Race, Ancestry, and Genetics Survey

Preamble

The purpose of this survey is to learn what researchers and healthcare providers in genetics know and think about the relationships among race, ancestry, and genetics. We are also interested in what definition(s) or conception(s) of race are used. We understand that the term race has many possible definitions, varies among contexts and is highly influenced by an individual's personal experiences and identities (e.g., social, political, etc.). For the purposes of this survey, unless otherwise stated, we have used the U.S. Office of Management and Budget (OMB) racial and ethnic categories; this usage may differ from how one uses racial or ethnic descriptions to identify themselves, their friends, family, and others. This will allow us to compare our results to existing empirical data that uses these categories. These categories are the basis of many popular perceptions of race, a topic on which we seek information. Throughout the survey, we provide ample opportunity to comment on the usage of these terms, as they may vary depending on the circumstances defined by the question. We encourage you to use the comment boxes at the bottom of each section of the survey to help us better understand your responses and to provide feedback on the survey.

Race, Ancestry, and Genetics Survey

Instructions

The survey is divided into four sections of statements. For each statement, we ask you to indicate your degree of agreement or disagreement on a 5-point scale (1=strongly agree; 5=strongly disagree). If you so desire, you may comment on any statement or response in a corresponding comment box. We also ask that you complete a final section on professional and demographic information. This survey takes approximately 10 minutes to complete.

Race, Ancestry, and Genetics Survey

Statements about science

1. Please indicate the extent to which you agree with each of the following statements about science:

	1 strongly agree	2	3	4	5 strongly disagree
The human population may be subdivided into biological races.	○	○	○	○	○
Racial categories are determined by biology.	○	○	○	○	○
There are discrete biological boundaries among races.	○	○	○	○	○
Continental population categories—Africans, Asians, Europeans—are the same as standard anthropological racial classifications.	○	○	○	○	○
Continental population categories—Africans, Asians, Europeans—are useful for examining genetic relationships (i.e., relatedness) among people.	○	○	○	○	○
Race—as defined by the U.S. Office of Management and Budget (i.e., census categories)—is a useful proxy for ancestry.	○	○	○	○	○
Genetic ancestry—inferred from genetic markers—rather than race, is a better proxy for genetic relationships among sub-Saharan Africans, Asians, Europeans, Pacific Islanders, and Native Americans.	○	○	○	○	○
The distributions of physical traits overlap among races.	○	○	○	○	○
Genetic differences between racial groups explain most biological differences between individuals of different races.	○	○	○	○	○
Genetic differences between racial groups explain most behavioral differences between individuals of different races.	○	○	○	○	○

Comments

[ ]

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Statements about science

2. Please indicate the extent to which you agree with each of the following statements about science:

	1 strongly agree	2	3	4	5 strongly disagree
Most genetics professionals believe that humans may be subdivided into biological races.	◯	◯	◯	◯	◯
Most genetics professionals believe that categorizing human groups by race has no biological basis.	◯	◯	◯	◯	◯
Most genetics professionals believe that categorizing human groups by race has no genetic basis.	◯	◯	◯	◯	◯
The use of the term 'race' to describe human groups should be discontinued.	◯	◯	◯	◯	◯
The term 'race', as used to describe human groups, should be replaced by a more appropriate and precise term.	◯	◯	◯	◯	◯
Most genetic variants among sub-Saharan Africans, East Asians, and Western Europeans are shared.	◯	◯	◯	◯	◯
Most common genetic variants (i.e., alleles with a frequency >5%) are shared among sub-Saharan Africans, East Asians, and Western Europeans.	◯	◯	◯	◯	◯
Genetic variation data may be used to cluster racially ascribed people into groups of continental origin.	◯	◯	◯	◯	◯
Self-identified race in the U.S. highly corresponds to genetic inferences of ancestry.	◯	◯	◯	◯	◯

Comments

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Statements about medicine

3. Please indicate the extent to which you agree with each of the following statements about medicine:

	1 strongly agree	2	3	4	5 strongly disagree
Race influences health.	○	○	○	○	○
Race, in so far as it corresponds with genetic ancestry, influences health.	○	○	○	○	○
Genetic differences between races explain health disparities.	○	○	○	○	○
Categorizing individuals by race is important for biomedical research.	○	○	○	○	○
Genetics professionals should understand key concepts about the relationship among race, genetics and health.	○	○	○	○	○
Health professionals should understand key concepts about relationship among race, genetics and health.	○	○	○	○	○
The development of medicines for targeted racial groups is a necessary step toward the achievement of personalized medicine.	○	○	○	○	○
Race should be considered in diagnosing certain conditions or diseases.	○	○	○	○	○
Genetic ancestry should be considered in diagnosing certain conditions or diseases.	○	○	○	○	○
Race should be considered in treating certain conditions or diseases.	○	○	○	○	○
Genetic ancestry should be considered in treating certain conditions or diseases.	○	○	○	○	○

Comments

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Statements about social and societal issues

4. Please indicate the extent to which you agree with each of the following statements about social and societal issues:

	1 strongly agree	2	3	4	5 strongly disagree
Commercial genetic ancestry testing provides a good assessment of a person's ancestry.	○	○	○	○	○
Genetic ancestry testing is purely recreational.	○	○	○	○	○
Genetic ancestry testing does not warrant all the critique it is receiving from the genetics community.	○	○	○	○	○
Genetic ancestry testing is considered by the industry's consumers as purely recreational.	○	○	○	○	○
Consumers value genetic ancestry testing for non-medical reasons.	○	○	○	○	○
Commercial genetic ancestry testing in the U.S. is subject to specific, federal regulation.	○	○	○	○	○
Commercial genetic ancestry testing in the U.S. should be subject to specific, federal regulation.	○	○	○	○	○
Criticisms of genetic ancestry testing are overstated compared to the actual risks and limitations of the tests.	○	○	○	○	○
Genetic ancestry testing should not be used in U.S. criminal investigations.	○	○	○	○	○
Genetic ancestry testing should be used by U.S. law enforcement when evaluating conflicting eyewitness descriptions.	○	○	○	○	○
Genetic ancestry testing should be considered when agencies place children in foster and adoptive families.	○	○	○	○	○
Genetic ancestry testing should be used by universities to verify racial or ethnic identity of applicants.	○	○	○	○	○
Genetic ancestry testing reinforces biological conceptions of race.	○	○	○	○	○
Genetic ancestry testing undermines biological conceptions of race.	○	○	○	○	○

Comments

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5. Please indicate the extent to which you agree with each of the following common statements:

	1 strongly agree	2	3	4	5 strongly disagree
Races don't exist.	◯	◯	◯	◯	◯
Race has no biological basis.	◯	◯	◯	◯	◯
Race is biologically meaningless.	◯	◯	◯	◯	◯
Race has no genetic basis.	◯	◯	◯	◯	◯
Race has no biological influence on health.	◯	◯	◯	◯	◯

Comments

6. Have you ever had a genetic ancestry test?

◯ Yes

◯ No

7. If you have not had a genetic ancestry test, would you ever have a genetic ancestry test?

◯ Yes

◯ Maybe

◯ No

8. Do you use genetic inference of ancestry (or ancestry estimation) in your research?

○ Yes

○ No

○ Don't know

9. Do you work for a company that provides direct-to-consumer ancestry testing?

○ Yes

○ No

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Information about you

10. Please indicate below what approaches and for what purposes you have used genetic ancestry (check all that apply):

☐ Assessing associations between ancestry and a trait or condition

☐ Admixture mapping

☐ Correcting for confounding due to population stratification in candidate variant studies

☐ Correcting for confounding due to population stratification in genome-wide association studies

☐ None of the above

☐ Other purposes and/or approaches (please specify)

[   ]

11. Do you work with U.S. populations?

○ Yes

○ No

○ Don't Know

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Information about you

12. If you work with U.S. populations, please indicate the racial and ethnic population(s) with whom you work (check all that apply):

- [ ] American Indian and Alaska Native
- [ ] Asian
- [ ] Black, African American
- [ ] Hispanic or Latino
- [ ] Native Hawaiian and Other Pacific Islander
- [ ] White
- [ ] Other (please specify)

[ ]

13. Please indicate your profession: (choose the one or two that fit best)

- [ ] Clinical Geneticist
- [ ] Medical Geneticist
- [ ] Human Geneticist
- [ ] Population Geneticist
- [ ] Genetic Epidemiologist
- [ ] Genetic Counselor
- [ ] ELSI Researcher
- [ ] Nurse Practitioner
- [ ] Student or Trainee
- [ ] Other (please specify)

[ ]

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Information about you

14. Please list all of your post-baccalaureate degrees:

15. Please indicate the extent of your work in the following areas:

	All of the time	Most of the time	Sometimes	Rarely	Never
Basic science research	○	○	○	○	○
Clinical genetics research	○	○	○	○	○
Patient care	○	○	○	○	○
ELSI (ethical, legal, social implications) research	○	○	○	○	○

Other (please specify)

16. Which of the following best describes your work environment?

○ Academic

○ Private

○ Government

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Demographics

17. In what country do you live?

○ US (please specify state below)

○ Other (please specify country below)

Please specify state or country:

9

18. In what country do you work? (if different from where you live)

◯ US (please specify state below)

◯ Other (please specify country below)

Please specify state or country:

[   ]

19. Sex

◯ Male

◯ Female

20. Age

[   ]

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Demographics

21. How do you describe your ancestry?

[   ]

22. US respondents only: How do you typically identify yourself on the U.S. census? Are you Hispanic/Latino?

◯ No

◯ Yes

23. US respondents only: How do you typically identify yourself on the U.S. census? "Race": (Please check all that apply)

☐ American Indian or Alaska Native

☐ Asian

☐ Black, African American

☐ Native Hawaiian or Other Pacific Islander

☐ White

☐ Other

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24. Please list any additional questions and/or comments you may have:

[   ]