

# Through a Glass, Darkly: Nursing, Big Data, & Creating Knowledge for the Future of Health

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## My goals today are to convince you that ...

... big data approaches require nursing, and nursing requires big data approaches

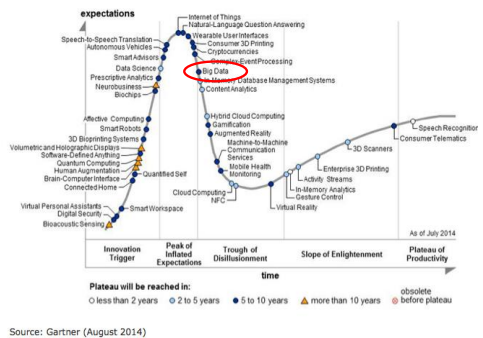
... questions get us to data and data gets us to answers (sort of!) *Analytics matter too!*

... success comes from leveraging investments and creating scalable knowledge-building teams

... nurses across the educational continuum can be generators, users, scholars and practitioners in a data-driven health care system

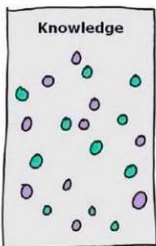
A Paradox:  
Theory trains us to discount outliers but data are *sooo* tantalizing

Figure 1. Hype Cycle for Emerging Technologies, 2014





With apologies to @ResearchMark, an edited version of this popular diagram.

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The amount of data in the world doubles every 18 months to two years

vizHOME:  
950,000,000  
data points  
per household  
(~1 gigabyte)

6.9 petabytes is a good start. That's how much data they manage and store in Information Technology at Kaiser Permanente— more than the Library of Congress can claim.  
(~7 000 000 000 000 000)

*But the data in the Library of Congress just sits there!*

### What makes Big Data *big*?

1. Uncountable elements
2. Broad range of data types and data sources
3. 4v data: velocity, volume, variety, **veracity**  
And maybe **value**
4. Differs whether it's at rest, in one place or in motion

Masys:

1. Exceeds the capacity of unaided human cognition for its comprehension
2. Strains current technology capacity and is therefore CPU-bound, bandwidth-limited and/or storage

### Where does Big Data come from?

*According to the NIH:*

1. Projects funded to produce important resources for the research community which yield large amounts of data
2. Large datasets useful for individual projects, which might be broadly useful to the research community
3. Small datasets whose value can be amplified by aggregating or integrating them with other data

The mission of the NIH Big Data to Knowledge (BD2K) initiative is to enable biomedical scientists to capitalize more fully on the Big Data being generated by those research communities.

### Nurses know- *there's more Big Data out there*

1. Clinical care: EHR Data; Billing & Claims; HIE
2. Biorepository (Aspirational)
3. The environment surrounding people
4. Patient defined and patient-generated

...so what is it that nurses deal with?

Signs  
Symptoms  
Observations of Daily Living (ODL)  
Images  
Biomarkers  
Family dynamics  
Patient experience  
Population phenotypes  
Biological specimens  
Every-day living spaces  
....

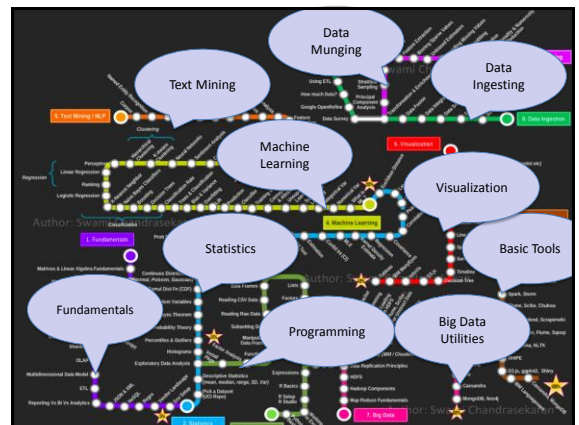
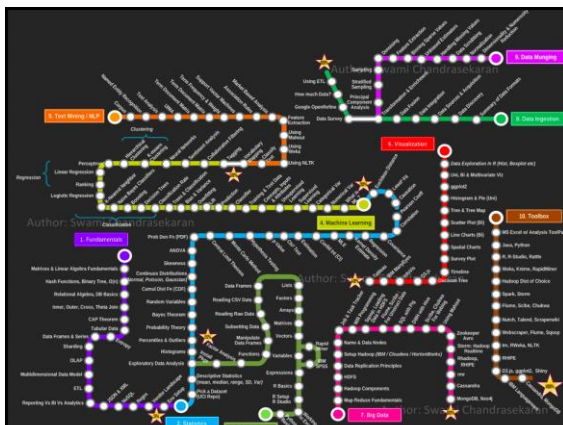
# Nursing, Big Data and the Patient Experience

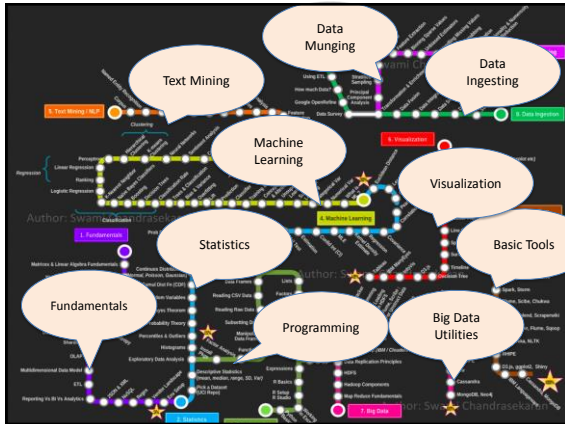
What questions would  
you answer  
if you had immediate,  
complete access  
to all of the data that  
you wanted?

....but we don't have to do it all ourselves!

In fact we should not!

...Lessons from our colleagues, the  
Big Data Scientists!





**Big Data can support many different types of study designs**

- Observational studies
- Clinical Trials
- Practical clinical trials
- Data exploration
- Descriptive research
- Survey Research
- Interpretive research
- Population health studies

...

big data is more than volume: diversity of data is just as influential

**QUESTIONS ARE EVEN MORE IMPORTANT**

**Rules of the Road for Handling Big Data**

Hilary Mason, bitly OSEMN

- Obtain
- Scrub
- Explore
- Model
- interpret

...but what do you do first???

... Ask the question!

**Because....**

Data will tell you whether A or B is correct  
 But it will not tell you what A and B are in the first place!

*And, by the way, big analytics, big storage can't keep up with big data*

Services as a pathway to data (Linked in, facebook)

But we knew this! (aka EHR! )

## Smart Handling of Big Data

1. Scheme on write vs schema on read
  - Traditional sql requires schema on write
  - Hadoop creates *schema on read* – no gatekeeping rules until the data are read
2. Analytic workflow is distributed and allows for interim results  
Converge on a consistent answer – allows for rapid engagement & handles consistently updating data sets

## Nursing Engagement in the NIH BD2K Initiatives

## BD2K workshops @ NIH

1. **Workshop on Enhancing Training for Biomedical Big Data July 29, 2013 - July 30, 2013**  
Co-chairs: Karen Bandeen-Roche, Ph.D & Zak Kohane, M.D.
1. **Enabling Research Use of Clinical Data September 11, 2013 - September 12, 2013**  
Co-Chairs: Robert M. Califf, M.D. & Daniel R. Masys, M.D.
2. **Frameworks for Community-Based Standards Efforts September 25, 2013 - September 26, 2013**  
Co-Chairs: Susanna Sansone, PhD & David Kennedy PhD

## Informatics Core of the BD2K Initiative

- Understand the processes and frameworks for data integration (Musen)
- Model biomedical domains
- Use standard metadata descriptions and standard ontologies
- Evaluate the appropriateness of existing ontologies for the data integration task at hand
- i2b2

## The Nursing Workforce

Nurse data scientists  
Nurse scientists with  
data sophistication  
Data-intensive nurses in practice

## Knowledge development: how big data might advance nursing science

- Informatics training to complement statistical training
- Team science
- Embedded laboratory partnerships (e.g. i2b2)
- More varied methodologies
  - Spatio-temporal dynamical modeling and flexible dynamical modeling (e.g., parameter fitting and optimization of complex time series data)
  - Mechanistic modeling, multi-scale modeling
  - Agent-based, Ordinary Differential Equation (ODE), Partial Differential Equation (PDE), and stochastic methods

# Through the glass, Darkly

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*Closing thoughts*

## **Key Themes of the Day**

1. What makes data big?  
Variety, velocity, veracity, volume  
(and maybe value)
2. Question asking > Question answering
3. The exchange:  
Nursing brings theory to big data;  
big data brings tools to nursing science
4. Nurses across the continuum participate  
in data driven health care

