

Day one, presentation-session I
Jim Cimino

Reuse of Clinical Health Records: Caveat Inquisitor
Jim Cimino

Vast troves of human health information exist, and more are on the way, in the form of electronic health records. It is tempting to consider these collections as "almost free" proxies for clinical research databases that would otherwise be extremely expensive to accrue. However, the data collected in the process of patient care can be markedly different from clinical research data, presenting challenges to their interpretation and reuse for research purposes. Some of the dimensions by which data can be characterized include accuracy, timeliness, completeness, granularity, and standardization. This talk will provide examples of how clinical data may fall along each of these dimensions in ways that not only deviate from the desired characteristics of research data, but may do so in ways that are subtle or misleading.



Uniting Rare Diseases

Advancing Rare Disease Research: The Intersection of Patient Registries, Biospecimen Repositories and Clinical Data

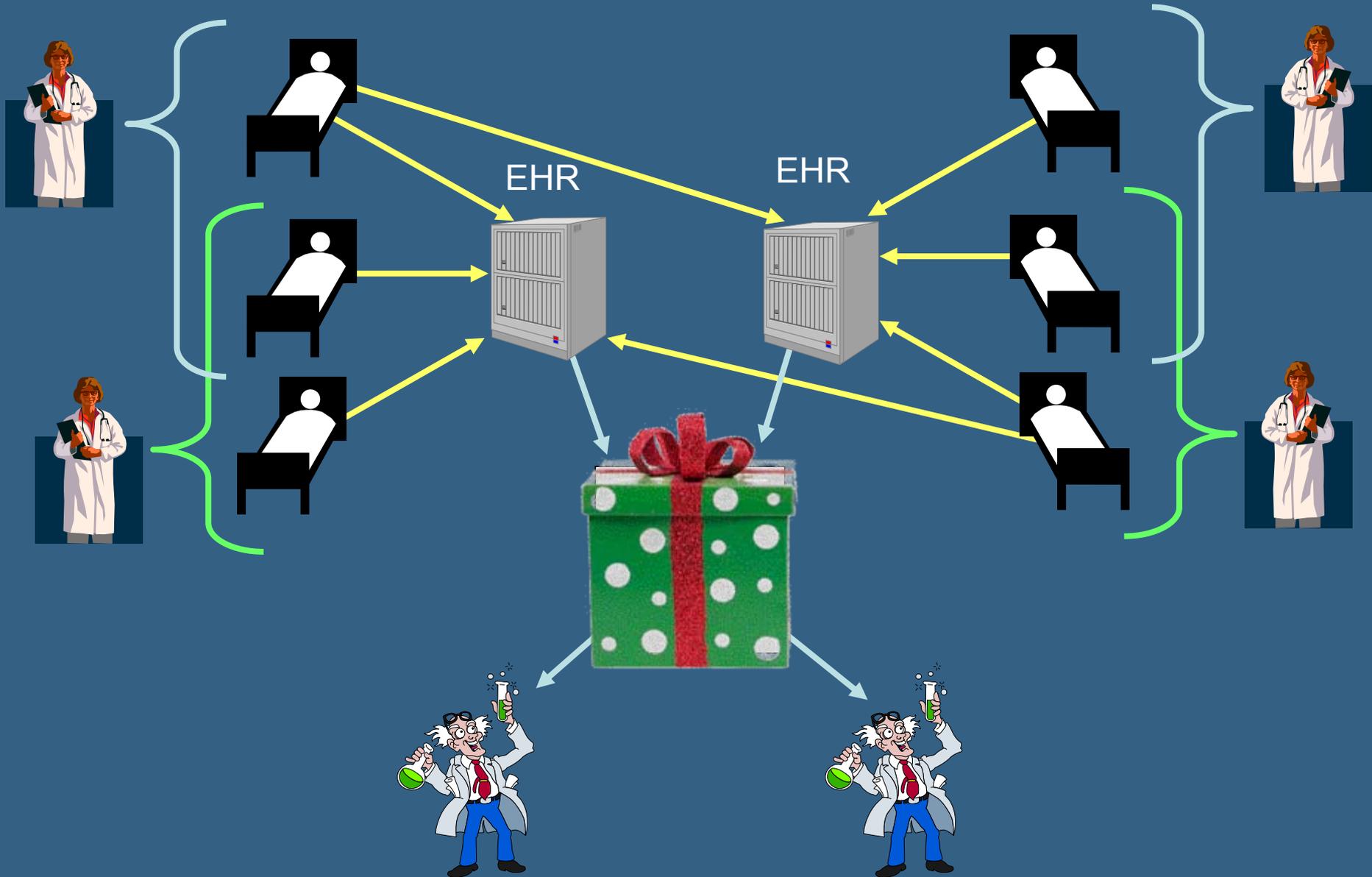
Session I Standards, Informatics and Technology

*James Cimino
Laboratory for Informatics Development
NIH Clinical Center*

Reuse of Clinical Health Record: Caveat Inquisitor

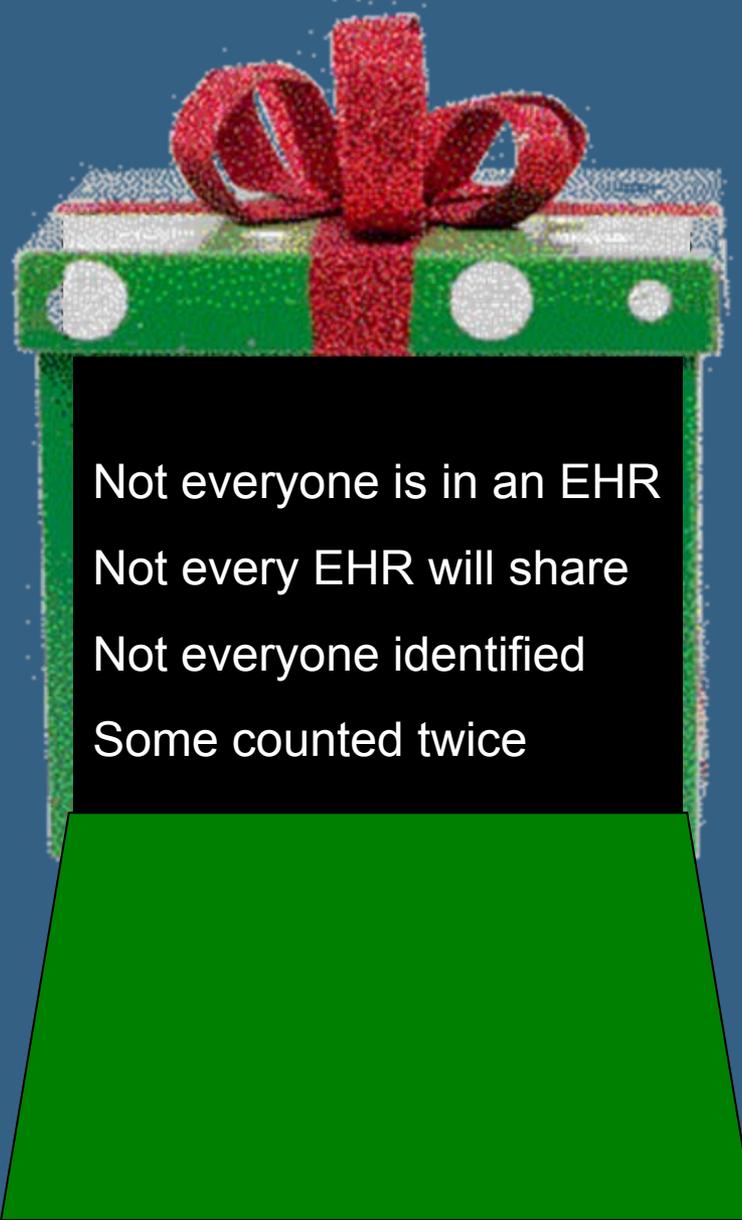


From EHR to Disease Registry



Beware Strangers Bearing Gifts

I hope it has everyone.



Not everyone is in an EHR
Not every EHR will share
Not everyone identified
Some counted twice

Beware Strangers Bearing Gifts

I hope cases will be coded correctly.



No Standard Terminologies

Celiac Disease

Nontropical sprue

Gluten enteropathy

Idiopathic steatorrhea

Gee disease

Gee-Herter disease

Beware Strangers Bearing Gifts

I hope cases will be coded correctly.



No standard terminologies
No standard data models

No Standard Data Models

Blood Type: A Positive

ABO Panel: Major: A
Rh: +

Culture: S. aureus
Meth: R

Culture: MRSA

MRSA Test: Present

Hep Panel: B S Ag: Positive

Hep Panel B S Ag Pos: Yes

Beware Strangers Bearing Gifts

I hope cases will be coded correctly.



No standard terminologies
No standard data models
Standard criteria not used

Standard Criteria Not Used

OTHER DISEASES OF DIGESTIVE SYSTEM (570-579)

579 Intestinal malabsorption

579.0 Celiac disease

Celiac:

crisis

infantilism

rickets

Gee (-Herter) disease

Gluten enteropathy

Idiopathic steatorrhea

Nontropical sprue

579.1 Tropical sprue

Sprue:

NOS

tropical

Tropical steatorrhea

579.2 Blind loop syndrome

Postoperative blind loop syndrome

579.3 Other and unspecified postsurgical nonabsorption

Hypoglycemia following gastrointestinal surgery

Malnutrition following gastrointestinal surgery

579.4 Pancreatic steatorrhea

579.8 Other specified intestinal malabsorption

Enteropathy:

exudative

protein-losing

Steatorrhea (chronic)

579.9 Unspecified intestinal malabsorption

Malabsorption syndrome NOS

Celiac disease

- small-bowel
- normal
- relapse

• EHR: “Patient
the time of

• Billing data

g diet

diet

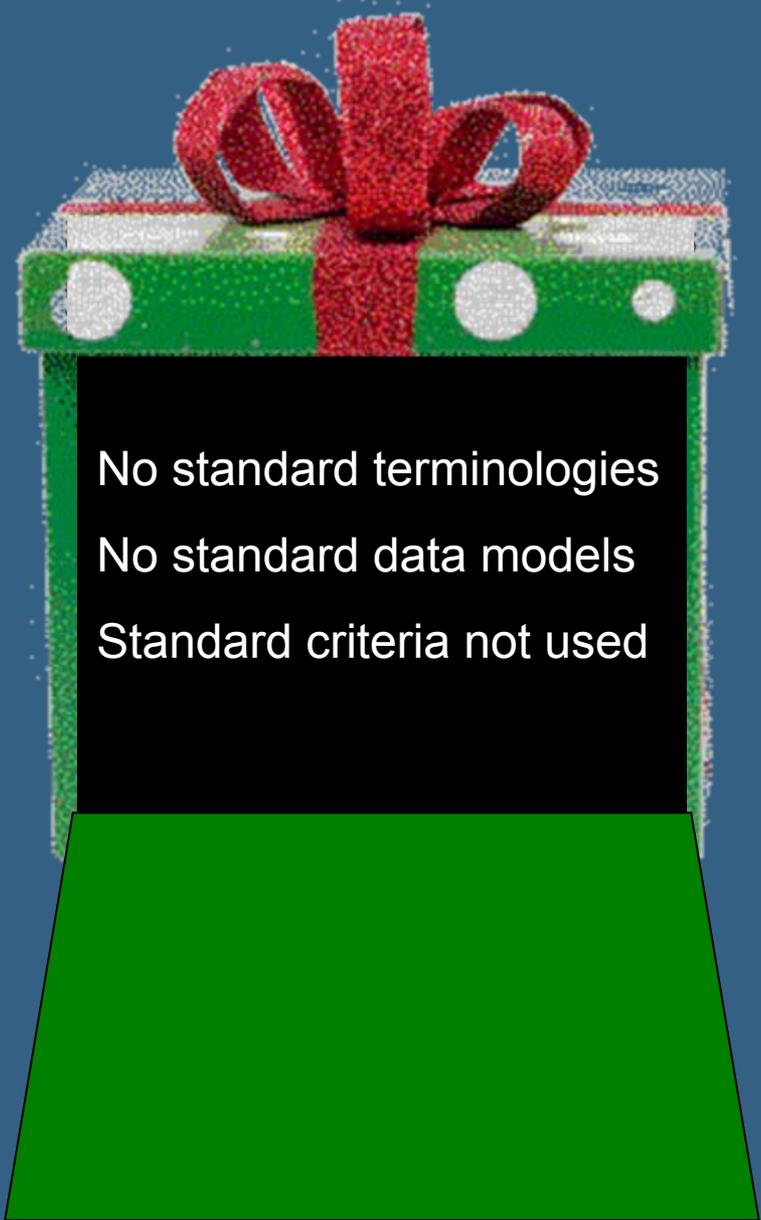
n challenge

orrhea. At
idiopathic).”

Celiac Disease

Beware Strangers Bearing Gifts

I hope cases will be coded correctly.



No standard terminologies
No standard data models
Standard criteria not used

Beware Strangers Bearing Gifts

I hope case descriptions are complete.

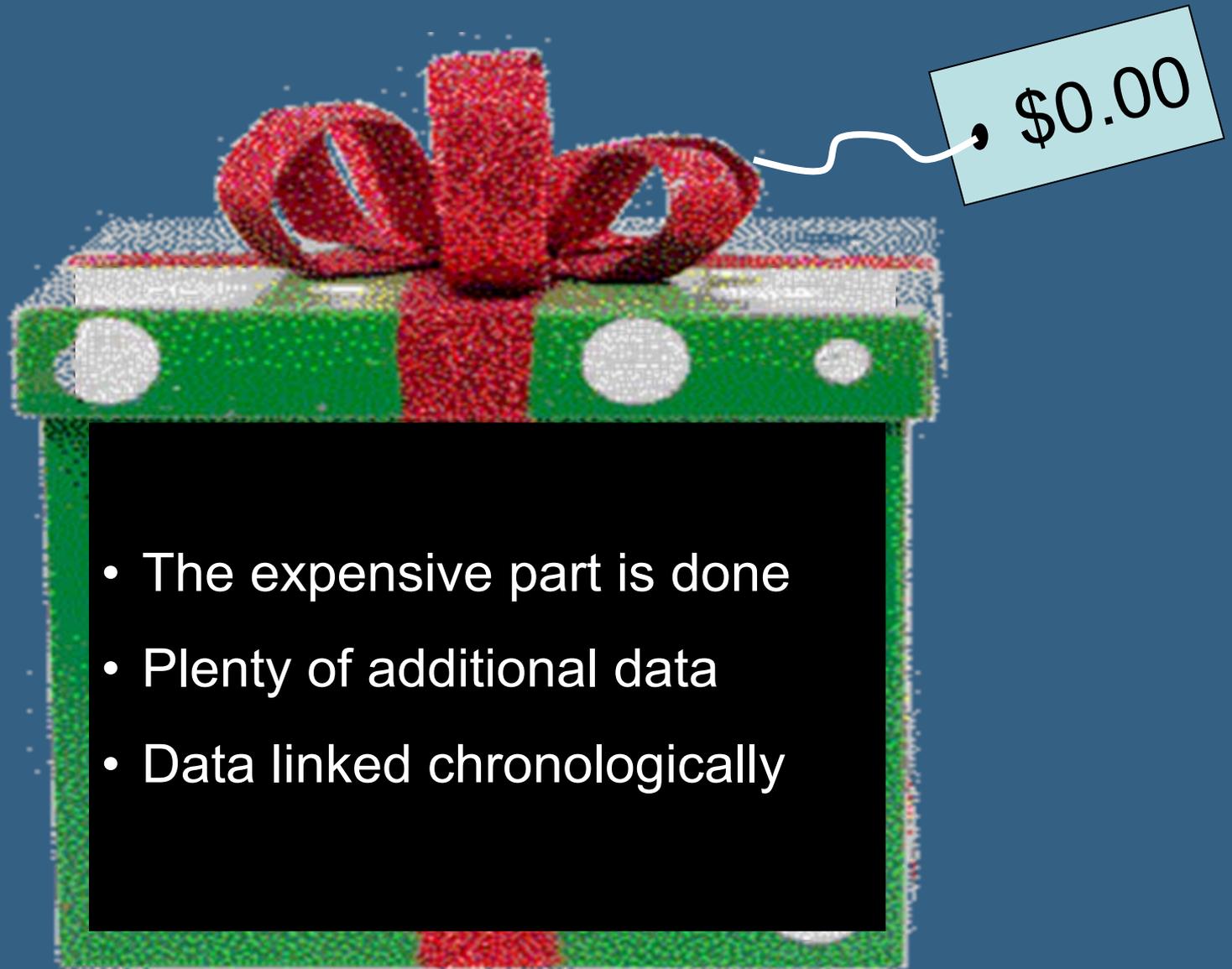


Data collected as
clinically indicated

Guidelines not generally
followed

Data are nonstandard

But there is a Santa Claus



- The expensive part is done
- Plenty of additional data
- Data linked chronologically

Is there hope?

- Federal incentive to adopt EHRs
- Terminology and data model standards mandated
- Computerized order entry can guide data collection
- Computerized documentation can guide data recording
- But: Caveat Inquisitor – let the researcher beware!