

NCI Cohort Consortium Data Pooling Questionnaire

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Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0766). Do not return the completed form to this address.

Dear NCI Cohort Consortium collaborator,

You are being invited to partake in a short (10-minute) questionnaire aiming to elucidate common goals, facilitators, and challenges and barriers to participation in collaborative data pooling projects within the NCI Cohort Consortium. Your participation in this questionnaire is voluntary. Your responses will be kept secure to the extent permitted by law, and no identifying information will be collected about you in this questionnaire.

1. Why do you participate in the Cohort Consortium (check all that apply)

I lead a project working group

Maximise use of my cohort's data/resources

Ensure my cohort data/resources are used appropriately

Develop new collaborations

Conduct research in a collaborative environment

Pursue a broader program of research

Develop my career

Identify data to use for research

Other (please specify)

The following questions (2-8) are about your own (individual) participation in any specific Project Groups within the Cohort Consortium

2. Have you participated in a Cohort Consortium Project Group?

Yes

No

3. What role(s) have you played in a Project Group? (check all that apply)

Project Group leader

Lead author of a Project Group publication

Co-author of a Project Group publication

Data collection for the Project

Data extraction or preparation for the Project

Data analysis for the Project

Attended meetings for the Project

Administrative support for the Project

Other (please specify)

4. What factor(s) facilitated your participation in a Project Group (i.e., what worked well)?

5. What were the main challenge(s) in your participation in a Project Group (i.e., what didn't work well)?

6. What could be done to address each of these challenges

7. Have you ever had an idea for a Cohort Consortium project that you did not submit as a proposal?

Yes

No

8. What were the main reasons you did not submit a proposal?

The following questions (9-16) are about your cohort study's participation in the Cohort Consortium

9. Are you affiliated with a cohort study?

Yes

No

10. Has there ever been a Cohort Consortium project that your study could have contributed data to but didn't?

Yes

No

11. If no, what were the main reasons your study didn't contribute data (check all that apply)

Insufficient local personnel/resources

Insufficient funding

Approvals required to participate

Unresolved issues/questions (please specify the issues/questions)

Overlap with study's research agenda

Lack of trust (e.g., in project lead)

Privacy concerns

Other (please specify)

12. Would you like to elaborate on any of the reasons identified above?

No

Yes

13. Please describe what you'd consider optimal participation for your study in the Cohort Consortium

14. What is the main barrier to optimal participation for your study in the Cohort Consortium?

15. What could be done to address this barrier to optimal participation for your study in the Cohort Consortium?

16. Please add below any further comments you'd like to make about your study's participation in the Cohort Consortium

17. Please select your primary role in the NCI Cohort Consortium or its project groups (select one only)

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Study PI

Researcher (other than study PI) affiliated with a cohort

Researcher (other than study PI) not affiliated with a cohort

Student

Data manager

Study coordinator

Contracts manager

Other (please specify)

18. Are you an NCI employee?

Yes (intramural)

Yes (extramural)

No

19. Please indicate your years of experience in your primary area of expertise:

Less than 5 years

5-10 years

10-20 years

More than 20 years

Thank you for participating in this survey. If you have any questions about this survey or your participation, please contact NCICohortConsortium@mail.nih.gov.