The Cancer Centers' Perspective
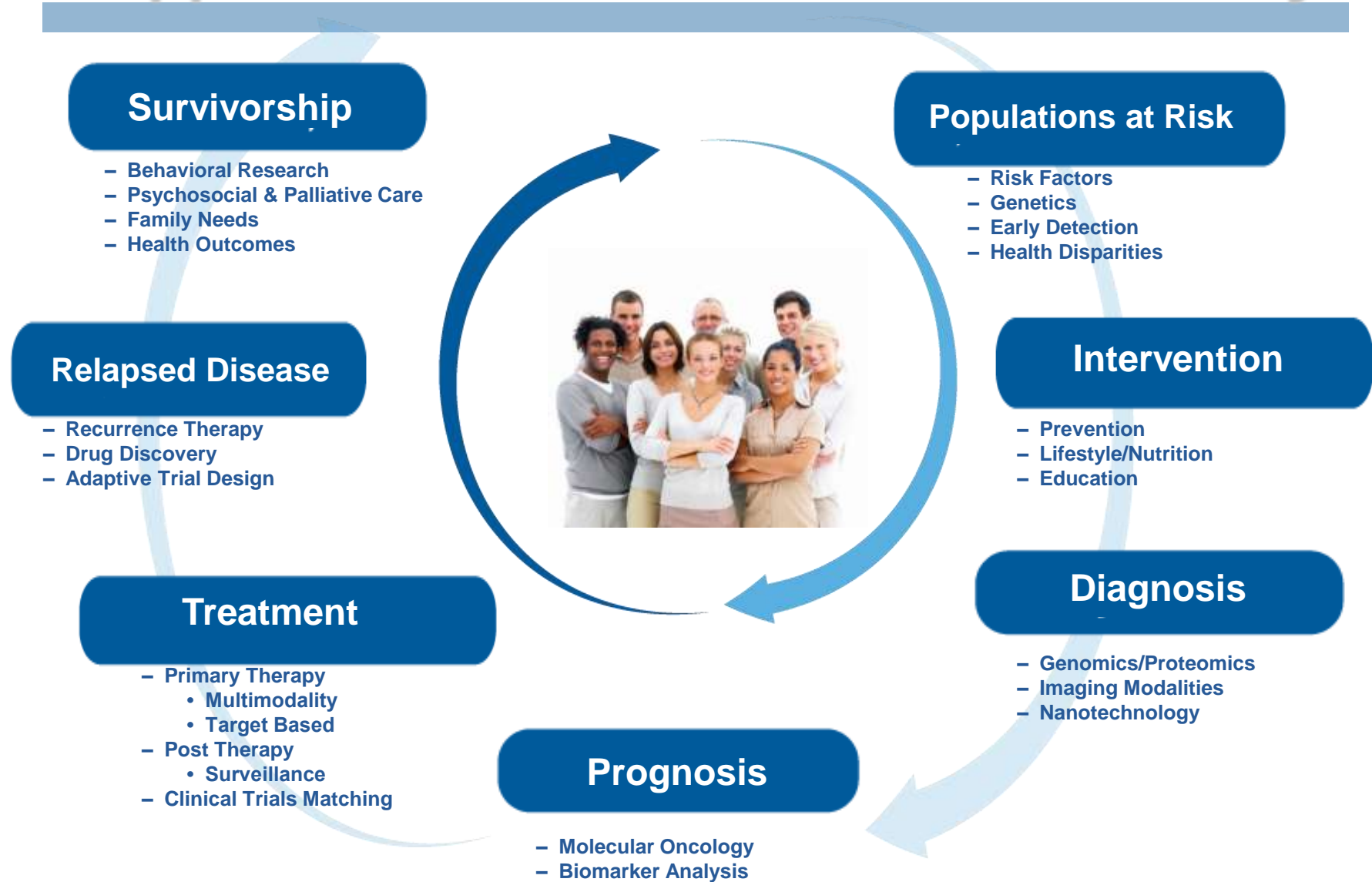
William S. Dalton, PhD, MD
Moffitt Cancer Center
Tampa, Florida

Disclosures

- No financial Conflicts of Interest
- CEO & Center Director, Moffitt Cancer Center
- CEO M2Gen, wholly owned subsidiary of Moffitt
- AACR, Chair – Science, Policy & Legislative Affairs Committee
- AACI, President

Generating Evidence by A Personalized Approach to a Patient's Health Journey

Survivorship
- Behavioral Research
- Psychosocial & Palliative Care
- Family Needs
- Health Outcomes

Populations at Risk
- Risk Factors
- Genetics
- Early Detection
- Health Disparities

Relapsed Disease
- Recurrence Therapy
- Drug Discovery
- Adaptive Trial Design

Intervention
- Prevention
- Lifestyle/Nutrition
- Education

Treatment
- Primary Therapy
  - Multimodality
  - Target Based
- Post Therapy
  - Surveillance
- Clinical Trials Matching

Diagnosis
- Genomics/Proteomics
- Imaging Modalities
- Nanotechnology

Prognosis
- Molecular Oncology
- Biomarker Analysis

The Challenge

How do we develop an integrated network information system that is obviously necessary to deal with the overwhelming amount of information being generated in basic, translational and clinical, research needed to support personalized medicine (aka, molecular medicine, precision medicine)?

Solution Elements for Personalized Medicine as a Solution for Improved Healthcare

- Addresses healthcare as a <u>public issue</u> and seeks to improve <u>access, affordability and quality of care</u> by developing an information system to assist in making clinical decisions based on outcomes and comparative effectiveness.

- Integrates <u>new technologies</u> into the standard of care in an <u>evidence-based</u> fashion to identify populations at risk, personalize treatment and improve individual outcomes.

- Provides an approach to identify the <u>best treatment for individual patients</u> based on clinical and biological characteristics of a patient and their disease.

- Creates a <u>network of health care providers, patients, and researchers</u> who contribute and share information from individual patients to ultimately improve care of all patients by learning from the experience of others.
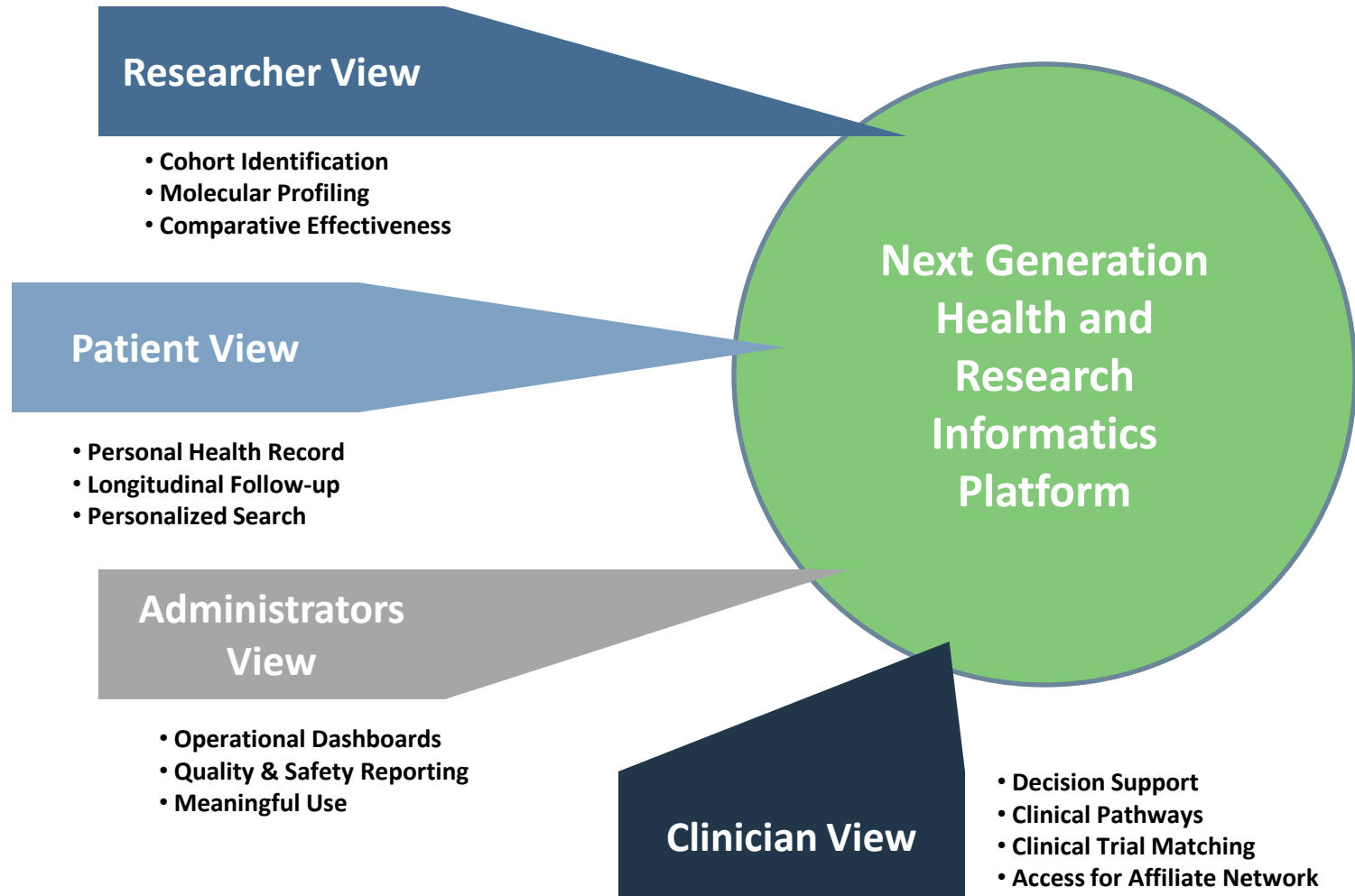
The Necessary Components

- Clinically annotated bio-repository for tumor and normal specimens

- Partnership among researchers, clinicians, regulators, policy makers, and patients to design an integrated information network system

The Approach
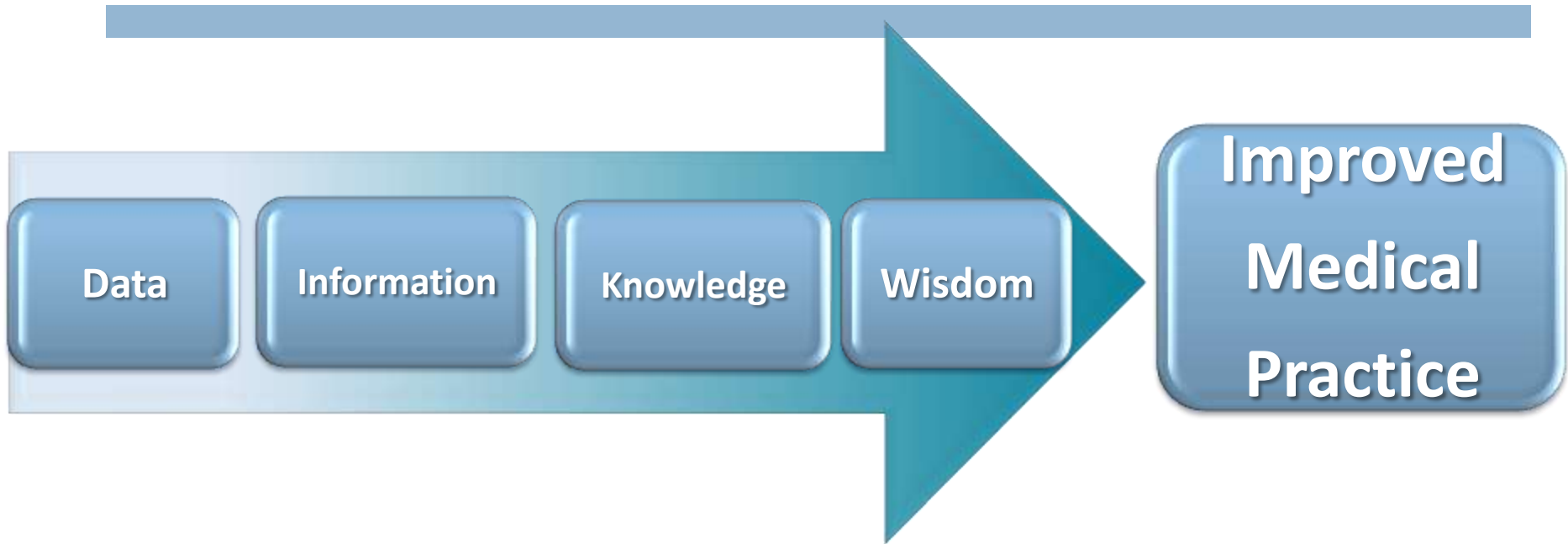
Create a delivery system that will integrate new technologies into the standard of care and develop evidence-based guidelines for the treatment of cancer.

Four Portals to Health/Research Informatics Platform

Researcher View

- Cohort Identification
- Molecular Profiling
- Comparative Effectiveness

Patient View

- Personal Health Record
- Longitudinal Follow-up
- Personalized Search

Administrators View

- Operational Dashboards
- Quality & Safety Reporting
- Meaningful Use

Clinician View

- Decision Support
- Clinical Pathways
- Clinical Trial Matching
- Access for Affiliate Network

Next Generation Health and Research Informatics Platform

Challenges in the Informatics Landscape – A Cancer Center's View

Challenges

- Technical
- Cultural
- Regulatory
- Financial

Challenges

- Data Sharing
  - Technical Architecture
  - Intellectual Property
 - HIPAA Privacy & Security
  - Human Subject Protection – IRB
- Data Governance
  - Validity & quality of the data
  - Semantic interoperability (harmonization)
  - Data dictionaries for metadata
  - Single truth (semantics & syntax) while maintaining multiple versions with user understanding of limitations/usefulness
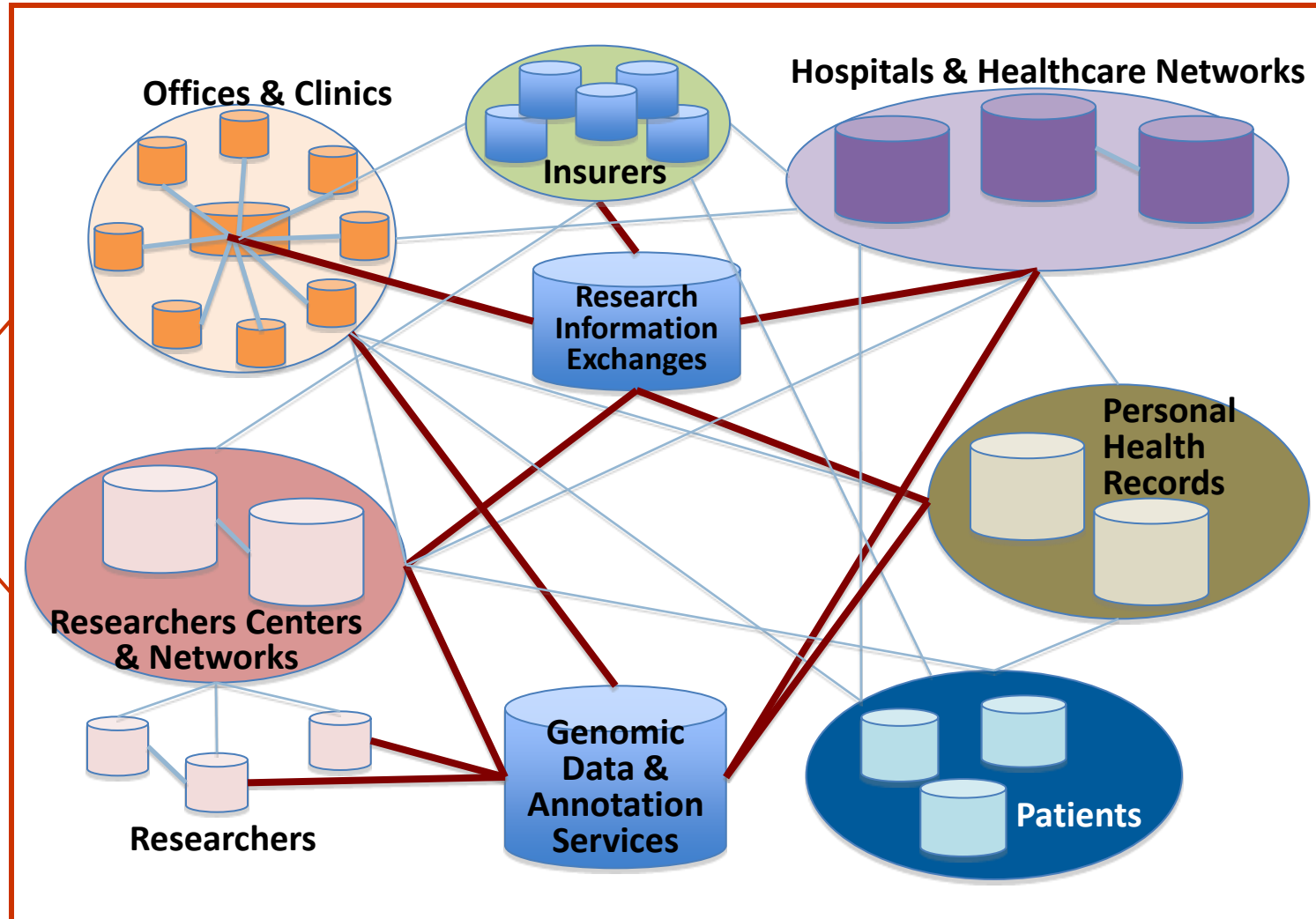
Issues Curtailing Patient Centered Outcomes Research (PCOR)

1. Information gap—lack of EMR and HER
2. Data standards lacking in healthcare organizations
3. Lack of data quality standards
4. No healthcare ID; patient mobility
5. Need to develop architecture of HIS

Research Information Exchange
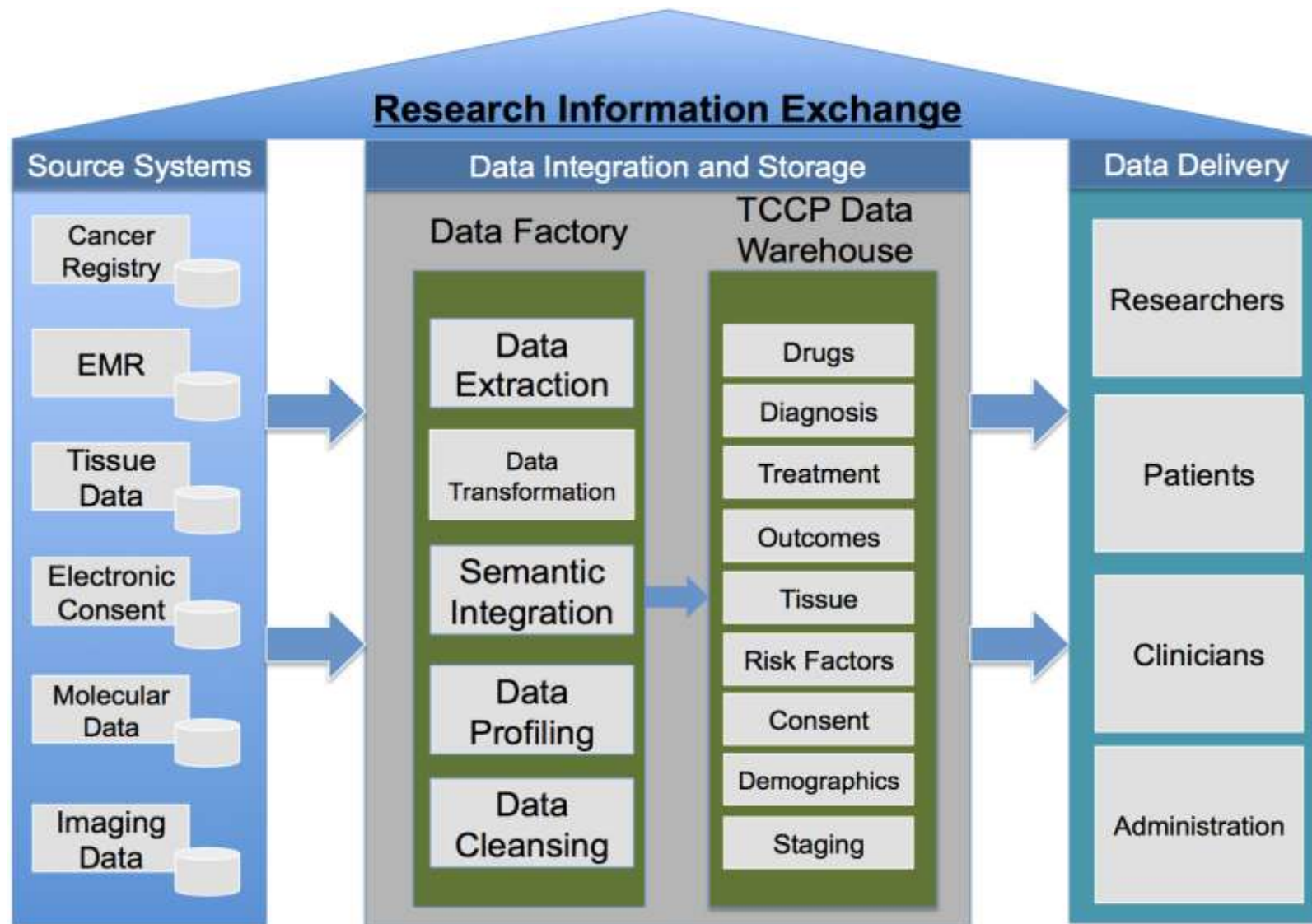
Designing a New Research & Healthcare Network Model

Thank you.