



Closing the Gap Between Interest and Enrollment among Persons of African Ancestry in the US for the Recruitment and Retention for Alzheimer's Disease Diversity Genetic Cohorts in the ADSP (READD-ADSP)

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BACKGROUND

- Enrolling persons of African Ancestry (AA) in the US into genetic Alzheimer's disease (AD) research remains a significant challenge, despite higher disease burden compared to individuals of European ancestry.
- In-person community-engaged practices are effective in generating interest in research participation but may not translate into high levels of study enrollment, which is costly.
- This study identifies strategies that contribute to closing the gap between written interest at community events and enrollment for the READD-Alzheimer's Disease Sequencing Project (ADSP). The READD-ADSP is recruiting 13,000 Africans, African Americans, and Hispanic/Latinx populations to build the largest genomic infrastructure to advance AD genetic research.

METHOD

- The outreach team provided culturally tailored education on AD and research participation to AA communities over a four-year period. Interested individuals completed interest forms and received follow-up telephone calls from the clinical team to schedule a time for enrollment.
- To assist with closing the interest-to-enrollment gap, the clinical team provided flexibility for timing of follow-up calls, methods of expressing interest (paper form, email, telephone call or QR code), and place of appointments for enrollment (e.g. at home, group ascertainment, at medical site).
- We measured enrollment, following initial follow-up calls at 2-3 business days, 4–7 days, 7–14 days, and ≥14 days. Final follow-up letters were sent to potential participants who remained unscheduled after three call attempts.
- In preparation for the enrollment visit, confirmation emails were sent to share how to prepare for enrollment and introduce the clinical team, including team photographs and telephone numbers.

RESULT

- From 202 community events, 2,371 AAs completed interest forms and 932 (39%) enrolled in the READD-ADSP, of which 77% were women, with males comprising 23%. The mean age of participants was 71.3 years (SD=7.5).
- While some month-to-month variability was observed across all four years, most individuals who ultimately enrolled in the study were contacted with the first 3 business days.
- Participants who were reached between 2-3 business days demonstrated the highest enrollments, with 73% completing enrollment in year 4 after initial contact, 6% of participants (n=19) were contacted within 4–7 days, 6% (n=24) within 7–14 days, and 16% (n=61) after 14 or more days.
- During years 2–4, participants reached on the first attempt demonstrated the highest enrollment yield and completion rate following initial outreach. Further emphasizing the importance of prompt communication.

Figure 1. READD-ADSP Recruitment Events

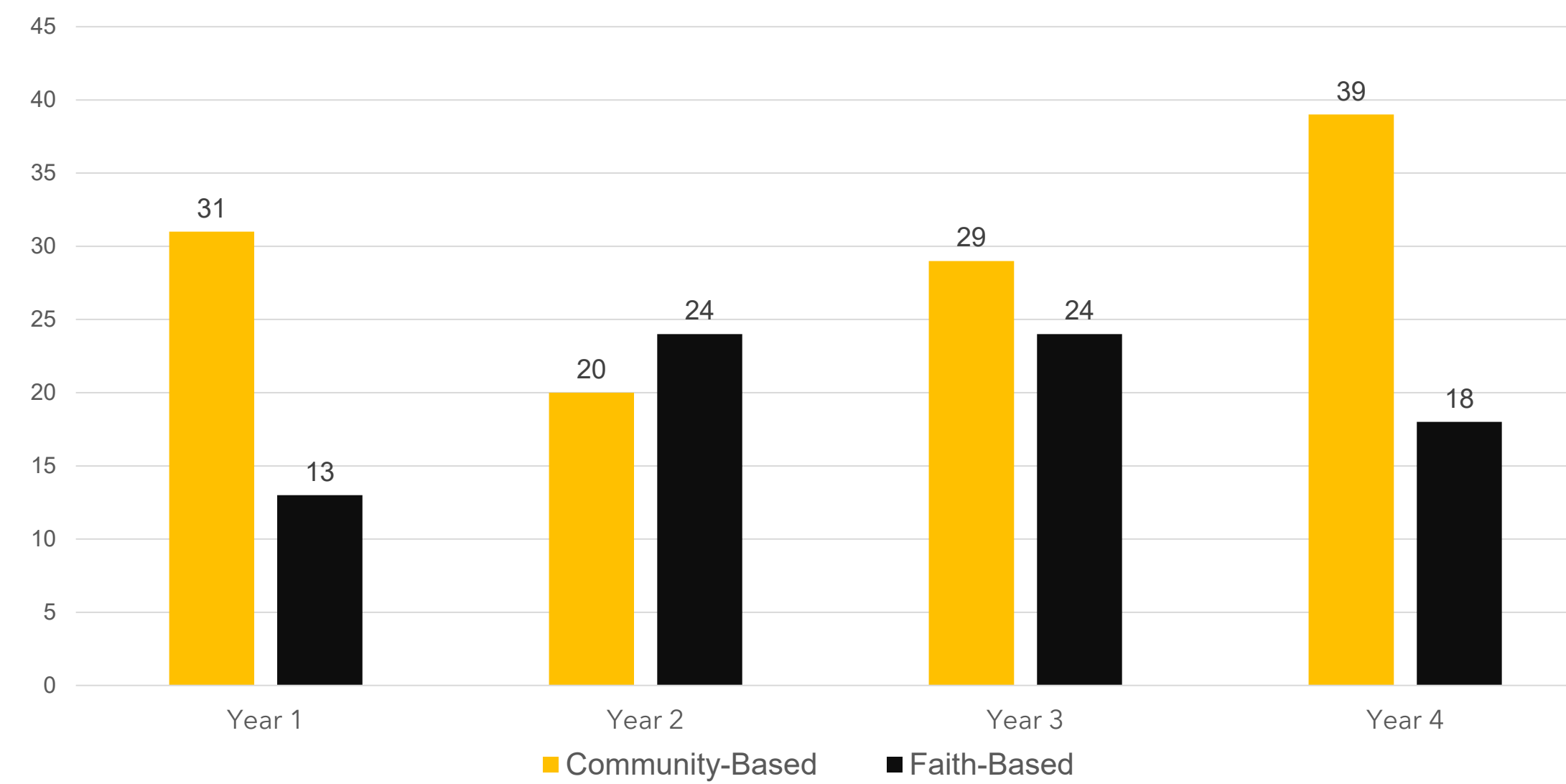


Figure 2. READD-ADSP Study Enrollment by Follow-up Time

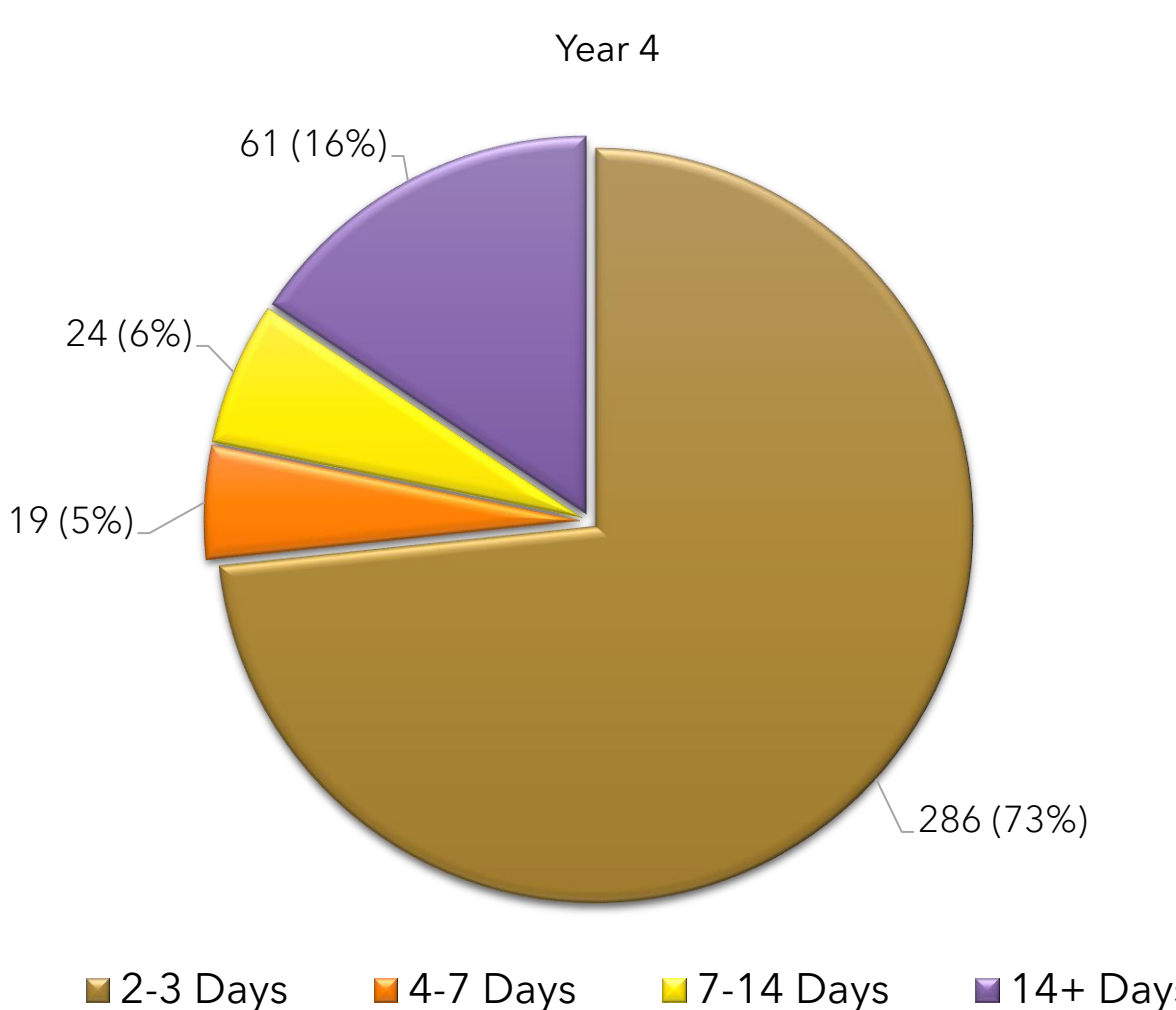
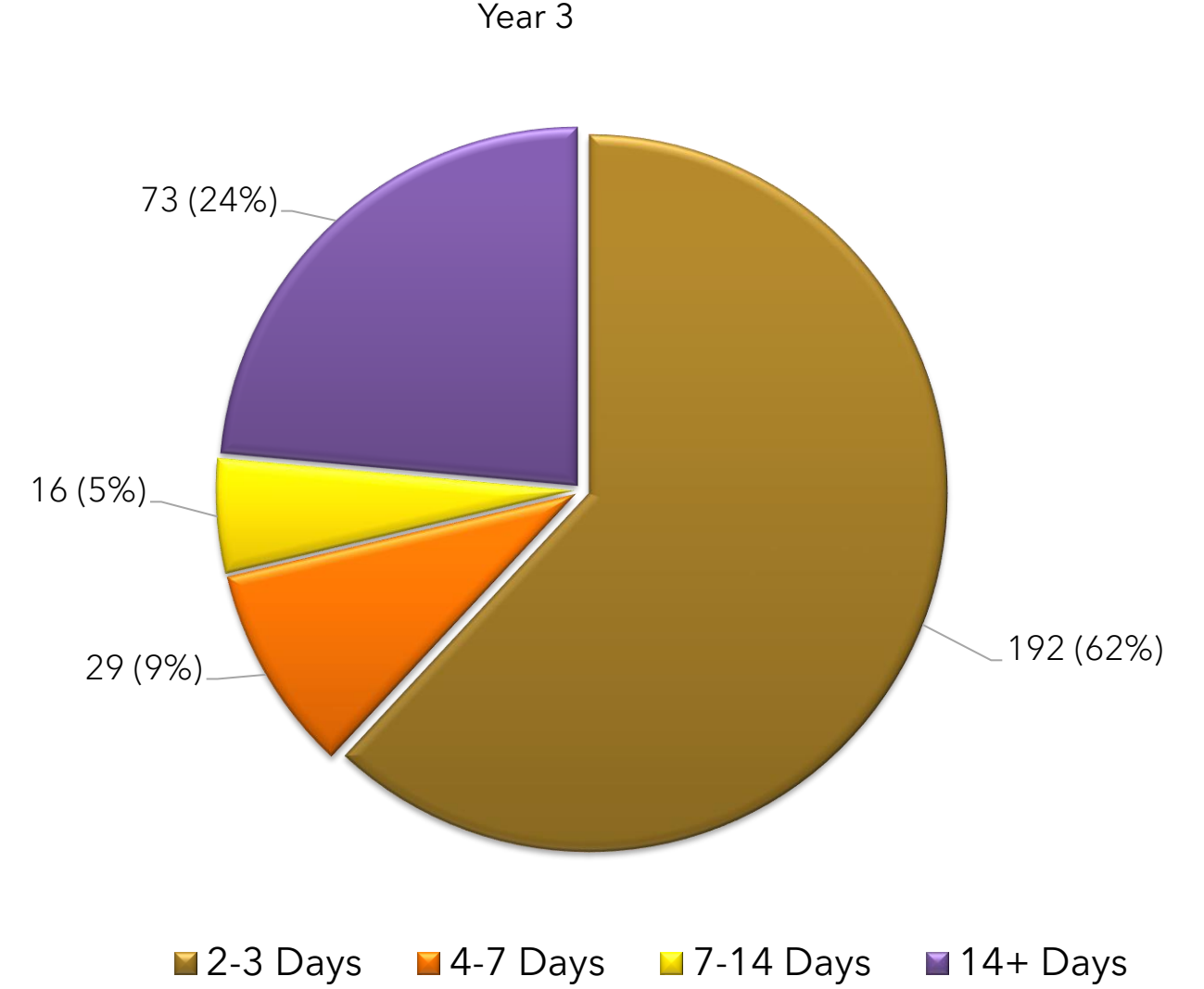
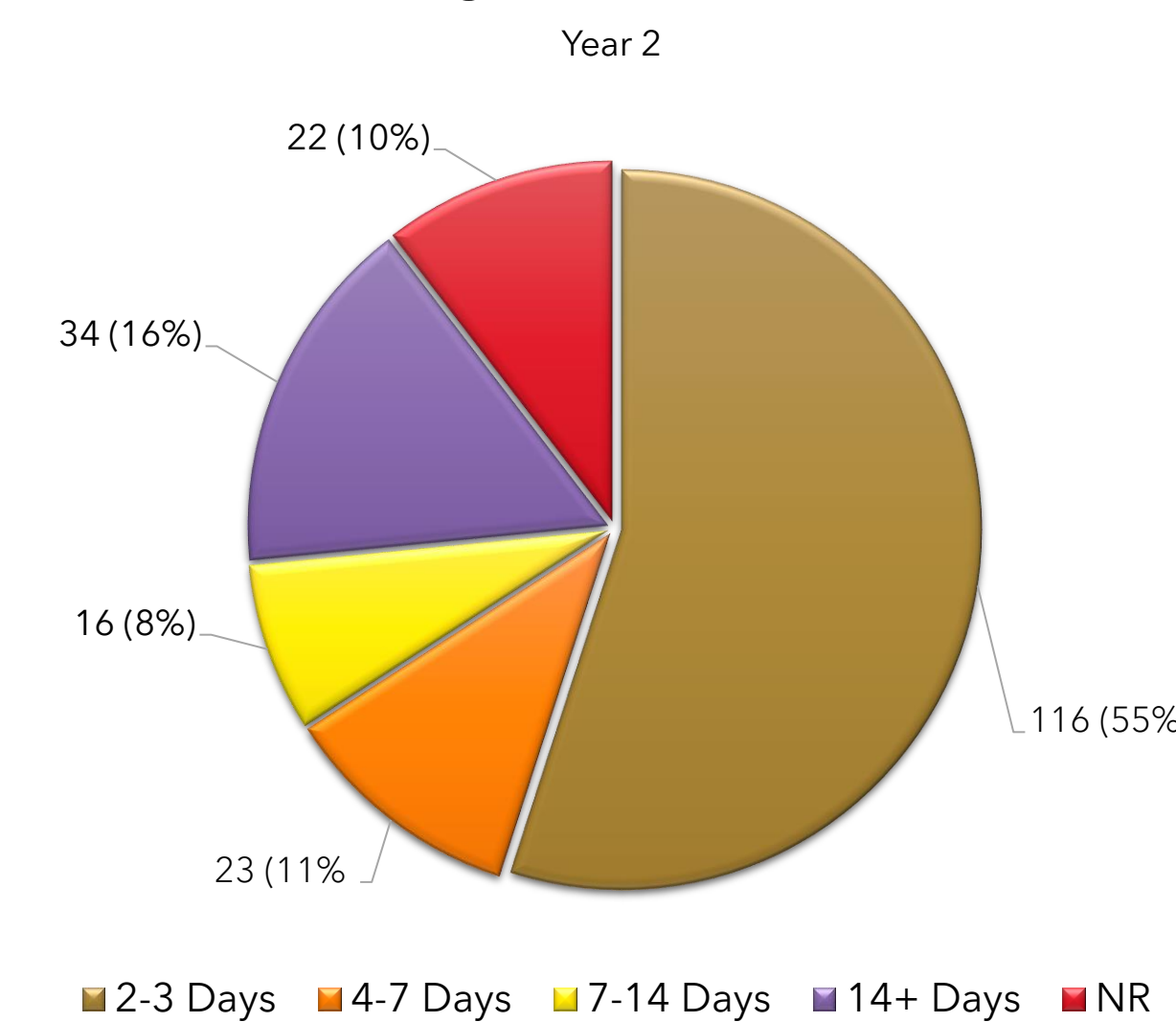
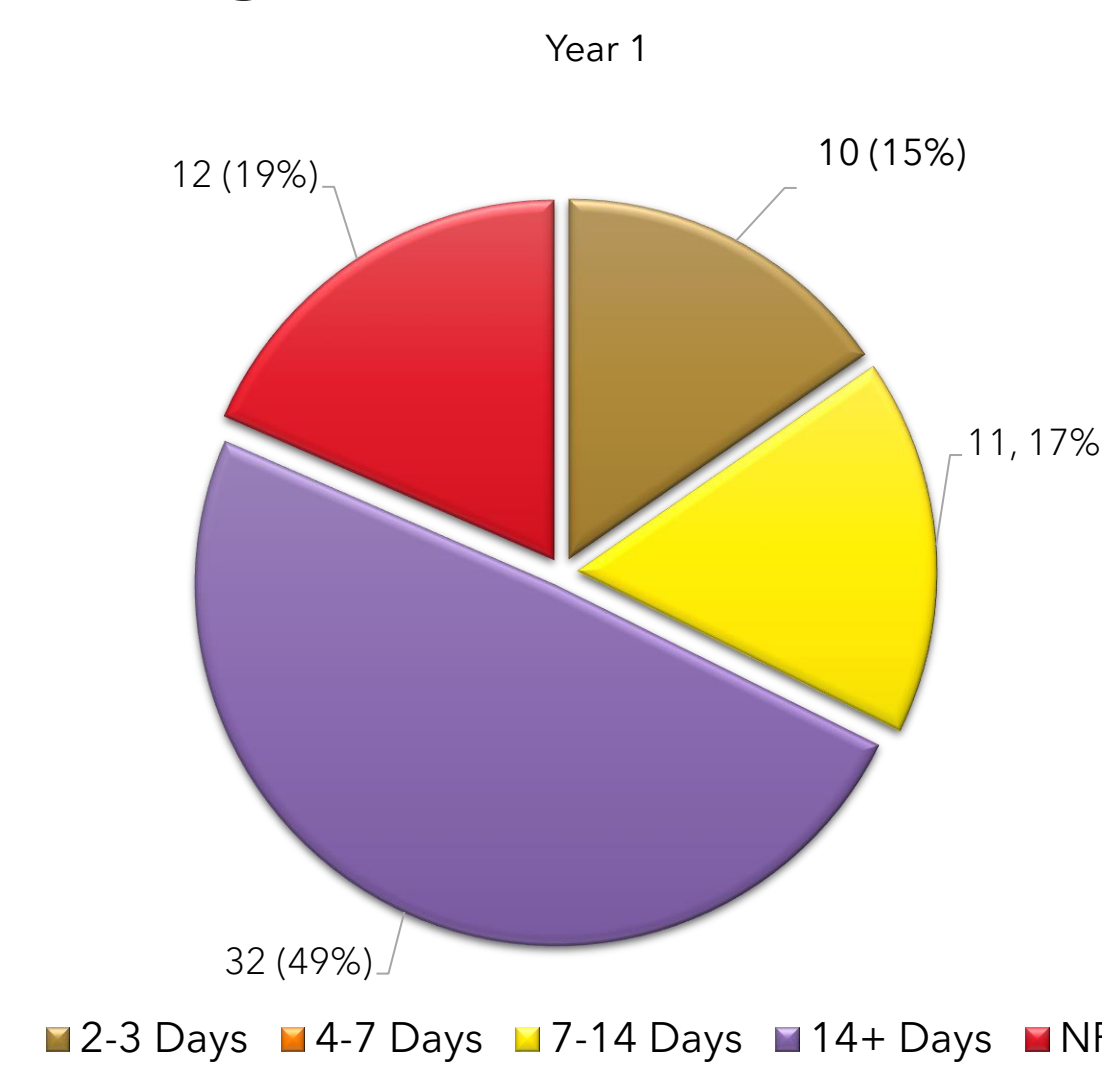
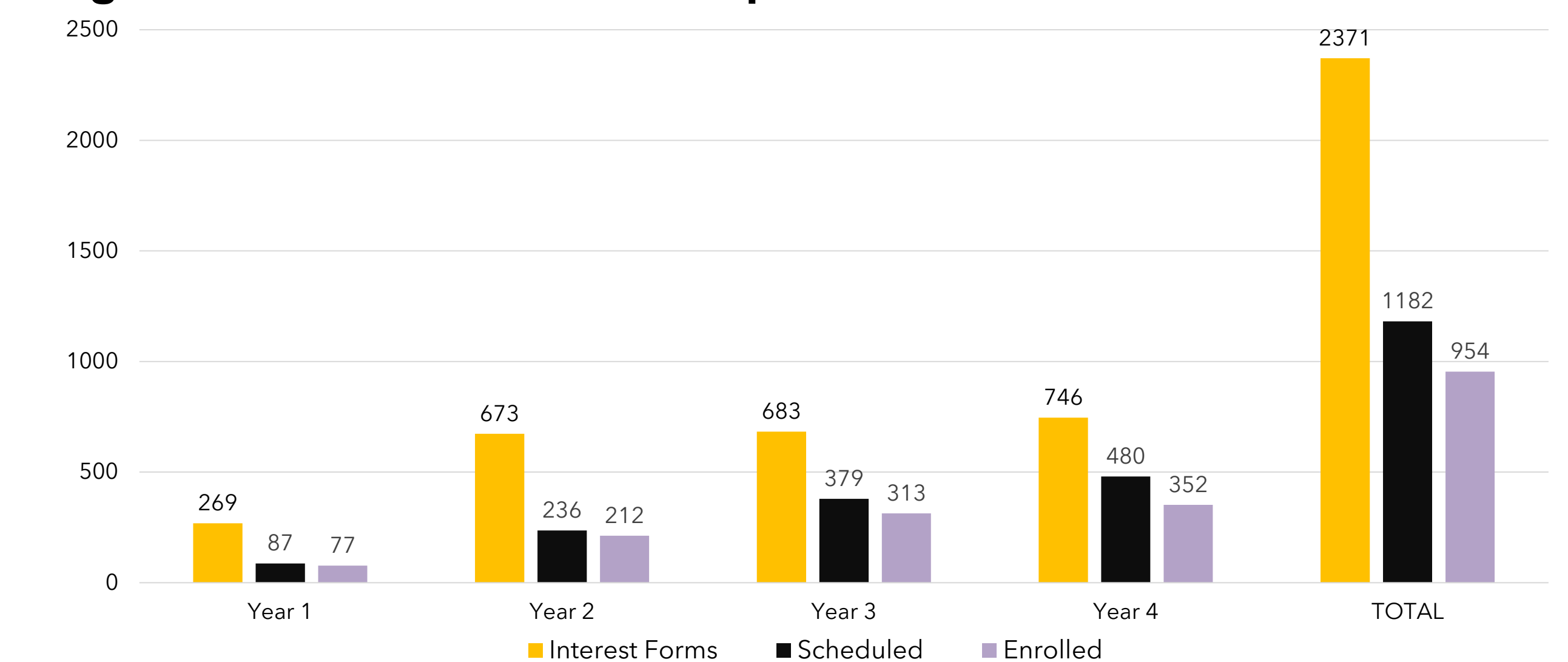


Figure 3. READD-ADSP Participants from Interest to Enrollment



CONCLUSION

- Prompt follow-up is a critical determinant of successful enrollment among AA participants in the READD-ADSP study.
- Contacting individuals within 2-3 business days consistently yielded the highest enrollment rates during years 2-4 from interest to enrollment.
- Strategic efforts, including flexibility and immediate follow-up with potential participants, may help close the gap between initial interest and study enrollment.
- Implementing these practices can enhance recruitment efficiency, reduce staff burden and costs, and strengthen efforts to increase AA representation in AD genetic research. These efforts will reduce study team's time and cost in community engaged recruitment of AA for AD genetic studies.

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