

National Hispanic Medical Association Overview

NHMA & All of Us Puerto Rico: Advancing Health Research in Puerto Rico

www.nhmamd.org HispanicHealth.info VaccinateForAll.org



About NHMA

Established in 1994 in DC, the National Hispanic Medical Association (NHMA) is a 501(c)(6) non-partisan, non-profit membership association representing the interests of 50,000 licensed Hispanic physicians in the United States.

The vision of the organization is to be the national leader in improving the health of Hispanic populations.

The mission of the organization is to empower Hispanic physicians to lead efforts to improve the health of Hispanic and other underserved populations in collaboration with Hispanic state medical societies, residents, medical students, and other public and private sector partners.





What does NHMA do?

Advocacy

Lead public and private sector efforts that improve the health and wellness of Hispanic and other underserved groups.

Leadership Development

Provides leadership development to Hispanic physicians and other health professionals.

Networking Opportunities

Provides career enhancement and growth for members through national and regional conferences.



What does NHMA do? (cont.)



NHMA provides a great learning network for every level:

- Current/Retired physicians and other health professionals
- International Medical Graduates
- Medical/Graduate students
- Pre-Health professional students



As a rapid growing national resource based in the nation's capital, NHMA:

- Serves as a resource to the White House, Congress, and the federal government
- Develops leadership for public health and private sector Boards and C Suite Positions
- Provides networking opportunities with stakeholders who impact Hispanic health



NHMA and All of Us

Nationwide Impact

NHMA has made a significant impact across the nation. Leveraging our extensive network of physicians, we have actively participated in community events, recruited participants and researchers, and hosted both in-person and virtual events.

Our efforts have strengthened community ties and advanced our mission to improve health outcomes for Hispanic and underserved populations.



All of Us Research Program Key Definitions & Acknowledgement

- Engagement: A broad range of relationship-building bidirectional interactions, including information sharing, consultation, collaboration in decision making, and empowered action between the program, people, awardees, and other partners.
- Outreach: Unidirectional interaction, such as providing materials and information to an audience.
- Recruitment: Facilitating enrollment in the program.
- Retention: Ongoing activities with participants after enrollment.

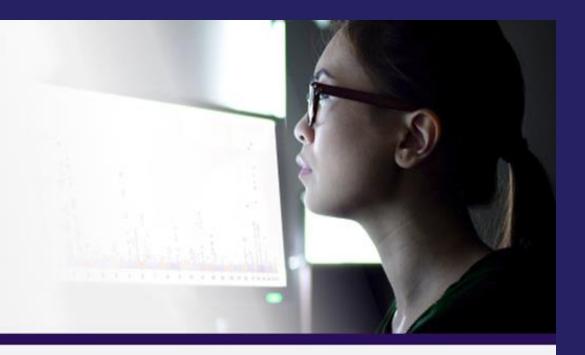
Source: All of Us Research Program protocol

Welcome to the All of Us Research Hub

The National Institutes of Health's All of Us Research Program is building one of the largest biomedical data resources of its kind. The All of Us Research Hub stores health data from a diverse group of participants from across the United States.

Register for the Researcher Workbench to access data and tools to conduct health research and improve understanding of health and disease.

REGISTER FOR ACCESS



All of Us Research HUB

Data Snapshots

Data Snapshots showcase the breadth and depth of the All of Us Research Program dataset. The snapshots provide participant demographics, geographic distribution, and more. We update the snapshots daily.







432,000+

Electronic Health Records

Biosamples Received

VIEW MORE DATA SNAPSHOTS



All of Us Research Program Key Definitions & Acknowledgement

- Researcher Engagement: Intentional, bidirectional relationship and capacity building with researchers and their communities across all career stages, institution types, and demographics, emphasizing researchers underrepresented in the biomedical workforce (UBW) through ongoing information sharing, collaboration, consultation, empowerment, and support.
- Outreach: Unidirectional interaction, such as providing materials and information to an audience.
- Researcher diversity: Defined across multiple dimensions, including demographics (inclusive of self-reported race/ethnicity, sex, gender, and SGM status, and disability), career stage, and institution type.

Source: All of Us Research Program protocol

Acknowledgement: This event is funded by the Division of Engagement and Outreach, *All of Us* Research Program, National Institutes of Health. Award Number [Pyxis Partners: OD028404]

All of Us Research: How It Works





1. Participants share their data with the All of Us Research Program through multiple sources. These data are sent to a secure cloud environment, managed by the Data and Research Center.



- 2. Participant data is received and funneled through a curation pipeline* within a secure repository that connects to the Research Hub tools.
- * researchallofus.org/data-tools/ data-sources



3. Anyone can visit the Research Hub to learn more about the types of data All of Us makes available for research. The Survey Explorer 1 and Data Browser 2 offer more information about the unique data elements and let visitors browse

researchallofus.org/data-tools/ survey-explorer

aggregated participant data.

² databrowser, research allofus, org



- 4. Researchers register* for access to the Researcher Workbench to analyze data.
- * researchallofus.org/register



5. Registered researchers in the Researcher Workbench can create research projects using collaborative workspaces, cohort-building tools, interactive notebooks, and more.



- 6. Research underway can be viewed on the Projects Directory.¹ Publications related to All of Us
 - Research Program data are posted on the **Publications page**.²
- researchallofus.org/research-projectsdirectory
- ² researchallofus.org/publications

Data access

Three Tiers



Public Tier

The Public Tier dataset is available at <u>ResearchAllofUs.org</u>. Visitors can explore aggregated overviews and interactive data previews—with participant identifiers removed—through the Data Browser. Registration is not required.



Registered Tier

Includes individual-level data from EHRs, wearables, and surveys, as well as physical measurements taken at the time of participant enrollment. Registration and a Responsible Conduct of Research training are required for access.



Controlled Tier

Includes data available on the Registered Tier, as well as genomic data and expanded demographic, survey, and EHR data. Genomic data includes whole genome sequences, long read sequences, genotyping arrays, and structural variants. Researchers must have amended institutional agreements and complete an additional training to access this tier.

How to Gain Institutional Access to the All of Us Dataset

The Data Use and Registration Agreement (DURA) Process



Researcher or institutional signing official submits access request form*

Request is
processed by the
Internal Access
Team at the All of Us
Data and Research
Center, operated by
Vanderbilt University
Medical Center
(VUMC)

VUMC signing official reaches out to institutional signing official

Communication between VUMC signing official and institutional signing official Institutional signing official submits a partially executed agreement that is then approved by a VUMC signing official

Once
approved,
institutional
access is
granted to
Registered
and/or
Controlled
Tiers

Researcher
can create
their
All of Us
Researcher
Workbench
account

Submit a DURA Request



Visit the *All of Us*Research Hub to
get started

https://allofus.org/DURAForm

*Researcher tip:

You will need to provide the name of a signing official at your institution.

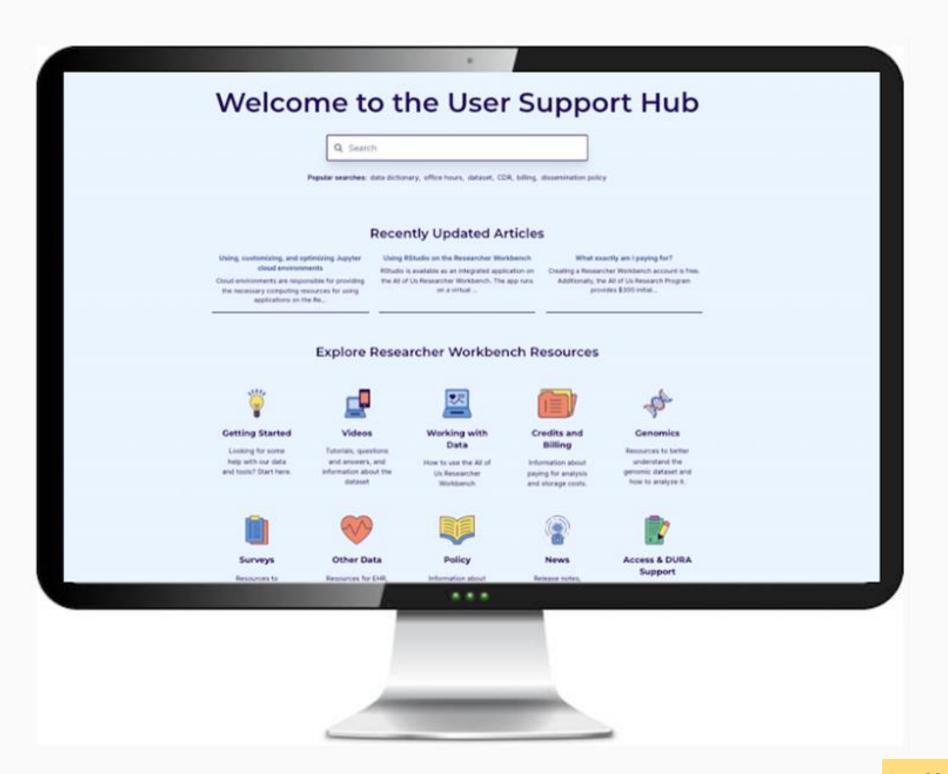






Resources from All of Us Research Program

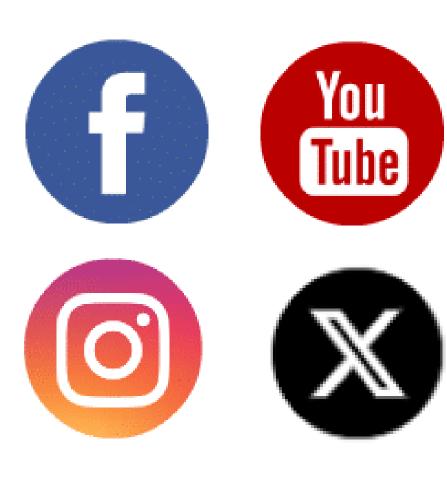
- . Researcher Hub
- Data browser
- Data Snapshots
- Privacy & Security
- Survey Explorer
- Workbench Create an Account
- User Support
- Research Highlights
- Spotlights
- Research Projects Directory
- Registered Institutions



Learn More



JoinAllofUs.org ResearchAllofUs.org



@AllofUsResearch
#JoinAllofUs



AllofUs.nih.gov



Puerto Rico Consortium for Clinical Investigation (PRCCI)

Presenters:

Zulmarie Vázquez Ortíz, MBA Juliemar Aponte González, MS



Subsidiary of the:



Conozca a nuestro equipo



Amarilys Silva-Boschetti, PharmD Investigadora Principal



Zulmarie Vázquez Ortíz, MBA Gerente de Programa



Juliemar Aponte González, MS Asociada de Investigación



Camille M. Ríos Ortíz, MSN
Coordinadora Clínica

¿Qué es PRCCI?

El Consorcio para la Investigación Clínica de Puerto Rico es una organización sin fines de lucro, subsidiaria del Fideicomiso para la Ciencia, Tecnología e Investigación de Puerto Rico, fundada en Abril del 2016.

Objetivos de PRCCI:

- Optimizar la calidad de los estudios clínicos en Puerto Rico
- Establecer las mejores practicas de ejecución de estudios clínicos en la isla
- Educar a pacientes, investigadores y al público en general sobre la importancia la investigación clínica

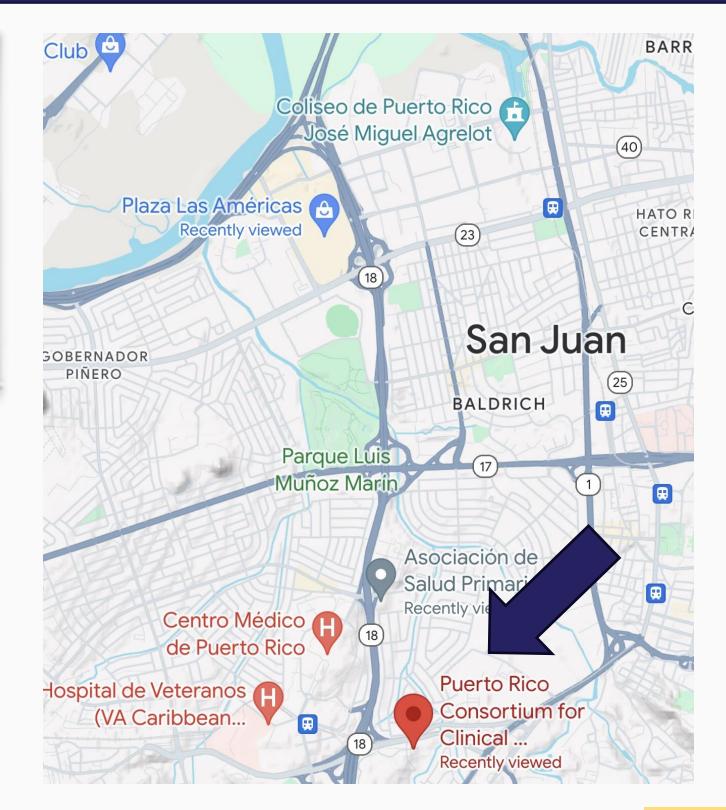


¿Dónde queda localizada nuestra clínica?









Sobre nuestro centro de reclutamiento para el Programa Científico All of Us

- Comenzamos a reclutar participantes el 2 de octubre de 2023 en Mindful Medical Research Center
- Al día de hoy: 322+ participantes registrados

275+ participantes completados

Recientes colaboraciones:

- Sociedad Americana del Cáncer
- Instituto SanaCoop
- Eli Foundation
- Fundación de Enfermedades Reumatológicas de PR
- Asociación Puertorriqueña de Diabetes
- Puerto Rico Public Health Trust
- Asociación de Alzheimer de Puerto Rico



(787) 360-6927 (787) 308-0968 JoinAllofUs.org/PRCCI



Subsidiary of the:









NHMA & All of Us Puerto Rico: Advancing Health Research in Puerto Rico

VA All of Us Research Program at the VA Caribbean Healthcare System





Elizabeth Laboy-Marte, MS - Research Coordinator Irma L. Molina-Vicenty, MD – ACOS for R&D

VA Caribbean Healthcare System, San Juan, PR

Disclaimer: "The contents of this Presentation do not represent the views of the Veterans Affairs Caribbean Healthcare System, the U.S. Department of Veterans Affairs, or the United States Government."

What is the NIH All of Us Research Program?



The *All of Us* Research Program is a historic, longitudinal effort to **gather data from one million or more people** living in the United States **to accelerate research and improve health**. By taking into account individual differences in **lifestyle**, **socioeconomics**, **environment**, **and biology**, researchers will uncover paths toward delivering **precision medicine** – **or individualized prevention**, **treatment**, **and care** – **for all of us**.



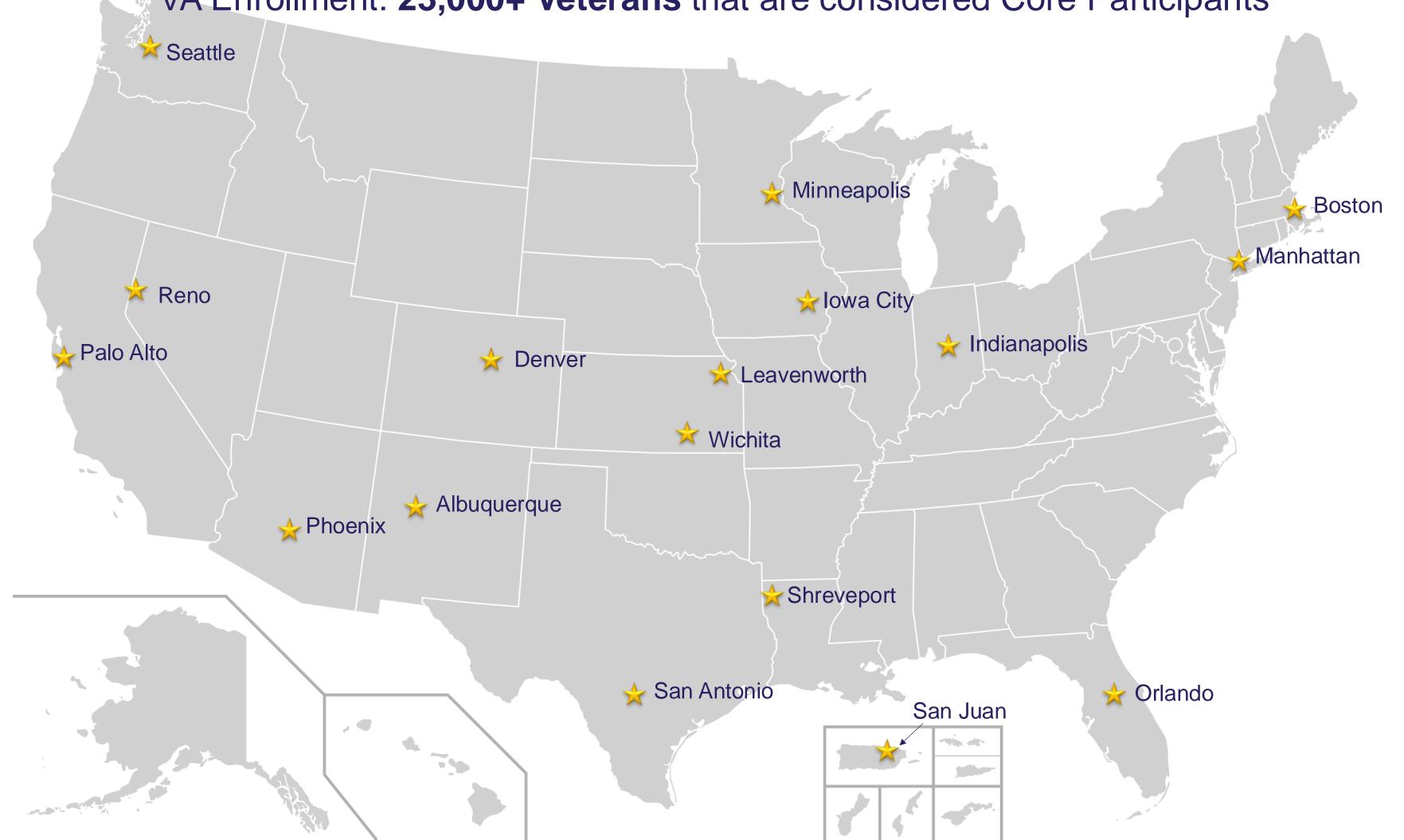
"All of Us is among the most ambitious research efforts that our nation has undertaken!"

NIH Director Francis Collins, M.D., Ph.D.

Importance of Veterans in the All of Us Research Program

- Diverse Health Profiles: Veterans often experience unique health issues, including PTSD, traumatic brain injuries, and other service-related conditions.
- Representative Data: Veterans comprise a significant portion of the U.S. population and have diverse backgrounds and experiences. Including them helps ensure that the research findings are representative of the entire population, not just civilian segments.
- Unique Environmental Exposures: Veterans may have been exposed to specific environmental factors during their service. Understanding the long-term effects of these exposures can lead to better treatments and preventive measures.
- Enhanced Healthcare Insights: The Veterans Health Administration (VHA) provides a rich source of health records. Integrating these records with the All of Us dataset can offer deeper insights into healthcare delivery and outcomes, potentially improving healthcare strategies for both veterans and the general population

VA Enrollment: 23,000+ Veterans that are considered Core Participants



VA Caribbean Healthcare System

- The VA Caribbean Healthcare System provides Veterans with outstanding health care, trains America's future healthcare providers, and conducts important medical research.
- We proudly serve nearly 71,000 Veterans from all municipalities of Puerto Rico and the US. Virgin Islands.
- Facilities include our San Juan VA Medical Center and 10 outpatient clinics: 8 Puerto Rican clinics in Arecibo, Ponce, Comerío, Ceiba, Guayama, Mayaguez, Utuado, and Vieques; and 2 in the U.S. Virgin Islands: St. Croix and St. Thomas.



- Integrity
- Commitment
- Advocacy
- Respect
- Excellence

VACHS All of Us

Site Launch

The VA All of Us Research Program officially launched at the VACHS SJ VA Medical Center the past July 17th, 2023.

Enrollment Numbers

467 Veterans enrolled as Core Participants

Main Challenge

 Many interested Veterans living outside the Metropolitan area face difficulties traveling to our San Juan site, causing enrollment barriers.

Main Focus

Bringing the All of Us Research Program to all VACHS
 Veterans, including those outside of the PR
 Metropolitan area, and the USVI.



VACHS All of Us - Outreach and Engagement Efforts

Passive Outreach 1/month

- VA Caribbean Healthcare System Facebook Page
- Todo Sobre Veteranos Radio Show @ NotiUno 630 Station

Active Outreach 2/month

- Tabling at VACHS Veterans Town Hall Meetings
- Tabling at USVI CBOCs
- Tabling at the SJ VA Medical Center

Enrollment Events at the Ponce OPC

VSOs Collaboration

- American Legion
- Disabled American Veterans
- Warrior Allegiance





Dr. Bonilla and Ms. Laboy at a Veteran Town Hall Meeting celebrated the past February 15th 2024 in Guayama, PR.



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The VACHS All of Us Site Staff



From left to right: Mrs. Elizabeth Laboy-Marte; Dr. Ingrid M. Bonilla Mercado; Dr. Irma L. Molina-Vicenty; Dr. Lourdes Guerrios-Rivera; Mrs. Nicole M. Cerón-Fidalgo



Ms. Xiomara Torres-Figueroa on her first Outreach Event at the VA Eurípides Rubio Ponce OPC

Visit Our Website to Learn More

Veterans.joinallofus.org



We're Bringing the Future of Health to America's Veterans. Join Us.

Clinic Phone – (787) 641-7582 x110174;110127 VHAAoUVACaribbean@va.gov AoU VA Call Center – (833) 805-0426 allofus@va.gov

<u>Acknowledgment:</u> This material is based upon work supported with funds from the National Institutes of Health Precision Medicine Initiative (Award # AOD16037; Subaward # 5021aIAA) and the use of resources and facilities of the Research and Development Service of the Department of Veterans Affairs, Caribbean Healthcare System San Juan, P.R.



All of Us
Research Program
COSSMA







COSSMA

- As a Federally Qualified Health Center (FQHC), it delivers primary health services to the population of the eastern region of the Island.
 - FQHCs are entities that serve medically underserved populations and people who do not have health insurance or whose health insurance is limited.

Some of the populations that COSSMA serve are:

- People who live under the Federally Poverty level (FPL).
- Farmers
- Elderly population
- People with limited access to healthcare
- Populations in need of primary healthcare services









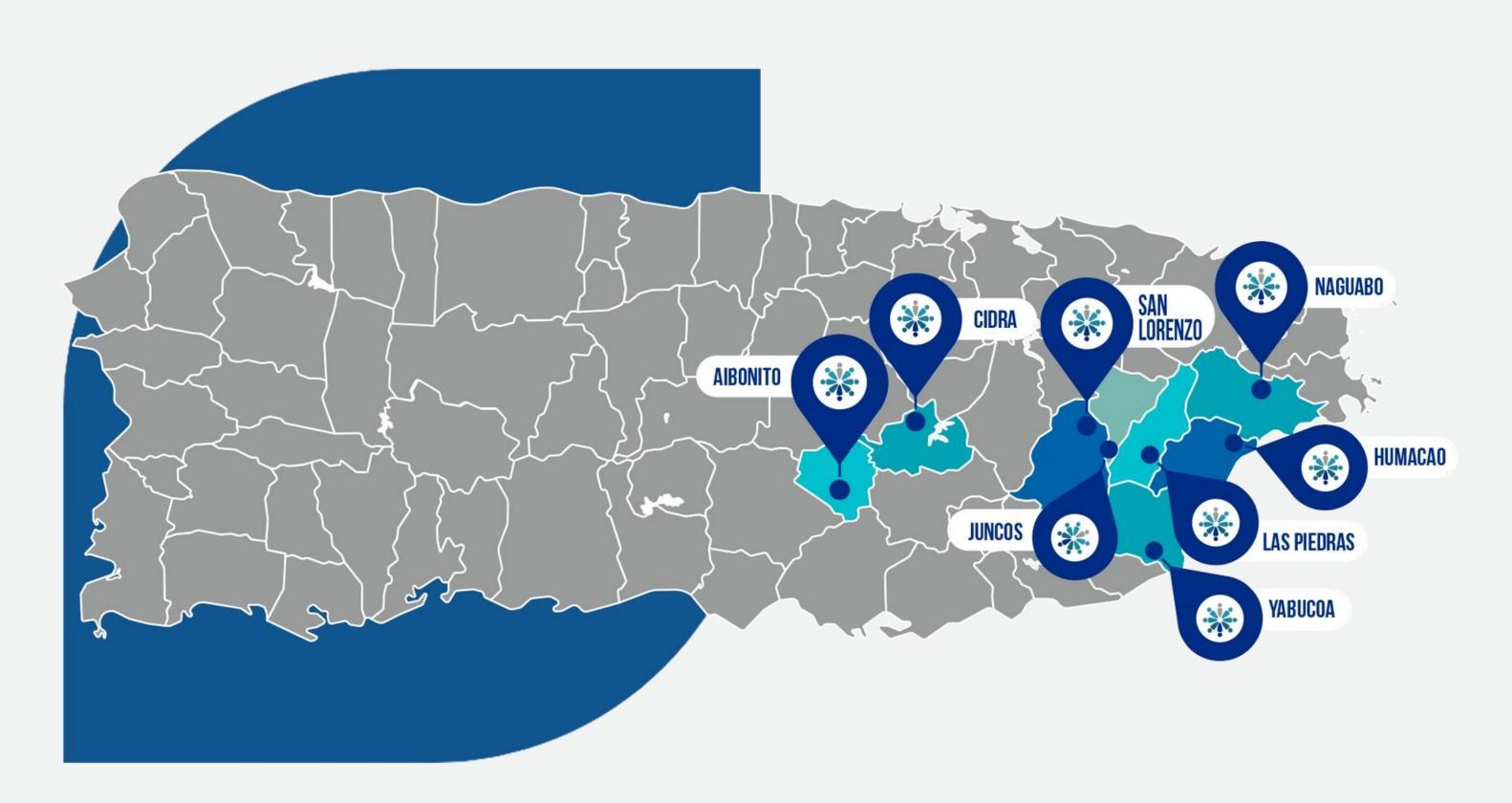






COSSMA Clinics



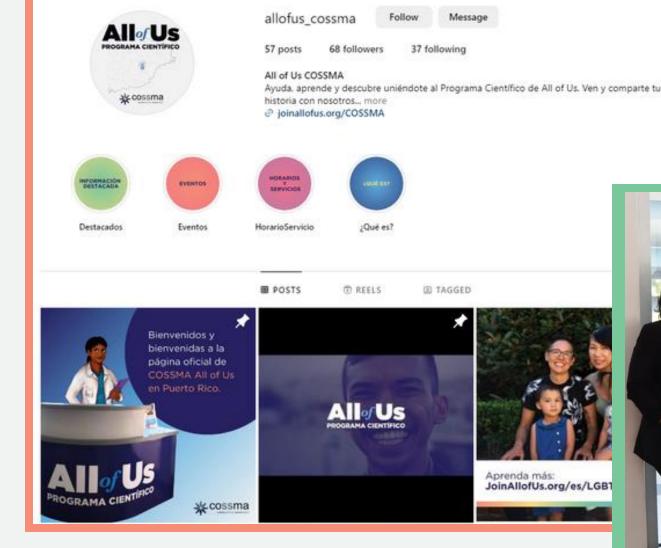


All of Us COSSIMA



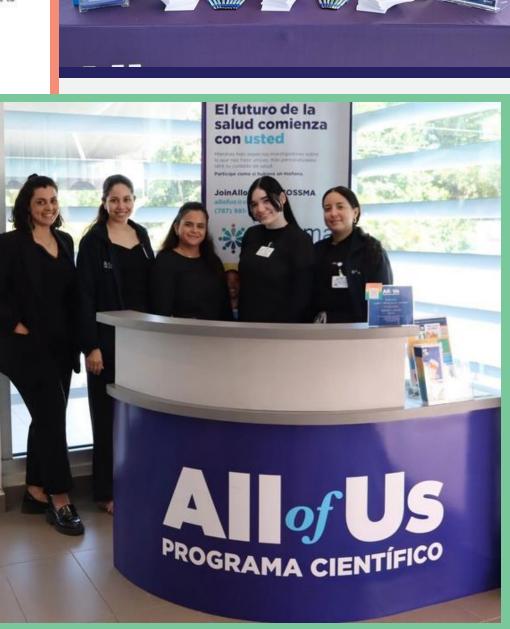
All of Us - COSSMA

- Recruitment at COSSMA clinics and Community Events
- Not required to be a COSSMA patient
- Assist Participants in the enrollment process
- Educational social media posts regarding Research Highlights and precision medicine









All of Us - COSSMA



Enrollment Sites



COSSMA Las Piedras

Main Enrollment Site Monday, Wednesday & Friday 7:30am-3:30pm



COSSMA Humacao

Modified Clinic Site Tuesday 7:30am-1:30pm



COSSMA San Lorenzo

Modified Clinic Site
Thursday
7:30am-1:30pm



Get Involved!

Refer Friends and Family

787-981-7570 | 787-378-2692

AllofUs@cossma.org

JoinAllofUs.org/COSSMA



UPR-Comprehensive

Cancer Center





UPR- Comprehensive Cancer Center



Consortium: South East Enrollment Center (SEEC)

PI: Dr. Vivian Colón López

Launched: March 6, 2023

Personnel: Coordinators, Recruiters, IT staff, Nurses, and laboratory technicians

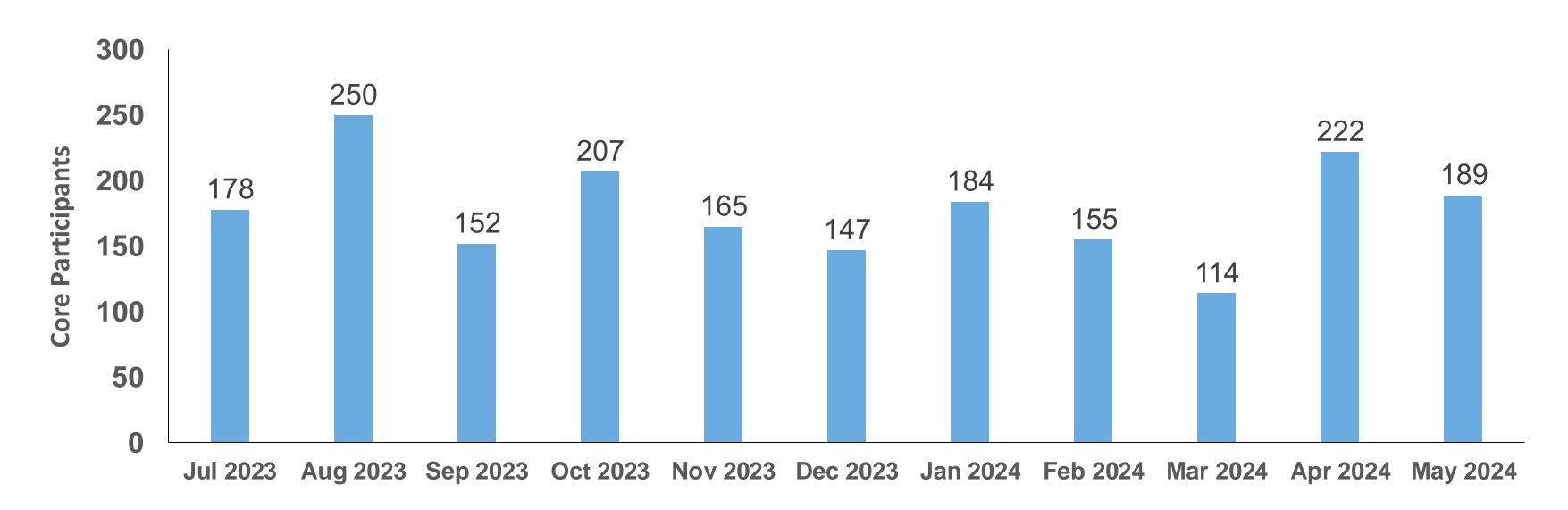




Efforts



Core Participants: Recruitment during the YR6 (n= 1963)



Source: All of Us HealthPro platform



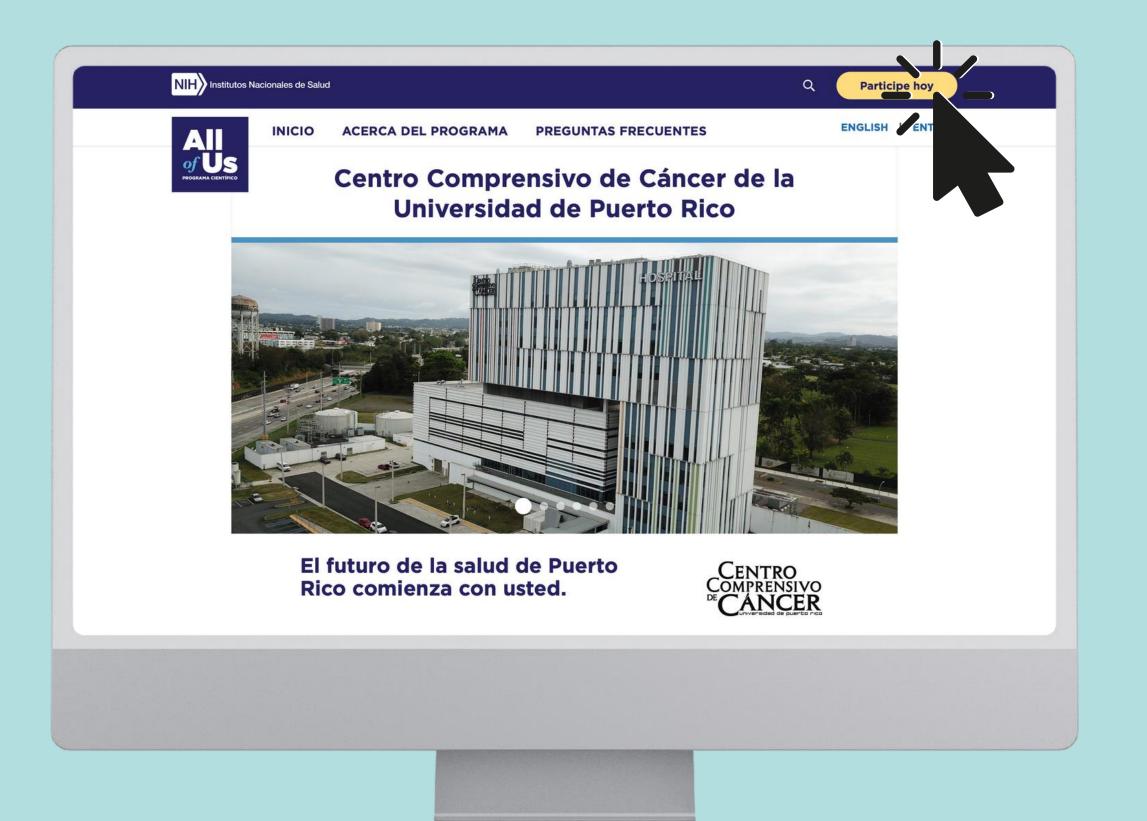
Outreach







Need more information...





Contact













CONTACT

www.nhmamd.org



nhma@nhmamd.org



(202) 628 - 5895



1920 L St NW #200, Washington, DC 20036





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THANKYOU