

Survey of Education Core recruitment strategies

ADC data compiled at NACC

- Often misunderstood by those outside the ADC community to be population-based.
- Inappropriate analyses undertaken
 - Survival analysis
 - Population-based incidence rates.
- Some ADCs doing some population-based sampling.

Objectives of survey

- Describe ADC recruitment methods.
- Provide suggestions to Ed Cores
 - Help with recruitment strategies.
 - How to take advantage of probability sampling methods, where feasible.

Methods

- Questionnaire to Ed Core list serve
- 3 questions:
 - AD cases
 - Controls
 - MCI.

Methods: for cases

1. What methods, if any, does your ADC use that would allow you to know the denominator of potential subjects from which your eventually-enrolled cases are drawn? This could include one or more of the following methods:

- Random sampling from all potential AD cases in a given clinic.
- Recording all potential AD cases from a given clinic, from which cases are eventually recruited.

Methods: for **controls (cognitively normal)**

2. What methods, if any, does your ADC use that would allow you to know the denominator of potential subjects from which your eventually-enrolled controls are drawn? This could include one or more of the following methods:

- Population-based sampling surveys (e.g. where all persons / households in a given area are randomly selected to be approached).
- Utilization of subjects from another study who are recruited by a population-based sampling method.

Results

- 27 Ed Cores contacted
- 16 (59%) responded.

Results: cases

- No population-based methods.
- No random selection of cases from clinics.
- 5 centers: could calculate percent enrollment for specific clinics.
 - But these constituted only part of enrollment.
- 5 centers: kept track of denominator of those approached:
 - e.g. sign up sheets for all persons who attend memory screenings.
- 6 centers: Other methods.

Results: controls (1)

- 2 centers: clinic based cohort
 - Drawn from large network (e.g. HMO).
- 1 center: used subjects recruited from a population-based study on cardiac disease
- 1 center: mail survey of all voters > 65 yrs in their county.

Results: controls (2)

- 6 centers: kept track of denominator approached.
 - Could calculate proportion enrolled.
- 1 center: not enrolling controls.
- 5 centers: Other methods.

Summary: 1. Cases

- Statistically-based probability sampling: seldom, if ever.
- Directed contact approach
 - As with clinical series.
- However, do try to get all cases possible from clinics where they recruit.
- Probably fairly representative.

Summary: 2. Controls

- Some statistically-based probability sampling from population and clinics.
- Only a small percent of controls.
- Some centers with interesting population-based methods:
 - Mass mailing to all registered voters.
 - Co-recruiting with other studies (population, clinic)

Summary:

3. Representativeness of controls

- More highly educated, less racially diverse than cases or general population.
- Difficulty in describing denominator.
 - Limited ability to draw inferences.
- Controls should come from same “population” with same boundaries (geography, demographics, etc) as cases.

Summary:

4. Improving representativeness of controls

- Recruiting by population-based means is feasible.
 - Does not need to be done on a large area.
 - E.g. Framingham study.
- Networks of clinics: probability sampling schemes

Conclusions

- Objectives:
 - Description of recruitment practices.
 - Suggest alternatives to ease recruitment burden.
 - Increase inferential capacity.
- Changes a challenge initially; but once established
 - Long-term stability in recruitment
 - Increased representativeness.

For further discussions:

Charles Mock cmock@uw.edu

Walter Kukull: kukull@uw.edu