

ELSI Research Methods Questionnaire

The Center for ELSI Resources and Analysis (CERA) invites you to complete this questionnaire to help us understand the research methodologies used in the study of the ethical, legal, and social implications (ELSI) of genetics and genomics. The anonymized results will inform CERA programming and may be published.

The mission of CERA is to enhance the production, sharing, and use of ELSI research and foster a community of multi-disciplinary scholars focused on high priority ELSI issues. CERA is funded by the National Human Genome Research Institute (NHGRI) and is co-led by the Stanford Center for Biomedical Ethics and the Division of Ethics at Columbia University in partnership with The Hastings Center and the Personal Genetics Education Project at Harvard University.

This questionnaire is anonymous, which means that your responses will not be linked to any individually identifying information such as your name, email address, or IP address. Thank you in advance for your thoughtful responses.

Part 1. Your Scholarship

The first set of questions will ask you to reflect on your research and experience with different research methods.

1. Do you conduct research on the ethical, legal, and/or social implications of genetics and genomics?

☐ Yes

☐ No

1a. You indicated that you do **not** conduct research on the ethical, legal, and/or social implications of genetics and genomics. Please confirm your answer choice or press the back button to revise your response to the last question.

☐ I do not conduct research on the ethical, legal, and/or social implications of genetics and genomics

2. What topic do you primarily work on?

3. **Most** of my scholarship is:

- ☐ Conceptual - Clarifying distinctions, organizing concepts, or making arguments
- ☐ Consensus/Engagement - Eliciting stakeholder perspectives and/or developing shared understandings
- ☐ Empirical/Descriptive - Identifying population characteristics, behaviors, knowledge, and attitudes
- ☐ Empirical/Evaluation Research - Assessing the effectiveness of interventions or programs
- ☐ Empirical/Experimental - Designing and testing novel interventions
- ☐ Legal Research - Analyzing legal materials to support a hypothesis
- ☐ Normative/Prescriptive - Determining what ought to be and whether actions are permissible or obligatory
- ☐ Other, please describe: _____

4. **Most** of my scholarship is:

- ☐ Qualitative
- ☐ Quantitative
- ☐ Mixed methods
- ☐ Not applicable (please explain)

5. Have you ever collected and analyzed empirical data?

☐ Yes

☐ No

5a. Would you consider using empirical methods in your scholarship in the future?

☐ Yes

☐ No

5b. Could you please describe briefly, why not?

6. Are you currently preparing an empirical research project (i.e., wrote an empirical research proposal, planning to collect, and/or analyze data)?

☐ Yes

☐ No

7. Which methods do you currently use? Please select all that apply.

- ☐ Community-based research
- ☐ Comparative policy analysis
- ☐ Content analysis
- ☐ Delphi method
- ☐ Focus groups
- ☐ Interview
- ☐ Legal research
- ☐ Meta analysis/systematic review
- ☐ Normative analysis
- ☐ Participant observation/ethnography
- ☐ Retrospective chart review
- ☐ Survey
- ☐ Other, please describe: _____
- ☐ None of the above

8. Did you complete empirical research methods course(s) as part of your education?

- ☐ Yes
- ☐ No

8a. If empirical research methods course(s) were not part of your education, how did you learn them?

- ☐ By reading about methodology
 - ☐ By working on research projects
 - ☐ By reading papers that describe examples of similar methods I wanted to use
 - ☐ Through courses outside of my degree(s)
 - ☐ By guidance of a mentor
 - ☐ Another way. Please describe:

 - ☐ Not applicable
-

Part 2. Research Dissemination and Translation

This next set of questions asks about how you will share your research findings, their relevance/impact, and your target audience(s).

9. Are there stakeholders who could benefit from understanding and/or applying your research findings?

- ☐ Yes
- ☐ No
- ☐ I don't know

9a. Who are the stakeholders?

9b. What methods have you used to foster the uptake of your research findings by those stakeholders?

10. Have you expected your research findings to inform the creation or revision of any of the following? Please select all that apply.

- ☐ Clinical practice guidelines
- ☐ International policy
- ☐ Professional guidelines
- ☐ Research policy
- ☐ State and/or federal laws
- ☐ Statements by professional societies
- ☐ U.S. health policy
- ☐ U.S. public health measures
- ☐ Other: _____
- ☐ All of the above
- ☐ None of the above

10a. Through what means do you imagine your research findings will inform statements, guidelines, laws, policies, etc.?

- ☐ I will disseminate my findings to the relevant stakeholders.
- ☐ The funder of my research will disseminate my findings to the relevant stakeholders.
- ☐ My university will disseminate my findings to the relevant stakeholders.
- ☐ The relevant stakeholders will discover my findings on their own.
- ☐ Another entity will disseminate my findings to the relevant stakeholders.
Please describe: _____
- ☐ I don't know.

11. I would like assistance with dissemination and translation of my research findings.

- ☐ Yes
- ☐ No
- ☐ I don't know

11a. How can the CERA help you with dissemination and translation of your research findings?

Part 3. Research Challenges and Opportunities

This set of questions explores specific challenges you may have encountered in your research and areas of expertise you would like to develop.

12. Which of the following are challenges you have faced in your own research? Please select all that apply.

- ☐ Understanding where and how to publish my interdisciplinary research.
- ☐ Identifying a collaborator that had the expertise I needed for my project.
- ☐ Hiring qualified research staff.
- ☐ Implementing a successful results dissemination plan.
- ☐ Other, please describe:

☐ None of the above

13. Please indicate your level of interest in training or resources related to the following research methods:

	Very interested	Somewhat interested	Not interested
Comparative policy analysis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Content analysis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Delphi method	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Focus group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interview	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Legal research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participant observation/ethnography	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Retrospective chart review	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Systematic review	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Survey	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other, please describe:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14. What are some areas you would like to develop additional skills in? Please select all that apply.

- ☐ Finding relevant literature in other disciplines
- ☐ Finding validated instruments
- ☐ Literature synthesis
- ☐ Formulating testable research questions, hypotheses, or theories
- ☐ Sample size calculation
- ☐ Participant recruitment/ retention strategies
- ☐ Quantitative data collection methods
- ☐ Qualitative data collection methods
- ☐ Conducting or designing focus groups
- ☐ Qualitative data analysis
- ☐ Quantitative data analysis
- ☐ Data analysis software
- ☐ Scientific writing or reporting
- ☐ Publication strategies
- ☐ Other, please describe: _____
- ☐ None of the above

15. Please **select all** the things you would like to know how to do.

- ☐ Design an interventional or experimental study
- ☐ Design a policy-relevant, empirical study
- ☐ Hear best practices in empirical research design from more experienced researchers
- ☐ Learn strategies for integrating different methodologies in a single research project (mixed methods)
- ☐ Learn virtual research best practices
- ☐ Validate a survey instrument
- ☐ Other, please describe:

- ☐ All of the above
- ☐ None of the above

16. I would like to have support for finding a collaborator with different expertise than my own.

- ☐ Yes
- ☐ No
- ☐ I don't know

16a. Please describe the expertise of the collaborator you are looking for.

Part 4. Demographic Information

Please answer the following demographic questions.

17. Highest level of education

- ☐ PhD, MD, JD, or equivalent
- ☐ Master's degree
- ☐ Other (please elaborate): _____

18. Please specify which domain/discipline your last completed degree was from.

19. Please select your current position.

- ☐ Full Professor
- ☐ Associate/Assistant Professor
- ☐ Academic Researcher/Project Manager
- ☐ Post-Doctoral Scholar
- ☐ Doctoral Student
- ☐ Other _____

20. Do you supervise student(s) who are doing empirical research on the ethical, legal, or social implications (ELSI) of genetics or genomics?

- ☐ Yes
- ☐ No

20a. What would help your students improve their understanding and use of empirical methods?

21. Please indicate your years of experience conducting empirical research (including while you were a student):

- ☐ N/A
- ☐ Less than 1
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5-10
- ☐ 10 or more

22. Please specify your country of current (main) employment:

- ☐ United States
- ☐ Other: _____