly taking on functions previously provided by physicians while maintaining a nursing perspective on collaborative, interdisciplinary care. This trend is likely to accelerate given the recommendations for facilitating full scope of practice for nurses and advanced practice nurses (e.g., certified nurse midwives, nurse practitioners) in the 2010 Institute of Medicine report on *The Future of Nursing*: *Leading Change*, *Advancing Health* (Committee on the Robert Wood Johnson Foundation Initiative on the Future of Nursing at the Institute of Medicine 2010). These changes broaden and diversify the demands for decision support, feedback about clinical effectiveness, and quality improvement as a team effort.

Physician practice models have shifted from single physician or small group offices to complex constellations of provider organizations. The structure of the model (e.g., staff model health-maintenance organization, captive-group model health-maintenance organization, or independent-practice association; see Chap. 14) determines the types of relationships among the physicians and the organizations. These include issues— such as location of medical records, control of practice patterns of the physicians, and data-reporting requirements—that have significant implications for the design and implementation of patient-care systems. In addition, the interdisciplinary and distributed care approaches of the 1990s and the 2000s have given impetus to system-design strategies, such as the creation of a single patient problem list, around which the patient-care record is organized, in place of a separate list for each provider group (e.g., nurses, physicians, respiratory therapists). Electronic whiteboards, wikis, and other communication tools have been advocated to address concerns that clinicians may not all be on the same page in regards to a patients' care goals and to promote common ground among the members of the interdisciplinary care team (Collins et al. 2011b).

#### 15.2.3.3 Payer Models

Changes in payer models have been a significant driving force for information-system implementation in many organizations. With the shift from fee for service to prospective payment in the 1980s, and then toward capitation in the 1990s, information about costs and quality of care has become an essential commodity for rational decision-making in the increasingly competitive health care marketplace. Because private, third-party payers often adopt federal standards for reporting and regulation, health care providers and institutions have struggled in the early 2000s to keep up with the movement toward data and information system standards accelerated by the Health Insurance Portability and Accountability Act (HIPAA)[5] and the initiatives to develop a National Health Information Network. With the advent of pay for performance (P4P), CMS has eliminated reimbursement for preventable conditions (e.g., catheter-associated urinary tract infections) that occur during hospitalizations ("CMS P4P,"). In this decade, there is no doubt that the implementation of the highly controversial Affordable Care Act of 2010 and evolving Accountable Care Organizations will profoundly impact patient-centered care and the information systems needed to support it. See Chap. 14 for a thorough discussion of the effects of health care financing on health-care information systems.

[5] http://hhs.gov/ocr/privacy/ (Accessed: 4/26/13).

#### 15.2.3.4 Quality Focus

Demands for information about quality of care have also influenced the design and implementation of patient-care systems. The quality-assurance techniques of the 1970s were primarily based on retrospective chart audit. In the 1980s, continuous quality improvement techniques became the modus operandi of most health care organizations. The quality-management techniques of the 1990s were much more focused on concurrently influencing the care delivered than on retrospectively evaluating its quality. In the Twenty-first Century, patient-centered systems-based approaches—such as practice guidelines, alerts, and reminders tailored on patient clinical data and, in some instances, genomic data (i.e., personalized medicine) —are an essential component of **quality management**. In addition, institutions must have the capacity to capture data for benchmarking purposes and to report process and outcomes data to regulatory and accreditation bodies, as well as to any voluntary reporting programs to which they belong. Increasingly, concurrent feedback about the effectiveness of care guides clinical decisions in real time and "dashboards" are used to display indicators related to different dimensions of quality.

### 15.2.4 Advances in Patient-Centered Care Systems

The design and implementation of patient-care systems, for the most part, occurred separately for hospital and ambulatory-care settings. Early patient-care systems in the hospital settings included the University of Missouri-Columbia System (Lindberg 1965), the Problem-Oriented Medical Information System (PROMIS) (Weed 1975), the TriService Medical Information System (TRIMIS) (Bickel 1979), the Health Evaluation Logical Processing (HELP) System (Kuperman et al. 1991), and the Decentralized Hospital Computer Program (DHCP) (Ivers et al. 1983). The Computer-Stored Ambulatory Record (COSTAR), the Regenstrief Medical Record System (McDonald 1976), and The Medical Record (TMR) were among the earliest ambulatory care systems. For a comprehensive review, see Collen (1995).

According to Collen (1995), the most commonly used patient-care systems in hospitals of the 1980s were those that supported nursing care planning and documentation. Systems to support capture of physicians' orders, communications with the pharmacy, and reporting of laboratory results were also widely used. Some systems merged physician orders with the nursing care plan to provide a more comprehensive view of care to be given. This merging, such as allowing physicians and nurses to view information in the part of the record designated for each other's discipline, was a step toward integration of information. It was still, however, a long way from support for truly collaborative interdisciplinary practice.

Early ambulatory-care systems most often included paper-based patient encounter forms that were either computer-scannable mark-sense format or were subsequently entered into the computer by clerical personnel. Current desktop, laptop, or handheld systems use keyboard, mouse, touchpad, or pen-based entry of structured information, with free text kept to a minimum. These systems also provide for retrieval of reports and past records. Some systems provide decision support or alerts to remind clinicians about needed care, such as immunizations or screening examinations, and to avoid contraindicated orders for medications or unnecessary laboratory analyses. The best provide good support for traditional medical care. Support for comprehensive, collaborative care that gives as much attention to health promotion as to treatment of disease presents a challenge not only to the developers of information systems but also to practitioners and health care administrators who must explicate the nature of this practice and the conditions under which agencies will provide it.

Patient-care information systems in use today represent a broad range in the evolution of the field. Versions of some of the earliest systems are still in use. These systems were generally designed to speed documentation and to increase legibility and availability of the records of

patients currently receiving care. Most lack the capacity to aggregate data across patients, to query the data about subsets of patients, or to use data collected for clinical purposes to meet informational needs of administrators or researchers. These shortcomings seem glaring today, but they were not apparent when the very idea of using computers to store and communicate patient information required a leap of the imagination.

More recently developed systems attempt with varying success to respond to the edict "collect once, use many times." Selected items of data from patient records are abstracted manually or electronically to aggregate databases where they can be analyzed for administrative reports, for quality improvement, for clinical or health-services research, and for required patient safety and public health reporting. Such functionality is a key aspect of meaningful use. See Chap. 16 for a full discussion of public health informatics.

Some recently developed systems offer some degree of coordination of the information and services of the various clinical disciplines into integrated records and plans. Data collected by one caregiver can appear, possibly in a modified representation, in the "view" of the patient record designed for another discipline. When care-planning information has been entered by multiple caregivers, it can be viewed as the care plan to be executed by a discipline, by an individual, or by the interdisciplinary team. Some patient-care systems offer the option to organize care temporally into clinical pathways and to have variances from the anticipated activities, sequence, or timing reported automatically. Others offer a patient "view" so that individuals can view and contribute to their own records. For example, patients hospitalized for cardiac conditions can review selected aspects of their records and enter data such as pain ratings into CUPID (Computerized Unified Patient Interaction Device), an iPad-based application (Vawdrey et al. 2011).

Electronic documentation of clinician progress notes has lagged behind other functions in electronic health records (Doolan et al. 2003). The process of entering notes may occur through dictation, selecting words and phrases from structured lists, use of templates, and typing free text. Amid concerns that salience may be lost in electronic notes (Siegler 2010), Johnson et al. (2008) advocated for a hybrid approach that combines semi-structured data entry and natural language processing within a standards-based and computer-processible document structure. Thus, ability for data re-use is preserved while maintaining clinician efficiency and expressivity.

The publication of the Institute of Medicine's reports *To Err is Human* (2000) and *Crossing the Quality Chasm* (2001) resulted in increasing demands from health care providers for information systems that reduce errors in patient care. Information system vendors are responding by developing such systems themselves and by purchasing the rights to patient care systems developed in academic medical centers that have demonstrated reductions in errors and gains in quality of care and cost control. **Closed loop** medication systems use technologies such as bar codes and decision support to guard against errors throughout the process of prescribing, dispensing, administering, and recording and have been identified as a key intervention to improve medication safety. In a before-and-after evaluation of the closed loop electronic medication administration system at Brigham and Women's Hospital (BWH), investigators found a significant reduction in the rates of transcription errors, medication errors, and potential adverse events (Poon et al. 2010). In other contexts, decision support systems offer "best practice" guidelines, protocols, and order sets as a starting point for planning individualized patient care; provide alerts and reminders; use knowledge bases and patient data bases to assess orders for potential contraindications; and offer point-and-click access to knowledge summaries and full-text publications. See Chap. 21 for more information about these systems.

Many health care agencies have substantial investment in legacy systems and cannot simply switch to more modern technology. Finding ways to phase the transition from older systems to newer and more functional ones is a major challenge to health informatics. To make the transition from a patchwork of systems with self-contained

functions to truly integrated systems with the capacity to meet emerging information needs is even more challenging (see Chap. 14). Approaches to making this transition are described in the Proceedings of the 1996 IAIMS Symposium (Stead et al. 1996) and in the Journal of the American Medical Informatics Association (Stead et al. 1996). More recently, some institutions have applied Web 2.0 approaches to create configurable user interfaces to legacy systems. For example, MedWISE integrates a set of features that supports custom displays, plotting of selected clinical data, visualization of temporal trends, and self-updating templates as mechanisms for facilitating cognition during the clinical decision making and documentation process (Senathirajah and Bakken 2009).

If patient-centered care systems are to be effective in supporting better care, health care professionals must possess the informatics competencies to use the systems. Consequently, many are integrating informatics competencies into health science education (See Chap. 23). For example, the Quality and Safety Education for Nurses (QSEN) initiative has produced competencies and associated curriculum to support patient-centered care competencies including those related to quality, safety, team work, and collaboration (Cronenwett et al. 2009).

To what degree do patient-care disciplines need to prepare their practitioners for roles as informatics specialists? To the degree that members of the discipline use information in ways unique to the discipline, the field needs members prepared to translate the needs of clinicians to those who develop, implement, and make decisions about information systems. If the information needs are different from those of other disciplines, some practitioners should be prepared as system developers.

The mere existence of information systems does not improve the quality of patient care. The adoption and use of advanced features (such as clinical decision support) that are sensitive to both workflow and human factors are needed to improve the quality of care (Stead and Lin 2009; Zhou et al. 2009). Recent safety reports, public policy, and reimbursement incentives raise awareness of the need for patient-centered care systems. Because traditional requirements for electronic health records (EHR) were provider-centric, existing information systems rarely provide the comprehensive suite of advanced features needed to support patient-centered care. However, the ability of systems to support patient-centered care is essential for achieving the vision of health care reform. What are the requirements for patient-centric information systems? How do these requirements drive the design of systems that will support patient-centered care?

## 15.3 Designing Systems for Patient-Centered Care

In the second decade of the twenty-first century, the vision for systems that support patient-centered care practices such as inter-professional care planning, care coordination, quality reporting, and patient engagement is becoming more widely shared. This evolution is fueled in part by meaningful use requirements that aim to engage patients and families in their health care and to improve care coordination and the overall quality of care provided. Traditional EHR functionality must be expanded to support new features, functions and care practices including seamless communication, inter-professional collaboration, and patient access to information. To achieve sound human factors and integration of systems and workflow, these features must be built into information systems as core requirements, rather than as an afterthought.

The *Principles to Guide Successful Use of Health Care Information Technology* described by the National Research Council (Stead and Lin 2009) provide a comprehensive framework for defining a set of core requirements that will support the design of systems for patient-centered care. This framework defines nine principles related to both evolutionary (i.e., iterative, long-term improvements) and radical (i.e., revolutionary, new-age improvements) changes occurring in the United States' health care system. The principles and associated system design prerequisites are included in Table 15.3.

**Table 15.3** Principles to guide successful use of health care information technology

| | Principle | System design prerequisites |
|---|---|---|
| Evolutionary change | 1. Focus on improvements in care—technology is secondary | Gaps in patient-centered care are clearly defined and operationalized. Health care IT is employed to enable the process changes needed to close gaps in patient-centered care. |
| | 2. Seek incremental gain from incremental effort | An organization's portfolio of health care IT projects has varying degrees of investment. Each project is linked to measurable process changes to provide ongoing visible success with closing gaps in patient-centered care. |
| | 3. Record available data so they can be used for care, process improvement, and research | Health care IT systems support auto capture of data about people, processes, and outcomes at the point of care. Data are used in the short term to support incremental improvements in patient-centered care processes. An expandable data collection infrastructure is employed that is responsive to future needs that cannot be anticipated today. |
| | 4. Design for human and organizational factors | Clear consideration is given to sociological, psychological, emotional, cultural, legal, economic and organizational factors that serve as barriers and incentives to providing patient-centered care. Health care IT should eliminate the barriers and enable the incentives, making it easy to provide patient-centered care. |
| | 5. Support the cognitive functions of all caregivers, including health professionals, patients, and their families | Health care IT systems include advanced clinical decision support for high-level decision-making that is sensitive to both workflow and human factors. |
| Radical change | 6. Architect information and workflow systems to accommodate disruptive change | Health care IT systems are designed using standard interconnection protocols that support the patient-centered care processes and roles of today while accommodating rapidly changing requirements dictated by new knowledge, care venues, policy, and increasing patient engagement. |
| | 7. Archive data for subsequent re-interpretation | Health care IT systems support archival of raw data to enable ongoing review and analysis in the context of advances in biomedical science and patient-centered care practices. |
| | 8. Seek and develop technologies that identify and eliminate ineffective work processes | Health care IT system design is preceded by a thorough investigation of current and future state work processes of all stakeholders (including patients and their families). Health care IT systems support efficient workflows that leverage ubiquitous access to information and communication and are not constrained by existing care venues or provider-centric practice patterns. |
| | 9. Seek and develop technologies that clarify the context of data | Health care IT systems facilitate patient-centered care by presenting information in context with patient values and preferences and in a format that is understandable and actionable. |

## 15.4 Current Research Toward Patient-Centered Care Systems

Friedman (1995) proposed a typology of the science in medical informatics. His four categories build from fundamental conceptualization to evaluation as follows:

- Formulating models for acquisition, representation, processing, display, or transmission of biomedical information or knowledge
- Developing innovative computer-based systems, using these models, that deliver information or knowledge to health care providers

- Installing such systems and then making them work reliably in functioning health care environments
- Studying the effects of these systems on the reasoning and behavior of health-care providers, as well as on the organization and delivery of health care

While the Friedman typology continues to be useful more than 15 years after its inception, we propose extending the second and third categories in Sects. 15.4.2 and 15.4.3 to expand the focus from clinical informatics as a provider-centric discipline to a discipline that enables and supports patient-centric care. Following are examples of recent research with implications for patient-centered care.

### 15.4.1 Formulation of Models

For several decades, standards development organizations (SDOs) and professional groups alike have focused on the formulation of models that describe the patient care process and the formal structures that support management and documentation of patient care. The efforts of SDOs are summarized in Chap. 7. Early SDO efforts focused primarily on representing health care concepts such as professional diagnoses (e.g., medical diagnoses, nursing diagnoses) and actions (e.g., procedures, education, referrals). These efforts were complemented by professional efforts such as those of the Nursing Terminology Summit (Ozbolt 2000). As a result of multi-national efforts, SNOMED CT became an international standard that provides a formal model for concepts that describe clinical conditions and the actions of the multidisciplinary health care team (International Health Terminology Standards Development Organization 2011). Toward the goal of patient-centered care, attention has also been paid to approaches for formal representation of terms that patients use to describe their problems and actions (Doing-Harris and Zeng-Treitler 2011).

In more recent years, the focus has turned to the development of information models and formal document structures that support sharing of data across heterogeneous information systems. In regards to the latter, the Continuity of Care Document (CCD) standard is of particular importance to patient-centered care because it provides a formal structure for representing a core set of data elements across the life span. Dolin and colleagues demonstrated its relevance to a key patient safety issue, medication reconciliation (Dolin et al. 2007). Moreover, the CCD standard serves as the foundation for some personal health records and as an output format for data accessed through regional health information organizations. For example, a CCD designed specifically for socioeconomically disadvantaged persons living with HIV/AIDS (PLWH) was implemented for viewing by PLWH members of an HIV special needs plan, their clinicians, and case managers to promote coordination and quality of care (Schnall et al. 2011a, b).

Supporting interdisciplinary, collaborative, patient-centered care requires information systems that adequately represent the concepts of practice of all the professions involved in patient care. In addition, in the home care setting it is essential to include relevant concepts for domestic help, social services, and family caregivers. In Sweden, a shared care plan was developed to include all these elements (Hagglund et al. 2011). The concepts and relationships in the shared care plan were then compared with those represented in two standards, the European continuity of care model (CONTsys) and *open* EHR, to determine the semantic interoperability of the shared care plan. The investigators found that additional archetypes were needed in both standards to represent some of the concepts and relationships in the shared care plan. It is to be expected that much additional work will be needed around the world to model and represent concepts and relationships in the transition from clinician-centered care to patient-centered care.

Through the Strategic Health IT Advanced Research Projects (SHARP) Program, the Mayo Clinic is leading ONC-initiated efforts to create and advance models that promote integration and re-use of electronic health data ("Strategic Health IT Advanced Research Projects (SHARP) Program,"). Such efforts are essential to enable patient-centered care systems.

### 15.4.2 Development of Innovative Systems

For the purposes of developing innovative *patient-centered* computer-based systems, the second category of the Friedman Typology described in 15.4 is expanded to address the use of models that deliver information or knowledge to both health care providers *and* patients. Consumers regularly use information and communication technology to support decision making in all aspects of their lives. However, access to tools to support health care decision making is suboptimal (Krist and Woolf 2011). Krist, Woolf, & Rothemich (2010) proposed five levels of functionality for patient-centered health information systems.

- Level 1: Collects patient information related to health status, behaviors, medications, symptoms, and diagnoses (e.g., electronic version of traditional paper records maintained by patients)
- Level 2: Integrates patient information with clinical information (e.g., personal health record tethered to an EHR)
- Level 3: Interprets information to provide context in an appropriate level of health literacy
- Level 4: Provides tailored recommendations based on patient information, clinical information and evidence-based guidelines
- Level 5: Facilitates patient decision-making, ownership and action

The levels of functionality needed to support patient-centered health information systems relate directly to several of the *Principles to Guide Successful Use of Health Care Information Technology* described by the National Research Council (Stead and Lin 2009) and outlined in Sect. 15.3; specifically principles 5, 8 and 9 (see Table 15.3).

Partners Health Care System (PHS) in Boston, MA, developed Patient Gateway, a secure patient portal serving over 65,000 patient users from primary and specialty care practices affiliated with the Dana Farber Cancer Institute, Brigham and Women's Hospital (BWH), and Massachusetts General Hospital (MGH). Patient Gateway is a **tethered personal health record** (see Chap. 17) that provides functionality in line with the five levels described by Krist and Woolf. For example, tools for management of chronic illness are used by patients and providers to promote adherence with evidence-based health maintenance guidelines and to improve collaboration on diabetes self-management plans (Grant et al. 2006; Wald et al. 2009). Research on patient response and satisfaction with Patient Gateway suggests that patients appreciate the ability to communicate electronically with providers, they welcome greater access to their health information including test results and they believe that Patient Gateway enables them to better prepare for visits (Grant et al. 2006; Schnipper et al. 2008b; Wald et al. 2009). Evaluations of patient satisfaction with personal health records with similar levels of functionality at other sites including Geisinger Health System (Hassol et al. 2004), Group Health Cooperative (Ralston et al. 2007), and Virginia Commonwealth University (Krist et al. 2010) are consistent with the results reported at PHS.

The involvement of end-users has been identified as fundamental to well designed systems that are usable and useful in the context of busy patient care workflows (Rahimi et al. 2009). Some examples of development activities where end-user involvement is needed are content standardization, workflow modeling, and usability testing.

- *Content standardization*: Content standardization includes identifying EHR content needed to support documentation of care provided and identification of data needed for reuse (e.g., decision support, quality reporting, and research). Content that is shared across disciplines and patients is identified. Content is modeled using standards to ensure data reuse and interoperability (Principle 3, Table 15.3) (Chen et al. 2008; Dykes et al. 2010; Kim et al. 2011).
- *Workflow modeling*: Sound modeling of the clinical workflow that underlies an electronic system is essential to designing systems that are usable by care team members (Peute et al. 2009). Workflow models are based on

observations of current state clinical workflows including interactions with patients, staff, equipment, and supplies. Understanding of workflow interactions, including current state inefficiencies, is leveraged to inform effective and efficient future state workflows, use-case development, and system prototypes (Rausch and Jackson 2007). Workflow modeling of patient-centered systems includes clear evaluation of ways to use technology to identify and eliminate ineffective work processes (Principle 8, Table 15.3). Design of new systems is an opportunity to provide ubiquitous access to information and communication by all care team members including patients. Therefore, future state workflows are not constrained by existing care venues or provider-centric practice patterns.

- *Usability testing*: A key lesson learned from CPOE implementations is electronic systems with poor usability interfere with clinical workflow. The unintended consequences of poorly designed systems are well known and some widely disseminated papers (Ash et al. 2004, 2009; Koppel et al. 2005) have called into question the safety of using such systems with patients. Examples of common usability problems include overly cluttered screen design, poor use of available screen space, and inconsistencies in design. Involving end-users in design and enforcing usability design standards when building clinical systems prevents implementing systems that are difficult to use and interfere with, rather than support, patient-centered care (Principles 4, 5 and 8, Table 15.3).

Innovative systems to support patient care often take advantage of information entered in one context for use in other contexts. For example, the Brigham Integrated Computing System (BICS), a PC-based client–server HIS developed at BWH in Boston, used information from the order entry, scheduling, and other systems to prepare drafts of the physician's discharge orders and the nurse's discharge abstract, thus minimizing the information to be entered manually. The professionals reviewed the drafts and edited as needed (O'Connell et al. 1996). The BICS system's success in this and other functions led to its acquisition for commercial deployment.

The principle of entering information once for multiple uses also drove development of the low-cost bedside workstations for intensive-care units at the University Hospital of Giessen, Germany (Michel et al. 1996). The client–server architecture combined local data-processing capabilities with a central relational patient database, permitting, for example, clinical nursing data to be used in calculating workload. These workstations also combined data from many sources, including medical devices, to support the integrated care of physicians, nurses, and other caregivers.

Even as systems such as these begin to fulfill some of the promises of informatics to support patient-centered care, research and development continue to address the demands that the complexities of patient care place on information systems. Hoy and Hyslop (1995) reported a series of projects directed toward the development of a person-based health record. They found problems with traditional approaches to automating paper-based care-planning systems that resulted in loss of data detail, inability to use data for multiple purposes, and limitations in the capacity to aggregate and query patient data. Hoy and Hyslop (1995) recommended:

- Making the structure of the clinical record (including the care plan) more flexible and extensible to allow summarized higher-level data, with lower-level details where appropriate
- Simplifying the elements of that structure to make data entry and retrieval easier and more effective

Hoy and Hyslop (1995) built a prototype system to demonstrate their recommendations. Like other investigators, they concluded that "the issues of language and structures must be dealt with before the integration of person-based systems can be realized." As noted in Chap. 7, significant headway has been made in this regard during the last 5 years.

At Vanderbilt University Medical Center, patient-care systems have evolved since the mid-1990s to support patient safety and quality of care in a variety of ways. Clinical teams, assisted

by specially trained clinical librarians, develop evidence-based order sets as templates for interdisciplinary care. These order sets are instantiated in Vanderbilt's order-entry system, where they serve as the starting point for planning and documenting each patient's care. When a patient is admitted to the hospital, a decision-support tool helps the physician to identify the appropriate evidence-based order set and then to edit the template to produce an individualized plan of care. In this way, the most current clinical knowledge provides the basis for each patient's care. Özdas et al. (2006) demonstrated that use of the evidence-based order set increased physician compliance with quality indicators for treating acute myocardial infarction. Other research opportunities are to explore the impact (positive or negative) of deviations from the template order sets in the context of different patient characteristics and comorbidities, thereby refining the evidence base and adding to clinical knowledge. Patient care systems like this make it possible to learn from data collected in the course of patient care about the effectiveness and safety of specific care practices and to integrate that emerging knowledge in continual quality improvement (Ozbolt et al. 2001; Ozbolt 2003).

At Partners Health Care, system developers are working with clinical teams to identify system requirements, to iteratively develop, and to test patient-centric systems that integrate decision support into the clinical workflow. For example, Dykes et al. (2010) developed a fall prevention toolkit that reuses fall risk assessment data entered into the clinical documentation system by nurses and automatically generates a tailored set of tools that provide decision support to all care team members, including patients and their family members at the bedside (Dykes et al. 2009). The fall prevention toolkit logic was developed from focus groups of professional and paraprofessional caregivers (Dykes et al. 2009), and of patients and family members (Carroll et al. 2010). As nurses complete and file the routine fall risk assessment scale, the documentation system automatically generates a tailored bed poster that alerts all team members about each patient's fall risk status and patient-appropriate interventions to mitigate risk. In addition, a patient education handout is generated that identifies why each individual patient is at risk for falls and what the patient and family members can do while in the hospital to prevent a fall. In a randomized control trial of over 10,000 patients, the toolkit was associated with significantly fewer falls than usual fall prevention practices (Dykes et al. 2010). This work is currently being expanded to reuse data from provider order entry and the clinical documentation systems to display icon-based alerts on an electronic white board at each patient's bedside to communicate the core set of information needed by care team members to safely care for individual patients.

### 15.4.3 Implementation of Systems

Much has been written about health information technology failures and associated costs and consequences (Bloxham 2008; Booth 2000; McManus and Wood-Harper 2007; Ornstein 2003; Rosencrance 2006). Higgins and associates (see Rotman et al. 1996) described the lessons learned from a failed implementation of a computer-based physician workstation that had been designed to facilitate and improve ordering of medications. Those lessons are not identical to, but are consistent with, the recommendations of Leiner and Haux (1996) in their protocol for systematic planning and execution of projects to develop and implement patient-care systems.

As these experiences demonstrate, the implementation of patient-care systems is far more complex than the replacement of one technology with another. Such systems transform work and organizational relationships. If the implementation is to succeed, attention must be given to these transformations and to the disruptions that they entail. Southon and colleagues (1997) provided an excellent case study of the role of organizational factors in the failed implementation of a patient-care system that had been successful in another site.

To realize the promise of informatics for health and clinical management, people who develop and promote the use of applications

must anticipate, evaluate, and accommodate the full range of consequences. In early 2003, these issues came to the attention of the public when a large academic medical center decided to temporarily halt implementation of its CPOE system due to mixed acceptance by the physician staff (Chin 2003; Ornstein 2003). A case series study by Doolan, Bates, and James (2003) identified five key factors associated with successful implementation: (1) having organizational leadership, commitment, and vision; (2) improving clinical processes and patient care; (3) involving clinicians in the design and modification of the system; (4) maintaining or improving clinical productivity; and (5) building momentum and support amongst clinicians. A collaboration of ten **American Medical Informatics Association** (AMIA) working groups and the **International Medical Informatics Association** (IMIA) Working Group on Organizational and Social Issues cosponsored a workshop to review factors that lead to implementation failure. These include poor communication, complex workflows, and failure to engage end-users in clearly defining system requirements. Recognizing that the problems encountered in failed implementations tend to be more administrative than technical, they recommended the following set of managerial strategies to overcome implementation barriers; (1) provide incentives for adoption, remove disincentives; (2) identify and mitigate social, IT, and leadership risks; (3) allow adequate resources and time for training before and after implementation (i.e., ongoing); (4) learn from the past and from others about implementation successes and failures and about how failing situations were turned around (Kaplan and Harris-Salamone 2009).

For the purposes of promoting successful implementation of patient-centered systems, the third category of the Friedman typology is expanded to provide access to information to all team members including patients and their families or caregivers outside of traditional health care settings as follows: *Installing such systems and then making them work reliably in functioning health care environments and other settings where information is needed to promote health and well being*. The majority of self-care occurs outside of traditional health care settings. As noted in Table 15.3, a prerequisite for patient-centered systems is that they support efficient workflows that leverage ubiquitous access to information and communication and are not constrained by existing care venues or provider-centric practice patterns (Principle #8). Strategies to involve end-users in system design or selection and customization will support successful implementation of systems that meet user expectations (Burley et al. 2009; Rahimi et al. 2009; Saleem et al. 2009b). End-user involvement in defining future state workflows contributes to a shared understanding about the impact of information systems on clinical tasks and workflows (Leu et al. 2008).

Careful attention to the *Principles to Guide Successful Use of Health Care Information Technology* during system design will support successful implementation. For example, the principles related to evolutionary health care changes keep the focus on designing and implementing usable systems that enable patient-centered care practices. Principles related to radical change focus on development of flexible, adaptable systems that are architected to accommodate disruptive change and iterative development based on end-user feedback.

### 15.4.4 Effects of Clinical Information Systems on the Potential for Patient-Centered Care

Electronic health records (EHRs) and computer-based provider order-entry (CPOE) systems are intended to support safe, evidence-based, patient-centered care by examining patient-specific information, agency-specific information, and domain-specific information in the clinical context and proposing appropriate courses of action or alerting clinicians to potential dangers. Many current systems, however, fail to follow design principles that take into account the real contingency-driven, non-linear, highly interrupted, collaborative, cognitive, and operational

workflow of clinical practice (Ash et al. 2004). These flaws can lead to errors in entering and retrieving information, cognitive overload, fragmentation of the clinical overview of the patient's situation, lack of essential operational flexibility, and breakdown of communication. Physicians, in particular, have found themselves chagrined by changes in the power structure as they have devoted more time to entering information and orders while other members of the health team have gained greater access to information and the concomitant capacity to make certain decisions without consulting the physician. Clinicians across the range of professions have expressed concern about the decrease in face-to-face communication with its verbal and non-verbal richness, negotiation, and redundant safety checks as more and more clinical information is exchanged via the computer (Campbell et al. 2006; Ash et al. 2007). These and other unintended consequences of EHRs and CPOE systems are the subject of ongoing research. Detecting and finding ways to prevent or mitigate the adverse, unintended consequences of these systems will be critical for supporting patient-centered care.

A number of unintended consequences stem from the incompatibility of system design with the clinician's cognitive workflow. For example, systems that make it difficult to find and retrieve information can interfere with patient-centered care. In a hospital preparing to implement a commercial CPOE system, investigators compared the efficiency, usability, and safety of information retrieval using the vendor's system, the current paper form, and a prototype CPOE developed on principles of User Centered Design. They found the prototype system to be similar to the paper form and both to be significantly superior to the vendor's system in efficiency, usability, and safety (Chan et al. 2011).

Other unintended consequences arise from over-reliance on the information system because of limited understanding of its design and capacities. To date, many clinical decision support systems are somewhat limited in their ability to incorporate patient-specific data into their decision algorithms. A synthesis of 17 systematic reviews conducted with sound methodology found that clinical decision support systems often improved providers' performance, especially in medication orders and preventive care. The reviewers noted, "These outcomes may be explained by the fact that these types of CDSS require a minimum of patient data that are largely available before the advice is (to be) generated: at the time clinicians make the decisions" (Jaspers et al. 2011, p. 327).

On the other hand, many systems offer functionalities that support patient-centered care. An important component of patient-centered care is the application of evidence in a plan of care tailored to the patient's needs. To increase the use of evidence-based order sets, investigators at Sinai-Grace Hospital in Detroit, Michigan, embedded order sets for the most common primary and secondary diagnoses for patients admitted to their medical service into the general admission order set. The result was a fivefold increase in the use of evidence-based order sets in the 16-month period following implementation (Munasinghe et al. 2011).

As in the examples above, most systems to support the cognitive workload have been directed toward physicians. Patient-centered care requires a broader perspective. A study of the information needs of case managers for persons living with HIV found that the most frequent needs were for patient education resources (33 %), patient data (23 %), and referral resources (22 %) (Schnall et al. 2011b). The investigators recommended that targeted resources to meet these information needs be provided in EHRs and continuity of care records through mechanisms such as the Infobutton Manager.

Key to patient-centered care is communication among all the health care professionals on the patient's team. A study at one academic medical center (Hripcsak et al. 2011) reviewed electronic medical records of hospitalized patients, along with usage logs, to make inferences about time spent writing and viewing clinical notes and patterns of communication among team members. In this setting, the core team for each patient consisted of one or more attending physicians, residents, and nurses, with social workers, dieticians, and various therapists joining the team later. Results showed that clinical notes were

more likely to be reviewed within the same professional group, with attending physicians and residents viewing notes from nurses or social workers less than a third of the time. The investigators proposed that it might be useful to develop ways for EHRs "to summarize information and make it readily available, perhaps with the ability of the author to highlight information that may be critical and that has a high priority for communication" (p. 116). They also noted that their study was limited to communications within the EHR and did not take into account face-to-face or telephone communications that might have occurred, especially in urgent situations. They suggested further research involving direct observation of clinicians, time-motion analyses, and think-aloud methods to develop deeper knowledge of how clinicians communicate about patient care, especially across the professions.

The quality of documentation tools can have a profound effect on whether information, even if communicated face-to-face, is acted upon in clinical care (Collins et al. 2011b). In a neurovascular intensive care unit, therapeutic goals for patients were stated during daily interdisciplinary rounds. In this setting, the interdisciplinary team treated the attending physician's note as a common patient-focused source of information. Although the attending physician's note contained 81 % of the stated ventilator weaning goals, it included only 49 % of the stated sedation weaning goals. Overall, nearly a quarter of stated goals were not documented in the note. If a goal was not documented, it was 60 % less likely to have a related action documented. Nurses' documentation rarely mentioned the goals, even if actions recorded were consistent with the goals as stated during rounds. Notably, the nurses' structured documentation system did not support sedation-related goals, even though sedation weaning was a nursing responsibility in this setting. The authors noted that the frequent omission of sedation goals from the attending physician's note might be because this nursing function was not a billable goal or act. They also expressed concern that the omission from the EHR of evidence of important clinical judgments nurses make could impair patient safety, quality improvement, and development of nursing knowledge. Thus, in this example, although the interdisciplinary team was collaborating in setting and reaching therapeutic goals, deficiencies in their processes and in the nurses' documentation system limited their achievement of patient-centered care.

A study at Vanderbilt University Medical Center also demonstrated both strengths and shortcomings in the ability of a clinical information system to support patient-centered care. Attending physicians in the Trauma and Surgical ICUs established protocols for Intensive Insulin Therapy (IIT) that were built into a CDSS to advise nurses on insulin doses based on a patient's blood glucose and insulin resistance trends. In 94.4 % of studied instances, nurses administered the recommended dose. When nurses over-rode the recommended dose, they overwhelmingly administered less insulin than the recommended dose, leading to a higher incidence of hyperglycemia than when the recommended dose was administered. Nurses appeared more concerned about hypoglycemia than hyperglycemia and to consider the patient's blood glucose but not the insulin resistance trend. They also noted that their workflow was impeded by the need to record information about the blood glucose, insulin dose, and primary dextrose source in two places—the CPOE that included the CDSS and the separate nurse charting system. The investigators' recommendations included displaying information about insulin resistance trends on screen (provided that this did not produce clutter and confusion) and developing clinical information systems that do not require double documentation. Strengths of this example for supporting patient-centered care include the collaboration of physicians and nurses in maintaining blood glucose in the desired range based on patient data. Shortcomings include the failure to present nurses with information about the patient's insulin resistance trend to aid their decision-making and the requirement that they record the same data in two places, thereby reducing time for direct patient care (Campion et al. 2011).

Patient-centered care systems not only support the cognitive work and communications of

clinicians; they also take into account the resources patients and families use to manage their health concerns. Increasingly, patients and family members engaged in promoting their own health turn to social networking sites on the Internet. An examination of ten sites focused on diabetes mellitus, however, found significant gaps in quality and safety (Weitzman et al. 2011b). On only half the sites was content aligned with current medical science. Of nine sites that carried advertising, only four made a clear distinction between advertising and editorial content; two sites contained advertisements about a "cure" for diabetes. Six sites, including four moderated sites, contained member-posted misinformation about a "cure" for diabetes. Privacy practices were generally poor. The authors offered straightforward, readily implementable recommendations for improving the quality and safety of health-related social networking sites, but they noted that there is no authority or agency empowered to enforce them.

To provide patients with high quality information resources, many health care organizations are offering their own Web sites and portals. Atkinson et al. (2011) demonstrated the importance of involving users in evaluating the design of such resources, including giving them more than one version to evaluate and varying the order of presentation. Notably, they found that users liked the opportunity to explore the site and assess its credibility and authoritativeness before registering and entering personal information. A survey of individuals using health-related social networking sites provided by three major medical centers found that the most important factor determining the degree of empathy that people perceived they received from the site was the effectiveness of seeking information, as compared with social support or personal similarity of participants (Nambisan 2011). The investigator recommended that health care organizations providing such sites take pains to make it easy for participants to find the information they need.

Although such sites can be helpful to patients, they are not readily accessible to everyone. An examination of the usage of Kaiser Permanente's patient portal by adults in northern California with a diagnosis of diabetes found that African Americans and Latinos had a higher probability of never logging on compared to Caucasians. Similarly, those with a college degree were much more likely to log on to the site than those without a college degree (Sarkar et al. 2011b). The investigators expressed concern that already disadvantaged populations might be further deprived of needed health information and education as providers turn increasingly to the Internet for patient communication and education.

When patients are willing and able to use electronic communications with providers, clinicians have special responsibilities to assure safe, ethical, patient-centered care. Mittal et al. (2010) measured 18 indicators of response quality to a fictional patient email. The respondents were 50 first- or second-year rheumatology residents from six different fellowship programs over a period of 4 years (2005–2008). Responses tended to be concise (74 %) and courteous (68 %). However, the residents did less well on two other dimensions: understanding the role of email as a complement to a visit and not for urgent matters, and understanding the administrative and legal aspects of email, such as the need for proper documentation and encryption. Thus, even though 92 % of the residents acknowledged that the patient's condition (as described in the fictional email) required immediate medical attention, few (30 %) took steps to contact the patient other than by email response. None of the residents encrypted their messages. The investigators acknowledged that the residents might have responded differently to an email from a real patient but concluded that there is a need for more formal training in the proper use of email in the provider-patient relationship.

In patient-centered care, **personal health records** (PHRs; see Chap. 17) are often viewed as a means of communication between patients and providers and as a method of engaging patients in understanding and acting in the interests of their own health. The Military Health System (MHS), charged with providing patients with access to their health information through an interoperable system, initiated a pilot project in 2008 to allow patients a choice of platforms, Google Health

(now-defunct) or Microsoft HealthVault, as the repository for their health data (Nahn et al. 2011). A portal called MiCare was created as the gateway to the repository of choice and to other PHR functionalities. MiCare also provided the platform for transferring data, at the patient's request, from various Department of Defense sources to the PHR repository of choice. Users were generally satisfied with MiCare as a portal to their information, but they wanted more functionalities, such as secure messaging and appointment scheduling. The investigators cited four important lessons learned. First, although most patients requested automatic transfer of all their data to the repository, this slowed response time to an unacceptable level. The designers then changed the model to transfer data only upon specific patient request. Second, although the patient representatives to the project requested instant access to all their data, providers insisted on a 7-day publication delay for routine information, to give them time to contact the patient and explain the results. For sensitive information such as pregnancy, positive cancer findings, and sexually transmitted diseases, the providers required direct contact with the patient, with publication happening only with patient request and provider concurrence. Third, providers found that accessing the PHR impeded their workflow and that lack of complete information from the MHS might pose a danger of ill-informed clinical decisions. A dashboard that integrated patient requests with full MHS data on the patient might have helped. Fourth, giving patients the power to determine what medical information to share with the provider could similarly lead to clinical decisions made in the absence of vital information, with resulting harm to patients. The investigators concluded that while there is broad agreement on desired functionalities for PHRs, challenging tensions remain between patients' desire for access to and control of health information and providers' needs for full information about the patient and for appropriate opportunities for ethical disclosure of information to patients.

Electronic health records and other computer-based information resources can influence the provision of patient-centered care even when the patient and the provider are in the same room. A study of computer use during acute pediatric outpatient visits found that female physicians were more likely than males to be communicating with patients and families while using the computer (Fiks et al. 2011). An observational study involving 20 primary care physicians and 141 of their adult patients showed how the inclusion of the computer in the clinical consultation can help patients shift the balance of power and authority toward shared decision-making and patient-centered care (Pearce et al. 2011). This Australian study found that about one-third of the patients actively included the computer as a party to the consultation, drawing the physician's attention to it as a source of information or authority. They concluded, "In the future, computers will have greater agency, not less, and patients will involve themselves in the three-way consultation in more creative ways—for example, through online communication, or through the plugging into computers of their own electronic records, creating a situation where they co-own the information in the computer …. By democratizing and commoditizing information flows and authority in the consultation, we may in fact create truly patient-centered medicine, with the patient directing the action" (p. 142).

As these examples illustrate, the complexity of collaborative, interdisciplinary, patient-centered care poses serious challenges to the design of clinical information systems. Many systems fall short in supporting cognitive work, even from a clinician-centric perspective. Supporting communications among clinicians, between clinicians and patients, and among patient and family support groups presents myriad technical and ethical problems. Still, researchers and clinicians increasingly share a vision of patient-centered care that drives them to push the frontiers and develop support for this emerging model of care.

## 15.5 Outlook for the Future

Social and political forces have begun to transform health care in the United States, and health information technology is advancing to support

the changes. The transformation is rapid, disruptive, and not always smooth, but mandates and incentives are aligning with social and economic imperatives to maintain progress.

To meet demands for patient-centered care, changes must occur in clinician practice patterns and processes, in the organization and management of health services, and in the education of health care professionals and the public. To support patient-centered care, clinicians, informatics professionals, and computer scientists must develop health information and communication technologies that support collaboration; cognitive processes and operational workflow; communication and shared decision making between and among clinicians, patients, and family members; and trustworthy tools for the management of personal and family health.

Transformational change is daunting, and resistance is inevitable. Still, the chances for success have never been better. The vision of health care articulated by the National Academy of Sciences is guiding policy, research, and practical action by government agencies, health care providers, and the public.

## Suggested Readings

Adams, K., & Corrigan, J.M. (Eds.). (2003). *Priority areas for national action*: *Transforming health care quality*. A report of the Institute of Medicine. Washington, DC: National Academy Press. This book outlines a plan for transforming health care, identifying specific chronic diseases and conditions as targets for initial work and describing cross-cutting changes, including the widespread use of health information technologies, to achieve a better health care system.

Ahern, D. K., Woods, S. S., Lightowler, M. C., Finley, S. W., & Houston, T. K. (2011). Promise of and potential for patient-facing technologies to enable meaningful use. *American Journal of Preventive Medicine, 40*(5 Suppl 2), S162–S172. This article describes specific technologies that patients can use in the interests of their health and that support patient-centered care.

Committee on Quality of Health Care in America. (2001). *Crossing the quality chasm*: *A new health system for the 21st century*. A report of the Institute of Medicine. Washington, DC: National Academy Press. This book articulates a vision of better health care and emphasizes the importance of health information technology in creating and maintaining better systems of care.

Dykes, P. C., Carroll, D. L., Hurley, A., Lipsitz, S., Benoit, A., Chang, F., et al. (2010). Fall prevention in acute care hospitals: a randomized trial. *Journal of the American Medical Association, 304*(17), 1912–1918. This article describes development and testing of an electronic fall prevention toolkit integrating decision support into clinical workflow at the bedside and intended for use by all team members including patients and family.

Kohn, L.T., Corrigan, J.M., & Donaldson, M.S. (Eds.). (2000). *To err is human*: *Building a safer health system*. A report of the Institute of Medicine. Washington, DC: National Academy Press. This book describes flaws in the American health care system that result in unnecessary death and suffering.

Stead, W.W., & Lin, H.S. (Eds.). (2009). *Computational technology for effective health care*: *Immediate steps and strategic directions*. A report of the National Research Council. Washington, DC: National Academy Press. This book proposes principles and methods to achieve the best functionality from existing health information technologies and proposes collaboration to advance technologies to the level needed for a transformed health care system.

**Questions for Discussion**

1. What is the utility of a linear model of patient care as the basis for a decision-support system? What are two primary limitations? Discuss two challenges that a nonlinear model poses for representing and supporting the care process in an information system.
2. Compare and contrast additive, clinician-centered versus coordinated, patient-centered models of interdisciplinary patient care. What are the advantages and disadvantages of each model as a mode of care delivery? What are the broad implications for design of information systems to support clinician-centered versus patient-centered models of care?
3. Imagine a patient-care information system that assists in planning the care of each patient independently of all the other patients in a service center or patient-care unit. What are three advantages to the developer in choosing such an information architecture? What would

be the likely result in the real world of practice? Does it make a difference whether the practice setting is hospital, ambulatory care, or home care? What would be the simplest information architecture that would be sufficiently complex to handle real-world demands? Explain.

4. Zielstorff et al. (1993) proposed that data routinely recorded during the process of patient care could be abstracted, aggregated, and analyzed for management reports, policy decisions, and knowledge development. What are three advantages of using patient care data in this way? What are three significant limitations?
5. A number of patient-care information systems designed in the 1970s are still in use. How do the practice models, payer models, and quality focus of today differ from those of the past? What differences do these changes require in information systems? What are two advantages and two disadvantages of "retrofitting" these changes on older systems versus designing new systems "from scratch"?
6. What challenges exist in modeling information for patient-centered care? What considerations are important in designing patient-facing health information and communication technologies?