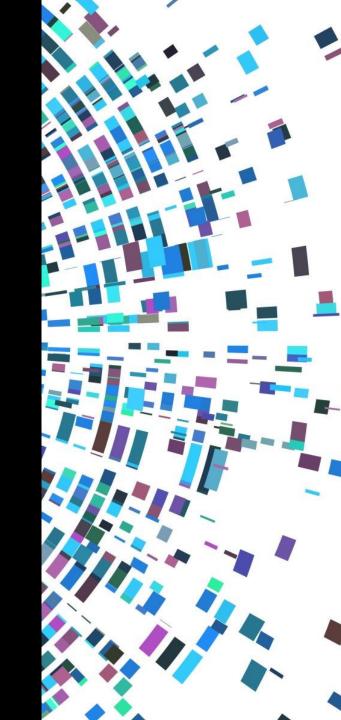


Design and Review in a World of Bots, Hackers, and Evolving Technology



Presenters

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Learning Objectives

- Identify signs of online survey compromise, differentiate fake from real research participants, and modify procedures to protect from further compromise through real-life case study examples
- Discuss how the IRB and principal investigators can work together to address survey compromise in terms of reporting requirements, compensation provision, and maintaining data confidentiality
- Share best practices for design of online research and for cybersecurity monitoring of survey data
- Describe best practices for data interpretation postcompromise



Online Research Methods

- Research methods that utilise the internet as medium for research
- Sometimes referred to as internet mediated research
- Includes research methods designed to investigate both online & offline phenomena
- surveys, experiments, interviews, observation, document analysis, virtual ethnographies, web analytics & content analysis, simulations, GIS





Benefits & Perils of Online Research

Investigators

- Can help achieve adequate participant numbers for data analyses;
- Can allow a national or international scope;
- Can access harder-to-reach populations;
- Can lead to more representative sampling;
- Expedite the data collection process;
- Cost-effective
- Reduced social desirability effects

Potential Participants

- Less burdensome;
- May heighten comfort with provision of sensitive information (decrease personal risk)
- May facilitate participation in research (balanced power relationship)
- DEI consideration

Benefits & Perils of Online Research





Digital literacy



Reduced levels of control over procedures



Identity verification



Building rapport with participants



and institutional support



Ethical considerations



Study Design Considerations

Conceptualization

- Research question and target population, including key characteristics and type of data
- Benefit vs risks of online research
- Design and layout: organization of questionnaires/measure
- Software: contract, ownership of data, incentive distribution
- <u>IRB submission</u>: Informed consent forms; surveys, scripts for social media, communication with participants, contingency plan, monitoring plan

Recruitment

- Community partners and key stakeholders
- FB pages, private groups, events, FB Ads, Creation of Institution level website for online research efforts
- Social Media posting, template, QRC
- Study information survey
- Prevent indexing, multiple submission
- Phone Screening
- Piloting
- Incentives: exercise caution

Data Management

- Distinguish between study information survey and full questionnaire
- Password protected
- Individualized link, created for the participant unique e-mail
- Set expiration date
- Develop standard procedure to distribute survey access/ info
- Limit accessibility: US, State, City level
- Consider HIPAA compliant tools for qualitative research and team sharing in post-COVID19 research





ARE YOU A WOMAN DIAGNOSED WITH **BREAST CANCER DURING THE COVID-19 PANDEMIC?**

A STUDY IS SEEKING 120 WOMEN DIAGNOSED WITH EARLY-STAGE BREAST CANCER

TO BETTER UNDERSTAND HOW COVID-19 HAS IMPACTED THEIR DECISIONS AND EXPERIENCES OF CARE

TO BE CONSIDERED FOR THIS STUDY, YOU MUST:

- · Self-identify as Black/African American, Hispanic/Latina or White/Caucasian; Have received a diagnosis of early-stage breast cancer in January 2020 or later;
- · Be receiving care for breast cancer at time of the study;
- Be at least 18 years of age;
- · Have access to a computer, smartphone, tablet, or other device to complete
- an internet-based survey;

Be able to read and understand English.

THE STUDY INCLUDES:

- + 120 women will complete an online survey that will take about 30-40 minutes; survey respondents will receive a \$30 Amazon gift-card
- · 30 of the survey participants will be invited to participate in a 60-90 minutes online interview; interview participants will receive a \$60 Amazon gift-card.







(713)743-9204



Are you

Interested?

Please contact us:

Dr. Chiara Acquati

(713) 743-4343

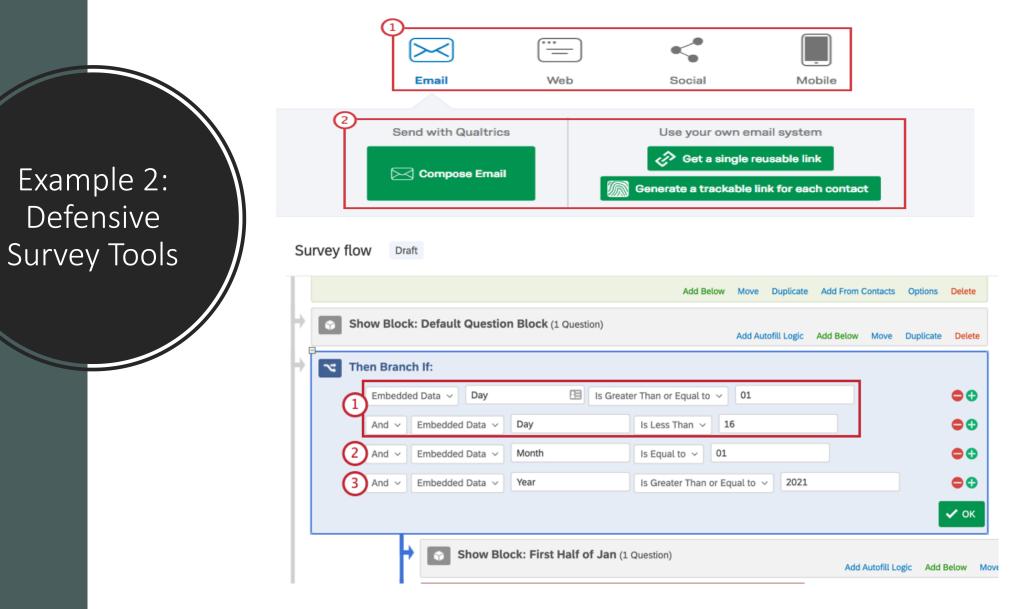
cacquati@uh.edu

or email us

This project has been reviewed by the University of Houston Institutional Review Board, which can be reached at



How do you want to distribute your survey?



Example 2: Defensive Survey Tools

Data & Analysis Actions Distributions Reports Options Saved at 4:23 PM Draft General Prevent multiple submissions Language, title, survey description respondents trying to take your survey multiple times. Responses Expiration, incomplete, change responses On On Security Action Passwords, uploads, bots, indexing Redirect to URL \sim Post-Survey Website URL Thank you email, completed survey message https://www.qualtrics.com/support/ Advanced Bot detection Scoring We'll look for bots that might be taking your survey and flag their responses with an embedded data field Attach point values to specific answers (reCAPTCHA). Learn More Off Quotas

Set conditions you want responses to meet

Translations

Survey

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7

Tranclate this survey into other languages

Security scan monitor

Prevent security scanners from accidentally starting surveys when they test your link (reCAPTCHA). Learn More

End the survey for respondents and display a custom message, redirect to a different website, or flag the data for

Preview

Publish

Is this within the IRB's purview?

Risks v. Benefits

- Even minimal risk to participants should be offset by at least minimal potential benefit of the research
- For many studies, particularly minimal risk survey studies, the only benefit is scientific value, which may be lost if the data is compromised
- Data compromise may also introduce risk to participants of not being compensated appropriately, or potential loss of confidentiality if research data is hacked and additional identity verification is needed



Institutional Review Board (IRB)

Impact on IRB review



- The IRB submission should include a detailed recruitment plan, especially for social media recruitment
 - Consider targeted advertising rather than public blasts
 - Consider use of closed or moderated specific topic groups or professional accounts
 - Avoid advertising on more publicfacing platforms like Twitter or Reddit
- Describe defensive study designs and data monitoring
 - Examples: screening to verify identity, attention checks, validity questions
- Consider adding language in advertisements and consent forms warning participants that compensation may be withheld if verification checks are not passed, that additional follow-up may be needed to verify identity, etc.

Incentives/ Compensation Information

Compensation may attract bots/scammers

- Consider the risk of data compromise against benefits of compensation
- Ensure minimal focus on compensation in study advertisements
 - Avoid images like dollar signs, money bags, etc.
 - Avoid providing the \$ amount
- Consider if compensation should be reduced or removed
- Consider multi-step screening and compensation procedures
- Include a time-frame for the expected compensation to be distributed

Anonymous v. Identifiable



Collecting IP addresses or contact information may be worth it for identity verification

The threat of compromised data validity may outweigh the risks of collecting identifiers from participants.

IRBs and researchers can work together to ensure appropriate confidentiality and privacy measures are in place to handle identifiable data

Work with Information Security or IT for guidance on preferred secure platforms

If surveys will be anonymous, reviewing for targeted recruitment plans, defensive survey designs, and minimized compensation plans are even more important as there will be no way to go back to verify identity.

How YOUR IRB can HELP!



Train IRB staff and reviewers on what to look for



Educate the research community

Develop and disseminate institutional best practices

Consider creating Social Media Recruitment Guidance: Work with your institution's stakeholders to develop this; Create template management plans to help researchers develop their strategy

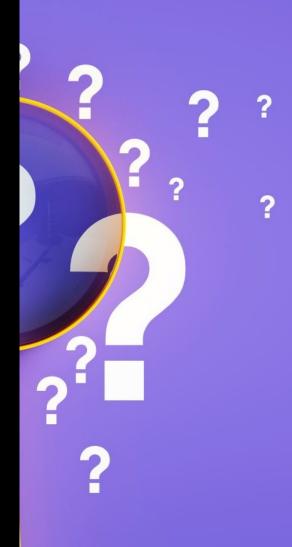


Work proactively with institutional stakeholders to raise awareness and set researchers up for success.

Example: Encourage institutionally supported online accounts that can be used to disseminate research advertisements and survey links via secured and monitored accounts



Things are going wrong... What to do?



Strategies to Identify and Prevent Fraudulent Data

Software-enabled tools

- Software with fraud prevention detection capabilities
- Screening questions, CAPTCHA
- •IP address and GIS (cluster)
- •Time stamps, compare with estimated completion time
- •Track methods for survey completion (Link, QRC)
- Quota

Duplicate or unusual responses, Bots

- •Survey completion time (estimate and range)
- •Patterns in answers: straight lining
- •Exact response provided multiple times
- Content of the response: irrelevant, too general, not applicable to the target population, duplicate from website
- •Zip code and GIS do not match, cluster of responses from one area of the country
- Identify a source beyond the list of organizations/contacts
- •Hidden items = bots

Experience and IRB collaboration

•Remuneration Letter;

•Request acknowledgement of eligibility/exclusion criteria

Set a % of the survey with mandated answers

| | A | В | С | D | E | F | G | н | 1 | J | К | L |
|----|---------------------|------------------|------------------|---------------|--------------|--------------|----------------|--|--------------|-------------------------|-----------------------------|------------------------------|
| 1 | StartDate | EndDate | Status | IPAddress | Progress | Duration (in | Finished | RecordedDat | Responseld | RecipientLastName | RecipientFirstName | RecipientEmail |
| 2 | Start Date | End Date | Response Type | IP Address | Progress | Duration (in | Finished | Recorded Da | Response ID | Recipient Last Name | Recipient First Name | Recipient Email |
| 3 | {"ImportId":"startI | {"ImportId":"end | ["Importid":"sta | {"Importid":' | {"ImportId": | {"Importid": | {"Importid":"f | {"ImportId": | {"Importid": | {"ImportId":"recipientL | {"ImportId":"recipient | {"ImportId":"recipientEmail" |
| 4 | 11/20/19 12:06 | 11/20/19 12:06 | 0 | | 100 | 34 | TRUE | ###################################### | R 5u2duLx3 | Peterson | James | peterson@example.com |
| 5 | 11/20/19 12:06 | 11/20/19 12:06 | 0 | | 100 | 35 | TRUE | ############ | R_e4JwAog5 | Petersen | Tara | petersen@example.com |
| 6 | 11/20/19 12:06 | 11/20/19 12:06 | 0 | | 100 | 24 | TRUE | ############# | R_Oulsv6tBF | Culp | Maggie | mculp@example.com |
| 7 | 11/20/19 12:06 | 11/20/19 12:06 | 0 | | 100 | 36 | TRUE | aunnnaunn | R_8A2wbEZf | Clickinbeard | Bram | clickme@example.com |
| 8 | 11/20/19 12:06 | 11/20/19 12:06 | 0 | | 100 | 24 | TRUE | ******* | R_eh9Kh3sK | Perez | Josh | jp@example.com |
| 9 | 11/20/19 12:06 | 11/20/19 12:06 | 0 | | 100 | 26 | TRUE | ******* | R_7UU01Xx) | Chang | Wendy | wendywanda@example.com |
| 10 | 11/20/19 12:06 | 11/20/19 12:06 | 0 | | 100 | 35 | TRUE | ******* | R_OCib6Xflz) | Nyugen | Lauren | laurenn@example.com |
| 11 | 11/20/19 12:06 | 11/20/19 12:06 | 0 | | 100 | 34 | TRUE | ******* | R_aVp9v93s | Smith | Phoenix | phoenix212@example.com |
| 12 | 11/20/19 12:06 | 11/20/19 12:06 | 0 | | 100 | 23 | TRUE | ппппппппп | R_9sKyloWB | Witherspoon | Во | bow@example.com |
| 13 | 11/20/19 12:06 | 11/20/19 12:06 | 0 | | 100 | 22 | TRUE | ппппппппп | R_OIYudgLB9 | Foucault | Andre | andref@example.com |
| 14 | | | | | | | | | | | | |

Example 3 – Fraudulent Data Detection

| | Record | Show response for ticket | Stat |
|-----|---|--------------------------|-------|
| > F | Record at: September 21, 2017 | | |
| ~ F | Record at: September 21, 2017 | | pen |
| | Location ID: 33456 Q_RelatedResponseField: Location ID | | Ema |
| 1 | Q_RelatedResponseFieldValue: 33456 | | -1114 |
| ic | Location Data | | I |
| | Location: (40.296905517578, -111.69460296631) Source: GeoIP Estimation | | |
| | Ogden Salt Lake City Santy UINTAH AND OURAY | | |
| | | Close | |

Reporting to the IRB

The IRB will need to consider if the event involved any of the following:

- increased risk or harm to participants
 - Ex: risk to data confidentiality, inability to compensate, etc.
- increased risk to scientific integrity of the study
 - Ex. loss of valid data; inability to separate good data from bad, etc.
- noncompliance with the approved protocol
 - Ex. procedures intended to mitigate compromise not followed; compensation not provided as promised in the consent; altering recruitment strategies or data management plan without IRB approval.

Corrective Actions

- Balance the risk of losing data or not compensating valid participants against the risk of stopping the entire study and/or loss of research funds to pay scammers.
 - Can the PI compensate all (including scammers) and still salvage the research?
 - Can the PI reasonably determine who should not be compensated?
- If the survey will be re-posted, what changes are needed to the approved protocol to avoid a repeat incident?
- How will the event and any changes to compensation or screening be communicated to participants, and how will complaints be handled?
- Case study example
 - Corrective action plan for survey of registered nurses



Takeaway for Investigators

- Enhance Software: contract, ownership of data, incentive distribution, fraud prevention detection capabilities
- Assess recruitment methods that will mitigate the problem
- Establish data collection and management methods that will reduce the opportunity for fraudulent submissions
- Monitor the data for Duplicate or unusual responses, Bots





Takeaways for IRB Review and Institutional Support

- Provide a detailed recruitment plan to help the IRB make an appropriate risk/benefit determination
- Describe how you will implement defensive study designs such as screening to verify identity, attention checks, validity questions
- Consider if collecting identifiers is more effective for deterring bad actors, and explain this in the IRB submission
- Evaluate compensation plans
- Encourage training for IRB members/staff and Research Investigators
- Encourage the development of institutional resources

