Informatics

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Introduction

Clinical informatics is the study of information technology as it applies to clinical care within the health system. The American Medical Informatics Association (AMIA) considers informatics when used for healthcare delivery to be essentially the same regardless of the health professional group involved. *Clinical informatics* is concerned with information use in healthcare by clinicians. Clinical informatics includes a wide range of topics ranging from clinical decision support (CDS) to visual images; from clinical documentation to provider order entry systems; and from system design to system implementation and adoption [1]. In this chapter, our goal is to introduce the reader to new and old concepts that will allow the user to assess information and knowledge to meet the needs of healthcare professionals and patients. The reader will be able to characterize and evaluate information technology, so that they are better able to refine clinical workflow processes, develop new processes, implement those processes, and refine clinical decision support systems [2]. Knowledge of these elements will aid providers in clinical care to their patients. We will discuss workflow, clinical decision support, information technology systems, and communication, concluding with a discussion of cancer registries and research.

Workflow Process Redesign and Quality Improvement

Workflow has been studied both as a concept and a phenomenon. As a concept, workflow is defined as the sequence of physical and mental tasks performed by people within and between work environments. The flow of information, objects, and people using information and objects through space and time represents the phenomena of workflow. Clinical workflow studies aim to model a simplified version of work in the complex healthcare setting [3]. The simplification achieved by modeling aids in making complex systems more comprehensible as a result of the explanatory nature of such models [4, 5].

Multilevel perspectives are useful to understand workflow comprehensively in the complex system of healthcare [6]. Workflow can occur sequentially or simultaneously and at various levels (individual or organization). Workflow occurs interorganizationally, between clinic employees, and for individual employees before, during, and after a patient encounter. Cognitive workflow occurs as cerebral processes in collecting data and making decisions.

An example of workflow can be illustrated in the ordering of a medication. The workflow of ordering a medication includes communication between the provider and the patient, the provider's mental processes, and the physical action by the provider of writing the prescription on paper or electronically into an electronic health record and sending the order electronically or the patient taking the paper prescription to the pharmacy. In this example, one can see the use of cognitive, individual, organizational, and intraorganizational workflow.

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Any time there is a change in practice, particularly related to health information technology, workflow changes occur. Delays in patient care, billing, and communication are prone to occur if the workflow is unaccounted for, overlooked, or oversimplified. All healthcare organizations, regardless of size, must identify a person or group to monitor and assess current and anticipated workflow. Workflow information should be collected as early as possible, ideally before implementing a health IT system, and continually assessed including post implementation as a form of continuous process improvement.

Workflow Analysis

Workflow analysis may be used to improve the outcome of healthcare processes and products, including the practice of healthcare informatics. Institute of Medicine landmark reports call for the use of workflow analysis in an effort to improve healthcare quality, efficiency, effectiveness, and safety [7]. Analysis of workflow requires a reduction of a complex process into analyzable parts in a stepwise fashion.

Various tools can be used during workflow analysis, and a single approach will likely capture a small subset of the complexity. Methods to capture workflow data include qualitative, quantitative, and mixed methods [8]. Qualitative methods focus on naturalistic observation of subjects and activities using artifact collection, spatial analysis, and interviews. Quantitative methods are a more structured approach. Time-motion studies can track the efficiency and quality of healthcare workflow, quantifying the time involved in tasks by observation, self-reporting, or automation to collect temporal data [9]. Questionnaires and surveys are also used as workflow analysis methods. Data collected from the electronic medical record including audit logs, a form of metadata, is a new and emerging area of data collection for workflow methodology.

Visualizing workflow is an important tool as it provides users with cognitive support for visualizing detailed processes, showing parallel processes and allowing different perceptions of processes [10]. The most common method of visualization is flowcharting (process mapping). Flowcharting shows how processes really happen, rather than how they are expected or supposed to happen. This method helps one understand what contributes to different types of flows for the same process, find ways to improve the flows, and identify ways that health IT will affect workflows. Flowcharting is accomplished in five general steps: (1) decide on the process to examine; (2) create a preliminary flowchart; (3) add detail to the flowchart; (4) determine who needs to be observed and interviewed; and (5) do the observations and interviews [11]. An example of a flowchart from a patient being diagnosed with cancer and undergoing treatment and follow-up is shown in Fig. 3.1.

Workflow Redesign

The goal of workflow redesign is to create workflow that supports improved outcome of workflow activities (patient care). Workflow reengineering requires deliberate steps including changes to the mental and physical steps of people who move through a workflow process and changes to the steps in the interactions among organizations involved in a process. Karsh and Alper suggested a system to ten steps of process redesign as seen in Table 3.1 [12]. Broadly, process redesign is achieved by assessing the current state, envisioning the desired future state, planning to get to the future state, carrying it out, and evaluating the outcome.

Quality Improvement

Quality improvement in healthcare is a continuous method for improving process performance. Several quality improvement methodologies are used in healthcare. The Plan-Do-Study-Act (PDSA) is a prominent method that leads quality improvement cycles. The "plan" phase includes identifying a problem and potential solutions. "Do" involves a polar testing of a solution. The "study" phase evaluates if the change was successful. "Act" involves adopting, adjusting, or abandoning the implemented solution. Lean is another process improvement strategy that emphasizes value to customers by utilizing root cause analysis to eliminate waste and improve process flow. Six Sigma is another process improvement methodology that emphasizes quantitative and statistical approaches in continuous quality improvement at the project level to reduce process variations and eliminate defects.

Conclusion

Workflow is the sequence of tasks performed by various people within and between work environments. Workflow analysis is an integral part of quality improvement implementation and health informatics. In this chapter, we have outlined workflow analysis tools, a framework for workflow redesign, and gave an overview of quality improvement methodologies.

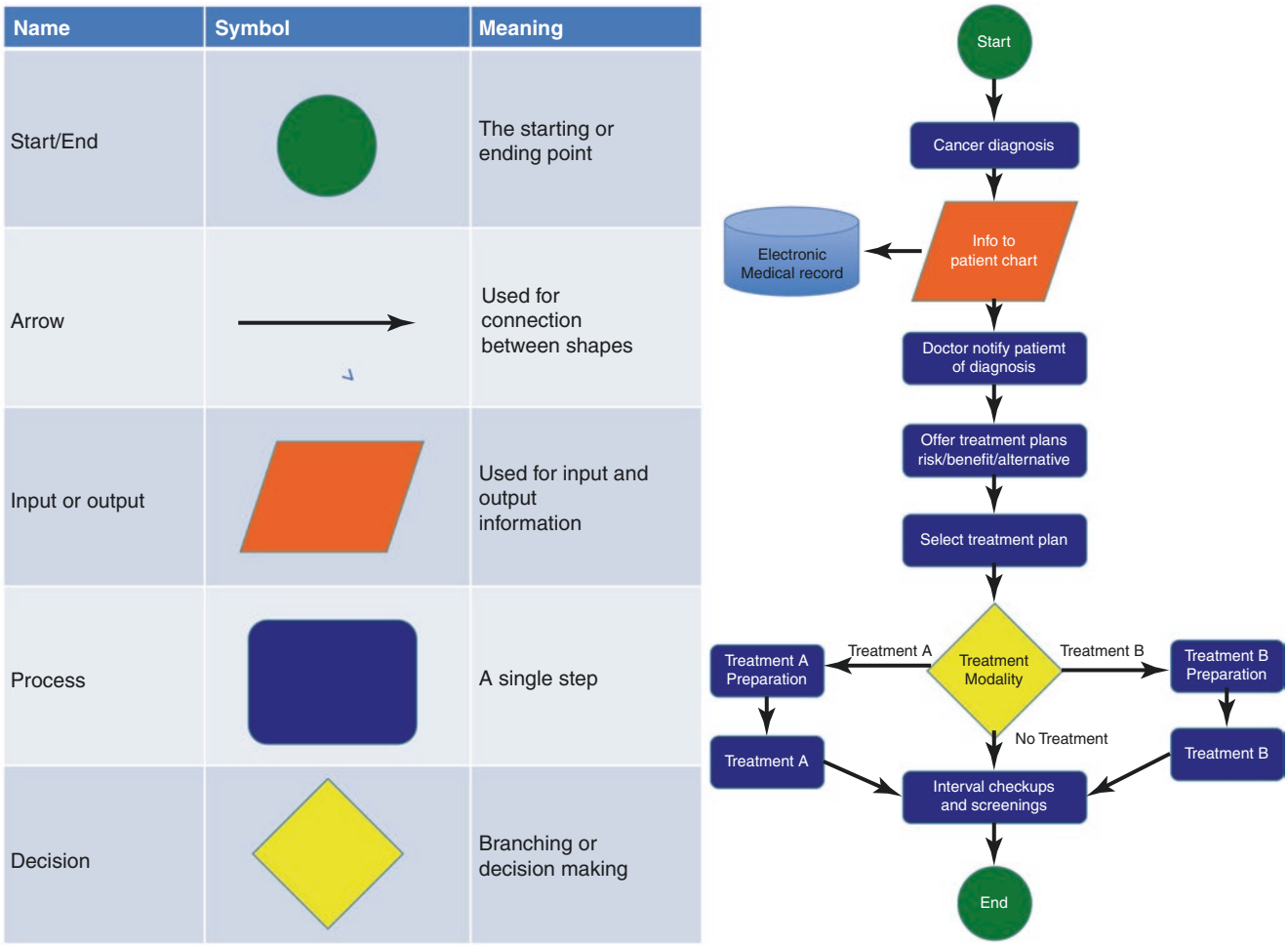

Fig. 3.1 Example flowchart of a patient being diagnosed with cancer, undergoing treatment and follow-up

Table 3.1 Karsh and Alper's ten steps of process redesign [12]

Ten steps of process redesign	
Step 1	Decide what system will be the subject of analysis
Step 2	Produce a preliminary work system map
Step 3	Use the preliminary workflow map to determine who should be represented on the team that will carry out the analysis
Step 4	Conduct an initial scan of the system with the team
Step 5	Determine boundaries of the system under study
Step 6	Determine performance expectations for each step in the system
Step 7	Begin formal data collection to review and update the workflow map. Gauge the current performance of the system, and determine baseline measures that will be used to evaluate the effectiveness of the redesign
Step 8	Analyze the data
Step 9	Once hazards (i.e., causes of failure modes or variance) have been identified, control strategies should be developed
Step 10	Analyze redesign ideas. Decide on a redesign idea, pilot testing, and implementation

Clinical Decision Support

The Office of the National Coordinator for Health Information Technology (ONC) defines clinical decision support (CDS) as providing clinicians, staff, patients, or other individuals with knowledge and person-specific information, intelligently filtered or presented at appropriate times, to enhance health and healthcare [13]. CDS are set of tools and logic to assist providers in making uncertain decisions. All medical decisions come with some percentage of uncertainty: diagnosis, testing, natural progression of disease process, treatment, and subsequent effects. CDS has evolved to remove some of the cognitive burden involved in medical decision-making.

There are some fundamental concepts we will review in order to leverage additional tools to aid in CDS. The first is the concept of expected value and expected utility. *Expected value*

(mathematical expectation, mean or average) is the random variable in a simplification of the weighted average and intuitively is the arithmetic mean of many independent realizations of that variable [14], whereas *expected utility* concerns people's preferences about choices that have uncertain outcomes (gambles). The expected utility states that the subjective value associated with an individual's gamble is the statistical expectation of that individual's valuations of the outcomes of that gamble, where these valuations may differ from the dollar value of those outcomes [15]. *Expected utility theory* is a theoretical approach to making optimal decisions under risk [16].

An example of these two concepts: in the presence of risky outcomes, a decision-maker does not always choose the option with higher expected value investment. Suppose there is a choice between a guaranteed payment of $1.00 and a gamble in which the probability of getting a $100 payment is 1 in 80 chances and the alternative, far more likely outcome (79 out of 80) is receiving $0. The expected value of the first alternative is $1.00 and the expected value of the second alternative is $1.25. According to expected value, people should choose the $100-or-nothing gamble; however, as stressed by expected utility, some people are risk averse enough to prefer the sure thing, despite its lower expected value. People with less risk aversion would choose the riskier, higher-expected-value gamble [15].

Expected value of gambling:

- If you gamble and win, you get $100.00.
- If you gamble and lose, you get nothing ($0.00).
- If you don't gamble, you are guaranteed $1.00.

$$\text{Formula}: \$100 * \left(\frac{1}{80}\right) + \$0 * \left(\frac{79}{80}\right) = \$1.25$$

Similar to engineering as it relates to healthcare, diagnostic inferences models have two elements: *tests* and *conclusions. Tests* include any source of information that can be used to determine the health of a system. *Conclusions* typically represent faults, including hardware fault modes, functional failures, specific non-hardware failures, and specific multiple failures. A conclusion may also indicate the absence of a failure indication (no fault). With this model, one can revise and refine opinions with imperfect information, comparable to a differential diagnosis. There are three characteristics to consider in making a diagnosis: detection, localization, and isolation, as defined in Table 3.2. In developing a diagnosis, the reader should focus on concepts emphasizing a structured approach to system testing and diagnosis. These include:

Table 3.2 Characteristics considered when making diagnoses

Characteristics	Definition
Detection	The ability of a diagnostic strategy to identify that a failure in some system has occurred
Localization	The ability to say that a fault has been restricted to some subset of the possible causes
Isolation	The identification of a specific fault through some test, combination of tests, or diagnostic strategy

- Maximizing reuse of design and test data, information, knowledge, and software
- Integrating support equipment and manual testing, to provide complete coverage of diagnostic requirements
- Integrating available diagnostic information, to minimize required resources and optimize performance

Capturing the relationships between tests and diagnosis provides a knowledge representation that can be processed by a reasoning system for health management. Initially, equal quality among test results is assumed and that every test outcome reflects the state of the unit being tested. In practice, this assumption is often relaxed to allow a measure of confidence to be associated with each test [17, 18].

Concepts of CDS include *heuristics*, which are patterns of bias in CDS. Heuristics is any approach to problem solving that employs a practical method that is not guaranteed to be optimal, perfect, or rational, but is nevertheless sufficient for reaching an immediate, short-term goal. Heuristics can be mental shortcuts that ease the cognitive load of making a decision [19]. Heuristics are the strategies derived from previous experiences with similar problems. These strategies depend on using readily accessible, though loosely applicable, information to control problem solving in people, machines, and abstract issues [20]. Some of the more common heuristics that apply to healthcare can be seen in Table 3.3 [21–27].

Cost-effectiveness analysis is a form of analysis that compares the relative costs and outcomes (effects) of different courses of action. Cost-effectiveness analysis is distinct from cost-benefit analysis, which assigns a value to the measure of effect. Typically, the cost-effectiveness analysis is expressed in terms of a ratio where the denominator is a gain in health from a measure (years of life, sight-years gained) and the numerator is the cost associated with the health gain. Cost-utility analysis can be used in decision analysis to define the "value" of an outcome node by adjusting the value of the outcome based on the perceived utility of that outcome for the patient. The most familiar outcome measurement is quality-adjusted life years (QALY) [28].

Table 3.3 Common heuristics in healthcare

Heuristics	Definition	Example
Availability	Overestimating the probability of unusual events because of recent or memorable instances [21]	*The last patient I saw with symptom X had disease Y, so we should test for Y*
Representativeness	Overestimating of a rare disease by matching patients to "typical picture" of that disease [22]	*He has features of the rare disease X, so we should test for it*
Anchoring	The failure to adjust probability of a disease or outcome based on new information, like "premature closure" [23]	*I was told in sign out that he had condition X, so I didn't consider it might be condition Y, despite lab results*
Value-induced bias	Overestimating the probability of an outcome based on value associated with that outcome [24]	*It would be horrible to miss a brain tumor in this patient with new onset headache, so we should get a head CT*
Affect heuristic	A mental shortcut that uses emotion to influence the decision. Emotion is the affect that plays the lead role that makes the decision or solves the problem quickly or efficiently. It may be used while judging the risks and benefits of something [25]	Your "gut decision" about the presentation of a patient
Familiarity heuristic	A mental shortcut applied to various situations in which individuals assume that the circumstances underlying the past behavior still hold true for the present situation and that the past behavior thus can be correctly applied to the new situation [26]	*I am familiar and comfortable with the Arrow Triple Lumen kit by Teleflex; I now need an arterial line kit, so I will choose the Teleflex brand since I am familiar with their other products*
Simulation heuristic	A simplified mental shortcut in which people determine the likelihood of an event happening based on how easy it is to mentally picture the event happening [27]	When the provider can easily "mentally undo" the sequence of events that led to a specific outcome like the placement of a chest tube or a cardiac arrest resuscitation

So, what makes a good test? Most would say a test with a high sensitivity and high specificity. Sensitivity is the measure of the proportion of actual positives that are correctly identified. Specificity is the measure of the proportion of actual negatives that are correctly identified. Sensitivity is the extent to which actual positives are not overlooked (minimizing false negatives), and specificity is the extent to which actual negatives are classified as such (minimizing false positives). The *positive predictive value* (PPV) and *negative predictive value* (NPV) describe the performance of a diagnostic test. A high result can be interpreted as indicating the accuracy of such a test [29]. The false-positive rate is the proportion of all negatives that still yield positive test outcomes, i.e., the conditional probability of a positive test result given an event that was not present. *False-positive rate* is equal to the significance level. The specificity of the test is equal to 1 minus the false-positive rate. *False-negative rate* is the proportion of positives yielding negative test outcomes with the test, i.e., the conditional probability of a negative test result given that the condition being looked for is present.

Of note, false positives should be differentiated from the phenomenon of *overdiagnosis* [30]. The finding of an insignificant pulmonary nodule or an adrenal "incidentaloma" on a chest CT ordered for a patient with a suspected pulmonary embolism is an example of overdiagnosis. The use of CDS tools has the potential to minimize, or at least standardize, the use of advanced imaging technology in such cases.

By reviewing the 2 × 2 tables shown in Table 3.4, we can design the most efficient CDS questions or tests.

Key elements of CDS are best described in a quote from Wyatt and Spiegelhalter: "Active knowledge systems which use two or more items of patient data to generate case-specific advice" [31]. More specifically, leveraging a good foundational knowledge base along with patient-specific information such as vitals or laboratory results and using the most appropriate mode of communication will assist the user to make the most appropriate choice. As the user designs and builds their CDS, it is important to consider the following targets:

1. What are the desired outcomes/clinical targets of CDS?
2. How will the CDS tool improve efficiency?
3. Are we looking for early detection/screening of the CDS?
4. Can CDS assist in the diagnosis or treatment protocol?
5. Can CDS provide preventative adverse outcome?
6. Can CDS provide follow-up management?
7. How does CDS provide cost reductions/conveniences?

Other design considerations should include the target audience. Which member of the healthcare team is the target for CDS? Is the intervention targeted to patients or families? Also consider the level of control of the CDS (preemptive, suppressible, hard-stop, or interruptive). Preemptive or active CDS is a rule based upon simple logic or systems-based upon probability. Active CDS includes rules and alerts. Respectively, hard-stop or suppressible control levels either prevent the user from taking an action altogether or allow them to proceed only with the external override of a third party. Interruptive CDS occurs when a process is interrupted

Table 3.4 Table to derive sensitivity and specificity

Total Population	Condition Positive	Condition Negative	Prevalence
Predicted Condition Positive	***True positive***	***False positive***	Positive Predictive Value $\frac{True\ Positives}{True\ Positives+False\ Positives}$
Predicted Condition Negative	***False Negative***	***True Negative***	Negative Predictive Value $\frac{True\ Negatives}{False\ Negatives+True\ Negatives}$
	Sensitivity $\frac{True\ Positive}{True\ Positives+False\ Negatives}$	Specificity $\frac{True\ Negative}{True\ Negatives+False\ Positives}$	
	False Negative Rate $\frac{False\ Negatives}{True\ Positives+False\ Negatives}$	True Negative Rate $\frac{True\ Negatives}{False\ Positives+True\ Negatives}$	
True positive	Sick people correctly identified as sick		
False positive	Healthy people incorrectly identified as sick		
True negative	Healthy people correctly identified as healthy		
False negative	Sick people incorrectly identified as healthy		

Table 3.5 Example categories of clinical decision supports

Therapeutic duplication
Single and cumulative dose limits
Allergies and cross allergies
Contraindicated route of administration
Drug-drug and drug-food interactions
Duplicate orders
Contraindications/dose limits based on patient diagnosis, age, weight, prior laboratory, or radiology studies

and requires the user to acknowledge its information by taking one or more actions, such as in computerized order entry (CPOE) systems. Three types of interruptiveness are on-demand (link to formulary from within order), in-line or modeless (unread lab result notification on sidebar), and popup or modal (alerts or reminders requiring acknowledgment).

Table 3.5 shows some examples of CDS categories.

When designing CDS, the user should always ask themselves the following questions to make sure they have addressed the five "rights" to assess their success [32]:

1. Right information – quality of knowledge base
2. Right person – target of CDS
3. Right format – implementation of CDS (speed, ease of use, comprehensibility)
4. Right channel – mode of CDS
5. Right time – workflow integration

Do I have the right information for the question? Have I accessed the right knowledge base and provided the correct resources and references? Who is my target audience, and have I reached them successfully? Do I have my question in the right format? Am I providing them with knowledge only, or is my aim to stop the user's process or redirect them? Do I have my CDS in the correct spot to provide the user the correct additional knowledge to make an informed decision?

Having created a CDS plan or outline, the user will most likely need to submit a proposal to a CDS committee that oversees all CDS and provides continuous feedback for the system. Many institutions may have forms to complete or submit. You will see in Fig. 3.2 that the example CDS form request follows the "5 Rights."

David Bates summarized the goals and expectations for CDS in his 2003 AMIA article (Table 3.6) [33]. He believes it is key that information systems provide decision support to users at the time they make decisions, thus promoting improved quality of care. Providers make many errors, and clinical decision support should help identify and avoid such errors.

Clinical Decision Support Request Form

Person submitting the request	
Purpose of goal for the CDS	
Evidence-based need	**RIGHT** information *What are the clinical grounds and supporting evidence for the CDS?*
Intended audience	**RIGHT** person *Who will see it? - e.g., physicians, RNs, pharmacists, etc.*
Clinical champion(s)	*Who will be the clinical champion (s) responsible for the success of implementing this alert?*
Primary stakeholders	*Who are the primary group (s) or committee (s) that have a stake in this CDS? This is important, as they may need to sign off prior to enabling CDS.*
Established level of consensus?	*Do we know whether stakeholders all agree on need for CDS?*
Clinical criteria for the CDS	**RIGHT** time – workflow integration *When should the CDS be triggered?*
Impact on patienr care	*What is expected to change as a result of the CDS?*
Impact on workflows	**RIGHT** channel – mode of CDS *What groups, activities and workflows is the CDS limited to? What is the frequency that it will occur?*
Urgency	*What is the urgency for this CDS? Why is it urgent?*
Monitoring success of the CDS	**RIGHT** format – implementation of CDS (speed, ease of use, comprehensibility) *What specific outcomes will be used to determine success of the CDS?*
Future clinical review	*What is the expected frequency and method for future clinical review of the CDS?*

Fig. 3.2 Example of a clinical decision support (CDS) form request that follows the "5 Rights"

Table 3.6 Ten commandments for effective clinical decision support [33]

1.	Speed is everything – expect sub-second latency
2.	Anticipate needs and deliver in real time – e.g., showing relevant labs with med orders
3.	Fit into users' workflow – external tools are not as good as those at POC
4.	Little things can make a big difference – "usability matters – a lot," "make it easy to do the right thing"
5.	Physicians resist stopping – do not tell doctors to not do something without offering an alternative
6.	Changing direction is easier than stopping
7.	Simple interventions work best – try to fit guidelines onto a single screen
8.	Asked for additional information when you really need it – "likelihood of success is inversely proportional to the number of extra data elements needed"
9.	Monitor impact, get feedback, and respond. Evaluate your CDS
10.	Manage and maintain your knowledge-based systems. Keep up with clinical care

Information Technology Systems

Telehealth

The desire to constantly improve the access, delivery, and quality of healthcare has resulted in the application of novel technologies to nearly all domains of medicine. Telehealth, also referred to as telemedicine, is defined by CMS as the electronic transmission of patient information from one distant site to another and has evolved to also include electronic communication between patients and providers in order to facilitate healthcare. Telehealth can employ many different types of technology to achieve patient to clinician communication including telephonic, short message service (SMS), fax, email, and real-time audio-video communication utilizing Internet connectivity and computers.

The utility of telehealth is vast and constantly evolving. Commonly cited benefits include improved clinician access in rural areas where such expertise is not available, decreased healthcare costs, and increased healthcare system workforce resilience, as well as patient and provider convenience [34]. During the COVID-19 pandemic, telehealth was utilized as a mechanism to reduce the use of one-time use personal protective equipment [35]. Some patients report preferring telehealth in place of traditional in-person visits for certain encounters, such as for birth control prescriptions [36]. Immunocompromised patients, including oncologic and rheumatology patients, have utilized telehealth to limit pathogen exposure associated with in-person visits at healthcare facilities.

Case Study 1

A 65-year-old female with a history of acute promyelocytic leukemia (APL) presents by ambulance to a rural hospital emergency department (ED) with complaints of altered mental status and worsening rash. Her husband at bedside reports 1 day of fever, increasing confusion, and, most recently, epistaxis. On examination of her skin, a diffuse petechial rash is discovered.

The clinician at bedside recognizes the patient is likely in disseminated intravascular coagulation (DIC) likely due to her APL. Basic supportive interventions are initiated, and diagnostic testing is ordered to confirm the suspected diagnosis. The clinician recognizes that this patient would benefit from specialty consultation and transfer to a higher level of care. A tablet computer mounted on a bedside cart is then used to connect a live video communication with an oncologist hundreds of miles away. After consultation with the oncologist, a live encounter with the patient and spouse is performed by the remote physician. Written treatment recommendations are captured and electronically transmitted by the electronic health record (EHR) from the oncologist to the emergency physician, and transfer to a quaternary care center is initiated.

History of Telehealth Although telehealth is widely used today all across the globe, its origins began over 60 years ago with the application of live video to facilitate psychiatric evaluations [37]. The National Aeronautics and Space Administration (NASA) researched telehealth heavily throughout the 1960s–1970s, culminating in pilot studies delivering healthcare to astronauts during space travel [38]. The birth of the Internet in the early 1990s, coupled with increased use of consumer video conferencing applications such as Skype in the early 2000s, further advanced the adoption of real-time audio-video communications as a way to deliver healthcare.

Today, there are hundreds of software and hardware telehealth products and services. Many telehealth encounters are performed on smartphones or tablet computers, as such devices have become ubiquitous in many parts of the world. The integration of telehealth with remote biometric sensor technology has also created new opportunities, such as telehealth intensive care units (ICU) and remote stroke consultation. Although many clinicians today do not incorporate telehealth into their practice, some have elected to only practice by telehealth, often citing increased flexibility and consumer demand.

Technology The safe evaluation and care of patients in any environment or by any medium requires some basic standards in place, such as clear audio, adequate visuals, and

timely data access. These specific standards initially led to the development of specialized telehealth hardware such as high-definition cameras and microphones. Early hardware was often large, bulky, fragile, and expensive. Early telehealth efforts were hindered by lagging pixelated video and fragmented audio. As Internet bandwidth increased and wireless technology decreased barriers to bringing devices to patients' bedsides, older hardware was replaced with smaller, cheaper, and better-quality devices, often affixed to carts.

Along with advances in hardware came new specialized healthcare software: the electronic health record (EHR). The replacement of paper medical records by digital records further aided telehealth adoption, as patient records could be stored on servers or in the cloud to be accessed by clinicians quickly and remotely. Most modern EHRs also support computerized provider order entry (CPOE) allowing rapid electronic ordering and reporting of diagnostic tests and ordering of medication prescriptions. Some EHR vendors have now started building telehealth directly into their products.

Telehealth Regulation Telehealth in the United States, like much of healthcare generally, is highly regulated at both state and federal levels. Restrictions on telehealth traditionally fall under three main categories: allowable locations/applications, requirements of service, and billing. Rural patients without access to robust care were seen as the greatest beneficiaries of telehealth. This led to regulations limiting telehealth services in urban areas where the need was postulated to be less. Furthermore, limits on what types of encounters (ambulatory vs. inpatient) qualify for telehealth are commonplace. The requirements of service are also used to tier the classification for reimbursement of telehealth. For example, a simple telephone audio-only call may not qualify as telehealth despite robust history gathering. Regardless of what type of telehealth tier is being utilized, the patient must verbally consent to telemedicine services. The business viability of telehealth has heavily relied on reimbursement policy set by agencies such as the Centers for Medicare & Medicaid Services (CMS). Many telehealth services are not reimbursed at the same rates as corresponding in-person encounters.

Many federal and state telehealth regulations were revisited and changed to respond to the COVID-19 pandemic of 2020. This led to the single greatest expansion of telehealth services in history and ushered in a new era where telehealth is commonplace and widely accepted. One of the most notable changes regarded the enforcement of patient privacy and security requirements from the 2009 Health Insurance Portability and Accountability Act (HIPAA). Although HIPAA still applies broadly, the enforcement of high encryption standards in video conferencing software was deferred. This allowed free consumer-focused telecommunication applications such as Skype (Microsoft Inc., Redmond Washington), Zoom (Zoom, San Jose California), and Hangouts (Google, Mountain View California) to be used instead of expensive niche telemedicine platforms.

Oncologic Emergencies and Telehealth The use of telehealth in the prevention of oncologic emergencies is growing. Telehealth may be deployed to reduce exposure to infectious disease in cancer patients at higher risk (e.g., immunocompromised), and telehealth has the obvious potential to reduce ED visits among cancer patients. Telehealth can also facilitate continuity of clinician-patient care, bringing in valuable context from the patient's own specialist when traveling. Remote video consultation and evaluation by oncologic specialists in both regular and emergent capacities can also aid in the diagnosis and treatment of patients. Many rural locations lack robust medical care systems and specialist oncologic expertise can be scant. Much more research is needed on the impact of telehealth on patient outcomes.

Conclusion Telehealth provides powerful tools in the care of oncologic patients during emergencies. Rapid technological developments will continue to change how clinicians care for patients. Changes in the regulation of telehealth have greatly expanded its applications and viability as a regular component of healthcare in the twenty-first century. Leveraging telehealth to assist in the care of patients with oncologic emergencies will prove more common and more powerful in the years to come.

Security

As healthcare continues to innovate and advance, the use of technology to care for oncologic patients continues to evolve and grow. From Internet-connected medical devices to artificial intelligence and machine learning, healthcare is increasingly digitized, connected, and complex. In this era of hyper-connected healthcare, it is important to focus not only on the care of oncologic patients but also on cybersecurity and privacy of sensitive patient data.

Case Study 2

After a long and busy shift in the ED, an attending physician posts on social media the following statement: "Just had the honor to treat one of our nation's last surviving World War II veterans in the Emergency Department at General Hospital! Despite his chronic lymphocytic leukemia, Albert is going to be okay! #VeteransRock #CancerSucks." The next day, he is

Table 3.7 18 HIPPA patient identifiers

Name
Address (all geographic subdivision smaller than state, including street address, city-county, and zip code)
All elements (except years) of dates related to an individual (including birthdate, admission date, discharge date, date of death, and exact age if over 89)
Telephone numbers
Fax number
Email address
Social Security number
Medical record number
Health plan beneficiary number
Account number
Certificate or license number
Vehicle identifiers and serial numbers, including license plate numbers
Device identifiers and serial numbers
Web URL
Internet Protocol address
Finger or voiceprint
Photographic image – photographic images are not limited to images of the face
Any other characteristic that could uniquely identify the individual

called into an administrator's office and is subsequently terminated from his employment for violating the hospital privacy policy.

Health Insurance Portability and Accountability Act (HIPAA) The Health Insurance Portability and Accountability Act (HIPAA) was a law passed by the US Congress in 1996 that, among other things, provided regulation around the security of protected health information (PHI) [39]. Beyond defining PHI, this law provided 18 "identifiers" (Table 3.7) constituting sensitive data elements that can be used to identify and subsequently violate the privacy of patients. Additionally, the law established a reporting and enforcement mechanism to ensure parties responsible for protecting PHI could be heavily fined if they suffered a breach or were negligent in securing the data.

Today, HIPAA continues to be a very important part of healthcare regulation. It remains regularly enforced, leading many hospitals to devote significant resources to the protection of PHI and compliance with federal regulation. When PHI is lost or exposed, it is termed a breach. Breaches of greater than 500 patient records often result in mandatory reporting to the federal government as well as the patients whose records were compromised. Common causes of breaches include (1) failure to dispose of paper records properly, (2) loss of computers containing PHI, (3) hacking of records by malicious actors, and (4) loss or records by a third party that was trusted with records (e.g., healthcare contractor or business affiliate).

Conclusion In the care of oncologic patients, as with other patients, the security and privacy of their PHI is important. As healthcare continues to become more digitized, the risk of exposing this information increases. Federal law protects patient data privacy, and failure to protect these data can lead to significant harms to patients, providers, and organizations. Oncologic patients can be at particular risk of PHI breach as they are often high utilizers of healthcare resulting in more records and can carry sensitive diagnoses.

Communication

Order Sets

AMIA defines an *order set* as a predefined template. Order sets are lists of orders that frequently include medication, laboratory, nursing, diet, activity, and other orders. They existed prior to the advent of electronic health records as paper templates. A common example is an admission order set. This would frequently include an admission order, a diet order, nursing orders, vital signs, activity orders, IV orders, medication orders, laboratory orders, radiology orders, consultation orders, and provider preferences. Order sets allow physician to easily select from commonly used orders to save time and ensure consistency for certain procedures, such as a surgery, admission, or discharge [40].

AMIA indicates that order sets have been "…the standard of care in hospitals for many years. While in the past, it took the form of pen and paper, today, it is, indeed, electronic" [41]. The Institute for Safe Medication Practices (ISMP) has developed guidelines around order sets [42]. The ISMP indicates that well-designed order sets have the potential to "integrate and coordinate care by communicating best practices through multiple disciplines, levels of care, and services, modify practice through evidence-based care, reduce variation and unintentional oversight through standardized formatting and clear presentation of orders, enhance workflow with pertinent instructions that are easily understood, intuitively organized, and suitable for direct application to current information-management systems and drug-administration devices, decrease the potential for medication errors through integrated safety alerts and reminders, and reduce unnecessary calls to prescribers for clarifications and questions about orders" [42]. The ISMP goes on to state that order sets that "are not carefully designed, reviewed, and maintained to reflect best practices and ensure clear communication, they may actually contribute to errors" [42].

The astute observer will note that order sets have been used for many years to standardize workflows, remind providers, and make suggestions about clinical care that has been vetted by best practices and evidence. In the case of patients presenting to the ED, oncologic patients present a

unique challenge. These patients are frequently immunosuppressed, which leaves them susceptible to several unique conditions, such as those infections that only spread in the immunocompromised state (i.e., neutropenic fever) and that may present with various metabolic derangements, such as tumor lysis syndrome. Given the infrequency with which emergency physicians encounter these conditions and the morbidity and mortality associated with them, these cases are ripe for use of order sets. Oncologic emergencies also demonstrate the need for collaboration in design of order sets. Many large healthcare organizations have informatics teams of healthcare practitioners that work in concert with information systems (IS) personnel to develop content for their electronic health record (EHR). The oncologic emergency is an example where various stakeholders and specialties work together to develop content. Polling providers for preference, along with scouring the literature for recommendations and guidelines, is often the first step in designing an order set. Usually one or more clinical "champions" are identified to begin the process of consulting literature, guidelines, experts in the domain, and practitioners in the affected departments. Their next step is usually to form a working group of affected stakeholders. In this case, ED providers, oncologists, and nursing would likely comprise the group. The two specialties would then discuss recommendations for order sets and request feedback from their respective departments. Much like the legislative reconciliation process, the groups then rejoin, find common ground, and resolve differences. This design would then be submitted to IS for testing and, later, implementation. Once implemented, as indicated by the ISMP, a properly verified and scrutinized order set has the ability to standardize and improve care.

Transition of Care Tools

The order set itself is one way of communicating care standards. The literature on emergency physician to ambulatory provider and vice versa communication is sparse, but it demonstrates differences in communication preferences [43]. Transitions of care are a topic of much discussion and are heavily scrutinized by The Joint Commission [44]. This is especially the case after an ED visit. While not all visits to the ED or hospital are avoidable, there has been increased attention in recent years on avoiding as many visits as possible.

One factor contributing to avoidable ED visits is provider-to-provider communication. Open and clear communication decreases errors and costs [45]. Some health systems have found communication to be so important for patient care that caseloads have been limited to ensure that provider-to-provider communication takes place [46]. With all the focus on communication, one might assume this problem would have been resolved. However, communication is regularly cited for the last 15+ years as one of the major factors in malpractice cases, regulatory citations, and poor patient reviews [47].

Healthcare organization management has taken this seriously and imagined a variety of solutions. After the HITECH Act was signed into law, electronic health records (EHRs) adoption greatly increased. It was theorized that EHRs would foster provider-to-provider communication. Communication increased, but it was mostly asynchronous communication (i.e., email, text messages, assigning providers to notes, etc.). This was a different form of communication than existed previously, which was largely sharing information face-to-face or via telephone [48]. If these communications methods were equal in terms of patient care, this chapter would end early. Interviewees have indicated that EHRs allow for easier and more frequent asynchronous communication, though this does not remove the need for physician-to-physician communication. Learning from each other is much less likely to occur through an email as opposed to a phone call. Proposed solutions involving the EHR include building infrastructure to allow for "preferred mode of contact" and standardizing communications [48]. EHRs may assist with this, but if the workflow hasn't been designed prior to initiation, it's easy for staff to use more and more asynchronous communication.

In addition, proper configuration of EHRs is necessary to ensure that the right information flows to the right person, in the right format and channel, at the right time. These rights are collectively known as the "5 Rights of Clinical Decision Support" [49]. This is usually referenced regarding tools in the EHR, though the rights apply to any information in an EHR. Globally, it applies to communication in general. The authors recommend a similar approach to that applied for workflow analysis, order set design, and other aspects of informatics. This is to perform a thorough analysis of the situations in question, engage stakeholders and leaders, form consensus, test, implement, and review. The advantage of engaging leaders (or the early adopters) in the department or division is the outsized influence they may have on those resistant of adoption. It equally applies in the design of EHR implementation, design, and flow of information. It is *critical* to find the consensus on the preferred method of communication. When differences occur, technology may assist to resolve the issue of differing preferences.

At the authors' institution, the EHR was utilized to engage clinicians, administrators, researchers, and stakeholders by considering a patient visit for particular specified reasons as a "unit of communication." For a given patient visit, different stakeholders wished to be notified in different ways. Some clinicians preferred a text notification, while others preferred an email. Administrators preferred a spreadsheet or interactive database. Informatics personnel coordinated with lead-

ership in IS, the ED, ambulatory space, and leadership to develop a system that would create reports and send notifications to a group of providers. Review of the system after implementation demonstrated increased satisfaction for all parties involved. An additional bonus was closer to real-time data on those presenting to the ED for the identified reasons. Before this system, monthly SQL queries were necessary to create spreadsheets and graphs to monitor patient care. The new system utilized EHR tools and allowed those involved in care to easily identify the individuals affected, as well as relevant data to inform care processes.

The agreement on the pre-implementation of this plan led to less utilization of resources to better understand trends in the healthcare system. It also led to improved adherence with notification, as the prior system would not always notify the provider. Prior to implementation, ED staff was to send a secure email to the identified individuals. Adherence with this was poor, as the event was not common enough for the ED providers to implement the event in their workflow. For a variety of technical reasons, an order set for this scenario could not be implemented. However, enhanced communication was fostered utilizing the methods outlined in this chapter.

Research and Registries

Cancer Registries

A cancer registry is an information system that collects and analyzes data from a census of cancer cases. Registry data can be used to define and monitor cancer incidence, investigate treatment patterns, evaluate efforts to prevent cancer, and improve survival [50]. This allows public health officials and healthcare professionals to be apprised of cancer-related measures used to guide cancer prevention and control efforts.

Cancer data are collected in two different types of registries. Population-based registries are tied to state health departments, while hospital registries are a part of a healthcare organization's cancer program [51]. Population-based registries collect information on all cases within a certain geographic area from multiple reporting organizations including hospitals, doctors' offices, nursing homes, clinical labs, and ambulatory care organizations, as well as chemotherapy and radiation treatment centers. Hospital registries provide more complex data used to assess clinical care at a particular hospital. These data typically guide education of healthcare providers and focus on patient care. Pooled data can be used to observe trends with specific populations, providers, or locales [52, 53].

Cancer registrars with standardized training aid in collecting data for cancer registries. Registrars prepare accurate and timely data that is reported to the registry. Identifying individuals with cancer, or *casefinding*, is the first step in cancer registration. This is initiated during clinical care when physicians note the cancer site, type, stage, and patient demographics in the medical record. Registrars summarize and record other information for certain registries, such as treatments and follow-up to record recurrence and survival data [52]. The HITECH Act, through the electronic health record meaningful use program, incentivized case-based reporting.

Cancer Surveillance Programs

In 1971, the National Cancer Act was established which mandated collection, analysis, and sharing of cancer patient data in the United States for research, detection, and treatment of cancer. The National Cancer Institute established the first national cancer registry, the Surveillance, Epidemiology, and End Results (SEER) program, in 1973. This large population-based system of cancer registries provides data on cancer incidence, mortality, treatment, and survival [51, 53]. Data are collected regionally, representing 28% of the US population [51].

In 1992, the US Congress established the Cancer Registries Amendment Act which authorized the Centers for Disease Control and Prevention (CDC) to provide regional assistance to improve cancer registries, implement registries in absent regions, model legislation, provide training for registry personnel, set standards, and aid in establishing a reporting and data processing system. The National Program of Cancer Registries (NPCR) was established to accomplish these goals and supports cancer registries in 45 states, representing 96% of the population [53]. The NPCR and the SEER program, together, collect data for the entire United States.

Together with data regarding cancer incidence and death rates, cancer survival measures provide a comprehensive picture of the burden of cancer in a population and support public health efforts to prevent new cancers, extend survival and quality of life after a cancer diagnosis, and reduce cancer health disparities [50].

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