

# JERHRE NOTES

*Skills for Solving Ethical Problems in Human Research*

## Public Disclosure Regarding Emergency Research

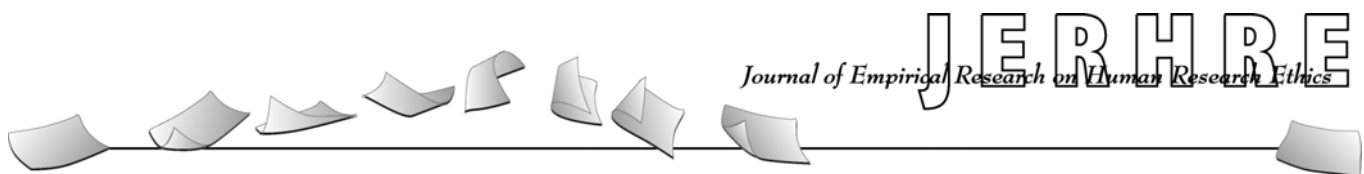
In emergency medical research where subjects may be unconscious, an exception from informed consent is allowed by US federal regulations, provided that community members are informed about the purposes, risks and benefits of the study. They must have an opportunity to ask questions, and provide input through public meetings and other forms of consultation.

Research has sought to learn what constitutes effective public disclosure. Information about pending emergency experiments with PolyHeme, an artificial blood product that is compatible with all human blood types, was disseminated in local newspapers, and on radio and television stations, the host hospital's website, and in a series of town meetings. A random-digit dialing survey of 200 individuals assessed the effectiveness of this disclosure. It was found that:

- About 10% of respondents had heard about the trial.
- Newspaper articles were the most effective form of disclosure.
- Opinions about participating in this kind of research were more favorable among those who were aware of the trial, though understanding of the trial was poor.
- About 50% of the respondents would not wish to receive PolyHeme (implying that about 25% of emergency subjects might receive it against their wishes).

Much remains to be known about the appropriate definition of "community," and the most effective methods of communicating with the community. The survey underscored the importance of using random sampling, as opposed to convenience samples most commonly used until recently, to evaluate the effectiveness of public disclosure.

**Jacoby, L. H., et al. (2008). Public disclosure in research with exception from informed consent: The use of survey methods to assess its effectiveness. *JERHRE*, 3(1), 79-88.**



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