Medicine Based upon Data

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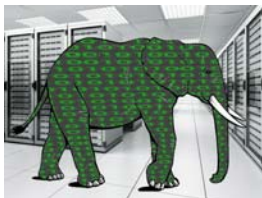

Outline

The Dream
The Reality
The Limitations
The Future

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The dream of evidence-based medicine is that quality evidence exists to guide clinicians through the clinical conundrums

they routinely face

- which test to order;
- how to interpret the test results
- what therapy to try

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The RCT Gold Standard

- Expensive
- Only a faction of clinical situations
- Inclusion and Exclusion criteria limit generalizability

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Only 5% of data is structured

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Electronic Health Records are real-time, patient-centered records. They make information available instantly, *whenever and wherever it is needed.*

- Contain information about a patient's medical history, diagnoses, medications, immunization dates, allergies, radiology images, and lab and test results
- Offer access to evidence-based tools that providers can use in making decisions about a patient's care
- Automate and streamline providers' workflow
- Increase organization and accuracy of patient information
- Support key market changes in payer requirements and consumer expectations

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Goals of EHRs

- Quality and convenience
- Accuracy of diagnoses and health outcomes
- Care Coordination
- Practice efficiencies and cost savings
- Patient Participation

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Clinical Data

- Collected at some cost and for some reason
- Data are missing
- No quality control
- No normalization
- Inherent biases
  - Selection
  - Intent
- Time relationships not captured

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Clinical Data is a Mess

- 50% of CIO's don't trust their data
- 95% of data is unstructured
- Standards usually address syntax not meaning
- Local knowledge is lost in aggregation

BUT

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Imperative to Combine Data

- RCTs not the answer

- Common Complex Conditions are really multiple rare diseases

- Person-sourced data

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Personal Health Records

What is a personal health record ?
- An on-line software communication tool between clinicians and patients

My Problem List   My Vital Signs   My Lab Results   My Allergies

What does a personal health record do ?
- Facilitates clinician-patient collaboration
- Utilizes the patient as a resource for patient self management

My Medication Schedule   My Appointment Schedule
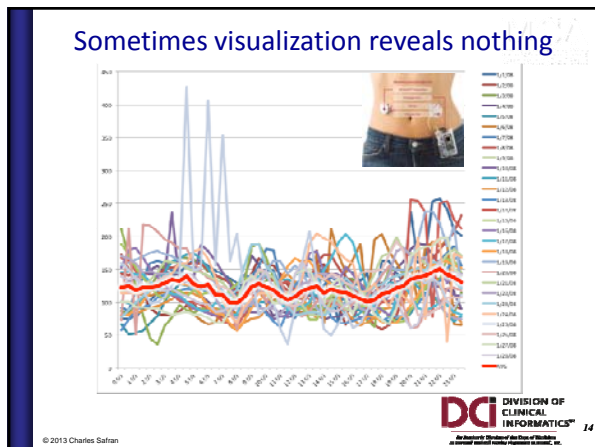
How does it do this ?
- Access to medical information
  - online medical record e.g. clinical notes, investigations, lab results, diagnosis list
  - electronic medical education and knowledge support
  - patient self-monitoring
- Administration – online appointment making
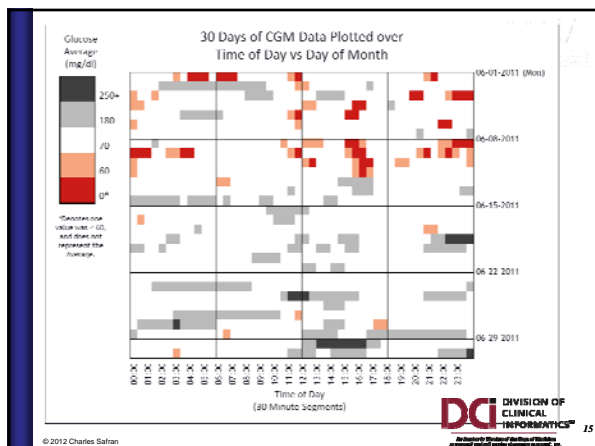- Electronic messaging between clinicians and patients

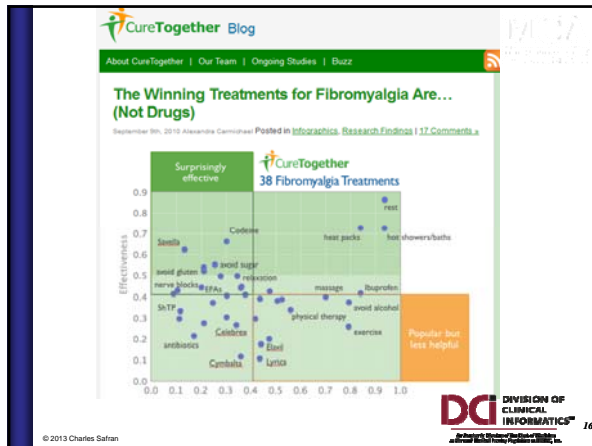My Protocol   My Education Center   My Care Team   My Personal Information

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Sometimes visualization reveals nothing

30 Days of CGM Data Plotted over Time of Day vs Day of Month

Consuming Digital Crumbs

Connecting the Dots

Slide 19

PEDIATRICS
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Spread of Methicillin-Resistant *Staphylococcus aureus* in a Large Tertiary NICU: Network Analysis

From Geva et al, *Pediatrics* 2011

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Analytics

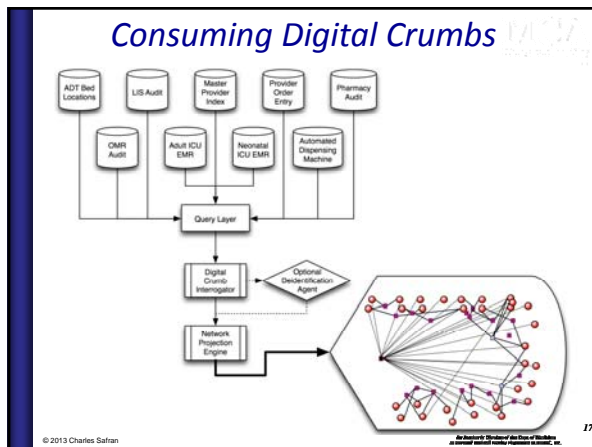DIVISION OF CLINICAL INFORMATICS

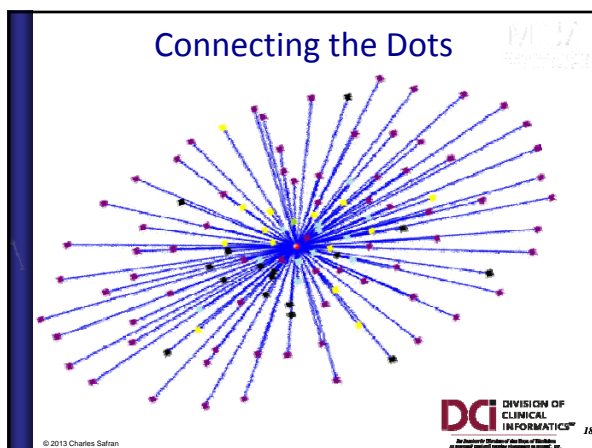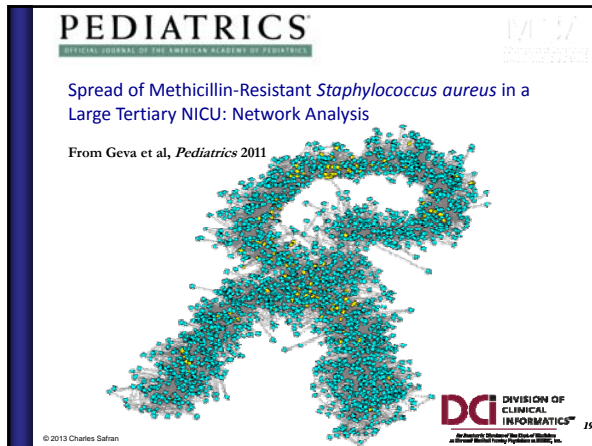© 2013 Charles Safran *20*

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- Maybe we can store the data
- Maybe integrate or fuse the data
- Maybe we have tools to visualize the data
- Maybe we can make some sense of the data

BUT

- Do we have the PEOPLE trained for these tasks

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It is a very sad thing that nowadays there is so little useless information.

Oscar Wilde 1894

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Where is the wisdom we have lost in knowledge?

Where is the knowledge we have lost in information?

T.S. Eliot

Where is the information we have lost in data?

C Safran

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