



Internet ~~Research~~: Doing "Virtual" Research Virtuously

Joe Konstan, University of Minnesota
Dean Gallant, Harvard



(and a special thanks to Scott Bradner)

Summary

- It's not different from offline research
 - Except where it is!
- Evaluation follows the same principles
 - But may bring forward different questions



Dividing Up the Space

- Online Recruitment of Subjects
- Online Surveys
- Observing Online Behavior
- Experimenting in Online Environments
- Delivering Experiments Online
- ... and plenty more



Online Recruitment

A Researcher Proposes to:

- Conduct a study of *Gay men seeking sex online*, recruiting subjects via:
 - Keyword-linked *Google ads*
 - Advertisements on *Gay sex sites*
 - Researchers entering *Gay chat rooms* to recruit subjects individually

What are the issues here?



Latino Men's Internet Sex Study
Click here and earn \$20 on-line
University of Minnesota



Recruitment Issues

- Is this the right subject pool?
 - Risk of bias (lack of random sample)
 - Consider alternatives to validate subject pool
 - Minors or others who should be ineligible
- Appropriate informed consent
 - Understanding how people read online
 - What degree of risk? What degree of consent process?
- Risks of fraud
 - Repeat subjects seeking multiple payments
- Risks of subject confidentiality
 - What trail is left behind on subject's computer? Logs?



Some Lessons from MINTS

- Men's Internet Study
 - Internet-recruited Latino men who have sex with other men



Informed Consent Online

- Online reading different from print
 - Jumping around, hypertextual
 - Skimming, not reading
 - Bullets, not sentences
 - Nobody reads long consent forms
 - Harder to read on screen
- Solution: Chunked consent with active consent statements




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Chunking Consent: How Internet consent differs from conventional

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WHAT WILL I BE ASKED TO DO AS A STUDY PARTICIPANT?

If you agree to participate in the study, we will ask you to enroll in the study. You will then be asked to answer about 200 questions online about your experiences, attitudes, and beliefs concerning sexuality, drug use, and related issues. These questions will take you about 45 minutes to answer.

I understand I will be asked questions about my sexuality, drug use and related issues.

I CONSENT and wish to enter the study →

← I DO NOT CONSENT and wish to leave the study


If you have any problems during the study, please contact the research team at MINTS@mail.comosedice.umn.edu.

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Chunk 2: WHAT ARE THE RISKS AND BENEFITS OF PARTICIPATION?



Benefits. Some men may find that this study helps them to think about HIV, the Internet, and the importance of safer sex. Also some men feel good about participating in research studies.

Risks. If you find that being asked questions about sex is embarrassing, you may feel uneasy about answering certain personal questions on the survey. We need to ask these questions in order to complete the study, but this study is entirely voluntary. So, you can choose not to answer any question, to stop at any time, or to pause and come back later to finish the survey.

If you are particularly concerned about confidentiality, then [Click Here](#) for more information on how to best keep your answers confidential.

I understand the benefits and risks for this study as outlined above

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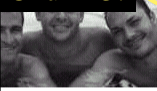
[General Privacy Statement](#)

If you have any problems during the study, please contact the study coordinator, Jeffrey Stanton (phone: 800-715-5864, email: MINTS@mail.comosedice.umn.edu), the principal investigator, Professor Simon Rosser (email: rosse001@tc.umn.edu), or the University of Minnesota Research Subjects' Advocate line (phone: 612-625-1650, email: irb@umn.edu).

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Chunk 3: WILL I BE IDENTIFIED?



No. We do not require you to provide any information that identifies you. We do ask you for your zip code and birthdate to make up a unique identifier that only you will know. This is necessary to register for the study. We will also ask you to provide an email address so we can contact you if there are any problems during the study. All email addresses will be deleted at the end of the study. Because we are asking sensitive questions, we have obtained a Certificate of Confidentiality from the National Institutes of Health. The researchers will use this certificate to challenge any demands for information that would identify you. For more information, press [here](#).

I understand that the study is confidential, and that only an email address will be used to contact me during the study

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Links to more detailed page:

ABOUT YOUR CONFIDENTIALITY

We are very concerned about the confidentiality of the information you provide us. As a government-funded study, the data we collect may be requested by others. Accordingly, we take the following precautions in collecting the data:

- We do ask for an email address to aid communication. If you are worried that this may identify you, you can go to Hotmail, Yahoo or other web sites and create an email address just for this study. You may also opt not to provide an email address. All email addresses will be destroyed at the end of the study.
- We will not share, give or sell your email address to any other organization. It will be used solely for this study.
- We do not require you to provide any information that legally identifies you. At the end of the study, your unique identifier (based on your birthdate and zip code) will be destroyed.
- Any information you provide for purposes of receiving compensation will be stored separately from the rest of the study data and will be deleted after the completion of the study.
- We will not secretly record or log any information about your visit to us. During data collection, we do collect IP addresses to ensure participants are valid. Email addresses are requested in case of problems with completing the survey. This information is deleted at the end of the study.
- We provide a secure web server to protect against intermediate sites intercepting your data.

In addition, to help us protect your privacy we have obtained a Certificate of Confidentiality from the National Institutes of Health. With this Certificate, we cannot be forced to disclose information that may identify you, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative or other proceedings. We will use the certificate to resist any demands for information that would identify you, except as explained below.

- The Certificate cannot be used to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation of this project.
- You should understand that a Certificate of Confidentiality does not prevent you from voluntarily releasing information about yourself or your involvement in this research. If you provide us with your written consent to receive research information, then we may not use the Certificate to withhold that information from you.
- You should also understand that a Certificate of Confidentiality does not prevent the researchers from releasing information about you to prevent serious harm to you or to someone else. However, it is highly unlikely that we would need to make such a disclosure, since we are not asking specific questions about such matters as child abuse, suicidal or homicidal intent or intentionally transmitting HIV.

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- We will not share, give or sell your email address to any other organization. It will be used solely for this study.
- We do not require you to provide any information that legally identifies you. At the end of the study, your unique identifier (based on your birthdate and zip code) will be destroyed.
- Any information you provide for purposes of receiving compensation will be stored separately from the rest of the study data and will be deleted after completion of the study.
- We will not secretly record or log any information about your visit to us. During data collection, we do collect IP addresses to ensure participants are valid. Email addresses are requested in case of problems with completing the survey. This information is deleted at the end of the study.
- We provide a secure web server to protect against intermediate sites intercepting your data.

In addition, to help us protect your privacy we have obtained a Certificate of Confidentiality from the National Institutes of Health. With this Certificate, we cannot be forced to disclose information that may identify you, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative or other proceedings. We

Section 1: how we will treat the personal information provided

- The Certificate cannot be used to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation of this project.
- You should understand that a Certificate of Confidentiality does not prevent you from voluntarily releasing information about yourself or your involvement in this research. If you provide us with your written consent to receive research information, then we may not use the Certificate to withhold that information from you.
- You should also understand that a Certificate of Confidentiality does not prevent the researchers from releasing information about you to prevent serious harm to you or to someone else. However, it is highly unlikely that we would need to make such a disclosure, since we are not asking specific questions about such matters as child abuse, suicidal or homicidal intent or intentionally transmitting HIV.

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ABOUT YOUR CONFIDENTIALITY

We are very concerned about the confidentiality of the information you provide us. As a government-funded study, the data we collect may be requested by others. Accordingly, we take the following precautions in collecting the data:

- We create...
- We v...
- We e...
- We c...
- Any information you provide for purposes of receiving compensation will be stored separately from the rest of the study data and will be deleted after completion of the study.
- We will not secretly record or log any information about your visit to us. During data collection, we do collect IP addresses to ensure participants are not the same. Email addresses are requested in case of problems with completing the survey. This information is deleted at the end of the study.
- We provide a secure web server to protect against intermediate sites intercepting your data.

In addition, to help us protect your privacy we have obtained a Certificate of Confidentiality from the National Institutes of Health. With this Certificate, we can be forced to disclose information that may identify you, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative or other proceedings. We will use the certificate to resist any demands for information that would identify you, except as explained below.

- The Certificate cannot be used to resist a demand for information from personnel of the United States Government that is used for auditing or evaluating this project.
- You should understand that a Certificate of Confidentiality does not prevent you from voluntarily releasing information about yourself or your involvement in this research. If you provide us with your written consent to receive research information, then we may not use the Certificate to withhold that information from you.
- You should also understand that a Certificate of Confidentiality does not prevent the researchers from releasing information about you to prevent serious harm to you or to someone else. However, it is highly unlikely that we would need to make such a disclosure, since we are not asking specific questions about such matters as child abuse, suicidal or homicidal intent or intentionally transmitting HIV.

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Chunk 6: Ways of asking questions prior to participation

HOW CAN I CONTACT FOR MORE INFORMATION ABOUT THIS STUDY?

This study is funded by the National Institutes of Health and conducted by researchers at the University of Minnesota studying HIV prevention. If you want to ask any questions about the study before deciding to begin, you can contact the study coordinator, Jeffrey Stanton (phone: 800-715-5864, email: MINTS@mail.comosedice.umn.edu) in English or Spanish. If you have any problems during the study, please contact the study coordinator, Jeffrey Stanton (phone: 800-715-5864, email: MINTS@mail.comosedice.umn.edu), the principal investigator, Professor Simon Rosser (email: rosse001@tc.umn.edu), or the University of Minnesota Research Subjects' Advocate line (phone: 612-625-1650, email: irb@umn.edu).

I know that I can email or telephone the researchers with any questions now, during or after the study is completed.



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MINTS-I Data



| | |
|--|------------------------------------|
| 47,496,771 banner ads displayed on gay.com | |
| 33,024 click-throughs, indicating visits to the study site | |
| 1742 enrollments – completion of eligibility screening and consent | |
| 1150 completed surveys | |
| 1026 surveys deemed valid and complete | |
| 18 of these surveys are first completions by people who later completed one or more additional surveys | |
| 119 repeat surveys (second or later complete survey from a single subject) | |
| 65 surveys from 'Subject Naught' | 54 surveys from 17 other repeaters |
| 5 surveys from participants deemed ineligible to participate | |
| 3 evidence of non-Latino identity | 2 evidence of non-US residence |
| 534 incomplete surveys, therefore rejected | |
| 520 surveys deemed incomplete but otherwise valid (from a unique person) | |
| 14 surveys deemed incomplete and invalid (repeat submission) | |
| 58 surveys not started (did not answer any questions) | |

Online Surveys

A Researcher Proposes to:

- Conduct an online survey, of existing research subjects, through SurveyMonkey

What are the concerns?

Online Survey Concerns

- Data integrity and security
 - Can you trust SurveyMonkey site?
 - Doesn't require secure link
 - Many routes through which data can be obtained and/or changed
 - What alternatives exist?
 - Professional survey tools run by your IT group (e.g., limesurvey)
 - Outsource surveying to reliable vendor who is experienced with research integrity



But There's More!

- Survey design may raise ethical questions:
 - Are there options to skip questions?
 - Can these be invoked after an initial answer
 - Potential coercion later in a paid survey
- And what other identifying information do you receive?



Observing Online Behavior

- A Researcher Proposes to:
 - Study online social networks in FaceBook
 - Joining Facebook networks and groups where possible
 - Collecting data about what people make visible to those they haven't "friended"



Issues To Consider

- Expectations of Privacy vs. Reality
 - This is a tough one; research continues to show that users are surprised when information they make public is later used.
 - A useful line: what is actually public behavior vs. behavior normally only seen by a limited group



Experimenting in Online Environments

- Researcher 1 wants to:
 - Pose sets of questions in online Q&A sites, paying for answers when appropriate, and studying the answers
- Researcher 2 wants to:
 - Repost old messages in online cancer support discussion groups, varying the rhetoric and observing the results



Issues to Consider

- Is there any risk here at all?
 - May depend on how much the research activity risks perturbing the group
 - Small percentage, unnoticed, no risk
 - High percentage, notices, possible risk
 - Is there ever a need to inform "subjects?" Is this human subjects research at all?



Internet Delivery

A researchers proposes to:

- Deliver an innovative HIV-prevention system online, logging user actions and behaviors.



Risks to Consider

- How is the data protected?
 - On the client end (monitoring, encryption, etc.)
 - On the server end (OS protection from viruses, account access limitations, hacking, firewalls, and more)

This is not something for the non-expert to undertake: Involve IT experts at your university.



A Few General Rules

- Don't Over-React
 - If it would be OK to do the research in a public park or mall, it's probably ok online
- Don't Under-Prepare
 - If you'd require a "locked file cabinet" then you need equivalent (and perhaps more extensive) computer guidelines.



More General Rules

- Flexibility is Necessary
 - Online consent, online payment mechanisms are very different from conventional
 - The online environment changes very rapidly
- Make sure research teams have the needed expertise (co-PI, IT staff)



Some Useful Principles

- Anonymity has trade-offs against
 - Inducements (payment trails)
 - Data integrity
- Security that makes work too hard gets circumvented!
- There are significant cost/benefit trade-offs

