PUBLIC HEALTH SURVEILLANCE OF LOW-FREQUENCY POPULATIONS

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Abstract Public health agencies often require data that address the needs of special populations, such as minority groups. Sources of surveillance data often contain insufficient numbers of subjects to fully inform health agencies. In this review, we address the problems of and potential approaches for situations with insufficient surveillance data. We use the examples of race and ethnic minority groups throughout our discussion. However, many of the broad issues are applicable to other special groups with low frequency or who are especially hard to reach. Our recommendations are based, in part, on a symposium held in Missouri with the collaboration of state health agency, community, and academic research participants. We review problems in using existing data and collecting new data, especially from nonprobability samples. We also describe fieldwork issues for reaching and collecting information from special populations. Decisions among methods and solutions may require seeking additional resources for surveillance.

INTRODUCTION

Public health agencies often wish to acquire data that address the needs of special populations. One of the most common concerns is the need for data about minority groups to address their unique health concerns and potential disparities. The public health community of practitioners and researchers is explicitly concerned about minority populations, as demonstrated by the decades of the Healthy People plans for the nation (e.g., see 96; http://www.healthypeople.gov/document/). The most commonly used data come from surveillance systems and surveys, for example, from the data provided by vital statistics, the Behavioral Risk Factor Surveillance System (BRFSS), etc. Surveillance systems are intended to be ongoing, systematic collections of public health data about health that are used to inform public health actions, develop health policy, plan and evaluate programs, and formulate...
hypotheses for research (14, 90, 91). Often, surveillance data are too sparse to address specific groups and concerns (e.g., risk factors among Hispanic/Latino populations). In this review, we address the problems of and potential approaches for situations with insufficient surveillance data. We use the examples of race and ethnic minority groups throughout our discussion. However, many of the broad issues are applicable to other special groups, for example, older adults and people with disabilities.

Our recommendations are based in part on a 2002 symposium organized by the Missouri Department of Health and Senior Services (MDHSS). This project convened a group of experts to provide guidance to the MDHSS for minority representation in surveillance and data. The list of participants is shown in the Appendix. We extend our thanks for their hard work and many ideas, and we incorporated many of the decisions of this group into our analysis of the special population issues facing health agencies, researchers, and their constituencies.

Our objective in this review is to describe the problems that arise in using or collecting data from small special populations, and to provide strategies to improve public health information that will enhance the quality of information about and representation of ethnic and racial minority populations. For these purposes, we offer a descriptive cutoff to classify small groups. When a subgroup composes less than 10% of the population (e.g., of a state), we classify it as a special population with potential surveillance data problems.

In Missouri, for example, about 11% of the population is African American, which is the predominant minority group. Although there are always additional potential efforts to fill data gaps, the State has sufficient data for both African American and White Missourians. Oversampling and special surveillance initiatives have helped the MDHSS conquer many of the problems of sparse data for African Americans (e.g., 62). Approximately 4% of Missouri residents are members of the remaining ethnic and racial minority groups (63, 93; http://www.census.gov/census2000/states/mo.html). Overall, 2.2% of Missouri’s population is Hispanic/Latino, 1.1% is Asian, and 0.4% is American Indian or Alaska Native. Except for Latino groups, where some stratified or geographical oversampling might provide some valid estimates, our experts did not believe that oversampling could obtain sufficient numbers for the other groups. Missouri symposium participants deemed it infeasible to include sufficient numbers of some minority group respondents to allow for subgroup comparisons of health and health disparities using usual surveillance sampling techniques.

The percentage of minority groups varies from state to state, and therefore the quantity of surveillance data also varies. The following example is based on the BRFSS, the national state-based telephone survey supported by the CDC (see 31, 77, and below for more information on the BRFSS). For example, in the 2001 national BRFSS, 8.3% of the adults who were interviewed said they were Hispanic (12.9% weighted). However, on the Missouri BRFSS 1.6% of respondents (weighted percentage of 1.5%) reported they were Hispanic, compared to 23.2% in California (weighted percentage of 30.1%). In Colorado, 12.7% of the 2001 BRFSS
sample reported they were Hispanic. State BRFSS sample sizes also provide some insight into how these data might be used for purposes based beyond simple estimates; for example, subgroup analyses comparing older and younger people and their risk factors might involve only a small number of older people who were Hispanic. In these three example states, the number of Hispanic respondents to the BRFSS was 68 in Missouri, 986 in California, and 258 in Colorado. In Missouri and California, sample sizes for the BRFSS were over 4000 adults. States where the sample size is lower (e.g., in Colorado it was slightly over 2000) have problems based on the percentage of minority groups and the number of completed interviews.

Table 1 demonstrates how the problem of low numbers affects the precision of the information; that is, based on a small number of people there is a margin of error that may make it hard to be confident of the actual, underlying figures. In the first example, men were asked if they had ever had a Prostate-Specific Antigen (PSA) test for prostate cancer screening. The figures are shown for all men nationally, and also by men aged 65 and older. PSA was reported less frequently by Hispanic men overall, and also above the age of 65. The estimate that 7.1% of older Hispanic men had PSA is compatible, statistically, with an estimate as low as 5.4% and as high as 9.0% (95% confidence intervals; 27). The problem of small numbers is very apparent when examining the Missouri and Massachusetts data: In Missouri, there were only 4 Hispanic men over age 65 interviewed, and none reported having a PSA test. In Massachusetts, where the BRFSS sample was much larger, there were still only 14 older Hispanic men interviewed, and there is very poor precision of the estimate of 42.9% having had PSA. The second example shows the results of asking about health insurance. In this example, both men and women were asked the question, and with the larger samples, the precision is much better even for Hispanic subjects, and even in Missouri. However, while 76.5% of Hispanic adults in Missouri reported they had health insurance, the 95% confidence interval is fairly wide (64.3%, 84.7%).

As noted in more detail in this review, one potential source of data on large numbers of people is the 2000 Census itself; however, health data are limited from this source. Clearly, more innovative solutions are required to address the need of public health agencies and their constituents. Although some of the suggestions may not fit the straightforward description of surveillance given above, it may be necessary to use data more flexibly to understand the populations of interest.

We divide our discussion among several primary aspects of surveillance. We include information collected both from people by surveys and from other data streams, such as data from hospitals or other medical encounters. In addition, we address questions about current and future data resources, and current and potential partners for improving public health information. Decisions to acquire more primary data, or to markedly change the completeness and detail of current data streams, are likely to require substantially more funding. Where possible, we provide general guidelines about the financial impact of various options. Individual organizations that want to extend the amount of information on
### TABLE 1  Examples of surveillance sample data and precision based on the 2001 Behavioral Risk Factor Surveillance System

<table>
<thead>
<tr>
<th>Health variable of interest</th>
<th>All subjects nationally</th>
<th>Missouri</th>
<th>Massachusetts</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Hispanics</td>
<td>Others</td>
<td>Hispanics</td>
</tr>
<tr>
<td>Men who report having a Prostate-Specific Antigen (PSA) test</td>
<td>80/3336 (2.4%)</td>
<td>1772/49,479 (3.6%)</td>
<td>0/4 (0%)</td>
</tr>
<tr>
<td>Over age 65</td>
<td>55/776 (7.1%)</td>
<td>1396/13,225 (10.6%)</td>
<td>—</td>
</tr>
<tr>
<td>Any kind of health insurance</td>
<td>13,593/17,588 (77.3%)</td>
<td>171,580/194,097 (88.4%)</td>
<td>52/68 (76.5%)</td>
</tr>
</tbody>
</table>

*95% confidence intervals (95% CI)*

a based on unweighted data.

b of 53,110 men who were asked the question on PSA and 212,510 adults who were asked about health insurance.

c 95% confidence intervals are not calculated for a zero observation.
special groups will need to balance their need for data with changes in resource allocation. Methodological changes to existing surveillance could also require agreement from partners like the Centers for Disease Control and Prevention (CDC), state health agencies, and changes to contracts and financial arrangements for data collection. Changes to data collection or analyses may also require modification of staff training at agencies to enhance the technical and analytic skills.

BACKGROUND

Public Health, Disparities, and Small Samples

As described above, the need for health information on subgroups is partly driven by health disparities for minority groups. The document *Healthy People 2010* (96) provides a comprehensive view of disparities in health for minority Americans and outlines goals to improve the differences. These goals are based on a broad set of surveillance sources like the BRFSS, Medical Expenditure Panel Survey (MEPS), and the National Health Interview Survey (NHIS). A few examples set the context in which public health agencies operate and the data they need for their own local and state populations (96). Forty-seven percent of White Americans reported they had a dental visit in the last year compared to 30% of Hispanics and 27% of African Americans. Formal diabetes education is reported for 46% of Whites with diabetes, compared to 34% of Hispanics. The data are too sparse to be statistically reliable for American Indians/Alaska Natives. More White Americans under the age of 65 were estimated to have health insurance: 84% versus only 62% of American Indian/Alaska Natives and 66% of Hispanics. Even within the latter group, there are disparities. Sixty-one percent of Mexican Americans have health insurance compared to 79% of Cuban Americans and 81% of Puerto Rican Americans. Americans may be too sedentary, but the prevalence of adults who report they do not engage in any leisure-time physical activity varies from 38% of White Americans to 53% of Hispanics. These examples underscore the problems and also highlight at least one of the issues: National-level data are rarely sufficient to help determine the problems and differences relevant to smaller geographic areas and across heterogeneous minority groups.

These national data may not address the needs of public health agencies. For example, what do agencies need to know about Hispanic health? Local health agencies have responsibility for the health of Hispanics, even in communities where they are few in number. The health agency needs to monitor their health, identify and take care of special needs, advocate for special programs to meet those needs, ensure health promotion, etc. To address these responsibilities, data are often needed. Some examples of questions that might be asked are “What number of Hispanics: are insured, have a usual source of care, have access to health care, need a translator, are aware of services offered by the community?” These questions might be divided into generic (applying to everyone) and Hispanic-specific.
Because public health agencies have constrained resources, it is important that they make optimal use of data that already exist. A question about Hispanic health does not necessarily require Hispanic data. For example, the health of Hispanics with AIDS is surely worse than the health of Hispanics without AIDS, even in the absence of specific data on Hispanics. A question about what proportion of the population needs a Spanish-language translator would require data on Hispanics. Information might be inferred from other available data. For example, if insurance is highly tied to employment, and the census or Current Population Survey provide data about unemployment in Hispanics, the percent uninsured might be estimated from that. Data on the percent of hospitalizations covered by insurance might be known by race/ethnicity and used as an estimate of the percentage in the population. Thus, not every new question about Hispanic (or another small group) health will require new data collection.

Even if new information is needed, it may be possible to obtain reasonable information without use of a probability sample. The use of probability samples is important when the interest is in generalizing individual parameter estimates to the population of interest. However, it is not unreasonable to assume that the multivariate correlational relations among variables of interest in a population might hold in a less expensively obtained convenience sample as well. A large nonprobability sample could be augmented by a smaller (and more expensive) probability sample to determine whether key relationships are reasonably similar in the two samples. The nonprobability convenience sample might then be reweighted to account for biases if problems in the convenience sample are detected. We elaborate our review of these issues in the sections that follow.

Other Data Problems from Surveillance Surveys and Research

We described the potential problem of small samples above in regard to the BRFSS, including low prevalence and small number of respondents on which to base health estimates. There are also concerns that surveillance questionnaires may lack cultural relevance and that there are content gaps in the data. We noted the higher prevalence of inactivity for minority groups above. But specific inquiry about physical activity and exercise demonstrates that not all groups define and describe their activities in the same way. Eyler and her colleagues (25) found that women of different ethnic backgrounds described physical activity in different domains and as different activities, and when a revised set of questions was used in a national survey, ethnic minority women were not always less active than majority White women if all domains of physical activity, including work, were assessed (12). Another example of cultural differences is nutrition, where standard questions on dietary patterns may require substantial revision to provide valid data for ethnic minority groups (103). As we describe in one of our later sections, these data gaps and problems of cultural relevancy may need to be addressed by community-based participatory research (30).

In the following sections we provide more in-depth discussion and suggestions under two general categories. We first review issues about the use of current
data and then recommendations about potential new data and methods for low-prevalence populations.

MAKING BETTER USE OF EXISTING DATA SOURCES

Improving the Analysis

AGGREGATING DATA  A common and useful technique to accommodate sparse sample size is to aggregate data by geography or time. Barring strong philosophical or political objections, this technique can substantially augment information about subgroups. For example, in assessing urban subgroups, Missouri’s two largest cities (St. Louis and Kansas City) each form a part of larger metropolitan areas shared with neighboring states. For some purposes, data from compatible surveillance systems (e.g., the BRFSS) might be useful for ethnic subgroups. For example, Lindquist and colleagues used the BRFSS to examine drinking patterns among regions from 1990 to 1993, and also by race and gender (44). For data that need to relate back to the populations of states (or counties), borrowing data from other similar or neighboring geographic areas may not be acceptable. Data from ongoing surveillance systems also can be accumulated over time (e.g., BRFSS, cancer registries) to accommodate subgroup comparisons (e.g., BRFSS, cancer registries). However, temporal trends are then obscured (83, 105).

These techniques may still be insufficient to provide state-level information on many small ethnic and race groups, and in most cases these techniques are also insufficient to accommodate smaller areas, for example county-level data. County health agencies usually request, and need, data for their own planning and evaluation, and also to assist them in comparisons among areas (e.g., to the overall state, or among counties). Until some information is provided at this more specific local level, it may be difficult to assure counties that aggregate data (by time, area) are sufficient for their own surveillance and planning activities.

Simple geographic aggregation has a number of limitations. First, the arbitrary nature of most geographic boundary definitions (e.g., ZIP codes) provides no guidance as to which geographic locations should be merged together. Second, simple aggregation of rates often has the effect of treating geographic areas with small population samples (and hence less-reliable rate estimates) with the same weight as geographic areas with larger samples and more reliable estimates. To address these limitations, and provide a more sophisticated manner of aggregation, the technique of spatial smoothing can be utilized.

SPATIAL SMOOTHING  Spatial smoothing arises from Geographic Information Systems (GIS) and is used to average or smooth out measurements of some variable of interest among neighboring geographic areas. Spatial smoothing has been used in public health in a number of ways in the past decade, including mapping mortality rates, cancer incidence, and exploring patterns of insurance coverage (47,
Spatial smoothing can be used to magnify the underlying trend or structure in the data while simultaneously reducing the effects of unusual or outlying values (48). Bayesian smoothing techniques are particularly useful for the situation here, where there will be numerous geographic areas with small numbers of minority populations. Bayesian smoothing works by employing a weighted combination of the measurement within a geographic area with an averaged measurement across the immediately neighboring areas:

$$\theta_i = w_i r_i + (1 - w_i) \gamma,$$

where $$\theta_i$$ is the Bayesian smoothed estimate of some health-related variable for the $$i$$th geographic location; $$r_i$$ is the raw (unsmoothed) measurement; $$\gamma$$ is a pooled average measurement across the nearest neighbors of $$i$$; and $$w_i$$ is an estimate of the reliability of $$r_i$$ (44). Thus, if the measure is highly reliable, there is less smoothing of the score, whereas if it is unreliable, the smoothed score approaches the values of the neighboring scores. Another approach to smoothing is to use a head-banging algorithm, which bases the smoothing on medians, rather than means (66, 78). This may produce more robust estimates, especially for unreliable or skewed data.

SMALL AREA ESTIMATION

Small area estimation is an approach for obtaining estimates for small areas, such as counties, when the only available data are at a higher level, such as the state (76, 86). For example, if we had a sample of state residents from a source such as the Current Population Survey (CPS) that included their age, sex, and health insurance, we could estimate the percentage in each age/sex grouping who were insured. We could then apply those percentages to the age/sex distribution in each county, which is likely to be known. This seemingly logical procedure would tend to give the same estimate for every county; however, because counties do not vary greatly by age and sex, the counties will all tend to have the same estimated value. Diehr (20) and MacKenzie and colleagues (54) noted severe problems when they compared the estimated percentages to known percentages. A more complicated model that draws on data from individuals (person-level) is needed to provide good person-level estimates, but this can be applied only to characteristics that are actually known in the correct form for the counties. This approach has limited usefulness unless the counties are known to be very similar on the variable of interest.

EXACT STATISTICS

In some circumstances the data are all available, but the numbers are too small for normal-based confidence intervals or tests based on the Central Limit Theorem. In this case, exact statistical methods can provide better estimates. Exact statistics uses modern computer-based statistical algorithms to sidestep parametric model assumptions such as normality. For example, in Table 1, the 95% confidence interval for 6/14 Hispanics in Massachusetts over 65 having a PSA is reported as 18.8 to 64.4; the exact confidence interval is 28.9 to 71.1. The CI for the 0/4 men over age 65 with PSA cannot be calculated using normality-based methods, but is (0, 0.53) using exact methods. Hypothesis tests,
such as comparing the rate for Hispanics to that for African Americans, would also require exact tests. Exact analyses can be used for both parametric and nonparametric modeling (e.g., logistic regression, chi-square, etc.). Exact analyses can be performed using specialized software such as StatXact (http://www.cytel.com) or in more comprehensive statistical packages such as SAS and S-Plus. These exact statistical procedures are based on a resampling theory using techniques such as Monte Carlo simulation, permutation tests, bootstrapping, and jackknifing (23). For more information about exact statistics and their underlying statistical theory and mechanisms, see Mooney & Duval (65) and Weerahandi (102).

**PROVIDER PROFILING METHODS** If there is interest in comparing rates among counties, or other small groups, provider profiling methods, which were developed to compare such quantities as error rates among physicians or hospitals, may be used (11). These methods attempt to provide valid estimates and comparisons among the providers (or counties) by modeling both the variation among persons and the variation among providers. Rates calculated from very small numbers of cases are “shrunken” back toward the mean so that a provider with only two patients, one of whom has a complication, will have an estimated rate of less than 50%. Such methods could easily be used in the comparison of small counties.

**Improving Future Information from Existing Data Systems: Examples**

**BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM** The BRFSS is the largest surveillance survey in the world (31, 77). In 2001, over 212,000 adults aged 18 and older were interviewed. Each state, territory, and the District of Columbia participates in the survey, which is supported by the CDC. Data acquired from the BRFSS rely on random-digit dialing (RDD) telephone interview techniques, which have well-known problems with nonresponse and noncoverage. There are large differences in the number of surveys administered in each state, and some states chose to enhance their BRFSS samples. The average sample of states and territories is about 2500 respondents. Missouri has steadily increased the number of survey respondents to over 4000 per year, and in 2001, Connecticut, Kentucky, and Massachusetts each sampled over 7000 BRFSS respondents. States may use simple random sampling RDD techniques. However, many states augment these sample sizes and stratify their sampling by regions to provide better estimation for sparse (i.e., rural) or special interest (e.g., high proportions of special subjects) areas. Missouri respondents currently are sampled from 7 geographic areas: 600 respondents each from metropolitan Kansas City; metropolitan St. Louis; Southwest, Southeast, Central, Northeast, and Northwest Missouri. The two cities and Central regions contain the largest urban and suburban areas, whereas the remainder of the state is largely rural. Among these areas, Missouri has had a strong increase in Hispanic populations in both urban (Kansas City) and rural areas. However, even with attempts at oversampling, there have been insufficient Hispanic respondents...
to allow for informative subgroup responses. Adding to these issues is the fact that Hispanics may be undersampled by telephone methods because of lower telephone coverage and lack of Spanish speaking interviewers. Although the BRFSS has been translated into Spanish, bilingual administration of the BRFSS is conducted in only three states. In a broad sense, the addition of language-specific interviewers is unlikely to be cost-effective given the low prevalence of respondents who request or require such interviewers. For most survey situations, the addition of bilingual interviewers will need to be done for oversampling or augmented sampling situations and the cost implications planned for as part of special initiatives.

As described above in general terms regarding surveys, the content of the BRFSS also may require additional attention to represent the health, health barriers, and behaviors of interest and relevance to minority groups. Examples included adding appropriate dietary and nutrition content for Latinos, and measures of racism experiences and of social support. See the section below containing additional details about adding content to surveys.

Finally, the problem of small numbers can rarely be solved for individual counties for BRFSS data. State health agencies may need to partner with individual counties to add (a) over sampling and (b) content to the usual BRFSS sampling frame and interviews. Because the data demands come from the local (usually county) level, the resources and experts at the state level may not be able to provide detail for all data needs from the BRFSS. However, for the BRFSS and other data streams, the state may be able to offer a “menu” of options that they support, including oversampling in a county, to accommodate the data needs of individual public health agencies. Other potential methods issues are described in the sections on sampling, analysis, and auxiliary data streams.

**REGISTRIES AND HOSPITAL DISCHARGE DATA**

Cancer is the second leading cause of death for adults, and as a result, states have centralized cancer registries or reporting mechanisms for both fatal (death certificate–based) and incident cancers (http://www.cdc.gov/nccdphp/bb_cancer_reg/index.htm). In Missouri, for example, numerator data concerning cancer incidence are the total number of cancer cases for Missouri; denominator data are based on the Census. Data are reported for regions, and county, when possible. Constraints on cancer reporting include confidentiality; if a county has a very small population, then reporting cancer incidence and cases by even basic subgroups (type of cancer, gender, age) may identify individuals. Only six counties have sufficient numbers of reported cancer cases to report race-specific data on cancer. This problem of insufficient numbers for a majority of counties is not unique to Missouri: Nationally, nonmetropolitan areas cover more than 80% of the land area and include about 20% of the population (95). Most counties include small populations compared to cities.

For ethnicity, problems with missing data are evident in many registries. Using Missouri again as an example racial composition of cancer data usually is complete. However, Hispanic ethnicity (yes/no) is missing for about one third of cases.
reported to the Missouri Registry (J. Jackson-Thompson, personal communication). Without these data, the State is hampered in its ability to report on disparities. As with other cancer registries, case reporting is primarily based on data in medical records; ethnicity often is not reported by staff responsible for intake or discharge data (who may not ask these questions and report “observer” classifications).

Improvement of data recorded in hospital records should be a target of multiple special group interests nationally and within states. State health agencies may find partners for improving data quality and completion among other key data users. Partnership might include the state Quality Improvement Organizations (QIO) (state “PRO” organizations), which are part of the Centers for Medicare and Medicaid Services (SMS) quality-assurance infrastructure (15; see http://www.medqic.org for a list and link to each state organization). The state QIOs have substantial ties to hospitals and state organizations and a vested interest in improving data to monitor and intervene on quality for their constituents. Another potential partner is a state’s hospital association (e.g., 64; see http://web.mhanet.com/asp/connections/state_hospital_associations.asp). For both types of partners, the issue of data for minorities is important, and this is also expected to increase in importance in coming years. For example, hospitals in rural and urban areas may need to plan for language interpretation and community outreach programs. Finally, state health agencies themselves can consider augmenting training and encourage hospitals to comply with the required data elements that are often missing.

CENSUS DATA  The Decennial Census normally is viewed as the source of denominator data for public health statistics. However, in the 2000 Census, a series of questions on the long form (sampled in 1/6 households) asked about functional status, sensory impairment, and activity limitations (6). These data provide minimal detail but more comprehensive coverage than most other data sources. Census data are largely untapped by public health agencies for use in understanding potential race and ethnic health disparities and should be considered further. At the environmental level, it may be possible to apply sociodemographic measures from Census or other public data to examine hypothesized effects of disparities and health outcomes even without individual data (e.g., see 1, 5, 7, 19, 79). Ecological-level variables include measures of socioenvironmental conditions (5); collective efficacy (79); segregation and racism (1); and undereducation, unemployment, working-class composition, and poverty (19).

RECOMMENDATIONS FOR NEW DATA COLLECTION AND METHODS

Sampling Strategies

When new data must be collected, the first question to answer is whether there is a need for a census, a probability sample, or whether a nonprobability sample will do.
A census requires that all persons in the population be enumerated, and many examples have been listed above. These include the U.S. census itself, a cancer registry, or data on all hospital admissions. When these exist, and contain the information of interest, they are the best available sources of data. When there is interest in a small minority population in a clearly defined and localized geographic area, it may be feasible to perform a census of that population. For example, a state health agency might be able to afford a tightly focused survey of smoking behavior for all adult residents of Native American Reservations within a particular state.

A probability sample requires that there be a frame, a (possibly hypothetical) list of all the people in the population of interest. Samples are drawn from the frame. The gold standard of a probability sample is the area sample, since the frame is most complete. Samples could be drawn from some other frame, such as Medicare recipients or a city directory, and the resulting sample would be specific to that frame. Issues in obtaining probability samples of minority groups are discussed in detail in a recent article by Kalsbeek (49).

Some RDD surveys are probability samples in that every person can be shown to have the same probability of being selected, although that probability is unknown (97). The frame of an RDD study is households or persons with telephones, which may underrepresent the lowest income families of greatest interest. It is also necessary to account for the number of phone numbers that a person has to ensure that all persons in the frame have an equal probability of being sampled (73).

Random samples are unlikely to pick up large numbers of minorities. Some improvement can be attained by oversampling areas that have more minorities and adjusting the survey to obtain unbiased estimates of the rates of interest. Oversampling methods, especially those supplemented with screening questions to determine and differentiate minority respondents, could also be useful if there were a rotating pattern that covers a state by region. For example, each region would have an oversample of minority groups every three years; within region, the sampling would be based on high-yield zip codes. In this manner, data would be systematically acquired over time for the entire state, but no one year would require a stratified oversample of the entire state. This method also has an advantage of advance fiscal planning. Kalsbeek (49) showed that sampling areas with many minorities at about four times the rate of the other areas can improve estimates for minorities, but at the cost of degrading the accuracy of the entire survey. Oversampling by a ratio above four may even degrade estimates for the minorities, owing to inefficiencies of using survey weights that differ greatly from one another (49).

Another approach that may yield a sample of minority groups is Time-Space Sampling. This approach is described for a probability sample of Hispanic migrant workers by Kalsbeek (49) and samples of men who have sex with men (MSWM) (87). For the migrants, the issue was to count the number of migrants who were moving among venues during the period of the survey. A three-dimensional frame
was constructed of time by venue by migrant subpopulation, and four methods of sampling from the frame were discussed. For the MSWM study, venues where targeted groups were expected to be present were sampled from a list; then times for approaching subjects were randomly drawn, followed by a random sequence of subjects. Extended to groups like Hispanic/Latinos, this would involve using a list of venues (e.g., households, churches, community centers, festivals, etc.) and times and having bilingual interviewers available for in-person recruitment and interviews. To maximize the utility of these data, a formal comparison with other sources of information would be required, e.g., comparing subjects to expected percentages of gender, age groups, etc., based on the Census, or comparing responses to expectations from the BRFSS.

Probability samples can be extremely expensive. Because a major part of the expense is in making the initial contact, surveys of minorities are expensive even if none of the nonminorities screened out are interviewed. Such samples are not immune to problems of low overall response rate that may result in a biased sample. In addition, there is often no reasonable frame. For these reasons, we next discuss some nonprobability sampling methods.

**NONPROBABILITY SAMPLING METHODS** Random sampling methods are often insufficient to accumulate large enough samples for stable statistics on minority group health data. Oversampling, e.g., in zip codes with larger percentages of subgroups, also provides a relatively low yield for state-level estimates. A series of nontraditional methods may be needed to augment minority group-level information. These data will not be a random sample from the population of interest, but some of the resources saved can be used in careful validation studies, perhaps a probability sample of a much smaller group for comparison. Some common nonprobability sampling designs are presented in the following.

**Convenience sampling** Convenience samples may be drawn from a group or organization that is easy (and convenient) to recruit. The group may not be representative of the general target population, but some questions such as relationships among variables may be similar in this group and the target population. Clinics and community organizations (clubs, churches, etc.) are typical sites, and the types of inherent biases are obvious. As an example, Meyer & Colten (60) compared samples of gay men collected by RDD ($n = 52$) with a sample recruited from an event at the Gay Community Center ($n = 26$). The RDD sample was less affiliated with the gay community, had higher levels of internalized homophobia, and differed in the attitudes they endorsed. The authors recommend that RDD samples be used in studies of gay/bisexual men to avoid these biases. There are few such specific studies that can provide evidence of bias or similarities in convenience versus RDD sampling. However, a thorough discussion of the potential problems of proposed convenience samples is vital before opting for this easier sampling method.

Contact interviewing is another example of convenience sampling. Primarily used in commercial market sampling, contact interviews can be done by in-person
recruitment at places with large numbers of potential subjects, often at a shopping mall. For example, RJ Reynolds Tobacco Company examined smoking prevalence in a mall-contact study of women (67). For selecting people based on ethnic characteristics, this method probably has a strong dependence on the interviewer, and the resulting sample selection is likely to be biased on people who are “friendly looking,” “overtly Hispanic” and, of course, “shoppers.” Whether this is a sample from the population of interest depends on the question. A variant is the quota sample, which also specifies the number of respondents needed in each age and sex category. Under this design there is no way to compare the age/sex distribution of the population of Hispanics at the mall to the general population of Hispanics. Cummings compared a probability sample (area sampling with 65% response rate) to a quota sample (in shopping centers) with the goal of providing information for the planning of local health promotion programs. Results from the two surveys were very similar: The author speculated that similar selection biases operated in both surveys (18).

Snowball methods Snowball sampling is a type of purposive chain sampling most useful when members of a population are extremely hard to reach. First developed by sociologists and network analysts (33), it has grown in popularity and has been used in a wide variety of research areas including education, substance abuse, community psychology, urban development, epidemiology, health services, and community health (e.g., 24, 59, 89). A snowball sample starts with identification of one or a small number of potential participants who are representative of the population of interest. These first respondents (sometimes called first-order zone members) then identify other potential respondents who meet the same inclusion criteria. Each interviewed respondent is given the opportunity to identify other respondents in a series of chains until the entire network/population has been identified or the sample size limits have been reached. Snowball samples are generally considered to have high validity, but representativeness cannot be proven given the nonrandom nature of the technique. However, Heckathorn and his colleagues have been able to show how a variation of snowball sampling, called respondent-driven sampling, can provide unbiased estimates of behavior for hidden or hard-to-find populations (41, 42). For more information see Wasserman & Faust (100), Thompson (92), Watters & Biernacki (101), and Faugier & Sargeant (26).

Publicly available sampling frames and lists A number of other combinations of sampling frames and “enriched” sampling lists have also been used and compared. Stanek and colleagues (85) compared commercial directories and governmental lists of dwelling units in low-income urban African-American communities as potential frames in four eastern cities. Less than 90% of dwelling units were included in any one list, and no list adequately identified multiple dwelling-unit structures. Because household income is likely to be lower among households in such structures, all lists tend to miss the very poor, who may have the highest health risk. Adimora and colleagues compared driver’s lists with voter registration
lists as possible population-based sampling frames for rural African Americans (4). For men, 54% appeared only on the driver’s list, 17% only on the voter’s list, and 30% on both lists. For women the percents were 35%, 25%, and 41%. They concluded that driver’s lists provided better coverage. Wilson and colleagues compared samples from RDD and Electronic White Pages (EWP) (104). They reported better response rates with EWP, which permitted mailing approach letters in advance. RDD required four times as many calls per interview. Demographic profiles and health estimates were substantially similar. The authors recommend EWP over RDD.

Publicly available lists such as telephone books or county rosters can be used to detect Hispanic names. Although this method is certainly biased against finding potential subjects with no phones, private numbers, and non-Hispanic surnames (2), the pragmatic benefits are clear. The usefulness of this approach depends on the list and on whether people with a group of ethnic-identified names are a biased subset for one’s purposes. In Missouri, for example, the BRFSS plans an annual sample of 4200 completed telephone interviews of which 2.2%, or fewer than 100 respondents, are expected to self-report they are Hispanic (see Table 1 for an example). A national commercial firm provides a list of nearly 23,000 Missouri phone numbers with Hispanic surnames. For Missouri and other states with similar “small sample” problems, there is a need to conduct a formal test of these kinds of special recruitment methods to compare the resulting sample with Census-based population estimates. As with other recruitment solutions, the costs of adopting this kind of extra sampling and its biases need to be balanced with the urgent need for more extensive data about a special population.

The same method has been applied to Chinese surnames. Hage and colleagues chose Chinese surnames from a population register in Melbourne, Australia (39). They found this method to be feasible and efficient for a prevalence study of health-related characteristics of Chinese residents, yielding a sample demographically comparable to the corresponding census population. Sasao also describes special issues in telephone interviews of Asian Americans including (a) identifying and sampling Asian-American respondents; (b) obtaining respondent cooperation; (c) designing bilingual interview protocols; (d) dealing with possible biases due to interviewer gender, language, and topical sensitivity; and (e) cost of the phone survey (81). Their study found low to moderate response rates, which suggests that personal information may be reliably collected by telephone to the extent that phone-number lists contained Asian surnames that were clearly unique to a particular Asian group.

Purchasing commercial lists Another nonprobability sample method to enrich sample sizes of minorities uses data purchased from marketing or telemarketing firms. A model study was conducted by Psaty and colleagues (75), who purchased a list of names and phone numbers of persons over 65 in San Francisco. They first compared the list to another list of known seniors. Only about half were on the list, and those in lower-income areas were somewhat less likely to be listed. They
then conducted telephone surveys with persons on the list, in parallel with an RDD survey, and compared the results. Results from the RDD and the marketing lists were very similar, and the marketing list survey cost about 25% as much as the RDD survey per completed interview. This study design also could be applied to in-person samples if addresses were purchased rather than a telephone list.

Olson and colleagues compared a commercial database to RDD to identify controls for patients with ovarian cancer (68). The mailing list owner grouped cases into “lifestyle” clusters based on their zip code microneighborhoods and generated a random sample of potential controls with the same distribution across clusters. The two control samples were similar to each other, differing only on education and income, for which the commercial list sample was closer to the cases than was the RDD sample. Only 28% of the RDD sample was included in the mailing list, indicating that it did not reflect the source population of the cases. Use of a commercial database provided a control group whose socioeconomic factors were similar to those of cases at a lower cost than when RDD was used, but it did not result in a higher response rate.

One appeal of the commercial lists is that they are efficient; another is that some research exists about how well the population they cover meshes with the population of interest. Findings above, that such lists included less than half the subjects of interest and were somewhat upscale, should be kept in mind in interpreting results. Depending on the question, this may not be a severe problem. Finding lack of health care access in the upscale group would probably imply worse problems in the lower-income persons in the same neighborhood, which might be sufficient evidence for an intervention. It seems likely that telemarketers could develop lists with high numbers of Hispanics using some combination of surname and Hispanic associations, such as memberships and purchases. To our knowledge such an approach has not been tried or validated.

Improved Field Methods for Increasing Participation of Special Populations

EXTENDING SURVEY MODES Primary sources of surveillance information are based on surveys (e.g., BRFSS), vital statistics, and available institutional data (e.g., hospital discharge data). However, public health agencies also use special techniques like mailed surveys and door-to-door sampling with in-person interviews to augment data streams. Each of these additional modes of data collection can add to existing surveys for depth of content or samples, or can stand as independent methods. Survey data quality and response deteriorate across sampling modes: They are best for in-person techniques, moderate for telephone samples, and lowest for mailed surveys. However, expense of these different survey modes is in the reverse order, with in-person interviews costing the most to administer. Because nonresponders in health surveys tend to have lower health and poorer health habits than responders (e.g., 50, 106), there are trade-offs between data quality, bias, and costs. In a study of older women, in-person, telephone, and self-administered
questionnaires were compared for response, data completeness, and cost (74). Although the cost of data collection for self-administered questionnaires was 25% to 30% lower than for the other two modes, it also demonstrated the lowest response and highest level of missing data. Aquilino & Wright (8) compared RDD and in-person sampling modes and found substantially lower response by telephone. However, the two techniques produced similar responses about substance-abuse profiles. In a direct comparison of mailed and telephone-administered surveys about health, data-collection costs were substantially higher for phone interviews, but missing data were more common for mailed surveys and there also was evidence of lower health ratings for mailed compared to interview survey modes (58). Given the cost and quality trade-offs, and the existence of available methods for state-level telephone surveys, it may be difficult to apply other data-collection modes. Unknown mode effects also hamper adopting multi-mode strategies, and the example by McHorney and her colleagues is unusual in that it compares modes directly (58). “Bridge” studies to accommodate mode effects may help alleviate these problems. Bridge studies would involve estimating response differences for techniques like different modes, so that the results could be combined and potential biases interpreted. However, at present, we are unaware of studies that would provide comparative data and algorithms to interpret mode effects and data quality for common surveillance surveys.

IMPROVING RECRUITMENT AND PARTICIPATION Low response of targeted subjects hampers the generalizability of any survey. Levels of response vary by a variety of demographic characteristics, like age, gender, and race/ethnicity (e.g., 82, 106). Responders may also be different by key health characteristics (e.g., 29, 82, 106). For surveillance surveys, there are a number of enhancements that can improve response.

In general, these methods all require substantially more labor-intensive methods and increased total survey costs. However, increased response can decrease the cost per completed survey. In addition, the same methods that increase response generally also improve the quality and completeness of data, and increase the participation of minority groups (22, 40, 46, 52, 84, 88). The following is a selected list of recommended strategies for field methods to increase response and quality of data from surveillance survey methods. For improving general field research techniques there are a number of excellent reference texts (e.g., 28, 36, 37, 38). Before tackling special group recruitment, we also strongly recommend reviewing the relevant specific literature. Authors with substantial field research and ethnographic experiences provide insight for special groups, for example older adults (e.g., 98), Hispanic groups (e.g., 3, 9, 55, 56, 72), African Americans (17, 34, 70), and people with disability (61). A sample of recruitment-enhancement techniques is listed below.

Staff and training There is no substitute for welltrained staff to achieve high levels of subject participation and quality data. Training of phone or in-field
interviewers can take up to ten days for an initial training, and a new and extensive recruitment or interview protocol may add another week to this time period. Well-trained and carefully selected interviewers are expensive and valuable. However, they assure high levels of subject participation and provide high quality data. These characteristics reduce future expenses, for example in editing and missing-data problems. In addition, when appropriate and feasible, interviewing teams often include specialists who have skills in overturning subject refusals.

Matching interviewer characteristics to potential participants, for example gender and ethnic backgrounds, is sometimes recommended to improve subject response (e.g., 32). However, there is not a clear advantage to this matching above the characteristics of a quality interviewer: that is, a professional interviewer who is motivated, confident, and respectful of the targeted respondents. Ad-hoc interviewers recruited only for their demographic characteristics are not preferable to highly experienced and skilled staff.

**Survey modes and logistics** Advance contacts, for example telephone calls before a personal interview, can improve the recruitment of subjects [e.g., see the early classic example of Bergsten and others (10)]. Various incentives and embellishments also are shown to increase response usually regardless of survey mode (e.g., 16, 43, 46, 51, 57). In general, each additional technique to improve response tends to increase total cost of the data collection, although it does not always increase the cost per competed interview. In a carefully constructed trial of mail and telephone strategies, Harris and colleagues (40) found that a telephone-first strategy followed by mail survey provided better response, fewer missing data, and lower cost compared to the reverse. The usual trade-off in cost must be assessed and compared with the importance of nonresponse and biased samples and information. Whether incentive strategies work differently for ethnic minority groups or other special populations appears to be unknown.

Strategies to improve participation also include informing and involving the community of interest. Community participatory research has recently been embraced as a vital public health intervention and research technique (30). Improvement in minority participation in research has been demonstrated in a variety of community research and education campaigns (e.g., 17, 34, 69, 70). Beyond the evidence of improved research, the issue of ethics and response to community interests will compel future surveillance strategies to involve these groups in planning surveillance efforts and research, assuring the value and utility of the information.

**Other recruitment and participation issues** During the Missouri Symposium, participants raised concerns about expanding special group data collection from the usual RDD techniques with in-person surveys and recruitment efforts. Two generalizable problems were raised about recommended efforts to extend field methods: interviewer safety and compatible language.

Interviewers may be called on to recruit or interview special groups in neighborhoods and situations with real safety concerns. Methods like time-and-space
sampling could require interviewers to attend crowded social events or locations where alcohol is consumed. Door-to-door recruitment methods and in-home interviews also present safety challenges. General interviewer training sessions must be augmented in these special circumstances with clear rules and protocols for safety. These protocols may include clear rules of disengagement with potential subjects, and requiring frequent, scheduled interviewer call-ins to field supervisors. All in-person interviewing protocols should include clear rules for identification, professional conduct, and availability of supervisors and/or investigators to answer questions of subjects and interviewers. Local police and/or community organizations can be alerted before implementing fieldwork. A team approach can be implemented before beginning a new field site: Two or more interviewers can be assigned to time-and-location blocks. Interviewer teams also can be supervised and monitored by a study aid or an extra staff member whose responsibility includes transportation and safety issues for interviewers. These methods also improve the safety and trust of potential respondents, which is important.

Language compatibility between respondents and data-collection tools is also an ongoing challenge for surveillance surveys and other general-population data-collection efforts. Having questionnaires available in languages other than English and using bilingual interviewers are clear goals. However, not all surveillance surveys are available in multiple languages. Even for the BRFSS, where Spanish-language adaptations are available, individual states may opt to add modules for which no professional translation is available. Each of these additional questions, modules, or surveys requires extensive translation and adaptation procedures [e.g., in health-related quality-of-life reports (13); and see (99)]. In addition, professional bilingual interviewers are at a premium in some locations despite their benefit to achieving ethnic group participation. Centralized interviewing labs are the norm for telephone data collection (e.g., the BRFSS), and access to recruiting special interviewers is difficult.

**Multi-Method and Auxiliary Data-Collection Methods**

As with techniques that involve nonrandom sampling methods, improved information could be acquired for small groups based on multiple methods of data collection and auxiliary methods. These data can provide more in-depth information to add to sparse (randomly selected) surveillance data.

First, qualitative data provide a rich resource to understand health issues and interests not included in surveillance surveys. Qualitative methods depend on purposeful rather than random sampling to include especially informative subjects. Successful qualitative methods can be used to acquire more in-depth information. These may include involving community leaders and organizations, or interviews with key informants and focus groups. A growing literature on participatory research methods can be useful (e.g., 35, 45). However, public health researchers now are advised to adopt community participatory research as a standard strategy, and not only in regard to qualitative methods (30). Public health agencies and
researchers need to learn and adopt these methods when community participation is relevant to their questions and populations.

Second, multi-method surveys can acquire more data from individuals and from communities. For example, telephone or in-person follow-back surveys could add additional detail about health behaviors for minority respondents. In-person recruitment in targeted neighborhoods can augment the data from telephone surveys to improve representation (e.g., nontelephone households) and the level of detailed survey information. Additional recommendations about improving response for these methods are described in the sections above.

**SUMMARY OF RECOMMENDATIONS**

We encourage broadening current surveillance methods to enhance information about ethnic and minority health for states and even smaller geographic areas. There are two broad groups of recommendations: those that may be amenable as short-term or rapid changes, and those requiring substantial planning or more long-term goals. Figure 1 provides a brief summary of the methods we provide here.

Immediate action steps include partnering with other agencies (e.g., state hospital associations) for mutual data interests and data aggregation, especially across years. In addition, nontraditional resources, like the Census, could be used immediately to examine broad characteristics of health and environmental risk factors. In addition, reaching out to involve communities affected by any changes and planned improvements of surveillance activities is immediately essential. Longer-term actions generally require changes in ongoing systems of data collection or substantial additions and new techniques. These include adding special-language interviewers, adding participation enhancements, and including nontraditional recruitment methods to enhance samples. These kinds of decisions require carefully weighing the added costs and benefits.

We emphasize that not all small-sample problems can be overcome by standard and even enhanced surveillance methods. For example, although requested by counties, minority group-level information is likely to be unreliable for estimating differences or changes at the county level. Changes in statistical methods may require added training and methodological support to assist these localities in use and interpretation of their local and state-provided data. Steps that require changes in data collection are likely to be more long-term objectives.

Finally, in addition to methodological solutions, there are additional broad and long-term issues regarding the content and sociological aspects of race, ethnicity, and information for communities and states. The material presented here is designed to encourage steps in a process, rather than a definitive set of recommendations and solutions. We believe that other researchers and public health practitioners can examine their options with the kind of collaborative process employed among public health practice, community partners, and academic researchers such as our Missouri Symposium.
<table>
<thead>
<tr>
<th>Type of strategy</th>
<th>Strategy</th>
<th>Strengths</th>
<th>Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Analytic</td>
<td>Aggregate data over time</td>
<td>Increase sample size, low cost</td>
<td>Lose time-trends, complex variance</td>
</tr>
<tr>
<td></td>
<td>Synthetic (small area) estimates</td>
<td>Provide data on small areas, e.g., counties, low cost</td>
<td>Variable accuracy, requires skilled analyst</td>
</tr>
<tr>
<td>Sampling</td>
<td>Regional or subgroup over sampling</td>
<td>Better precision for subgroups</td>
<td>Cost, complex variance</td>
</tr>
<tr>
<td></td>
<td>Time-space</td>
<td>Enhanced sample for small and/or “invisible” groups</td>
<td>Unclear translation to estimates based on random sampling, cost</td>
</tr>
<tr>
<td></td>
<td>Snowball</td>
<td>Enhanced sample for small and/or “invisible” groups</td>
<td>Unclear translation to estimates based on random sampling, cost</td>
</tr>
<tr>
<td></td>
<td>Commercials lists</td>
<td>Enhanced sample sizes for small groups</td>
<td>Unclear translation to estimates based on random sampling, cost</td>
</tr>
<tr>
<td>Field methods</td>
<td>Door-to-door surveys</td>
<td>Greater representation of minority groups, accuracy and length of surveys</td>
<td>Cost, potential survey mode effects</td>
</tr>
<tr>
<td></td>
<td>Special language surveys</td>
<td>Expand representation</td>
<td>Cost, small samples</td>
</tr>
<tr>
<td></td>
<td>Improve data completeness (e.g., medical records)</td>
<td>Enhance summary data on ethnicity, other demographics groups</td>
<td>Costs of training data-collection personnel, increased supervision</td>
</tr>
<tr>
<td>Other data methods</td>
<td>Enhance survey content</td>
<td>Add domains for understanding disparity</td>
<td>Survey length, standardization, small samples, cost</td>
</tr>
<tr>
<td></td>
<td>Bridge studies</td>
<td>Interpretation of variable strategies</td>
<td>Cost</td>
</tr>
<tr>
<td></td>
<td>Qualitative or multi-method studies</td>
<td>Increased depth of information, triangulation</td>
<td>Cost, representativeness of data and samples, inexact methods for combining estimates and information</td>
</tr>
</tbody>
</table>

**Figure 1** Summary of methods and issues for data on special populations.
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