

LAFANS staff instituted “elaborate controls over access to potentially identifying data on respondents” to ensure that respondents were never identified and “obtained a certificate of confidentiality from the Department of Health and Human Services which protects LAFANS from having the data subpoenaed.” The survey did not ask respondents directly whether they were undocumented but asked 5 questions about respondents’ US citizenship; residency; refugee status; tourist, student, or work visas; and validity of these documents.³ These data are available to the research community, but availability of potentially identifying data is restricted (for more information, see <http://www.lasurvey.rand.org>). Other health interview surveys are using a more limited set of questions. For example, the California Health Interview Survey contains 1 question on US citizenship and 1 on permanent residency.⁴

A Centers for Medicare and Medicaid Services (CMS) program to help cover the costs of uncompensated emergency health services does not ask questions on US citizenship or whether a patient is an undocumented alien.⁵ CMS has stated, “We believe that asking a patient to state that he or she is an undocumented alien in an emergency room setting may deter some patients from seeking needed care.”^{5(p42)} The California Health Interview Survey and the CMS provider payment determination form⁶ state that legal status information will not be provided to the Immigration and Naturalization Service (now US Citizenship and Immigration Services).

We support recommendations to obtain proxy measures of acculturation (e.g., language use, birthplace/generation, time in the United States) and socioeconomic status to better understand immigrant health,⁷ but additional legal protections (e.g., the US Department of Health and Human Services confidentiality certificate⁸) and controls are needed to protect people’s confidentiality and privacy when legal status is collected. ■

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COLLECTION OF LEGAL STATUS INFORMATION: CAUTION!

Health care providers are increasingly called upon to collect legal status information to facilitate program enrollment and reduce uncompensated care costs. A recent Journal article suggested that collection of information on legal status in national surveys “is essential” to the study of health insurance coverage.¹ Although we agree that legal status may play an important role in access to health care,² we are concerned that collection of this information without additional safeguards to protect confidentiality and privacy could endanger the health and well-being of research participants or service recipients.

Safeguards put into place by the Los Angeles Family and Neighborhood Survey (LAFANS) to protect the confidentiality and privacy of respondents providing this highly sensitive information go beyond standard informed consent procedures (J. Prentice, PhD, e-mail, June 2005 and August 2005).