BEHIND THE SCENES: ONE SIZE DOESN'T FIT ALL IN A COMMUNITY-BASED REGISTRY

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A community-based population health study located in North Carolina, the Duke-MURDOCK Study currently has >11,000 residents enrolled who contribute data, biological specimens, annual follow up, access to medical records, and consent to participate in other approved research studies. More than six years of engagement efforts have demonstrated that no single approach is sufficient to achieve recruitment and retention across diverse groups of participants. Rather, tailored communications and thoughtfully implemented enrollment strategies have been successfully deployed.

MURDOCK STUDY

Referral Sources by Quarter, 2014

	1Q (N)	2Q (N)	3Q (N)	4Q (N)
Churches	28.0 (64)	11.3 (30)	19.1 (50)	4.7 (11)
Healthcare providers	25.3 (58)	22.6 (60)	27.5 (72)	45.5(106)
Community events	12.7 (29)	19.6 (52)	15.3 (40)	12.0 (28)
Local businesses	10.1 (23)	9.4 (25)	11.1 (29)	17.6 (41)
Schools	-	10.5 (28)	5.7 (15)	2.2 (5)
Free advertising	13.5 (31)	16.9 (45)	15.3 (40)	8.2 (19)
Paid advertising	10.5 (24)	9.8 (26)	6.1 (16)	9.9 (23)

Tailored Communications Strategies

In order to improve the representativeness of the MURDOCK Study Community Registry and Biorepository, communication efforts have been adapted to address demographics, educational, linguistic, and cultural needs of our diverse participant pool. Frequent evaluation and adjustment are performed, addressing changing needs of the local community.

Examples of tailored communications strategies include:

(1) **Translated study materials**– all enrollment and marketing materials are translated into Spanish, resulting in better representation of Hispanics (~12%)

(2) **Social media platforms** – the study's social media presence has been developed, allowing for greater engagement with younger, more tech-savvy audience

(3) **Outreach and education** – community events are organized and attended by MURDOCK Study staff who explain clinical research activities to community members of all cultural and educational backgrounds.

Diverse Enrollment Locations

A network of diverse enrollment sites, ranging from free clinics to large hospital systems, facilitates recruitment of residents who represent all parts of the local community. Enrollment locations and time of enrollment can be adjusted to the needs of participants, e.g. evening/weekend and in-home appointments. Bilingual clinical coordinators enable the enrollment of Spanish-speaking participants.

Bethesda Health Center: One of 10 enrollment sites located in the study catchment area.

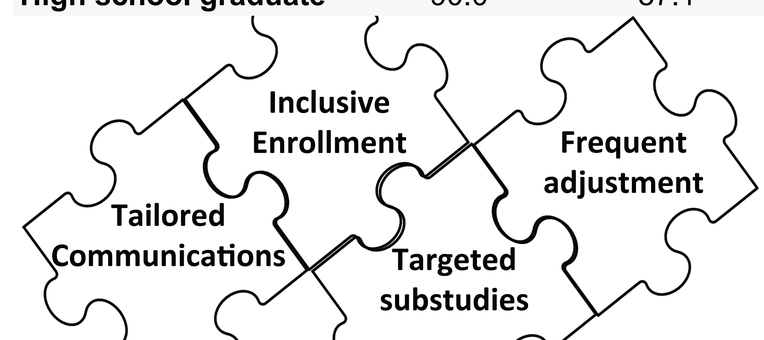
Community Events: Staff members attend a variety of health fairs and festivals held in the local community.

Thoughtful sub-study design

Sub-studies that stratify recruitment by age have resulted in more representative age distributions. For example, a memory health study generated expedited registry enrollment among volunteers age 55 and older. More than 1500 participants were enrolled in the registry in just two years. New disease-specific sub-studies are anticipated to increase participation and overall retention through the targeted recruitment.

Demographics (Registry vs Catchment Region)

	% of Registry	% of Region
Hispanic	12.4	10.9
African American	13.6	25.3
Female	65.9	51.3
High school graduate	90.0	87.1



Future efforts to improve cohort representativeness:

(1) **Communications** – Given eligibility criteria of the adult population (18 or older), engaging younger generations while still connecting with older populations is a key initiative

(2) **Population Random Sampling** – a pilot household random sampling is underway, which will help identify effective techniques and strategies in achieving a true representative sample

(3) **Disease-specific Sub-Studies** – sub-studies enrolling specific disease cohorts (e.g. prostate cancer) will increase men into the registry

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www.murdock-study.org

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