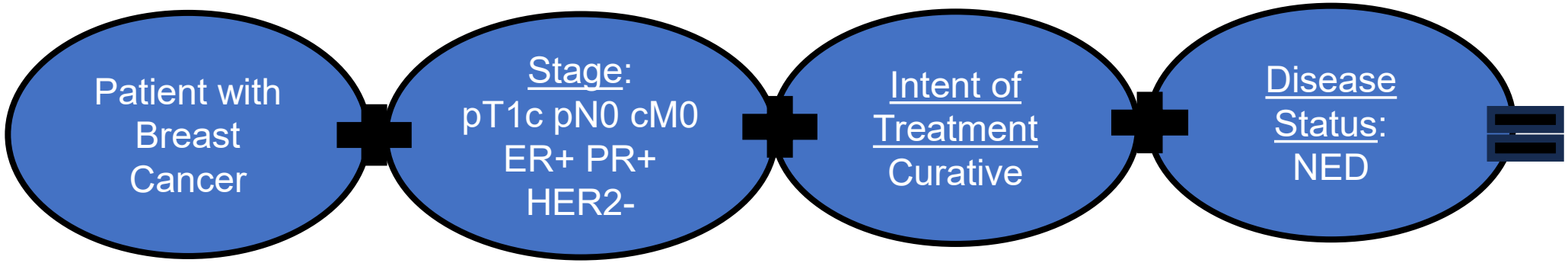
Want to deliver the right care to the right patient at the right time & location?

A fundamental change is required in how we create, capture and leverage data…..

Population Health Maintenance Relies on Data



Health Maintenance or Care Pathway: ER+ PR+ HER2- Early Stage Breast Cancer

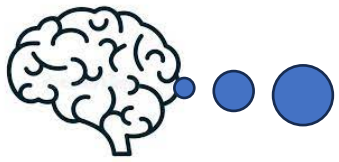
TASKS	Year 1			Year 2			Year 3
Imaging:	DEXA, MMG			MMG			DEXA, MMG
Meds:	Taking AI?	Taking AI?		Taking AI?	Taking AI?	Taking AI?	Taking AI?
Symptoms	ePRO	ePRO		ePRO	ePRO	ePRO	ePRO

*med change

“High Touch” vs “Higher-Tech” Follow-up

(Tevaarwerk et al, Moving beyond static survivorship care plans; Cancer 2018)

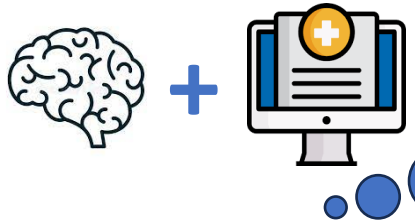
- Clinician
  - Assigns patient to a population
  - Defines tasks needed for that patients
  - Checks to see if these tasks are completed
  - Orders placed
- Patient
  - Schedules
  - Goes to appointment
- Manual review required to ensure necessary tasks completed



Person intensive, Requires Knowledge, Costly, Inefficient, Inequitable, Burnout

VS

- Electronic Health Record (EHR)
  - Defines patient as belonging
  - Defines tasks needed for population
  - Checks to see if tasks are completed
  - If not, orders – “teed up”
- Clinician
  - Reviews, signs
  - EHR prompts if not completed
- Patient
  - Schedules
  - Goes to appointment
  - Portal prompts if not completing



Less resource intensive, Equitable, Supports clinician/survivor? **Cykert et al, JNMA, 2019**

System Problem: Lack of Structured EHR Data

- For clinical purposes, we rely on clinician review of data during care
  - Relies on clinician knowledge, time….
- For administrative or QI purposes, we use cancer registries or other external databases
  - Manually abstracting data from medical records and transferring to software external to the EHR (even when/if using AI this is largely happening)
  - Limits how **much** information we can capture
  - Limits how **fast** we can capture the information
  - Limits our ability to **use** the data in care pathways and leverage the EHR to place necessary orders, etc
- This is true even though we have data languages and EHR functionality to capture these data as structured/discrete data

System Problems

Most cancer centers capture little structured data about patients with cancer via EHR[1] or patient portals[2]

- Data are usually present as free-text within clinical notes, even when there might be a place in the EHR to capture them as structured data[1]
- Structured data capture within an EHR can be challenging when provider input is required[1]
- Patients can input data in structured format (e.g. ePROs)[2]
  - System may not be able to “react” to that data[3]
  - Not all data can/should come from patients

1. Emamekhoo et al, JCO CCI, 2022
2. Stetson et al, JNCCN, 2021
3. Cracchiolo et al, Cancer, 2023

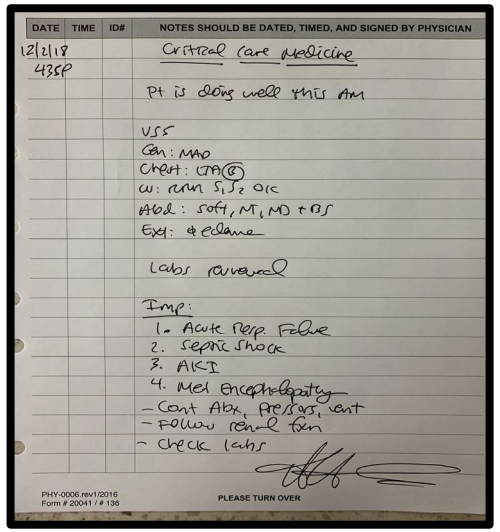
Partially Leveraged Tools

- Electronic health records (EHRs)
  - Already structured: Orders, some results
  - Largely unstructured data: Notes, Tumor Boards, etc
- Patient-generated health data
  - Already structured: App data (e.g. activity, weight, blood pressure, etc)
  - Potentially structured: Electronically captured Patient-Reported Outcomes (ePROs), Social determinants of health (SDoH)
- Care pathways, consensus guidelines, other clinical decision support
  - Have defined algorithms, but data not necessarily linked to “defined languages” nor decision points defined by structured data in EHRs

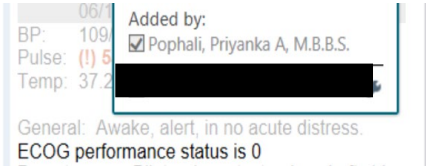
Structured (Discrete) EHR Data

- Health-related information entered and stored in an organized manner for extraction at later time points[1]
  - Each category has a defined meaning assigned
  - Each answer(s) is also defined with assigned meaning
- Structured data can be retrieved by the EHR, is easy to search, compile and analyze[1,2]
- With a common standard, can be shared between systems

Not Discrete or Structured → **Increasingly Structured**

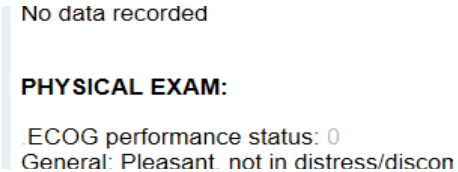


Dictated/Typed Free Text



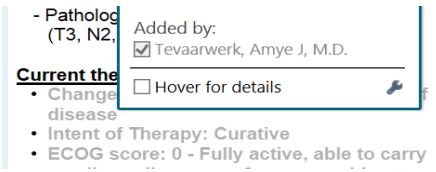
- "PS is good" or "PS is fine"
- Flexible, ONLY accessed with manual chart audit

SmartList – no "data tag"



- Defined: 0, 1, 2, 3, 4
- ONLY accessed with manual chart audit

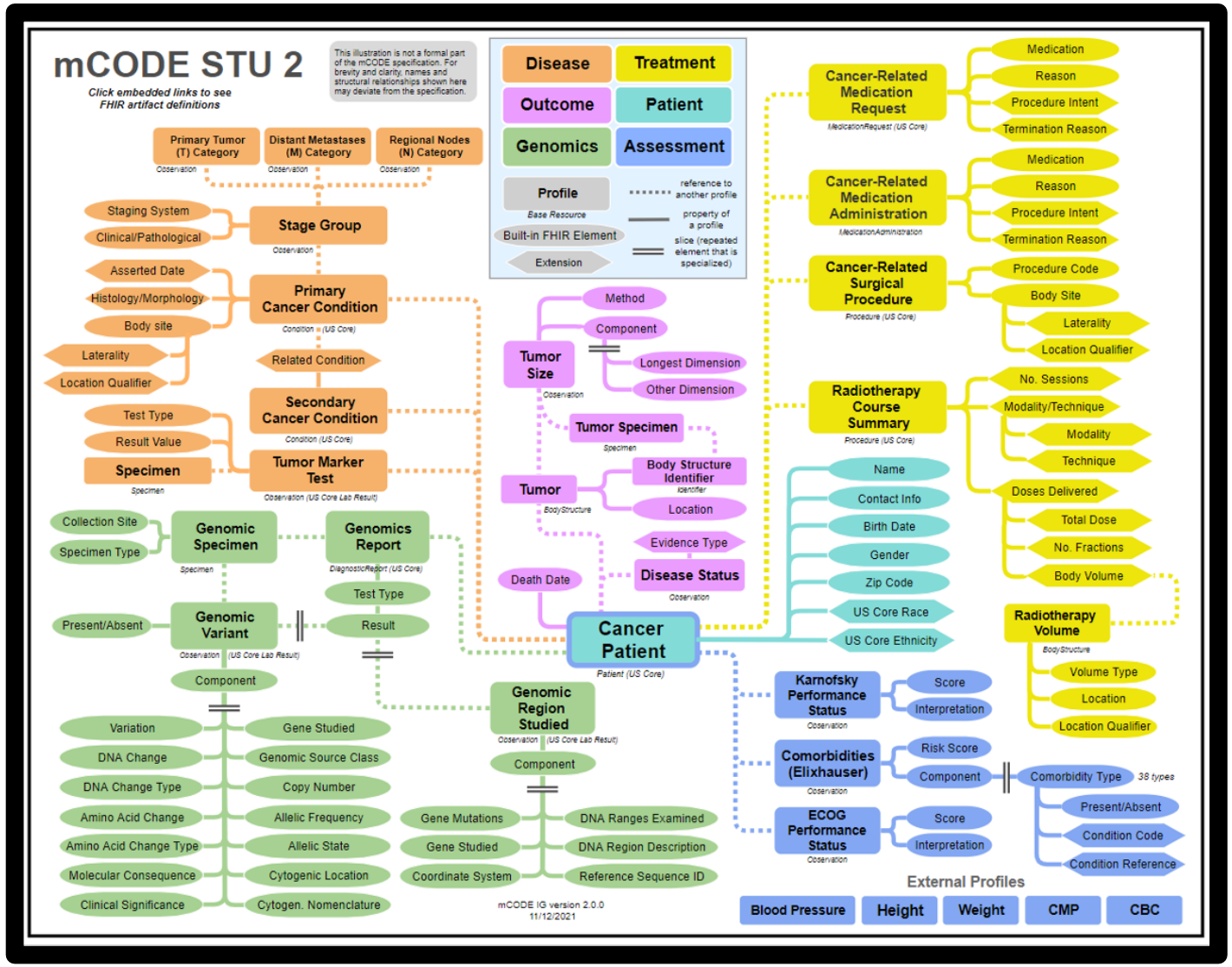
SmartList with data "tag"



- Defined: 0, 1, 2, 3, 4
- Can be pulled by EHR – no manual chart audit needed!

1. Joukes al, Appl Clin Inform, 2018
2. Häyrinen K, Saranto K. Stud Health Technol Inform 116:131-136, 2005

Cancer Data Language & Standard



Minimal Common Oncology Data Elements (mCODE)[1]

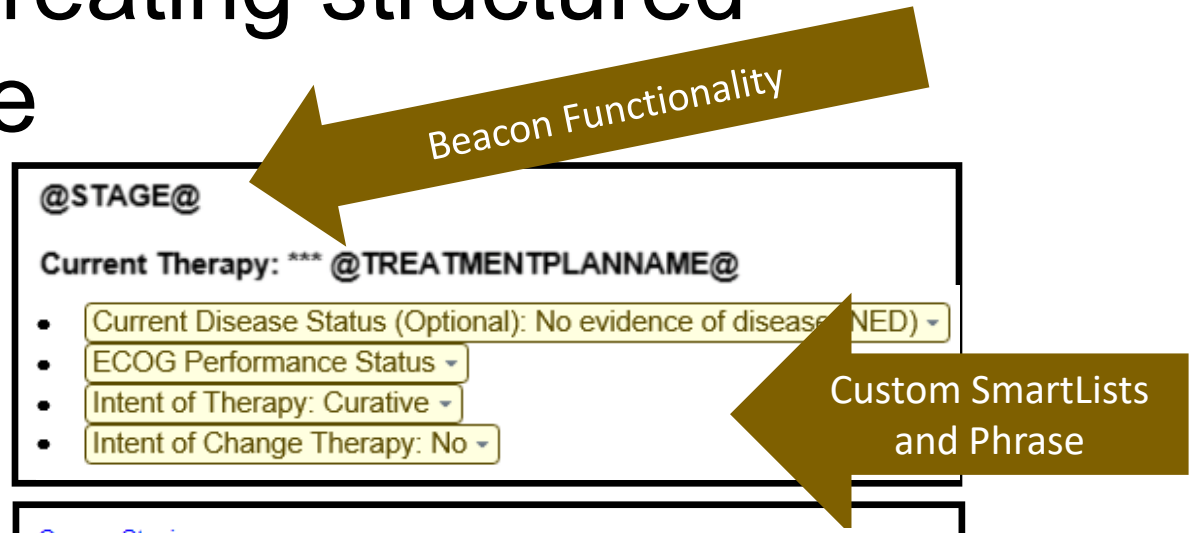
- FHIR-based core set of common data elements for cancer that is standardized, computable, clinically applicable in every electronic health record for patients with a cancer diagnosis
- Data categories used in the example:
  1. **Patient with cancer**
  2. **Stage (TNM)**
  3. **Treatment intent**
  4. **Cancer disease status**
  5. **Intent to change therapy**

1. Osterman et al, *Improving Cancer Data Interoperability: The Promise of the Minimal Common Oncology Data Elements (mCODE) Initiative*, JCO Clin Cancer Informatics, 2020

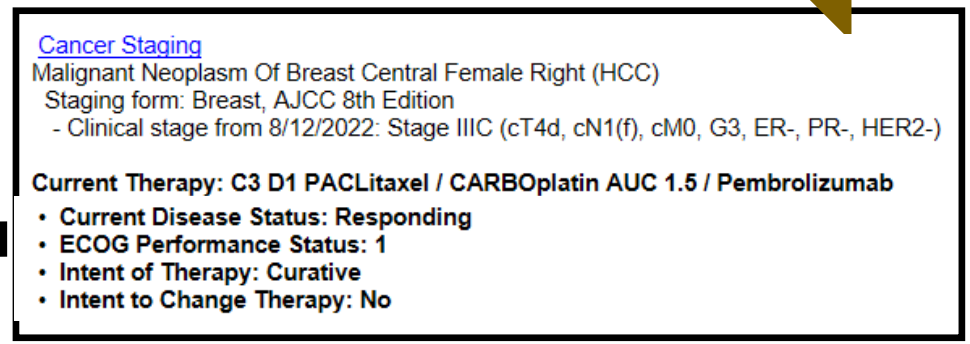
System-level Intervention: Creating structured cancer data during routine care

Structured Data entered ("created") by providers while creating a note for office visit

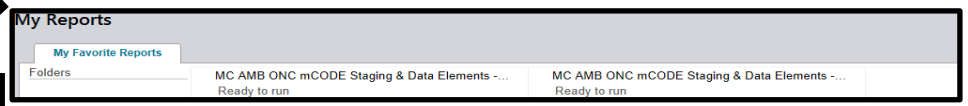
Note Template:



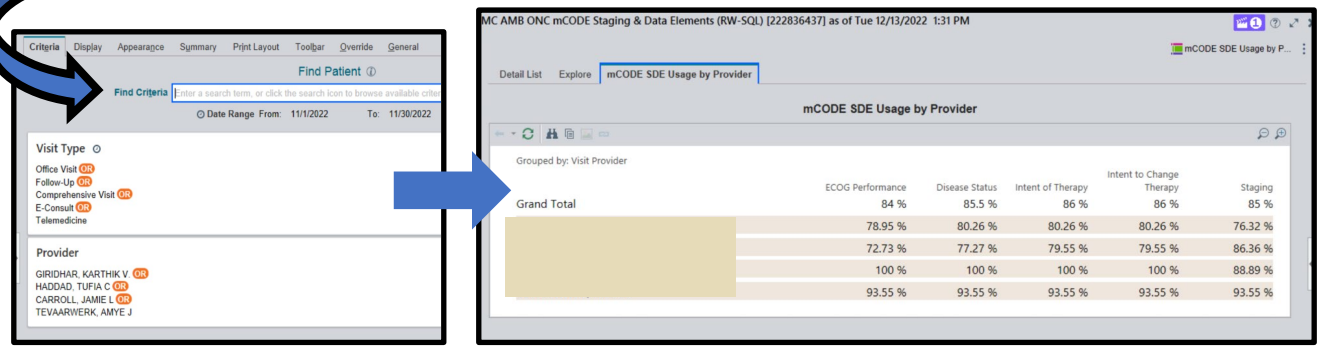
Sample Text in Note:



Report:



Filtered & Summarized Data:



Structured Data Capture: 4995 encounters

Timeframe	Pre-intervention	Month 1 (11/1-11/30)	Month 2 (12/1- 12/31)	Month 3 (1/1- 1/30)	Month 4 (2/1- 2/28)	Month 5 (3/1- 3/31)	Month 6 (4/1- 4/30)
Structured data category; N=category present; (present/encounter*100)							
Stage							
Disease Status							
Perform Status							
Intent c Therapy		(73)	(72)	(79)	(76)	(78)	(72)
Intent to Change Therapy	NA*	N=702 (73)	N=561 (72)	N=658 (80)	N=555 (77)	N=753 (78)	N=537 (72)

*Data may have been present as free text within provider notes, but no implementation existed for providers to capture information in a structured format within MCCCC's EHR

Timely: Data available in EHR at chart closure

Actionable: Data "lives" in the EHR and drives clinical decision support

Population Health Management Tools Need Structured Data

Health Maintenance or Care Pathway: ER+ PR+ HER2- Early Stage Breast Cancer

Patient with Breast Cancer

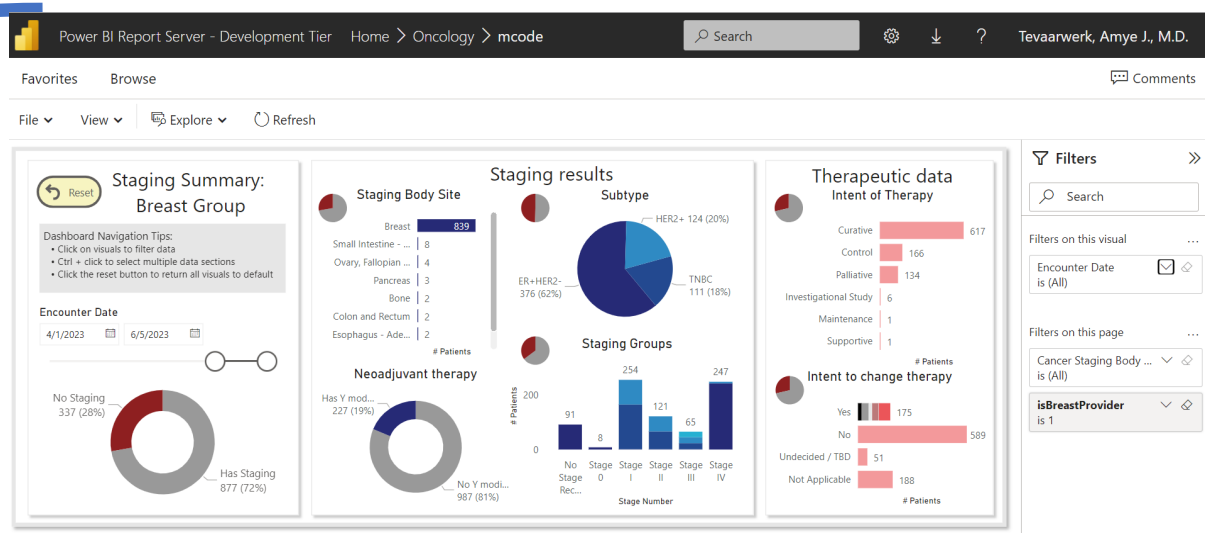
Stage: pT1c pN0 cM0 ER+ PR+ HER2-

Intent of Treatment Curative

Disease Status: NED

Year 1

Imaging	DEXA
	MMG
Meds	Taking AI?
Symptoms	ePROs



Rochester Breast Group Dashboard (courtesy of Dr. Karthik Girdihar)

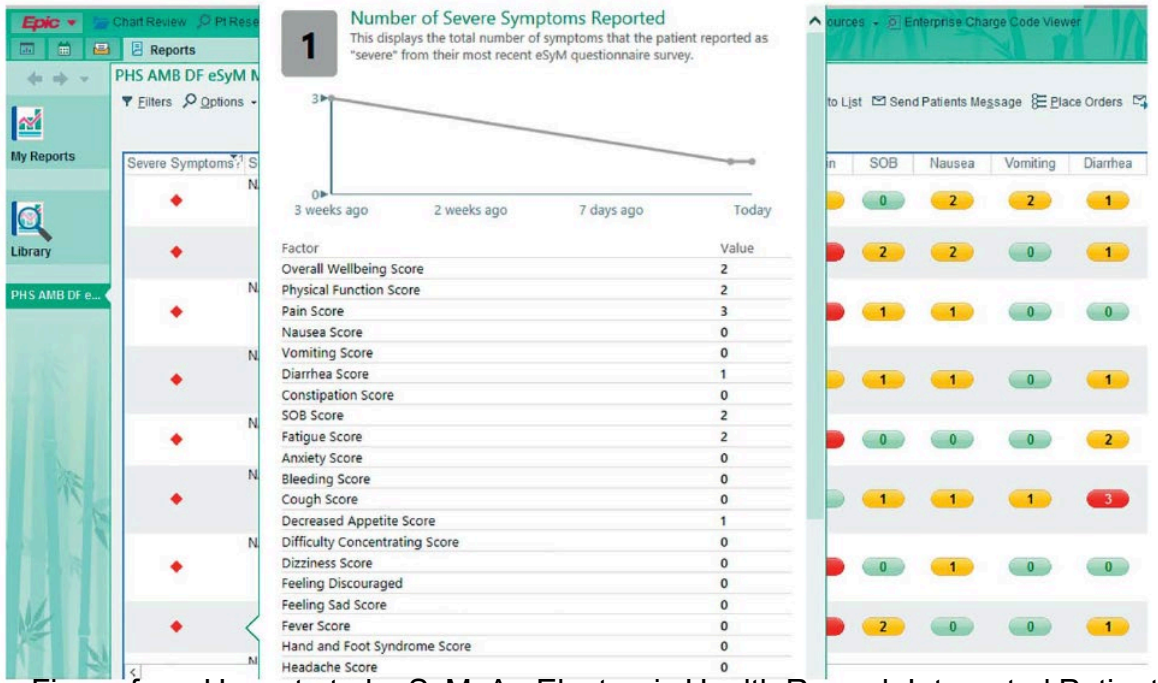
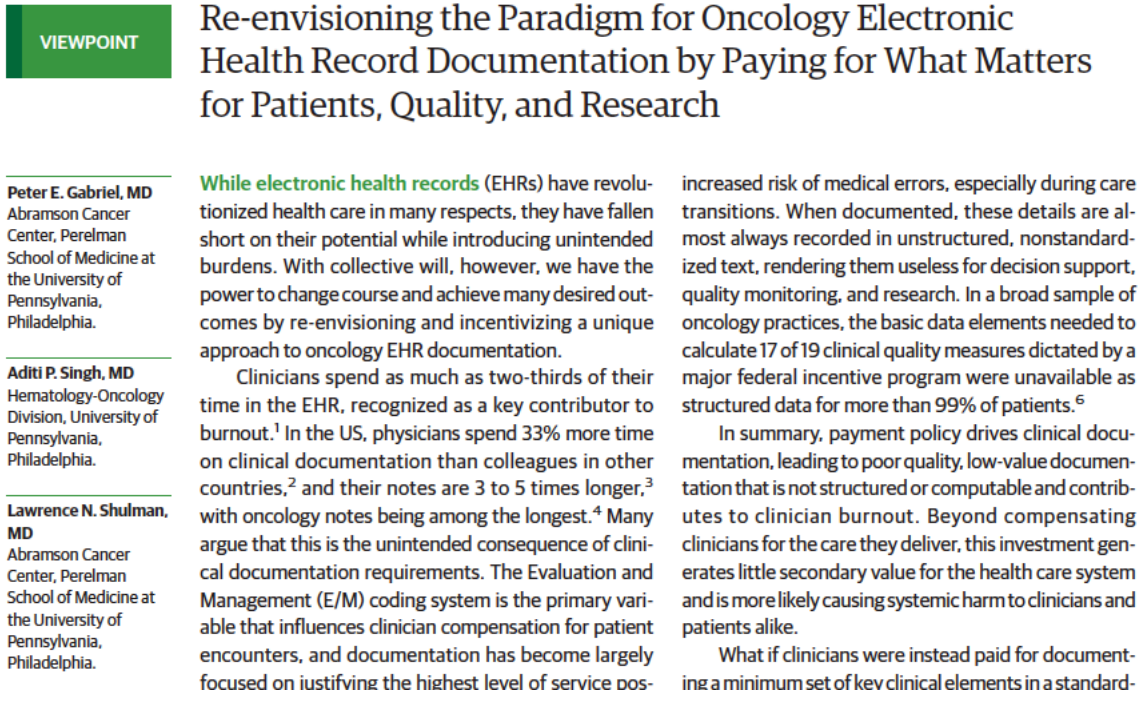


Figure from Hasset et al, eSyM: An Electronic Health Record–Integrated Patient-Reported Outcomes–Based Cancer Symptom Management Program Used by Six Diverse Health Systems; JCO CCI 2021

More System & Financial Issues….

- Are we asking systems to create these data?
  - Clinicians?
  - Registrars?
  - Survivors?
  - AI?
- Are we asking vendors to provide (the right) places to capture?
- Do we have the IT resources to build and support care pathways?
- Do we support systems, clinicians and survivors in using this data?
- What does it cost the system?



VIEWPOINT

Re-envisioning the Paradigm for Oncology Electronic Health Record Documentation by Paying for What Matters for Patients, Quality, and Research

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While electronic health records (EHRs) have revolutionized health care in many respects, they have fallen short on their potential while introducing unintended burdens. With collective will, however, we have the power to change course and achieve many desired outcomes by re-envisioning and incentivizing a unique approach to oncology EHR documentation.

Clinicians spend as much as two-thirds of their time in the EHR, recognized as a key contributor to burnout.[1] In the US, physicians spend 33% more time on clinical documentation than colleagues in other countries,[2] and their notes are 3 to 5 times longer,[3] with oncology notes being among the longest.[4] Many argue that this is the unintended consequence of clinical documentation requirements. The Evaluation and Management (E/M) coding system is the primary variable that influences clinician compensation for patient encounters, and documentation has become largely focused on justifying the highest level of service pos-

increased risk of medical errors, especially during care transitions. When documented, these details are almost always recorded in unstructured, nonstandardized text, rendering them useless for decision support, quality monitoring, and research. In a broad sample of oncology practices, the basic data elements needed to calculate 17 of 19 clinical quality measures dictated by a major federal incentive program were unavailable as structured data for more than 99% of patients.[6]

In summary, payment policy drives clinical documentation, leading to poor quality, low-value documentation that is not structured or computable and contributes to clinician burnout. Beyond compensating clinicians for the care they deliver, this investment generates little secondary value for the health care system and is more likely causing systemic harm to clinicians and patients alike.

What if clinicians were instead paid for documenting a minimum set of key clinical elements in a standard-

Gabriel et al, *JAMA Oncology,* 2023

Want to deliver the right care to the right patient at the right time & location?

→→→

Have the right data in the right place at the right time for the right patient….