

DESIGNING MULTI-ETHNIC STROKE STUDIES: THE BRAIN ATTACK SURVEILLANCE IN CORPUS CHRISTI (BASIC) PROJECT

The Brain Attack Surveillance in Corpus Christi (BASIC) project is a population-based stroke study comparing Mexican Americans and non-Hispanic whites. Extensive effort is made to detect all patients regardless of ethnicity and ensure equal participation in the interview among both groups. We describe here the study's design and process evaluation with a focus on reducing bias in case ascertainment and participation. During the first 28 months of the project, 11,829 subjects were screened. Availability of neuroimaging did not differ by ethnicity ($P=0.22$), nor did confidence in the validated diagnosis of stroke ($P=0.10$). Participation rate in the interview also did not differ by ethnicity ($P=0.92$). There was excellent agreement of ethnic classification between chart abstraction and self-report ($\kappa=0.94$, $P<0.001$). We conclude that multi-ethnic stroke comparison studies are feasible. Utilizing epidemiologic principles to design, recruit and analyze data are critical. Process evaluation to examine for sources of bias is important to study conduct. (*Ethn Dis.* 2004;14:520–526)

Key Words: Community, Design, Epidemiology, Ethnic, Hispanic, Methods, Quality Assurance, Stroke, Surveillance, Underserved

From the Stroke Program, University of Michigan Health System (MAS, NG, LBM), Department Epidemiology, University of Michigan School of Public Health (LBM), Ann Arbor, Michigan; Department of Epidemiology (JMHR), Department of Biometry (LAM, OA), University of Texas School of Public Health at Houston, Texas; Department of Neurology, University of Pittsburgh, Pennsylvania (KU).

Address correspondence and reprint requests to Lewis B. Morgenstern, MD; Stroke Program; University of Michigan Health System; 1500 East Medical Center Drive; TC 1920/0316; Ann Arbor, MI 48109-0322; 734-615-7390; 734-936-8763 (fax); lmorgens@umich.edu

Melinda A. Smith, MPH; Jan M. H. Risser, PhD; Lemuel A. Moyé, MD, PhD; Nelda Garcia; Olubumi Akiwumi; Ken Uchino, MD; Lewis B. Morgenstern, MD

INTRODUCTION

Stroke has a predilection for racial and ethnic minority populations.^{1,2} The National Institute of Neurologic Disorders and Stroke identifies further assessment and treatment strategies aimed at minorities to be a high priority for future cerebrovascular research.³ Stroke epidemiologic, observational and clinical trial studies that aim to generalize their results to multi-ethnic populations must include specific design strategies. Stroke studies focusing on multi-ethnic populations need to assure equal recruitment, participation, and evaluation. Several studies have demonstrated that this is a difficult process.^{4–11} Recruitment of minority subjects often lags behind that of non-Hispanic White (NHW) subject recruitment. Evaluation, compliance, retention and follow-up are critical issues that require culturally sensitive approaches to assure maximal efficacy. While there is a lot of published information on strategies to improve recruitment of minority subjects,^{4–11} there is little information on the design and process evaluation to assure that bias is minimized while comparing multi-ethnic populations for stroke risk. Epidemiologic investigations that seek to uncover race/ethnic differences need to ascertain and evaluate stroke cases in the same fashion regardless of race/ethnicity.

We report here the design and process evaluation of the *Brain Attack Surveillance in Corpus Christi* (BASIC) project. The BASIC project is a multi-ethnic population-based stroke surveillance study designed to identify and validate all stroke cases within a community. The purpose is to compare stroke

attack rates, and to uncover the conventional risk factors and access to care/cultural differences among Mexican American (MA) and NHW stroke patients. It was imperative that BASIC identify all stroke cases and obtain complete documentation of demographic, social, and clinical information on all stroke patients.

METHODS

Study Population

Nueces County, Texas is located on the Texas Gulf coast. The total population of Nueces County was 313,645 in 2000,¹² with approximately 89% of the county population residing within the city of Corpus Christi. Of the total population, 56% are persons of Hispanic origin, 38% are NHW, and 6% are African American or of other races. There are sociodemographic differences between Mexican Americans (MAs) and NHWs in Nueces County. The levels of income and education for MAs and NHWs in Nueces County are quite similar to the levels for these respective ethnic groups in the State of Texas as a whole.¹² This suggests that this population may closely reflect the conditions and characteristics of the broader population of MAs.

The MA community in Corpus Christi is not an immigrant population. In fact, in a population-based survey, MAs had resided in the community longer, on average, than NHWs.¹³ The MAs in this community are predominantly second and third generation born United States citizens. This study was fully integrated into the community utilizing print, television, and radio stories.

Stroke studies focusing on multi-ethnic populations need to assure equal recruitment, participation, and evaluation.

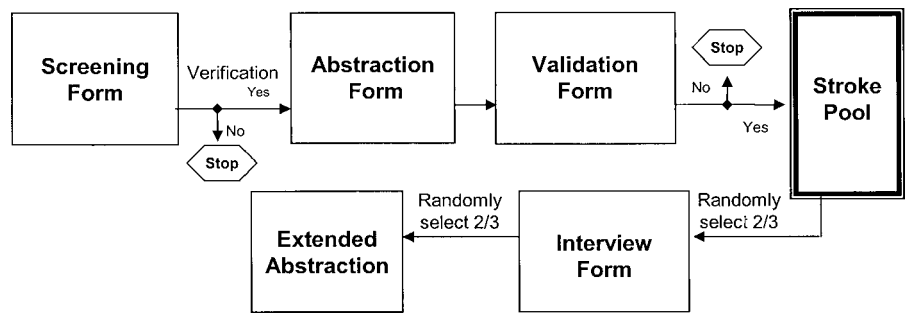


Fig 1. Data flow in the BASIC project. Nueces County, Texas, January 2000–present

All materials were available in Spanish and English, and project staff communicated with subjects in the patient's language of choice.

Medical care in Nueces County is highly self-contained, a situation which is essential to the accurate population-based ascertainment of stroke events. There are 6 acute care hospitals whose combined catchment areas encompass the resident population of the County. Computed tomography (CT) and/or magnetic resonance imaging (MRI) units are available at all these hospitals. Houston and San Antonio, the nearest urban centers, are both well over 150 miles from Nueces County; therefore, the likelihood of referral outside the County for first medical contact for acute stroke care is extremely low. In fact, Corpus Christi is the regional medical center for south Texas. The contiguous counties are relatively sparsely populated.

Surveillance Methods

Data collection began January 1, 2000 and is on-going. Cerebrovascular events are defined based on published criteria.^{14–18} Case identification of hospitalized events is accomplished by using both active (“hot pursuit”) and passive (“cold pursuit”) ascertainment procedures at all hospitals serving the Corpus Christi population. The combination of active and passive surveillance was shown to be superior to either method alone for complete case ascertainment for stroke surveillance studies.¹⁹ The “Hot Pursuit” method is similar to that used by the World Health Organization

Monitoring Trends and Determinants in Cardiovascular Disease (MONICA) study.¹⁴ For hospitalized patients, both emergency room and admission logs are reviewed daily by BASIC abstractors. Hospital wards and intensive care units are routinely examined for stroke patients as well. Abstractors undergo a formal stroke education program. They are trained to review medical records and abstract data into an electronic case report form.

To assure complete ascertainment of hospitalized stroke events, lists of discharges with Stroke International Classification of Diseases, Ninth Revision (ICD-9)²⁰ codes 430–438 (cerebrovascular disease) are obtained monthly from each hospital (passive surveillance). In-hospital stroke patients are carefully sought after by both routine canvassing of hospital wards and through ICD-9 codes. Finally, out-of-hospital stroke deaths are identified from emergency department screening, reports from the county medical examiner, and the Texas Department of Health Death Database.

Exclusion criteria are: subjects less than 45 years old, individuals who had a stroke as a result of head trauma, and non-Nueces County residents. Because United States zip codes are not county specific, the United States Census bases county status on the physical address of the resident. To assure that only Nueces County residents are included in this study, we have identified all Nueces County specific zip codes and 5 problematic zip codes. These 5 problematic

zip codes cross county lines, so subjects with these zip codes may not be Nueces County residents. If a subject has a problematic zip code, the physical address of the subject is entered into the United States Census Web Page to determine county status (<http://tier2.census.gov/ctsl/ctsl.htm>).

Figure 1 illustrates the process of case abstraction, verification, and validation. Screening for potential stroke cases is accomplished by searching admission and emergency department logs for any of a group of symptom or diagnostic terms that have been validated as predictors of cerebrovascular patients. These terms were validated during a pilot study where 1,077 charts were reviewed for patients presenting with stroke symptoms.²¹ Based on the list of screening terms, those patients with an admitting diagnosis/symptom suggestive of stroke are selected for case review by a “Hot Pursuit” abstractor. Abstractors immediately review the medical record of each patient and complete a Screening Form for those cases that meet criteria for this project. All data are directly entered into a computer database on a laptop at the site of medical record review.

At this point the verification step takes place. The verification step requires the abstractor to determine if the patient has a potential for diagnosis of stroke. Abstractors have been trained extensively and proven capable (>95% sensitivity) of differentiating between “potential stroke, yes” and “potential

stroke, no.” They are taught to include any subject with any possibility of having a stroke. A study neurologist is always available to review the case with the abstractor. If the patient is determined to be a potential stroke case, abstractors collect additional information on the Abstraction Form and copy relevant data from the patient’s medical record. The Abstraction Form collects additional risk factor information, prior history, and neuroimaging results. The BASIC project also facilitates an estimation of stroke severity at onset by extrapolating the National Institutes of Health Stroke Scale (NIHSS) score. This method of chart abstraction to estimate the NIHSS has been validated.²²

All information is then sent to the study neurologists for a final validation of stroke or no stroke. Following verification, the specifically developed computer program randomizes all subjects regardless of stroke classification to interview (75%) or no interview (25%). Subjects are approached while hospitalized to assure best recall of pre-morbid conditions. The subject and closest friend/relative are interviewed for completeness. Before the interview begins a series of orientation questions are asked to assure that the patient is capable of providing accurate responses. If the subjects do not answer the questions correctly, the closest friend/relative (proxy) is interviewed. This procedure was validated in a large trial of patients interviewed soon after intracranial hemorrhage.²³ Two thirds of the interviewed group are randomized to have an extended abstraction form completed. This form includes all pertinent lab and stroke evaluation data and will provide a sample of very detailed information on MA and NHW stroke patients.

Finally, non-hospitalized stroke cases are ascertained via a scientific sample of out-of-hospital stroke cases that are extrapolated to the total community. A list of all primary care physicians (internal medicine, family practice, or general practice) and neurologists from the Nu-

eces County Medical Society (not just members of the society) was obtained. A similar list of nursing homes was obtained from the yellow pages. Random selection was done by computer program to obtain a group of 47 primary care physicians, 4 nursing homes and all of the 11 neurologists to be in the sample. The size of the sample was selected to accommodate the ability of one FTE individual to screen these sources.

The sample of 62 were approached and agreed to participate. They met with the investigators to discuss the goals of identifying non-hospitalized stroke patients. Screening at the offices is accomplished through a variety of mechanisms. Some offices keep an electronic record and are screened like a hospital passive listing. Some offices keep a hand written log and are screened like an active emergency department log. Some offices volunteer cases to us as we routinely canvas each site, providing aggressive front and back office and physician contact. Some physicians report that their policy is to admit all TIAs and strokes and support this with evidence of admissions of these patients. Our local physician supporters contact the sample group to encourage continued participation. Our community procedures follow the principles of modeling, medical detailing, and audit-feedback well known among Health Behavior and Health Promotion researchers.

Extensive communication with the public through print, radio, and television media encourages county residents to call 911 immediately for stroke or TIA symptoms. A self-report system was not utilized due to the reliance on source medical documentation for case validation.

Cases are assigned a classification of either: definite stroke, probable stroke, or possible stroke based on the following definitions:

Definite. Onset of an acute focal neurological deficit with confirmatory evidence of stroke by neuroimaging and

documented exclusion of other possible etiologies (hypoglycemia, seizure, tumor, hysteria, encephalopathy).

Probable. Onset of an acute focal neurological deficit with normal initial neuroimaging and documented exclusion of other possible etiologies (hypoglycemia, seizure, tumor, hysteria, metabolic encephalopathy).

Possible. Onset of an acute focal neurological deficit with absent neuroimaging or without supportive clinical or laboratory evidence to exclude other possible etiologies (hypoglycemia, seizure, mass/tumor, hysteria, metabolic encephalopathy).

The purpose of this classification into definite, probable, or possible is only to determine whether an ethnic difference exists in our confidence on case status. All cases, regardless of possible, probable, or definite designation are included in the stroke pool and considered eligible for interview and extended abstraction. Patients with TIA may meet the above definition of either probable or possible with the addition that their symptoms resolve within 24 hours.

Estimation of Population Size

To compute appropriate rates of stroke occurrence, population data will be needed by age, sex, and race/ethnic group of the County. Such detailed population data is available for the census year 2000 from the US Bureau of Census.¹² Postcensal population estimates and projections are provided in detail by the Texas State Data Center at Texas A&M University, an affiliate of the US Bureau of the Census. The population in Nueces County is stable. This county is not a border community and very little immigration occurs.

Analysis Plan and Sample Size

The aim of this study is to estimate the relative stroke burden of MAs and NHWs. Sample size estimates were based on a pilot investigation of stroke hospitalization rates in this communi-

Table 1. Stroke patient screening in the BASIC project. Nueces County, Texas, January 2000–April 2002

Ethnic Category	Men	Women	Total
Hispanic or Latino	3,747	2,260	6,007
Not Hispanic or Latino	3,484	2,210	5,694
Unknown	75	53	128
Total	7,306	4,523	11,829

ty²¹ and extrapolated for the planned 3 year surveillance time in BASIC. Assuming an alpha error rate of 0.05 and a power of 80%, the sample size was calculated to distinguish a 30% ethnic difference in stroke attack rates (first ever and recurrent ischemic stroke + intracerebral hemorrhage + subarachnoid hemorrhage), ischemic stroke alone, and stroke mortality alone. It was recognized that 3 years of surveillance was insufficient to detect a 30% ethnic difference in intracranial hemorrhage (intracerebral + subarachnoid hemorrhage).

We also wished to investigate the factors contributing to the ethnic differences in stroke attack rates and mortality. The underlying hypothesis is that ethnic differences in stroke will be related to poor access to care and acculturation and to increased prevalence of risk factors among MA stroke patients relative to NHWs. The power computation is provided for a comparison of the insurance frequency of stroke patients between NHW and MA patients. Specifically, we are interested in testing if the prevalence of insurance (an important measure of access to care) be-

tween NHW and MA populations at risk is different. The initial estimate of the prevalence of insurance coverage in the NHW population who suffered a stroke is 94% from the pilot study. Using the expected cohort of 600 interviewed patients, we will have 84% power to detect an absolute difference of 7 percentage points in insurance prevalence between the 2 ethnic groups.

Quality Control

Several BASIC protocols have been developed to assure the best data collection. The protocols involve: training and certification of abstractors and study neurologists; standardized data collection procedures; and inter-rater reliability methodology. Study abstractors must undergo a standardized training and certification process before they can begin to collect data independently. This includes a period when they collect data under the supervision of the primary investigator (PI). Abstractor training is a continuous process involving stroke workshops on a regular basis. Abstractors also take a yearly recertification exam.

Data collection has been standardized and all data collection procedures are clearly outlined in a Procedure Manual to assure that all abstractors collect the data in the same manner. Inter-rater reliability is checked on a monthly basis. Abstractors re-abstract patient charts and a comparison of the original data collection and quality control (QC) re-abstractation is made. For the entire group, the overall discrepancy rate has been less than 1% for the entire project and it has been necessary to retrain only one abstractor. One area of particular QC importance is the verification step. This step determines if a subject will be included in the study. Abstractors must call study neurologists and review patient data to determine if a subject should be included in the study. Abstractors have to achieve and maintain a 97% agreement rate with the study neurologists for 2 months before they can verify cases independently. This agreement rate is checked on a yearly basis. Study neurologists also must adhere to rigorous QC standards. All study neurologists were trained to validate stroke cases according to the standards set forth in this study. An algorithm was developed to aid the neurologists in stroke validation. Strict adherence to the algorithm is essential to maintain diagnosis continuity between neurologists. Ten percent of all validated charts are re-validated by a different study neurologist. Neurologists must maintain less than a 1% discrepancy rate or they are re-trained. This has been unnecessary to date.

The BASIC project was approved by the University of Michigan and the University of Texas at Houston's Institutional Review Boards, all local hospitals, and the County Health District. Finally, the BASIC project adheres to all HIPAA regulations and recommendations. Since this research could not practicably be conducted without access to public health information (PHI) or without a waiver of consent from screened subjects, a HIPAA research waiver was ap-

Table 2. Distribution of validated definite, probable and possible stroke by ethnicity, the BASIC project, Nueces County, January 2000–April 2002.

	Definite	Probable	Possible	Total
Complete Ischemic*				
MA	212	265	93	570
NHW	210	242	61	513
TIA†				
MA	0	131	112	243
NHW	0	148	117	265

* χ^2_1 4.72, $P=.10$.
 † χ^2_1 0.193, $P=.66$.

Table 3. Neuroimaging among verified stroke cases, the BASIC project, Nueces County, January 2000–April, 2002

Race/ Ethnicity	CT	MRI	No Imaging	Total*
MA	995	37	57	1089
NHW	881	45	62	988
Total	1876	82	119	2077

* χ^2 3.0, $P=.22$.

plied for and granted. Additional security mechanisms were put into place to protect PHI and all material is de-identified and cases are assigned a random subject ID code that contains no PHI. A consent form is signed by all subjects or their next of kin who are contacted.

RESULTS

During the first 28 months of the study, 11,829 subjects were screened. Table 1 provides the ethnic and gender information on screening of potential strokes with a combination of active and passive surveillance. Based on the pilot study, we expected a sample size of 1,184 completed ischemic strokes over 3 years. In 28 months, we validated 1,083 subjects with completed ischemic strokes. This extrapolates to 1,397 in 3 years, far ahead of schedule.

Ethnic Classification

Ethnicity is determined from information available in the medical record. Medical record data used for classification of ethnicity includes physician reports, nursing notes and assessments, and administrative forms. If a discrepancy is found in the medical record, ethnicity is recorded according to a hierarchy. Hispanic ethnicity takes precedence to non-Hispanic White. This protocol has yielded a 97% agreement ($\kappa = 0.94$, $P < .001$) between the interview and medical record for ethnic classification in the first 28 months. Virtually all of the Hispanic population is MA. During the first 28 months of the BASIC project, only one Hispanic pa-

tient interviewed described their origins other than from Mexico (<.5%).

Ethnic Differences in Stroke Evaluation

The ethnic distribution of definite, probable, and possible stroke reflects the availability of the information and certainty of the validation process. Table 2 shows that there is no association to date of ethnicity and distribution of definite, probable, or possible completed stroke (4.72, $P=.10$) or transient ischemic attack (TIA) (0.193, $P=.66$) in BASIC to date. Similarly, Table 3 shows there is no ethnic difference in the availability of neuroimaging by ethnicity (3.0, $P=.22$) among stroke cases verified potential stroke by abstractors.

To accurately compare access to care and acculturation differences among MAs and NHWs, the response rate for the interview must be similar. Table 4 provides this data. There is no association of interview completion by ethnicity, 0.009, $P=.92$. Importantly for our study, and those comparing ethnic populations, as Table 5 demonstrates, during the first 24 months of the study, there was no association of ethnicity and

use of proxies in the BASIC project (0.50, $P=.48$).

Proxy and Subject Interview Agreement

The protocol for interview specifies that a proxy will be used to supplement or replace the subject interview if the subject is unable to correctly answer a set of screening questions used previously in other stroke epidemiology investigations.²³ We performed an investigation of the agreement among 20 proxies and subjects for 7 critical items contained in the interview. This data is shown in Table 6 and reflects the very high proxy/subject agreement.

Out-of-Hospital Stroke Surveillance

During the first 16 months of the sampling procedure 54 of 60 (90%) out-of-hospital stroke cases were found from sample locations despite the fact this group makes up only about 25% of potential out-of-hospital physician contacts for stroke. Extrapolating this to the total population, we believe 105 additional strokes occurred in the population, 43 (6% of total) in the MAs, and 62 (9% of total) among NHWs. This effort has provided more precise estimates of the stroke rate in each of these 2 populations. Without the out-of-hospital sample effort, we would underestimate stroke attack rates in both populations. We would also overestimate the relative burden of disease in MAs since NHWs are more likely to visit an outpatient facility for stroke.

Table 4. Interview inclusion information, the BASIC project, Nueces County, January 2000–December 2001

Race/ Ethnicity	Complete	Refused/ Cannot Locate	Total*
MA	324	66	390
NHW	335	67	392
Total	659	133	692

* χ^2 0.009, $P=.92$.

Table 5. Use of proxy interview subjects in the BASIC project, Nueces County, January 2000–December 2001

Race/ Ethnicity	Proxy	Subject	Total*
MA	105	219	324
NHW	100	235	335
Total	205	454	659

* χ^2 .50, $P=.48$.

DISCUSSION

There were 2 main strategies employed in BASIC to capture all stroke patients and enable equal interview participation rates regardless of ethnicity. The first was to be exhaustive in searching for inpatient cases, those that present to emergency departments and those that are only seen as outpatient visits. Because of limitations in access to care among minority populations, certain groups are more likely to seek care from outpatient settings and others from emergency departments.⁹ Previous studies have shown that stroke patients of different race/ethnic backgrounds are likely to die in different locations (home, hospital, or nursing home), and that all locations should be included when making race/ethnic comparisons.²⁴ The BASIC solution is to aggressively search all possible sources for stroke cases with equal rigor.

The second strategy was to fully integrate the study into the community. This strategy facilitates reporting of stroke cases for complete case capture. It also improves minority response rates for the interview section of the protocol.

The strategy employed community contact through print, radio, and television media. It also relied on physician and nurse education through lectures at medical society meetings, newsletters, and hospital activities. Local physician support is critical to BASIC. The BASIC field staff are all indigenous to the region. University researchers remain out of the spotlight. It seems critical to avoid the notion that researchers from outside the community are coming into the community to work. Some studies, particularly clinical trials, have employed local lay community leader support.²⁵ This was not done in BASIC.

All subject information is available in Spanish and English. Spanish-speaking individuals are approached by a bilingual abstractor. The interview questions were translated and back-translated from Spanish. More importantly, extensive pilot testing was utilized to assure that the questions were culturally-sensitive and measuring the objectives they were intended to study. The fact that the interview participation rate did not differ by ethnicity is critical to ethnic comparisons. Further, the study suggests no differences in proxy use for in-

While self-report may be important for socio-cultural studies including access to care and acculturation, it may not be as informative for genetic studies.

terviews. Ethnic differences in proxy use could bias the study. Controversy exists on the accuracy of proxy responses. Some studies have found that the agreement between participant-proxy information is acceptable.^{26,27} Others have found that proxy information significantly biases the results,²⁸ and still others have found that the loss of data if proxy information was not used contributed more bias than if the proxy information was used.²⁹

The agreement of the ethnic classification between chart abstraction and self-report in the interview sample is excellent. Classification of ethnicity is complicated. While self-report may be important for socio-cultural studies including access to care and acculturation, it may not be as informative for genetic studies. Studies frequently grossly underestimate Hispanic mortality rates due to misclassification of ethnicity for numerator calculation (events) but retaining inclusion into denominator data (population estimates).³⁰

The BASIC project's limitations include the inability to find stroke patients who never present for any type of medical contact. A prospective cohort study with frequent examinations and neuroimaging is necessary for this type of work. The cost of such an investigation is quite high and event rates are low, requiring many years of surveillance. Further, Corpus Christi is not an immigrant population, and we speculate that this type of project would encounter added difficulties in an immigrant

Table 6. Pilot study of proxy/subject interviews. The BASIC project, Nueces County, Texas

	% Agreement	Kappa	P
No insurance	100%	1.00	<.05
No routine physician	100%	1.00	<.05
History of hypertension	84.2%	0.31	.08
History of diabetes	100%	1.00	<.05
Current smoker	94.7%	0.83	<.05
Less than high school education	100%	1.00	<.05
Trust doctors and nurses	89.5	0.44	<.05

community. These may include having subjects return to their native country for medical care or to die, more extreme impediments to access to care and therefore under reporting of mild events.

Another limitation is the age range chosen, >44. This was done to include the overwhelming majority of strokes with limited resources. However, much of the disparity is found in younger age groups. Future studies need to investigate this younger population. The BASIC project does serve as a representative study paradigm that is well incorporated into the community and appears to be acquiring and analyzing data in a multi-ethnic community with consistency among population sub-groups.

As minority populations in North America grow, discovery and elimination of health disparities is an important goal. Studies that aim to focus on multi-ethnic groups must carefully plan out strategies to effectively study these populations while minimizing potential sources for bias.

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AUTHOR CONTRIBUTIONS

Design and concept of study: Smith, Risser, Morgenstern
Acquisition of data: Smith, Moye, Garcia, Akiwumi, Uchino, Morgenstern
Data analysis and interpretation: Smith, Risser, Moye, Akiwumi, Uchino, Morgenstern
Manuscript draft: Smith, Risser, Morgenstern
Statistical expertise: Risser, Moye
Acquisition of funding: Smith, Morgenstern
Administrative, technical, or material assistance: Smith
Supervision: Smith, Morgenstern