

Today's Patient Portal and Sharing of Patient Data Across EHR Systems for Cancer Care and Research

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Today’s Patient Portal

Public Law 114–255
114th Congress

An Act

To accelerate the discovery, development, and delivery of 21st century cures, and
for other purposes.

Dec. 13, 2016
[H.R. 34]

*Be it enacted by the Senate and House of Representatives of
the United States of America in Congress assembled,*

SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) SHORT TITLE.—This Act may be cited as the “21st Century
Cures Act”.

21st Century
Cures Act.
42 USC 201 note.

Notes

Results

Today's Patient Portal

Reduce abbreviations

Stick to facts

Think about a patient reading the record

Set expectations for when results return



May 1, 2021

ONCOLOGY WATCH

Open Notes Are Here: Are We Ready?

As of April 1, 2021, "Open Notes and Results Transparency" as required by the 21st Century Cures Act was implemented. Gasp! Now my patients can read exactly what I say about them! I'm accustomed to using the record for professional communication, not lay communication. What if I get something wrong or inadvertently say something demeaning? What if something I write erodes trust or interferes with our relationship? Yikes!

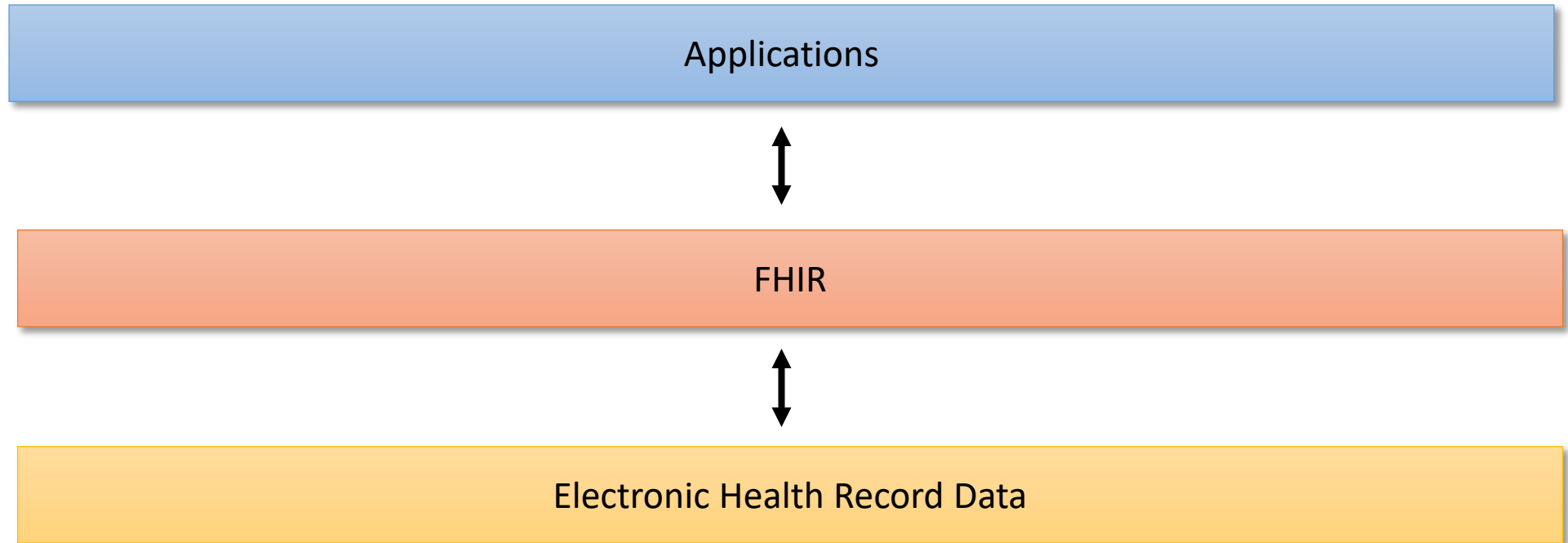
Actually, I'm not worried about any of this. In oncology, patients gathering up their own records and bringing them to me for review has always been routine. So, patients have always been able to see what we write, and I have always been sensitive to that. Of course, electronic access makes it easier. Remember the old days when patients had to wait in the medical records department for personnel there to dredge up reams of paper to copy? In the new world, both we and the patients can more easily find the information they want.



MARGARET TEMPERO, MD

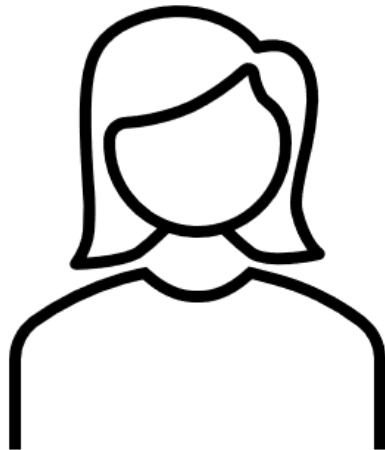
Margaret Tempero, MD, is a Professor of Medicine and Director of the UCSF Pancreas Center and editor-in-chief of JNCCN.

Fast Healthcare Interoperability Resources (FHIR)



The Current State of FHIR-Enabled Interoperability for Breast Cancer

65 year-old women with recently-diagnosed breast cancer



Accessible

- ✓ Demographics
- ✓ Conditions
- ✓ Procedures
- ✓ Encounters
- ✓ Medications
- ✓ Devices
- ✓ Labs / Vitals
- ✓ Allergies
- ✓ Smoking Status
- ✓ Care Plan/Team
- ✓ Clinical Notes
- ✓ Immunizations

Inaccessible

- X Disease response
- X Adverse events
- X Hormone Receptors
- X Tumor Markers
- X Pathologic / Clinical Staging
- X Tumor Size
- X Nodal Status
- X Metastatic Status
- X Body Site
- X Histology, morphology, behavior
- X Karnofsky / ECOG scores
- X Chemotherapy dose and cycle
- X Radiation technique and fractions
- X Patient reported outcomes

A FHIR-based core set of common data elements for cancer that is standardized, computable, clinically applicable and available in every electronic health record for patients with a cancer diagnosis

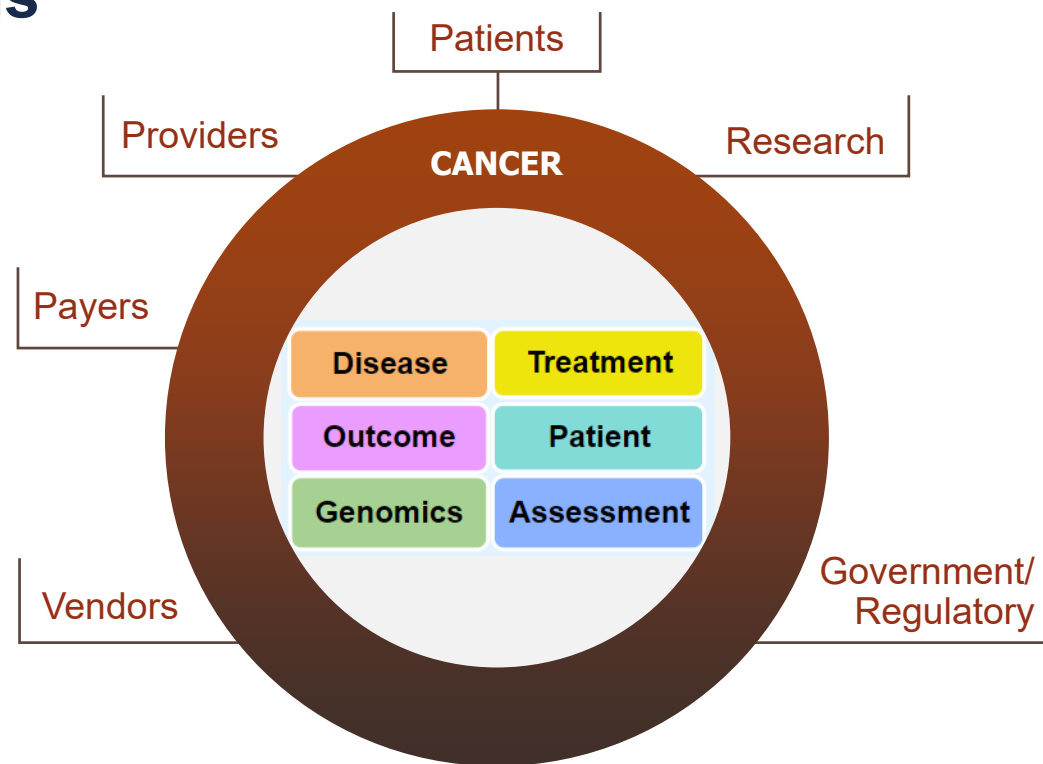
A **standard health record** for oncology

The **minimal set of data elements** applicable to all cancers, and collected for:

Standardized
information exchange

Use-case driven and
targeted use

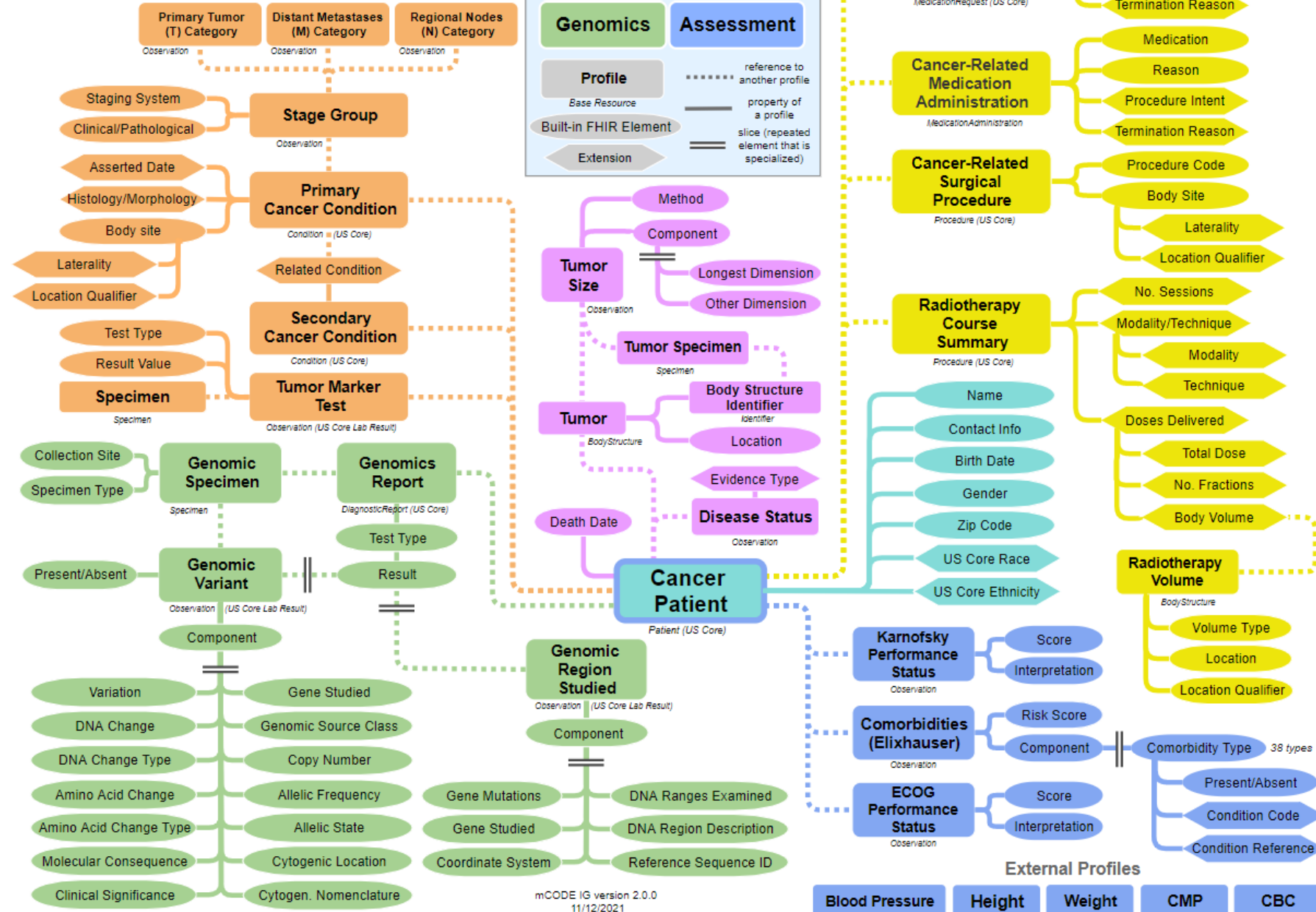
Oncology data element domains:
**patient, disease, treatment,
outcomes, genomics, lab/vital**



mCODE STU 2

Click embedded links to see
FHIR artifact definitions

This illustration is not a formal part
of the mCODE specification. For
brevity and clarity, names and
structural relationships shown here
may deviate from the specification.



CodeX™ / mCODE™ Community of Practice

A group of health systems, specialty societies, government agencies, pharmaceutical manufacturers, researchers, EHRs and supporting organizations, participating in a **monthly public forum focused on real-world applications of mCODE.**



Latest developments on
mCODE, CodeX, and
cancer data exchange



Ask questions and learn from
the experience of other
community participants



Develop and share best
practices for clinical workflows,
data modeling, and exchange



45
Health
Systems



7
Payers



4
Pharma



70
EHRs and
other tech
companies



12
Medical Societies
and Consortia



10
Government
Agencies



5
Research
Organizations



7
Nonprofits/
Foundations



2
Patient Advocacy
Organizations

<https://confluence.hl7.org/display/COD/mCODE+Community+of+Practice>

Next Challenges

- Portability of complex data
- Computable guidelines
- Computable clinical trial criteria
- Programs to address barriers to access