Leveraging Real-time Data Platforms to Advance Data-Driven Recruitment: A Demonstration of Cross Core and Cross ADRCs Collaboration

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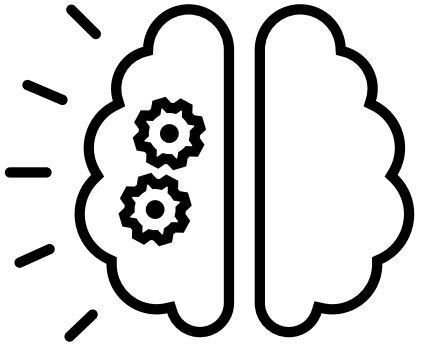
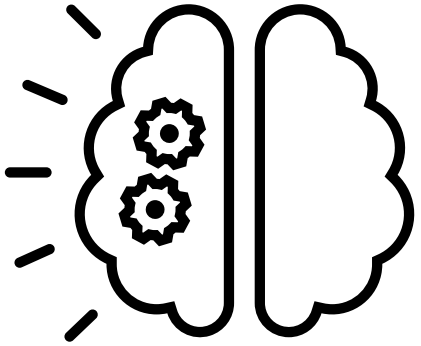
Background: Recruitment Challenges



- Transformative treatments are increasing interest in Alzheimer's disease and related dementias (ADRD) research
- In the rush to enroll eligible participants, many studies lack adequate representation across socio-economic, geographic, and racial/ethnic lines
- ADRD researchers are challenged with recruiting diverse and representative samples of participants as efficiently as possible
- The existing recruitment model was inadequate to meet the increasing research needs before and will only fall further behind in the future

Background: Recruitment Challenges

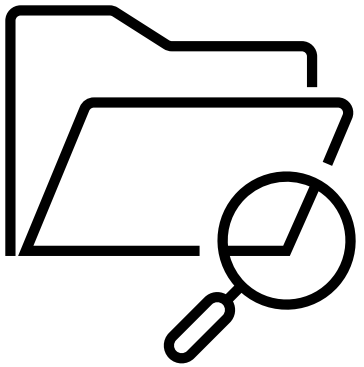


- Kansas University ADRC developed a centralized, data-driven model to accelerate clinical trial and research study recruitment

- Key elements of the KU Recruitment Model include:
  - dedicated staff to handle research inquiries
  - a “customer” oriented approach
  - accessible intake information for recruitment and study team members
  - regular process evaluation of recruitment efforts

- **These activities are supported and enhanced by a data backbone**

Participant Information Tracking and Coordinating Hub (PITCH)



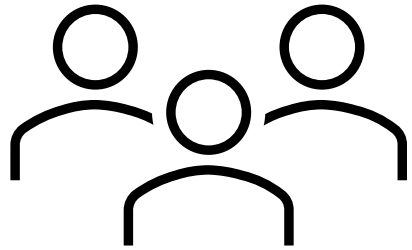
Overall Goal:

- Support all Vanderbilt ADRC (VADRC) outreach, recruitment, and engagement activities

Primary Functions:

- Evaluate the effectiveness of VADRC community engagement and recruitment strategies
- Monitor participants' progression through the VADRC enrollment pipeline
- Support the simultaneous enrichment of multiple ADRD studies
- Offer a web platform for external investigators to access registry participants

User-Centered Design Development



User-Centered Design:

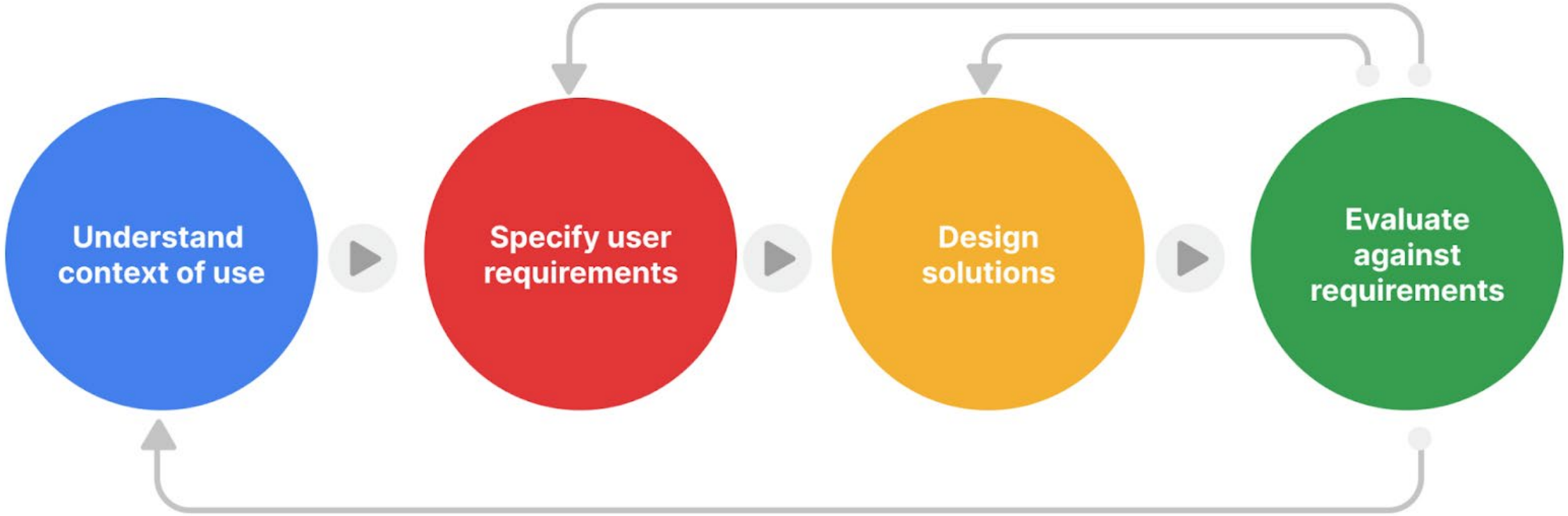
- Feedback from end-users is iteratively incorporated into platform development and updates

End-Users:

- Local ADRD investigators and staff
- Users based at other ADRCs
- The broader ADRD research community

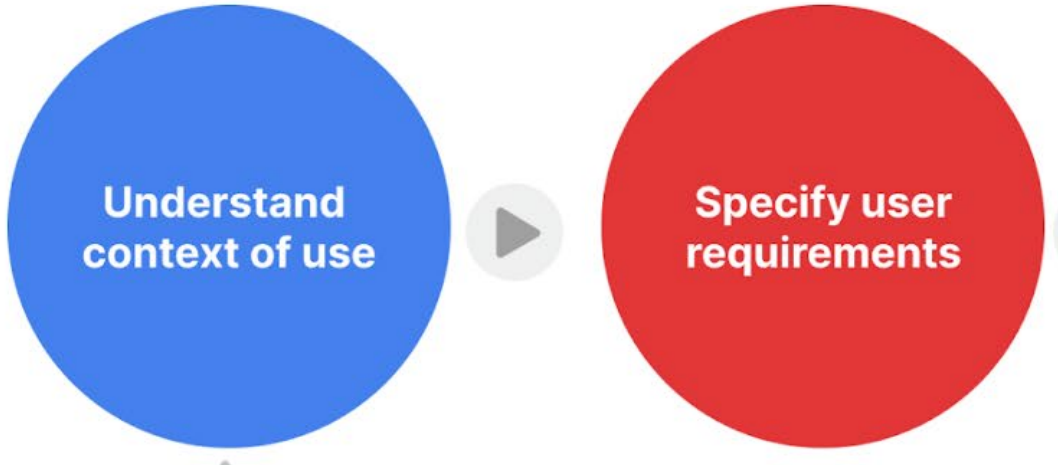
User-Centered Design Development

Each iteration of PITCH user-centered design involved four distinct phases:

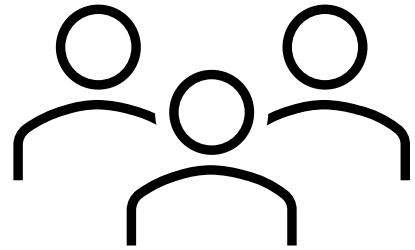


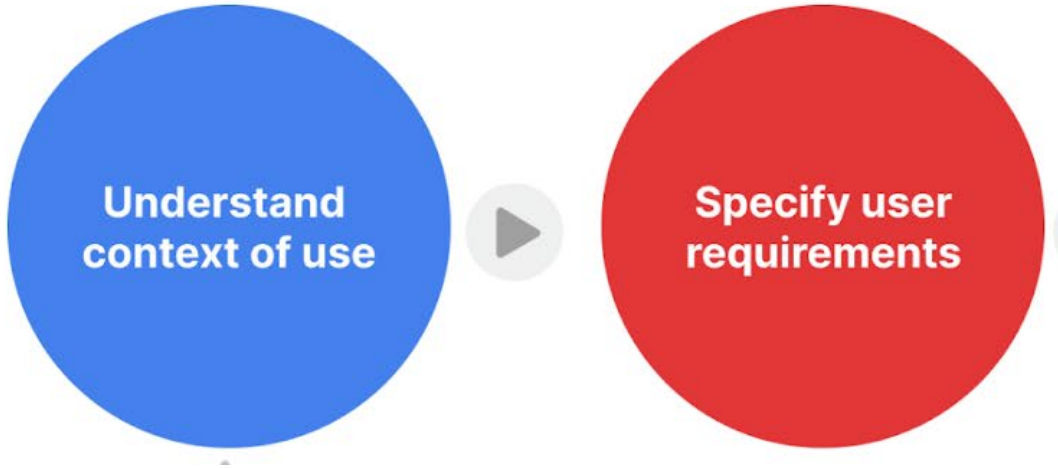
User-Centered Design Development

Fall 2021: Listening sessions with ADRD investigators, Outreach, Recruitment, and Engagement (ORE) team members, and clinic study staff.



User-Centered Design Development



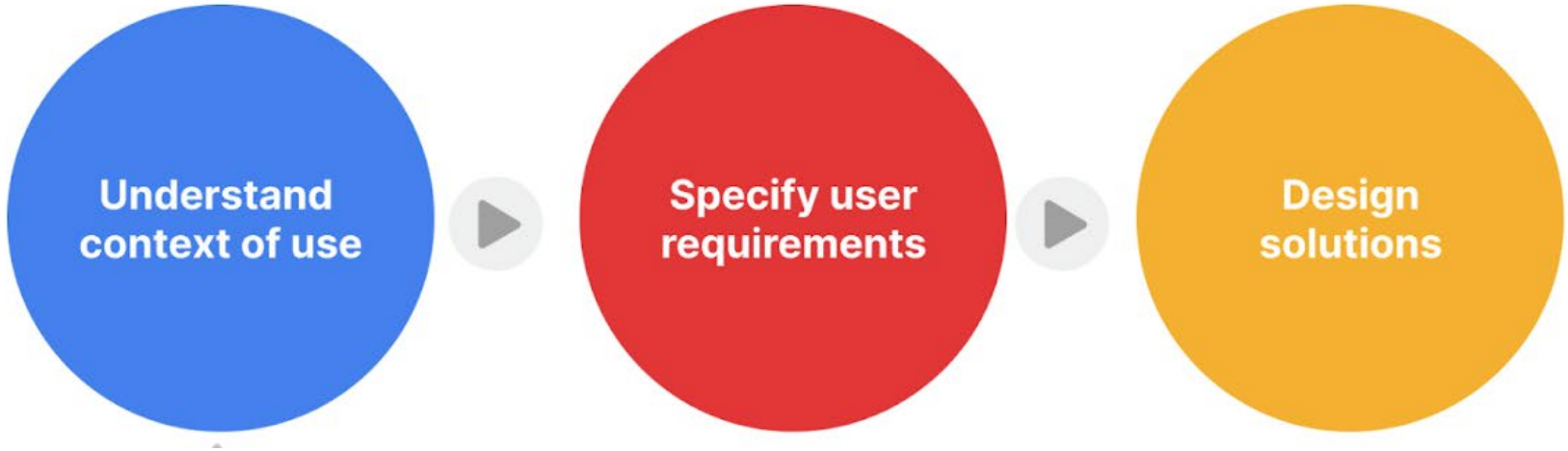


Specified Requirements:

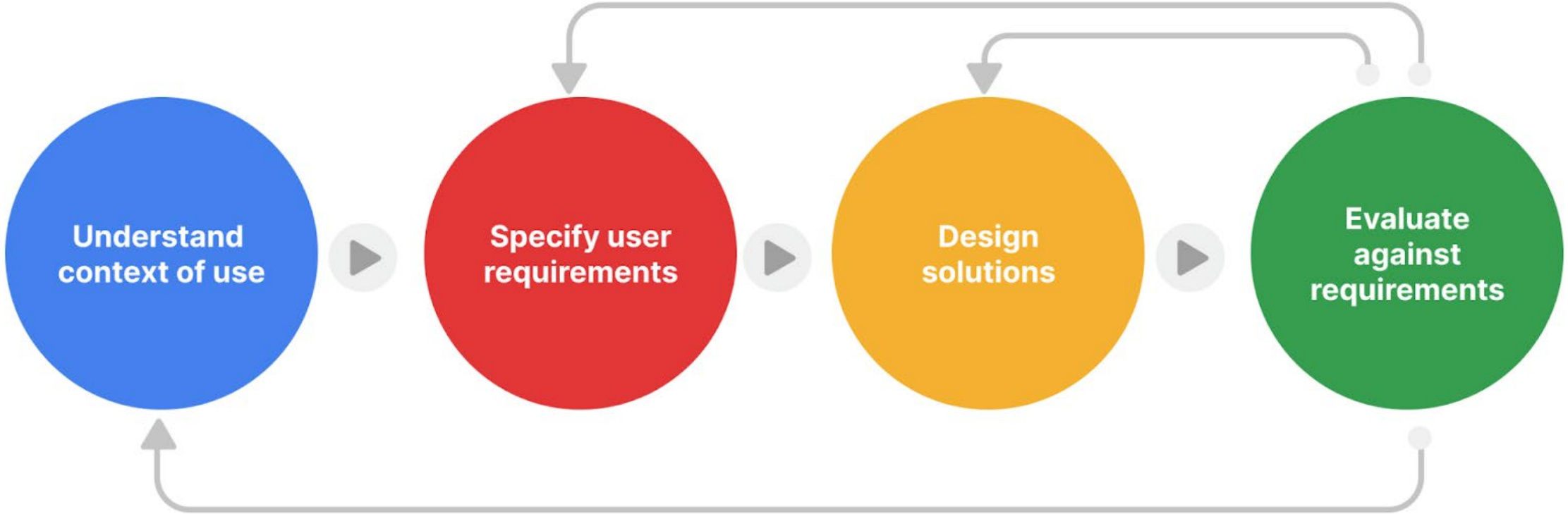
- Summarize eligible study participants
- Capture outreach and engagement event statistics
- Track participant recruitment and referral processes
- Use data pulled in real-time and be dynamic and interactive

User-Centered Design Development

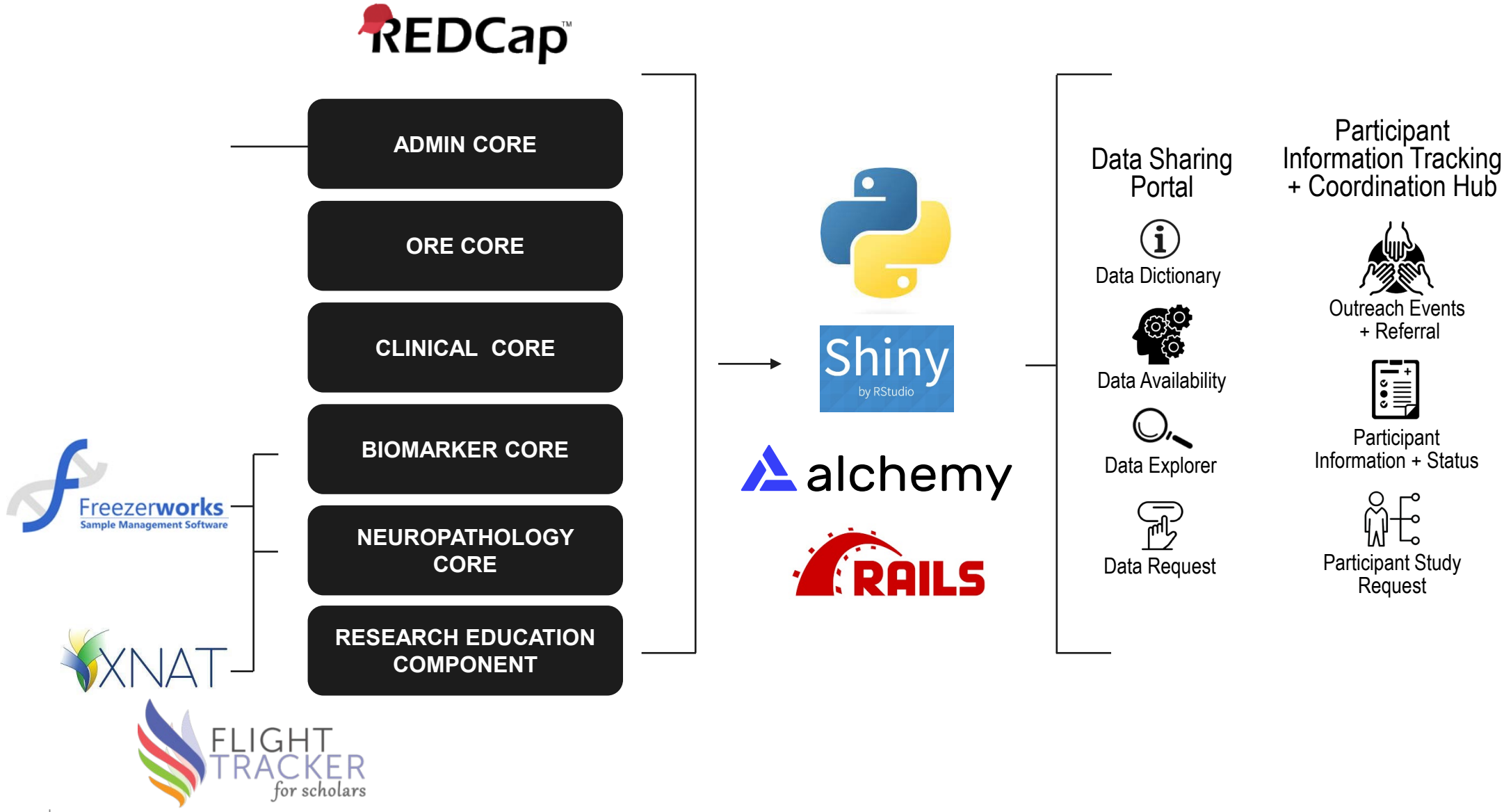
VADRC Data Management and Statistics Core partnered with our local Vanderbilt Biostatistics Data Coordinating Center (VBDCC) to develop the envisioned platform



User-Centered Design Development



VADRC Data Infrastructure

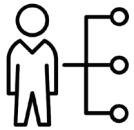


PITCH Functionality

The Outreach Events and Referral Dashboard

The Participant Information and Status Dashboard

The Internal Report Dashboard

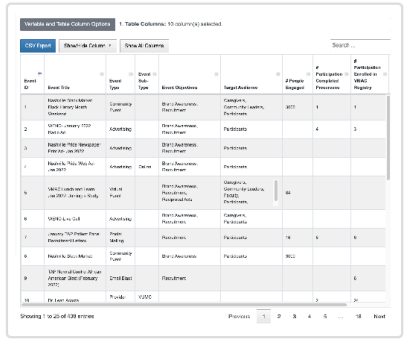


The Participant Study Request Dashboard

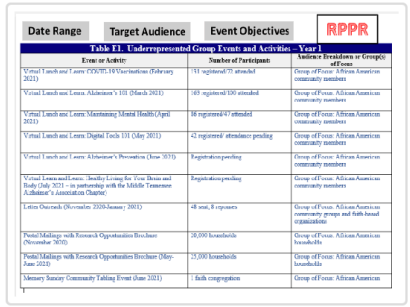
Outcome 1. Tracking and Evaluating Outreach & Recruitment Efforts

Outreach

EDT: Events Data Table

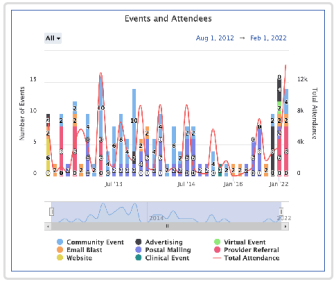


RPPR Reports Events

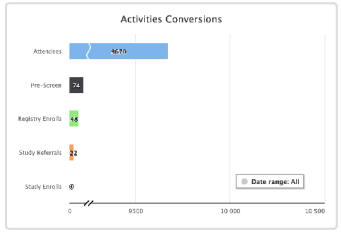


Events Status

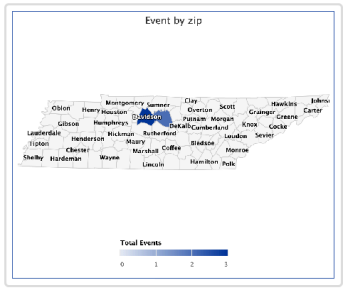
ES 1: Activities and Attendees



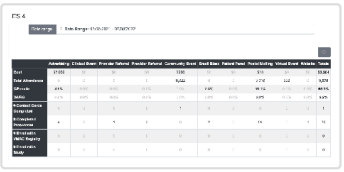
ES 2: Activities Conversions:



ES 3: Events by Zip



ES 4



Outcome 1. Tracking and Evaluating Outreach & Recruitment Efforts

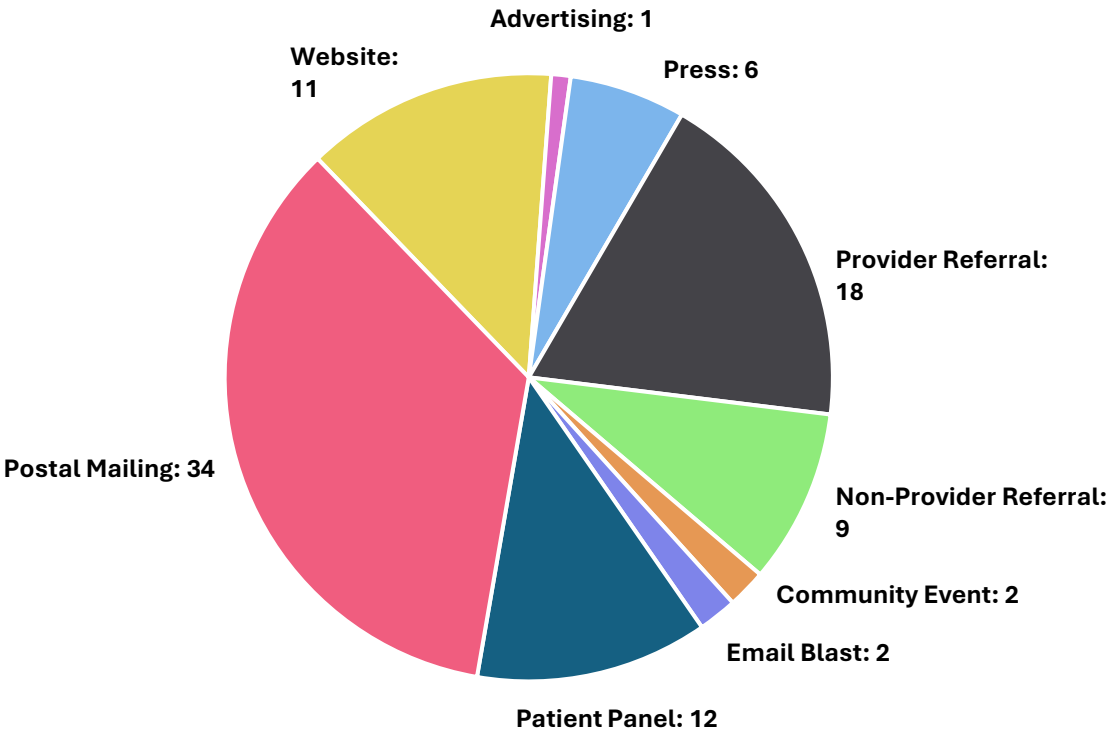
VADRC Clinical Core Cohort began recruitment in August 2021

1/3
Cognitively Healthy

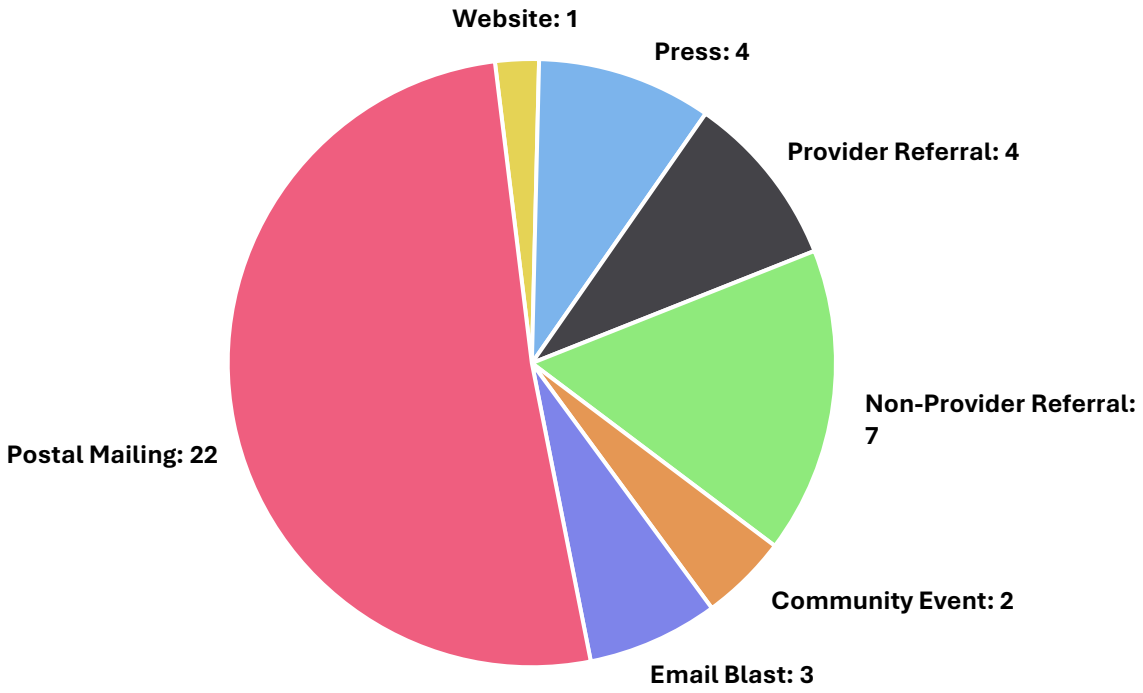
1/3
Mild Impairment

1/3
AD Diagnosis

Outcome 1. Tracking and Evaluating Outreach & Recruitment Efforts



Enrolled Impaired Participants



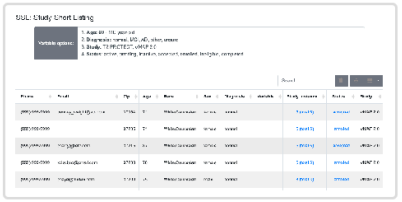
Enrolled Unimpaired Participants

Outcome 1. Tracking and Evaluating Outreach & Recruitment Efforts

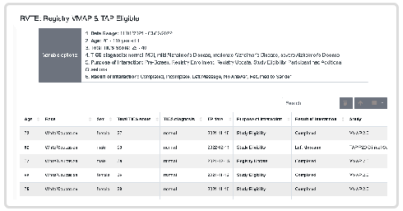
Participant Information & Status

Participant Information

SSL

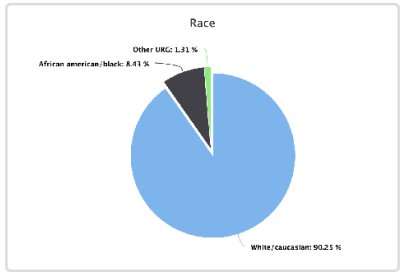


RVTE

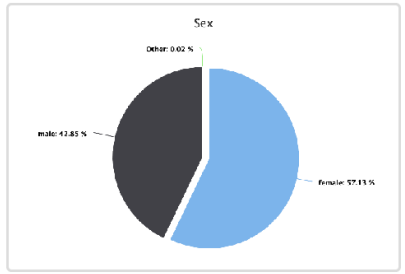


Registry Health Reports

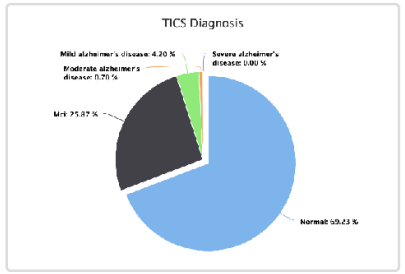
RHR 1: Race



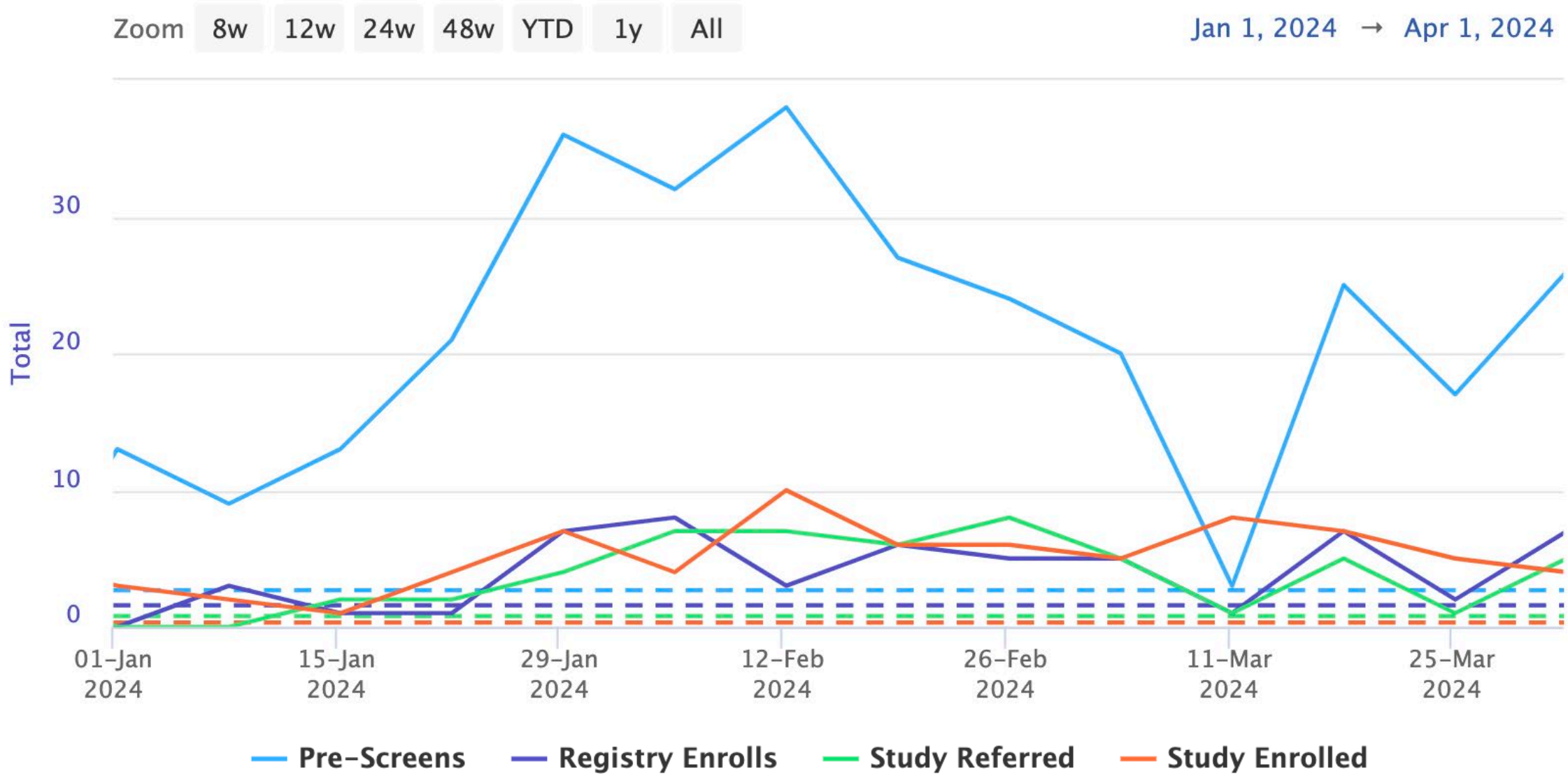
RHR 1: Sex



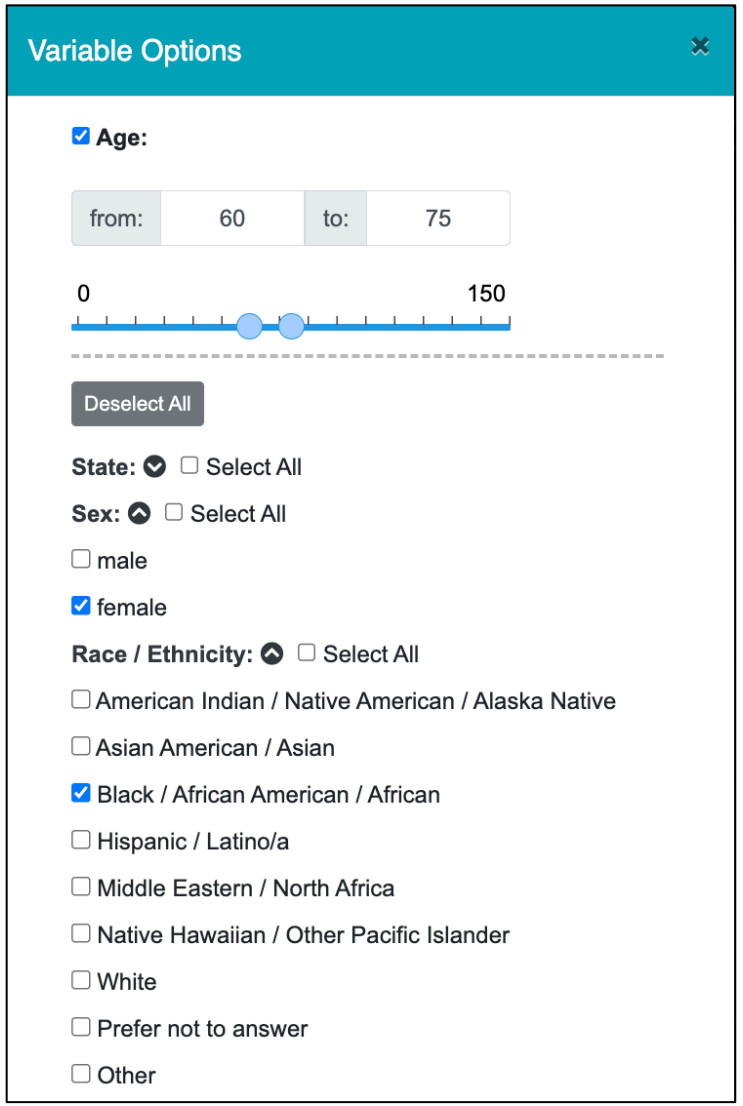
RHR 2: TICS Diagnosis



Outcome 1. Tracking and Evaluating Outreach & Recruitment Efforts



Outcome 2. Identify Eligible Participants for Study Referral



SSL: Study Short Listing

- Use real-time database on this page.
- Default `Exclude lastest "VMAC Participant Status" = inactive`

Variable Options

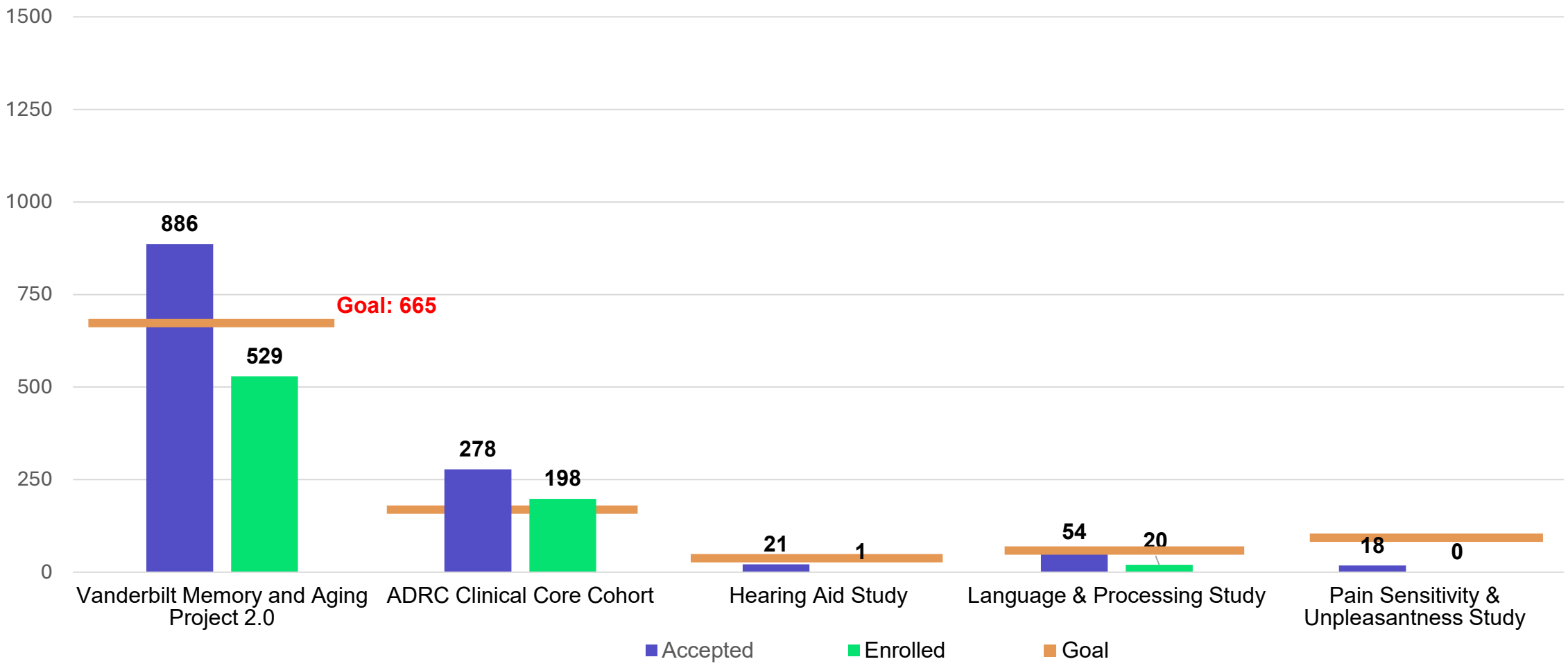
1. **Age** 60 - 75 year-old
2. **Sex** female
3. **Race** Black / African American / African
4. **TICS Diagnosis** MCI, mild Alzheimer's Disease, moderate Alzheimer's Disease, severe Alzheimer's Disease
5. **VMAC Participant Status** active

Age range: min to max Reset Filter

CSV Export | Show/Hide Column Group: | Show/Hide Single Column | Show All Columns | Search ...

	VMAC Participant Questionnaire Static			VMAC Participant Questionnaire			TICS	Study Referral		
VMAC ID	Age	Race / Ethnicity	Sex	City	State	zip	TICS diagnosis	Study Instance	VMAC Participant Status	Study Name
00182	71	Black / African American / African	female	Madison	TN	37115	MCI	1 (total 1)	active	
00241	71	Black / African American / African	female	Nashville	TN	37207	MCI	3 (total 3)	active	
01153	74	Black / African American / African	female	Nashville	TN	37216	MCI	1 (total 1)	active	
01184	70	Black / African American / African	female	Nashville	TN	37216	MCI	1 (total 1)	active	
01369	70	Black / African American / African	female	Nashville	TN	37208	MCI	3 (total 3)	active	
01398	73	Black / African American / African	female	Nashville	TN	37214	MCI	1 (total 1)	active	
01479	68	Black / African American / African	female	Lavergne	TN	37086	MCI	1 (total 1)	active	

Outcome 3. Track Progress on Study Recruitment Timelines & Goals



Outcome 4. Facilitating External ADRD Investigators

Participant Study Request

For all qualified investigators looking to request participants from our Center, the participant request process begins here.

Request Process

You can start the process of requesting access to participants here. Submitted requests are reviewed by our Center's Scientific Review Committee. After your study is approved, a point person on your team will be granted access to the Study Status part of our hub and receive training on how to access and update participant information.

Manage Staff Access

Approved studies can manage staff access and manage permissions through this portal.

Study Status External

Approved studies can view eligible participants who have agreed to be contacted about research opportunities.In this portion of the hub, investigators and their study staff can view analytics on participants who have been referred to their studies, update the enrollment or eligibility status of participants, and visualize and download data from our Center for progress reports or for inclusion in other study documentation materials.

Take Home Points

- Recruitment efforts must adapt to match the pace of ADRD research investment
- We developed a web-based platform to centralize participant recruitment and track the entire participant life cycle from outreach to study referral
- Our centralized data-driven approach to ADRD recruitment will improve:
    1) **efficiency** of recruitment within recruitment budgets
    2) **effectiveness** of reaching the community members we want to reach
    3) **transparency** of recruitment efforts for external VADRC-affiliated studies
    4) **accountability** to study participants and the community we intend to serve
- The development and implementation of PITCH represents a significant advancement in ADRD research participant recruitment and management

Thank You For Your Attention