



Spanning the Gulf: Maturing Research Solutions for the Enterprise



ROBERT H. LURIE
COMPREHENSIVE CANCER CENTER
OF NORTHWESTERN UNIVERSITY



NORTHWESTERN
UNIVERSITY

NUCATS

Clinical and Translational Sciences Institute
nubic Northwestern University
Biomedical Informatics Center

Warren A. Kibbe, PhD

wakibbe@northwestern.edu


<http://www.cgm.northwestern.edu/cgm/Faculty-Research/Faculty/Warren-Kibbe>
http://wiki.bioinformatics.northwestern.edu/index.php/Warren_Kibbe

What does enterprise mean to me...

- Enterprise computing means scalable infrastructure
- Mature, supportable application
- Well audited and monitored
- Centrally managed, centrally deployed, flexibly provisioned (depending on the application)

9/9/12

BRIITE, 3/2012, WAKibbe



Northwestern University Biomedical Informatics Center



- Useful
- Interoperable
- Maintainable
- Open source
- Renewable
- Modular

9/9/12

What should enterprise mean?

- Interoperable
- SAAS or SOA
- Semantically aware
 - Semantic web
 - Ontology driven
 - Workflow engine
- Standards!

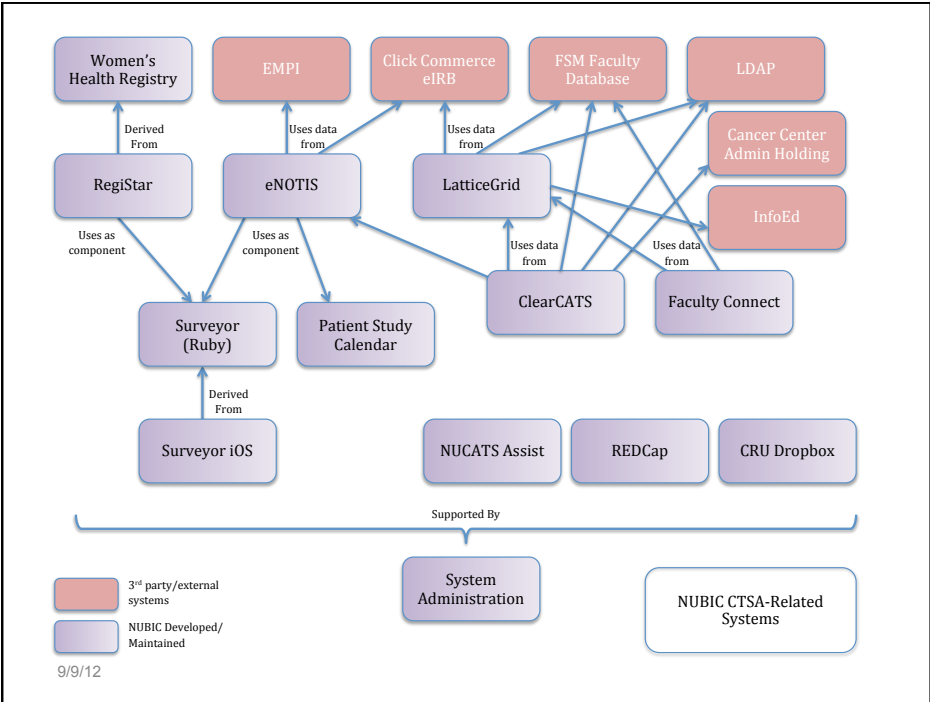
9/9/12

BRIITE, 3/2012, WAKibbe

My environment

- Peoplesoft for financials, HR, student systems
- InfoEd for grants and contracts
- eIRB for IRB
- Granite for IACUC
- Epic for outpatient
- Cerner for inpatient
- IDX and Primes for scheduling and PatReg
- Homegrown registries, RDC, CTMS

9/9/12 BRIITE, 3/2012, WAKibbe



My worries

- Obvious holes
 - Firewall
 - Device encryption
 - Federated identity for staff
 - Federated identity for patients and participants
 - Employee awareness
 - Behaviors

9/9/12

BRIITE, 3/2012, WAKibbe

What's missing?

- Enterprise data governance
- Central, tiered, proportional planning
- Federated identity
- Properly provisioned LDAP
- Easily consumable identity resources
- Path for maturation

9/9/12

BRIITE, 3/2012, WAKibbe

The positives

- Secure Storage
 - My group has a few hundred TBs of HIPAA and FISMA compliant storage
 - University, NMFF (faculty practice) and NMH (hospital) have HIPAA-compliant storage
- Shared liability
- Enterprise Data Warehouse
- Increased trust & better harmonization of practice

9/9/12

BRIITE, 3/2012, WAKibbe

Actionable needs

- Research Registries
- CTMS
- Support for Data Coordinating Centers
- Integration between CTMS, IRB, grants&contracts, billing, compliance
- Data governance
- Molecular medicine -> precision medicine

9/9/12

BRIITE, 3/2012, WAKibbe

More Challenges

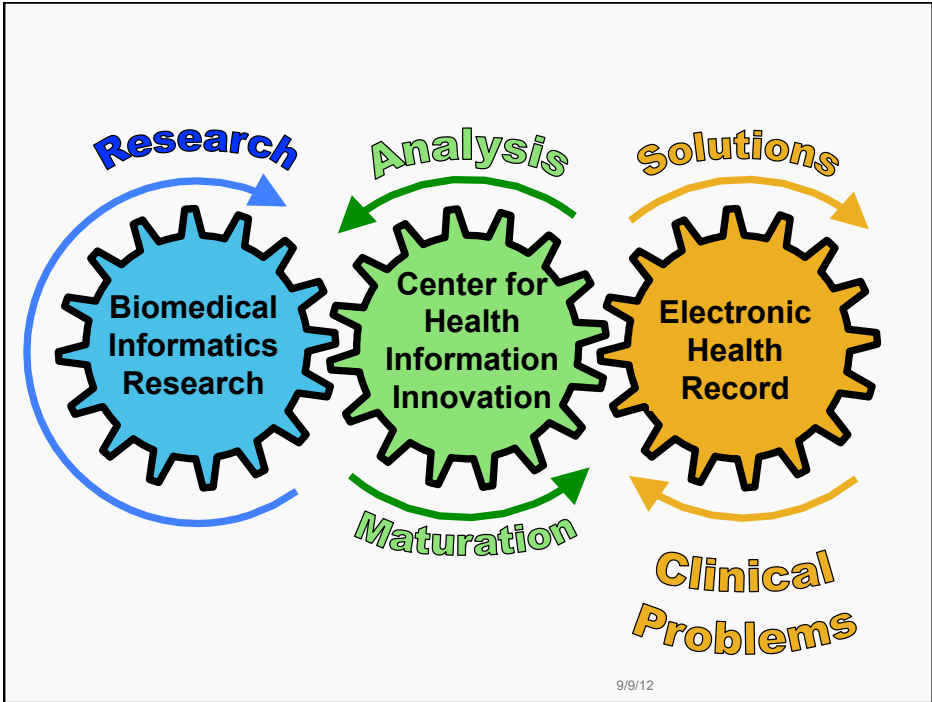
Governance Technical Financial Standards Operations and Culture	Regulatory Compliance Data Sharing Data Security QC / QA
---	--

9/9/12
Healthcare summit, 3/2012, WAKibbe

Clinical Perspective

<p>Researcher Portal</p> <ul style="list-style-type: none"> Cohort Identification Molecular Profiling Comparative Effectiveness <p>Clinicians Portal</p> <ul style="list-style-type: none"> Decision Support Clinical Trials Matching Clinical Pathways 	<p>Patient Portal</p> <ul style="list-style-type: none"> Personalized Health Record Personalized Search Follow-up <p>Administrative Portal</p> <ul style="list-style-type: none"> Meaningful Use Operation Dashboards Reporting and Services
---	--

9/9/12



Case Study

- Rolling out an enterprise Research Registry system based on lessons learned from cancer and women's health

Case Study

- Moving from a cancer only CTMS to a campus solution

9/9/12

Case Study

- Truly integrated decision support based on our Enterprise Data Warehouse

9/9/12

Case Study

- Building a National Children's Study information management system and deploying across ten institutions

9/9/12

9/9/12

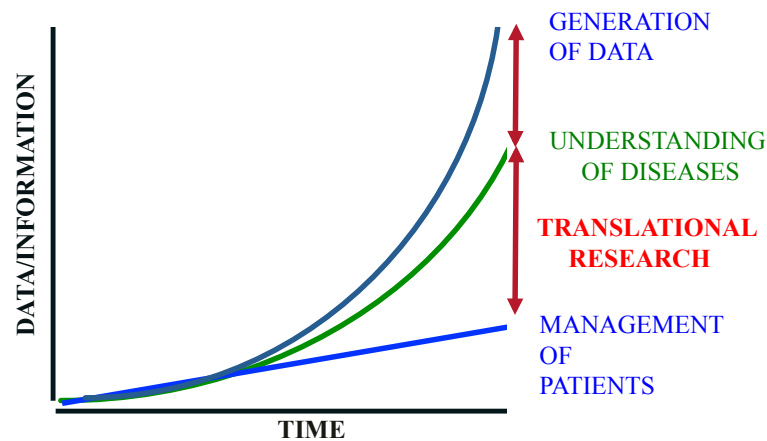
Change is accelerating

“Science is evolving at an incredible pace. It’s a revolutionary period. The fundamental change is that biomedical science has converged...”

– Elias Zerhouni, M.D.

9/9/12

21st Century Translational Research



9/9/12

The -omic data tsunami

- Arrays (Gene Expression, SNPs, Methylation)
- Proteomics
- Next Generation Sequencing
- Whole genomes
- Exome sequencing
- Genomic methylation patterns
- Metagenomics
- Fine resolution transcript/splicing

9/9/12

-omics, research, and care, oh my

- 600K SNP chips <\$400
- NGS exome sequencing, < \$300
- NGS a full human genome, 3x coverage, < \$1000
- Expression profiling
- Proteomics
- Metabolomics
- Limitations of SNPs
- Exome data – sufficient?
- Genome – belongs to the individual
- Genotype – where we usually are for care
- Storage, representation
- Care relevance
- CLIA, CAP, HIPAA

9/9/12

The Challenge

- The landscape of clinical, basic science, and translational research is **changing**
- How do we further enable an integrated network of information systems impacting translational research :
What is our needed Data Interoperability?
 - Why to do this?
 - How to do this?
 - One Size Fits All Approach?
 - Overwhelming amount of information being generated in Clinical, Basic, and Translational Research
 - Technology based Dependencies

9/9/12

Structural impediments

- Need to address a lot of fundamental issues in order to take advantage of new technology, whether biological, imaging, omics or social media and behavioral change in our patients
- Prevention will always be better, but not the way incentives are structured

9/9/12