

The Use of Academic-Community Partnerships in Participant Accrual to an Inherited Cancer Registry



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Background

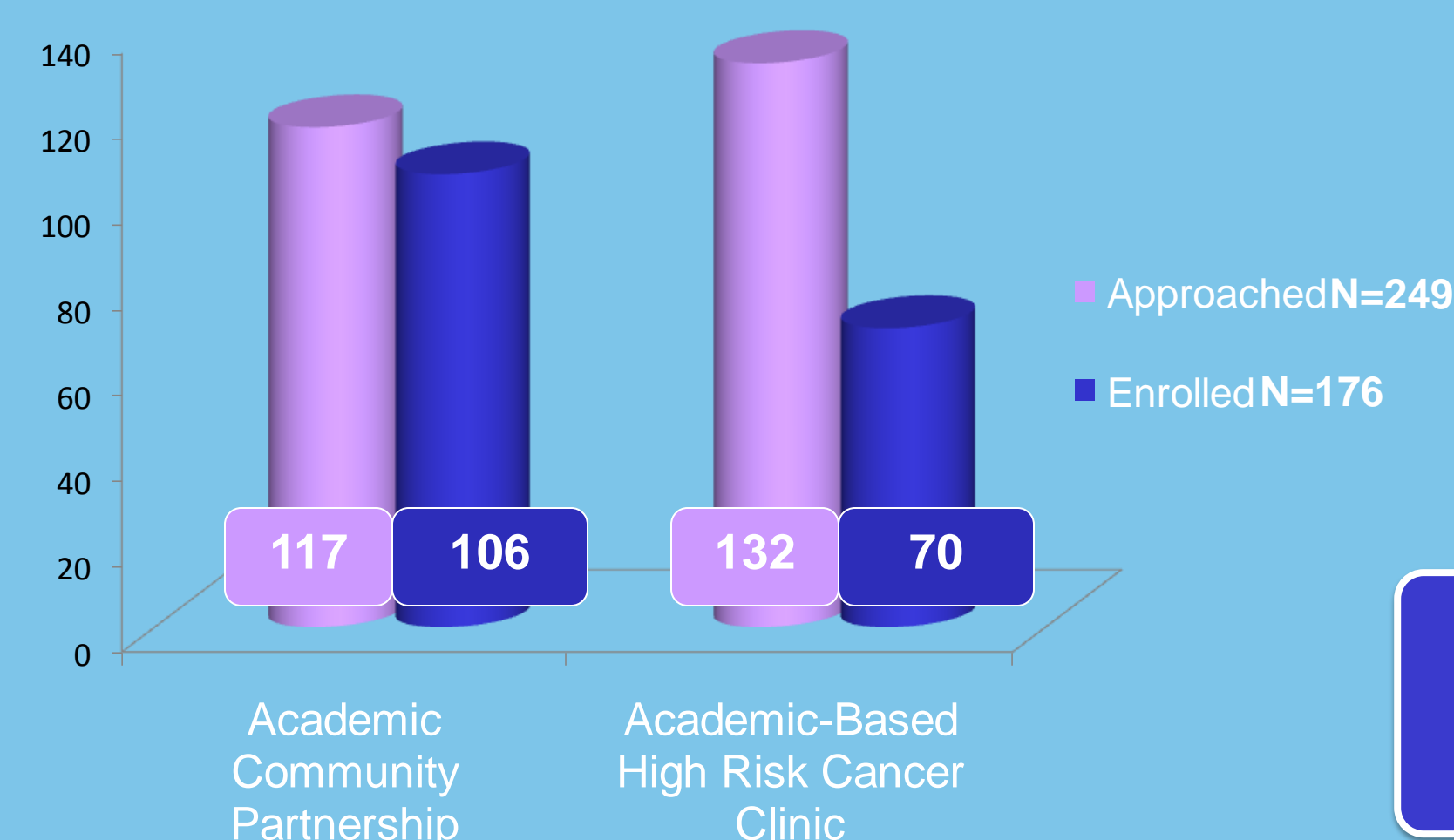
- Inherited cancer registries have increased participation in genetic-based cancer research.
- Traditionally, participants have been recruited heavily through academic-based high risk cancer clinics.
- An Inherited Cancer Registry (ICARE) was established at Moffitt Cancer Center.
- Participants were recruited through academic-based high risk cancer clinics and an academic-community partnership called Facing our Risk of Cancer Empowered (FORCE), a non-profit organization for individuals affected by hereditary breast and ovarian cancer.

Recruitment Aids

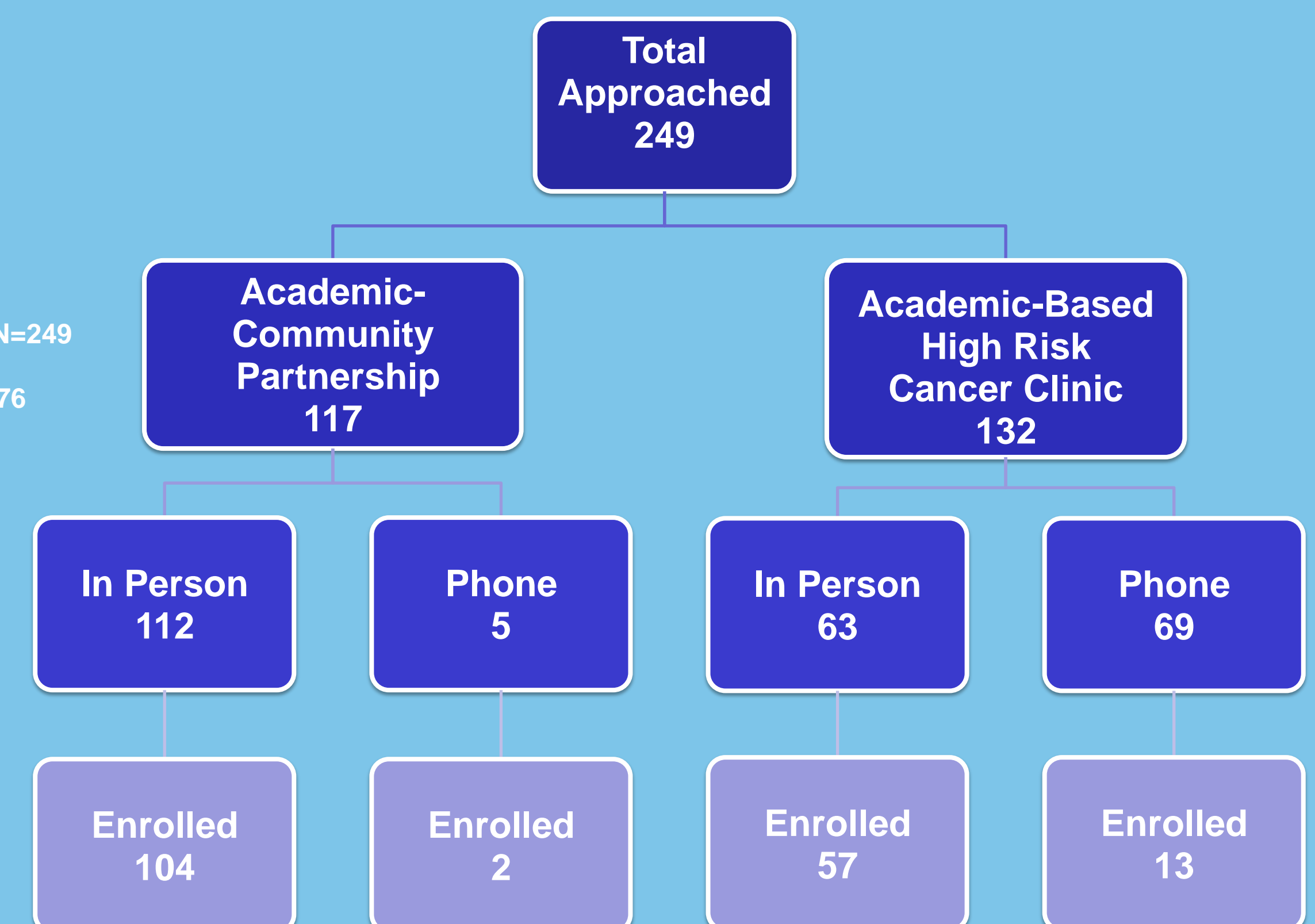


Summary of Key Findings

Approached vs. Enrolled



Accrual Flowchart



Objective

To determine the efficacy of recruiting participants to ICARE through Academic-based high risk cancer clinics versus FORCE.

Academic-Community Partnerships are an important recruitment source

- 60.2 % of participants enrolled into ICARE were recruited through an Academic-Community Partnership
- 90.6 % of subjects approached for participation through an Academic-Community Partnership were enrolled in ICARE

Recruitment via the phone is more challenging than in person recruitment

- 20.3% of participants approached over the phone were enrolled into ICARE compared to 92.0% of participants approached in person

Methods

- Data was collected from a pre-existing dataset tracking accrual into the ICARE registry from June 2010 to March 2011.
- Frequencies were calculated for the number of participants accrued through each recruitment method as well as the number of subjects approached, number of subjects who expressed interest in participation, and number of participants consented to the registry through each method.
- These frequencies were then further stratified by the method of contact via in person or over the phone.

Conclusions

- Although inherited cancer registries have historically heavily recruited through academic-based high risk cancer clinics, recruitment through academic-community partnerships proves to be a valuable tool in accruing registry participants as well.
- Our results also suggest through both recruitment sources, accrual to an inherited cancer registry is most effective when potential participants are approached in person.
- Participants recruited through an Academic-Community Partnership had been diagnosed with cancer less than participants recruited through Academic-Based high risk cancer clinics.

Demographics of Enrolled Participants (N=176)

Demographic	Variable	Academic-Community Partnership	Academic-Based High Risk Cancer Clinic
Age		45.9 ± 11 N=106	50.8 ± 13.8 N=69
Sex	Female Male	103 (99.0%) 1 (1.0%) N=104	66 (94.3%) 4 (5.7%) N=70
Ethnicity	White Black Asian American Indian, Aleutian or Eskimo	79 (95.2%) 3 (3.6%) 0 (0%) 1 (1.2%) N=83	64 (97.0%) 1 (1.5%) 1 (1.5%) 0 (0%) N=66
Marital Status	Single Married Cohabiting/Living Together Divorced Widowed	5 (6.0%) 57 (68.7%) 5 (6.0%) 13 (15.7%) 3 (3.6%) N=83	5 (7.9%) 48 (76.2%) 2 (3.2%) 5 (7.9%) 3 (4.8%) N=63
Education Level	High School Some College/Vocational School College Graduate Post-Graduate	9 (10.8%) 14 (16.9%) 31 (37.3%) 29 (24.8%) N=83	10 (17.5%) 13 (22.8%) 20 (35.1%) 14(24.6%) N=57
Personal History of Cancer	Yes No	30 (36.1%) 53 (63.9%) N=83	45 (64.3%) 25 (35.7%) N=70
Family History of Cancer	Yes No	82 (96.5%) 3 (3.5%) N=85	62 (98.4%) 1 (1.6%) N=63
Mutation Carrier Status	Yes No	71 (92.2%) 6 (7.8%) N=77	46 (76.7%) 14 (23.3%) N=60

Participants recruited through an Academic-Community Partnership had been diagnosed with cancer less than participants recruited through Academic-Based High Risk Cancer Clinics

- 36.1% of participants recruited through an Academic-Community Partnership reported having a personal history of cancer compared to 64.3% recruited through Academic-Based High Risk Cancer Clinics