Crossing Organizational Boundaries: Knowledge Management and Sharing to Advance Evidence Generating Medicine (EGM)

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Improving People's Lives
through innovations in personalized health care

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Overview

1. **Motivation**
   - Realizing the promise of “Big Data”
   - Moving beyond traditional organizational boundaries
2. **Critical Approaches and Technologies**
   - Knowledge management
   - Integrative informatics platforms
3. **Challenges and Opportunities**
   - Reducing the distanced between data and knowledge generation
   - Enabling a systems-level approach to EGM
4. **Discussion**

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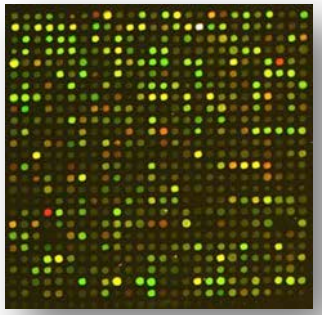
Many Sources of Data!

Emergent Sources
PHR, Instruments, Etc.

Enterprise Systems and Data Repositories:
EHR, CTMS, Data Warehouses



Molecular Phenotype

Environment

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Big Data + Computing = Improved Health?

- **"Sergey Brin's Search for a Parkinson's Cure"**
  - Wired Magazine, July 2010
- **Leveraging Google's Computational Expertise To Mine Big Data**
  - Distributed computing
  - Reasoning across heterogeneous data types
  - Exchanging traditional measures of result validity for the predictive power of increasingly large data sets

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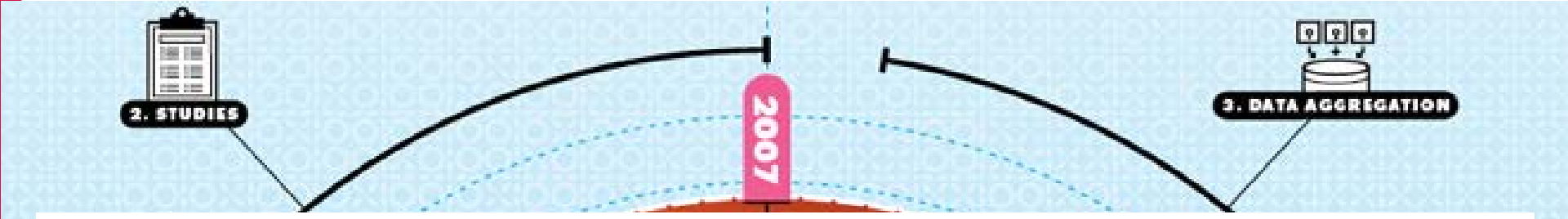
But Reasoning on Big Data Is Hard…

- **Unexpected problems**
  - Algorithms behave differently
  - Applicability of convention metrics
    - P-values don't mean allot peta-byte scale data sets
  - Signal vs. noise
    - Detection
    - Understanding of patterns
- **Physical computing**
  - Data storage
  - Computational performance



Traditional Model

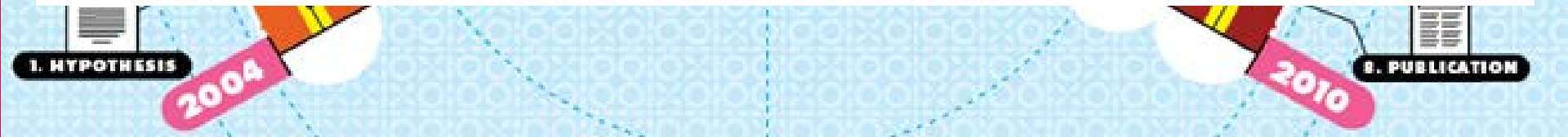
1. Hypothesis: An early study suggests that patients with Gaucher's disease (caused by a mutation to the GBA gene) might be at increased risk of Parkinson's.
2. Studies: Researchers conduct further studies, with varying statistical significance.
3. Data aggregation: Sixteen centers pool information on more than 5,500 Parkinson's patients.
4. Analysis: A statistician crunches the numbers.
5. Writing: A paper is drafted and approved by 64 authors.
6. Submission: The paper is submitted to *The New England Journal of Medicine*. Peer review ensues.
7. Acceptance: *NEJM* accepts the paper.
8. Publication: The paper notes that people with Parkinson's are 5.4 times more likely to carry the GBA mutation.

Total time elapsed: 6 years

Parkinson's Genetics initiative

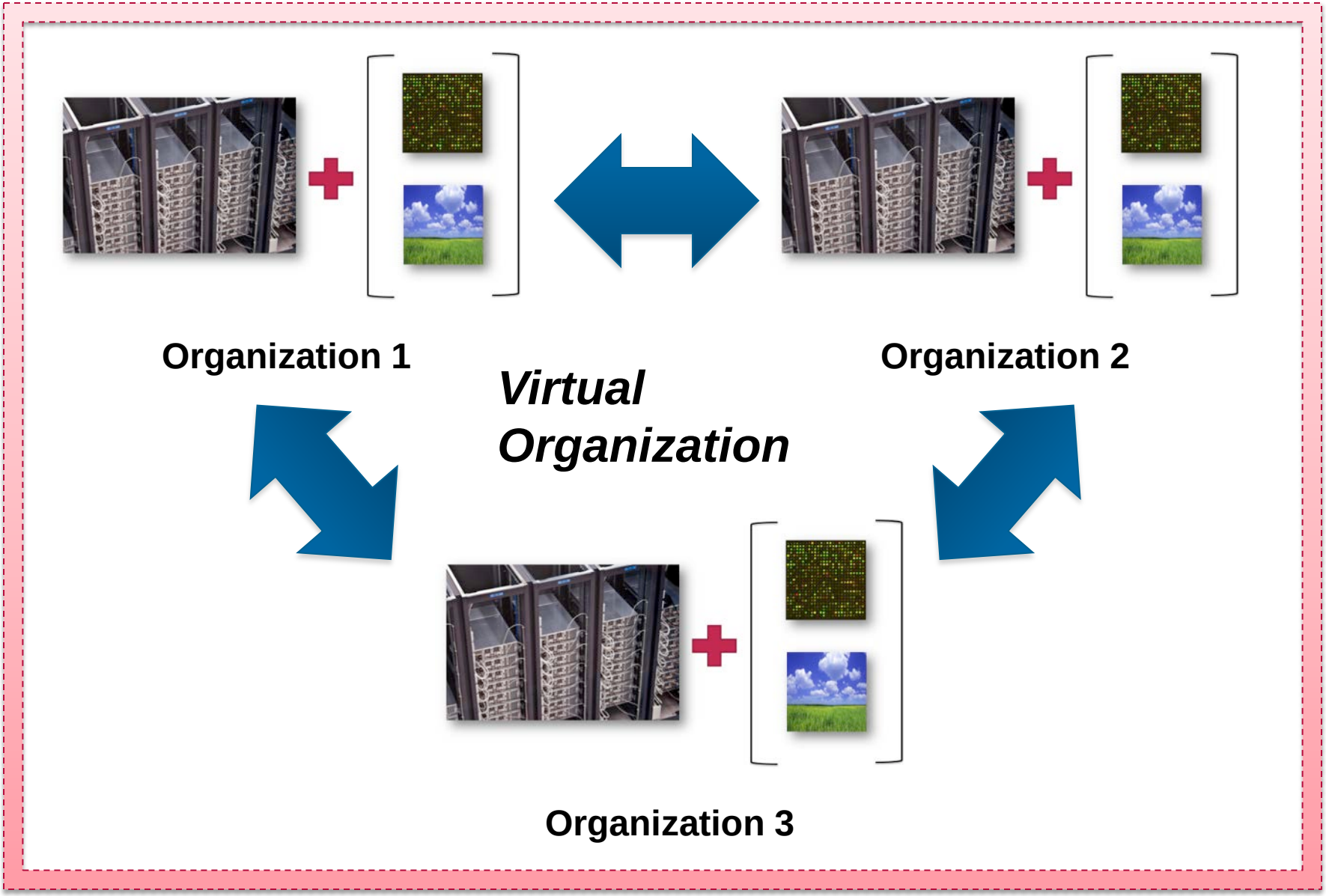
1. Tool Construction: Survey designers build the questionnaire that patients will use to report symptoms.
2. Recruitment: The community is announced, with a goal of recruiting 10,000 subjects with Parkinson's.
3. Data aggregation: Community members get their DNA analyzed. They also fill out surveys.
4. Analysis: Reacting to the *NEJM* paper, 23andMe researchers run a database query based on 3,200 subjects. The results are returned in 20 minutes.
5. Presentation: The results are reported at a Royal Society of Medicine meeting in London: People with GBA are 5 times more likely to have Parkinson's, which is squarely in line with the *NEJM* paper. The finding will possibly be published at a later date.

Total time elapsed: 8 months



Adapted From: "Sergey Brin's Search for a Parkinson's Cure", Wired (July, 2010)

Moving Beyond Organizational Boundaries



Benefits of Virtual Organizations

- **Larger patient populations**
  - Increased diversity
  - Ability to detect less common “signals”
- **Economies of scale**
  - Expertise
  - Resources
- **Extensibility of study outcomes**

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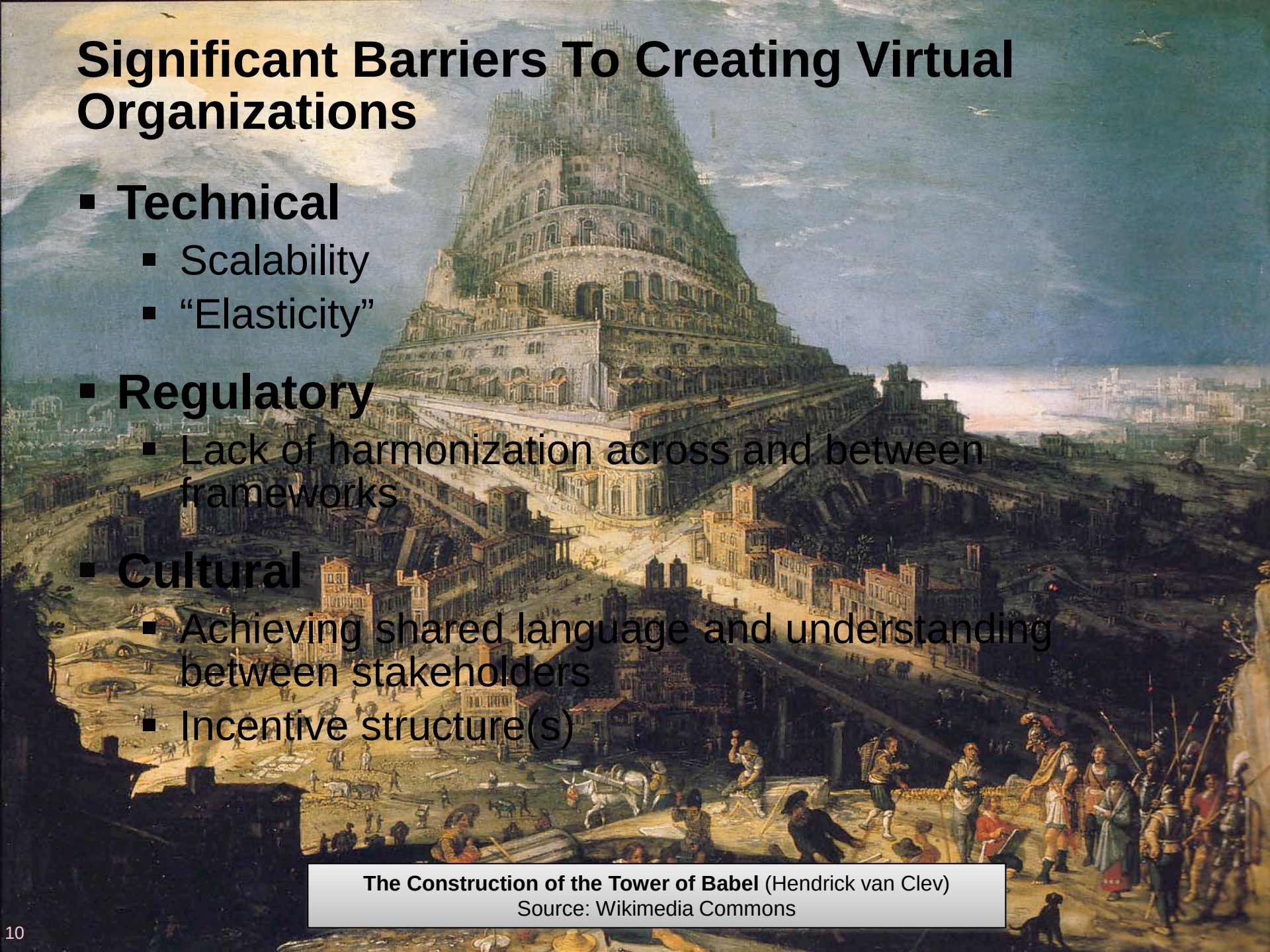
Significant Barriers To Creating Virtual Organizations

- **Technical**
  - Scalability
  - “Elasticity”
- **Regulatory**
  - Lack of harmonization across and between frameworks
- **Cultural**
  - Achieving shared language and understanding between stakeholders
  - Incentive structure(s)



The Construction of the Tower of Babel (Hendrick van Clev)
Source: Wikimedia Commons

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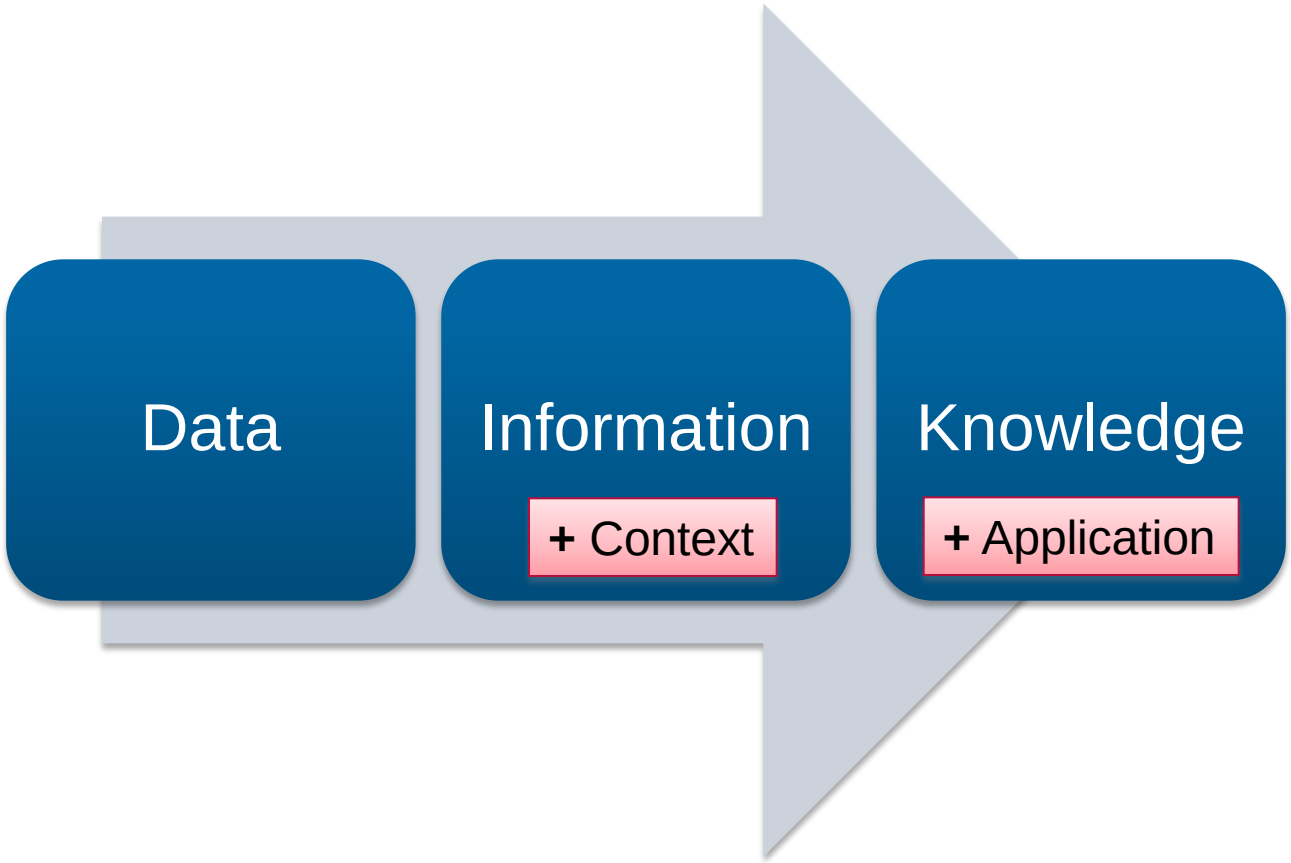
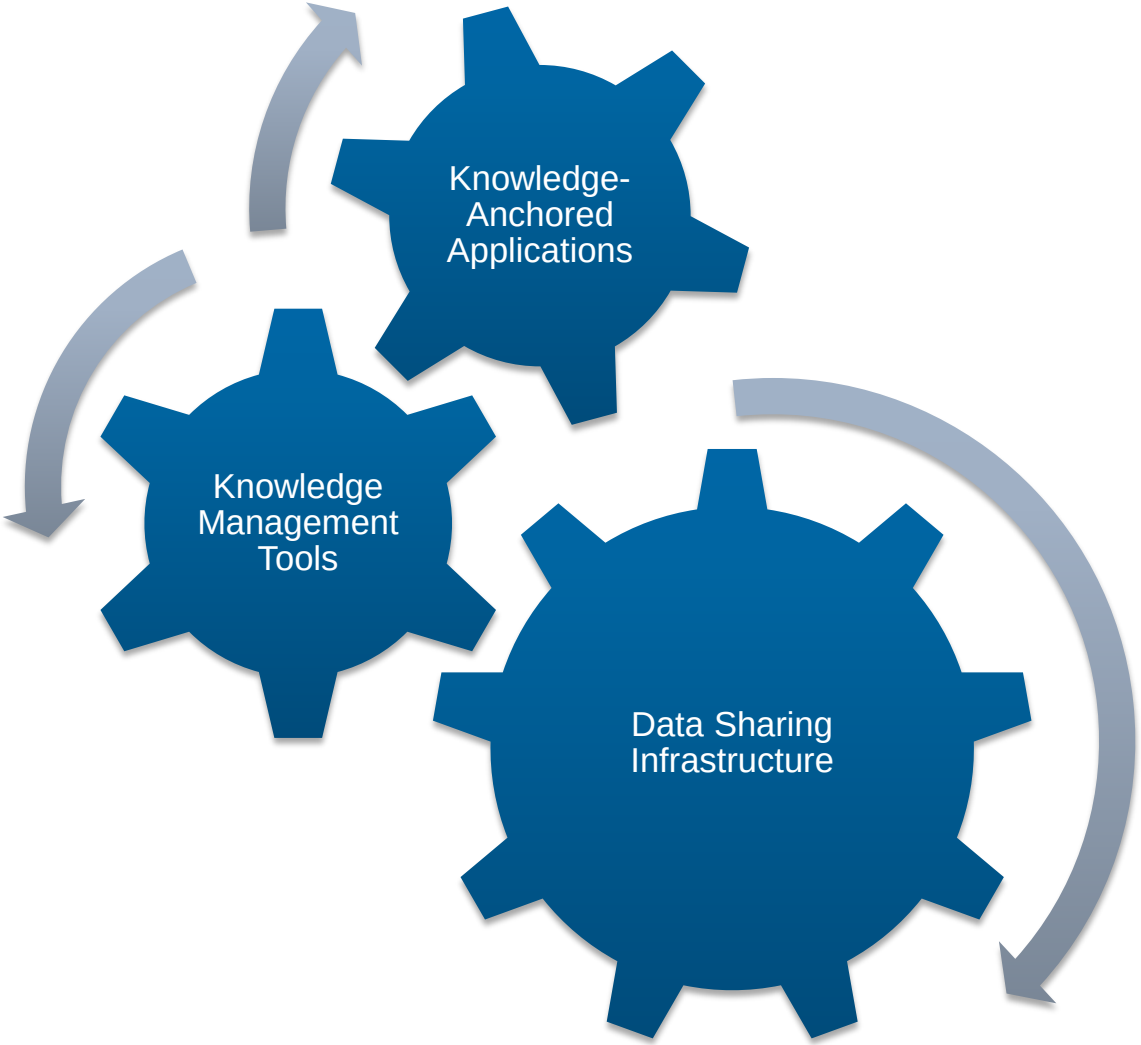
The Role of Biomedical Informatics and HIT: Generating Information and Knowledge



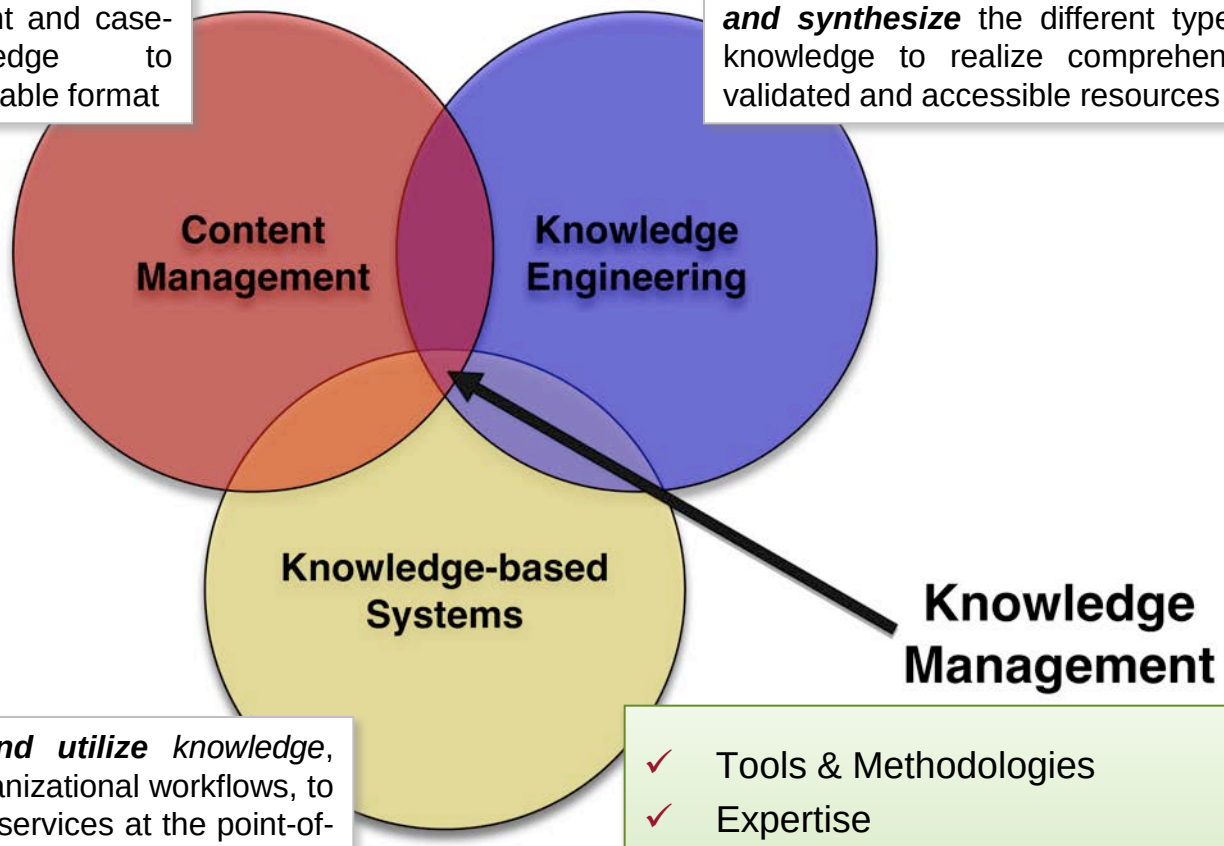
Core Platforms Supporting Virtual Organizations



Knowledge Management (KM):
A Core Competency

Access, share and disseminate current and case-specific knowledge to stakeholders in a usable format

Capture, represent, model, organize and synthesize the different types of knowledge to realize comprehensive, validated and accessible resources



Operationalize and utilize *knowledge*, within existent organizational workflows, to provide pragmatic services at the point-of-need (e.g., point-of-care decision support)

- ✓ Tools & Methodologies
- ✓ Expertise
- ✓ Focus on integration and dissemination of heterogeneous and multi-dimensional biomedical data sets

Abidi SSR. *Healthcare Knowledge Management: The Art of the Possible*. In: Knowledge Manage
Smaltz DH and RC Pinto. *Organizational Knowledge – Can You Really Manage It?* In: Proc HIM

Slide Source: Tara Payne, "*Knowledge Management for Research*"

The Importance of KM: Coping With Constant Evolution in Technology

1950-60's: Specialized computing facilities, programming languages, decision support, bibliographic databases, basic clinical documentation systems, first training programs

Today: Tele-health, mobile computing, widespread EHR adoption, service-oriented architectures, genomic and personalized medicine applications, translational research

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Examples of Knowledge Management Tools

- **Terminology and Ontology Services**
  - Common data elements (CDEs)
  - Metadata and model repositories
- **Content Management Systems**
  - Document Management and Version Control
  - Wikis
- **Knowledge-bases**
  - Operational
  - Scientific
- **Social media**
  - Crowdsourcing
  - “Folksonomies”

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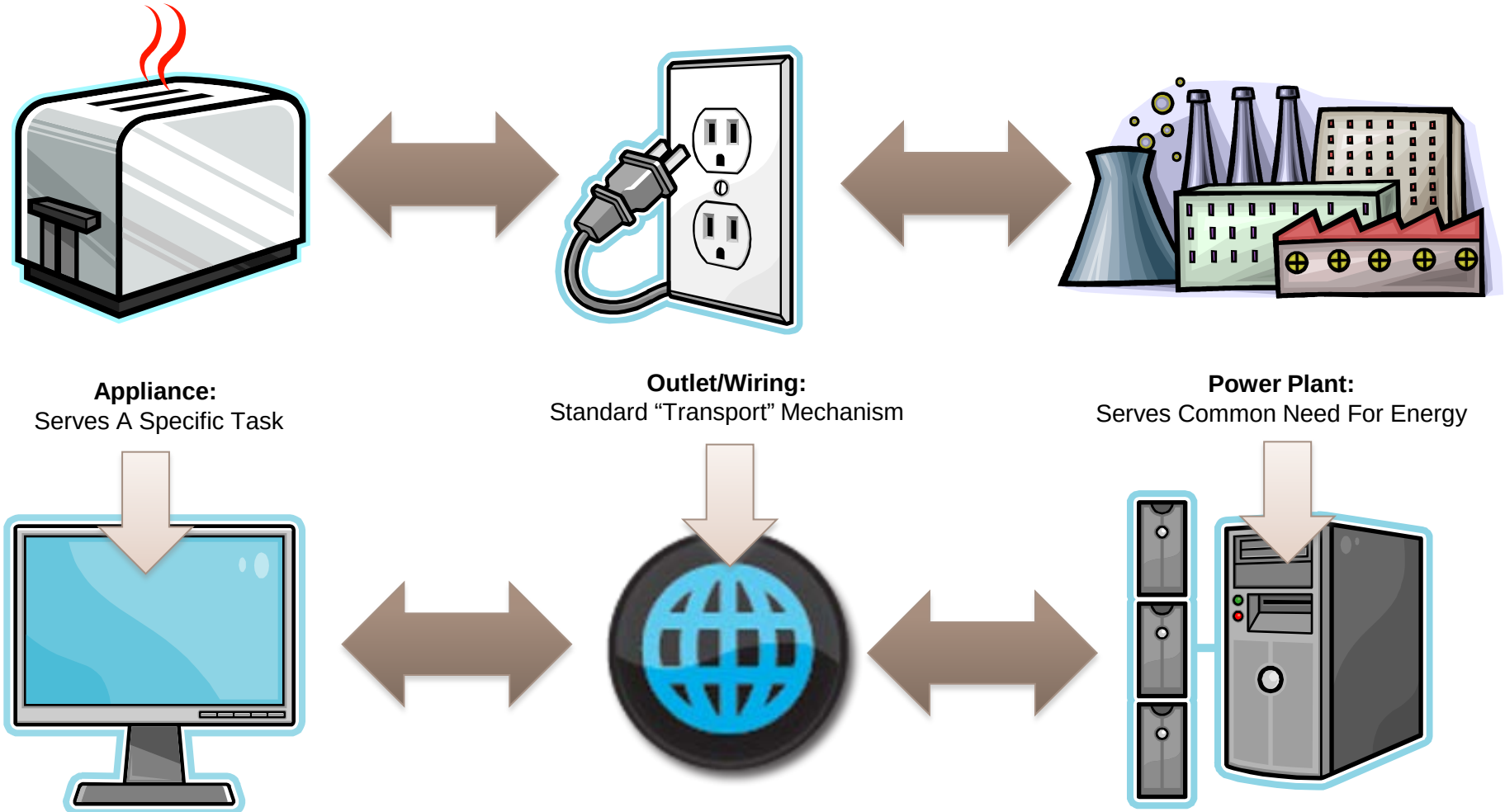
Bridging Organizational Boundaries: Service Oriented Architecture (SOA)



The Value Proposition for SOA-based Approaches to Data Federation

- **Reduced need to replicate data**
  - Data “lives” where it is initially generated or stored
  - Lowers infrastructure costs
- **Increased ability for data stewards to oversee access**
  - Fine-grained and policy-based access control
  - User-centered locus of control
- **“Elasticity”**
  - Ability to expand or contract resources based on current needs (e.g., plug and play)
- **Adaptability**
  - Platform-independent design allows for rapid evolution

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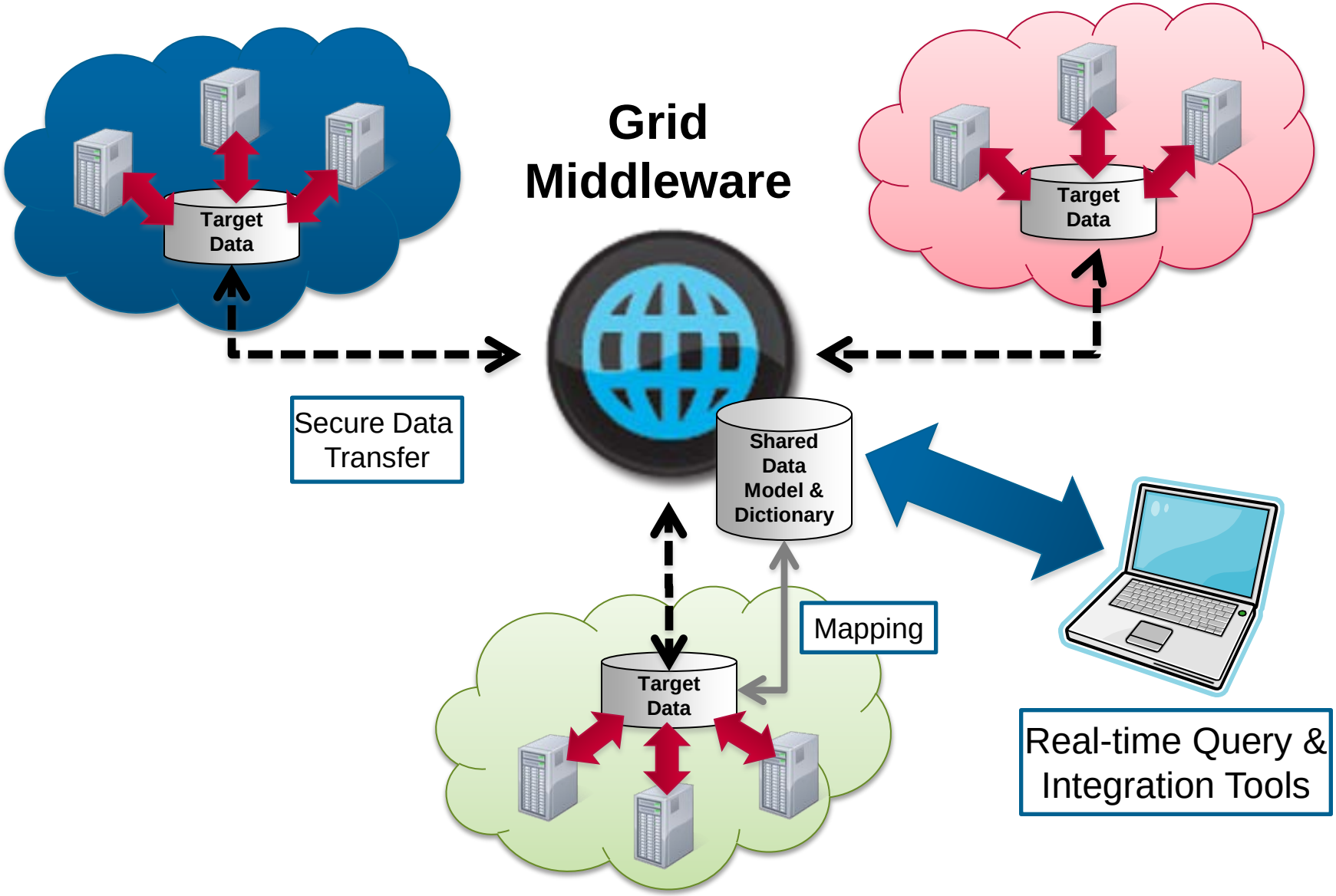
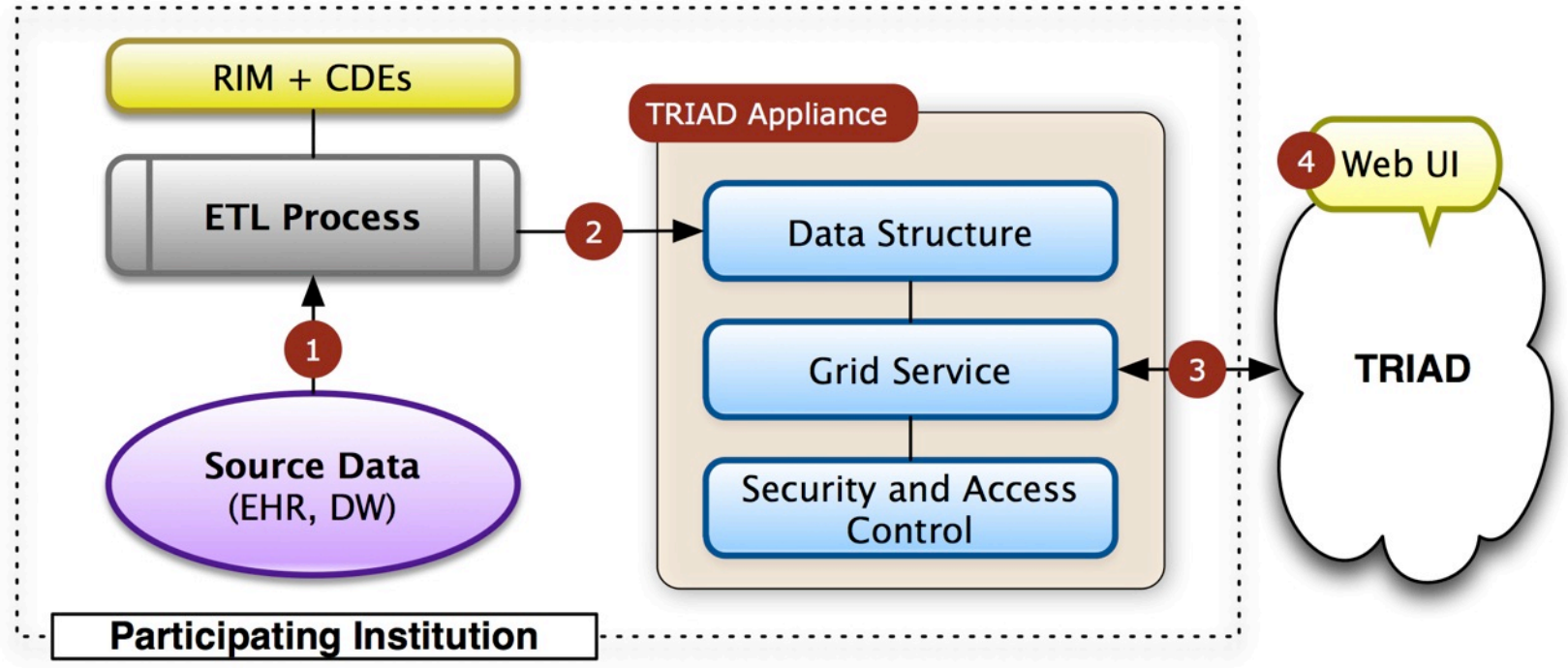
caGrid and TRIAD (Translational Research Informatics and Data Management Grid)

- ***caGrid and TRIAD are a generic and domain agnostic set of middleware and tools that enables service oriented science.***
  - Robust developer and adopter community
  - Developed and supported by the OSU Informatics Research and Development team
- caGrid and TRIAD aims to solve some of the basic challenges in research collaboration and data sharing across organizational boundaries

Use Case: Creating a Virtual Data Warehouse Using caGrid/TRIAD

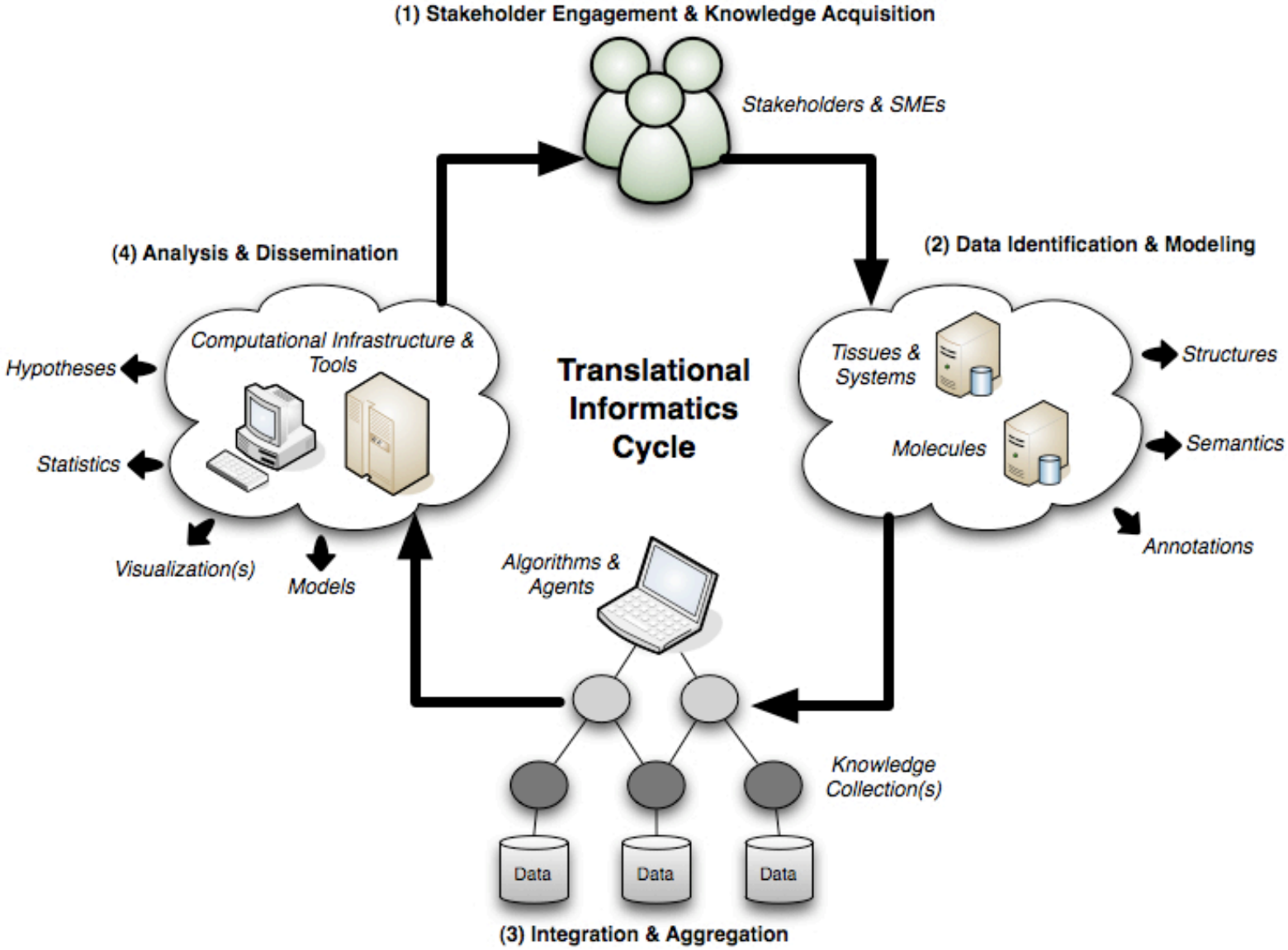


TRIAD Virtual "Appliance"



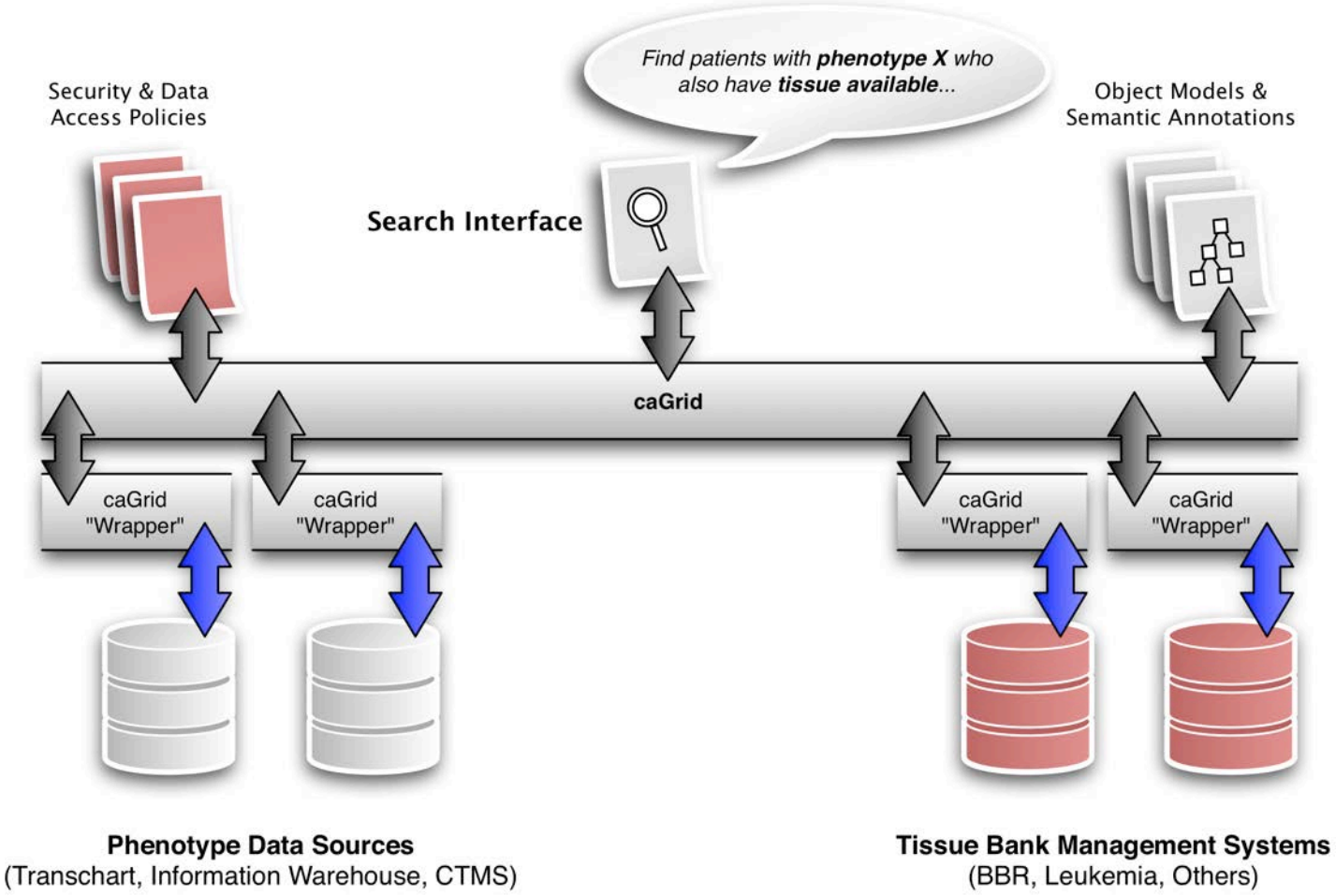
In this deployment model, a virtual server image containing the VA is installed at a participating site. Local source data that will be shared is subject to an Extract-Transform-Load (ETL) process (1) that is informed by a common reference information model (RIM) and common data elements (CDEs). Subsequently, conformant data is loaded into a data structure harmonized with the RIM (2) that is part of the VA, and securely exposed for discovery and distributed query purposes via TRIAD (3). End-users employ a simple, GWT-based user interface to construct and execute distributed queries spanning multiple VAs (4).

Designing Knowledge-Anchored Applications



Payne PR et al. *Translational informatics: enabling high-throughput research paradigms*. In: Physiol. Genomics 39: 131-140, 2009

Use Case: Distributed Cohort and Tissue Discovery



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CohortIQ Portal Interface

Diagnosis

Procedures

De-Identification

- History
- Results

Displaying 1 to 10 of 21 results. Export to Excel Export to XML

enterDateTime	outDateTime	postOperatingRoomDiagnosis	postOperatingRoomProcedure	preOperatingRoomDiagnosis	preOperatingRoomProcedure	scheduledOperatingRoomEnterDateTime	id
2008-05-31T07:19:00.000-04:00	2008-05-31T15:10:00.000-04:00	COLON CANCER	LAPAROSCOPIC SUBTOTAL COLECTOMY	COLON CANCER	LS VS OPEN HEMICOLECTOMY WITH ILEORECTAL ANASTAMOSIS	2008-05-31T07:30:00.000-04:00	AAF6p6AAKAAAM0kAAS
1899-12-10T00:00:00.000-05:00	1899-12-10T00:00:00.000-05:00			UNSTABLE ANGINA Iodine: N LHC CORS UA IPD IPD	LHC CORS UA IPD IPD	2009-01-20T09:00:00.000-05:00	AAF6p6AAKAAAM1HAAF
2008-10-19T13:16:00.000-04:00	2008-10-19T15:04:00.000-04:00	LARYNGEAL CANCER	LARYNGOSCOPY DIRECT OPERATIVE WITH BIOPSY;	LARYNGEAL CANCER	DLE WITH BX POSS SML WITH LASER EXCISION	2008-10-19T09:00:00.000-04:00	AAF6p6AAKAAAM4eAAH
2009-02-25T12:30:00.000-05:00	2009-02-25T20:46:00.000-05:00	NEUROGENIC BLADDER	ILEAL CONDUIT	NEUROGENTIC BLADDER	ROBOTIC CYSTECTOMY W/ILEAL CONDUIT URINARY DIVERSION	2009-02-25T10:00:00.000-05:00	AAF6p6AALAAAPmJAAB
1899-08-12T00:00:00.000-05:00	1899-08-12T00:00:00.000-05:00			MAL NEO BRONCH/LUNG NOS LUNG CANCER	AF BRONCH LEFT THOR LEFT UPPER LOBECTOMY RIB	2009-05-02T11:30:00.000-04:00	AAF6p6ABBAAANjHAAK
2008-11-22T11:58:00.000-05:00	2008-11-22T14:22:00.000-05:00	GOITER	TOTAL THYROIDECTOMY	GOITER	THYROIDECTOMY	2008-11-22T11:15:00.000-05:00	AAF6p6ABBAAANj2AAS
1899-12-10T00:00:00.000-05:00	1899-12-10T00:00:00.000-05:00			ANGINA PT SEEN IN ER9.14 Io OPD OUTPATIENT DIAGNOSTIC	ANGINA PT SEEN IN ER9.14 Io OPD OUTPATIENT DIAGNOSTIC	2009-08-24T06:00:00.000-04:00	AAF6p6ABBAAANqHAAD
2009-06-18T09:12:00.000-04:00	2009-06-18T11:53:00.000-04:00	PROSTATE CANCER	LAPAROSCOPY SURGICAL PROSTATECTOMY RETROPUBIC RADICAL INC	PROSTATE CANCER	ROBOTIC PROSTATECTOMY WITH BPLND	2009-06-18T09:00:00.000-04:00	AAF6p6ABCAAAYLNAAR
2002-08-16T07:05:00.000-04:00	2002-08-16T11:45:00.000-04:00	RECURRANT PERTIONEAL CA	EXP LAP PELVIC DISSECTION STENT PLACEMENT	OVARIAN CA	EXPL LAP REMOVAL OF PELVIC MASS	2002-08-16T07:00:00.000-04:00	AAF6p6ADTAAAADJAAW
2006-06-21T08:49:00.000-04:00	2006-06-21T09:53:00.000-04:00			BURN OF LEFT HAND	DEBRIDEMENT STSG OF LEFT HAND	2006-06-21T08:00:00.000-04:00	AAF6p6ADTAAADSVAAZ

Tissue Availability Filter

Cohort Discovery Tool

Specimen Available: True

Sex Genotype: UNKNOWN

Submit Query

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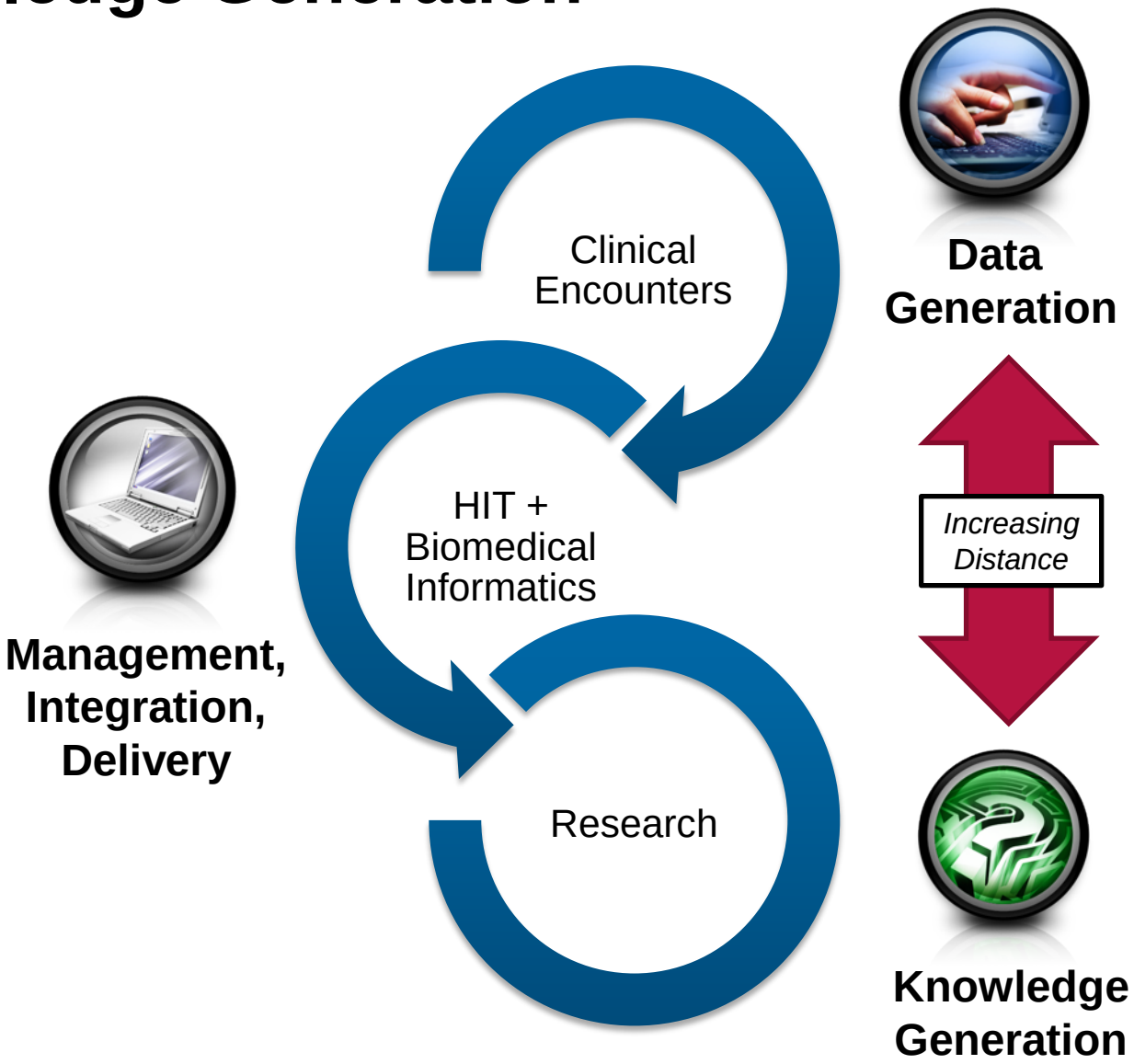
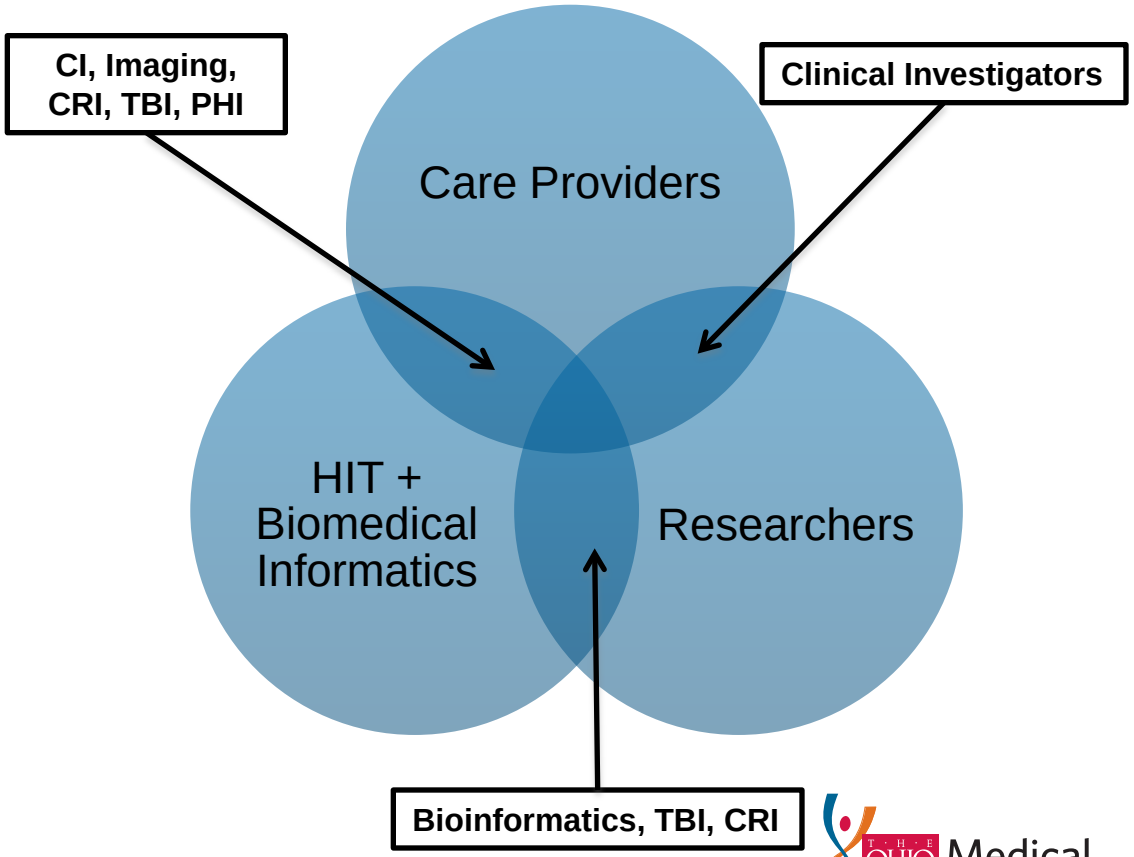
Increasing Distances Between Data and Knowledge Generation



Contributing Factors (1)

Regulatory, Technical, and Cultural Barriers Between Data and Knowledge Generation

- High performance systems require rapid adaptation
- Increasing demand for better, faster, safer, more cost effective therapies
- Simultaneous demand for increased controls over secondary use of clinical data
- Artificial partitioning of access to data for knowledge generation purposes
- **Critical overlaps and potential sources of conflict between these factors**



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Contributing Factors (2)

- **Historical precedence for reductionism in the biomedical and life sciences**
  - Break-down problems into fundamental units
  - Study units and generate knowledge
  - Reassemble knowledge into systems-level models
- **Influences policy, education, research, and practice**
- **Recent scientific paradigms have illustrated major problems with this type of approach**
  - Systems biology/medicine
- **Reductionist approach to data, information, and knowledge management is still prevalent**
  - HIT vs. Informatics
  - Informatics sub-disciplines

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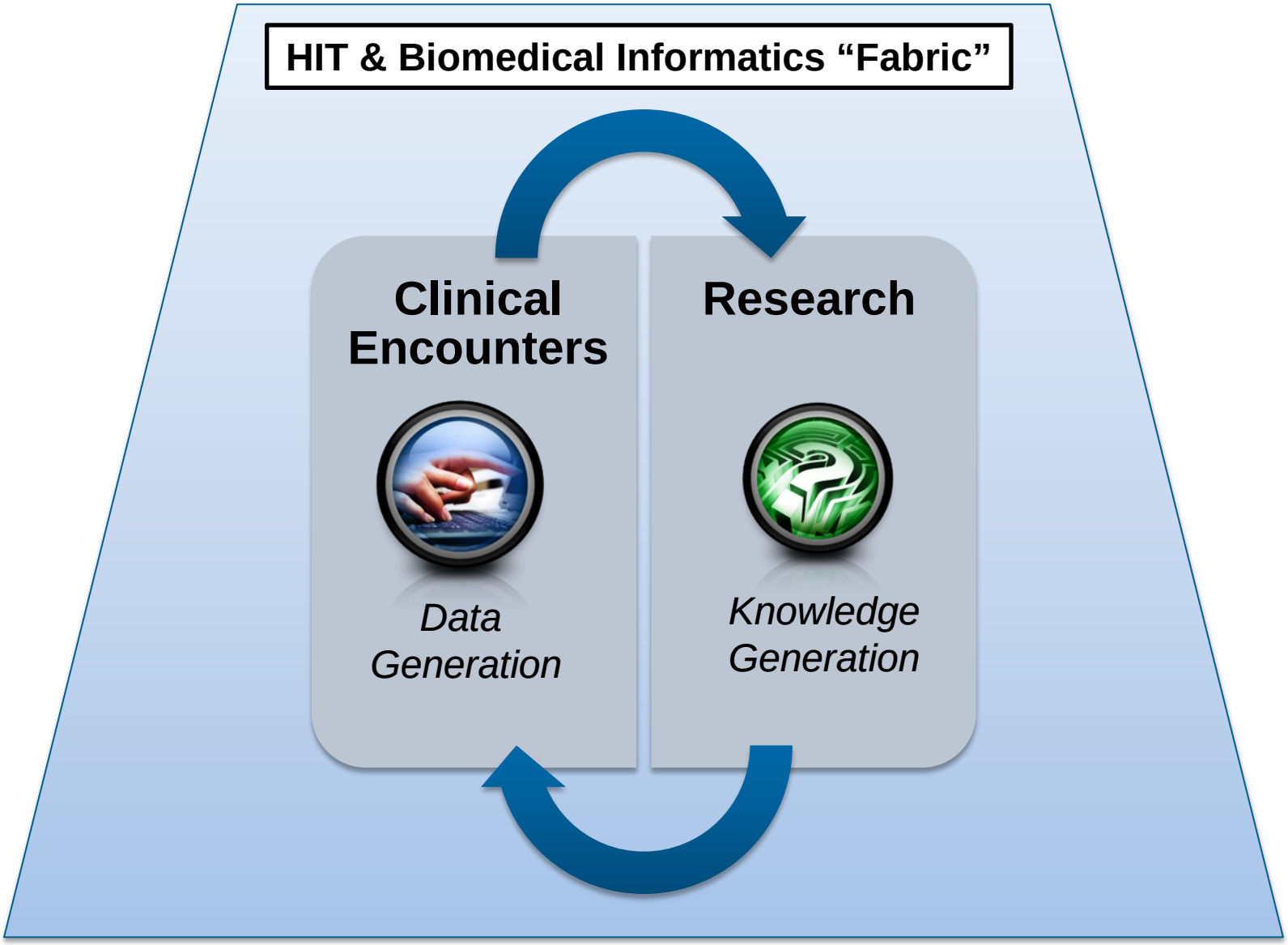
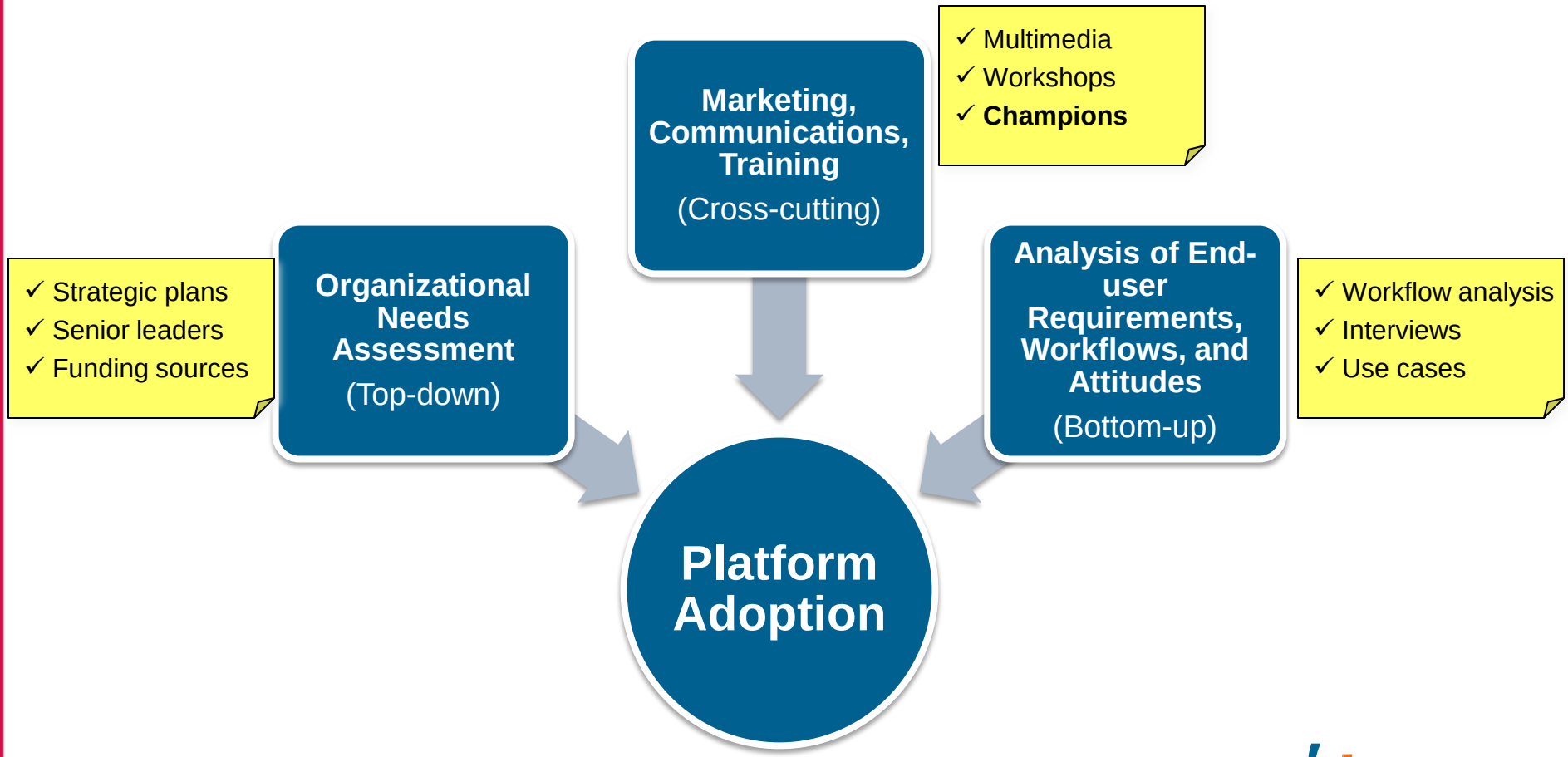
Towards a Solution: A Systems Approach to Biomedicine



Overcoming Barriers: Socio-technical Approaches to Enabling Platform Adoption



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Realizing The Promise of BMI and HIT Requires Us To Build Robust and Innovative Infrastructures

Thank you for your time and attention!

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