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## Risk of disclosure of participating in an internet-based HIV behavioral risk study of men who have sex with men (MSM)

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### Abstract

As the frequency of internet-based research has increased, it is important for researchers to consider how the conditions in which data are collected may influence the risks to participants. In particular, because internet-based data collection often occurs outside a clinical or research setting, there may be unintentional disclosures of a participant's involvement in a research study of which the researcher is unaware. The current analysis examined the responses of men who have sex with men participating in an internet-based HIV behavioral risk study when queried about the possible disclosure of their participation in the study. Fewer than 2% of participants indicated that their participation in the research study was disclosed, and all but one indicated no negative outcomes associated with the disclosure. As the field of online research continues to expand, it is important to consider risks that are unique to internet-based research, and to monitor these risks to ensure that the confidentiality of research subjects is maintained.

### INTRODUCTION

In the past 10 years, the internet has become an increasingly popular venue for men who have sex with men to meet potential sex partners. In parallel, the number of internet-based HIV prevention research studies has increased dramatically.<sup>1-5</sup> This trend is also noted in the broader context of behavioral health research, as the ease of collecting data online and the ability to reach geographically diverse study populations at low cost provide an attractive alternative to traditional data collection mechanisms. Although methodological disadvantages of online data collection, such as low response rates and concerns about the reliability and validity of data, have been noted<sup>6</sup>, there may be additional risks to individuals who participate in internet-based studies. The fact that the completion of internet-based surveys often occurs outside a research or clinical setting complicates the protection of confidentiality. Because data are collected in conditions that researchers cannot control (i.e., the participant's residence or public internet cafe), there may be risks to participation in research, such as breaches of confidentiality or disclosure of participation in a research study, of which the researchers are unaware. To examine the extent to which these breaches of confidentiality might occur, we included a series of questions in an online follow-up survey to query individuals participating in an internet-based HIV prevention study about possible disclosure of their participation in the study

### METHODS

Internet-using men who have sex with men were recruited through banner advertisements on <http://www.MySpace.com> from March to April 2009. Men aged 18 years of age or older

reporting at least one male sex partner in the previous 12 months were eligible for the baseline survey, and a subset of participants was offered enrollment in an online follow-up survey. Men who agreed to participate in the follow-up survey were asked to provide an email address, and the link (URL) to the follow-up survey was then emailed to them at the 3-month follow-up time point. In order to begin the follow-up, survey respondents had to answer correctly two security questions, which related to the content of the baseline survey.

A breach of confidentiality was considered to be a disclosure that a participant was enrolled in a research study. This disclosure was assessed by two questions in the follow-up survey: (1) if an individual known to the participant found out that the participant had taken the first (baseline) survey; and (2) if an individual known to the participant saw the email inviting the participant to take the follow-up survey. Respondents reporting either occurrence were asked a series of follow-up questions to determine the negative outcomes, if any, that the participant experienced as a result of the disclosure of his participation in the study. The study was approved by the Institutional Review Board of Emory University

## RESULTS

Of the 517 participants who began the follow-up survey, 7 (1.4%) indicated that an individual known to them found out that they had taken the first survey. Of the individuals who learned of the participant's completion of the baseline survey, five were sex partners of the participant, one was a friend (not a sex partner), and one was a roommate. Six of the seven participants answered the follow-up questions about the outcomes resulting from the disclosure of their participation in the study. Each of these six respondents indicated that their participation in the baseline survey was disclosed when the individual walked into the room while the respondent was completing the survey. All six respondents noted that they did not care that their participation in the survey had been disclosed.

Nine participants (1.7%) indicated that an individual known to them saw the email inviting them to take the follow-up survey. Six individuals who saw the email were a friend (not a sex partner) of the participant, two were sex partners, and one was a roommate. Seven of the nine participants indicated that the individual had walked into the room when they had been reading the email, resulting in the disclosure of their participation in the study. One participant indicated that he had left his email open and visible and the individual saw the email, and one participant indicated that the individual had received the same email (i.e., was also a participant in the study). Participants were also queried on the immediate reaction of the individual when the individual saw the email invitation: four participants responded that the individual had attempted to enter the survey by clicking on the link in the email, four participants indicated that the individual had inquired about the email content, and one participant stated the individual who saw the email invitation had no reaction. Regarding the participants' reactions to the disclosure, the majority (n=8) did not care that their participation in the study had been disclosed. One participant indicated he was upset by the disclosure, but stated that there were no negative outcomes or problems in his relationship with the individual to whom the disclosure was made (a sex partner).

## CONCLUSION

As the field of internet-based research continues to expand, it is critical to ensure that the confidentiality of individuals who participate in online research is maintained. Our results indicate that the vast majority of participants (> 98%) did not, to their knowledge, have their participation in the research study disclosed. Among those participants whose participation in the study was disclosed, nearly all stated that they did not care that an individual known to them had learned of their participation in the study, and only one participant noting that

he was upset by the disclosure. The majority of disclosures occurred as a result of an individual walking into the room when the participant was either taking the survey or viewing the follow-up email, which presumably would not occur if the participant had been in a private room in a clinical/research setting as opposed to a residence. Although breaches of confidentiality are possible, our results provide evidence that it is a low-probability event, and that preserving the confidentiality of participants in internet-based research is achievable.

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