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Maintaining Privacy During Psychosocial Research on the International Space Station

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It is crucial to pay special attention to privacy and confidentiality concerns when conducting psychosocial research with astronauts and cosmonauts.

Conducting psychosocial research on the International Space Station (ISS) requires rigorous privacy precautions that exceed standard scientific human subject protocols. In our previous study involving crewmembers on Mir, and in our ongoing ISS work, special precautions were taken during each phase of the missions. Pre-flight, participants received detailed consent forms explaining that only group-level data would be presented, and they chose ID codes known only to them. In-flight, special procedures protected data during collection and transmission. Post-flight, our analytic strategy further masked participants' identities, and participant representatives were invited to review manuscript drafts prior to publication. In this paper we describe lessons learned during our on-orbit studies and discuss their relation to maintaining privacy on studies of future long-duration space missions.

It is crucial to pay special attention to privacy and confidentiality concerns when conducting psychosocial research with astronauts and cosmonauts. This type of study is unusual in the field of space research because it is psychosocial. It is unusual in the field of psychosocial research because it involves high-profile subjects who typically believe that their careers may be severely adversely affected by the slightest breach of privacy (Institute of Medicine [IOM], 2001). Therefore, the usual procedures in either field may not be fully adequate for these unusual studies.

Our international research team is comprised of American project members affiliated with the University of California at San Francisco (UCSF) and the Northern California Institute for Research and Education at the Department of Veterans Affairs Medical Center in San Francisco, and Russian collaborators associated with the Institute for Biomedical Problems (IBMP) in Moscow. Members of our group have conducted several studies in space and space-analog environments (Gushin, et al., 1997; Gushin, Efimov, Smirnova, Vinokhodova, & Kanas, 1998; Kanas, Weiss, & Marmar, 1996; Kanas, Salnitskiy, Grund, Gushin, Weiss, et al., 2000a, 2000b, 2002; Kanas, Salnitskiy, Grund, Weiss, Gushin, Bostrom, et al., 2001; Kanas, Salnitskiy, Grund, Weiss, Gushin, Kozerenko, et al., 2001a, 2001b; Kanas, Salnitskiy,

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Gushin, et al., 2001; Kanas, Salnitskiy, Weiss, et al., 2001; Kelly & Kanas, 1992,1993,1994; Kanas & Ritsher, 2005; Ritsher, 2005; Ritsher, Ihle & Kanas, 2005).

Psychosocial research in space includes such issues as crewmember tension, cohesion, leadership role, culture and language differences and the relationship between crewmembers and mission control personnel. These issues can be formulated at varying levels of analysis. For instance, our investigations concern both intrapsychic (feelings and thoughts within individuals) and interpersonal (interactions between individuals) functioning, and our subjects include both crewmembers (astronauts and cosmonauts) and ground personnel (American and Russian mission control staff). We believe it is critical for everyone involved in such research to be aware of the special privacy issues involved. A comprehensive array of rigorous privacy protection measures is essential for gaining subject compliance. With anything less, subjects may be reluctant to participate fully in research, even though they may fully support the ultimate goal of such work, which is to optimize psychosocial health and functioning on future space missions (IOM, 2001).

The concept of privacy is less straightforward than it may first appear. We have found that many people confuse privacy with anonymity. *Anonymity* means that the subject's identity is never attached to the data. *Privacy* means that the study team will take steps to prevent disclosure of personal information. It is essential that subjects in any study understand that which they are being promised.

The need for clear explanations and examples is especially acute for international populations. For example, there is no word that exactly corresponds to "privacy" in Russian. Well-articulated ethical guidelines may also be necessary in space research that involves multinational collaboration. The policies and research traditions of participating nations may differ in regard to such issues as subject privacy (Lanzerath, 1999; IOM, 2001).

We will use our experiences in conducting studies in space with astronauts and cosmonauts to illustrate the special privacy concerns in this type of work and to offer some specific privacy-protecting measures that we have found helpful.

PROGRAM OF PSYCHOSOCIAL RESEARCH

Our current on-orbit study of psychosocial issues during space missions involves International Space Station (ISS) personnel (Kanas, 2002). Questionnaires on mood and group climate are administered weekly to the crew on board the ISS, as well as to the ground control personnel covering the mission in the US and Russia. Computerized or hard-copy versions are available in both English and Russian. Data collection covers several ISS missions.

This is a partial replication and extension of our study during the Shuttle/Mir program (Kanas, Salnitskiy, Grund, Gushin, Weiss, et al., 2000a, 2000b, 2002; Kanas, Salnitskiy, Grund, Weiss, Gushin, Bostrom, et al., 2001; Kanas, Salnitskiy, Grund, Weiss, Gushin, Kozerenko, et al., 2001a, 2001b; Kanas, Salnitskiy, Gushin, et al., 2001; Kanas, Salnitskiy, Weiss, et al., 2001). That study found that crewmembers displaced on-board tension and dysphoria (unpleasant emotions) outwardly to mission control personnel, and that mission control personnel displaced tension and dysphoria to management. We also found that mission control personnel scored higher than crewmembers on several measures of unpleasant emotions, and that Russian subjects were more comfortable with their work environment than were their American colleagues. Overall, we found ample evidence that psychosocial issues are important factors that are worthy of study in long-duration space missions despite the extra complications in methodology that are needed to protect the subjects' data.

SPECIAL PRIVACY CONCERNS

In addition to the types of privacy protections that typically are included in psychosocial research, such as using subject identification codes, restricting access to data, and storing consent forms separately from the data, we also have had to address special privacy concerns arising from a unique subject population.

Data from these high profile subjects are likely to be of interest to others (e.g., the media) now and into the future. Also, astronauts and cosmonauts often perceive the risk inherent in divulging sensitive psychological information to be high. They are concerned about embarrassing the space program or about jeopardizing their flight status for future missions.

Moreover, the fact that our subject pool is relatively small makes it potentially easier than in most psychosocial research for outsiders to guess who provided a given set of data. For example, knowing the approximate date of data completion and the gender or nationality of the subjects involved might be enough to identify individual crewmember subjects and the

data they provided.

The public and historic nature of space missions raises the possibility that our data will be preserved alongside information from other sources pertaining to the same subjects. This would allow others to draw conclusions far beyond the intent of our study. For example, journalists might be curious about the effect of a specific on-board event on the mood of the crewmembers, and they could speculate beyond what the data indicated if this information were available. Also, the privacy of data is at risk for a long period of time, potentially well after the current study has ended and archive personnel have changed. Breaches in confidentiality might thus occur by people who are less sensitive to privacy protections.

We have found that privacy issues are critical at every stage of each mission studied. Below, we summarize the key privacy issues relevant to each stage of a mission, and we offer some methods of addressing each one that we have found to be effective.

Pre-Flight Privacy Issues

Procedures designed to maximize privacy while still providing useful data are used in the pre-flight stage. A NASA affiliated Institutional Review Board (IRB) reviews any research projects submitted to NASA involving human subjects. When crewmembers are involved the review is conducted by the IRB at Johnson Space Center. Additionally the institution to which the authors are affiliated also requires approval from its own IRB. Accordingly, our NASA-approved procedures were also approved by the UCSF Committee on Human Research in the US and by the IBMP Ethical Board in Russia. As required by the IRB for both UCSF and NASA, privacy measures are explained in detail in "nontechnical, easily understood language" in the layman's summary and consent form that are provided to each subject on enrollment. Although the subjects' names must be on the consent forms, they never appear in association with the data. Each participant chooses a personal ID code, which is not written on the consent form and is not known to anyone else. Thus, the list of study participants cannot be matched to the list of ID codes, even by our study staff.

In-Flight Privacy Issues

During the mission, the ISS crew use an on-board computer to complete weekly in-flight questionnaires. The data are collected using customized software that automatically triple-DES encrypted the data when the participant finished the questionnaire. This encryption process uses mathematical algorithms to convert plain text data into an otherwise meaningless jumble called cipher in order to preserve its integrity and confidentiality while in transmission or storage. A corresponding decrypting cipher is required to revert the data back to its original form. The Triple Data Encryption Standard that we use (Triple-DES, a.k.a. Triple Data Encryption Algorithm (TDEA)) had been approved by the National Institute of Standards and Technology for use by federal organizations to protect sensitive data (NIST, 1999). When a new crew is brought to the ISS by a Space Shuttle, the previous crew's computer hard disks are removed and brought back to Earth with them. The next crew begins with fresh hard disks and new copies of the software. If the Space Shuttle is not available, the encrypted data are either telemetered to the ground or left on board until they can be brought down, at the subjects' choice. In either case, the data cannot be decrypted before it arrives at our lab because our study team maintains permanent exclusive control of the decryption procedure.

Ground subjects supporting the mission also fill out the same questionnaire. If they complete it using computer software, the encrypted file is then posted on our secure server. If they use hard copies, these are inserted into a ballot box or the subject seals the completed questionnaire into an envelope that is sent directly to the lab. During our study of several Shuttle/Mir missions (Kanas, Salnitskiy, Grund, Gushin, Weiss, et al., 2000a, 2000b, 2002; Kanas, Salnitskiy, Grund, Weiss, Gushin, Bostrom, et al., 2001; Kanas, Salnitskiy, Grund, Weiss, Gushin, Kozerenko, et al., 2001a, 2001b; Kanas, Salnitskiy, Gushin et al., 2001; Kanas, Salnitskiy, Weiss, et al., 2001), the ballot boxes were opened only in the presence of one representative from each country (Russia and the U.S.) to monitor each other while the data were prepared for shipment to our lab. Once in our lab, the hardcopy data are entered onto the computer and encrypted. Data and consent forms are stored separately in locked containers.

Similar procedures are used to collect baseline questionnaire data from crewmembers before and after flight.

Post-Flight Privacy Issues

After the data have been collected, we take further steps to protect privacy. First, we do not conduct for-

mal data analyses until the last mission included in our study is complete. Further, we do not conduct analyses that might identify individuals. For example, we might stratify by gender or nationality in separate analyses, but not both in a single analysis because this would produce too small of a sample to preserve privacy.

When publicly disseminating results, only summary data that are aggregated enough to protect confidentiality are reported. Specific missions are not identified, and the order of mission sequence is randomized in our presentations. As a further precaution, drafts of our manuscripts are reviewed by some of our subjects to look for possible breaches of privacy.

We are very careful about how the data are archived. NASA data are archived and publicly available, and these archives may outlast changeovers in study and NASA personnel. We want to make sure that the protections we promise to subjects remain in place permanently. However, we recognize that it is important to maintain a complete archive of these valuable data and to provide colleagues and the public with access to this resource. We have tried to balance these considerations in our agreement with the Life Science Data Archive at NASA. A full set of the encrypted data is archived as a backup, but our team retains the decryption software. Only a version of the dataset that has been stripped of all identifying information is archived without encryption. For example, the subject ID number, the mission number, and the date are removed.

Even these precautions are not enough. We feel that it is also part of our responsibility as researchers to monitor the way that our study is portrayed in media reports, NASA websites, and other venues. When we speak with the press, we are careful not to say which missions we studied or did not study, or which individuals were or were not included. Even if a given individual consents to be identified as a subject, this might indirectly identify his or her fellow crewmembers as having also participated, and it may give other subjects the impression that we are unilaterally identifying subjects.

In short, we do whatever we can to prevent or correct portrayals of our study or our data that could identify individual participants or expose their personal information.

SUCCESS OF PRIVACY MEASURES

These privacy measures seem to have been successful, as judged by anecdotal reports of subjects' comfort level with the study. In addition, we have had high participation rates. During the Shuttle/Mir study, 100% of astronauts and cosmonauts from the missions studied agreed to participate and signed informed consent (Kanas, Salnitskiy, Weiss, et al., 2001). They also provided data on 76% of the possible weekly response dates. In the ISS study so far, crewmembers are providing data at an even higher completion rate as in the prior study. All eligible astronauts and cosmonauts have enrolled so far except for one crew and one additional crewmember (creating a response rate of 81%, or 17 of 21 crewmembers to date). Although we do not know for certain all the factors leading these individuals to decline to participate, we believe that at least two factors were involved--a negative impression of psychosocial research, or a concern that participating in too many science experiments would hamper one's ability to carry out the construction tasks that are the first priority of these early ISS missions.

Looking at the data itself, we found during the Shuttle/Mir study that we had robust item variances and response ranges, which indicated that subjects were giving thoughtful, discriminating responses. The full range of response options was used on 63 of 65 items of the mood questionnaire, and on all 126 of the items of the group environment questionnaire. Because we do not publicly report any analyses of our data until after the end of our entire data collection period, we cannot yet specify corresponding statistics for our ongoing ISS study.

CONCLUSION

In conclusion, we would like to stress that maintaining privacy is crucial in psychosocial studies, and that it can be a complex, multifaceted, and never-ending task with this type of a study population. It is a long-term commitment and can sometimes be limiting. For example it can make tracking drop-outs or contacting individual subjects to thank them for their participation difficult since the subjects chose their own anonymous ID codes which they might forget or change accidentally. Also it can limit the options of combining responses from different measures. For example subjects in the current ISS study filled out a one-time only survey of their culture and language (C&L) backgrounds upon enrollment in addition to weekly questionnaires that they might have begun at a later time. In future analyses we would like to compare those C&L responses to responses to the weekly

study questionnaires. Even at the group level, the ability to accurately pool the two datasets depends solely on subjects putting the same ID on both forms. Another limitation of our rigorous privacy protections is that they can interfere with the completeness of interpretation of our analyses. For example a number of individual differences may exist with regard to hypothesized effects (e.g. changes over time). The nature of these differences cannot be publicly identified or discussed however because our analyses cannot be presented at a level of detail that would identify a specific mission or individual. Similarly, as with other psychosocial research with a disproportionate number of men and women, gender differences can be hard to explore and report because of the danger that the female subjects (in this case) could be easily identified, particularly if any contextual information was included. Fortunately, even with these limitations due to enhanced privacy measures, our analyses of group level data have described a number of significant phenomena.

The privacy concerns reviewed above may be even more challenging for Moon and Mars missions than they have been for ISS and Mir missions, because the number of missions and the number of crewmembers will be smaller. Thus, it is essential to design studies of these future missions so that despite the inevitable restriction in scientific yield necessitated by the privacy measures, the studies will produce useful information about high-priority topics that will help us to promote psychological well being during missions. Based on our team's experience with the specialized data collection methods described here as well as other more naturalistic observation methods (e.g., Gushin et al, 1997), we believe this will be possible. Overall, we feel that despite the difficulties, this type of work is quite feasible and well worth the effort because of the importance of understanding the impact of psychosocial issues on long-duration space missions.

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AUTHOR NOTE

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