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CHAMPIONS OF HEALTH UNITE

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From Print to Interoperability: Cancer Staging in the EHR

Session #201, February 14, 2019

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AJCC
American Joint Committee on Cancer
Validating science. Improving patient care.



AMERICAN COLLEGE OF SURGEONS
Inspiring Quality: Highest Standards, Better Outcomes

Conflict of Interest

Martin Madera

Has no real or apparent conflicts of interest to report.

Agenda

- What is the American Joint Committee on Cancer?
- Why the AJCC needed to evolve for the 8th Edition
- How learning from our partners informed change
- What we had to change to fulfill our mission
- Lessons learned from our transformation
- Developments in Interoperability

Learning Objectives

- Recognize the challenges of modernizing a historically successful organization
- Illustrate the value of collaboration and learning from innovators in the field
- Calculate the costs and benefits of changing a content development model
- Evaluate the success and impact of your project on quality patient care



What is the AJCC?

A Brief Historical Perspective

What is TNM and Cancer Staging?

T Extent of the primary tumour

N Absence or presence and extent of regional lymph node metastasis

M Absence or presence and extent of distant metastasis

Stage I: tumour in the organ of origin only

Stage II: involvement of regional lymph nodes

Stage III: locally advanced disease or non-regional lymph node involvement

Stage IV: distant metastatic disease



Combining TNM for Stage Grouping

		STAGE GROUPING			
T1*	Tumor 2 cm or less in greatest dimension	Stage I	T1a	N0 or N1a	M0
	T1a No fixation to underlying pectoral fascia or muscle		T1b	N0 or N1a	
	T1b Fixation to underlying pectoral fascia and/or muscle				
T2*	Tumor more than 2 cm but not more than 5 cm in its greatest dimension	Stage II	T0	N1b	M0
			T1a	N1b	
			T1b	N1b	
		T2a	N0 or N1a		
		T2b	N0 or N1a		
		T2a	N1b		
T3*	Tumor more than 5 cm in its greatest dimension	Stage III	Any T3	Any N	M0
			Any T4	Any N	
			Any T	N2	
T3b	Fixation to underlying pectoral fascia and/or muscle		Any T	N3	
T4	Tumor of any size with direct extension to chest wall or skin	Stage IV	Any T	Any N	M1

*Breast Staging from *Manual for Staging of Cancer 1977*

How Cancer Stage is Used

- Stage is used in treatment decision making
- Stage gives an indication of prognosis for patients
- Stage recorded as cancer is reportable disease
- Surveillance and analytics on a national level
- Serves as data for cancer research and advancement



Historical Perspective

Cancer Staging based on the TNM concept was first championed by Dr. Pierre Denoix a surgical oncologist from Institut Gustave-Roussy, Paris (1943-52)



Historical Perspective

American Joint Committee on Cancer (AJCC)

1959 North American effort first organized as the American Joint Committee for Cancer Staging and End Results Reporting (AJC)

1970 AJC – adopted “objectives, rules & regulations of the AJC” which resulted in formulation and publication of systems of classification of cancer

1977 First Edition of AJC Staging Manual published

1983 Second Edition, changed to American Joint Committee on Cancer

Union for International Cancer Control (UICC)

1943-52 TNM system proposed by Pierre Denoix

1968 First UICC publication, Editor Pierre Denoix

1987 Unified UICC/AJCC TNM



Manual for Staging of Cancer (1977), 1st Edition

Philosophy of staging by the TNM system:

*“It is intended to provide a way by which designation for the state of a cancer at various points in time can be **readily communicated** to others to **assist in decisions** regarding treatment and to be a factor in judgment as to prognosis. Ultimately, it provides a mechanism for comparing like or unlike groups of cases, particularly in regard to the results of different therapeutic procedures”*



Interoperability: Section 4003 from the 21st Century Cures Act.

“The term ‘interoperability’ with respect to health information technology means such health information technology that-

(a) **enables the secure exchange of electronic health information with, and use of electronic health information from, other health information technology without special part of the user; ”**



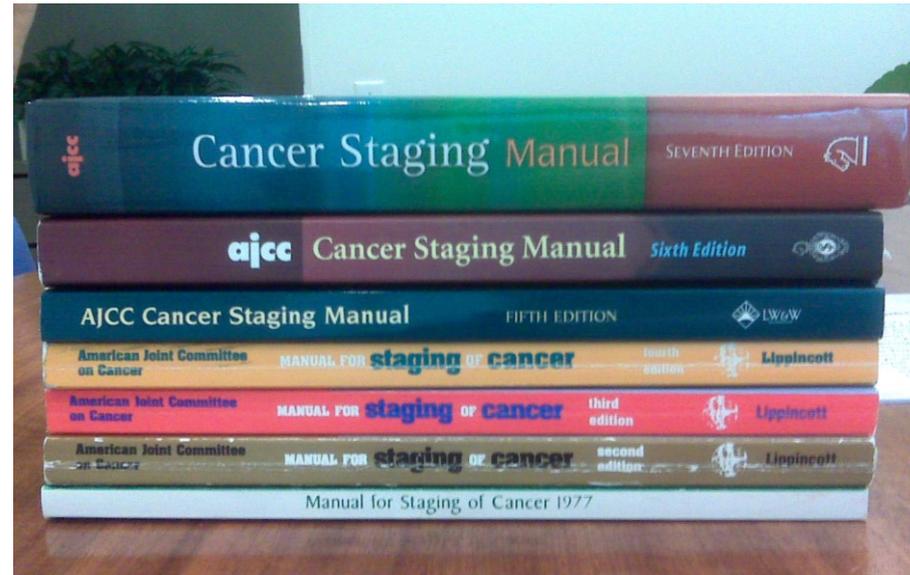
Modernizing the AJCC

If it's not broke why do we need to fix it?

Historic Success of AJCC Staging Manuals

Source of Cancer Staging for Decades

- 1st Edition, 1977
- 2nd Edition, 1983
- 3rd Edition, 1988
- 4th Edition, 1992
- 5th Edition, 1997
- 6th Edition, 2002
- 7th Edition, 2010
- 8th Edition, 2017



The Case for Change

AJCC User Survey in 2013

- Physician and Cancer Registrar data requirements are changing and increase in complexity
- Content enhancements: common and consistent definition and taxonomy usage for ease and accuracy of interpretation, and single source content
- Integration: improved accuracy of EMR staging software, inclusion of AJCC staging in software, and validation of content through single definitive source of content

Policy Changes

- Changing environment of healthcare practice embracing technology
- HITEC pushing hospitals to adopt EMRs and impact workflows



AJCC Content Incorporated into Software

- Inaccuracies
 - Incorrectly translated paper staging forms
 - Incorrect stage calculated in some EHR platforms
 - New prognostic and predictive factors modify staging and in some cases required in data collection
- Misinterpretation
 - Software programmers are not physicians- may misinterpret staging rules and exceptions
 - Programmers were not taking into account foot notes or General Staging Rules in calculating stage
 - Collaborative Stage Data Collection System designed for surveillance community, inappropriately referenced for clinical use



Was our Publishing Model Broken?

- Books no longer sufficient to communicate such critical info
 - AJCC needed to take control of the content to ensure fidelity and accuracy
 - Needed to make our content more clear and usable for both physicians but also software developers delivering it in EHRs
- New Workflows needed for Increasing Complexity
 - Critical to forge closer partnerships with organizations and vendors who use AJCC content
 - Modernize dissemination of staging information to allow for growing prognostic factors



Collaboration and Learning from Partners

Have a little help from your friends

Wisdom and Insight of Others

Critical AJCC Member Organizations

- American College of Surgeons (ACoS)
- Centers for Disease Control and Prevention (CDC)
- National Cancer Institute (NCI)
- College of American Pathologists (CAP)
- American Society of Clinical Oncologists (ASCO)
- National Comprehensive Cancer Network (NCCN)
- North American Associations of Central Cancer Registrars (NAACCR)

Important Industry Partners

- EHR Vendors, Publishers, App Developers, Innovators

Looking Outside of Healthcare

- Identified content success stories in other arenas that informed our work



Efforts in Cancer Data Standards

- CA BIG
- LOINC
- SNOMED
- HL7 (v1 &v2)
- CDA
- FHIR
- Structured Data Capture
- Collaborative Stage Data Collection System (CS)
- NAACCR Data Record Layout

Collaboration with Partners

Learning from the Success of Friends

- CAP electronic Cancer Checklist adopted by EMRs
- CDC registry software and support with validation and testing
- EHR vendors communicating challenges with AJCC content
- ASCO's leadership and facilitation of Cancer Interoperability Efforts
- Many other important conversations, demonstrations all contributed to finding the right path forward
- All our partners were supportive of the success of the AJCC's transformation



What We Learned

- The Challenge was not a Technology Problem
 - It was a content problem, one that the AJCC had to solve
- Investment of Time and Resources would be Significant
 - Future updates would be more efficient and patient care could be improved
- Open Source standards can reduce costs and increase adoption
 - Choice of DITA XML and RESTful API
- Getting to Interoperability Requires Partnerships and Collaboration
 - AJCC learned what was needed in the area of Cancer Staging and was ready to contribute to this goal



Calculating Change

Investing in accurate cancer staging at the point of care

Enabling Better Patient Care

- Physicians no longer using printed book to stage patients
- Desire of having AJCC content at the point of care, in EHR
- Overlooking this user need could result in AJCC content being ignored, or become irrelevant
- Inaccurate cancer staging can result in poor patient care

AJCC and the American College of Surgeons (ACoS) decided it was critical to invest in modernizing the AJCC Content Development and Dissemination to meet the needs of physicians who provide care for patients everyday.



The Goal of AJCC's Change

To develop a means of electronically distributing AJCC content at the highest possible fidelity and highest usability, for the purpose of advancing cancer interoperability and improving patient care.



New Strategy for AJCC Content

Moving towards Interoperability with the 8th Edition Cancer Staging System

Development of 8th Edition

- Two Parallel Projects
 - Content Development (No longer just writing a book, creating content)
 - Content Transformation (Making content machine readable to help EHRs)
- New Process and Sequences
 - Thinking of content separate from format (i.e. traditional book)
 - Templated authoring structure for Expert Panels
 - Information Architecture to support current and future content
- Steps Needed to Meet our Goal
 - **Development of Component Content Management System (CCMS)**
 - **Creation of Application Programming Interface (API) to deliver AJCC content to EHRs with highest level of accuracy and fidelity**

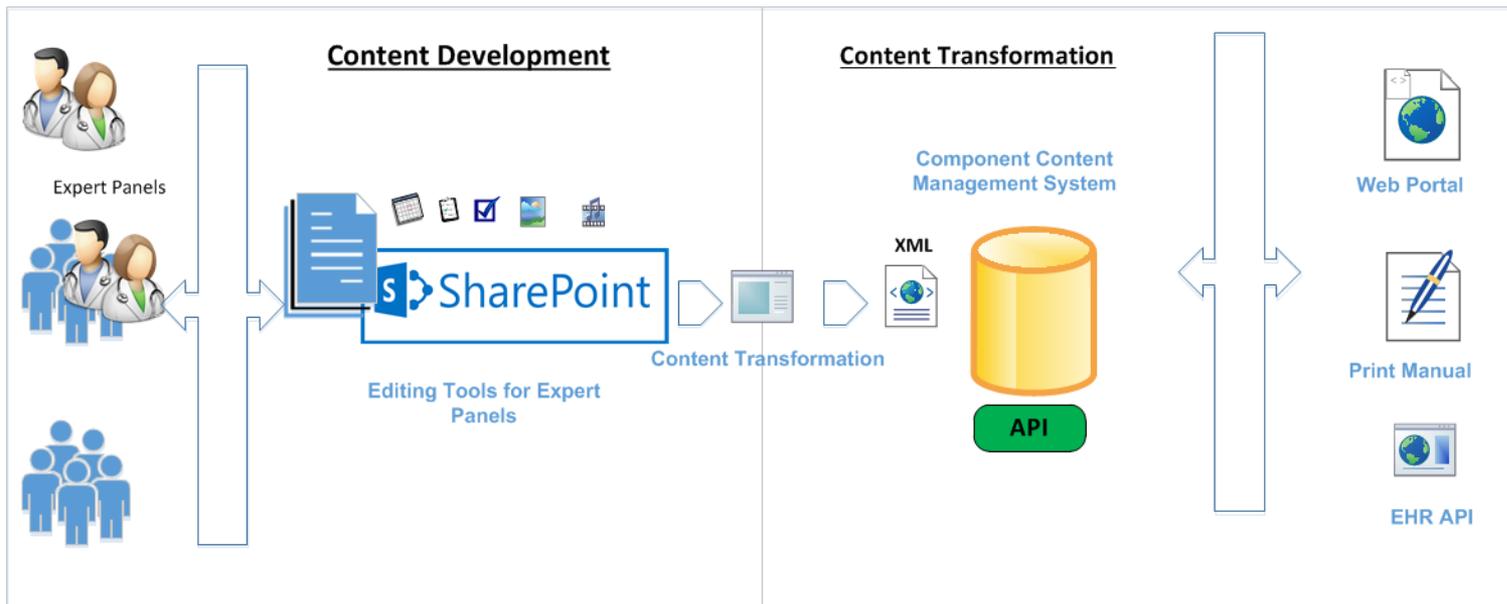


Key Steps for Developing AJCC API

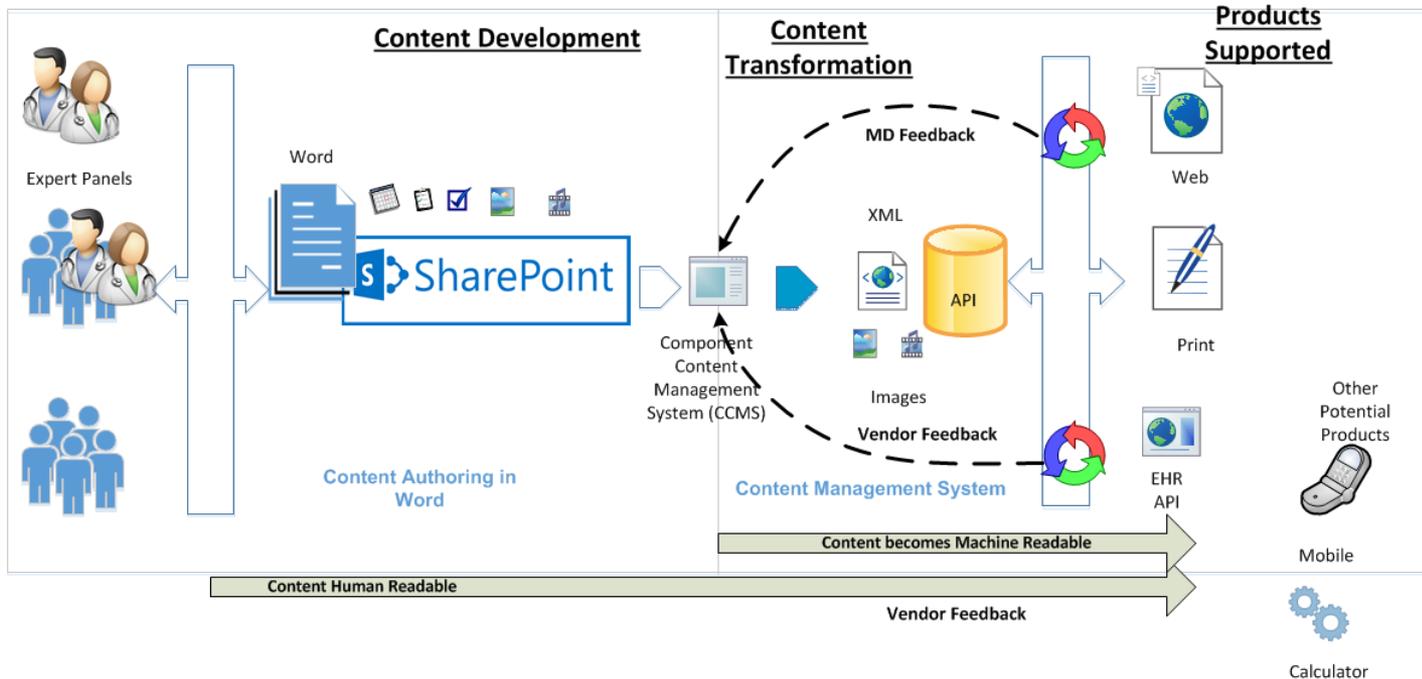
- Investment into harmonization and standardized staging rules
 - Taking a critical look at previous content
- Develop and organize content with API, not book, in mind
 - Conceptual shift required for returning authors
- Identify vendors for design and development of CCMS and API
 - Intensive 24 month selection and build process
- Transform complete chapters from authors to XML
 - Future editions should be written in authoring software
- Publish content CCMS to API Gateway
 - Test API calls for accuracy and consistency



Content Development and Transformation



Physician and Vendor Feedback



Structure of the CCMS

GET Diseases/NET_STO/Content/Definitions/cN

Definition of Regional Lymph Node (N)

<i>N Category</i>	<i>N Criteria</i>
NX	Regional lymph nodes cannot be assessed
N0	No regional lymph node metastasis
N1	Regional lymph node metastasis

N

▾ Ntable

stentry	stentry	stentry	stentry
stentry	NX	stentry	Regional lymph nodes cannot be assessed
stentry	N0	stentry	No regional lymph node metastasis
stentry	N1	stentry	Regional lymph node metastasis

▹ Ntable

N



XML Code delivered through API

```
<N>
  <Ntable>
    <sthead>
      <stentry></stentry>
      <stentry></stentry>
    </sthead>
    <strow>
      <stentry>NX</stentry>
      <stentry>Regional lymph nodes cannot be assessed</stentry>
    </strow>
    <strow>
      <stentry>N0</stentry>
      <stentry>No regional lymph node metastasis</stentry>
    </strow>
    <strow>
      <stentry>N1</stentry>
      <stentry>Regional lymph node metastasis</stentry>
    </strow>
  </Ntable>
</N>
```



New Specificity Required to Calculate

STAGE GROUPING

Stage I	T1a	N0 or N1a	M0
	T1b	N0 or N1a	
Stage II	T0	N1b	M0
	T1a	N1b	
	T1b	N1b	
	T2a	N0 or N1a	
	T2b	N0 or N1a	
	T2a T2b	N1b N1b	
Stage III	Any T3	Any N	M0
	Any T4	Any N	
	Any T	N2	
	Any T	N3	
Stage IV	Any T	Any N	M1

Historically, Calculating Stage involved 3 factors

$T+N+M = \text{Stage Group}$

Ranges (T1-2) and rules like “Any” value presented a challenge for programmers



New Complexity with Prognostic Factors

When T is...	And N is...	And M is...	And G is...	And HER2 Status* is...	And ER Status is...	And PR Status is...	Then the Prognostic Stage Group is...
T0-1	N1	M0	3	Negative	Negative	Any	IIIA
T2	N0	M0	2	Negative	Negative	Negative	IIIA***
T2	N0	M0	3	Negative	Positive	Negative	IIIA***
T2	N0	M0	3	Negative	Negative	Any	IIIA***
T2	N1	M0	1	Negative	Positive	Negative	IIIA
T2	N1	M0	2	Positive	Negative	Negative	IIIA
T2	N1	M0	2	Negative	Positive	Negative	IIIA
T2	N1	M0	3	Positive	Positive	Negative	IIIA
T2	N1	M0	3	Positive	Negative	Negative	IIIA

How successful were we at achieving Interoperability?

Probably giving the Keynote if we solved Interoperability

Communicating and Meeting Expectations

- Allow each software developer the flexibility they need for their product
 - Simpler functionality preferred by most users of API
- Distinguishing scientific and technical issues in content and delivery system
 - New quality control introduced thanks to vendor feedback
- Revision of Breast chapter presented unique set of challenges
 - Managing content updates for API and book
- Stage table expansion, valid values, and other improvements are currently underway





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Lessons Learned



Evaluation of Success and Impact

Change is Hard

- Making the Case for Change is Not Easy
 - Data and Facts are Your Friends
- Stakeholders Must Understand the Case for Change and Buy-In
- Lean on Others for Advice and Insight to Avoid Pitfalls
 - Be eager to return the favor and share lessons learned
- Be Comfortable with Uncertainty
 - Embrace the fact that the plan will be imperfect and be ready to adjust
- Evaluate and Improve Processes to Produce Long Term Success



Evaluation of Success and Impact

Interoperability is Harder

- Making the Case for Interoperability is Easy
 - Achieving it is Not
- Play to Your Organization's Strengths
 - We are the standard for Cancer Staging
 - AJCC has cancer staging expertise from around the world
 - Over 50 years of academic collaboration and consensus building on cancer science
- Understand where you can make the biggest impact and where other groups should lead the way
- Requires expertise from many domains
 - Need to overcoming language/terminology gaps



Promising Developments in Interoperability

Hope ahead...



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2019 Full of Potential for Interoperability

ONC 2018 Report to Congress

- Prioritize improving health IT and reducing documentation burden, time inefficiencies and hassle for providers, so they can focus on their patients rather than their computers.

HL7 Published FHIR Release 4

- Passed normative and will be submitted to the American National Standards Institute

Blockchain

- Not a panacea, but ledger approach presents a unique way to address shared challenges and offer mutual value to participants
- **All of you!**
- Intelligent energized people gathering and conversing on the topic



Questions

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