# ETHICS and CONSENT HOW TO THINK ABOUT SHARING SENSITIVE DATA

From the Global Collaboration on Traumatic Stress FAIR Data Workgroup

# Risk of identifiability

Can the data be modified to lower the risk?



Consider whether it is possible to make data accessible with more restrictive terms / arrangements.



### **Research ethics**

Did research participants provide consent for data sharing?



In some cases, de-identified data may still be shared if not precluded in the information given to participants.

Consult with ethics committee.



## **Research ethics**

Was data sharing approved by an Ethics Committee?



#### **Share data**

Select repository.
Set appropriate terms for data access.

What goes in a consent form? Consult your Ethics Committee to be sure you meet their requirements.

#### **Example sentences for consent forms:**

"This study will collect information that may be useful for research in the future. Your data (with personal information removed) will be stored in a data archive and may be used in future analyses."

"Personal information that could directly identify you will be removed or changed before files are shared with other researchers or results are made public."

Are you working with data that involve or impact Indigenous peoples? Also consider the CARE principles for data governance. Info here: https://doi.org/10.1038/s41597-021-00892-0