Long COVID/ COVID-19 Impact Study

Lessons learned

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Study design

Aims

- Gather prevalence of long COVID; descriptive epi
- Understand impact and current resources
- Improve COVID-19 data quality
  - Receive results from those we personally tested OR results forwarded from other counties
  - Agreements with certain PRCDA counties in WEDSS; sharing ability variable

Design

- Interview-based, around 30 minutes; non-technical interviewers
- Adapted questionnaire, five sections, mostly quantitative
- Cross-sectional
- Stratified random sample + convenience
- $100 incentive

Study design

Design

- DOH had good knowledge of COVID burden on **some** counties
  - Numbers reflected more of whom we were more likely to get information from vs actual burden

- Took COVID-19 list from WEDSS
  - Stratified sample by county, then random sample to meet quota to weight responses
  - Oversampled by 10%
  - Try to contact 3x and send letter before LTF

- Allow others to call in and volunteer
  - Convenience sample, if on selected list crossed out
  - Everyone allowed to participate as long as they were eligible

Study design

Eligibility

1. Ho-Chunk Enrolled Tribal member OR Descendant
    a. Had to prove tribal affiliation to receive incentive
    b. Tribal ID, CDIB, family lineage- some documents in EHR
2. Must live in Wisconsin
3. Must live in one of the 15 PRCDA counties in Wisconsin
4. All ages welcome, youth must have parental consent and/or complete the interview on their behalf
5. Received a positive lab-confirmed COVID result
    a. Within a certain timeframe, minimum 6 weeks from day of interview

Lessons learned

- Lots of information, many ways to go....hard to capture everything!
  - Try to have source to verify information (e.g., medical records, vaccine records, etc.) because of response bias
- Competing interest of stakeholders/audiences made it challenging to design

Study design

- Ideally, pilot study on defining impact
  - No indigenous scales in the literature, tried to adapt the best we could
- Initially, measured impact on type OR # of impacts; too variable
  - What about severity? Duration?
  - Used self-rated impact of infection on physical and mental health
- Emphasis on mixed methods
  - Survey + open-ended interview
- How to deal with reinfections?
  - If multiple infections, supposed to focus on initial infection...worked sometimes

Lessons learned

Recruitment/Participation

- Snowball sampling worked better with hard-to-reach counties
- People move! Impacted county estimates '
- Ensure eligibility process is quick or can be done immediately
  - Lose people if you need to reach them again
- Hard to contact by phone number, in-person more ideal
  - Unreliable based on service, incorrect phone number, phone turned off
- Must be contacted in a variety of ways and times
  - Calls + texting, evening and weekend important
  - Work phones for interviewer with caller ID of organization
- Many people wanted to participate last minute dispute numerous reminders being shared
  - Slow return of surveys, even way after its closure

Lessons learned

Recruitment/Participation

- Issues with tribal verification + financial incentive
  - Missing documents; requirement of W-9
  - Slow turn-around for financial processing
- Exclusion of members based on geography due to budget/sampling hurt feelings
  - Hard to explain in-plain language about limits in technology + statistics
- Those with ineligible test types (e.g, self-test, antigen) felt we viewed them as untrustworthy because they couldn't participate (test wasn't good enough for proof)