



Ensuring Continuity of Care Through Electronic Health Records

Recommendations From the ASCO Electronic Health Record Roundtable

With a one in three chance of getting cancer in one's lifetime, Americans will either experience or know someone who has survived cancer. According to the Institute of Medicine report *From Cancer Patient to Cancer Survivor: Lost in Transition*, more than 10 million Americans live with a personal history of cancer; all are considered cancer survivors.

Some survivors experience few effects from their cancer treatment. Many survivors, however, manage psychological distress, sexual dysfunction, infertility, impaired organ function, cosmetic changes, and limitations in mobility, communication, and cognition. Others face risks from secondary cancers and such comorbidities as diabetes, cardiovascular disease, osteoporosis, or reproductive disorders. The good news is that with intervention, much can be done to avoid, ameliorate, or arrest these late effects of cancer, particularly if caregivers have access to key information regarding the patient's cancer, care, and treatment.

The transition from active treatment to post-treatment care is critical to long-term health. If care is not planned and coordinated, cancer survivors are left without knowledge of their heightened risks or a follow-up plan of action. Fragmented and poorly coordinated cancer care systems and poor communication mechanisms are among the hurdles cancer survivors often face.¹ Remarkably absent from many survivors' care plans is a treatment summary containing critical information from the treating oncologist about the patient's cancer type and treatment.² If a treatment summary were made available and exchanged in a secure electronic environment, it would enable the survivor and caregivers to effectively facilitate provider-to-provider and provider-to-patient communication.

This report (available at www.asco.org/ehr) identifies the unique communication issues for cancer patients and survivors, discusses the role of the treatment plan and treatment summary in continuity of care for cancer patients, and describes ASCO's position on the benefits of electronic medical record software for oncology practitioners and patients.

Background

Patients referred to an oncologist have almost always been recently dealt a sudden blow and usually restructure their everyday lives to focus on their health. By the time they present to an oncologist, patients typically have had visits with their primary care physician and other specialists, may have had surgery, and have had laboratory tests, x-rays, and other sophisticated radiological studies. When establishing a care plan, the oncologist analyzes reports from these encounters and, together with the patient, determines treatment methods, which may include chemotherapy, surgery, radiation therapy, or a combination of the three.

Chemotherapy Treatment Plan

A chemotherapy treatment plan is a synoptic document prepared at the initiation of a chemotherapy treatment course. Key elements of the treatment plan include diagnosis, goals and anticipated benefits of therapy, the regimen name, the planned duration and number of treatment cycles, a strategy for assessing response, and an assessment of major risks and benefits (available at www.asco.org/treatmentsummary). Ideally, the treatment plan should be reviewed with the patient and his or her family members when treatment is started. Because patients are often overwhelmed at the time of diagnosis, having a document that can be referred to later is valuable. Preparation of a plan

Figure 1. Sample treatment plan for colon cancer (available at www.plwc.org/ASCO/ArticleASCO/TabColonCancerTreatmentPlanandSummaryposting.pdf).

Colon Cancer Treatment Plan – Adjuvant Chemotherapy 01/2007		
Insert Practice Name/Info Here		This Treatment Plan is a brief record of major aspects of colon cancer adjuvant chemotherapy. This is not a complete patient history or comprehensive record of intended therapies.
Provider name:		
Patient name:	Patient ID:	
Patient DOB: ___/___/___	Age at diagnosis:	Patient phone:
Support contact name:		Support contact phone:
Support contact relationship:		
BACKGROUND INFORMATION		
Cancer detection: Screening Symptoms Incidental		
Site in colon: Right Transverse Left Sigmoid		
Predisposing conditions: None Inflammatory bowel disease FAP HNPCC		
Family history: None 2 nd degree relative 1 st degree relative Multiple relatives		
Pre-op colonoscopy to cecum: Yes No		
Other lesions: None Low risk polyps High risk polyps		
Primary colon operation:		Date of surgery: ___/___/___
Surgery type: Elective Emergent	CEA pre-op:	CEA post-op:
Stage: IIA IIB IIA IIB IIC	T stage: T1 T2 T3 T4	N stage: N0 N1 N2
Number of nodes removed:		Number of positive nodes:
Notable pathology findings:		
Notable surgical findings/complications:		Ostomy: Yes No
Comorbidities:		
PLAN FOR ADJUVANT TREATMENT		
Name of regimen:		Start date: ___/___/___
Treatment on clinical trial: Yes No		
Chemotherapy drugs	Administration	Major side effects
Number of planned treatments:		For how many weeks:
Central venous catheter placement needed: Yes No		
General health status at start of treatment: Excellent Very good Good Fair Poor		
Nutritional status at start of treatment: Excellent Very good Good Fair Poor		
Special circumstances:		
Oncology Team Members	Name	Contact Information/Location
Medical oncologist		
Oncology nurse		
Surgeon		
Pharmacy		
Comments:		

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Important caution: This is a summary document whose purpose is to review the highlights of the colon cancer chemotherapy treatment plan for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with colon cancer and adjuvant chemotherapy in detail. Both medical science and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for colon cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

at the start of treatment simplifies preparation of a summary at the conclusion of treatment (Fig 1).

Chemotherapy Treatment Summary

The transition from active treatment to post-treatment care is daunting. The Institute of Medicine has identified four essential components of survivorship care:

1. Prevention of recurrent and new cancers and other late effects;
2. Surveillance for cancer spread, recurrence, or second cancers, as well as assessment of medical and psychosocial late effects;
3. Intervention for such effects of cancer and its treatment as lymphedema and sexual dysfunction, pain, fatigue, psychological distress of both cancer survivors and caregivers, and concerns related to employment, insurance, and disability; and
4. Coordination between specialists and primary care providers to ensure all of the survivor's health needs are met.¹

Even though the long-term effects of cancer treatment vary by cancer type, survivors share commonalities. For example, many can name the location or type of cancer, yet few survivors recall clinical details. A breast cancer survivor knows

which side was treated, but is unlikely to recall the size of the tumor, whether there were lymph node metastases, the names of chemotherapy drugs, starting or ending dosages, pathology findings, toxicities or adverse effects, or why treatment was interrupted.

Recognizing cancer survivorship as a distinct phase of cancer care, the Institute of Medicine's (Washington, DC) *Lost in Transition* report set forth 10 recommendations to improve survivors' health and well-being. Recommendations 1 and 2 are particularly pertinent:

Recommendation 1. Health care providers, patient advocates, and other stakeholders should work to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care.

Recommendation 2. Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This survivorship care plan should be written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by third-party health care payors.¹

An ASCO-commissioned study conducted by Harvard University (Boston, Massachusetts) and RAND Health (Santa Monica, California) confirmed the Institute of Medicine's findings. Researchers working on the National Initiative on Cancer Care Quality learned that patients with breast cancer received 86% of recommended care, and colorectal patients received 78% of care overall.³ But there was also room for improvement.

The most surprising finding of the National Initiative on Cancer Care Quality study was that it was difficult for chart reviewers to locate the patient's chemotherapy doses and administrative notes in the medical oncology records because there was no standard place to find them. Furthermore, the oncologist's record typically did not document all of the patient's oncology treatments, pointing to the need for oncologists to compile an easily accessible treatment summary.⁴

The chemotherapy treatment summary is a succinct document prepared at the end of a chemotherapy treatment course. Essential elements of a treatment summary include identifying the treatment that was planned and delivered, how treatment was tolerated, the patient's response to treatment, and next steps for the patient's care. The treatment summary is not intended to take the place of more detailed communication between the oncologist and the patient or the oncologist and other treating physicians, but is intended to be a communication tool and a resource for the patient (available at www.asco.org/treatmentsummary). As a further example, Figure 2 shows a sample treatment summary for colon cancer.

Figure 2. Sample treatment summary for colon cancer (available at www.plwc.org/ASCO/ArticleASCO/TabColonCancerTreatmentPlanandSummaryposting.pdf).

Colon Cancer Treatment Summary – Adjuvant Chemotherapy 01/2007		
Insert Practice Name/Info Here		<i>This Treatment Summary is a brief record of colon cancer adjuvant chemotherapy. This is not a complete patient history or comprehensive record of therapies administered.</i>
Provider name:	Today's date: / /	
Patient name:	Patient ID:	
ADJUVANT CHEMOTHERAPY TREATMENT RECEIVED		
Name of chemotherapy regimen:	Notes	
Date of first dose:		
Date of last dose:		
Number of cycles planned:		
Number of cycles administered:		
Number of cycles containing oxaliplatin:		
Reason for stopping adjuvant treatment:		
Extent of dose reduction:		
Hospitalization for toxicity during treatment:	Yes No	
Grade 3/4 toxicities during treatment (list all):		
Neuropathy at end of treatment (Grade):	0 1 2 3 4	
Disease status at end of treatment:	No evidence of disease Possible recurrence Recurrence	
Overall health status at end of treatment:	Excellent Very good Good Fair Poor	
SURVIVORSHIP CARE COORDINATION AND PLAN		
Symptoms that should be evaluated by a physician:		
Special precautions:		
Follow up care	When/How often?	Provider to contact
Medical oncology visits		
Lab tests		
Radiology scans		
Colonoscopy		
Routine health care		
PROVIDER CONTACTS		
Provider	Name	Contact information
Surgeon		
Gastroenterologist		
Primary care physician		
Comments/Notes:		
<small>© 2006 American Society of Clinical Oncology. All rights reserved. Important caution: This is a summary document whose purpose is to review the highlights of the colon cancer chemotherapy treatment plan for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with colon cancer and adjuvant chemotherapy in detail. Both medical science and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for colon cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.</small>		

Patient Benefits From the Treatment Plan and Treatment Summary

The treatment plan and treatment summary are important tools toward care coordination and high-quality cancer care. The treatment summary is a synopsis of the actual treatment and is not intended to be a comprehensive report, but must include such information as serious complications and adverse effects of treatment. The treatment summary's most important function is to provide an outline of care that can be transmitted between providers or from provider to patient.

Patricia Ganz, MD, chair of ASCO's Electronic Health Record (EHR) Workgroup and a medical oncologist at the University of California at Los Angeles' Jonsson Comprehensive Cancer Center, has been instrumental in the development of ASCO's treatment plan and treatment summary. She recalls her own experience in opening a survivorship program and notes that the process of going through records of patients who have gone through treatment is very labor intensive, especially if those patients received multiple rounds of treatment. The treatment summary becomes most critical when a patient:

- Completes curative treatment,
- Faces treatment failure or a recurrence of cancer, and/or

- Coordinates cancer treatment or survivorship care with multiple providers.

The treatment summary also is an essential tool when oncologists and other health care providers attempt to reconstruct medical records following a natural disaster, as demonstrated during the 2005 hurricane season. At that time, patients who had been dislocated from providers presented at new care facilities with little or no information about their stage of illness or treatment. Oncologists assuming care had tremendous difficulty taking on patients without such information and were forced to repeat testing, staging, and other services to ascertain appropriate next steps. The oncology treatment summary and its integration into an EHR provide an important opportunity to ensure continuity of care following natural or manmade disasters.

Promoting Industrywide Adoption of an Oncology Treatment Summary

As oncologists continue to assess ways to improve the quality of cancer care, they also seek answers about selection and implementation of electronic clinical information systems. ASCO has identified the EHR as an important vehicle for advancing quality and has established a series of initiatives that would advise and hasten adoption of EHRs among its members, as well as facilitate the adoption of treatment summaries. Working closely with members of its EHR Workgroup, ASCO hosted an EHR Roundtable in Washington, DC, on January 23-24, 2007.

The EHR Roundtable brought together senior thought leaders from government, academia, community-based oncology practices, and patient advocacy organizations. These 40 national thought leaders and practitioners invested 2 days exchanging firsthand knowledge of their experiences with EHR selection and implementation and developing recommendations to enable the effective exchange of health information between cancer patients and their caregivers.

Roundtable participants were asked to focus on the following objectives:

1. Achieve consensus and prioritize recommendations from key stakeholders about the functional elements needed to capture chemotherapy administration data in an EHR;
2. Identify interoperability challenges affecting development and implementation of EHRs for oncology; and
3. Challenge EHR vendors to incorporate functional elements of the ASCO-developed Chemotherapy Treatment Plan and Summary into EHR products.

Oncology Workflow Challenges

Roundtable Chair Robert Miller, MD, presented workflow in a medical oncology setting as a framework to engage participants to discuss their experiences with EHR planning, development, implementation, and process re-engineering.

Table 1. Typical Treatment Day Workflow for Infusion Visit

Workflow
1. Patient has blood drawn prior to or day of visit (generally a CBC; may include other laboratory tests as well).
2. Physician visits (generally includes history and physical as well as assessment of toxicity from prior therapy).
3. Physician orders chemotherapy treatment (may be single day or multiday therapy).
4. Patient proceeds to outpatient treatment room or center.
5. Drugs are mixed by RN, pharmacist or admixture technician.
6. Patient receives drug therapy (typically 15 minutes to > 6 hours); RN documents on flow sheet (includes drugs, doses, and patient response).
7. Patient is discharged home.

Table 1 presents the typical workflow, and Table 2 presents challenges that come with this complex workflow.

Functional and Clinical Elements in an Oncology EHR

A primary goal of the EHR Roundtable was to achieve consensus and prioritize recommendations from key stakeholders about the functional elements needed to capture chemotherapy administration data in an EHR. To maintain a focus on oncology, participants identified two defining facets of care provided by medical oncologists: the process of developing treatment plans and summaries for patients receiving chemotherapy, and the process by which patients undergo chemotherapy and their course of treatment in the chemotherapy chair. Presented with the following core elements for the Chemotherapy Treatment Plan and

Treatment Summary, the group endorsed these as the essential elements for an oncology EHR:

Core elements of a chemotherapy treatment plan:

- Diagnosis, including the cancer site, histology, and stage
- Goals of therapy (may be specified by the type of template; eg, adjuvant chemotherapy plan)
- Patient health status and comorbidities
- Surgical history and notable pathology findings
- Chemotherapy regimen and starting dosages
- Duration of treatment and number of planned cycles
- Major adverse effects of chemotherapy

Core elements of a chemotherapy treatment summary:

- Chemotherapy treatment delivered, including number of cycles administered, duration, and extent of dose reduction
- Reason treatment was stopped
- Major toxicities and/or hospitalizations
- Treatment response
- Follow-up care and relevant providers

The Roundtable also recommended additional oncology-specific EHR core elements and functionality, such as the ability to generate a chemotherapy flow sheet and provide drug interaction alerts and dosing safety limits. A complete list of the EHR Roundtable's recommended core elements and functionality is presented in Table 3.

Treatment plans and treatment summaries should be generated dynamically by the EHR. The expectation is, therefore, that the EHR software can extract data from relevant fields throughout the EHR to pull together a chemotherapy treatment plan and/or summary, and EHR

Table 2. Challenges of Oncology Workflow

Challenges	Concerns
Treatment selection should be based on established guidelines and/or best practices.	<ol style="list-style-type: none"> 1. The oncologist's database for receiving information from pathology, labs, and other diagnostic studies may be incomplete. 2. There is no single authoritative source for verification of the drug regimen. 3. Patient assessment for eligibility for clinical trials may be incomplete.
Modification of treatment regimens should be based on accepted toxicity guidelines (National Cancer Institute's Common Terminology Criteria for Adverse Events).	<ol style="list-style-type: none"> 1. Access to guidelines may be limited. 2. Documentation of toxicity may be incomplete, inconsistent, and may not use standard terminology.
Physician drug ordering is usually done on an individual basis.	<ol style="list-style-type: none"> 1. This opens the risk of computational errors and drug interactions.
Patient handoff from physician to nurse or pharmacist increases the risk for errors.	<ol style="list-style-type: none"> 1. Handwriting can be misinterpreted. 2. Admixture errors occur (wrong drug, wrong dose, or wrong route). 3. Maximum drug dose and lifetime cumulative dose may be exceeded. 4. There can be infusion incompatibilities.
Drug administration errors may occur.	<ol style="list-style-type: none"> 1. Patients may be misidentified. 2. Documentation may be incomplete or inaccurate. 3. Charges may be missed.

Abbreviation: EHR, electronic health record.

Table 3. Oncology EHR Core Functional Elements

Element/Functionality	
Treatment plan core elements	Flow sheet: inclusive of all chemotherapy, non-chemotherapy medications, transfusions, tumor measurements, lab values
Demographics, including referring provider and PCP	
Diagnosis: ICD-9 or 10; possibly more clinically relevant system	Flow sheet: physical findings, including tumor measurements, imaging, relevant procedures, nursing assessment*
Stage	Oncology-specific review of systems
AJCC for relevant diagnoses: tumor registry staging system for other diagnoses	Patient provided with copy of treatment plan and summary
Disease status at each course of therapy	Documentation of investigational drugs
Site/histology/pathology findings: menu-driven by disease	Capture date of death*
Intent/goals of therapy: adjuvant/curative v palliative	Oncology-specific EHR functions
Performance status	EHR-generated treatment plan
List of comorbid conditions expected to complicate chemotherapy, eg, hepatic insufficiency	EHR-generated treatment summary
Cancer surgical history	Ability to update treatment summary
Chemotherapy/biotherapy regimen planned	EHR application to generate specific reports, eg, specific types of flow sheets
Body surface area and starting doses	Mechanism to capture verbal orders*
Duration of treatment and number of planned cycles	Drug interaction alerts
Major toxicities associated with planned treatment	Basic safety limits for dosing
Radiation therapy planned or previously delivered	Body surface area safety monitoring
Pain assessment and supportive care needs: advanced cancer	Lifetime cumulative chemotherapy dose
Treatment on clinical trial	Clinical decision support, eg, guidelines or trial eligibility*
Sites of disease monitored: advanced cancer	Treatment preauthorization support*
Treatment summary core elements	Drug inventory control*
Patient demographics	Internal and external communications*
Chemotherapy/biotherapy delivered: IV and oral	Import key external reports, eg, pathology, operative note, radiation
Number of cycles planned and administered	Radiofrequency identification technology for patient/drugs given, eg, barcodes*
Duration: date of first and last dose	Open database with query capabilities*
Extent of dose reduction	Interoperability: health information exchange with labs, imaging centers, etc.*
Reason treatment stopped	Compliance safeguards
Major toxicities experienced	Privacy and security safeguards in place
Hospitalization required for toxicity	Disaster recovery plan in place
Disease status at completion of treatment	
Performance status at completion of treatment	
Coordination of follow-up care	
Provider contacts	
Other oncology-specific documentation	

Abbreviations: EHR, electronic health record; PCP, primary care physician; ICD-9, *International Classification of Diseases, 9th Edition*; AJCC, *American Joint Committee on Cancer*.

* Denotes elements characterized by Roundtable participants as desirable, not critical.

products without this functionality should be viewed in a considerably less favorable light. The format and presentation of treatment plans and summaries need not be identical across

different EHRs; however, the inclusion of these core elements is important and is what practitioners should come to recognize and expect as a standard in oncology EHRs.

EHR vendor representatives were presented with the list of core elements and functionality as well as the treatment plan and treatment summary. The vendors agreed to take the Chemotherapy Treatment Plan and Summary back to their respective companies and determine whether they could incorporate ASCO's identified core elements into their software. Vendors meeting ASCO's selection criteria have been invited to participate in an EHR lab and demonstrate their application of the chemotherapy treatment plan and summary at ASCO's Annual Meeting in June 2007.

Next Steps

There is an urgent need for better tools to manage the highly complex clinical activities involved in treating cancer patients. The delivery of cancer care typically involves multiple physicians and other health professionals, as well as multiple sites of care. The National Initiative on Cancer Care Quality study highlighted the need for improved documentation to facilitate communication between caregivers and patients, and ultimately, to promote a higher quality of patient care. Patients on a course that includes surgery and radiation therapy benefit when the oncologist, surgeon, and radiation oncologist are in communication. "Snowbird" seniors who may see physicians in different parts of the country at different times of the year are at an advantage when this additional documentation occurs. For those patients who experience unanticipated separations from their health care team due to natural or other disasters, such a treatment record is critical. As the primary provider of chemotherapy, the medical oncologist plays a pivotal role in improving the communication between physicians, as well as between oncologists and patients, through the use of the treatment plan and treatment summary.

While the overall delivery of cancer care is distinctive, so are the data requirements for oncology EHRs. For example, stage of cancer is a core data element that is not always readily found in the cancer treatment record. An EHR for a patient with cancer must be able to integrate and keep up with multiple and evolving systems for cancer staging. In general, the body of knowledge around the science, technology, and treatment of cancer continues to increase at a rapid pace. Accordingly, there should be an expectation for continued innovation and refinement in oncology EHRs to adapt to these changes.

The Roundtable served to identify areas for future work by ASCO:

References

1. Institute of Medicine Committee on Cancer Survivorship: From Cancer Patient to Cancer Survivor: Lost in Transition, Washington, DC, National Academies Press, 2004, pp 1-7
2. National Initiative on Cancer Care Quality, American Society of Clinical Oncology, 2005

1. ASCO should continue the dialogue with members and EHR vendors to ensure that EHR products meet the requirements of this complex patient population.
2. ASCO should provide practical guidance and resources to address implementation and workflow issues for those practices who have already selected and purchased EHRs, as well as those considering a purchase in the near future.
3. The core functional elements for an oncology EHR should be further refined so that each of these elements are associated with a clear and standard definition, thereby facilitating adoption and integration into EHRs. ASCO should collaborate with other members of the cancer community as well as medical informatics and standards-developing organizations to pursue this effort.
4. ASCO should explore partnerships with the National Cancer Institute (NCI) and other groups who are working to enhance researchers' ability to access and use aggregated data collected through EHRs. The NCI, through the Cancer Biomedical Informatics Grid program, has made great strides in establishing an infrastructure for discussion around cancer-related data.

ASCO looks forward to continuing discussions with other stakeholders in the cancer community about the role of EHRs in advancing quality cancer care.

Appendix

Attendees included representatives from the following organizations:

American Society of Clinical Oncology; National Cancer Institute; Oncology Nursing Society; Administrators in Oncology/Hematology Assembly, Medical Group Management Association; Aetna; United Healthcare; Agency for Healthcare Research and Quality; Louisiana Health Care Review Inc; American Medical Informatics Association; American Cancer Society; Veterans' Administration Medical Center; American Academy of Family Physicians; National Coalition for Cancer Survivorship; EHR Vendor Association; IMPAC Medical Systems; Smart ID Works LLC; Eclypsis; Altos Solutions; MediNotes Corp; Intrinsic; Emerging Meds; Epic Systems; DocComply; IKnowMed/US Oncology; e-MDs; Misys Healthcare Systems; NextGen; Varian.

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3. Malin JL, Schneider EC, Epstein AM, et al: Results of the National Initiative for Cancer Care Quality: How can we improve the quality of cancer care in the United States? *J Clin Oncol* 24:626-634, 2006
4. Bailes JS: ASCO's groundbreaking study on cancer care quality: NICCQ. *J Oncol Pract* 2:48, 2006