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Planning and Conducting a Research Survey

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Why would I do a survey?

- To measure or assess the relationship between past exposures and a disease or health outcome.
  - To create a data record for later analysis

- As a first step, define your hypothesis based on the research question and then decide which **study design** will be best suitable to answer that question.
- Is your study observational or experimental?

Observational: Case Control Study

- A survey can be used to determine the degree of association between various risk factors and outcomes.
- **Cases** have the disease outcome of interest when enrolled in study
- **Controls** do not have the disease of interest when enrolled in study
- A survey is a data collection tool that provides a retrospective assessment of exposures.
- Exposures can be harmful or beneficial.

Benefits and limitations of case-control studies

- Good for rare diseases that take a long time to develop
- Relatively inexpensive
- Quick – since you don't have to wait for disease to occur

- Limitations – recall bias or insufficient records of past exposures
- Does not prove causality but can provide evidence for a significant association between exposure and outcome.

Survey type and data source

Subjective sources

- Survey types used to find out which questions to ask
  - Focus group discussion
  - Key informant interviews
- Individual Questionnaire to record exposures
  - Interview study participant (or parent of minor)

Objective sources

- Medical record extraction including clinical lab values
- Blood test (if exposure can persist in the body, such as drug levels to see if patient compliant with a treatment regimen)

Observational: Cohort study

- Study participants are selected based on **EXPOSURE** of interest (exposed versus non-exposed)
- Both groups followed over time to determine how many develop the disease or outcome of interest.
- Longitudinal study design – length of observation time determined by disease or outcome of interest.
- Can be prospective or retrospective

Benefits and limitations of cohort studies

- Good for common diseases or outcomes that don't take a long time to develop
- Supports a causal link between exposure and disease outcome (relative risk)

- Limitations – takes time to complete study (can be years of data collection), more expensive, needs consistent and robust data collection team to prevent operator bias.

Survey types and data source

Objective outcome measurement

- Diagnostic test to confirm disease outcome
- If exposure time was definitive, able to assess progression of disease (how long it takes from exposure to disease presentation)
- More than one outcome can be assessed if exposure is suspected to cause multiple diseases

Observational: Cross-sectional study

- Measures both exposure and outcome at one time for individuals(snap shot)
- Determines prevalence of exposure and disease (scope of the problem and suspected causes)
- Quick and easy to do
- Limitation - cannot conclude cause-effect relationship between exposure and outcome

Observational: Ecological study

- Measures both exposure and outcome at one time for a population (snap shot)
- Determines prevalence of exposure and disease (scope of the problem within a community and suspected causes)
- Quick and easy to do (large scale)
- Limitation - cannot conclude cause-effect relationship between exposure and outcome
- Beware of ecological fallacy (attributing population level data to individuals)

Survey type and data source

Objective sources

- Population level databases, if available (some examples)
  - cancer or other disease prevalence registry
  - pollution records
  - introduction of a product, extent of use and availability, etc.
  - Census records

Experimental: Randomized clinical trial

- Study participants randomized to control group or experimental group
- Both groups followed over time to determine how many achieve the outcome of interest
- Longitudinal study design – length of observation time determined by outcome of interest.
- Prospective in nature – considered **GOLD STANDARD** as it proves cause-effect relationship

Benefits and limitations of clinical trials

- Demonstrates causal link between intervention and disease outcome (i.e. survival analysis for treatment studies or protection from disease for vaccine studies)
- Avoids confounding and selection bias

- Limitations – takes time to complete study, most expensive, needs consistent and robust data collection team to prevent operator bias and monitors for severe adverse events.
- Study participant refusal, crossover, drop outs and lack of compliance

Survey types and data source

Objective exposure and outcome measurements

- Controlled intervention (i.e. drug treatment or vaccine)
- Robust diagnostic test to confirm disease or outcome
- Since exposure is pre-determined, able to conclusively assess how long it takes from exposure to achieve outcome
- Can determine benefit of intervention compared to no intervention on health outcomes
- Cost-benefit analysis

Paperless data collection

- RedCap (https://en.wikipedia.org/wiki/REDCap)

Research Electronic Data Capture

Ensures security and protection of health data linked to a study participant

Free – but password protected

Developed by Vanderbilt in 2004

Used by 2400 institutional partners in over 115 countries, with more than 590,000 total end-users employing the software for more than 450,000 ongoing research studies.[2]

What types of data do you want to collect and how do you make sure it's accurate?

Designing your data collection/survey tool

Demographic data (protected health information)

- Name
- Date of birth
- Date of survey
- Sex (different from gender)
- Home location
- Name of family members (spouse or parents of minors)

21 variables considered PHI = can this data be used to identify a study participant?

https://en.wikipedia.org/wiki/Protected_health_information

sources

- https://www.ncbi.nlm.nih.gov/books/NBK470342/