

CHECKLIST:

Reducing Re-Identification Risk in Traumatic Stress Research Data

From the Global Collaboration on Traumatic Stress FAIR Data Workgroup

A. Address content of dataset

- ☐ Remove direct identifiers
- ☐ If required by your national / regional regulations, replace subject identification numbers with a new set of identification numbers in a different random sequence
- ☐ Remove free text containing personally identifiable information
 - ☐ If needed for analytic value (data re-use), recode information into aggregated categories
- ☐ List quasi-identifiers
 - ☐ Considering the context of your study, list those of greatest potential concern (alone or in combination) for re-identification risk

B. Assess potential for harm if participants were re-identified

- ☐ Were participants promised confidentiality? (true for nearly all trauma research)
 - Potential for harm to trust in research, researchers, institutions.
- ☐ Would disclosure of study participation or of specific attributes cause harm or stigma?
 - ☐ List items of greatest concern for harm / stigma if connected to identified individuals
 - ☐ Characterize level of harm if disclosed
 - Low risk – Would not cause more than minimal harm / would not be of use to attackers.
 - High risk – Potential to embarrass or otherwise cause harm to respondents.

C. Assess relationship between sample (cases in dataset) and population (reidentification frame)

- ☐ Potential to construct a reidentification frame (Could someone construct a list of people who might be in the study / dataset?)
- ☐ Estimated size and nature of re-identification frame?
- ☐ Relationship of sample size to re-identification frame

In relation to the re-identification frame, cases in dataset represent:	Risk related to sample size / proportion
Complete or nearly complete sample of the re-identification frame.	Very high
More than 10% sample of re-identification frame (10:1 ratio).	High
Between 10% and 1% sample of re-identification frame.	Medium
1% or less sample of re-identification frame (100:1 ratio).	Low
0.1% or less of re-identification frame (1000:1 ratio or higher)	Very low

D. Conduct systematic analysis to assess and mitigate risk within the dataset

- ☐ Initial inspection for k-anonymity
- ☐ Penetration testing – check univariate and bivariate combinations of select quasi-identifiers for outliers, unusual cases, and small groups
- ☐ Use the above to make recommendations for changes to improve anonymity
 - ☐ Data reduction – generalize, suppress, delete specific variables?
 - ☐ Balance data reduction with analytical value for data re-use
(consider more restrictive sharing / access if data reduction harms data usefulness)
- ☐ Reassess after changes.

E. Consider how data will be shared / made accessible for re-use.

Select method that is compatible with re-identification risk assessment as well as funder and legal / regulatory requirements

- ☐ High potential for harm and high relative risk based on sample relationship to reidentification frame? → Implement more restrictive conditions for data sharing and re-use.
- ☐ For all data sharing methods: Inform data users of their responsibility to respect participant privacy and to inform the original research team or data repository in the case of any inadvertent re-identification.

Range of possibilities includes:

- Openly available data, with stated terms of use for public download.
- Data in repository that is accessible upon request / application. Might require user registration with written / digital agreement to terms of use.
- Restricted data with greater access controls. Might require formal inter-institutional agreements that include terms of use for data.

Learn about FAIR Data practices and tools: <https://www.global-psychotrauma.net/fair-tools>

RESULTS & RECOMMENDATIONS

Study / Dataset name:

Theoretical study population	[Describe target population]
Potential harm	Relative risk of potential harm IF re-identified = high / medium / low
Potential to construct a re-identification frame	[Is it possible to construct a list of individuals who could have been invited to participate in study? Describe.]
Relationship of survey sample to reidentification frame	[Sample N] [estimated size of re-identification frame] Relative risk based on sample proportion = high / medium / low
Direct identifiers	[List any that remain in dataset – will they be deleted?]
Free text with personally identifiable information	[List any that remain in dataset –will they be deleted? recoded?]
Select demographic quasi-identifiers of concern	Variables of potential concern: <ul style="list-style-type: none"> [List here]
Initial inspection for k-anonymity	[Is it possible / appropriate to assess formally for k-anonymity? -- based on sample size and number of quasi-identifiers of concern] [Summarize results of k-anonymity testing]
Penetration testing – univariate and bi-variate checks of select quasi-identifiers for outliers and small groups	[Describe results of penetration testing] Relative risk: [Were unusual cases, outliers, high-risk combinations found?]
Recommendation	[List specific action recommendations here] Assessment: [Can risk be reduced if recommendations implemented?] Assessment after changes are made:
Appropriate means of data sharing / access	[Describe options for method(s) of making data accessible that fit <i>re-identification risk assessment</i> , as well as <i>funder & legal / regulatory requirements</i>] <ul style="list-style-type: none"> Publicly available // Repository with clear access options // Other [Describe how users will be informed of and agree to terms of use that protect against re-identification]

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