A Partnership to Develop a National Health & Research Information Exchange (NHRIE)

May 31, 2012

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Question

How do we, as a nation, create a health care and research system which will provide the following for cancer patients?

1. Create a system to identify the needs of individual patients;
2. Identify markers that would predict needs and risks so that interventions could become preemptive;
3. Identify molecular signatures for patients who are not likely to respond to standard of care;
4. Utilize clinical characteristics and molecular profiling techniques to match the right patient to the right treatment at the right time and the right place;
5. Raise the standard of care for all patients by integrating new technologies in an evidenced based approach to maximize benefits and reduce costs.

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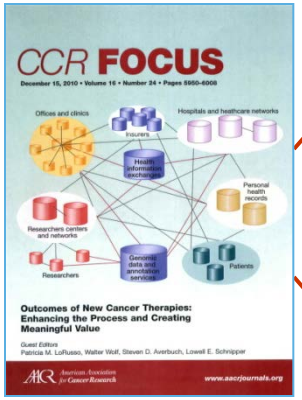
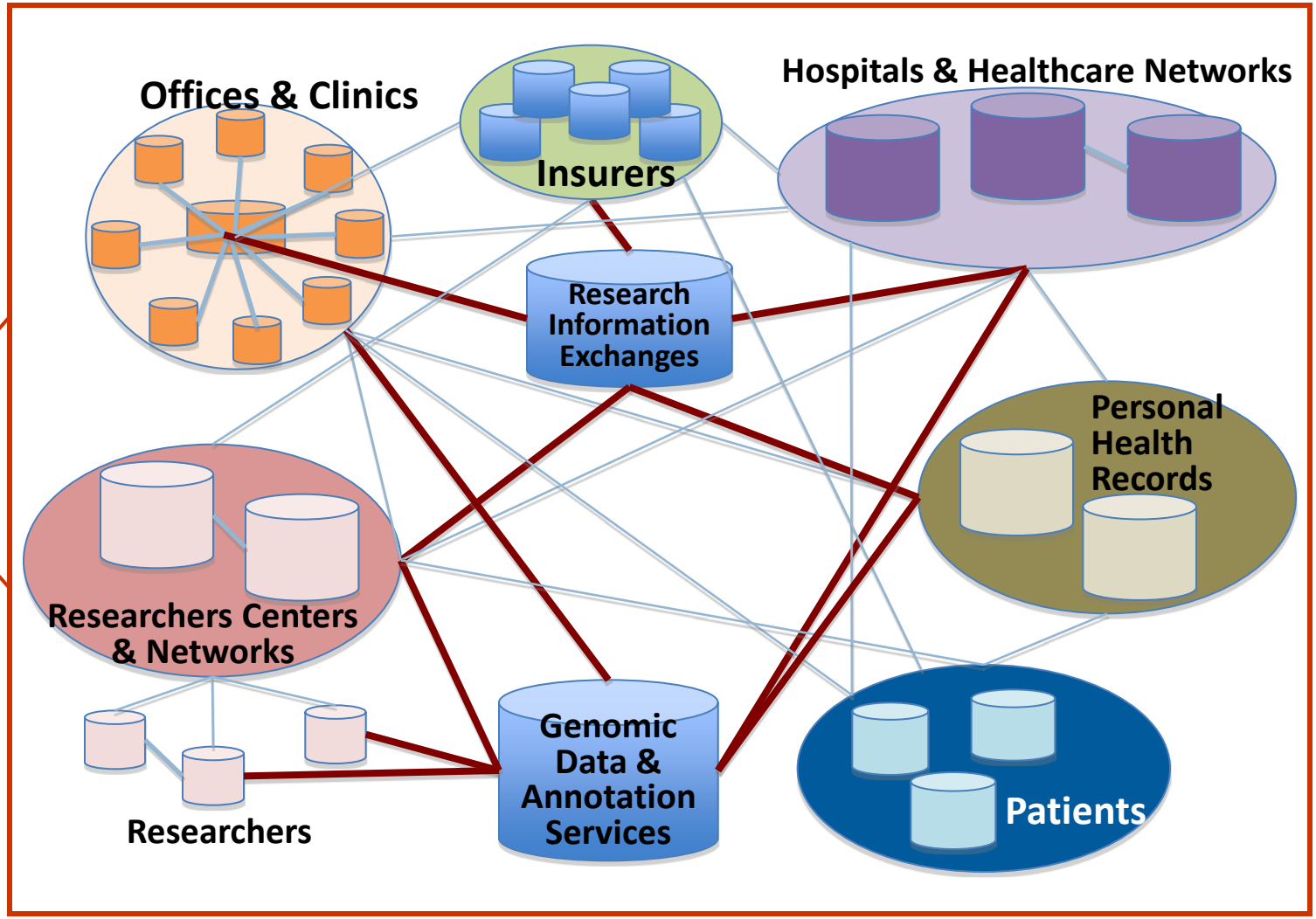
Designing a New Federated Model for Research & Healthcare





Dalton, Fenstermacher, et al, Clin Cancer Res; 16 (24) December 15, 2010

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The Approach for Cancer

CONFIDENTIAL

MCC# 14690
IRB# 184189

Title:	***Total Cancer Care Protocol: A Partnership with High Risk and/or Diagnosed Cancer Patients For Life***
Principal Investigator:	Timothy J. Yeatman, M.D.
Sub-Investigator(s):	William S. Dalton, Ph.D., M.D.
Sponsor:	H. Lee Moffitt Cancer Center and Research Institute Inc.

Version 07: April 02, 2010 pg. 1 of 15

The Total Cancer Care Protocol

- Can we follow you throughout your lifetime?
- Can we study your tumor using molecular technology?
- Can we recontact you?

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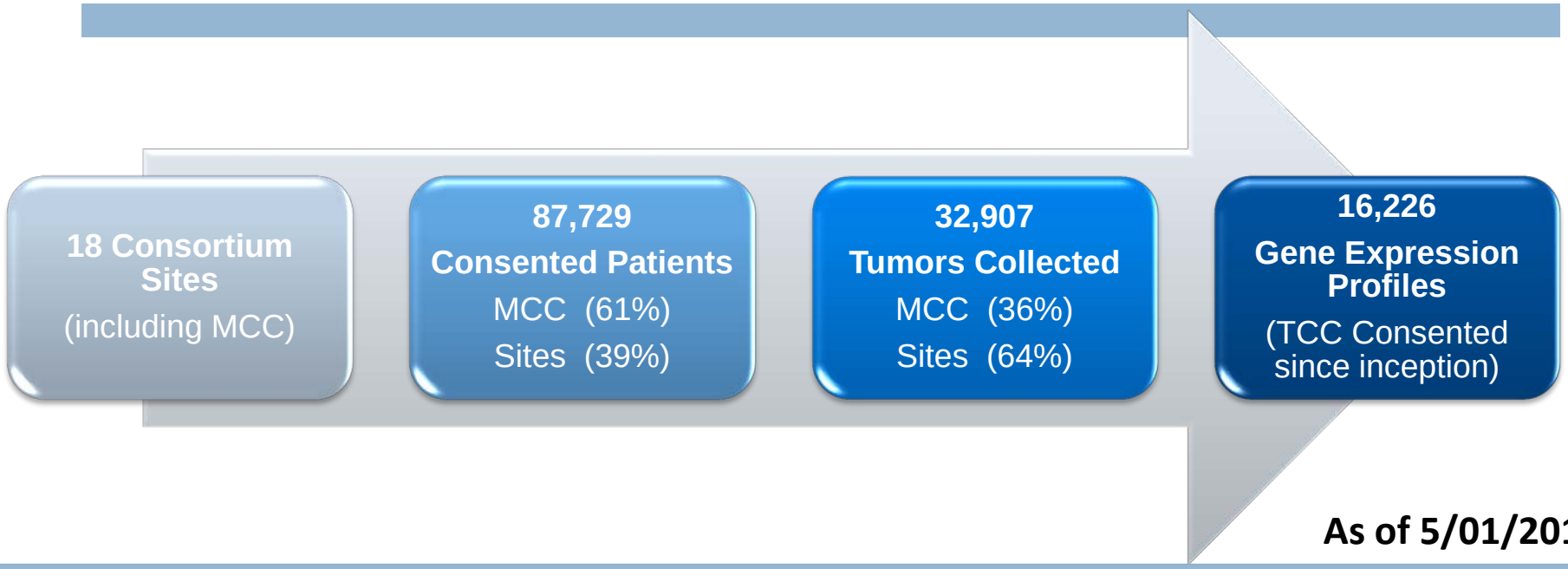
Total Cancer Care Protocol To-Date



As of 5/01/2012

Data Generated from Specimens	
CEL Files (Gene Expression Data)	16,226 files
Targeted Exome Sequencing	4,016 samples
Whole Exome Sequencing (Ovary, Lung, Kidney)	535 samples
Whole Genome Sequencing (Melanoma)	13 samples with normal pairs
SNP/CNV (Lung, Breast Colon)	559 samples

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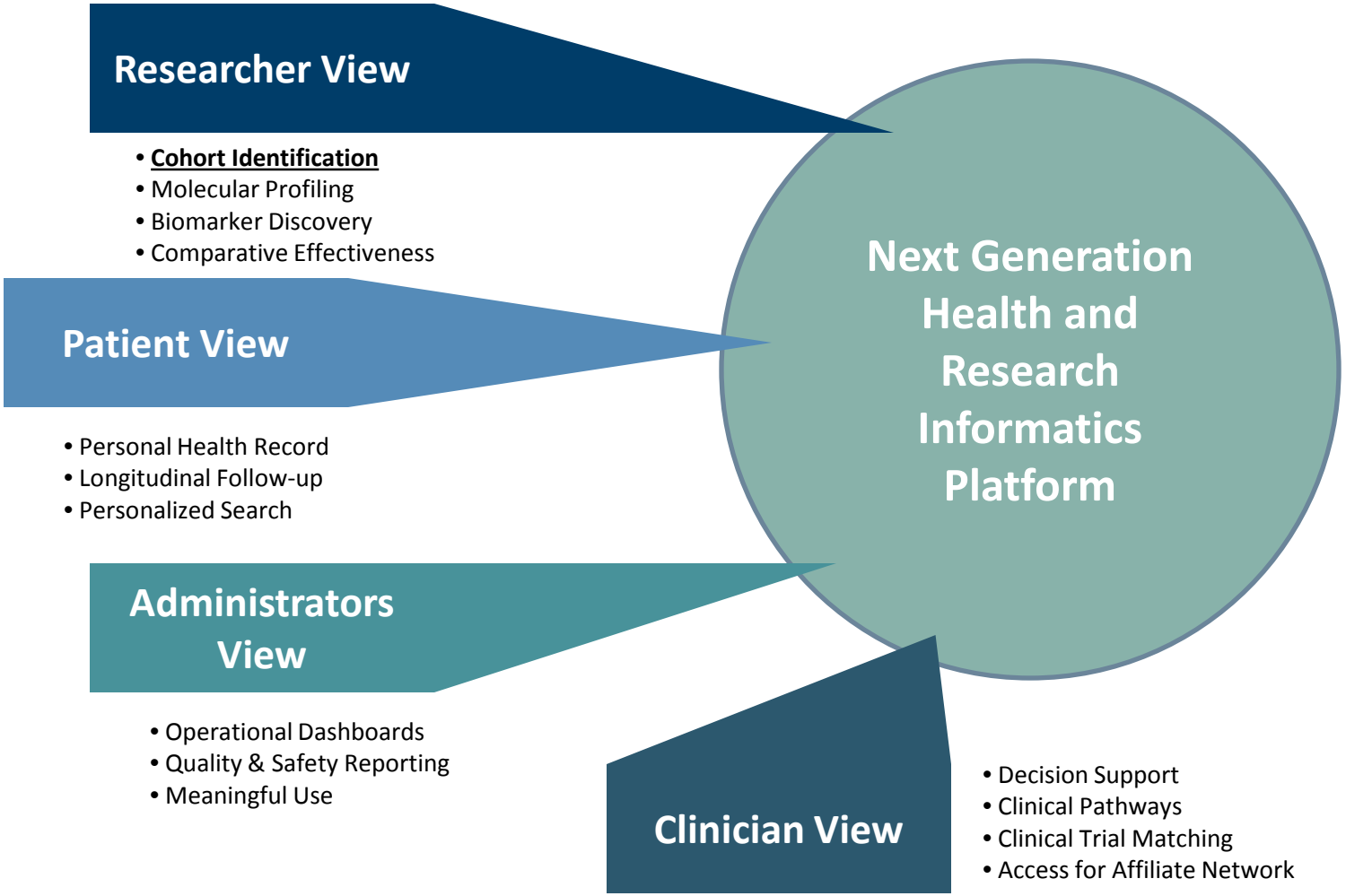
Four Portals to Total Cancer Care™



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The Critical Tool - *Information*
A Health & Research Informatics Platform

An integrated information platform that will create real-time relationships and associations from disparate data sources needed to create new knowledge for improved patient treatments, outcomes and prevention.

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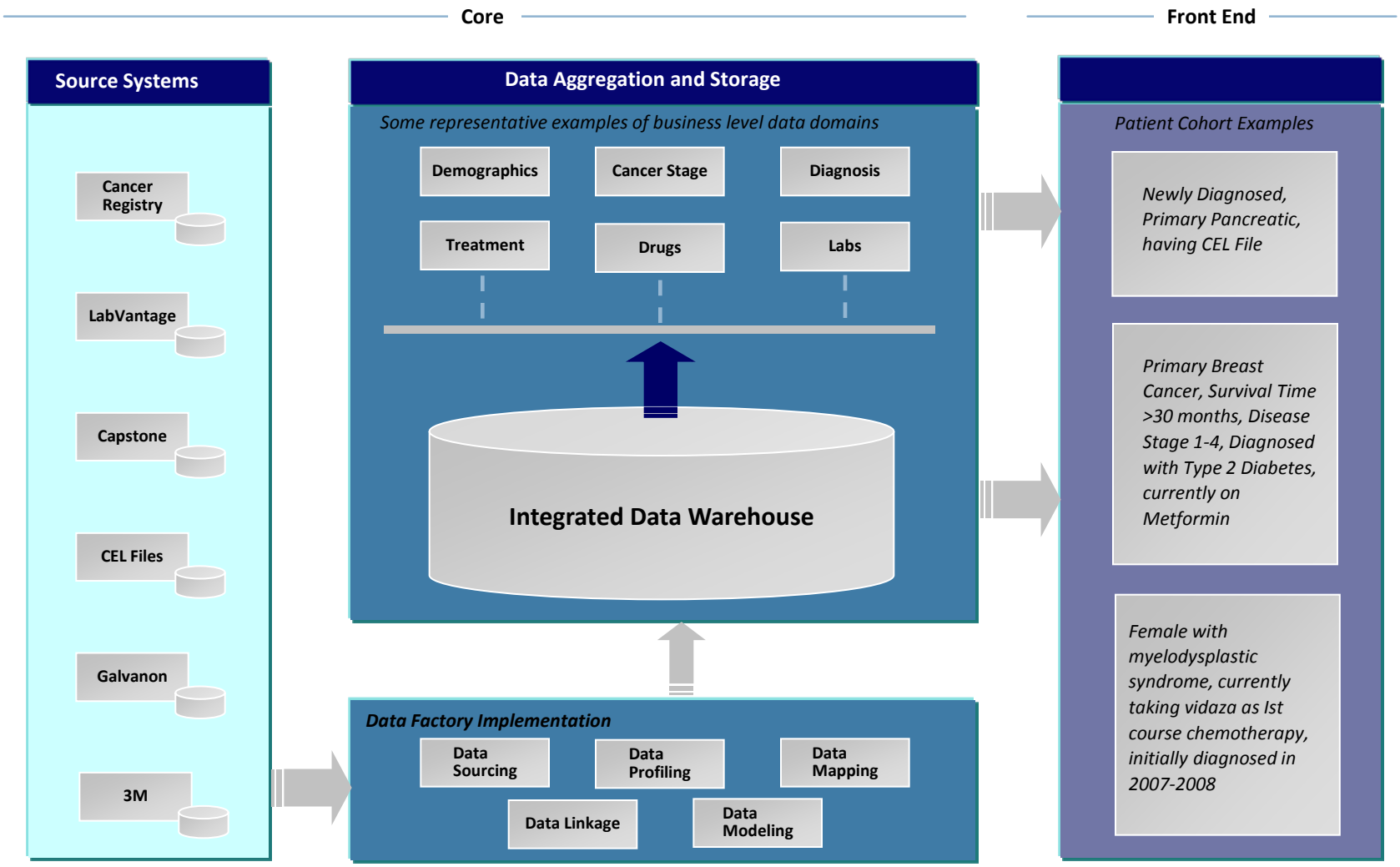
HRI Solution: Conceptual Architecture



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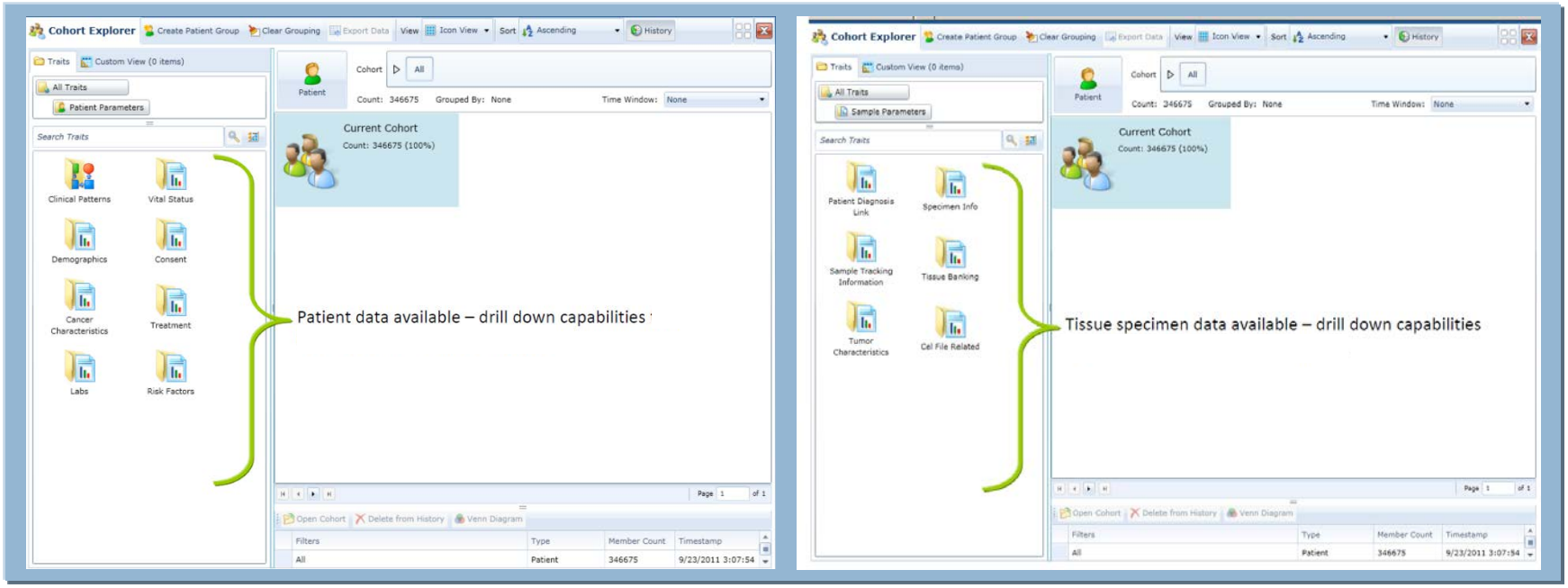
Robust Cancer Patient Database

- Database is a robust, scalable dataset of oncology patients across multiple indications
- Database links TCC patient, clinical and molecular data and enables granular, customized and efficient searches
  - Incorporates secondary data derived from the database – clinical trial results, third-party research, etc.
- Standardized data format across the platform facilitates integration of data from outside sources
- “Hub and spoke” model provides standardized data quality and easy access to information



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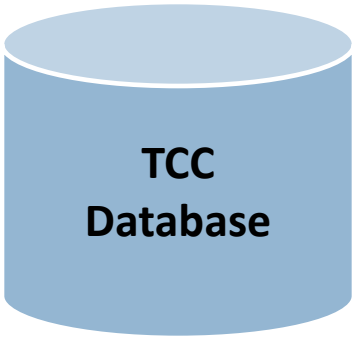
Power of the TCC Database



- **Linking of molecular, clinical, biospecimen and patient self-report data**
  - Gene expression data, Exome sequencing data, SNP/CNV data for new diagnostics, prognostic response and new drug discovery
- **Ability to match patients to clinical trials**
  - Right treatment for the right patient using molecular markers for patient selection
- **Development of "Secondary Use" of Data, including Comparative Effectiveness Research and Pharmacovigilance**
  - What works best for whom based on evidence by following patients throughout their lifetime
  - Clinical Decision Tool for Diagnostics & Therapy

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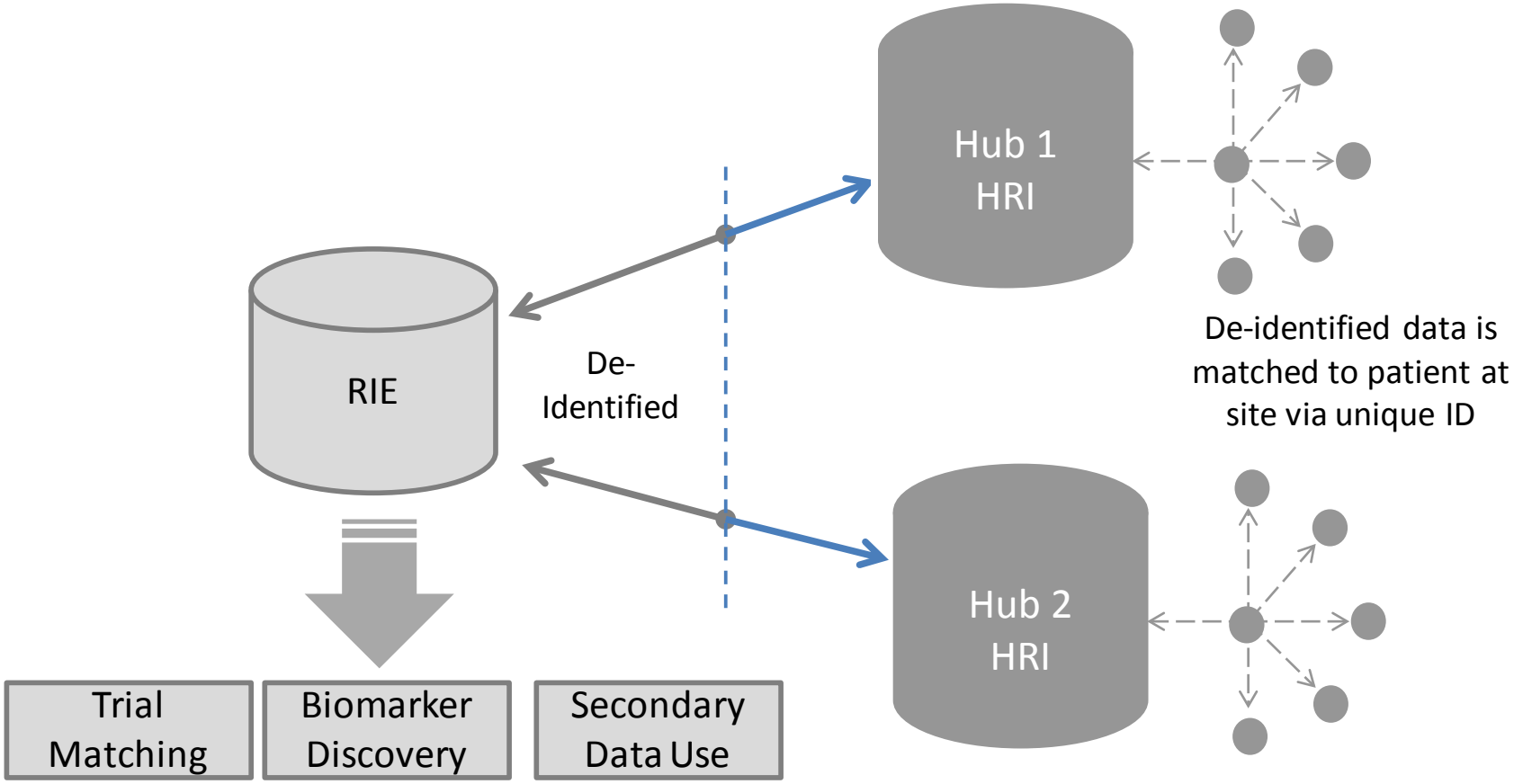
Cancer Center Hubs



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Guiding Principles For Developing The Cancer Center Collaboration

- **Inclusiveness**
  - Participation by Cancer Centers in their respective communities
- **Accessibility of Data**
  - Real time access to research data through RIE using a hybrid model of a federated and central data warehouse: a network model
- **Public-Private Partnerships**
  - Establish trusted business relationships across sectors to achieve long-term program sustainability

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Moving Forward and Addressing Challenges

- Challenge of capturing data in the source systems themselves
- Creation of regional consortia that collect patient-level data (clinical, environmental, molecular, outcomes data) and expand to community hospitals and practices
- Development of a Hub-Spoke architecture with the “Hub” promoting centralized data management and the “Spoke” providing a data mart to create customized perspective and uses of data
- Development of Data Provisioning and Governance Systems for all stakeholders
- Development of applications to enhance querying functionality
- Development of a business model to build and sustain the RIE that capitalizes on private-public partnerships

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Differences: RIE and caBig

Similarities

- Semantics
  - RIE uses a expanded data dictionary that is based on ISO/EIC 11179 metadata standard
  - RIE will incorporate ISO 21090 (Health informatics - Harmonized data types for information interchange)
  - Adoption of many principles from Vocabularies and Common Data Elements Workspace

Contrasts

- No grid infrastructure
  - RIE is a Centralized Database of Metadata
    - Harmonizes data without requiring retooling of local databases at each cancer center
    - Data from multiple source systems or a data warehouse moved to materialized views or a "data appliance" to facilitate data exchange
    - Transient data exchange using federated queries
      - Aggregate data requires no data movement from cancer centers
      - Queries requiring advanced analytics will transiently move data from cancer center, aggregate at the RIE and analytics performed. Aggregated data can be deleted from temporary tables and cache
    - Ability to apply multiple programming strategies to access and query data
  - Shared Governance across participants of RIE
  - Focus is data aggregation and harmonization, not software tools
  - Foundation for a rapid-learning system, adoption of ONC guidelines

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Thank You

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