



MEMORANDUM TO INSTITUTIONAL REVIEW BOARDS / HUMAN SUBJECTS REVIEW COMMITTEES

TO: Institutional Review Boards / Human Subjects Review Committees

FROM: Anne Pebley and Narayan Sastry, Co-Directors, Los Angeles Family and Neighborhood Survey

RE: Review of Proposals for Analysis of Los Angeles Family and Neighborhood Survey Restricted Data

The Los Angeles Family and Neighborhood Survey (L.A.FANS) is an on-going longitudinal survey of Los Angeles County residents. L.A.FANS makes available to researchers both Public Use Data, available to all researchers, and Restricted Data, available only under contract to researchers who meet rigorous conditions. Public Use Data have been sufficiently purged of identifying information that we believe they pose no significant threat to respondent anonymity. Restricted Data, on the other hand, contain information that L.A.FANS believes significantly increases the risk of re-identification (deductive identification) of respondents.

It is because of this risk of re-identification of respondents that we request you to review portions of proposals to use Restricted Data from L.A.FANS, and to do so using the same standards you would use for surveys of live human subjects conducted at your own institution. Although researchers using L.A.FANS Restricted Data are conducting what is usually called "secondary data analysis", the increased risk of re-identification of L.A.FANS respondents (who are, for L.A.FANS, live human subjects) makes inappropriate the usual "Expedited Review" typically applied to such "secondary" analysis of anonymized data. The only circumstance in which an Expedited Review is acceptable is if there was a previous Full-Board Review of the same Restricted Data Protection Plan.

We request that you review specifically the Restricted Data Protection Plan, and those aspects of the Research Plan that deal with issues of respondent anonymity and data security. We ask for your review because you will be better able to judge the extent to which, in your institution's physical and computing environment, the plans are adequate to ensure respondent anonymity and limitation of access to the Restricted Data to the persons specified in the contract.

We are not asking that you review the entire Los Angeles Family and Neighborhood Survey. That review has been done by the relevant committees at RAND and the National Institute of Health, the primary funder of L.A.FANS.

If you have any questions about the nature and scope of this request, please contact us.

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