

Engaging Participants in Precision Clinical Trials: Examples from Alzheimer's Disease Prevention Trials

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Example of a Successful Recruitment Mechanism: Colombian Alzheimer's Prevention Registry

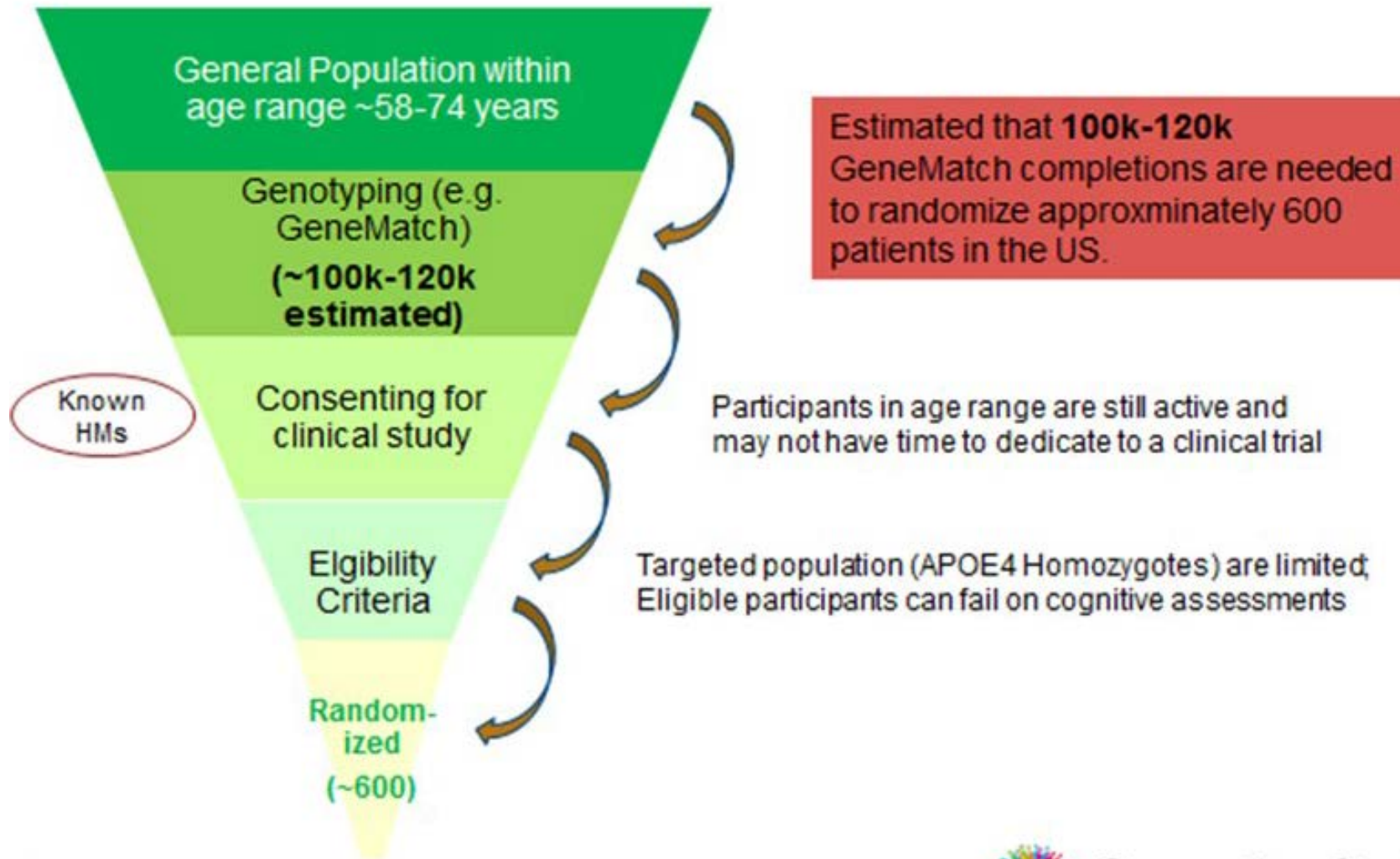
- Launched in anticipation of Alzheimer's prevention clinical trials, serving as a pre-enrollment recruitment mechanism to identify potential study participants
- To date, enrolled >5600 PSEN1 E280A mutation kindred members in Colombia
 - 1173 mutation carriers
 - 4420 kindred non-carriers
 - Required considerable community outreach, review of church records, family meetings, and other outreach tactics
- All participants for the Alzheimer's Prevention Initiative Autosomal Dominant Alzheimer's Disease Trial were recruited from the Registry.



Example of a Successful Recruitment Mechanism: GeneMatch

- Launched in November 2015 as an online, trial-independent genetic recruitment registry for Alzheimer's prevention trials in the US
 - www.endALZnow.org/genematch
- Participants are not told their APOE test results, but recruiting studies may require disclosure as part of screening/enrollment
 - Testing done by a CLIA certified / CAP accredited lab
- To date, enrolled >33,000 cognitively healthy adults ages 55-75
 - ~4% APOE $\epsilon 4/\epsilon 4$
 - ~30% APOE $\epsilon 3/\epsilon 4$
 - Required significant advertising, community outreach and talks
- Continued email engagement with participants is important since it may be months to years until they are matched to a trial
- Primary recruitment source in the US for the API Generation Study

Example of Recruitment Funnel for the API Generation Study



Thank you



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endALZnow.org



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PREVENTION
INITIATIVE