

If You Just Build It, They Won't Come



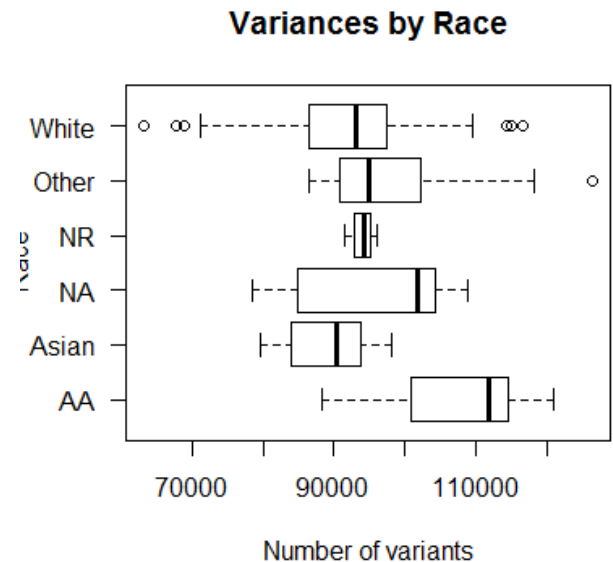
Minority Recruitment and Retention: The NCGENES Cascade Experience

Integrating Genomic Sequencing into
Clinical Care: CSER and Beyond

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The Importance of Minority Recruitment

- Social justice
 - In the research realm we need to ensure that what we learn is broadly applicable
 - In the clinical realm we need to ensure that advances aren't left to “trickle down”
- Science
 - 90,000 variants in the typical white subject/patient vs. 120,000 variants in the typical AA
 - Obvious implications for interpreting the AA's results
 - An understanding of variation for any one group will be benefitted by a global understanding of variation across all groups
 - Studying those with more variation will provide maximal information for all
- The meaning of “Minority” will differ with differing contexts
 - We have focused on AA and Hispanics



CSER Aggregate Minority Recruitment

Total enrollment 4,979

White, non-Hispanic	71.3%
Black or African American	12.3%
Hispanic/Latino	5.3%
Asian	3%
American Indian/Alaskan Native	1.7%
Native Hawaiian or other Pacific Islander	0.1%
> 1 race	2.2%
Not reported	4.2%

The Context of NCGENES

- North Carolina racial distribution:
 - 64% White, Non-Hispanic
 - 22% AA
 - 9% Hispanic/Latino
 - 2.6% Asian
 - 1.6% Native American

Targeting African American Participation

- In an effort to emphasize African American participation we established a collaboration with Vidant Cardiology
 - Located in Greenville, NC
 - Population 605,000
 - 34% AA
 - 35 cardiologists and a heart failure service with 2 advanced heart failure cardiologists, 5 advanced practice providers and a HF pharmacist
 - See 6500 patients/ year
 - Projected to double this number in the next 6 months with hiring of a new HF cardiologist and 1.5 APPs
 - Patient mix: 60% African-American; very few Hispanic patients



Targeting Hispanic Participation

- Hired a scheduler fluent in Spanish
- Native speaker
- Translated written materials for enrollment and education
- Ready access to interpreter for all visits, including enrollment and ROR visits
- Phone surveys via native Spanish speaker

NCGENES Participation Cascade

1153 Nominees

	<u>White</u>	<u>AA</u>	<u>Hispanic</u>
<u>Total</u>	<u>71%</u>	<u>23%</u>	<u>7%</u>
Enrolled (N=628)	79%	15%	8%
Non-Enrolled (N=507)	60%	33%	6%
Deceased (N=12)	33%	58%	8%
In Queue (N=279)	65%	29%	7%
Declined (N=83)	57%	39%	6%
Visit Incomplete (N=99)	48%	42%	7%

NCGENES Participation Cascade

- 18/62 of “visit canceled” entries are African-American
- 34/64 of “visit no-show” entries are African-American
- Thus, although AA were 23.1% of nominees, they accounted for 41.3% of the missed visits

NCGENES Participation Cascade

- 59 Vidant nominees
 - 88% AA
 - 26/52 enrolled (50%)
 - Consistent with the success rates for other populations in NCGENES
- Non Vidant nominees
 - 28.4% success rate with African-Americans

Suggests the importance of an outreach clinic and likely reflects the close relationship that they have with their patients

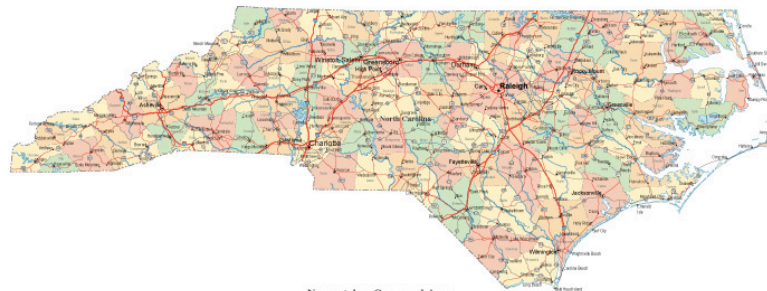
Lessons Learned

- Barriers involve practical issues
 - Time, money, transportation, health and language are all more challenging for our minority participants
 - They have trouble getting time off from their jobs
 - They have less money so things like gas money or bus fair matter (and they live in areas w/o good public transportation)
 - They are usually sicker so everything else takes a back seat
- And, historically, less tangible issues

Active, aggressive and targeted measures must be taken to ensure robust minority recruitment and retention

Enhancing Minority Participation

- Trust
 - Working with dedicated, community clinics who provide care to the participants
 - Issues of research vs. clinical care, leveraging the latter to help foster the former
 - Challenges to working with non-academic clinics
 - From IRBs to work flow in the clinic
- Health
 - Minority participants usually are sicker than their non-minority counterparts.
 - Coordinating clinic visits with research visits is essential
- Geography
 - You need to go out to these communities (4 hour round trip)



Enhancing Minority Participation

- Language
 - Facile and easy interpreter access in-person and on the phone
 - Translation of participant materials
- Economics
 - Pay for gas/transportation
 - Write notes for work
 - Provide monetary incentives (e.g. for surveys)
- Ensure backup contact information b/o changing addresses and phone plans

Note to Funders:

All of these measures are expensive and time consuming!

Thank You!

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