



**IMPATIENT PATIENTS  
SHARING DATA &  
CHANGING THE WORLD**

Moderator:  
Casey Quinlan  
@MightyCasey



# Speeding Up The Pace Of Research Using Patient-Provided Data

**Casey Quinlan @MightyCasey Mighty Casey Media LLC (moderator)**

**Amy P. Abernathy, M.D., Ph.D. @Flatiron Health | Flatiron Health**

**Jennifer C. King, Ph.D. @JenniferCKing | ShareForCures.org**

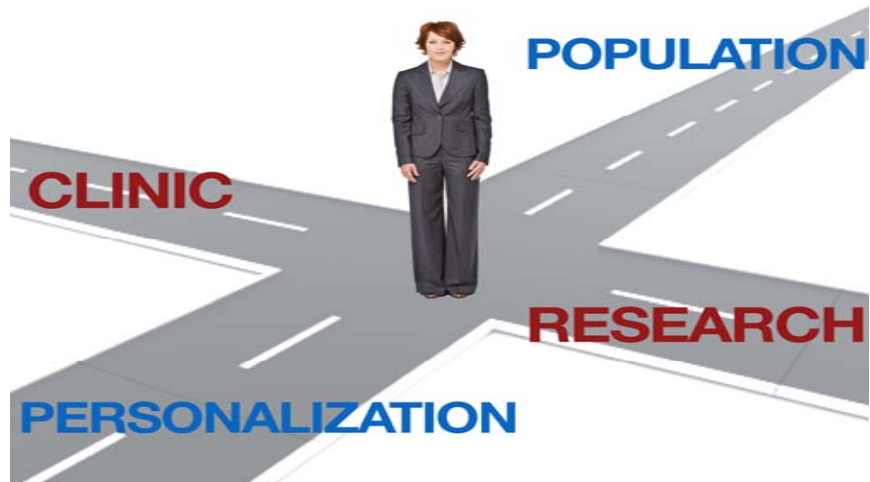
**Bray Patrick-Lake @BrayPatrickLake |Duke University CTSA**

**Vanessa Rangel Miller, M.A., M.B.A. @VRangelMiller |  
PatientCrossroads.com**



## Amy Abernethy, M.D., Ph.D. @FlatironHealth

- Oncologist and cancer researcher
- Chief Medical Officer of Flatiron Health
- Tasked with leading collaboration among cancer care providers, life science companies, and data partners to seek answers to patient-centered cancer treatment and precision medicine
- Co-director, Duke Center for Learning Health Care + Duke Cancer Care Research Center (on leave for Flatiron Health project)



## Optimizing process to achieve "research quality" clinical data

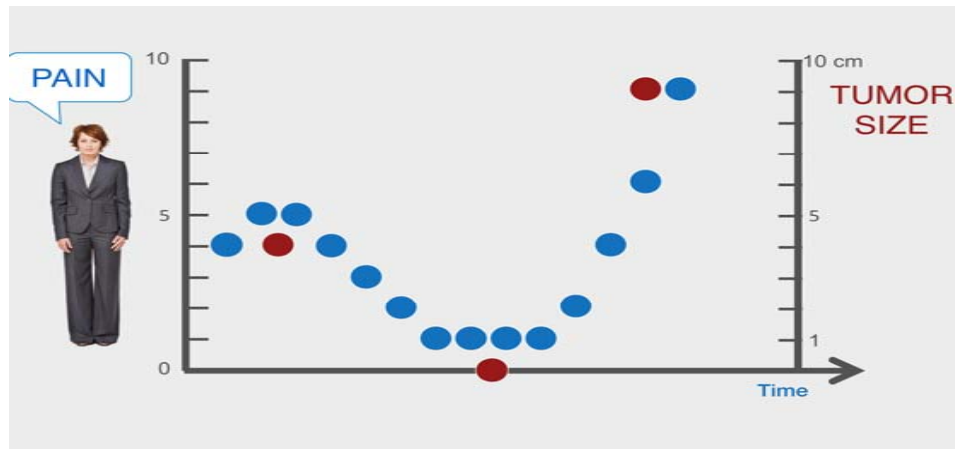
Equal quality of a clinical trial



(Abernethy et al, Health Services Research, 2008)



Reliable data can be parsed out for clinical trials, clinical care, quality monitoring, and outcomes research simultaneously



## Describing the Patient Experience

Research Reports

**JOURNAL OF CLINICAL ONCOLOGY**

JOURNAL OF CLINICAL ONCOLOGY



Individual Patient



Clinical Operations

21% with pain  $\geq 4/10$  on  $\geq 2$  visits



## Bray Patrick-Lake @BrayPatrickLake

- Director of Stakeholder Engagement/Director of Patient Engagement at Clinical Trial Transformation Initiative, Duke University CTSA
- Member, PCORnet Coordinating Center's Executive Leadership Committee
- Patient stakeholder or co-investigator for AHRQ and PCORI grants
- Develops patient engagement strategies for MDEpiNet's National Medical Device Registry, MDIC's Patient-Centered Benefit-Risk Steering Committee, and other orgs

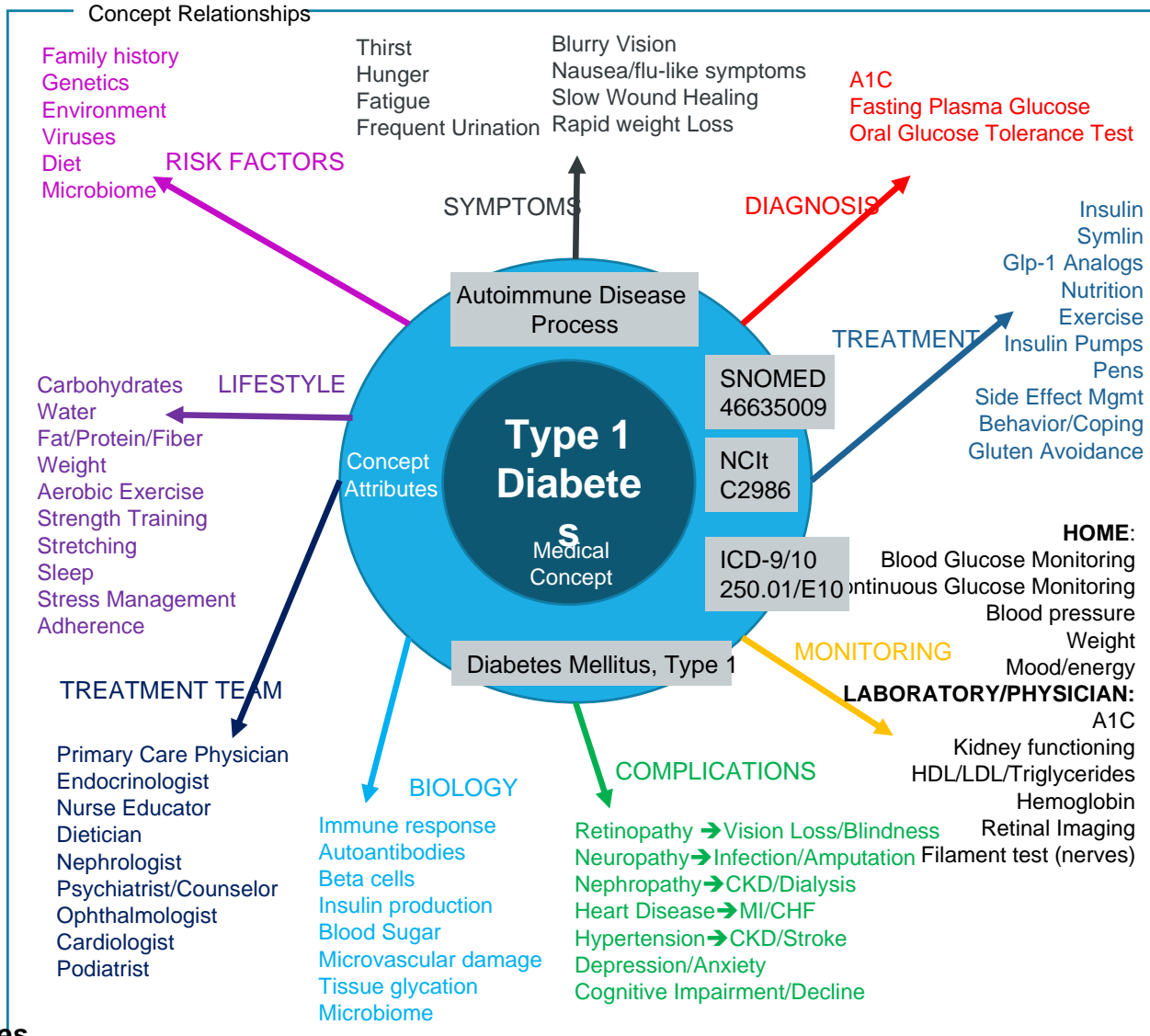


## Jennifer C. King, Ph.D. @JenniferCKing

- Director of Science & Research, Lung Cancer Alliance
- Co-Founder, SHARE For Cures
- Former Director, Data Governance for an oncology learning health system
- Former Scientific Reviewer for ASCO Conquer Cancer Foundation
- Cancer researcher (Memorial Sloan-Kettering + Jonsson Center UCLA)

# Type 1 Diabetes Patient Advocate:

“I can get my head around the fact that autoimmunity is difficult to understand and cure. I can't get my head around the fact that we have this data that is structured, machine readable, that we already understand, that's sitting in pockets in all of the living rooms and computers of patients that generate this data around the country and around the world. The fact that we can't combine that data so that researchers can understand patterns and make connections is incredibly frustrating to me”





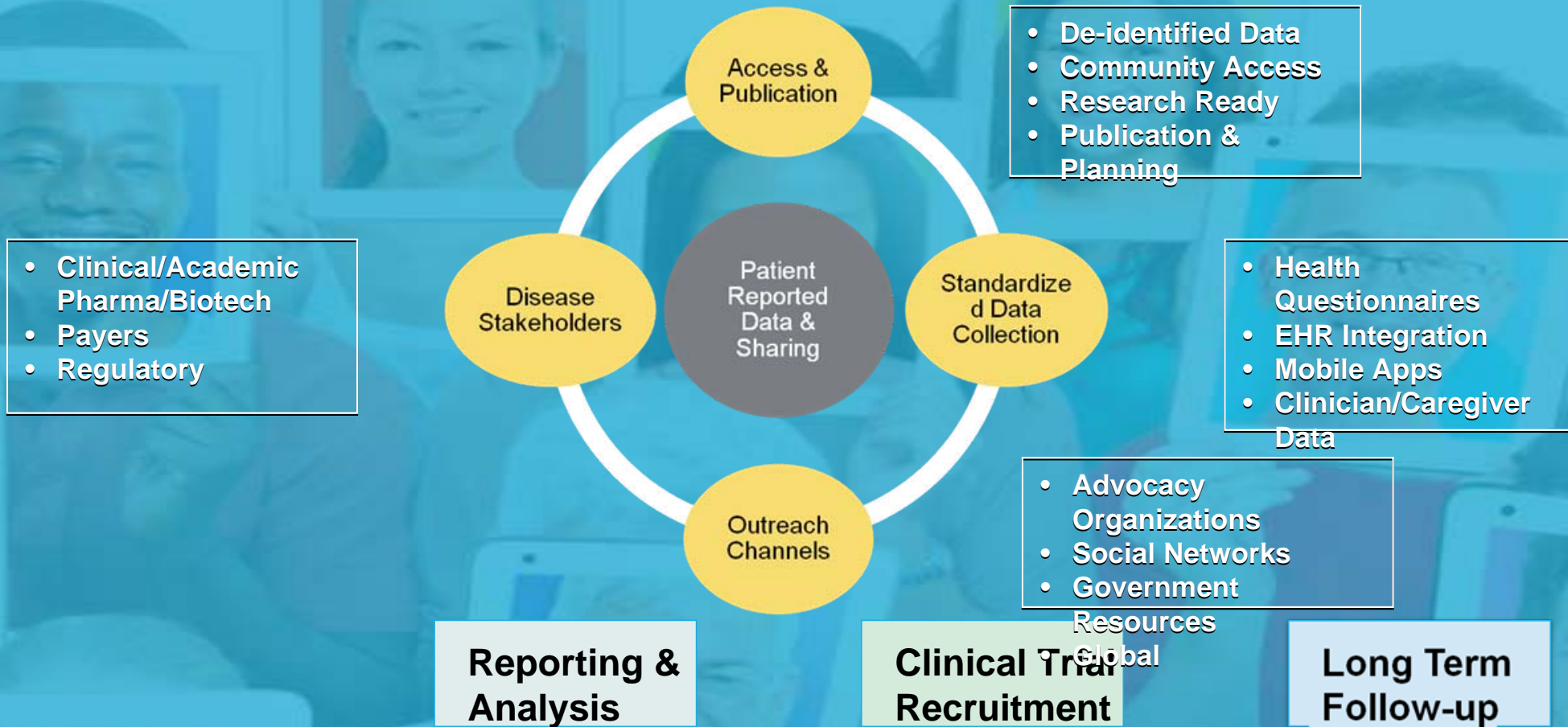
Vanessa Rangel Miller, M.A., M.B.A.  
@VRangelMiller

- VP Genetic Services, PatientCrossroads
- Certified genetic counselor focused on rare disease
- Managed DuchenneConnect & Congenital Muscle Disorders Registries prior to joining PatientCrossroads
- Member of Program Committee for the American College of Medical Genetics and Finance Committee for the American Board of Genetic Counseling



# Registries Empower and Engage Patients

## ILLNESS IS NOT A PERSONAL PROBLEM





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