All of Us Research Program: Engaging and Representing Health Center Patients in a National Research Program

Community Health Center Inc.

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The Precision Medicine Initiative Cohort Program – Building a Research Foundation for 21st Century Medicine

Partners in Success!

Two concurrent programs at CHC

NIH National Institutes of Health
All of Us Research Program

MITRE

Quest Diagnostics™

FY 2018 Advancing Precision Medicine Supplemental Funding Opportunity

HRSA
Health Resources & Services Administration

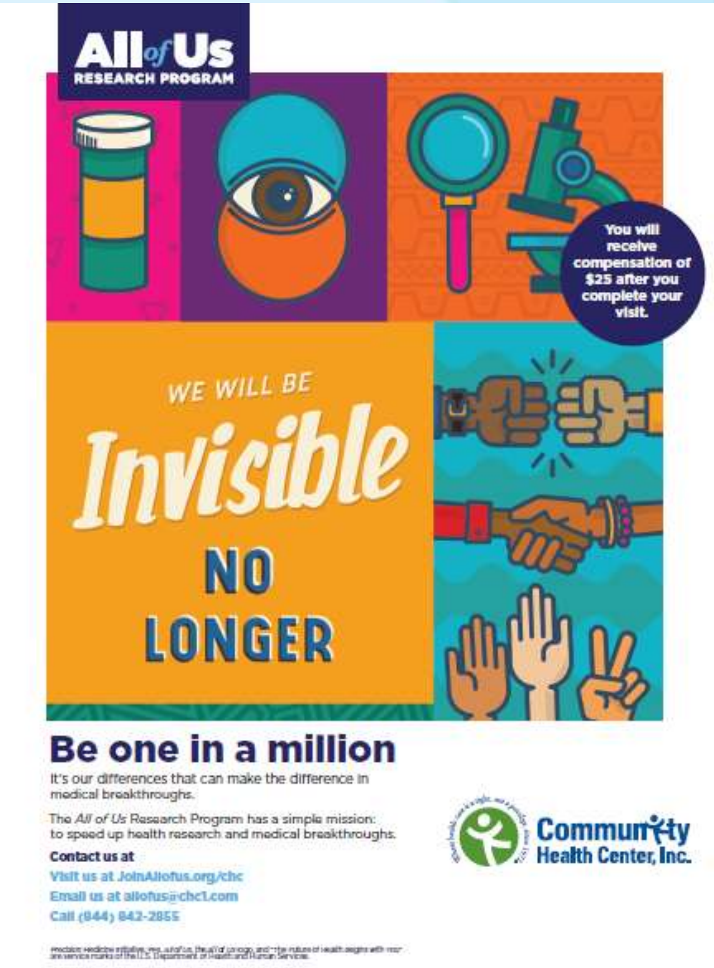
MITRE

Team Composition

- ✓ Principle Investigator and Deputy Principle Investigator
- ✓ Program Manager
- ✓ Engagement Lead
- ✓ Electronic Health Record Lead
- ✓ Electronic Health Record Data Specialist (Business Application Analyst)
- ✓ Communications Partner
- ✓ Research Technicians
- ✓ Engagement and Outreach Specialist

The Participant *JOURNEY*

- Community Outreach and Participant Exposure
- Participant Engagement
- Participant Registration
- Informed Consent & Electronic Health Record Consent
- Participant Enrollment
    - Participant Provided Information Modules 1-3
    - Physical Measurements
    - Biospecimens
    - Full Enrollment Incentive
- Participant Retention
    - Post-Enrollment engagement
    - Post-Enrollment activities
- Return of Information



You will receive compensation of $25 after you complete your visit.

Be one in a million

It's our differences that can make the difference in medical breakthroughs.

The *All of Us* Research Program has a simple mission: to speed up health research and medical breakthroughs.

Contact us at
Visit us at JoinAllofus.org/chc
Email us at allofus@chc1.com
Call (844) 842-2855

Strategies for *EXPOSURE and ENGAGEMENT*

"Exposure is the process of providing materials and information to an audience through a unidirectional interaction. Engagement is the process of listening to, responding to, and supporting the audience in a bidirectional interaction."

Methods of exposure and engagement

- Tabling
- Phone calls
- Letters
- Emails
- Information sessions

Strategies for *ENROLLMENT*

"Enrollment is the process of providing information to the program to enable full participation through registration and consent."

- Staffing
    - Bilingual
    - Culturally Competent
    - Relationship and Trust building
- Privacy of space
- Facilitated enrollment
    - Digital technology support
- Phone based enrollment
- On-site physical measures and biospecimens
- Partnership with Quest for biospecmin collection

Be one in a million.

The more researchers know about what makes each of us unique, the more tailored our health care can become.

Join a research effort with one million or more people nationwide to create a healthier future for all of us.

To start your journey, go to Participant.JoinAllofUs.org and:

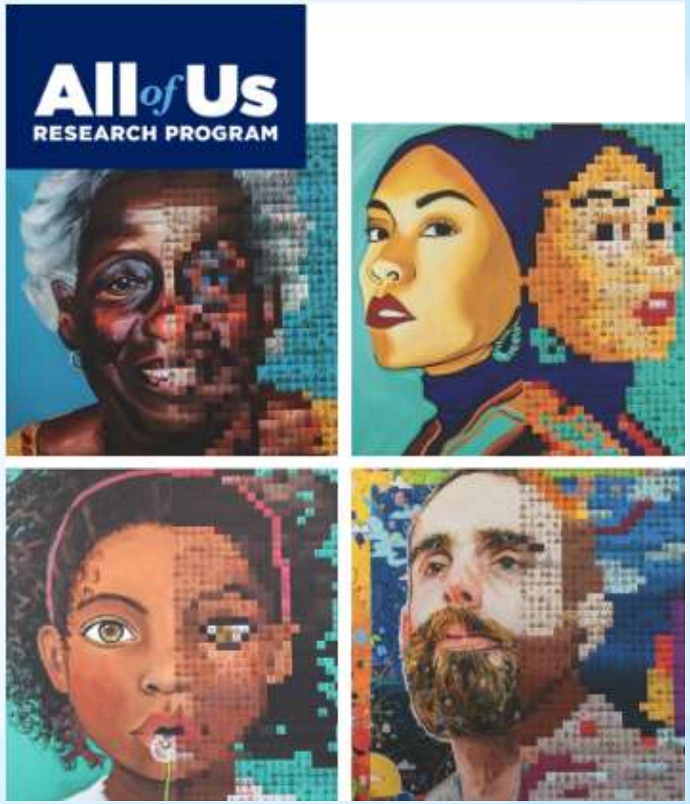
After completing these steps, you'll receive $25.

To learn more and to enroll, contact us at:

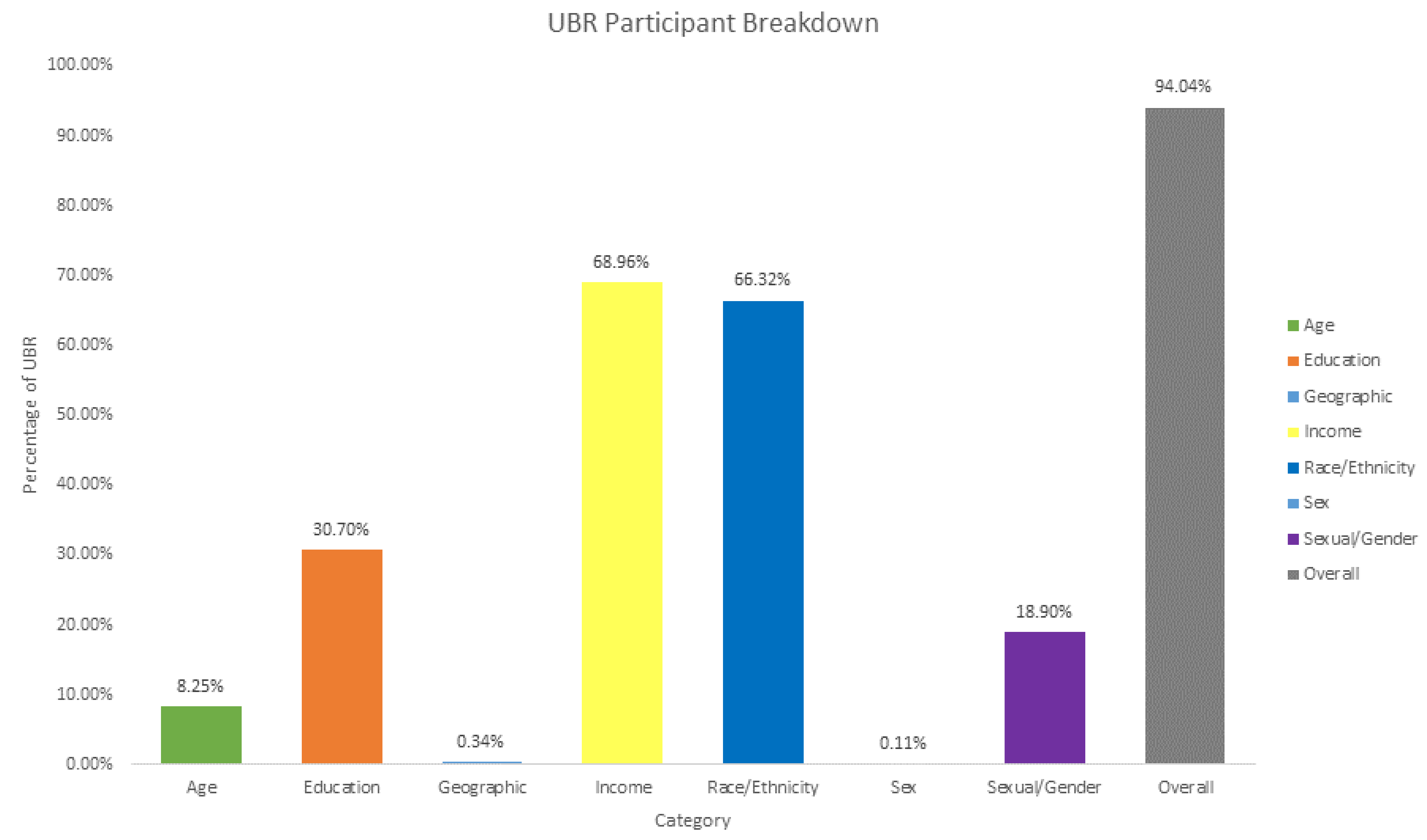
Strategies for *RETENTION*

“Retention is the process of providing ongoing activities with participants after enrollment.”

- Completion of PPI modules 4-6
- Phone calls
- Cards for birthdays & anniversaries
- Thank you packets
- Newsletters
- Communication from the program
- Presentation announcements
- Submission of wearable devices
- Retention parties



Participants Underrepresented in Biomedical Research



Challenges

Challenges to participation and retention

- Trust
- Digital Literacy
- Understanding of research
- Time
- Not have full information about program
- Other more important concerns

National Impact

- Unprecedented number and diversity of people impacted by program
- Provision of EHR data with national program while ensuring privacy and security standards are upheld
- Access to data by all levels of research from citizen scientists to international research institutes
- Groundwork for developing precision medicine
- Opportunity to promote FQHC-strength and expertise at national level with large research and academic medical centers
- Collaborative relationships with new national partners

CHC Impact

- Creation of a diverse team of researchers at CHC with a strong connection to clinical services
- Culture of data driven and continuous improvement
- Engagement with CHC IRB
- Expansion of CHC’s exposure/engagement in biomedical research/genomic medicine
- Inclusion of almost 1000 CHC patients in national research program
- Heightened awareness among CHC staff on precision medicine and UBR population
- New level of engagement with patients in a 10-year longitudinal study
- Opportunity to educate patients on use of patient portal
- Opportunity to outreach to communities
- Promotion of digital literacy among patients
- Patients sense of empowerment
- Opportunity to collaborate with school based health centers and local universities

Greatest benefit of program is for our patients

Not only is *health care a right, not a privilege*

But the opportunity to participate in research

is a right, not a privilege

Questions?

www.weitzmaninstute.org