

A LONG-TERM STUDY OF SOCIOCULTURAL, GENETIC, AND PHENOTYPIC VARIATION IN NEW MEXICO HISPANICS

Appendix 1. Sociocultural Questionnaire

Date and time: Month____ Day____ Year_____ Time_____

Location: _____

Interviewer: _____

Section I: Sociocultural Information

(Show NM map with counties to get county for questions #1-7. If answer is Bernalillo County, specify area using Albuquerque map.)

1. Where were you born?
 - a. city: _____
 - b. county: _____
 - c. state: _____
 - d. country: _____

2. Where did you grow up?
 - a. city: _____
 - b. county: _____
 - c. state: _____
 - d. country: _____

3. Where do you live now?
 - a. city: _____
 - b. county: _____
 - c. state: _____
 - d. country: _____
 - e. zip code: _____

4. Where was your **mother** born?
 - a. city: _____
 - b. county: _____
 - c. state: _____
 - d. country: _____

5. Where was your **father** born?
 - a. city: _____
 - b. county: _____

- c. state: _____
- d. country: _____

6. Where were your **mother's** parents born?

- a. Grandmother:
 - 1. city: _____
 - 2. county: _____
 - 3. state: _____
 - 4. country: _____

- b. Grandfather:
 - 1. city: _____
 - 2. county: _____
 - 3. state: _____
 - 4. country: _____

7. Where were your **father's** parents born?

- a. Grandmother:
 - 1. city: _____
 - 2. county: _____
 - 3. state: _____
 - 4. country: _____

- b. Grandfather:
 - 1. city: _____
 - 2. county: _____
 - 3. state: _____
 - 4. country: _____

8. How old are you? _____

9. What is your sex? _____

10. Does your **father** belong to an old New Mexico family (land grants)?

11. Does your **mother** belong to an old New Mexico family (land grants)?

12. Were any of your ancestors colonists from Spain? If so, who and when (e.g., number generations)?

13. Do you have any ancestors from Mexico? If so, who and when (e.g., number generations)?

14. Do you have ancestors from anywhere else? If so, where else, who and when (e.g., number generations)?

(Interviewer: describe observations of how NMS divide themselves into at least two distinct groups to contextualize the next set of questions.)

15. What are the groups (*within NMS*)?

16. Which group do you belong to?

17. Which group do you think your **mother** belongs to?

18. Which group do you think your **father** belongs to?

19. Are you married? yes no

(If yes) Which group do you think your **spouse** belongs to?

20. Which of the other groups you identified is most similar to yours?

21. Which of the other groups you identified is most different from yours?

22. Please describe how the members of _____ (*insert name of group identified as most different from subject's; answer to #21*) tend to differ from members of _____ (*insert name of subject's self-identified group; answer to #16*) in these features:

a. Skin color

1. same
2. different. How? _____
3. don't know
4. refuse

b. Hair

1. same
2. different. How? _____
3. don't know
4. refuse

c. Face

1. same
2. different. How? _____

- 3. don't know
- 4. refuse

d. Other physical difference

- 1. What feature? _____ Different how? _____
- 2. What feature? _____ Different how? _____
- 3. don't know
- 4. refuse

e. Amount of Spanish use

- 1. same
- 2. different. How? _____
- 3. don't know
- 4. refuse

f. Accent when speaking English

- 1. same
- 2. different. How? _____
- 3. don't know
- 4. refuse

g. Accent when speaking Spanish

- 1. same
- 2. different. How? _____
- 3. don't know
- 4. refuse

h. Other language difference

- 1. What feature? _____ Different how? _____
- 2. What feature? _____ Different how? _____
- 3. don't know
- 4. refuse

i. Food (what people eat)

- 1. same
- 2. different. How? _____
- 3. don't know
- 4. refuse

j. Clothing (what people wear)

- 1. same
- 2. different. How? _____
- 3. don't know
- 4. refuse

k. Make-up

1. same
2. different. How? _____
3. don't know
4. refuse

1. Other cultural difference

1. What feature? _____ Different how? _____
2. What feature? _____ Different how? _____
3. don't know
4. refuse

23. Between the members of the group you belong to and those of the group most different from yours, does either one:

a. Experience more discrimination?

1. yes, my group
2. yes, other group
3. neither
4. don't know
5. refuse

b. Have more wealth?

1. yes, my group
2. yes, other group
3. neither
4. don't know
5. refuse

c. Have more political influence?

1. yes, my group
2. yes, other group
3. neither
4. don't know
5. refuse

d. Have more education?

1. yes, my group
2. yes, other group
3. neither
4. don't know
5. refuse

("The last set of questions has asked you to define what groups exist in NMS and tell us about the differences between them. Because we know that participants will give us different groups, we now will ask you the same questions using a set of group names

that we've gathered from other participants so that we can compare everyone's opinions about these terms. The groups are listed in alphabetical order." For questions 23-26, ask for first choice and mark as #1. Then ask if there is a second-best choice and mark as #2. Then ask if any of the other terms also describe the person of interest, mark as #3, etc.)

24. With which of these groups do you identify?

- a. Chicano/a
- b. Hispanic
- c. Latino/a
- d. Mexican
- e. Mexican American
- f. Nuevomexicano/a
- g. Spanish
- h. Other _____

25. Which of these groups do you think other New Mexicans of Spanish-speaking descent would think that you belong to?

- a. Chicano/a
- b. Hispanic
- c. Latino/a
- d. Mexican
- e. Mexican American
- f. Nuevomexicano/a
- g. Spanish
- h. Other _____

26. Which of these groups do you think your **mother** would identify with?

- a. Chicano/a
- b. Hispanic
- c. Latino/a
- d. Mexican
- e. Mexican American
- f. Nuevomexicano/a
- g. Spanish
- h. Other _____

27. Which of these groups do you think your **father** would identify with?

- a. Chicano/a
- b. Hispanic
- c. Latino/a
- d. Mexican
- e. Mexican American
- f. Nuevomexicano/a
- g. Spanish
- h. Other _____

28. (if yes to #19) Which of these groups do you think your **spouse** would identify with?

- a. Chicano/a
- b. Hispanic
- c. Latino/a
- d. Mexican
- e. Mexican American
- f. Nuevomexicano/a
- g. Spanish
- h. Other _____

29. Which of the other groups on the list is most similar to your first choice?

- a. Chicano/a
- b. Hispanic
- c. Latino/a
- d. Mexican
- e. Mexican American
- f. Nuevomexicano/a
- g. Spanish
- h. Other _____

30. Which of the other groups you identified is most different from your first choice?

- a. Chicano/a
- b. Hispanic
- c. Latino/a
- d. Mexican
- e. Mexican American
- f. Nuevomexicano/a
- g. Spanish
- h. Other _____

31. Please describe how the members of _____ (insert name of group from the list named as most different from subject's; answer to #30) tend to differ from _____ (insert name of group from the list that subject most identified with; answer to #24) in these features:

- a. Skin color
 - 1. same
 - 2. different. How? _____
 - 3. don't know
 - 4. refuse
- b. Hair
 - 1. same

2. different. How? _____
3. don't know
4. refuse

c. Face

1. same
2. different. How? _____
3. don't know
4. refuse

d. Other physical difference

1. What feature? _____ Different how? _____
2. What feature? _____ Different how? _____
3. don't know
4. refuse

e. Amount of Spanish use

1. same
2. different. How? _____
3. don't know
4. refuse

f. Accent when speaking English

1. same
2. different. How? _____
3. don't know
4. refuse

g. Accent when speaking Spanish

1. same
2. different. How? _____
3. don't know
4. refuse

h. Other language difference

1. What feature? _____ Different how? _____
2. What feature? _____ Different how? _____
3. don't know
4. refuse

i. Food

1. same
2. different. How? _____
3. don't know
4. refuse

j. Clothing

1. same
2. different. How? _____
3. don't know
4. refuse

k. Make-up

1. same
2. different. How? _____
3. don't know
4. refuse

l. Other cultural difference

1. What feature? _____ Different how? _____
2. What feature? _____ Different how? _____
3. don't know
4. refuse

32. Between the members of the group you chose from the list and those of the most different group from yours on the list, does either one:

a. Experience more discrimination?

1. yes, my group
2. yes, other group
3. neither
4. don't know
5. refuse

b. Have more wealth?

1. yes, my group
2. yes, other group
3. neither
4. don't know
5. refuse

c. Have more political influence?

1. yes, my group
2. yes, other group
3. neither
4. don't know
5. refuse

d. Have more education?

1. yes, my group
2. yes, other group

- 3. neither
- 4. don't know
- 5. refuse

33. What religion did your parents raise you?

34. What is your current religion?

35. Have you

a. (*if female*) Had a quinceñera?

- 1. Yes
- 2. No
- 3. Don't know
- 4. No response

b. Participated in a pilgrimage to Chimayó?

- 1. Yes
- 2. No
- 3. Don't know
- 4. No response

c. Attended or taken part in the dance of the Matachines?

- 1. Yes
- 2. No
- 3. Don't know
- 4. No response

d. Participated in Las Posadas festivities?

- 1. Yes
- 2. No
- 3. Don't know
- 4. No response

36. Do you have any Jewish ancestors?

- a. Yes
- b. No
- c. Don't know
- d. No response

37. On a scale of 0% to 100%, with 0% being no European ancestry and 100% being pure European, what percentage of European ancestry do you think you have?

38. Of your European ancestry, what percentage of Spanish ancestry do you think you have, with 0% being no Spanish ancestry and 100% being pure Spanish ancestry?

39. On a scale of 0% to 100%, with 0% being no Native American/indigenous ancestry and 100% being pure Native American/indigenous, what percentage of Native American/indigenous ancestry do you think you have?

40. (if 37+39 doesn't add to 100%) What do you think makes up the rest of your ancestry?

41. We've asked about your ancestors, and now we'd also like to ask about your appearance. For these features, please tell us how you appear on a scale from completely European to completely Native Americans/indigenous:

a. Skin color

b. Hair

c. Face

d. Other physical feature: _____

42. The 2000 U.S. Census used the following categories for race. Which of these apply to you?

- a. American Indian or Alaska Native
- b. Asian
- c. White
- d. Black or African American
- e. Native Hawaiian or other Pacific Islander
- f. Some other race _____

43. Which of these racial categories do you think most New Mexicans would use to describe you?

- a. American Indian or Alaska Native
- b. Asian

- c. White
- d. Black or African American
- e. Native Hawaiian or other Pacific Islander
- f. Some other race _____

44. When you were growing up, were you expected to finish high school?

45. When you were growing up, were you expected to go to college?

46. What is **your** highest completed level of education?

- a. Some high school or less
- b. High school graduate/GED
- c. Some college or technical/vocational school/Associates degree
- d. College graduate (4-year college degree)
- e. Some postgraduate courses/Advanced or Professional degree
- f. unknown

47. Are you still in school? _____

48. What is your **mother's** highest completed level of education?

- a. Some high school or less
- b. High school graduate/GED
- c. Some college or technical/vocational school/Associates degree
- d. College graduate (4-year college degree)
- e. Some postgraduate courses/Advanced or Professional degree
- f. unknown

49. What is your **father's** highest completed level of education?

- a. Some high school or less
- b. High school graduate/GED
- c. Some college or technical/vocational school/Associates degree
- d. College graduate (4-year college degree)
- e. Some postgraduate courses/Advanced or Professional degree
- f. unknown

50. What are your **mother's parents'** highest completed levels of education?

A. Grandmother:

- 1. Some high school or less
- 2. High school graduate/GED
- 3. Some college or technical/vocational school/Associates degree
- 4. College graduate (4-year college degree)
- 5. Some postgraduate courses/Advanced or Professional degree
- 6. unknown

B. Grandfather:

1. Some high school or less
2. High school graduate/GED
3. Some college or technical/vocational school/Associates degree
4. College graduate (4-year college degree)
5. Some postgraduate courses/Advanced or Professional degree
6. unknown

51. What are your **father's parents'** highest completed levels of education?

a. Grandmother:

1. Some high school or less
2. High school graduate/GED
3. Some college or technical/vocational school/Associates degree
4. College graduate (4-year college degree)
5. Some postgraduate courses/Advanced or Professional degree
6. unknown

B. Grandfather:

1. Some high school or less
2. High school graduate/GED
3. Some college or technical/vocational school/Associates degree
4. College graduate (4-year college degree)
5. Some postgraduate courses/Advanced or Professional degree
6. unknown

52. What is **your** current occupation?

(If student) What occupation do you expect to have after finishing school?

53. What is/was your **mother's** occupation?

54. What is/was your **father's** occupation?

55. What were/are your **mother's parents'** occupations?

a. Grandmother _____

b. Grandfather _____

56. What were/are your **father's parents'** occupations?

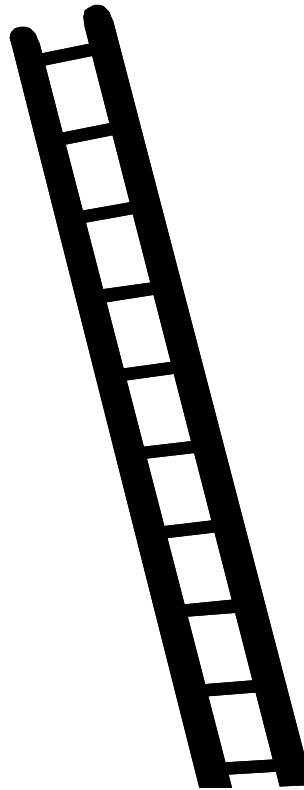
a. Grandmother _____

b. Grandfather _____

57. *Think of this ladder as representing where people stand in New Mexico. At the top of the ladder are the people who are the best off- those who have the most money, the most education and the most-respected jobs. At the bottom are the people who are the worst off- who have the least money, least education and the least-respected jobs or no job. The higher up you are on this ladder, the closer you are to the people at the very top; the lower you are, the closer you are to the people at the very bottom.*

Where would you place yourself on this ladder?

“Please place a large “X” on the rung where you think you stand at this time in your life, relative to other people in New Mexico.”



Rung # from bottom: _____

58. Choose all of the following that describe your current daily activities and/or responsibilities:

- a. Working full time
- b. Working part-time
- c. Full-time student
- d. Unemployed or laid off
- e. Looking for work
- f. Keeping house or raising children full-time
- g. Retired

59. How much did you earn, before taxes and deductions, during the past 12 months?

- a. Less than \$5,000
- b. \$5,000 through \$11,999
- c. \$12,000 through \$15,999
- d. \$16,000 through \$24,999
- e. \$25,000 through \$34,999
- f. \$35,000 through \$49,999
- g. \$50,000 through \$74,999
- h. \$75,000 through \$99,999
- i. \$100,000 and greater
- j. Don't know
- k. No response

60. Does one or both of your parents still claim you as a dependent on their taxes?

- a. Yes
- b. No
- c. Don't know
- d. No response

For questions 61-68, subject should respond for family household that claims subject if response was "Yes" to question 60. If response was "No", subject should respond for current household.

61. How many people are currently living in your household, including yourself? *Your parents' number of family members in 2009-2010. Include in your parents' household: (1) your parents and yourself, even if you don't live with your parents, (2) your parents' other children if your parents will provide more than half of their support between July 1, 2009, and June 30, 2010, or and (3) other people only if they live with your parents, your parents provide more than half of their support and your parents will continue to provide more than half of their support between July 1, 2009, and June 30, 2010.*

- a. _____ Number of people
- b. _____ Of these people, how many are children?
- c. _____ Of these people, how many are adults?
- d. _____ Of the adults, how many bring income into the household?

62. Which best describes the building in which you/your family lives? (Include all apartments, flats, etc., even if vacant.)

- a. A mobile home
- b. A house detached from any other house
- c. A house attached to one or more houses
- d. A building with 2 apartments
- e. A building with 3 or 4 apartments
- f. A building with 5 or more apartments
- g. Boat, RV, van, etc.

63. Is your/your family's residence:
- a. Owned or being bought by you (or someone in the household)?
 - b. Rented for money?
 - c. Other (specify)_____
64. Do you or your family own land?
- a. Yes
 - b. No
 - c. Don't know
 - d. No response
65. (If household size > 1) Which of these categories best describes your total combined family income for the past 12 months? This should include income (before taxes) from all sources, wages, rent from properties, social security, disability and/or veteran's benefits, unemployment benefits, workman's compensation, help from relatives (including child payments and alimony), etc.
- a. Less than \$5,000
 - b. \$5,000 through \$11,999
 - c. \$12,000 through \$15,999
 - d. \$16,000 through \$24,999
 - e. \$25,000 through \$34,999
 - f. \$35,000 through \$49,999
 - g. \$50,000 through \$74,999
 - h. \$75,000 through \$99,999
 - i. \$100,000 and greater
 - j. Don't know
 - k. No response
66. Beyond what your employer provides, do you have any financial investments?
- a. Yes
 - b. No
 - c. Don't know
 - d. No response
67. Do you have at least one car?
- a. Yes (Make:_____ Model: _____ Year: _____ *If subject has more than one car, ask to describe primary car he/she drives*)
 - b. No
 - c. Don't know
 - d. No response
68. Do you own a computer?
- a. Yes (#PC desktops:___#Mac desktops:___#PC laptops:___ #Mac laptops:___)
 - b. No
 - c. Don't know

d. No response

69. Choose one:

- a. I speak Spanish better than I do English
- b. I speak Spanish and English equally well
- c. I speak English better than I do Spanish
- d. I do not speak Spanish

70. Choose one:

- a. My mother does not speak English
- b. My mother speaks Spanish better than English
- c. My mother speaks Spanish and English equally well
- d. My mother speaks English better than Spanish
- e. My mother does not speak Spanish

71. Choose one:

- a. My father does not speak English
- b. My father speaks Spanish better than English
- c. My father speaks Spanish and English equally well
- d. My father speaks English better than Spanish
- e. My father does not speak Spanish

72. What language did you speak in your household growing up?

73. How many full siblings do you have?

74. At what store/s do you do the most of your grocery shopping?

75. How often do you listen to English-speaking radio stations?

- a. Never
- b. Occasionally
- c. Sometimes
- d. Often

76. How often do you listen to Spanish-speaking radio stations?

- a. Never
- b. Occasionally
- c. Sometimes
- d. Often

77. What radio station/s do you listen to most?

78. How often do you watch television and movies in English?

- a. Never
- b. Occasionally
- c. Sometimes
- d. Often

79. How often do you watch television and movies in Spanish?

- a. Never
- b. Occasionally
- c. Sometimes
- d. Often

80. What television station/s do you watch most?

81. What sport do you and/or your family members enjoy watching most?

82. Which are you more likely to eat with a meal made at home?

- a. Rice
- b. Potatoes
- c. Both equally
- d. Neither

83. Which are you more likely to eat with a meal made at home?

- a. Corn tortillas
- b. Flour tortillas
- c. Both equally
- d. Neither

Section II. Medical History

For questions #84-90, I am going to ask about your family history of several diseases. Please tell me whether you, your parents, or close relatives have/had any of these:

84. Cancer

- A. You: Yes* No Don't know *What type? _____
- B. Mother: Yes* No Don't know *What type? _____
- C. Father: Yes* No Don't know *What type? _____
- D. Other relatives:
 Who: _____ What type? _____

85. Diabetes

- A. You: Yes* No Don't know *What type? _____
- B. Mother: Yes* No Don't know *What type? _____
- C. Father: Yes* No Don't know *What type? _____

D. Other relatives:
Who: _____ What type? _____

86. Hypertension (high blood pressure)

A. You: Yes* No Don't know *What type? _____
B. Mother: Yes* No Don't know *What type? _____
C. Father: Yes* No Don't know *What type? _____
D. Other relatives:
Who: _____ What type? _____

87. Heart Attack

A. You: Yes* No Don't know *What type? _____
B. Mother: Yes* No Don't know *What type? _____
C. Father: Yes* No Don't know *What type? _____
D. Other relatives:
Who: _____ What type? _____

88. Gall Bladder disease

A. You: Yes* No Don't know *What type? _____
B. Mother: Yes* No Don't know *What type? _____
C. Father: Yes* No Don't know *What type? _____
D. Other relatives:
Who: _____ What type? _____

89. Oculopharyngeal Muscular dystrophy (OPMD)

A. You: Yes* No Don't know *What type? _____
B. Mother: Yes* No Don't know *What type? _____
C. Father: Yes* No Don't know *What type? _____
D. Other relatives:
Who: _____ What type? _____

90. Cavernous angioma/cerebral cavernous malformation/CCM

A. You: Yes* No Don't know *What type? _____
B. Mother: Yes* No Don't know *What type? _____
C. Father: Yes* No Don't know *What type? _____
D. Other relatives:
Who: _____ What type? _____

91. Do you smoke cigarettes? Yes No

92. Do you use any other form of tobacco (pipe/cigars/chewing)? Yes No

93. (If yes to either 91 or 92) What is your **best estimate** of the number of days you smoked part or all of a cigarette or used another tobacco product during the past 30 days?

a. 1 or 2 days

- b. 3 to 5 days
- c. 6 to 9 days
- d. 10 to 19 days
- e. 20 to 29 days
- f. All 30 days

94. (If yes to 91) On the days you smoked cigarettes during the past 30 days, how many cigarettes did you smoke per day, on average?

- a. Less than one cigarette per day/ 1 cigarette per day
- b. Less than half a pack a day (2 to 5 cigarettes per day)
- c. 6 to 15 cigarettes per day (about ½ pack)
- d. 16 to 25 cigarettes per day (about 1 pack)
- e. More than a pack a day

95. (If yes to 92) On the days that you used other forms of tobacco, how much?

96. (If yes to 91 or 92) How old were you when you first started using tobacco?

AGE: _____

97. Did you used to smoke cigarettes? Yes No

98. Did you used to use any other form of tobacco? Yes No

99. (If yes to 97 or 98) How many days per month did you smoke cigarettes or use tobacco?

- a. 1 or 2 days
- b. 3 to 5 days
- c. 6 to 9 days
- d. 10 to 19 days
- e. 20 to 29 days
- f. All 30 days

100. (If yes to 97) On the days that you smoked cigarettes, how many did you smoke per day, on average?

- a. Less than one cigarette per day/ 1 cigarette per day
- b. Less than half a pack a day (2 to 5 cigarettes per day)
- c. 6 to 15 cigarettes per day (about ½ pack)
- d. 16 to 25 cigarettes per day (about 1 pack)
- e. More than a pack a day

101. (If yes to 98) On the days that you used other forms of tobacco, how much?

102. (If yes to 97 or 98) For how many years did you smoke or use tobacco? ____

103. Do you drink alcohol? _____

104. (If yes to 103) On average, on how many days per week do you drink alcohol?

105. (If yes to 103) On days that you do drink, about how many drinks do you have, on average? _____

106. How often do you see a doctor?

107. For what reason/s would your parents have taken you to the doctor growing up?

- a. Regular checkup/exam
- b. Feeling sick
- c. Emergency (injury or severe illness)
- d. Treatment for condition doctor discovered earlier
- e. Other

108. Do you have health insurance? _____
(If student or under 25) Are you on your parents' health insurance plan? _____

109. Which of the following best describes **your** current health status?

- a. excellent
- b. good
- c. fair
- d. poor

110. Which of the following best describes your **mother's** current health status?

- a. excellent
- b. good
- c. fair
- d. poor
- e. N/A (not living or unknown)

111. Which of the following best describes your **father's** current health status?

- a. excellent
- b. good
- c. fair
- d. poor
- e. N/A (not living or unknown)

112. How often do you go to the dentist?

- a. At least once a year
- b. Every 2 years
- c. Less often than every 2 years
- d. Whenever needed - no regular schedule
- e. Other

113. What was the main reason for your last visit for dental care?

- a. Went in for checkup/exam/cleaning
- b. Something wrong/hurting/bothering
- c. Treatment for condition dentist discovered earlier
- d. Check/adjust appliance/orthodontia
- e. Other

114. What would you do if you had dental pain? _____

115. How would you describe the condition of your teeth and gums? Would you say:

a. excellent

c. fair

b. good

d. poor

These questions are about how you feel and how things have been with you. For each question, please give the one answer that comes closest to the way you have been feeling:

0. never

2. sometimes

1. occasionally

3. often

116. In the last month, how often have you felt that you were unable to control the important things in your life?

0 1 2 3

117. In the last month, how often have you felt nervous and “stressed”?
0 1 2 3
118. In the last month, how often have you felt that you were effectively coping with irritating life hassles?
0 1 2 3
119. In the last month, how often have you been angered because of things that happened that were outside of your control?
0 1 2 3
120. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?
0 1 2 3 4

The next set of questions is about how you are treated by other people. We’re coming back to the groups of NMS that we talked about earlier, and asking about discrimination you may have experienced as a member of your group. The answers are the same as above; please give the one that comes closest to how often you receive the type of treatment described:

121. As a _____ (*insert self-identified category from #16*), how often are you treated with less courtesy than other people?
0 1 2 3
122. As a _____ (*insert self-identified category from #16*), how often do you receive poorer service than other people in restaurants or stores?
0 1 2 3
123. As a _____ (*insert self-identified category from #16*), how often do people treat you as if they are better than you?
0 1 2 3
124. As a _____ (*insert self-identified category from #16*), how often do people act as if they are smarter than you?
0 1 2 3
125. As a _____ (*insert self-identified category from #16*), how often do you think that discrimination makes it more difficult for you to accomplish your life goals?
0 1 2 3
126. How often do you think that discrimination makes it more difficult for other _____ (*insert self-identified category from #16*) to accomplish their life goals?

- 0 1 2 3

Section III. Photograph responses

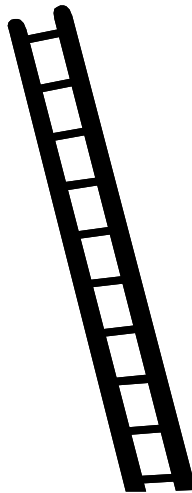
I am now going to show you some photographs of other participants in this study and ask you two questions about the person in each photograph.

127. Of the ethnicity terms you listed at the outset (remind them), which term would you use to describe this person?

128. Which of these terms would you use?

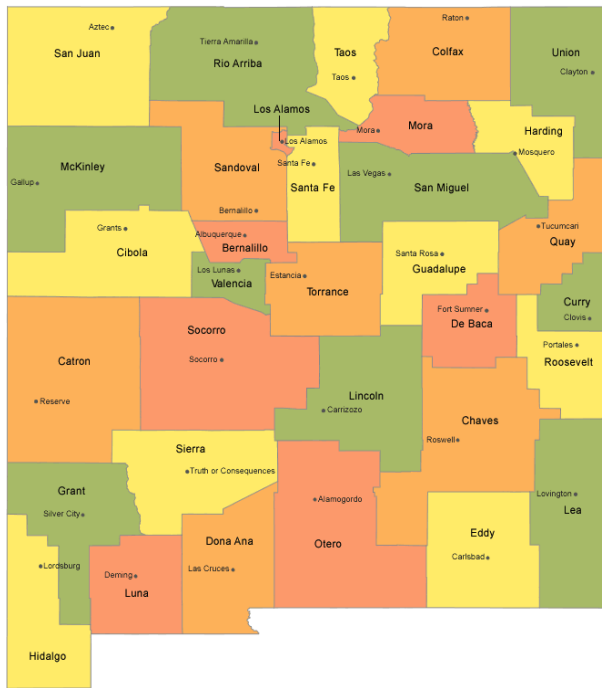
- a. Chicano/a
- b. Hispanic
- c. Latino/a
- d. Mexican
- e. Mexican American
- f. Nuevomexicano/a
- g. Spanish
- h. Other _____

129. Earlier, I asked you where you fall on a ladder relative to other people in New Mexico. Where would you place this person on this ladder?
Please place an "X" on the rung where you think this person stands at this time in his/her life, relative to other people in New Mexico.



Rung # from bottom: _____

Map I. New Mexico counties



Map II. Albuquerque areas



Section IV. Phenotypic Information

General health indicators

Blood pressure 1 (at survey start):
Blood pressure 2 (mid-survey):
Blood pressure 3 (end of survey):
Height:
Weight:
Waist circumference:
Hip circumference:
Body fat percentage:

Check box upon completion:

Facial photographs

DNA sample

Blood spot

Skin reflectance measurements

Forearm	Hand	Face

Appendix 2: Phenotypic data collection protocol

Blood pressure

Subject sits comfortably, with feet flat on the floor and left arm on a table such that upper arm is at same level as heart. The blood pressure cuff is wrapped around the subject's upper left arm, ½ - 1 inch above the elbow, with sleeve shifted above the cuff. The velcro attachment secures the cuff in place. Researcher presses ON/OFF button on the blood pressure monitor to turn on the machine, then presses the START button to take the reading. The monitor completes the reading and automatically displays the reading when complete. Systolic and diastolic pressures are then recorded on the interview form.

Height

Subject is asked to remove footwear. Stadiometer is positioned vertically against a wall. Spoon is lifted and subject stands facing away from the wall with head directly underneath the spoon. Stadiometer is adjusted such that the spoon rests, but does not press, on the tallest point of the subject's head. Height to the nearest half centimeter is recorded on the interview form.

Weight and body fat percentage

Body composition monitor is placed on a flat, hard surface. Researcher presses ON/OFF button to turn machine on, then presses GUEST/MEMORY button to enter a new subject. ▲UP and ▼DOWN arrow buttons are used to enter the subject's age, height (in centimeters) and sex. After each piece of information is entered, the SET button is pressed. Subject is asked to remove footwear and to stand with heels positioned on heel electrodes and holding onto the display unit with both hands using the grip electrodes. The monitor first displays the subject's weight in kilograms, which blinks twice when it stabilizes. After the weight measurement is taken, the monitor will display "START" and begin to calculate body composition. At this point, the subject should extend arms straight out in front at a 90° angle to the body and hold them there. When the calculation is completed, the subject's weight and body fat percentage are displayed on the monitor. Both are recorded onto the interview form.

Waist and hip circumference

For both measurements, the researcher stands to the side of the subject. Subject is asked to remove any extra layers of bulky clothing, but circumference is measured over top of clothing. For waist measurement, the subject's hip bone (top of iliac crest) is located and the tape measure placed around the abdomen just above the level of this bone. For hip measurement, tape measure is placed around the buttocks at the level of maximum posterior extension of the buttocks. For both measurements, the tape is placed snugly, but not so that it presses into the skin. Measurement in centimeters, to the nearest centimeter, is recorded onto the interview form.

Skin reflectance

Spectrophotometer is turned on using the ON/OFF switch. Scrolling device on top of the unit is used to scroll to "CALIBRATION" and select this option. Initial calibration is

required each time the unit is turned off and then on again. Scrolling device then used to scroll to “ZERO” and select it. Unit is then held upright, such that the opening faces open space, and the measurement button pressed. Light will flash three times for the calibration. Scrolling device then used to scroll to “WHITE” and select it. Unit is placed so that opening faces the white circle on the plate platform. The measurement button is pressed, and the light will again flash three times for calibration. Unit is then calibrated and ready to take measurements. The first measurement is taken on the inner side of the subject’s upper left arm. Opening is placed over the skin and measurement button pressed. The light will flash five times and then the measurements will be displayed on the screen. All measurements are recorded onto the table on the interview form. For the second measurement, the subject is asked to place left hand on the table with palm side down, with the measurement taken of the skin on the top of the hand. Measurement and recording follow same protocol as for the upper inner arm. The third measurement is done on the subject’s face, just underneath the left cheekbone on the fleshy part of the cheek. Measurement and recording again follow the same protocol as for the upper inner arm.

Dried blood spot sample collection

The participant’s finger is cleaned with isopropyl alcohol and then pricked with a sterile, disposable lancet of the type commonly used by diabetics to monitor blood glucose. These lancets are designed to deliver a controlled, uniform puncture that stimulates sufficient capillary blood flow with minimal injury. The first drop of blood is wiped away with gauze, and subsequent blood drops will be applied to filter paper (Whatman #903). A drop of blood is allowed to form on the finger and then absorbed into the filter paper without any direct contact between the finger and paper. We collect approximately 50 μ L of whole blood.

The samples are allowed to dry (from four hours to overnight), at which point they are stacked and stored with desiccant in re-sealable plastic bags or plastic containers. The desiccant has a colored humidity indicator to show when it should be replaced. Samples are packed with desiccant and frozen in a reliable laboratory-grade freezer to ensure sample integrity.

Samples from normal, healthy individuals (such as the participants in this study) are considered diagnostic specimens and are labeled as such for shipment to laboratories for analysis. Filter papers stored with desiccant in plastic bags and sealed in a secondary container (e.g., bond envelope, cardboard box) can be shipped domestically without special packaging or permitting.

Photographs*

Facial

If subject is wearing glasses, subject is asked to remove them. Subject may be asked to pull hair back from face. Subject is asked to hold centimeter scale level with face and facing the camera. Subject’s head should be positioned by researcher so that it is in Frankfort Horizontal plane (so that bottom of eye orbit is in line horizontally with auditory meatus). Researcher stands approximately three feet from subject at eye level. Photographs will be taken of various angles of the face.

* All photographs are kept linked to the subject’s participant ID.

Appendix 3: Genotypic sample collections protocol

DNA Mouthwash Sample:

First, 10 mL of Scope is poured into a 50 mL tube. Subject pours mouthwash from the tube into mouth and swishes mouthwash in mouth for one full minute. When one minute is complete, subject then spits mouthwash back into the tube. Top is screwed onto tube. Tube is labeled with participant's ID#. Tube can be stored in -20 freezer until DNA extraction is performed.

Appendix 4: Consent Forms

The University of New Mexico Main Campus IRB Consent to Participate in Research

A Long-term Study of Sociocultural, Genetic, and Phenotypic Variation in New Mexico Hispanics

Introduction

You are being asked to participate in a long-term research study that is being done by Keith Hunley, who is the Principal Investigator, and Heather Edgar, from the Department of Anthropology.

New Mexico has experienced a rich and complex history of early European colonization followed by more recent migrations from Latin America. This complex history has resulted in the mixing of diverse peoples, languages, and cultural traditions. Despite this long history of mixture many New Mexicans today, both Hispanic and non-Hispanic alike, think there are still different groups in New Mexico, and that the groups differ biologically and culturally. The goal of the proposed research is to determine if this is true, and to explore the biological and social implications of these differences.

When talking about biological implications, we mean that there may be genetic differences between the ethnic groups that are medically important. For example, some studies suggest that some rare diseases are more common in New Mexicans of Spanish descent than in more recent immigrants from Mexico. Our study will use body measurements, like height and weight, as well as DNA data, to measure biological differences between the groups.

When talking about social implications, we mean that there may be economic differences between the groups that affect the wellbeing of their members, for example, access to health care, employment, and education. If this is true, any of the medical or other biological difference that might exist between groups may actually be the result of social and economic differences between them, and not due to genetic differences. Our study will collect cultural and economic data that will allow us to determine whether there are significant economic differences between ethnic groups.

The study will collect genetic, economic, and physical data from 500 people from New Mexico. The research is funded by UNM and the National Science Foundation.

This form will explain the research study, and will also explain the possible risks as well as the possible benefits to you. If you have any questions, please ask one of the study investigators.

What will happen if I decide to participate?

Initial data collection.

If you agree to participate in data collection today, the following things will happen:

You will be asked to provide answers to a series of questions about:

1. Your age, place of birth, and place of birth of family members
2. Your ethnicity and the ethnicity of family members
3. Your education and the education of family members
4. Your income level and the income level of family members
5. Family health history
6. The ethnicities of other people whose faces you will be shown.

You may ask questions about groups and ethnicity at any time during this survey.

We will then measure your blood pressure, height, weight, body fat percentage, and skin color. The measurements are non-invasive and will take about 15 minutes to collect.

We will then collect a blood spot sample. Your finger will be cleaned, then pricked with a sterile, disposable lancet of the type commonly used by diabetics to monitor blood glucose. We will collect five drops of your blood on a piece of filter paper. This sample will be used to look at proteins in your blood that provide information about your risk of heart disease and diabetes and about your history of immune function.

If you consent, we will take digital photographs of your face. We will use these photographs to make measurements of your face. We will compare the facial measurements of different ethnic groups to see if there are differences between the groups. Only the researchers involved in this study will see these photographs, and they will be destroyed within five years from today unless you choose to participate in our longitudinal project. You may participate in the rest of this study even if you do not consent to this photography.

Also if you consent, your image will be shown to a subset of other research participants to learn about how people categorize each other into groups, and whether face shapes contribute to this categorization. Other participants will only see your face, and will not be provided with any other information about you. Only the investigators and a subset of other research subjects will see your image. The image will be destroyed within five years from today unless you choose to participate in our longitudinal project. You may participate in the rest of this study even if you do not consent to the photograph being shown to other study participants.

You will be asked for a mouthwash sample that we will use to see how much of your DNA comes from European ancestors and how much comes from Native American ancestors. The DNA tests will tell us about your combined maternal and paternal ancestry your mother's ancestry, and, if you are a male, your father's ancestry. It is important to stress that historical information indicates that we are very unlikely to find that your genetic ancestry is purely European or purely Native American. Previous historical

information and genetic analyses indicates that many New Mexicans who trace their ancestry to Spanish ancestors also have Native American ancestors. In fact, based on our research, the percent European ancestry in New Mexicans of Spanish descent ranges from about 50-95%. The remaining 5-50% is predominantly Native American. There is also evidence of African ancestry in some New Mexican Hispanics. It is also important to keep in mind that developing technology has variation in reliability. The results of the genetic tests, if you choose to receive them, will give you some idea about your ancestry, however, the exact percentage cannot be guaranteed.

If the tests identify Native American ancestry in your DNA, we will be unable to tell you anything about tribal affiliations. In addition, the results will provide no health-related information, such as your risk for any diseases. We will only collect DNA that provides information about ancestry.

About 5% of the time, the procedure we use to get you DNA out of the mouthwash sample will not work. This occasionally happens with other kinds samples as well, such as dried blood spot samples. If this happens, we will contact you to ask if you are willing to provide another sample. We will only use the personal contact information you provide.

We will be happy to meet with you to discuss your results and their possible meaning in terms of when and how mixtures among European and Native American people may have taken place during you family history.

It is possible that your results will be unexpected and that they will be inconsistent with what you have learned from you family about your ancestors. Again, one possibility for this potential outcome is error caused by the methods we will use. Another possibility is that the DNA results are providing accurate information about the mix of peoples of European and Native American ancestry in the past. We will meet with you as many times as you feel necessary to talk about the results and their meanings, and we will provide you information you can use to get a referral to a qualified counselor (this is information that is provided in the copy of the consent form you will receive) if you wish to discuss the matter further. If you are at all worried by this possibility, we recommend that you do not consent to receive your DNA results. If you choose to receive your results today, you may change your mind at any time in the future, and you may withdraw from the study at any time up until we destroy the consent forms, about five years from today. Whatever you decide today, we recommend that you consult with family members about whether you want to receive your results.

We will supply your DNA test results about your mixed parentage only (not the results specific to your mother or father), and only if you so request. If you decide you want the results today, but change your mind later, you can contact Keith Hunley (email: khunley@unm.edu phone: 277-4524) and say that you do not want your DNA results. You can do this any time before we send your results, which we expect to do sometime between six months and one year from now.

If you choose to receive your DNA results, we will supply you with a document showing the percentage of your DNA that is European and the percentage that is Native American. You will be required to view a short PowerPoint presentation that will be available on-line before you receive your results. This presentation will provide information about relevant New Mexico history, how we compute your DNA results, and how to interpret your results. If you wish, we will meet with you to answer any questions and explain the results and their potential causes in detail.

The samples will be sent to Prevention Genetics in Marshfield, WI and Fluidigm Corporation in San Francisco, CA for DNA analysis. The samples will not be associated with any personal information, and no one at Prevention Genetics will know the names of any participants. The DNA data will be collected within five years after you provide the sample. Unless you choose to participate in our longitudinal project, any remaining DNA sample will be destroyed as soon as the DNA data are collected using protocols approved by the University of New Mexico.

All information collected in the study will be stored in a database on password-protected computers and a password-protected network server. Access to the database is limited to the Principle Investigator and personnel approved by him to conduct research on this project. This signed consent form, answers to the questions, and physical data, including photographs, will be stored in locked file cabinets within the laboratory until they are transferred to this database. The DNA data will be stored in the same database. Only IRB-approved investigators will have access to the password-protected database.

To ensure your privacy, once the data have been stored in the database, and we have provided your genetic ancestry results if you so request, the consent forms will be destroyed. After the consent forms are destroyed, no one will be able to connect any of the data we have collected to you. As is customary protocol in genetic analyses, DNA data will be made available to other researchers once this study is over. This data will contain no personal information about you and will in no way be connectable to you.

After you have participated in this study today, we recommend that you discuss your participation with your relatives and friends, to help decide whether you want to receive your DNA ancestry results.

Continuing-data collection.

If you agree to be re-contacted about participating in future research, we will maintain your postal and email contact information indefinitely in a secure location. We will contact you every 6 months to 5 years to request your participation in continuing research related to the biological and social implications of ethnic variation in New Mexico. If you do not agree to be re-contacted every 6 months to 5 years, you may still participate in data collection today, and we will provide your DNA results of you so request.

If you consent to this part of the research, you are only giving us permission to contact you to request your participation in future studies. At that time, you may agree or decline to participate in any future study you are offered. You may also decide at any time to

withdraw your permission and have your contact information destroyed. We will only contact you using the postal address and email address you provide.

How long will I be in this study?

Today, it will take about 1.5 to 2 hours to complete the survey, provide the physical and photographic data, and collect the DNA and blood spot samples. If you agree to participate in the continuing research, your contact information will be maintained in a secure location indefinitely. You may decide at any time to withdraw your permission and have your contact information destroyed.

What are the risks of being in this study?

It is possible that your results will be unexpected and that they will be inconsistent with your understanding of your family history. This result may cause emotional stress for you and your family members.

There are risks of possible loss of privacy and confidentiality associated with participating in any research study.

Genetic Testing: The risks associated with genetic (DNA) tests are unknown. Genes may be shown at some point in the future to be related to mental illnesses or tendency to addiction. Since in some cases the results of these genetic tests may allow us to predict the risk of getting an illness, we will keep the results confidential (only scientists working on this research project will know the results). There may also be unexpected risks connected with this type of testing. At some time in the future, your genetic information could be used to identify you; however, we have put precautions in place to help reduce this risk. We will take every measure to protect you from the risks of other people finding out about the results of your genetic tests, which include people like insurance companies or future employers.

There are risks of loss of privacy, getting insured, being employed, and stigmatization (treated badly due to your genetic testing results). There are some protections afforded by the Genetic Information Nondiscrimination Act (GINA). For a detailed listing of protections, please read the information sheet that has been printed for you and that you have received with this consent. You can also find an information sheet on The Genetic Information Nondiscrimination Act at http://hsc.unm.edu/som/research/hrrc/docs/GINA_Information_Sheet.pdf.

For more information about risks, ask one of the study investigators.

What are the benefits to being in this study?

If you wish, we will provide your individual DNA results to you. The results will tell you how much of your genetic ancestry is European and how much is Native American. It is also hoped that information gained from this study help us understand the ethnicity in

New Mexico, whether ethnic groups differ biologically and culturally, and the larger biological and social implications of any differences that are identified.

There may be specific benefits to you, depending on which future studies you agree to participate in. These benefits may include information about your genetic ancestry, health information, or payment. The benefits will be described to you each time you are asked whether you want to participate in each future study.

What other choices do I have if I do not want to be in this study?

At any time during the questioning or mouthwash sample collection, or at any time up until the consent forms are destroyed, you may choose to withdraw from the study. You may choose to withdraw your permission to be re-contacted at any time.

How will my information be kept confidential?

We will take measures to protect your privacy and the security of all your personal information, but we cannot guarantee confidentiality of all study data.

Information contained in your study records is used by study staff and, in some cases it will be shared with the sponsor of the study. The University of New Mexico Main Campus IRB, which oversees human subject research, will be permitted to access your records. There may be times when we are required by law to share your information. However, your name will not be used in any published reports about this study.

What are the costs of taking part in this study?

You will not be charged for any study procedures or treatments. The costs of DNA analysis will be covered by the study.

Will I be paid for taking part in this study?

You will not be paid to take part in this today's study. You will not be paid to allow us to recontact you.

How will I know if you learn something new that may change my mind about participating?

You will be informed of any significant new findings that become available during the course of the study, such as changes in the risks or benefits resulting from participating in the research or new alternatives to participation that might change your mind about participating.

Can I stop being in the study once I begin?

Yes. Your participation in this study is completely voluntary. You have the right to choose not to participate or to withdraw your participation at any point in this study without affecting your future health care or other services to which you are entitled. You will be able to withdraw from the study until the consent forms are destroyed. Withdrawing will not adversely affect any course grades or educational opportunities.

Whom can I call with questions or complaints about this study?

If you have any questions, concerns or complaints at any time about the research study, Keith Hunley (phone 505-277-4524), or Heather Edgar (phone 505-277-4415) will be glad to address them. If you would like to speak with someone other than the research team in regards to any complaints you have about the study, you may call the UNM IRB at (505) 272-1129.

Whom can I call with questions about my rights as a research subject?

If you have questions regarding your rights as a research subject, you may call the UNM IRB at (505) 272-1129. The IRB is a group of people from UNM and the community who provide independent oversight of safety and ethical issues related to research involving human subjects. For more information, you may also access the IRB website at <http://hsc.unm.edu/som/research/HRRC/maincampusirbhome.shtml>.

If you wish to receive further counseling about you DNA results, please contact the following referral services or the UNM Institutional Review Board (505) 272-1129.

County	Provider	Number
Bernalillo	AGORA	505-277-3013
	AGORA after hours	800-SUICIDE
Catron	Border Area Mental Health	800-426-0997
	El Refugio	575-538-2125
Chaves	Counseling Associates, Inc.	575-623-1480
Cibola	Cibola Counseling	505-287-7211
Colfax	Tri County Services	575-758-1125
Curry	Mental Health Resources	800-432-2159
De Baca	Mental Health Resources	800-432-2159
Dona Ana	Families and Youth, Inc.	575-522-4004
	Mesilla Valley Hospital	800-877-3500
	Southwest Counseling Center	200-967-1542
Eddy	Carlsbad Mental Health	575-885-8888
Grant	Border Area Mental Health	800-426-0997
Guadalupe	NMBHICBS	505-454-2100
	NMBHICBS after hours	505-425-1084
Harding	NMBHICBS	505-454-2100
	NMBHICBS after hours	505-425-1084
Hidalgo	Border Area Mental Health	800-426-0997
	El Refugio	575-538-2125
Lea	Guidance Center	575-393-6633
	Guidance Center after hours	800-634-3666
Luna	Border Area Mental Health	800-426-0997
	El Refugio	575-538-2125
McKinley	Presbyterian Medical	888-920-6333
Mora	Helping Hands	575-387-2288
Otero	The Counseling Center	575-437-7404
Quay	Mental Health Resources	800-432-2159
Rio Arriba	Ayudantes	505-753-6483
Roosevelt	Mental Health Resources	800-432-2159
San Juan	Presbyterian Medical	505-325-1906
San Miguel	NMBHICBS	505-454-2100
	Aydantes Las Vegas	505-425-1084
Sandoval	Cochiti PHS	505-988-9821
Santa Fe	Presbyterian Medical	505-820-6333
Sierra	Sierra Vista Hospital	575-894-2111
Socorro	Socorro Mental Health	575-835-2444
Taos	Tri County Services	575-758-1125
Union	Tri County Services	575-758-1125
Valencia	Valencia Counseling	505-865-3359

Consent for Initial Data Collection

Participant ID#: _____

You are making a decision whether to participate in this study. Your signature below indicates that you read the information provided (or the information was read to you). By signing this consent form, you are not waiving any of your legal rights as a research subject.

A copy of this consent form will be provided to you.

I have had an opportunity to ask questions and all questions have been answered to my satisfaction.

When you check a box below, you are providing consent for that part of the study. Please check the boxes that you consent to and write your initials in the space provided.

- _____ You may use my data for future research.
- _____ You may not use my data for future research.

Additional questions

Would you like to receive your DNA results?
Please check the appropriate box and initial on the line next to it.

- _____ I wish to receive the results of my DNA analysis.
- _____ I do not wish to receive the results of my DNA analysis.

If you wish to receive the results, they will be sent to the email and/or postal address you provide within five years from today.

Email address: _____

Name and postal address (your permanent residence):

Can we use a photograph of your face for this research?

- _____ You may take a photograph of my face and use it for this research.
- _____ You may not take a photograph of my face for this research.

Can we show your photograph to other research participants to learn about how people categorize each other, and whether face shapes contribute to this categorization?

- _____ You may show my photograph to other research participants.
- _____ You may not show my photograph to other research participants.
- _____ You may re-contact me in the future to participate in future studies.

You are making a decision whether to participate in this study. Your signature below indicates that you read the information provided (or the information was read to you). By signing this consent form, you are not waiving any of your legal rights as a research subject.

A copy of this consent form will be provided to you.

I have had an opportunity to ask questions and all questions have been answered to my satisfaction. By signing this consent form, I agree to participate in this study, and allow you to re-contact me to offer me the opportunity to participate in future studies.

_____/_____
Name of Adult Subject (type or print) Signature of Adult Subject Date

I have explained the research to the subject and answered all of his/her questions. I believe that he/she understands the information in this form and freely consents to participate.

_____/_____
Name of Investigator/ Signature of Investigator/
Date Research Team Member
Research Team Member Research Team Member

Email address: _____

Name and postal address (your permanent residence):
