Connecting the Dots: Alzheimer’s PCPRN and the Learning Health System

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My Story
Thumbnail Sketch

• 20+ years as caregiver, healthcare and social services systems navigator, care transition team
• 3-out-of-4 parents/in-laws with different forms of dementia
• Activist on behalf of those with Alzheimer’s and their family caregivers
My Experience

- Healthcare system unprepared for Alzheimer’s/dementia and family caregivers
- Clinicians are poorly versed in dementia diagnosis and treatment
- Family caregivers assimilate the information they need via tribal knowledge (aka other family caregivers)
- Family caregivers amass critical information about the disease that could potentially help researchers
My Diverse PCORI Roles

- Advisory Council, Alzheimer’s and Dementia Patient and Caregiver Powered Research Network (AD-PCPRN)
- Ambassador
- Board Member, STRIDE study on Falls Prevention
- Technical Expert Panel, PCOR Translation Center (new)
PCORnet: the National Patient-Centered Clinical Research Network

PCORnet is a large, highly representative, national patient-centered clinical research network.

The vision is to support a learning U.S. healthcare system and to enable large-scale clinical research conducted with enhanced quality and efficiency.

The mission is to enable people to make informed healthcare decisions by efficiently conducting clinical research relevant to their needs.
With PCORnet, we have developed a nationwide functional research network that…

- **Engages** people, clinicians, and health system leaders throughout

- **Creates** infrastructure, tools, and policies to support rapid, efficient clinical research

- **Utilizes** multiple data sources including electronic health records, insurance claims data, data reported directly by people, and other data sources
PCORnet embodies a “community of research” by uniting people, clinicians & systems

20 Patient-Powered Research Networks (PPRNs) + 13 Clinical Data Research Networks (CDRNs) = PCORnet

A national infrastructure for people-centered clinical research
PPRNs: A Closer Look

Members of a PPRN may include:

- **Patients** impacted by the PPRN’s disease of focus
- **Caregivers** of those patients
- **Other stakeholders** who are passionate about people-centered research

PPRNs build on their foundation of trust within their patient communities and **ensure the patient voice is embedded into research**. In the process, they help researchers overcome common people-centered research challenges, including:

- Enrolling a diverse and representative patient population
- Engaging patients in governance
- Prioritizing research questions
- Identifying pathways to sustainability
20 PPRNs

- Arthritis
- Breast and ovarian cancer (hereditary)
- IBD and Crohn’s disease
- Epilepsy
- Genetic conditions (general)
- Behavioral health
- COPD
- Duchenne muscular dystrophy
- Heart disease
- Children’s IBD
- Autism
- Mood disorders
- Multiple sclerosis
- Alzheimer’s disease (and other dementias)
- Kidney disease
- Children’s disorders of the joints, muscles, and ligaments
- Phelan-McDermid syndrome
- Immune deficiency
- LGBT health
- Vasculitis (inflammation of blood vessels)
Alzheimer’s and Dementia Patient and Caregiver Powered Research Network (AD-PCPRN)
ALWAYS FATAL
NO TREATMENT

Courtesy: UsAgainstAlzheimer's
Alzheimer’s is the only leading cause of death that is still on the rise.

Courtesy: UsAgainstAlzheimer’s
Until now...

• Alzheimer’s research seriously underfunded compared to other major diseases
• Individuals with Alzheimer’s and their family caregivers disconnected from research
• Lack of participation in clinical trials...
• ...Even less participation by minorities and women
Women and Minorities

- African Americans make up 13.6% of the U.S. population but bear over 33% of the costs of Alzheimer’s and other dementias.
- African Americans are 2 to 3 times more likely to develop Alzheimer’s as non-Hispanic whites.
- More than 60% of costs are borne by women and their families.
- Latinos are about 1.5 times more likely to develop Alzheimer’s and are less likely to recognize the signs and symptoms.
- Latinos make up 16% of the US population but only 1% of clinical trial research participants.
In addition...

- Dementia = costliest disease in America according to RAND
- Dementia costs more to treat than cancer and heart disease, costing up to $215 billion a year
$20 TRILLION
TOTAL COST BY 2050

Courtesy: UsAgainstAlzheimer's
Requiring...

- Full-court press in Alzheimer’s research
- New approaches to finding better treatments and a cure
- Patients and family caregivers actively participating as research partners
Introducing...

• The National Alzheimer’s & Dementia Patient & Caregiver-Powered Research Network (AD-PCPRN)

• Amplifying the Patient and Caregiver voice to accelerate development of effective treatments for Alzheimer’s disease (AD) and related dementias
National AD-PCPRN Partners
AD-PCPRN Collaborators

Banner Health

MAYO CLINIC

GLOBAL ALZHEIMER’S PLATFORM FOUNDATION

US Against Alzheimer’s

Weill Cornell Medical College

BrainHealth REGISTRY

Alzheimer’s Disease Research Centers

Patient-Centered Network of Learning Health Systems (LHSNet) CDRN
National AD-PCPRN Goals

- Enroll an increasingly large number of subjects into this patient-centered network with a minority recruitment focus
- Obtain self-reported information and measures of cognition at baseline and longitudinally
- Screen & refer subjects for clinical trials
- Test a computable patient phenotype

Recruitment of the “right patient” for the “right trial”
One Stop...

Brain Health Registries

AD-PCPRN

Clinical Trials

Virtual Studies
National AD-PCPRN Attributes

- Virtual
- Prevention Observation and Intervention
- African Americans and Latinos
- Caregiver Impact
- Focus on Minority Populations
- Patients and Caregivers
- Developing, conducting, and disseminating patient-focused research
Five Registries

- **Brain Health Registry at UCSF**
  - free, web-based study designed to speed up cures for Alzheimer’s, Parkinson’s, depression, PTSD and other brain disorders
- **Banner Alzheimer's Institute Alzheimer’s Prevention Registry**
- **Cleveland Clinic’s Lou Ruvo Center for Brain Health**
- **TrialMatch, Alzheimer’s Association**
- **Weill Cornell’s AlzU**
Cornerstone Projects

- Recruitment into Registries and Trials
- Health-eBrain Study II
- "A" List 1000
- Patients, Caregivers and Families on the Path to a Cure
Recruitment into Registries and Trials

Our focus is to:

- support recruitment of the "right patient" to the "right trial"
- drive engaged traffic to registry/trial sites

We will be a test-bed for:

- recruitment messaging
- focus group feedback
- stronger minority recruitment
- closed-loop virtual engagement with zero rejection of self-identifying participants

Mobile/online patient recruitment
Health-eBrain Study II

Designed to longitudinally study the impact of caregiving on Alzheimer's and Dementia caregivers (ages 18+)

- using a mobile application approved by the FDA to track the cognitive health of caregivers across disease progression
- a virtual intervention will be offered to a subset of caregivers who meet a certain threshold for depression

Mobile/online cognitive assessment
"A" List 1000

Ethnically diverse assembly of advocates, represented by the UsAgainstAlzheimer’s Networks, committed to advancing clinical trials by:

- signing up for focus groups that respond to researcher queries
- consumer testing mobile health applications
- participating "in virtual clinical trial cohorts" and online registries
Patients, Caregivers and Families on the Path to a Cure

Includes innovative multimedia products:

• On Pluto Project
  ▫ Podcasts featuring people with Alzheimer’s telling their stories in their own words

• Clinical Trials Diary
  ▫ Blog series chronicling patients and family caregivers participating in trials
Important Differentiators

- Family caregivers are key research participants
- Data is shared BACK to the participant
- Continued involvement & engagement of participants after trial/study ends
Our goal is to...

- Change the culture of clinical trials
- Integrate the “Voice of the Patient and Family Caregiver” in drug development
Core Engagement Channels

- alzheimerspcprn.org and galaxybraintrust.org
- AD-PCPRN partner websites
- Social media
- Email
- Community-based outreach
- Presentations at events that reach a range of professional and lay audiences

Bringing Alzheimer’s research to the people
Engagement Messaging Goals

- Demystify trials and registries
- Remove stigma and distrust
- Customize to respect diverse populations
- Use diverse platforms, including mobile technology
- Promote caregivers’ health and validate their pro-active engagement as critical to recruitment and retention in AD clinical trials to accelerate cures
Galaxy: The Hub

- Unique multi-network, consumer-facing virtual hub
- Serves as a technology-driven coordinating center to:
  - connect patients, caregivers, patient advocacy organizations and researchers from industry, academia and government focused on developing, conducting, and disseminating patient-centered dementia research
Connecting the Dots...
Learning Health System and AD-PCPRN

- AD-PCPRN data can inform the Learning Health System
- At the intersection of patient-powered clinical research, improved treatments and care delivery
Working Together... Better Results
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Participatory Healthcare:
A Person-Centered Approach to Healthcare Transformation
(Chapter 7)