EDITORIAL

Embracing data preservation, sharing, and re-use in traumatic stress research

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ABSTRACT

This editorial argues that it is time for the traumatic stress field to join the growing international movement towards Findable, Accessible, Interoperable, and Re-usable (FAIR) research data, and that we are well-positioned to do so. The field has a huge, largely untapped resource in the enormous number of rich potentially re-usable datasets that are not currently shared or preserved. We have several promising shared data resources created via international collaborative efforts by traumatic stress researchers, but we do not yet have common standards for data description, sharing, or preservation. And, despite the promise of novel findings from data sharing and re-use, there are a number of barriers to researchers' adoption of FAIR data practices. We present a vision for the future of FAIR traumatic stress data, and a call to action for the traumatic stress research community and individual researchers and research teams to help achieve this vision.

Abrazando la preservación, el intercambio y la reutilización de datos en la investigación del estrés traumático

Esta editorial argumenta que es hora de que el campo del estrés traumático se una al creciente movimiento internacional hacia datos de investigación Hallables, Accesibles, Interoperables y Reutilizables (FAIR en su sigla es inglés), y que estamos en una buena posición para hacerlo. El campo tiene un recurso enorme, en gran parte sin explotar, en la enorme y rica cantidad de conjuntos de datos potencialmente reutilizables que actualmente no son conservados o compartidos. Tenemos varios recursos de datos compartidos prometedores creados a través de esfuerzos de colaboración internacional por investigadores de estrés traumático, pero aún no tenemos estándares comunes para la descripción, el intercambio o la preservación de datos. Y, a pesar de la promesa de nuevos hallazgos del uso compartido y la reutilización de datos, existen numerosas barreras para la adopción de prácticas de datos FAIR por parte de los investigadores. Presentamos una visión para el futuro de los datos de estrés traumático FAIR, y un llamado a la acción para la comunidad de investigación de estrés traumático y los investigadores individuales y equipos de investigación para ayudar a lograr esta visión.

在创伤应激研究中的数据保存, 共享和重复使用

本社论提出, 现在是创伤应激领域加入日益发展的'可寻找, 可访问, 可共同操作和可重复使用'(FAIR) 研究数据的国际运动的时候。并且我们有条件这样做。在目前尚未共享或保留的大量丰富的潜在可重复使用的数据集中, 具有大量尚未开发的资源。我们有一些有可能的共享数据资源, 这些数据是由创伤应激研究这通过国际合作创建的。但是我们还没有关于数据描述, 共享或保存的通用标准。而且, 尽管有望从数据共享和重复使用中获得新颖的发现, 但研究人员采用FAIR数据实践仍存在许多障碍。我们提出了有关FAIR创伤应激数据未来的愿景, 并呼吁创伤应激研究社区以及各个研究人员和研究团队采取行动以帮助实现这一愿景。

HIGHLIGHTS
• Existing traumatic stress research data is a rich and largely untapped resource, and our field is well-positioned to join the growing international movement toward FAIR data. This editorial presents a vision for the future of FAIR traumatic stress data, and specific steps that investigators and research teams, as well as the larger traumatic stress research community, can take to help bring this about.

With a growing international movement towards more open science (Olff et al., 2019) and making data findable and re-usable, it is time for the traumatic stress field to fully recognize the value of preservation, sharing, and re-use of data. This recognition will have implications for our current and future research practices, and will shape the choices we make now regarding the legacy of past research. Our field is sitting on a huge, largely untapped resource – the rich and potentially re-usable datasets that currently sit in the (paper and electronic) file drawers of investigators and research teams. Much of the data that we are not now preserving or sharing falls in the 'long tail' of research data (Ferguson, Nielson, Cragin, Bandrowski, & Martone, 2014). In contrast to the huge datasets of 'big data', the long tail is defined as the very large proportion of existing research data that come from 'numerous small independent research efforts yielding a rich variety of specialty research data sets' (Ferguson et al., 2014, p. 1443). As a field we have rarely created

findable and accessible shared data resources from this long tail.

A crucial underlying paradigm shift is to change our perception of research outputs such that well-documented and preserved data resources, rather than publications alone, are seen as primary and valuable products of research (Bierer, Crosas, & Pierce, 2017; Martone, Garcia-Castro, & VandenBos, 2018). These data resources not only support robust and reproducible science, they also allow novel uses and analyses of data that would not be possible from single studies. Sharing and re-use of properly de-identified and anonymized data also honours our ethical contract with research participants by expanding the value of their contribution (Bauchner, Golub, & Fontanarosa, 2016). Across observational and intervention research in traumatic stress, pooling individual-level data across studies for integrated analyses has demonstrated the value of re-using such data in new ways. For example, pooled data have been used to examine intervention effectiveness, improve estimates of PTSD risk prediction, and broaden network analyses of traumatic stress symptoms and trauma-related cognitions (De Haan et al., 2020; Fried et al., 2018; Mithoefer et al., 2018; Shalev et al., 2019; Stein, Davidson, Seedat, & Beebe, 2003).

1. Making traumatic stress research data Findable, Accessible, Interoperable, and Re-usable (FAIR)

A diverse group of stakeholders in the scientific community has developed a set of four foundational principles for data stewardship, stating that research data should be Findable, Accessible, Interoperable, and Re-usable (FAIR, see also https://www.go-fair. org/fair-principles/) (Wilkinson et al., 2016). These elements have been further elaborated to describe measurable aspects of implementing FAIR data practices. For example, to be findable, data should be indexed in a searchable resource, preferably a well-established and certified repository (Core Trust Seal); to be accessible, there should be a clear means of gaining (or requesting) access to the data; to be interoperable, data should be encoded in a way that is able to be read across various software systems; to be re-usable, data should be richly described in ways that meet domain-specific standards. FAIR data principles are applicable to a wide range of research data, but implementation may vary across disciplines and across data types.

While the FAIR data principles are related to open science practices, FAIR data are not the same as open data. Open data are generally defined as data that are freely and publicly available to any user. Instead, both the FAIR-ness and the openness of data are each best considered as a continuum; data may be FAIR but not open, or vice versa (European Commission Expert Group on FAIR Data, 2018). The guiding principle of 'as open as possible, as closed as necessary' (European Commission Expert Group on FAIR Data, 2018) is particularly applicable to traumatic stress research, where fully open and publicly available data will often not be possible nor desirable. Following this principle, much existing traumatic stress research data could be made findable by depositing a de-identifed/anonymized dataset in a searchable data repository where it could be accessible but not open (i.e. restricted to qualified researchers who request access), interoperable (if the repository supports download in multiple file formats), and re-usable (based on the quality of the metadata and documentation preserved with the dataset).

2. Does FAIR mean fair?

While 'FAIR' in this usage does not indicate fair or equitable, for the traumatic stress field it is especially important to consider this other meaning as well. As we create lasting data resources, we must respect the role and voice of research participants (Shah et al., 2019), and pay attention to equitable collection, preservation, and access to traumatic stress data (Fodor et al., 2014; Robson, Chang, & Kaminer, 2019; Serwadda, Ndebele, Grabowski, Bajunirwe, & Wanyenze, 2018). Pooling and re-using data can create unique opportunities to examine cross-cultural and cross-sample variability in key findings and to address health disparities in interventions and outcomes for trauma-exposed individuals and communities. Combining data from multiple studies can increase sample size of vulnerable or under-represented groups, and allow analyses within or across these groups that would not otherwise be possible, e.g. examining mediation and moderation of intervention effects, or potential variation in PTSD symptom structure or expression (Fried et al., 2018; Perrino et al., 2015).

3. FAIR traumatic stress research data: what is the current state?

At present, our ability to find, access, and re-use traumatic stress research data is inconsistent at best. There is no single repository focused on archiving research data in our field, nor is there a searchable index of such data resources. However, we can point to several promising examples of data resources created with the explicit aim of facilitating preservation, access, and re-use of traumatic stress research data. These resources demonstrate the variety of potential

approaches to data sharing and re-use; we highlight here several that are relatively broadly accessible.

- The prime example of data sharing and integration in traumatic stress is the Psychiatric Genomic Coalition PTSD workgroup (PGC-PTSD). This international coalition of researchers aims to understand the genetic architecture of PTSD; as of 2018 the sample included 32,000 PTSD cases and 100,000 trauma-exposed controls (Nievergelt et al., 2018). Analyses may be proposed by any of the several hundred investigators associated with the PGC-PTSD.
- Exemplifying the value of combining 'long tail' data from many smaller traumatic stress studies is the Prospective studies of Acute Child Trauma & Recovery (PACT/R) Data Archive. This international collaborative effort aims to preserve and share de-identified child trauma datasets and facilitate cross-study analyses of harmonized participant-level data. The archive currently includes 30 datasets from five countries representing over 5500 trauma-exposed children (Kassam-Adams et al., 2020). Data are available to any qualified researcher upon request.
- Pooling aggregate study-level data is another approach to creating useful and widely available data resources. The PTSD Trials Standardized Data Repository is a publicly available repository of international PTSD treatment research in adults, including over 300 pharmacological and non-pharmacological trials. Data are at the aggregate study level, capturing key study and sample attributes as well as outcomes (O'Neil, McDonagh, & Hsu et al., 2019).
- Studies can be designed from the beginning to generate widely accessible data resources. The Advancing Understanding of RecOvery afteR traumA (AURORA) Study is designed to collect, preserve, and share data (including banked biological samples) related to a range of post-trauma sequelae. Data is being collected prospectively from a sample of 5000 adults in the US exposed to acute trauma, and will be available via the NIMH Data Archive (McLean et al., 2019).

At present there is no single index of data resources relevant to trauma and traumatic stress. (Note that, as mentioned below, the Global Collaboration on Traumatic Stress is undertaking a project to build and maintain such an index.) Beyond the limited number of data resources focused on traumatic stress, where else might relevant data resources be found? Data repositories that are focused on a specific trauma type, e.g. crime victimization or child maltreatment (Cornell University; ICVS, 2017; USDOJ), can include datasets

relevant to addressing traumatic stress research questions. Relevant data may also be located within broad national or multi–institution repositories of health or social science data (Australian National University; CESSDA; ICPSR; National Institute of Mental Health). At present, the ability to find traumatic-stress-relevant datasets and variables within these broader repositories is variable, and depends on the quality of the metadata and documentation provided by the original research team as well as the systems provided by the repository for searching datasets and variables. Data accessibility varies: some resources are available only to collaborators or members, some to qualified researchers upon request, and (rarer for traumatic stress data) some repositories provide data that is open for anyone to download. Having found and accessed data, re-usability depends on the ability to understand how the data were collected as well as the meaning of each variable and response value. At present, even when relevant data has been archived and is accessible, the wide variation in quality of data documentation and metadata, and the lack of a common framework for data harmonization, mean that investigators who seek to combine and re-use data to address traumatic stress research questions may face considerable challenges.

4. Barriers and opportunities

Across most scientific disciplines, including the traumatic stress field, current barriers to adopting FAIR data practices include a research culture that has not recognized and valued the production and sharing of data resources as a key contribution, and a lack of training in data stewardship across the research lifecycle that can facilitate FAIR data practices (Houtkoop et al., 2018; Tenopir et al., 2015). Figure 1 presents barriers to data sharing in particular, and some potential strategies to address these challenges.

There is a need for resources and funding to support FAIR data practices; in the future many of these practices may not require substantial additional time or funds if they are built into the research lifecycle from the beginning. Treating data as a valued research product requires changes to a number of systems, including how we cite data resources and track their impact over time, and how contributions to the production of data are recognized and credited (Bierer et al., 2017). New standards for data citation are emerging (Data Citation Synthesis Group, 2014), but are still inconsistently applied by journals and authors.

Some funders and publishers now encourage or require investigators to deposit data and make it accessible to others. But because the goal of data archiving and sharing is meaningful use for replication and new analyses, depositing datasets without documentation about the meaning and provenance of the data is not sufficient. Metadata (information

Barriers to data sharing and strategies to address them

Barriers	Strategies to address barriers
Concern that career will be harmed if others use the data one has collected	• Track and reward production of reusable data resources as important research contribution to the field
Perception that original investigator "owns" the data	• Funder requirements or incentives for data sharing • Leading researchers model data sharing as an expectation and valued scholarly contribution
Lack of training in how to prepare datasets for sharing and re-usability	• Develop and implement training in data stewardship
Time and money required to support data sharing	• Encourage funders to include data stewardship costs in research grants • Embed best practices from the beginning of each project to reduce costs and burden
Consent process with research participants may not have anticipated data sharing	• Change current / future consent processes to incorporate expected sharing of anonymized data • Work with ethics boards to address past consent issues and allow sharing where possible • Share data with appropriate restrictions / conditions to mitigate concerns.

Figure 1. Barriers to data sharing and strategies to address them.

Vision for the future of FAIR traumatic stress data

Vision for the future:
What would it look like if traumatic stress data were FAIR?

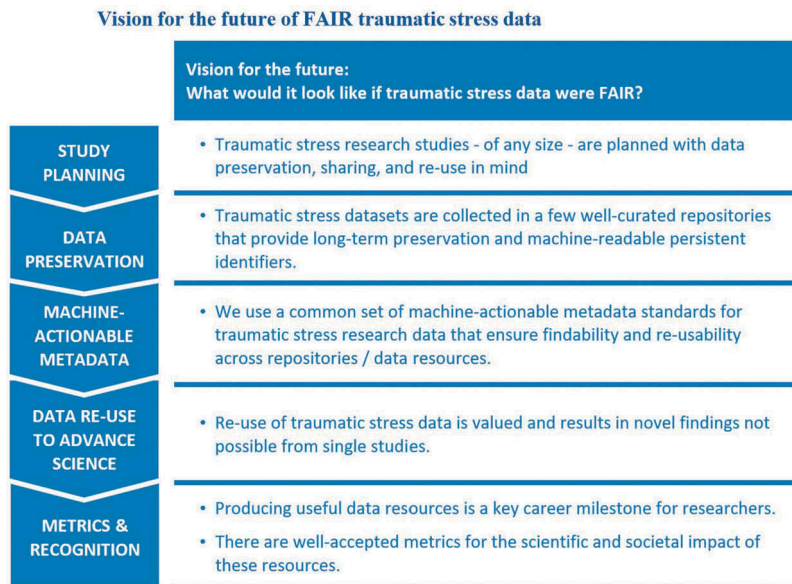| STUDY PLANNING	• Traumatic stress research studies - of any size - are planned with data preservation, sharing, and re-use in mind
DATA PRESERVATION	• Traumatic stress datasets are collected in a few well-curated repositories that provide long-term preservation and machine-readable persistent identifiers.
MACHINE-ACTIONABLE METADATA	• We use a common set of machine-actionable metadata standards for traumatic stress research data that ensure findability and re-usability across repositories / data resources.
DATA RE-USE TO ADVANCE SCIENCE	• Re-use of traumatic stress data is valued and results in novel findings not possible from single studies.
METRICS & RECOGNITION	• Producing useful data resources is a key career milestone for researchers. • There are well-accepted metrics for the scientific and societal impact of these resources.

Figure 2. Vision for the future of FAIR traumatic stress data.

about the data) is key to both findability and re-use. Ideally, metadata is machine-actionable and searchable, to enhance the findability and interoperability of data resources (Wilkinson et al., 2016). In the traumatic stress field, we have not yet established a set of common standards for describing or documenting our studies or our data. The heterogeneity of research measures, even for core concepts such as PTSD symptoms, makes this especially important.

5. FAIR traumatic stress research data: how do we get there?

Figure 2 presents a vision for a future in which traumatic stress data are easily findable, accessible to qualified researchers, interoperable across systems, and widely re-used to add value and address key research questions. Given current barriers, how do we move in the direction of achieving this future state? Getting there will require action by the broad traumatic stress research community (i.e. scientific and professional societies, funders, journals, research organizations) and by individual researchers and research teams.

(1) As a research community, we can:

a. Explicitly embrace data sharing and re-use as a common goal for the traumatic stress field.
b. Endorse the FAIR Guiding Principles for data management and stewardship.
c. Recognize FAIR traumatic stress research datasets as valuable research resources that are essential to advance the field.
d. Establish an ontology of traumatic stress concepts to serve as a foundation for indexing traumatic stress studies and variables.

e. Promote training in data stewardship and data re-use for traumatic stress researchers at every career stage.

f. Recognize the ways in which data re-use honours the contribution of research participants by expanding the value of their contribution and participation.

g. In the context of evolving societal standards for data privacy and re-use, commit to supporting appropriate consent processes and privacy protections that allow data sharing and re-use in traumatic stress research.

h. Ensure that journals in our field use best practices in data citation.

(2) As individual researchers and as research teams, we can:

a. Plan for data sharing and re-use from the beginning of each research project (at the design stage).

b. Ensure that our informed consent processes for research participants include clear and understandable information about data sharing and re-use.

c. Adopt data management practices, including metadata documentation, that facilitate re-use (by our 'future selves' as well as by others).

d. Remain aware of evolving standards and systems for documenting traumatic stress studies and variables (see item 1d above), and use these systems when documenting our studies to facilitate findability and re-use. If at all possible, avoid 're-inventing the wheel' with unique, study-specific systems of documentation.

e. Deposit well-documented datasets for long-term preservation in a repository that issues a unique and persistent digital object identifier (doi).

f. When depositing data for preservation, set the appropriate level of open vs restricted access ('as open as possible, as closed as necessary').

g. If depositing data is not possible due to funder or organizational restrictions, strive to make data as accessible as possible within those restrictions (i.e. limited data sharing for pooled analyses via a formal collaborative agreement, or providing aggregate data points for meta-analyses)

h. Re-use others' data for replication and for novel analyses, and cite these data resources using a persistent identifier (i.e. a digital object identifier [doi] for the dataset).

i. Insist that journals in which we publish our work use best practices in data citation

j. In our roles that involve assessing the impact of others' work (i.e. for career advancement), look for and give appropriate credit for the creation of lasting data resources and for the creative and impactful re-use of existing data.

6. Conclusion

It is time for the traumatic stress field to join the growing international movement towards FAIR research data. Fortunately, we are well-situated to do so. We already have examples of the value of data preservation, sharing, and re-use in our field. We have several promising data resources that represent international collaborative efforts by traumatic stress researchers to wrestle with the issues of data preservation, documentation, and harmonization. There is no time to waste, as we are in danger of losing (or may have already lost) a generation of seminal traumatic stress research data as pioneer researchers retire or move on to other endeavours.

The Global Collaboration on Traumatic Stress (Schnyder et al., 2017), representing ten scientific and professional societies around the world, has taken an important step in the direction of promoting FAIR traumatic stress research data, by adopting this topic as its fifth theme. The first two collaborative projects within this theme will address making traumatic stress data more findable (indexing existing data resources around the world and making this information available online) and more re-usable (delineating next steps for metadata and controlled vocabularies describing traumatic stress studies and variables). The third and fourth projects are focused on building and expanding specific data resources (in the areas of traumatic grief and child trauma). Researchers are invited to provide information on their dataset or other data resources by contacting the Global Collaboration FAIR Data project teams at FAIRTraumaData@gmail.com. Now is the time for individual researchers and research teams, as well as larger institutions and organizations, to examine our own data practices and to embrace the challenges and the promise of data preservation, sharing, and re-use.

Disclosure statement

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