

An Update on NIA's Clinical Research Recruitment & Retention Initiatives

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Minority recruitment initiatives

1. Clinical Research Operations and Management System (CROMS)
2. Increase Awareness of AD/ADRD Clinical Research
 - a. Materials Development
 - b. Online tool: Outreach Pro
3. Community Practitioner Research Network

Clinical Research Operations and Management System

CROMS

Clinical Research Operations & Management System (CROMS)

CROMS Purpose:

- Provide institute-wide informatics capability to track, report, and manage NIA's clinical enrollment data, activities, and grant portfolio in near real-time
 - All NIA clinical trials and studies that enroll human subjects

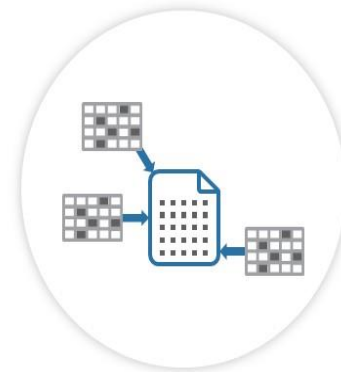
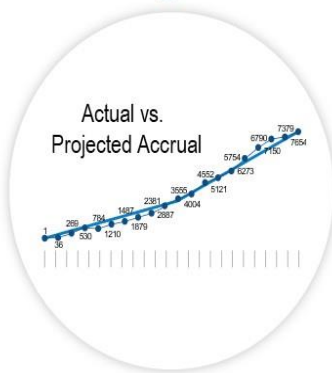


Why an NIA-wide clinical research IT system?



Institutional
Accountability for
Research

Operational Portfolio Management

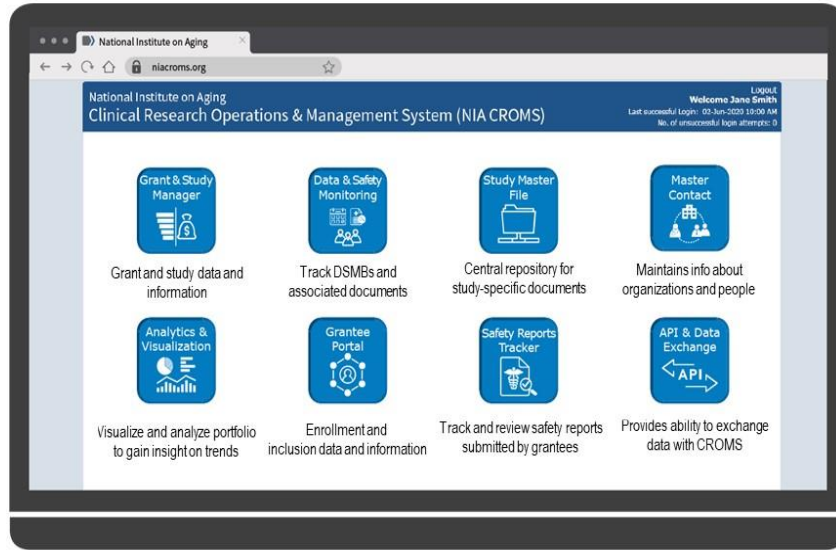


Data Management

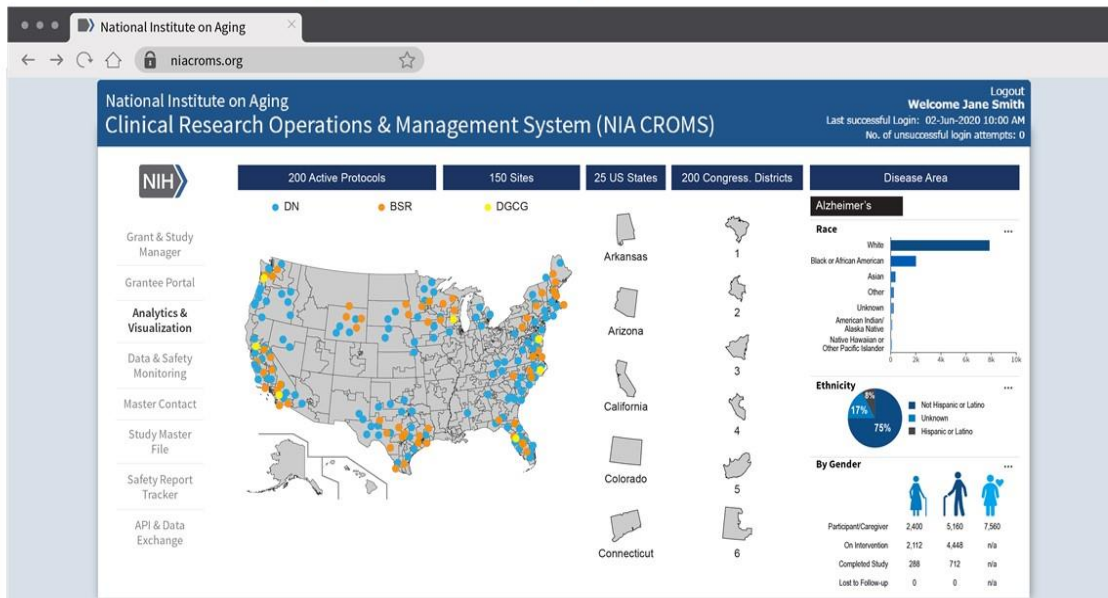
Timeline

- Project began in July 2020
 - Competitively bid
 - Awarded to Digital Infuzion (experience with NIAID, NCI, NIDCR)
- Currently on schedule, despite the many challenges COVID posed
- **First fully operational release scheduled for July 2021**
 - Will address AD/ADRD clinical trials
- Following, will add remaining trials and studies in the NIA portfolio

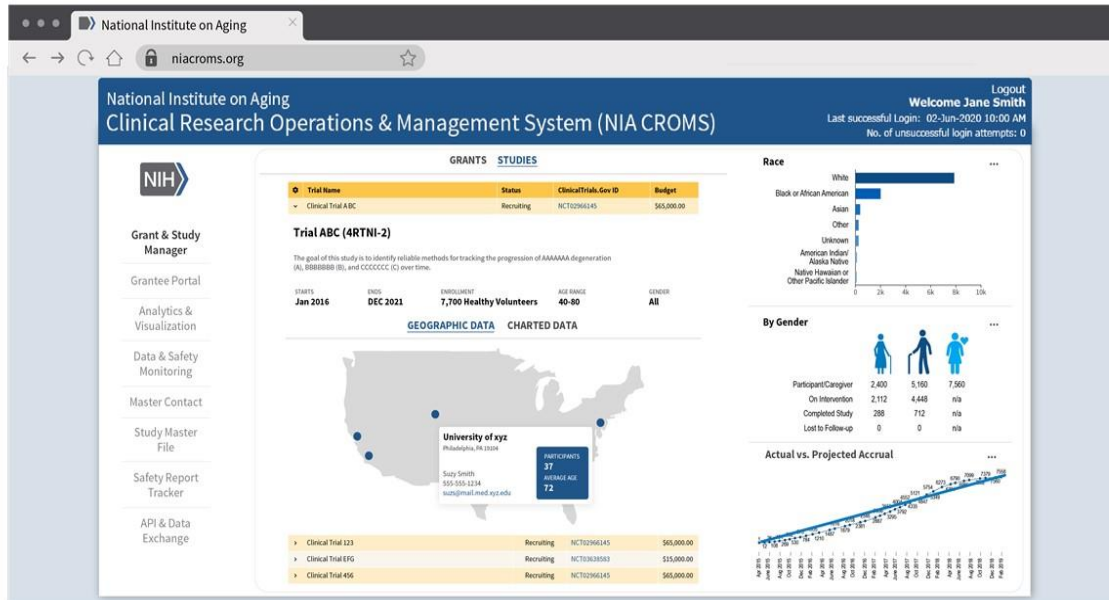
CROMS Components & Features



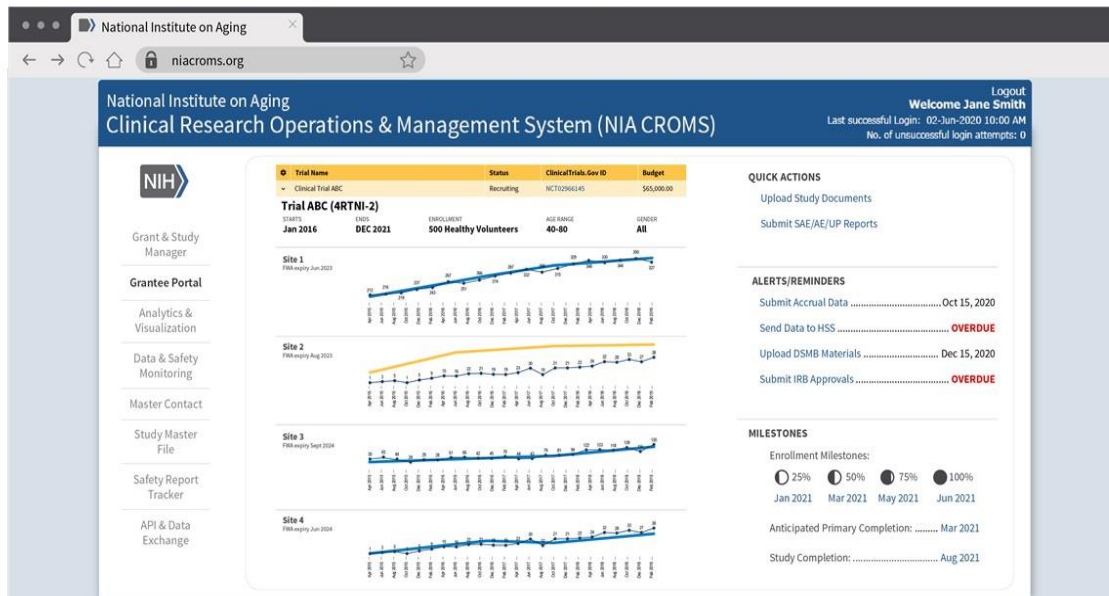
Dashboard Mockups – Overarching View



Dashboard Mockups – Study-Specifics



Dashboard Mockup – Site Performance



Increase Awareness of AD/ADRD Clinical Research

Well-tested Community Outreach Materials for Minority Populations

Objective

Develop AD/ADRD clinical research materials specific to the language and cultural needs of minority populations

- Design of a suite of recruitment outreach materials for minority groups:
 1. African Americans (2019)
 2. Latinos (2020)
 3. Asian American & Pacific Islanders (2021)
 4. Native Americans (2022)
- Materials can be tailored and branded by local community organizations

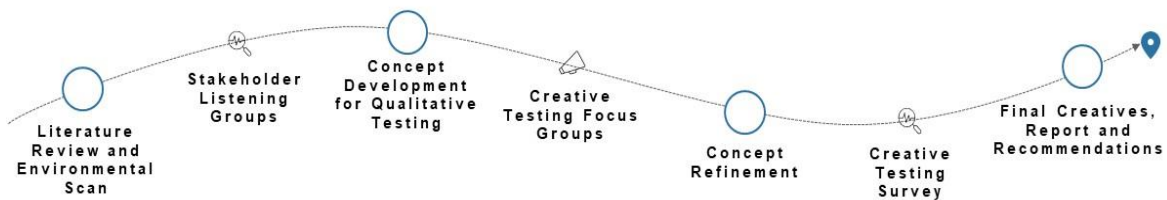
48

Process follows health communication best practices

Outreach Materials Development and Testing

- Conduct qualitative and quantitative research to develop and refine a suite of outreach materials tailored to increase the participation and retention of minority populations in AD/ADRD clinical studies.

Materials include: Leave-Behinds, Fact Sheets, Image Library, Videos, Social Media Posts, and Motion Graphics



49

Creatives

African American Audience



General Audience

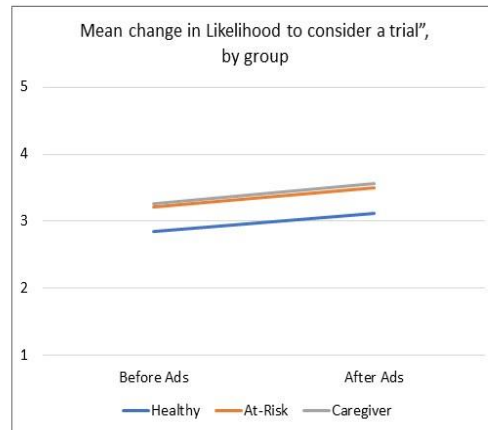
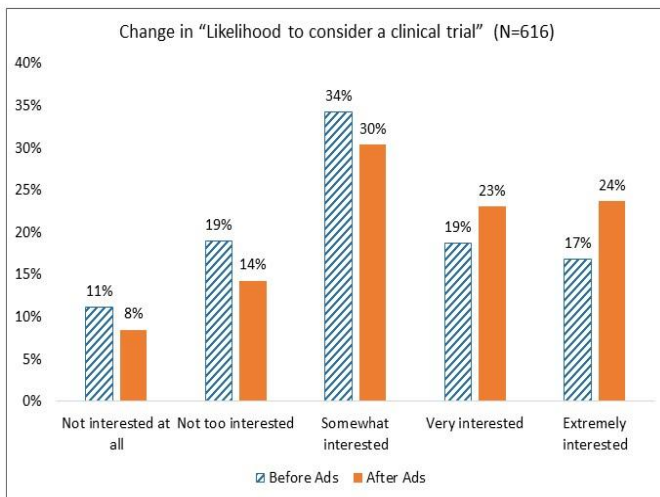


Hispanic Audience



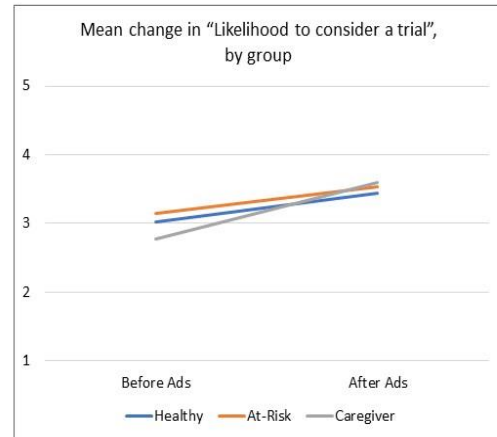
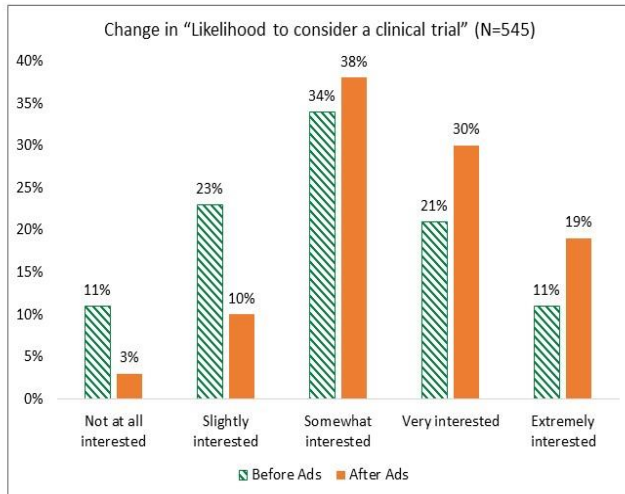
*Currently working with Asian American & Pacific Islander (AAPI) stakeholders to develop a third suite by September 2021

Moving the Needle: African American Research Results



All group increases are significant at $p < .001$

Moving the Needle: Latino Research Results

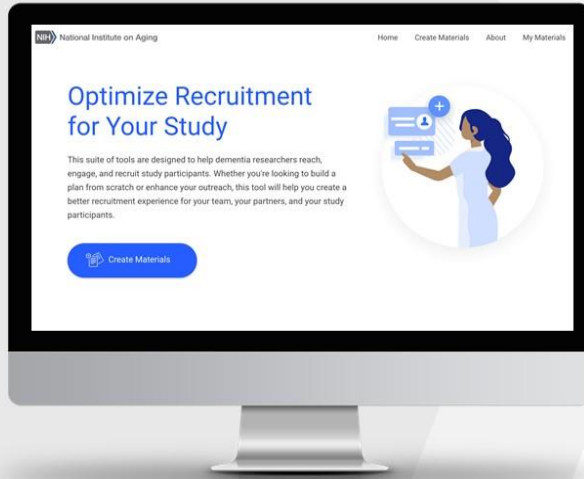


All group increases are significant at $p < .001$

Outreach Pro: NIA's Tool for Clinical Studies Recruitment and Education

Outreach Pro:

NIA's Online Tool for Clinical Studies
Recruitment and Education



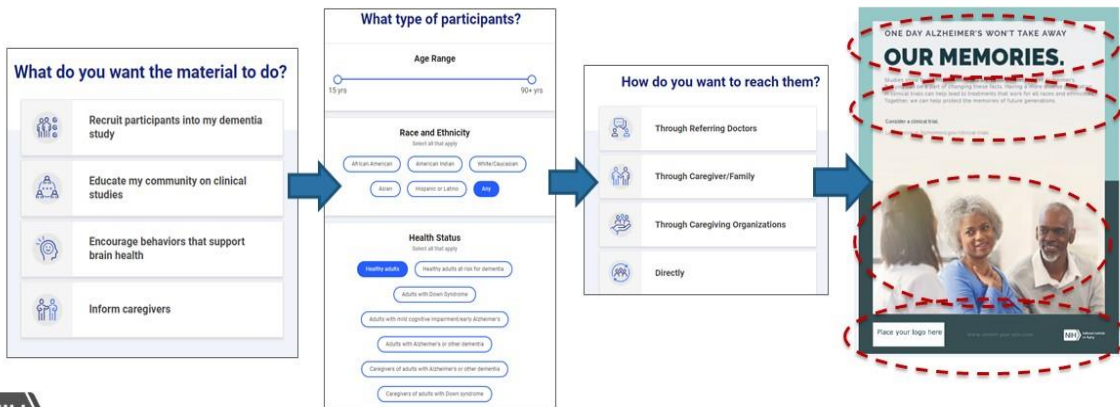
Objective

Provide community stakeholders access to well-tested, evidence-based AD/ADRD clinical research materials and strategies in an easy-to-use web-based communication tool

- Users answer a brief set of questions specific to their audiences of interest
- Tool produces a “package” of tailored materials and strategies that can be branded locally for the end-user’s community.

Outreach Pro

Online tool allows the research community to access, adapt, and personalize the materials that NIA has developed and tested for underrepresented communities through a user-friendly step-by-step process:



Plans for a Community Practitioner Research Network

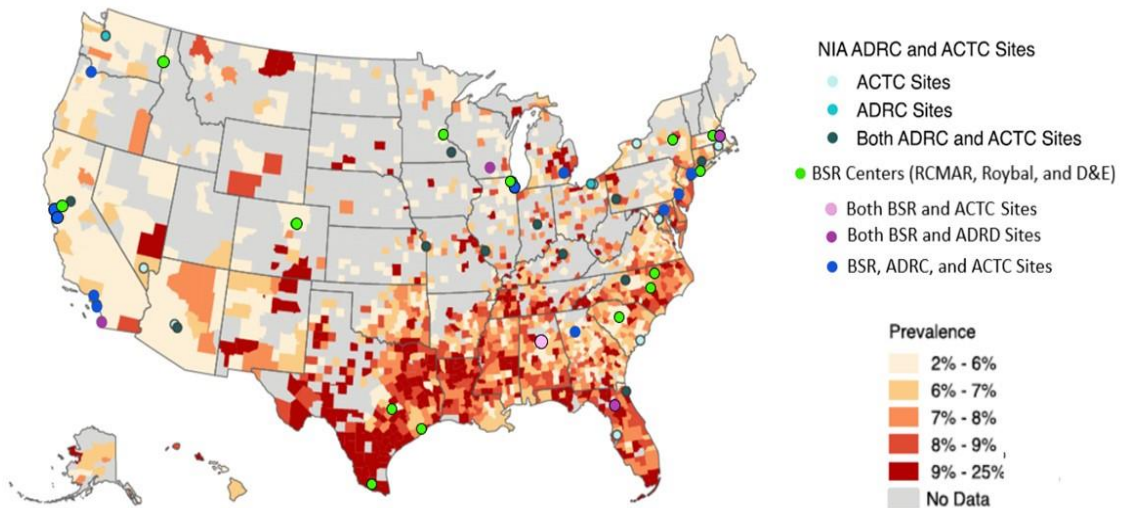
NIA Substantial Investments to Support Clinical Research

Including:

- Alzheimer's Clinical Trials Consortium (ACTC)
- Trial Ready Cohort for the Prevention of Alzheimer's Dementia (TRC-PAD)
- Alzheimer's Disease Research Centers (ADRCs)
- Resource Centers for Minority Aging Research (RCMAR)
- NIA Imbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory
- R24: Examining Diversity, Recruitment and Retention in Aging Research
- Others...

Geographic Distribution of AD/ADRD by Minority Populations

ADRD County-Level Prevalence
Blacks, Hispanic/Latinos, Asian Americans, & North American Natives
Medicare Fee for Service, 2016



Map Generated by National Alzheimer's Disease Index™ Powered by UsAgainstAlzheimer's

Question: How can we better enroll minorities?

- We do not adequately recruit minority participants commensurate to the disease impact
- NIA has programs and research sites across the U.S., though with potential geographic 'gaps' where minorities affected by AD live but have limited/no infrastructure
- Literature continues to report on AD/ADRD clinical research challenges with accessing minority community participation

Conclusion: Our current efforts and resources are important and necessary, but insufficient

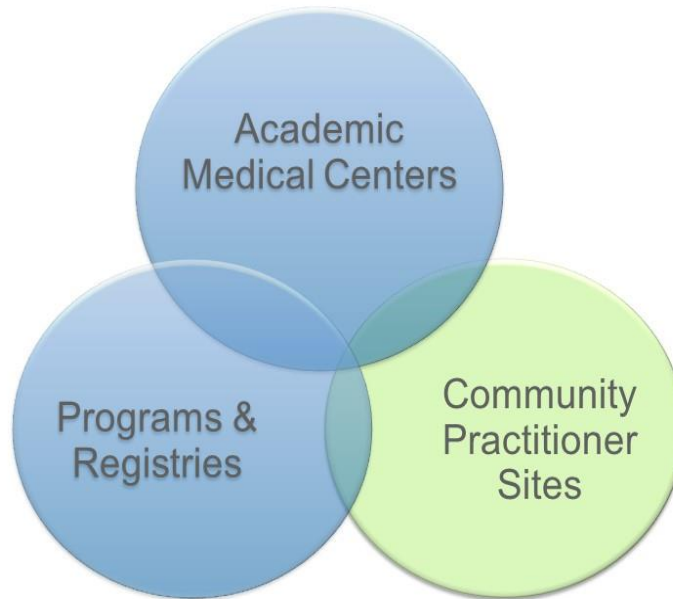
- No matter how hard our current system works to address the inclusion of minorities, it will be difficult to address the gaps

Premise: Go to where the participants live vs. asking participants to come to us

- Build a community infrastructure of PIs and sites in minority communities with high rates of AD/ADRD
- Select sites where doctors/staff have a research interest and relevant expertise
- Nurture and incentivize community sites directly to conduct research



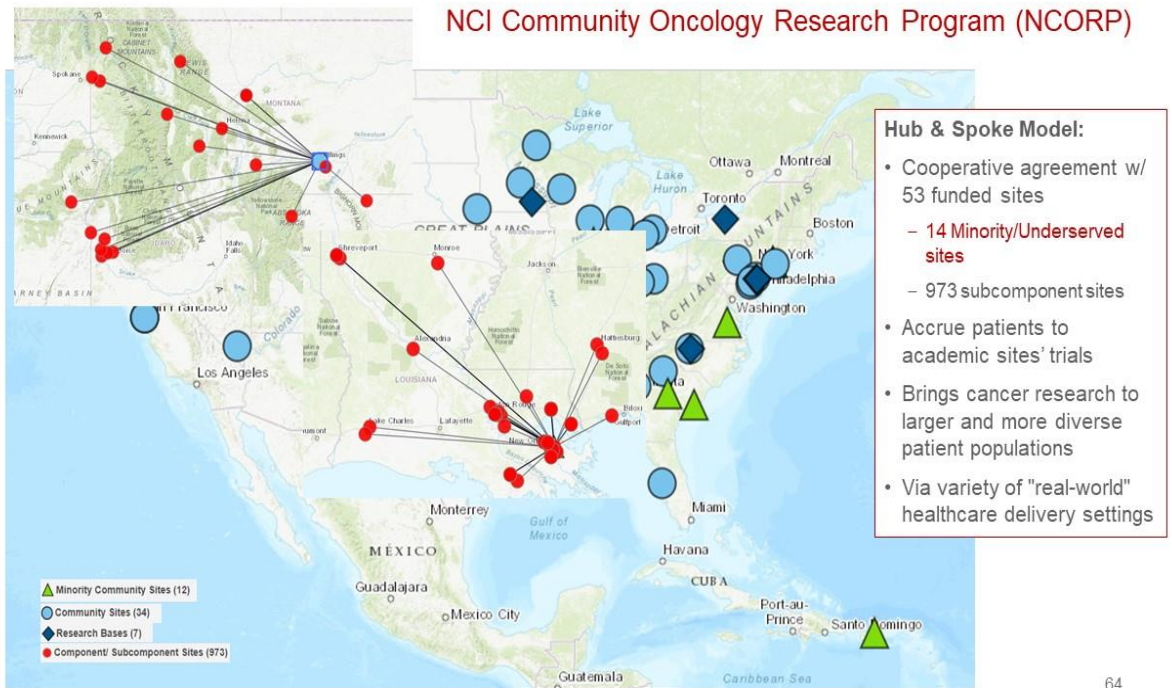
Complement our current resources:



NIH ICs with Community-Based Research Networks

IC	Network	Description
NEI	DRCR Retina Network	160 physician offices with over 500 physicians throughout the United States and Canada to conduct high quality, collaborative clinical research
NIDCR	National Dental Practice-Based Research Network (PBRN)	Over 6,500 dental clinicians conduct research on patient health outcomes, patient satisfaction, or the efficiency of the daily delivery of care.
NIDA	National Drug Abuse Treatment Clinical Trials Network (CTN)	Treatment researchers and community-based substance abuse service providers cooperatively develop, validate, refine, and deliver new treatment options to patients.
NCI	NCI Community Oncology Research Program (NCORP)	Comprised of 7 Research Bases and 46 Community Sites--14 designated as Minority/Underserved Community Sites-- that accrue individuals to NCI-approved cancer clinical trials and research studies.
NHLBI	Pulmonary Trials Cooperative (PTC)	Provides a framework for research leaders to work with a pool of major medical centers and community-based medical providers .
NINDS	Strategies to Innovate EmeRgENcy Care Clinical Trials Network (SIREN)	Enrollment is conducted in diverse patient populations and practice environments including academic medical centers and community ER hospitals to ensure that results can be generalized.
NINDS	StrokeNet	~500 US hospitals conduct small and large clinical trials and research studies to advance acute stroke treatment, stroke prevention, and recovery
NIAID	HIV/AIDS Clinical Trials Networks	Four publicly-funded network collaborations of community and academic sites around the world to address NIAID's five HIV/AIDS scientific priorities

NCI Community Oncology Research Program (NCORP)



64

NCI Minority-based Sites' Accrual Contribution

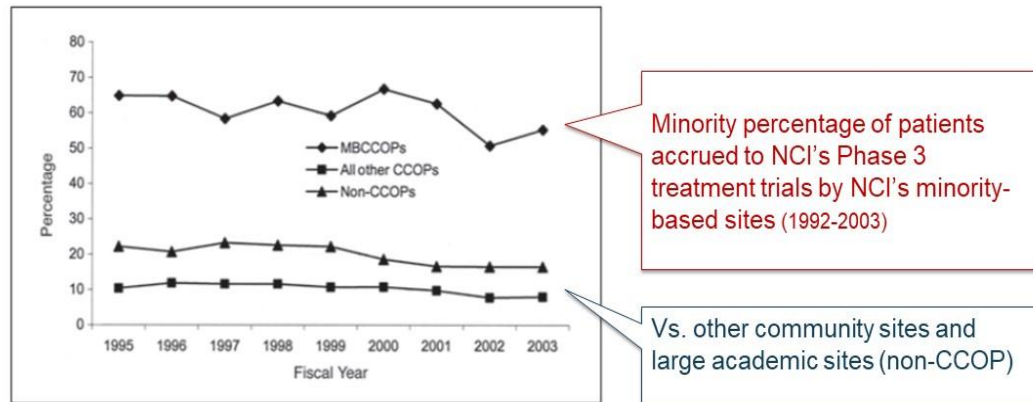


Fig 2. Minority percentage of patients accrued to cooperative group treatment trials by Minority-Based Community Clinical Oncology Programs (MBCCOPs), other Community Clinical Oncology Programs (CCOPs), and non-CCOP members/affiliates. Non-CCOP members of cooperative groups include academic medical centers, National Cancer Institute–designated cancer centers, and other large research institutions. Affiliates include community hospitals and oncology practices that affiliate with cooperative groups through “main member” institutions. *J Clin Oncol* 23:5247-5254, 2004.

65

Next Steps

1. Internal NIA Community Practitioner Research Network Committee
 - Meeting regularly to identify needs, define vision, propose strategy
2. Input from the Field: One-day Community Practitioner Research Network Symposium
 - Virtual meeting in early April 2021 (tbd), 12-5 pm EST
 - Invite stakeholders from around country to participate in a discussion exploring potential models for a NIA community practitioner research network

66

Thank you!

Questions?

67



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