1. The clinical research community should promote and facilitate clinical trial data sharing.

☐ 1 Strongly agree  ☐ 2 Somewhat agree  ☐ 3 Somewhat disagree  ☐ 4 Strongly disagree

2. Please briefly explain your answer.

The following questions focus on your perceptions of sharing clinical trial data through data repositories, archives of clinical trial data accessible to external investigators and managed by at least one research funder. For instance, you may be familiar with the data repository managed by the National Heart, Lung, and Blood Institute (NHLBI) of the U.S. National Institutes of Health (NIH).

3. Were you required by the research funder to share data from your study “[insert publication title]” through a data repository?

☐ 1 Yes  ☐ 2 No

4. If you had been required to share the deidentified data from this study through a data repository, would you have any of the following concerns? (Please check all that apply)

☐ Concerns Related to Investigator or Funder Interests
☐ Concerns Related to the Protection of Research Subjects
☐ Concerns Related to Appropriate Data Use
☐ Other Concerns
☐ No Concerns

4a. Which of the following issues related to investigator or funder interests would be concerning to you and how significant would they be?

☐ Q2_4_1 Ensuring my ability to publish original research using the data
  ☐ 1 Major concerns  ☐ 2 Minor concerns  ☐ 3 No concerns

☐ Q2_4_2 Ensuring my colleague’s ability to publish original research using the data
  ☐ 1 Major concerns  ☐ 2 Minor concerns  ☐ 3 No concerns

☐ Q2_4_3 Ensuring that I receive sufficient academic/scientific recognition for sharing my clinical trial data
  ☐ 1 Major concerns  ☐ 2 Minor concerns  ☐ 3 No concerns

☐ Q2_4_4 Incuring expenses associated with sharing data (i.e., direct costs)
  ☐ 1 Major concerns  ☐ 2 Minor concerns  ☐ 3 No concerns

☐ Q2_4_5 Spending undue time or effort to prepare data for sharing (i.e., indirect costs)
  ☐ 1 Major concerns  ☐ 2 Minor concerns  ☐ 3 No concerns

☐ Q2_4_6 Protecting commercially sensitive information
  ☐ 1 Major concerns  ☐ 2 Minor concerns  ☐ 3 No concerns
(Optional) Please briefly describe any other issues related to investigator or funder interests that would be concerning to you.

4b. Which of the following issues related to the protection of research subjects would be concerning to you and how significant would they be?

- Maintaining patient confidentiality
  - □ 1 Major concerns  □ 2 Minor concerns  □ 3 No concerns

- Obtaining research subject consent
  - □ 1 Major concerns  □ 2 Minor concerns  □ 3 No concerns

(Optional) Please briefly describe any other issues related to the protection of research subjects that would be concerning to you.

4c. Which of the following issues related to appropriate data use would be concerning to you and how significant would they be?

- Ensuring clarity of data elements for other investigators
  - □ 1 Major concerns  □ 2 Minor concerns  □ 3 No concerns

- Ensuring appropriate data use by other investigators
  - □ 1 Major concerns  □ 2 Minor concerns  □ 3 No concerns

- Preventing misinterpretation or misleading secondary analyses
  - □ 1 Major concerns  □ 2 Minor concerns  □ 3 No concerns

(Optional) Please briefly describe any other issues related to appropriate data use that would be concerning to you.

4d. Please briefly describe any other concerns you would have if you had been required to share the deidentified data from this study through a data repository.

5. Has the data been deposited in a repository?

- □ 1 Yes  □ 2 No
8. If required to share data through a data repository, how long after study completion (i.e., final study data set is ready for analysis) should investigators be entitled to the right of first use of the data?

- □ 1  No Right of First Use – the rights to data should be released immediately after study completion
- □ 2  One Year
- □ 3  Two Years
- □ 4  Three Years
- □ 5  Four Years
- □ 6  Five Years or More
- □ 7  No Time Limit – the right of first use is entitled until the main findings are accepted for publication

9. Assume that research funders take on the following responsibilities:

1) Provide for the assembly and maintenance of the repository
2) Cover all monetary expenses (i.e., direct costs) associated with the repository
3) Oversee the application process to ensure intended data use is appropriate

All authors of a published clinical study should be required to deposit the de-identified data from the study in a data repository.

- □ 1 Strongly agree
- □ 2 Somewhat agree
- □ 3 Somewhat disagree
- □ 4 Strongly disagree

10. (Optional) Do you have any additional comments related to sharing data through data repositories?

The following questions focus on your own experience with sharing clinical trial data in response to personal requests. A personal data sharing request is any situation in which the author of a published clinical study is directly contacted by an individual requesting access to data relating to that publication.

11. Have you received any personal requests to share patient-level clinical trial research data from your study “[insert study title]”?  

- □ 1 Yes
- □ 2 No

12. How many personal data sharing requests have you received for this study?

- □ 1 One
- □ 2 Two
- □ 3 Three
- □ 4 Four or More

13. For what purpose(s) were the data request(s) made? (Please check all that apply)

- □ 3.4.1 Systematic review/meta-analysis
- □ 3.4.2 Subgroup analysis of originally published study
- □ 3.4.3 Verification of originally published study
- □ 3.4.4 Non-academically oriented editorial
- □ 3.4.5 Did not specify
- □ 3.4.6 Cost analysis
- □ 3.4.7 Novel research question
- □ 3.4.8 Academically oriented editorial
- □ 3.4.9 Other purposes (please specify)
14. How many personal data sharing requests have you granted for this study?

- □ None
- □ One
- □ Two
- □ Three
- □ Four or More

15. How many personal data sharing requests have you declined/refused for this study?

- □ None
- □ One
- □ Two
- □ Three
- □ Four or More

16. For what general reason(s) did you share the study data? (Please check all that apply)

- □ Administrative Requirements
- □ Promote Open Science
- □ Academic Benefits or Recognition
- □ Other Reasons
- □ I would never share data if requested (only applicable to those who have never been asked to share data or have never shared their data)

16a. For what specific reason(s) related to administrative requirements did you share the study data? (Please check all that apply)

- □ Comply with journal policy on data sharing
- □ Comply with employer/research funder policy on data sharing

(Optional) Please briefly describe any other reasons related to administrative requirements.

16b. For what specific reason(s) related to promoting open science did you share the study data? (Please check all that apply)

- □ Belief in open scientific inquiry
- □ Promote new research using existing data
- □ Enhance robustness of previously conducted research
- □ Avoid redundant clinical trial data collection
- □ Facilitate student/fellow opportunities for data analysis

(Optional) Please briefly describe any other reasons related to promoting open science.

16c. For what specific reason(s) related to academic benefits or recognition did you share the study data? (Please check all that apply)

- □ Potential to receive additional academic recognition for sharing data
- □ Potential to increase the impact of own research
- □ Professional or personal relationship with requester

(Optional) Please briefly describe any other reasons related to academic benefits or recognition.
16d. For what other specific reason(s) did you share the study data?

17. For what general reason(s) did you NOT share the study data? (Please check all that apply)

- [ ] Protect Investigator or Funder Interests
- [ ] Protect Research Subjects
- [ ] Ensure Appropriate Data Use
- [ ] Other Reasons
- [ ] I would always share data if requested (only applicable to those who have never had data requested or have always shared data when requested)

17a. For what specific reason(s) related to protecting investigator or funder interests did you NOT share the study data? (Please check all that apply)

- [ ] Ensure my ability to publish original research using the data
- [ ] Ensure my colleague’s ability to publish original research using the data
- [ ] Monetary expenses associated with sharing data (i.e., direct costs)
- [ ] Time or effort involved in preparing data for sharing (i.e., indirect costs)
- [ ] Protect commercially sensitive information
- [ ] Protect patient confidentiality
- [ ] Prohibited by formal agreement with trial funder
- [ ] Unsure of employer/research funder policy on data sharing

17b. For what specific reason(s) related to protecting research subjects did you NOT share the study data? (Please check all that apply)

- [ ] Protect patient confidentiality
- [ ] Lack of patient informed consent to share

(Optional) Please briefly describe any other reasons related to academic benefits or recognition.

(Optional) Please briefly describe any other reasons related to protecting investigator or funder interests.
17c. For what specific reason(s) related to *ensuring appropriate data use* did you NOT share the study data? (Please check all that apply)

- [ ] Q3_28.1 Did not trust data requester’s intent
- [ ] Q3_28.2 Data not appropriate for requested purpose
- [ ] Q3_28.3 Potential for misinterpretation of data
- [ ] Q3_28.4 Potential for misleading secondary analyses

(Optional) Please briefly describe any other reasons related to *ensuring appropriate data use*.

17d. For what other specific reason(s) did you NOT share the study data?

18. If you had received a personal request, would you be willing to share patient-level clinical data from this study?

- [ ] 1 Yes
- [ ] 2 No

Q3_39

21. Have you ever made a personal request to another investigator with whom you were not collaborating to share patient-level clinical trial research data from a previously conducted study?

- [ ] 1 Yes
- [ ] 2 No

Q3_56

22. How many personal data sharing requests have you made to other clinical investigators?

- [ ] 1 One
- [ ] 2 Two
- [ ] 3 Three
- [ ] 4 Four or More

23. For what purpose(s) did you make the data sharing request(s)? (Please check all that apply)

- [ ] Q3_58.1 Systematic review/meta-analysis
- [ ] Q3_58.2 Cost analysis
- [ ] Q3_58.3 Subgroup analysis of originally published study
- [ ] Q3_58.4 Novel research question
- [ ] Q3_58.5 Verification of originally published study
- [ ] Q3_58.6 Academically oriented editorial
- [ ] Q3_58.7 Non-academically oriented editorial
- [ ] Q3_58.8 Other purposes (please specify)

Q3_58.8_TEX

24. How many of your personal data sharing requests were granted?

- [ ] 1 None
- [ ] 2 One
- [ ] 3 Two
- [ ] 4 Three
- [ ] 5 Four or More

25. How many of your personal data sharing requests were declined/refused?

- [ ] 1 None
- [ ] 2 One
- [ ] 3 Two
- [ ] 4 Three
- [ ] 5 Four or More

Comment [KS24]: Only see if Q3_23_3=1

Comment [KS25]: Only applicable to responders who received a request AND denied at least one request.

Comment [KS26]: Only see if Q3_23_3=1

Comment [KS27]: Only see if Q3_23_4=1

Comment [KS28]: Only see if Q3_2=2

Comment [KS29]: Only see if Q3_56=1

Comment [KS30]: Only see if Q3_56=1

Comment [KS31]: Only see if Q3_56=1

Comment [KS32]: Only see if Q3_56=1
26. Assume personal data sharing requests operate under the following conditions:
   1) The data requesters would cover all monetary expenses (i.e., direct costs) associated with sharing data in response to personal requests.
   2) Investigators would be under no obligation to release data in response to a personal request if they do not trust the data requester’s intent or determine that the data may not be used appropriately.

All authors of a published clinical study should be required to share the deidentified data relating to that publication in response to personal requests.

☐ 1 Strongly agree  ☐ 2 Somewhat agree  ☐ 3 Somewhat disagree  ☐ 4 Strongly disagree

27. (Optional) Do you have any additional comments related to sharing data in response to personal requests?

The final questions focus on you.

28. Please indicate your age range.
   ☐ 1  34 years or younger  ☐ 2  35-49 years  ☐ 3  50-64 years  ☐ 4  65 years or older

29. Please indicate your gender.
   ☐ 1  Male  ☐ 2  Female

30. How many years have passed since the completion of your highest professional degree?
   ☐ 1  0-9 years  ☐ 2  10-24 years  ☐ 3  25 years or more

31. Where did you receive scientific training while completing your highest professional degree?
   ☐ 1  United States or Canada  ☐ 2  Western Europe  ☐ 3  Elsewhere

32. Which of the following best classifies your current primary employer?
   ☐ 1  Academic institution  ☐ 4  Private Industry  ☐ 3  Non-profit organization
   ☐ 5  For-profit hospital  ☐ 2  Government

33. Which of the following best describes your academic rank?
   ☐ 1  Lecturer, Fellow, or Student  ☐ 2  Affiliated Professor  ☐ 3  Assistant Professor
   ☐ 4  Associate Professor  ☐ 5  Full Professor

34. What percent of your overall job effort did you devote to research time during fiscal year 2010-2011?
   ☐ 1  Less than 25%  ☐ 2  25% - 49%  ☐ 3  50% - 74%  ☐ 4  75% or greater
35. Over the past three years, approximately how many articles have you published in peer reviewed journals?

- □ 1  1-5
- □ 2  6-10
- □ 3  11-25
- □ 4  More than 25

36. Over the past three years, approximately how many research grants and contracts (either internally or externally funded) from any source have you been awarded on which you are the principal investigator?

- □ 1  None
- □ 2  1-3
- □ 3  4-6
- □ 4  7-10
- □ 5  More than 10

37. What type of organizations awarded these research grants and contracts? (Please check all that apply)

**Internal funding (funding from your employer):**
- □ Government
- □ Non-profit organizations
- □ Private industry

**External funding (funding from sources outside of your employer):**
- □ Government
- □ Non-profit organizations
- □ Private industry

38. Over the past three years, what was the total direct cost associated with these grants and contracts?

- □ 1  Less than $50,000
- □ 2  $50,000 - $499,999
- □ 3  $500,000 - $999,999
- □ 4  $1,000,000 - $4,999,999
- □ 5  More than $5,000,000

**Comment [KS34]:** Only see if Q4_10 in (2,3,4,5)

**Comment [KS35]:** Only see if Q4_10 in (2,3,4,5)

**ADDITIONAL DEMOGRAPHIC VARIABLES:**

**COMPLETION STATUS:**
- 0 = No, did not complete survey
- 1 = Yes, completed survey

**EMPLOYER:**
- 1 = Medical School or Hospital
- 2 = Private Industry
- 3 = Government
- 4 = Other

**LOCATION:**
- 1 = U.S. or Canada
- 2 = Western Europe
- 3 = Other

**TRIAL SIZE = Continuous count variable**

**FUNDER:**
- 1 = Government
- 2 = Industry
- 3 = Other
- 4 = Mixed

**JOURNAL:**
- 1 = NEJM
- 2 = Lancet
- 3 = JAMA
- 4 = Annals of Internal Medicine
- 5 = BMJ
- 6 = PLoS Medicine

**ARTICLES:**
- 1 = 1 - 10
- 2 = 11 - 25
- 3 = More than 25

**GRANTS:**
- 1 = None
- 2 = 1 - 3
- 3 = More than 3

**COST:**
- 1 = None
- 2 = < $1 million
- 3 = >= $1 million

**PLEASE NOTE:** The COST variable removes the skip pattern, however, Q4_12 still observes the skip pattern.