AMIA
2011 Summit in CRI
CRI Year-In-Review

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The Ohio State University Medical Center

Design for this Session

- Borrowed from Dan Masys and Russ Altman's approaches
  - Started with structured approach (akin to ACP "update" sessions)
  - Quickly moved to augment with "what seemed interesting" approach
- I'm going to **briefly** touch on some key, representative articles

Source of Content for Session

- Literature review:
  - Initial search by MESH terms:
    - ("Biomedical Research"[Mesh] NOT "Genetic Research"[Mesh]) NOT "Translational Research"[Mesh]) AND "Informatics"[Mesh] AND "2009/01/10"[PDat] : "2011/03/09"[Pdat]
    - Resulted in 87 articles; 35 were CRI relevant
  - Additional 51 articles through:
    - Recommendations from selected colleagues
    - Other keyword searches using terms like:
      - Clinical Trials, Clinical Research, Informatics, Translational, Data Warehouse
  - Result = 87 total CRI relevant
  - From those, ~22 will be presented

Thanks to:

- Philip Payne
- Michael Kahn
- Bill Hersh
- Paul Harris
- Shawn Murphy
- Michael Matheny
- Rachel Richesson
- Ida Sim

- *Dan Masys*
- *Russ Altman*

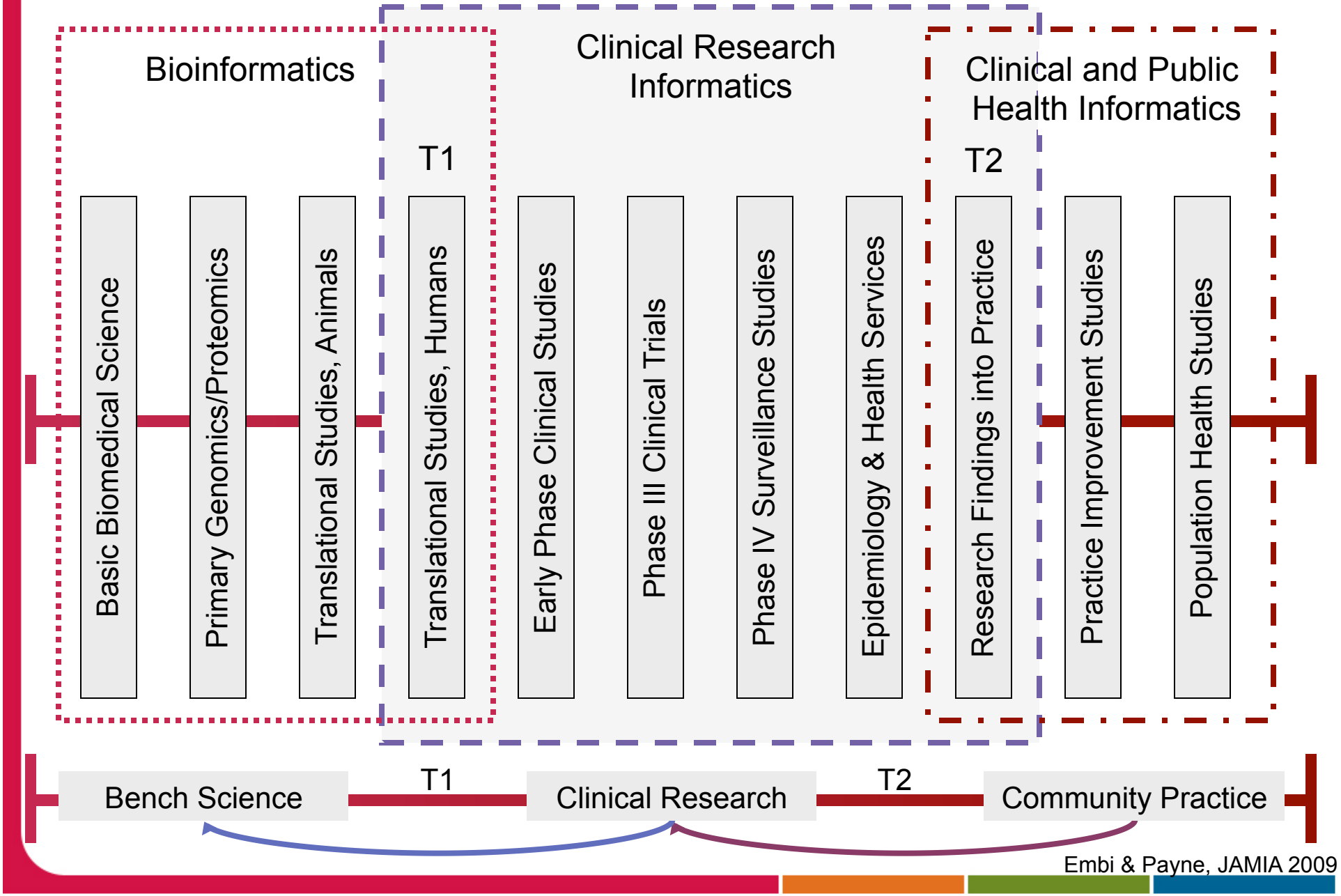
Session caveats

- What this is not…
  - A systematic review of the literature
  - An exhaustive overview
- What this is:
  - My best attempt at *briefly* covering *some* of the representative CRI literature from the past 1-2 years (since this is 1st time)
- This presentation and bibliography will be made available on the conference website and my Website <www.embi.net>

Apologies up front

- I’m CERTAIN I’ve missed a lot of great work
- I’m VERY SORRY about that

Clinical and Translational Research & Informatics: T1, T2, and Areas of Overlap for Informatics



Embi & Payne, JAMIA 2009

Topics

- From queue of 87 papers that seemed to fit the bill
- I selected 22+ representative papers that I'll present here (*briefly*)

- Touch on several CRI categories (but, not *all* CRI areas of work)
  - Data Warehousing and Knowledge Discovery
  - Researcher Support & Resources
  - Participant Recruitment
  - Drug & Device Surveillance
  - Patients/Consumers & Research Informatics
  - Policy & Vision pieces

Data Warehousing & Knowledge Discovery

"Serving the enterprise and beyond with informatics for integrating biology and the bedside (i2b2)" (Murphy et al, JAMIA, 2010)

- **Goal:** Provide tools to integrate medical record and genomic-age research data.
- **Methods:** NIH-supported NCBC created i2b2 software for cohort finding and query. Also enables easy data-mart creation.
- **Results:** Implemented at Harvard Partners, and exported to ~17 centers nationally, so far. Query capability across instances under development.
- **Conclusion:** i2b2 is becoming a valued and widespread resource for clinical and translational science.

Model formulation

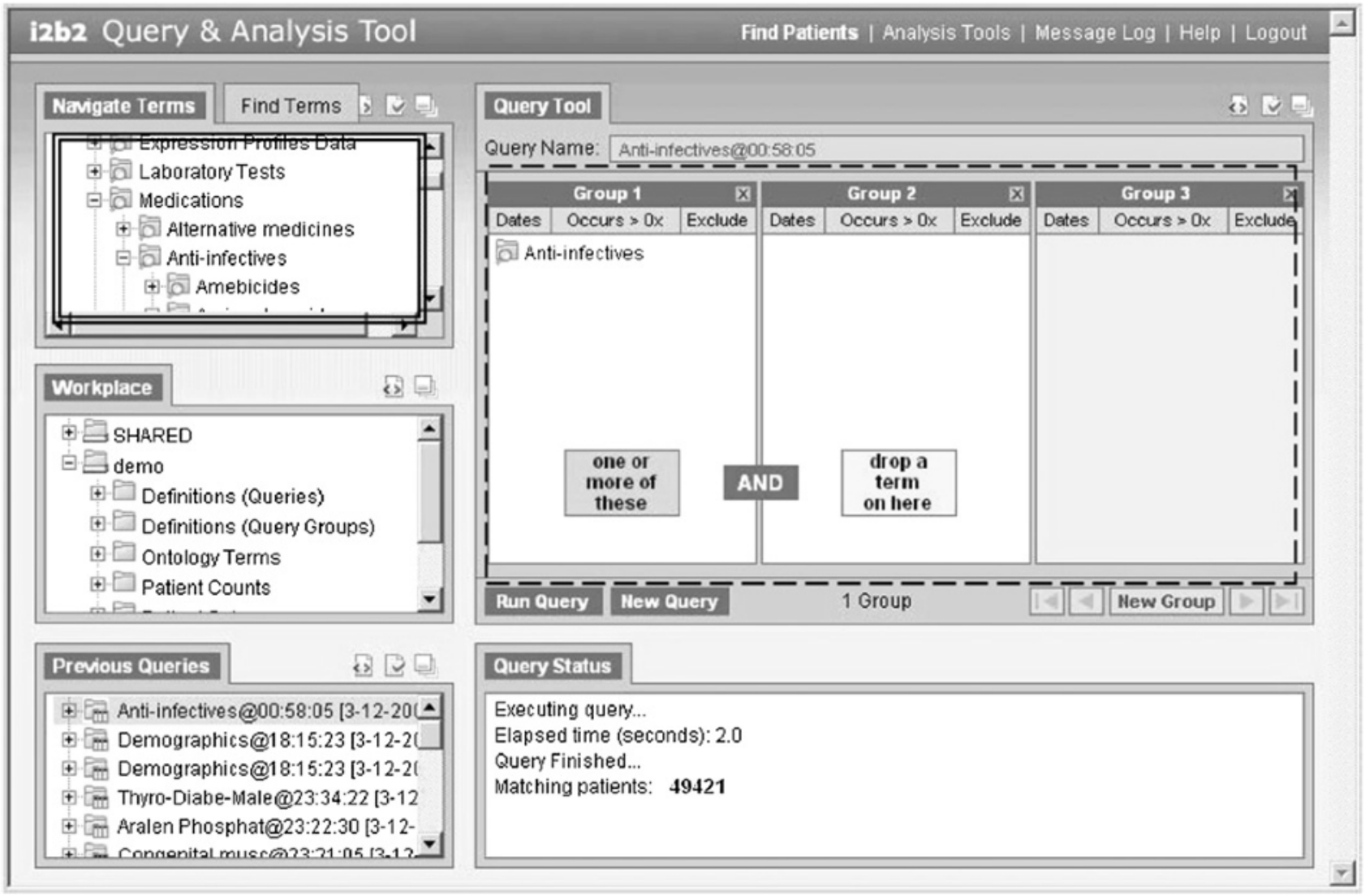


Figure 1 The i2b2 web client is used as the interface for the enterprise users to construct queries. Patient attributes are dragged from the "Terms" panels into the "Query Tool" panels, and the patient sets that result after running the query which can be accessed and reused from the "Previous Queries" panels.

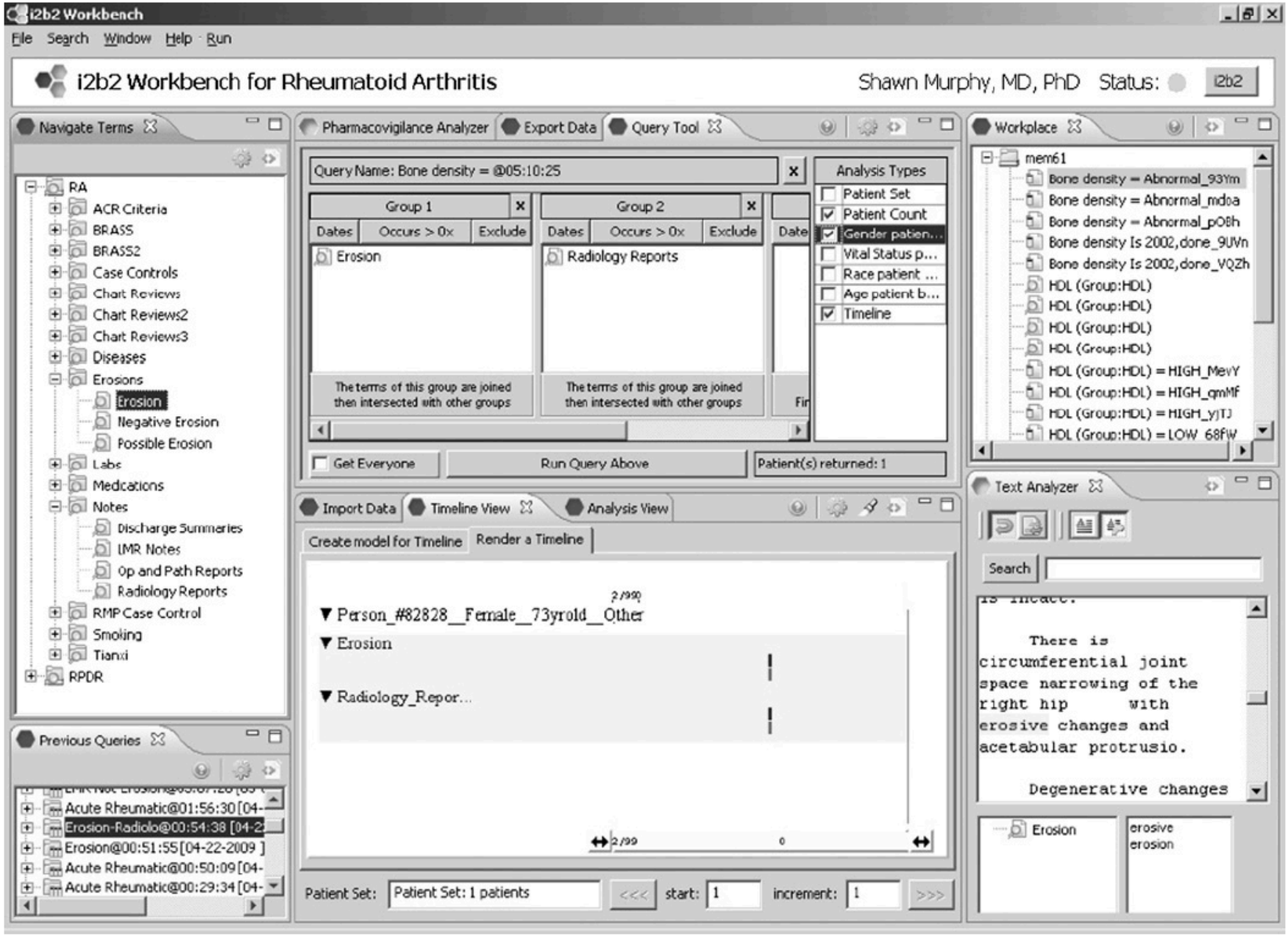


Figure 3 The i2b2 Eclipse Workbench is generally used as the interface for working with specific project databases. It offers views for exporting and importing data to the project database, as well as views focused on specialized analysis. The i2b2 software architecture is built with multiple "plug-in" points. The i2b2 web client, the Java i2b2 Workbench, and the (server-side) data repository cell all have open architectures for additional software plug-in functionality.

“The human studies database project: federating human studies design data using the ontology of clinical research”
(Sim I, et al. AMIA Summits Transl Sci Proc, 2010)

- **Goal:** To make machine-readable the design and results of interventional and observational studies for large-scale data mining, synthesis, and re-analysis.
- **Methods:** Define and implement an informatics infrastructure for institutions to share the design of their human studies.
- **Results:** Developed the Ontology of Clinical Research (OCRe) to model study features such as design type, interventions, and outcomes to support scientific query and analysis. Using OCRe as the reference semantics for federated data sharing of human studies over caGrid, and are piloting data exchange across several Clinical and Translational Science Award (CTSA) institutions.

“The human studies database project: federating human studies design data using the ontology of clinical research”
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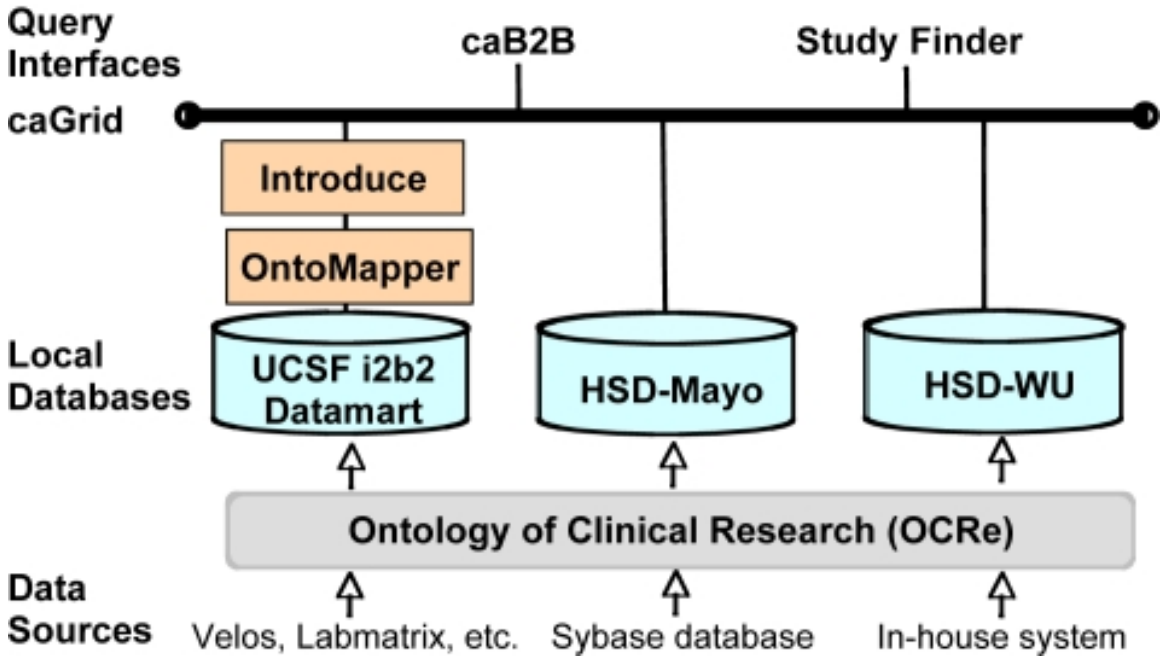


- Figure 1: The HSDBgrid architecture for federating human studies databases.

“The human studies database project: federating human studies design data using the ontology of clinical research”
(Sim I, et al. AMIA Summits Transl Sci Proc, 2010)

- **Conclusion:** Leveraging caGRID resources, i2b2 and other technologies, to enable access to research study information across institutions. Great potential to advance knowledge, and improve research design and administration.

"caTIES: a grid based system for coding and retrieval of surgical pathology reports and tissue specimens in support of translational research"
(Crowley et al., JAMIA, 2010)

- **Goal:** Report on the development of the Cancer Tissue information Extraction System (caTIES).
- **Methods:** Description of the application
- **Results:** caTIES leverages existing NLP methods, caGrid computing and security frameworks, and query visualization methods to addresses three critical issues for informatics support of clinical and translational research: (1) federation of research data sources derived from clinical systems; (2) expressive graphical interfaces for concept-based text mining; and (3) regulatory and security model for supporting multi- center collaborative research.
- **Conclusion/Importance:** Implemented at several Cancer Centers across the country to enable a potential network of caTIES repositories that could provide millions of de-identified clinical reports to users.
- A good example of integration of informatics systems and approaches to address important research need.

“R Engine Cell: integrating R into the i2b2 software infrastructure”
(Daniele Segagni,... Riccardo Bellazzi, et al. JAMIA 2011)

- **Goal:** Create new “cell” (R Engine) within i2b2 to facilitate easy access to R-statistical software for calculation of Kaplan Meier survival analyses by cardiology researchers.
- **Methods:** Develop new i2b2 “cell” (software module) that connects data from i2b2 to R statistical software and gives investigators easy Web-based interface to select patient set on which to perform pre-set analyses and display results in graphical form.
- **Results:** Cell was created and functioned as intended. The i2b2 instance it’s connected to contains vast database of 5369 cardiology patients. Started with Kaplan Meier analyses, but extensible to other R-package based analyses. Already being used by investigators.
- **Conclusion/Importance:** Components like this make the work of the investigator even easier, enabling more efficient research conduct.

Figure of the “R Engine” cell

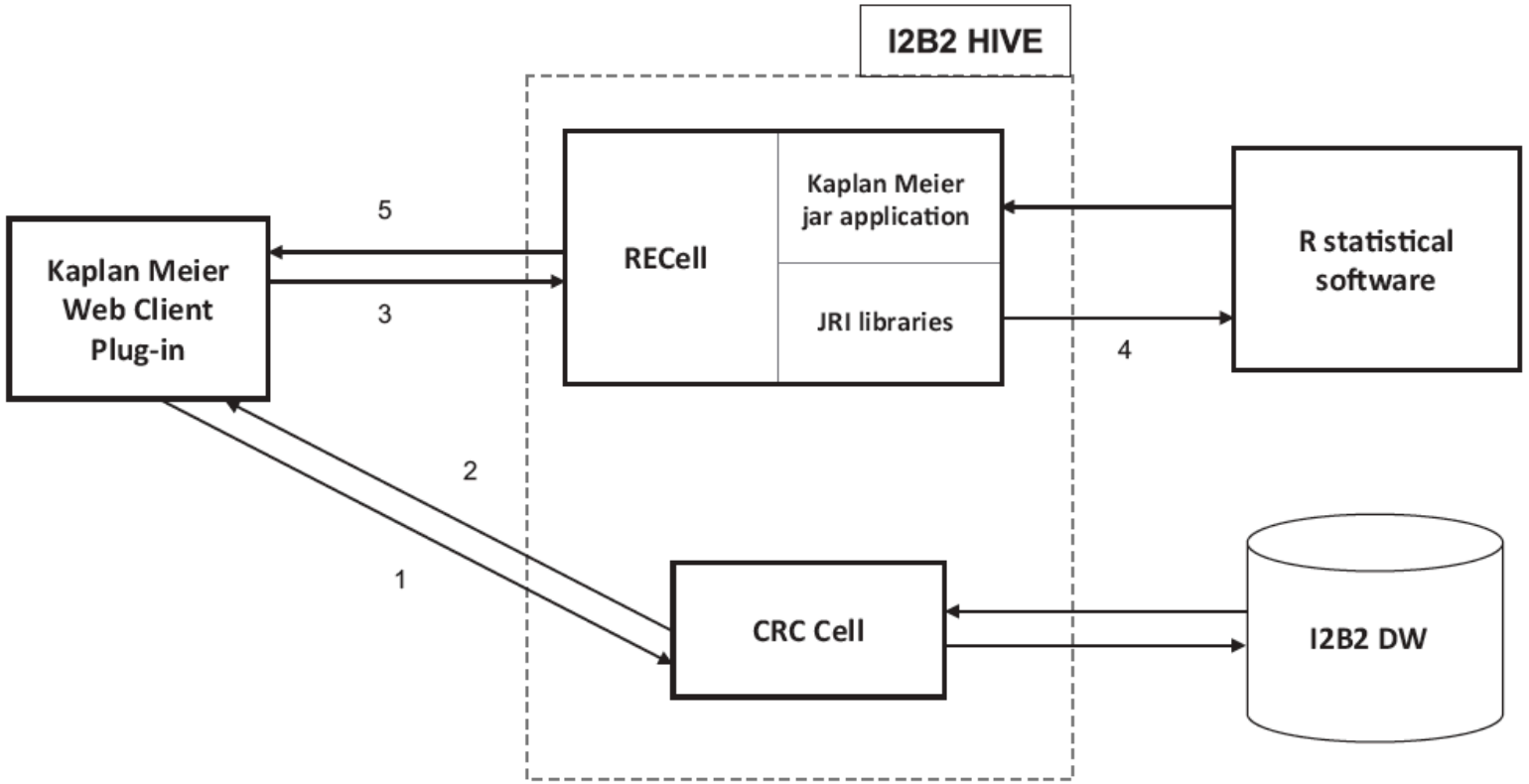
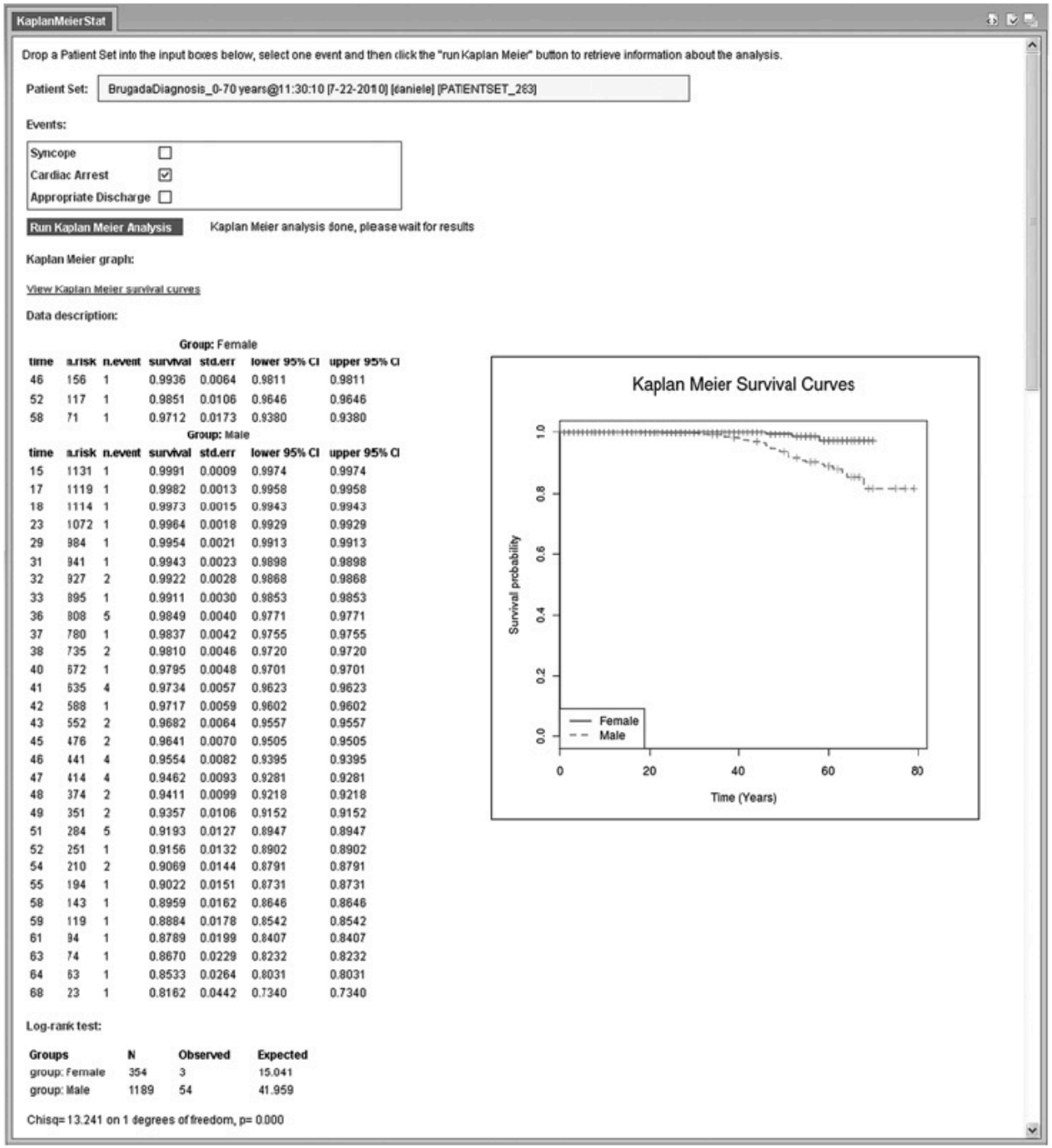


Figure 2 Screenshot of the plug-in results of a survival analysis for the event 'cardiac arrest.' The analysis was performed on 1548 patients with Brugada syndrome aged less than 70 years (354 females, 1189 males). The event occurred for three female and 54 male patients, giving rise to significantly different survival curves. The survival plot produced by the plug-in has been superimposed onto the screenshot.



“R Engine Cell: integrating R into the i2b2 software infrastructure”
(Daniele Segagni,... Riccardo Bellazzi, et al. JAMIA 2011)

- **Conclusion/Importance:** Integration of components like this will make the work of the investigator even easier, enabling more efficient research conduct.

Data Warehousing & Knowledge Discovery

- Many more projects and applications worth of mention, a few include:
  - “The TRITON Project: Design and Implementation of an Integrative Translational Research Information Management Platform” Payne et al. AMIA Ann Symp 2010
  - “Ontology Mapping and Data Discovery for the Translational Investigator” Wynden et al. AMIA 2010 CRI Summit
  - “Integrating existing natural language processing tools for medication extraction from discharge summaries” Doan, et al. JAMIA 2010
  - “Effective knowledge management in translational medicine” Szalma et al. Journal of Translational Medicine, 2010
  - “The Shared Health Research Information Network (SHRINE): a prototype federated query tool for clinical data repositories” Weber et al. JAMIA 2009
  - “Robust replication of genotype-phenotype associations across multiple diseases in an electronic medical record” Ritchie et al. Am Journ Human Genetics, 2010

Data Warehousing & Knowledge Discovery

- Significant forward progress in this domain
- Expect remarkable things for next year…

Researcher Support & Resources

"StarBRITE: The Vanderbilt University Biomedical Research Integration, Translation and Education portal"
(Harris et al. JBI, 2011)

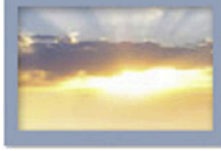
- **Goal:** Create one-stop, Web-based research portal to meet day-to-day needs of institutional researcher community.
- **Methods:** Home-grown content management system enabling easy maintenance and growth of component parts. Design informed by assessment of investigator needs.
- **Results:** Single, integrated portal for investigator needs from institutional clinical/translational science center. Also serves administrative needs of center.
- **Conclusion/Importance:** A good example of kinds of portals now being implemented across the nation. Potential to streamline, change the way institutions "care for" and "monitor" investigators and the research enterprise.

Vanderbilt StarBRITE

Search VUMC ask & know

My Research | Governance Dashboard | My Profile | Quick Links | Research on Practice and Policy | Contact Us | Logout

StarBRITE Home | Research Planning and Implementation | Participant Recruitment | Funding Support | Data Management | Educational Resources | BioVU & Synthetic Derivative







Welcome to StarBRITE: The Biomedical Research Integration, Translation and Education portal.

What is StarBRITE?

StarBRITE is an interactive system that provides one stop shopping for research needs. Use StarBRITE to identify resources, find experts, access templates for research preparation and study conduct, obtain database development software, learn about educational requirements and opportunities, and receive help with research application and approval processes. View the Town Hall Meeting presentation (10/23/2007) 25MB

Click on the interactive diagram on the left for help navigating StarBRITE.

What is VICTR?

VICTR is Vanderbilt's virtual home for clinical and translational research. The mission of the institute is to transform the way ideas and research discoveries make their way from origin to patient care. Visit the VICTR Public Website to Learn More About VICTR and the CTSA

VICTR Supported Clinics

Below is a list of regularly scheduled clinics available to assist you with various resources:

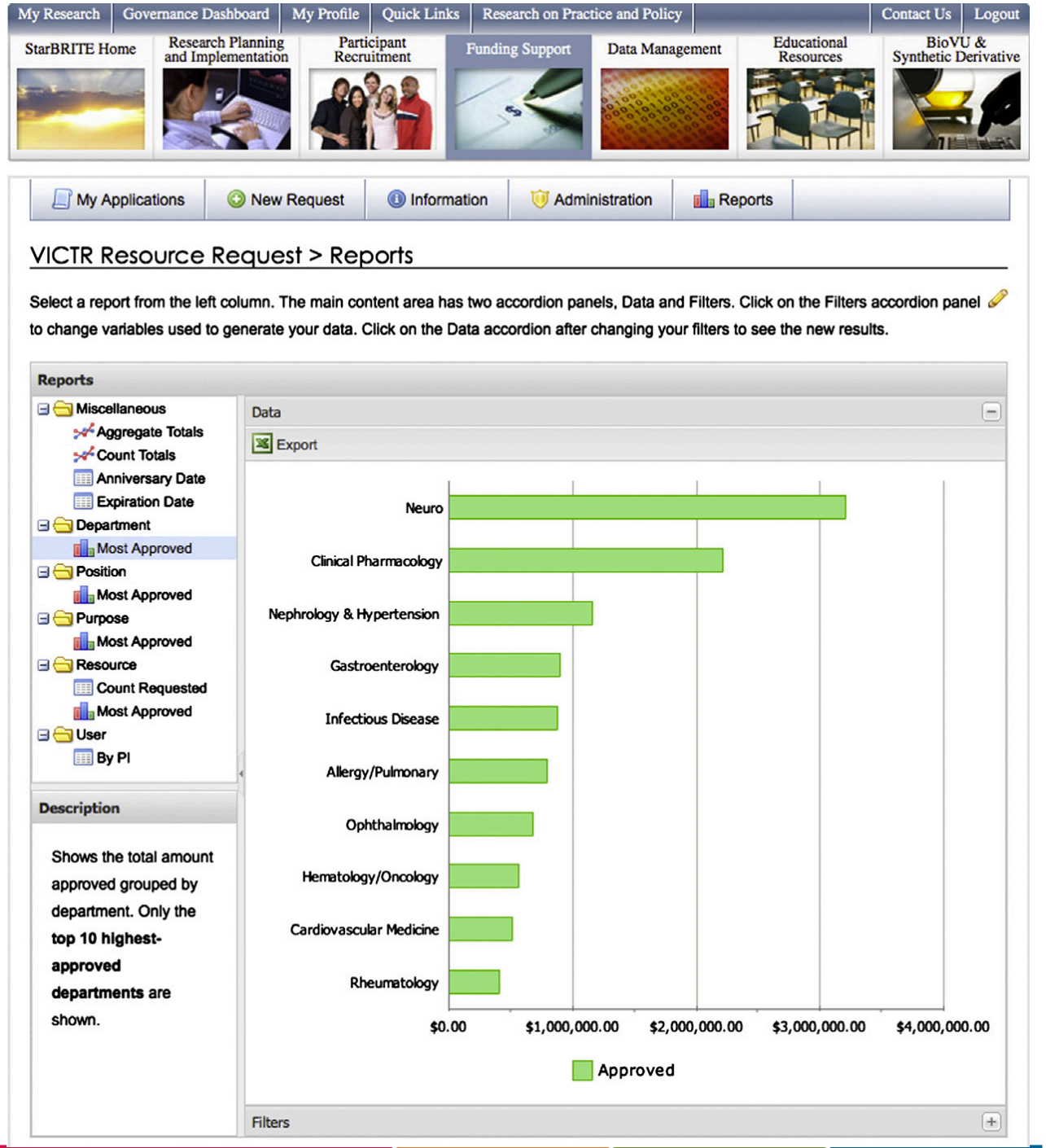
VICTR Funding Clinics: Weekly (Mondays), 10-11am, A-3210 MCN (CRC Conference Room); No registration necessary

REDCap Clinics:
REDCap 101: Weekly (Thursdays), A-3210 MCN (CRC Conference Room); Contact Veida Elliott for current session times available
REDCap 201: Bimonthly (2nd and 4th Tuesdays), 2-4pm, D-2212 MCN; require an understanding of REDCap basics; No registration necessary

BioVU Office Hours: Weekly (Tuesdays), 2-3pm by appointment, A-3210 MCN (CRC Conference Room)

Biostats Clinics: Daily, 12-1:15pm, MCN - see schedule for specific details; No registration necessary

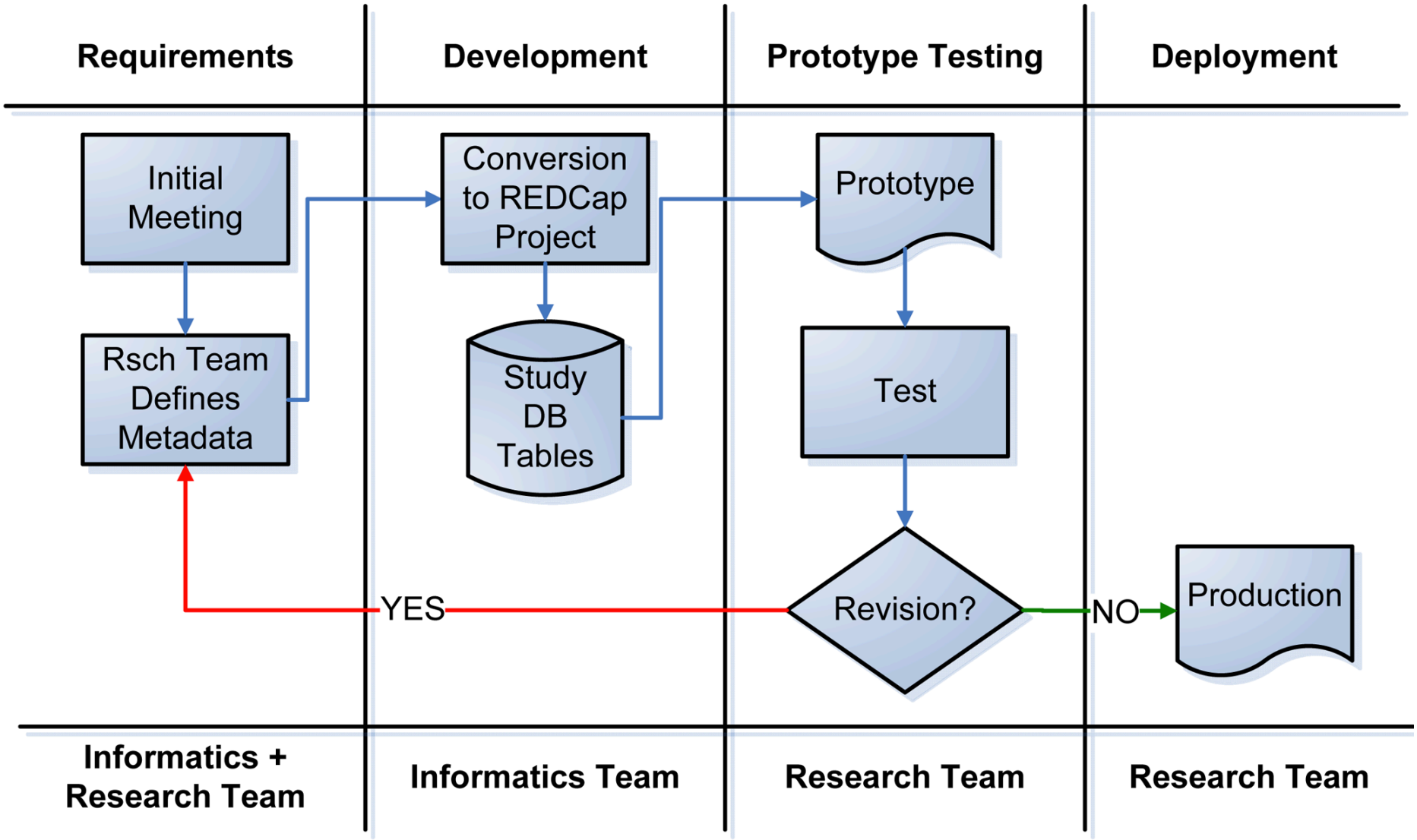
“StarBRITE” Administrative portal



“Research Electronic Data Capture (REDCap) - A metadata-driven methodology and workflow process for providing translational research informatics support”
(Harris et al. JBI 2009)

- **Goal:** Easy to manage and use electronic data capture solution for most investigator’s needs
- **Methods:** PHP+Javascript programming, MySQL database. Designed to meet key goals by meta-data driven set-up. Main goal being serve common research project needs without need for customization.
- **Results:** Used by over 213 partner sites, over 9200 studies, over 18,000 end-users. Recently added “REDCap Survey” as well as 21 CFR Part 11 compliance, and more on the way.

REDCap project initiation workflow:



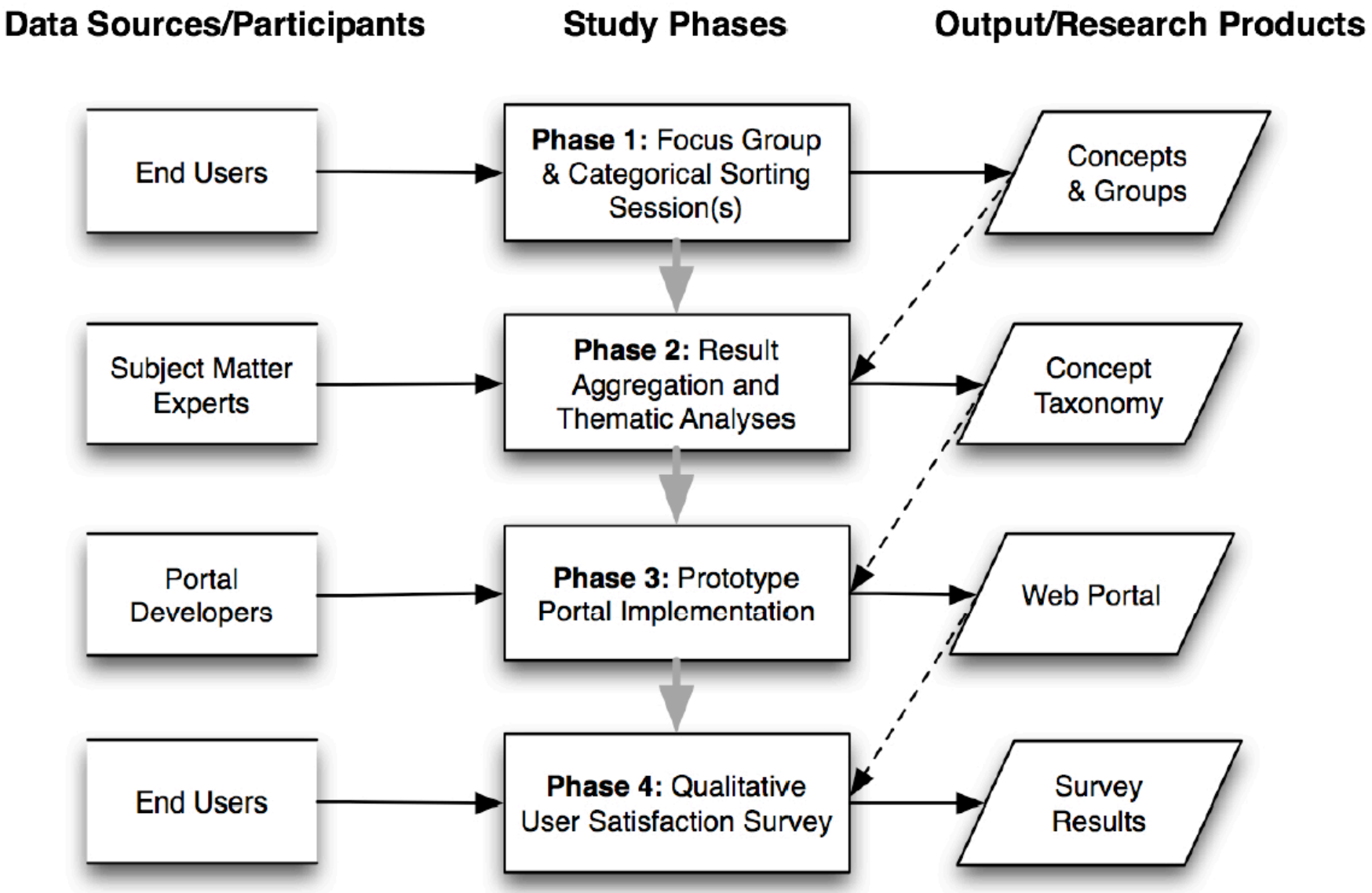
“Research Electronic Data Capture (REDCap) - A metadata-driven methodology and workflow process for providing translational research informatics support”
(Harris et al. JBI 2009)

- **Conclusion/Importance:** Has changed the way that data is captured, managed for many studies, and growing. Big impact on accelerating science among those who otherwise couldn’t afford a custom solution, and improving quality, security among users.

"Evaluating the Impact of Conceptual Knowledge Engineering on the Design and Usability of a Clinical and Translational Science Collaboration Portal" (Payne et al. AMIA Summits Trans Science, 2010)

- **Goal:** Evaluate the applicability and impact of conceptual knowledge engineering applied to design of collaborative science portal
- **Methods:** Apply CKE methods to design of collaboration portal for CTSA center. Focus groups, interviews with stakeholders, then feedback after build to gather perceptions.
- **Results:** The use of CKE methods was able to produce a consensus information needs taxonomy that informed the design of collaborative team-science portal.
- **Conclusion:** CKE methods can provide for a systematic approach to the design of team-science platforms.

Payne et al. Figure: Basic CKE process employed:



"Evaluating the Impact of Conceptual Knowledge Engineering on the Design and Usability of a Clinical and Translational Science Collaboration Portal" (Payne et al. AMIA Summits Trans Science, 2010)

- **Conclusion/Importance:** Application of a formal knowledge engineering processes (CKE) can inform development of team science portals.
- Remains to be demonstrated if better than intuitive builds, or less formal processes
- Worthy of note as an attempt at bringing scientific rigor to development of resources that can impact researchers and enterprise.

"An Informatics-Based Tool to Assist Researchers in Initiating Research at an Academic Medical Center: Vanderbilt Customized Action Plan"
(Pulley et al. Academic Medicine, 2010)

- **Goal:** Automated, interactive "interview" of investigators to provide guidance about steps in the research submission process.
- **Methods:** Web-based interface developed, enables investigators to walk through interview and then presents with
- **Results:** >70% respondents to user survey found it helpful. Usage has increased steadily since launch in 2006.

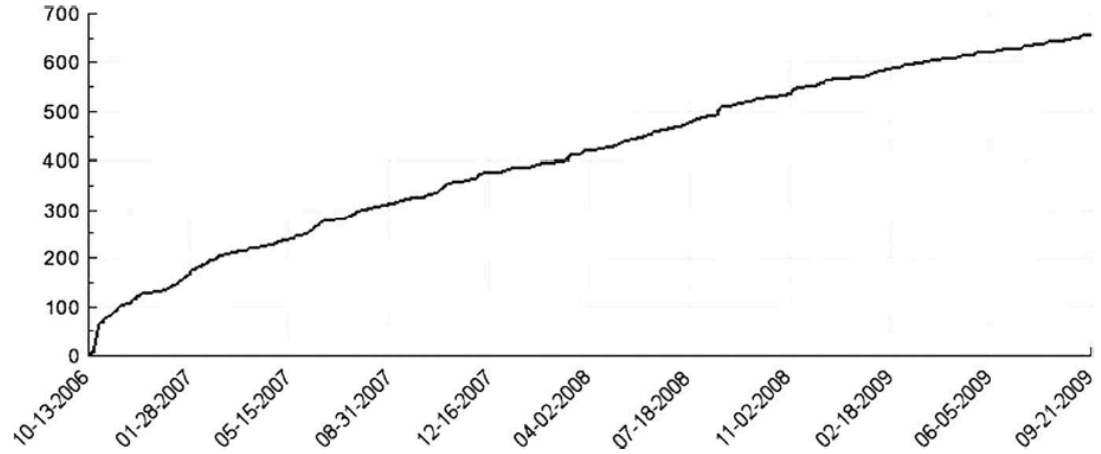


Figure 2 The number of studies initiated in the Vanderbilt Customized Action Plan (V-CAP) system since its launch in October 2006.

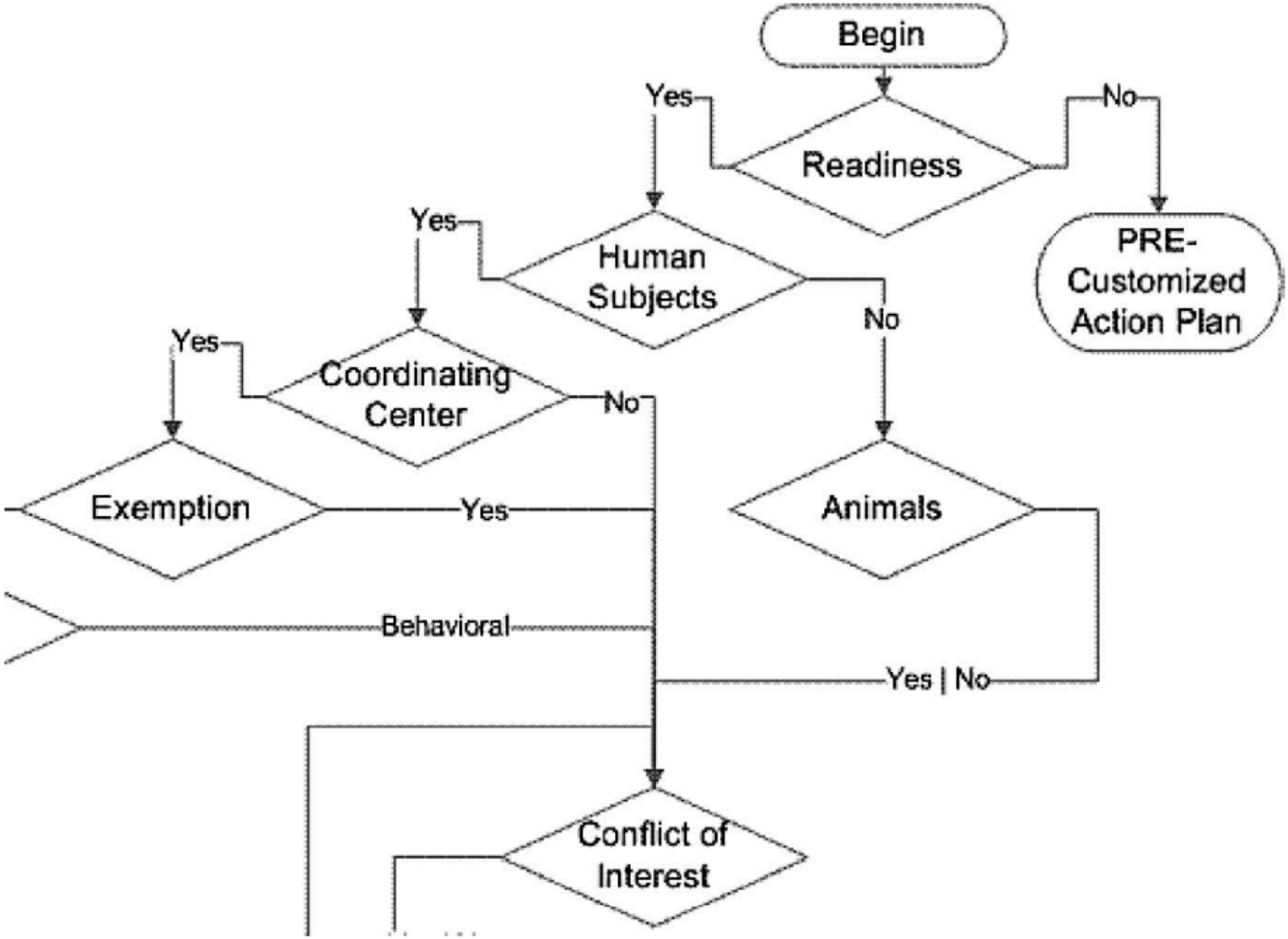


Figure 1 Excerpt from a flow diagram illustrating the branching logic used in the Vanderbilt Customized Action Plan (V-CAP) questionnaire to assist investigators through the regulatory approvals process.

"An Informatics-Based Tool to Assist Researchers in Initiating Research at an Academic Medical Center: Vanderbilt Customized Action Plan"
(Pulley et al. Academic Medicine, 2010)

- **Conclusion/Importance:**
- Early example of the kinds of innovation we're seeing in CRI to assist researchers with navigation of the increasingly complex organizational and regulatory environment at our institutions.
- Outcomes related to improved regulatory compliance, increased scientific efficiency and perhaps productivity are suggested, but remain to be measured.

"Cancer registries: a novel alternative to long-term clinical trial follow-up based on results of a comparative study"
(Shi et al. Clinical Trials, 2010)

- **Goal:** Determine if data from a cancer registry is as good as formal long-term follow-up of patients treated in two RCTs (different diseases conducted by two different groups), to save on costs.
- **Methods:** Data on 153 patients were compared between one hospital-based (Mayo) cancer registry and two RCT databases.
- **Results:** There was high concordance (>95%) for most demographic and treatment data between sources. Vital status was also 100% concordant for one RCT and 94.5% for other. Limitation – single site.
- **Conclusions/Importance:** Registry data was nearly identical to data from two Phase III RCTs in different diseases conducted by two different groups. Registries might be a feasible (and less costly) alternative to long-term follow-up for large clinical trials.

Recruitment Informatics

"Comparing the Effectiveness of a Clinical Registry and a Clinical Data Warehouse for Supporting Clinical Trial Recruitment: A Case Study"
(Weng et al. AMIA Annual Symposium, 2010)

- **Goal:** Compare a diabetes registry with a data warehouse to recruit participants for a diabetes clinical trial.
- **Methods:** Determine potentially eligible subjects from both data sources and compare results.
- **Results:** Clinical data warehouse generated higher positive accuracy (31% vs. 6.6%) and higher participant recruitment than did the registry (30 vs. 14) in a shorter time period (59 vs. 74 working days). There were many factors involved.
- **Conclusions/Importance:** Warehouse and Registry each had their pros and cons, and this finding may or may not hold in other studies/ settings. But important as a comparison of maturing informatics resources leveraged for a key clinical research activity and studied using a "comparative effectiveness" like approach. More such studies are needed.

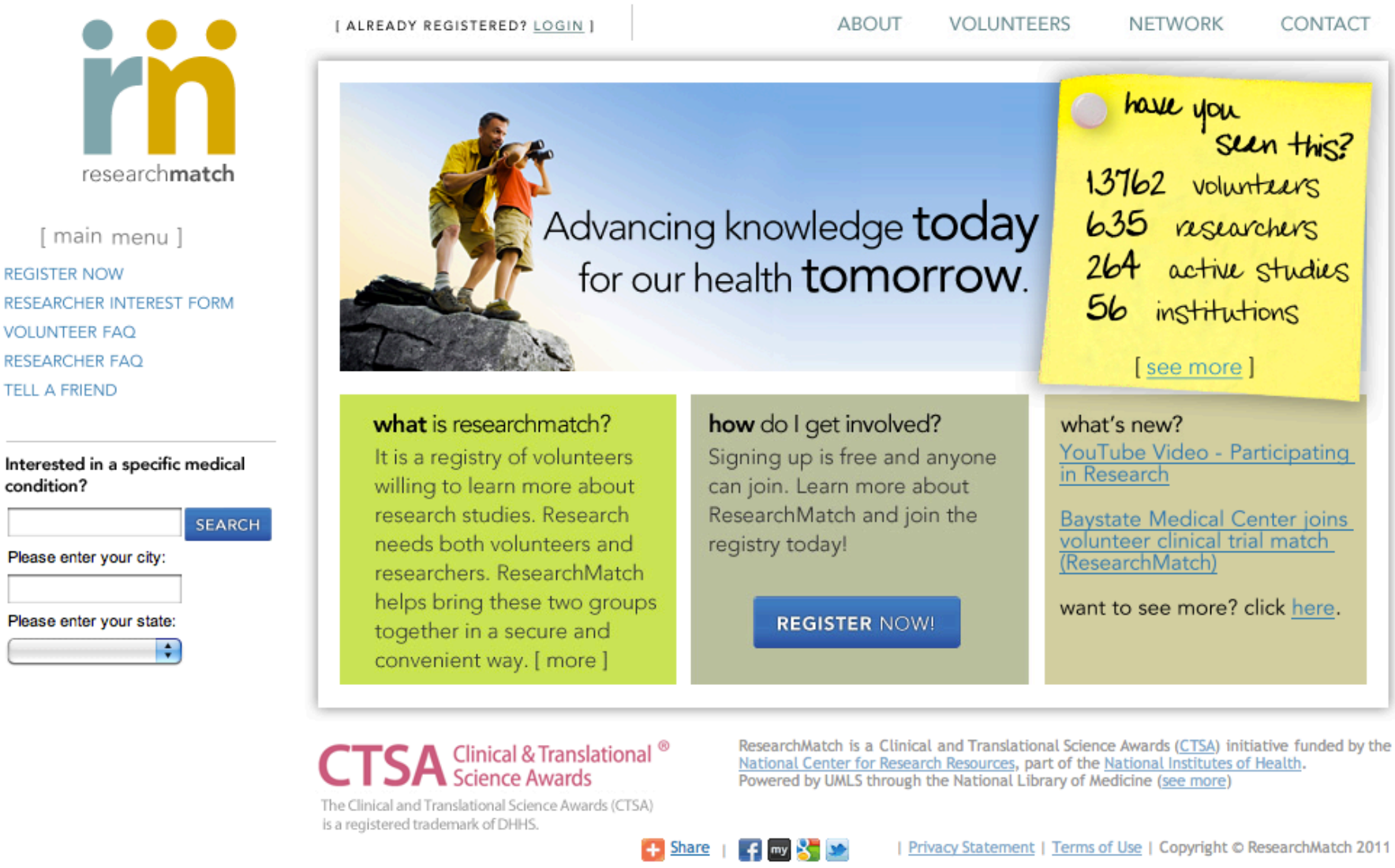
“Routine data from hospital information systems can support patient recruitment for clinical studies” (Dugas et al. Clinical Trials, 2010)

- **Goal:** Study whether a hospital information system in Germany can be leveraged to recruit patients via daily email alert with list to clinicians.
- **Methods:** HIS programmed to search for matches to selected eligibility criteria and send email to physician who then contacts patients. Rates of recruitment monitored.
- **Results:** Over 10 months, 1328 notifications were generated and 329 enrollments (25%) were documented for seven studies. Varied between study type (12%-85%), based on mapping of criteria to HIS data.
- **Conclusions/Importance:** Non-controlled intervention study, but adds to the limited literature on the ability to use health information systems to identify subjects and utility of various approaches to recruit identified patients – the major bottleneck.

"Formal representation of eligibility criteria: A literature review"
(Weng, Tu, Sim, Richesson. JBI, 2010)

- **Goal:** Review issue of standards-based, computable knowledge representations for eligibility criteria.
- **Methods:** Survey and analyze the literature on this topic.
- **Results:** Discovered 27 models identified aspects that contribute to various research and clinical applications. Authors' consider three of these aspects—expression language, codification of eligibility concepts, and underlying model of patient data—to be essential constructs of a formal knowledge representation for eligibility criteria; they present a conceptual framework for organizing eligibility criteria representations.
- **Conclusions/Importance:** Yes a review – but this excellent work covers the area of eligibility criteria, and is a must read for anyone working in this space. It lays a solid foundation for future users or developers of computable eligibility criteria to build upon.

Recruitment: **Researchmatch.org**



Drug & Device Surveillance

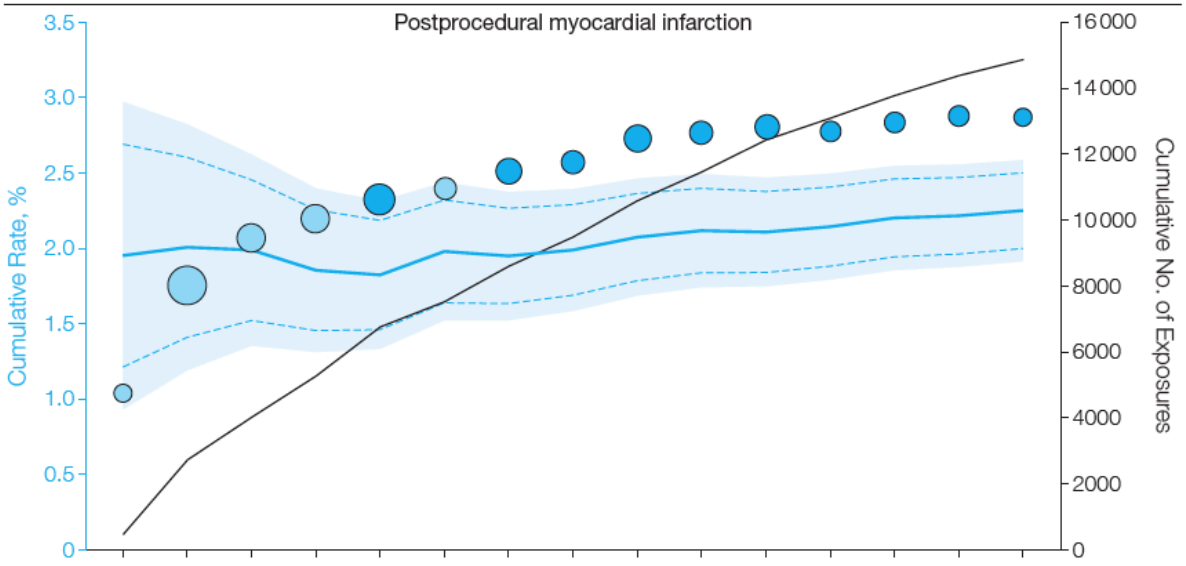
"Automated Surveillance to Detect Postprocedure Safety Signals of Approved Cardiovascular Devices" (Resnic, et al., JAMA, 2010)

- **Goal:** To determine whether automated safety surveillance of clinical registries using a computerized tool can provide early warnings regarding the safety of new cardiovascular devices.
- **Methods:** Prospective cohort analysis of 7 newly introduced cardiovascular devices, using clinical data captured in the Massachusetts implementation of the National Cardiovascular Data Repository CathPCI Registry for adults undergoing percutaneous coronary intervention from April 2003-September 2007. The surveillance tool was implemented at a central data repository to monitor the accumulating Massachusetts interventional cardiology registry for device-specific safety signals and to trigger safety alerts when specific statistical thresholds were achieved for any monitored device.

"Automated Surveillance to Detect Postprocedure Safety Signals of Approved Cardiovascular Devices" (Resnic, et al., JAMA, 2010)

- **Results:** 74,427 consecutive interventional coronary procedures. Three of 21 safety analyses triggered sustained alerts in 2 implantable devices. Patients receiving the *Taxus Express2 drug-eluting stents* experienced an increased risk of post-procedural myocardial infarction compared with those receiving alternative stents. Other device did not turn out to be problematic on sensitivity analyses.

Figure 1. Summary Safety Analysis of the Taxus Express2 Drug-Eluting Stent



"Automated Surveillance to Detect Postprocedure Safety Signals of Approved Cardiovascular Devices" (Resnic, et al., JAMA, 2010)

- **Conclusions/Importance:** Demonstrates feasibility of automated safety surveillance of implantable devices using clinical outcomes registry and computerized adverse event surveillance.
- Methods incorporated into the surveillance system were able to distinguish low-frequency medical device safety risks not highlighted in premarket approval studies (e.g. just trends in those studies)
- Such automated prospective surveillance can aid public health officials who rely on passive surveillance tools that lack denominator data.
- Automated safety surveillance may also complement plans for the recently announced Sentinel Initiative
  - Active surveillance program being implemented by the FDA to use existing electronic health care information sources to efficiently generate, strengthen, or confirm safety signals for medical products.
  - *Platt et al, NEJM, 2009*

CRI and Patients/Consumers

"Identifying Unpredicted Drug Benefit through Query of Patient Experiential Knowledge: A Proof of Concept Web-Based System"
(Pulley, et al., Clinical and Translational Scienc, 2010)

- **Goal:** Engage patients to inform about drug effects via a PHR.
- **Methods:** A pilot study was conducted for 18 months; 1,065 individuals using the MyHealthAtVanderbilt.com patient portal clicked on a research link to find more information about the study and take a survey about their medications and effects.
- **Results:** 375 completed the survey (response rate of 37%). Of those, 218 patients reported that they were currently taking at least one prescription. Statistical analyses determined known associations between drugs and intended benefits.
- **Conclusions/Importance**: This study suggests that with adoption of PHRs, patients can be engaged to augment the database. Potential for using patient-supplied information to generate hypotheses related to unexpected positive benefits associated with medications (for further study), or adverse events.

"The Readability of Information and Consent Forms in Clinical Research in France" (Ménoni, et al., PLOS One, 2010)

- **Goal:** Assess the readability of research information and consent forms (ICFs)
- **Methods:** Readability was evaluated based on three criteria: the presence of an illustration, the length of the text and its Flesch readablity score. Compared with everyday literature.
- **Results:** 209 protocols and the corresponding 275 ICFs. Median length was 1304 words. Flesch readability scores were low (median: 24), and only about half that of selected press articles. More than half (52%) of the text in ICFs concerned medical information, and this information was statistically ($p<0.05$) more readable (Flesch: 28) than statutory information (Flesch: 21).

Score	Notes
90-100	Easily understood by avg 11 yr old
60-70	Easily understood by avg 13-15 yr old
0-30	Best understood by university graduates

"The Readability of Information and Consent Forms in Clinical Research in France" (Ménoni, et al., PLOS One, 2010)

- **Conclusions/Importance**: Regardless of the field of research, the information and consent forms for protocols included had poor readability scores.
- With software tools available to assess readability, something we in CRI should at least be aware of, and perhaps build into our capabilities.
- Certainly relevant given discussions around consent not just to research, but also for biobanking, etc. (opt-in or opt-out)
- Increasingly, such forms will be electronic as well. That might make have an effect worthy of study.

Policy and Vision

"Reforming the HIPAA Privacy Rule Safeguarding Privacy and Promoting Research" (Gostin, et al., JAMA, 2009)

- The IOM recently concluded that the Privacy Rule does not adequately safeguard privacy and significantly impedes high- quality research.
  - The result is that patients' medical records are not well protected and researchers cannot effectively search for important discoveries.
- Multiple flaws noted:
  - Coverage gaps (i.e. data with non-covered entities not subject to HIPAA and Common Rule applies mainly to gov't funded work)
  - Inconsistencies (between Privacy Rule and Common Rule)
    - The standards for future consent, deidentification of data, and recruiting patients vary under the 2 rules, leading to contrary results.
  - Variable interpretations abound
    - IRBs often short-staffed by experts who can interpret so delays occur
    - More conservative interpretations often hamper research

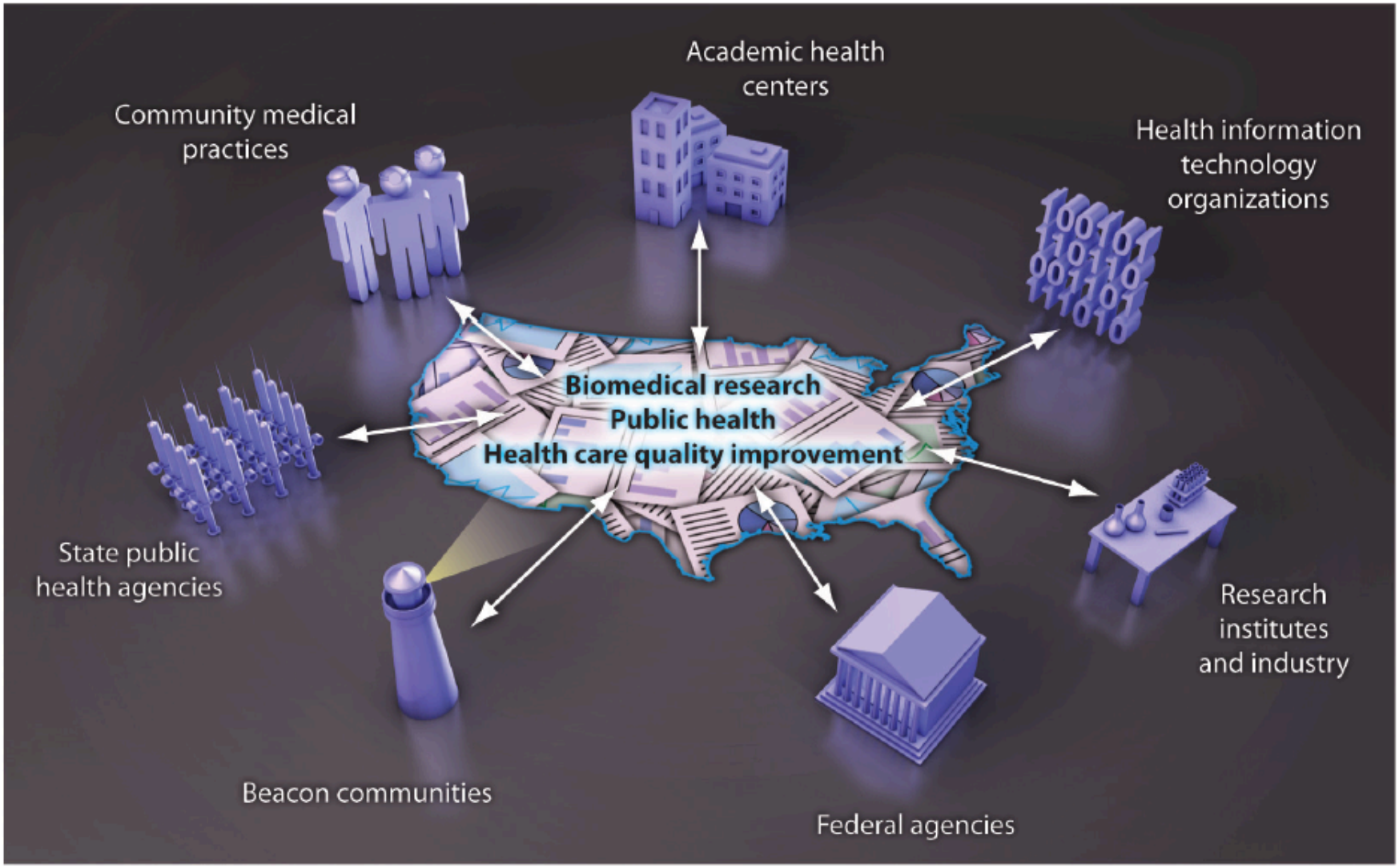
“Reforming the HIPAA Privacy Rule Safeguarding Privacy and Promoting Research” (Gostin, et al., JAMA, 2009)

- Call for new framework by IOM, under which Common Rule, but not Privacy rule would apply to research
- If not that, then call for revisions to Privacy rule, to include revisions to portions governing health information
- “Rather than seeing privacy and research as conflicting values, policy makers can improve both. To do so, they must move beyond formalistic rules toward fair information practices and uniform ethical oversight. They must also remove barriers to high-quality research, thereby attaining the societal benefits of scientific knowledge, medical advances, and protection of the public’s health.”

"Achieving a Nationwide Learning Health System"
(Friedman, et al., Sci Translational Med, 2010)

- Review of the Learning Healthcare System concept
- Ties it together with Meaningful Use
- Taking the learning system from an idea to a working reality will require mutually reinforcing technologies, standards, and policies created in specific anticipation of nationwide implementation.
- The national program to achieve EHR meaningful use will contribute many but not all of these.

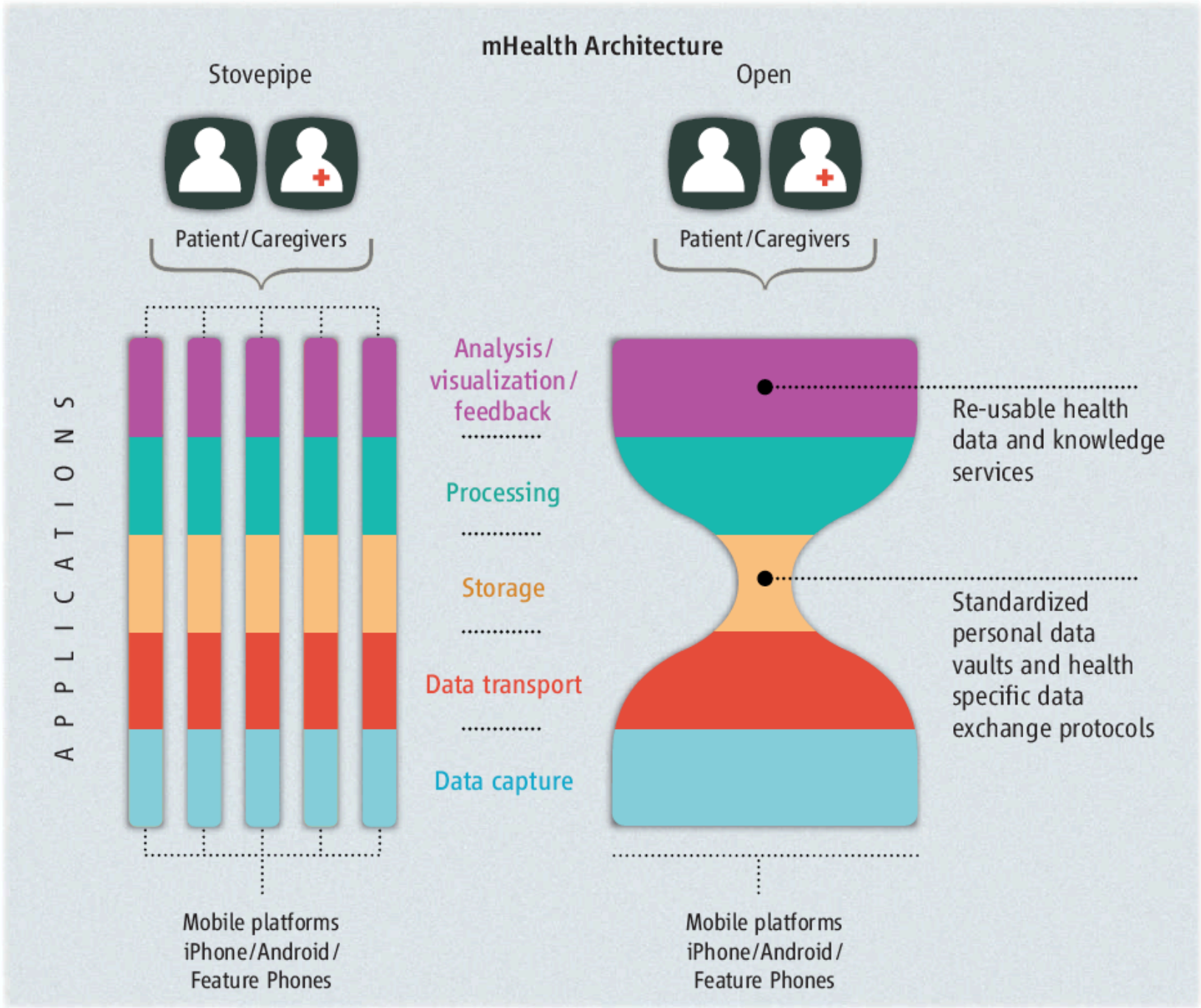
“Achieving a Nationwide Learning Health System” (Friedman, et al., Sci Translational Med, 2010)



“Open mHealth Architecture: An Engine for Health Care Innovation”
(Estrin & Sim, Science, 2010)

- Estrin and Sim lay out the potential value of mobile technologies for healthcare and research
- But, they emphasize the criticality of the open architecture to fully realize the benefits of mHealth
  - Avoiding the limitations of the “stove-piped” approaches that have plagued health IT in the past
  - Reap the benefits, including to research and innovation, of the open architecture

“


mHealth Architecture
Stovepipe
Open
Patient/Caregivers
Patient/Caregivers
APPLICATIONS
Analysis/
visualization/
feedback
Processing
Storage
Data transport
Data capture
Re-usable health
data and knowledge
services
Standardized
personal data
vaults and health
specific data
exchange protocols
Mobile platforms
iPhone/Android/
Feature Phones
Mobile platforms
iPhone/Android/
Feature Phones

"Biomedical Informatics: Changing What Physicians Need to Know and How They Learn" (Stead et al., Academic Medicine, 2010)

- Discussion of the future role of medical informatics given changes in biomedicine
- Recommend medical schools advance on four fronts:
  - Create academic units in biomedical informatics
  - Adapt the IT infrastructure of AHCs into testing labs
  - Introduce medical educators to BMI for them to model its use
  - Retrain AHC faculty to lead transformation of healthcare based on new systems approach enabled by BMI
- Propose embracing informatics-enhanced future of medicine will help advance education, care, **research**

“Health Care – HIT or Miss?”
Commentary(ies) - Nature, 2011

- Five combined and complementary pieces by:
  - Bill Hersh - Time to catch up with the pack
  - Julie Jacko - Narrow the gap in health literacy
  - Bob Greenes – Push for Deeper Innovation
  - Joseph Tan – Standardize to Avoid Waste
  - Janies, Embi & Payne – Collect Genetic Data on Pathogens

- All commented on aspects of HITECH for both healthcare and science. Key is, there are indeed impacts to research…

Health Information Technology for Economic and Clinical Health (HITECH)

- ARRA allocated $29 billion to the Office of the National Coordinator for Health IT (ONC) for incentives for “meaningful use” (MU) of health information technology (HIT) through
  - Adoption of electronic health records (EHRs)
    - up to $27 billion in incentives
  - Infrastructure ($2 billion in grants and contracts)
    - Regional extension centers – 62 covering country
    - State-based health information exchange (HIE)
    - SHARP research centers – four centers in specific areas
    - Beacon communities – 17 “beacon” demonstration projects
    - Workforce development – four programs

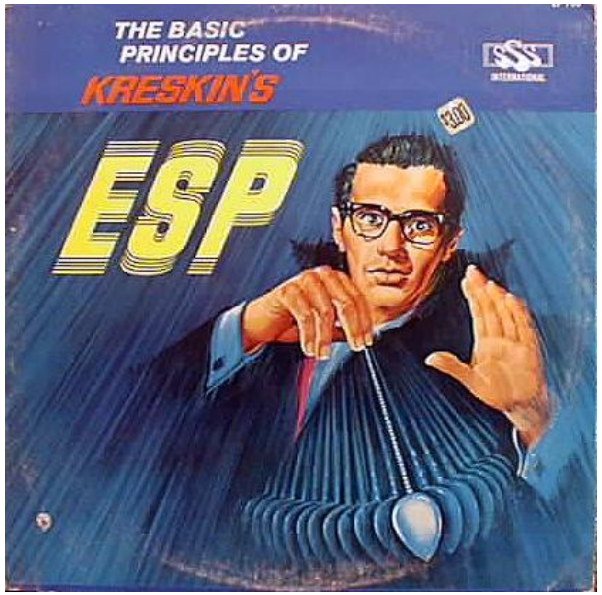
“Foundational biomedical informatics research in the clinical and translational science era: a call to action”

Payne et al, JAMIA, 2010

- Much emphasis thus far in CTRI has been on infrastructure development
- No doubt those are important to our research enterprise
- But, we as a CRI community need to drive forward the science of our domain even as we help build its infrastructure
- Speak to the need to drive that research agenda forward – a call to action

Predicting the future… just a few thoughts…

- Demonstration of maturing data infrastructure and exchange capabilities driving science
- Randomized controlled trial(s) of CRI interventions
- Real-world examples of “learning healthcare systems” in operation
- MESH term for CRI… Please…



Thanks!

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Slides will be posted on AMIA Website & on http://www.embi.net/ (click on “Informatics”)