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## Development of an international data repository and research resource: the Prospective studies of Acute Child Trauma and Recovery (PACT/R) Data Archive

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### ABSTRACT

**Background:** Studies that identify children after acute trauma and prospectively track risk/protective factors and trauma responses over time are resource-intensive; small sample sizes often limit power and generalizability. The Prospective studies of Acute Child Trauma and Recovery (PACT/R) Data Archive was created to facilitate more robust integrative cross-study data analyses.

**Objectives:** To (a) describe creation of this research resource, including harmonization of key variables; (b) describe key study- and participant-level variables; and (c) examine retention to follow-up across studies.

**Methods:** For the first 30 studies in the Archive, we described study-level (design factors, retention rates) and participant-level (demographic, event, traumatic stress) variables. We used Chi square or ANOVA to examine study- and participant-level variables potentially associated with retention.

**Results:** These 30 prospective studies (N per study = 50 to 568; overall N = 5499) conducted by 15 research teams in 5 countries enrolled children exposed to injury (46%), disaster (24%), violence (13%), traffic accidents (10%), or other acute events. Participants were school-age or adolescent (97%), 60% were male, and approximately half were of minority ethnicity. Using harmonized data from 22 measures, 24% reported significant traumatic stress  $\geq 1$  month post-event. Other commonly assessed outcomes included depression (19 studies), internalizing/externalizing symptoms (19), and parent mental health (19). Studies involved 2 to 5 research assessments; 80% of participants were retained for  $\geq 2$  assessments. At the study level, greater retention was associated with more planned assessments. At the participant level, adolescents, minority youth, and those of lower socioeconomic status had lower retention rates.

**Conclusion:** This project demonstrates the feasibility and value of bringing together traumatic stress research data and making it available for re-use. As an ongoing research resource, the Archive can promote 'FAIR' data practices and facilitate integrated analyses to advance understanding of child traumatic stress.

### Desarrollo de un repositorio internacional de información y recursos de investigación: el banco de información de los estudios prospectivos sobre trauma agudo y recuperación en el niño (pact/r por sus siglas en inglés)

**Antecedentes:** Los estudios que identifican niños luego de la exposición a trauma agudo y realizan un seguimiento prospectivo para identificar factores protectores o de riesgo, y respuestas al trauma en el tiempo requieren una gran cantidad de recursos; el tamaño pequeño de las muestras frecuentemente limita su poder y generalización. El Banco de Información de los Estudios Prospectivos sobre Trauma Agudo y Recuperación en el Niño (PACT/R por sus siglas en inglés) se creó para facilitar un análisis de datos más robusto e integrativo entre los estudios.

**Objetivos:** a) Describir la creación de este recurso de investigación, incluyendo la armonización de variables clave; b) describir las variables clave a nivel de estudios y de participantes; y c) evaluar la permanencia del seguimiento en los estudios.

**Métodos:** Describimos las variables 'nivel de estudio' (diseño, factores, tasas de permanencia) y 'nivel de participantes' (demografía, evento, estrés traumático) en los 30 primeros estudios del Banco. Empleamos Chi cuadrado o ANOVA para evaluar los niveles de estudio y de participante potencialmente asociados con la permanencia.

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### KEYWORDS

Traumatic stress; child and adolescent; FAIR data; data sharing; integrative data analysis

### PALABRAS CLAVE

Estrés traumático; niños y adolescentes; información FAIR; intercambio de datos; análisis integrado de información

### 关键词

创伤应激; 儿童和青少年; FAIR数据; 数据共享; 综合数据分析

### HIGHLIGHTS

- The first 30 prospective studies (overall N=5499) contributing datasets to the PACT/R data archive were conducted by 15 research teams in 5 countries, enrolled children exposed to injury, disaster, violence, traffic accidents, or other acute events, and utilized 22 different measures of posttraumatic stress.
- Across all datasets, 80% of participants were retained for at least 2 assessments. Using harmonized cross-study data, 24% reported significant traumatic stress 1 month or more post-event.
- The PACT/R project demonstrates the feasibility and value of archiving and harmonizing traumatic stress research data from multiple studies

**Resultados:** Estos 30 estudios prospectivos (N por estudio = 50 a 568; total N = 5499) realizados por 15 grupos de investigación en 5 países reclutaron niños expuestos a lesión (46%), desastre (24%), violencia (13%), accidentes de tránsito (10%) u otros eventos agudos. Los participantes estaban en edad escolar o en la adolescencia (97%), 60% eran varones y, aproximadamente la mitad pertenecían a una minoría étnica. Empleando la armonización de datos para 22 mediciones, el 24% reportó estrés traumático significativo mayor o igual a un mes luego del evento. Otros desenlaces comúnmente evaluados incluyeron a la depresión (19 estudios), síntomas internalizantes y externalizantes (19), y salud mental de los padres (19). Los estudios incluyeron entre 2 y 5 evaluaciones de investigación; 80% de los participantes fueron mantenidos para dos o más evaluaciones. En el nivel de estudio, una mayor permanencia se asoció a un mayor número de evaluaciones planificadas. En el nivel de participantes, los adolescentes, los jóvenes pertenecientes a minorías, y aquellos en niveles socioeconómicos más bajos presentaron menores tasas de permanencia.

**Conclusión:** Este proyecto demuestra la viabilidad y el valor de integrar la información sobre la investigación en estrés traumático y hacerla disponible para ser reutilizada. Como recurso de investigación en curso, el Banco puede promover el uso de prácticas de información 'FAIR' y facilitar el análisis integrado para generar progreso en la comprensión del estrés traumático infantil.

### 一个国际数据库和研究资源的开发：儿童急性创伤与康复 (PACT / R) 前瞻性研究数据档案库

**背景:** 急性创伤后识别儿童并长期前瞻性追踪风险/保护因素和创伤反应的研究是资源密集型的；小样本量通常会限制研究效能和普遍性。创建了儿童急性创伤与康复 (PACT/R) 前瞻性研究数据档案库，以促进更稳健的跨研究综合数据分析。

**目标:** (a) 描述次研究资源的创建，包括关键变量的统一化；(b) 描述研究水平和参与者水平的关键变量；(c) 考查跨研究的随访保留率。

**方法:** 对于档案库中的前30项研究，我们描述了研究水平变量（设计因素，保留率）和参与者水平变量（人口统计学，事件，创伤应激）。我们使用卡方或方差分析以考查可能与保留率相关的研究水平和参与者水平变量。

**结果:** 由5个国家的15个研究小组进行的这30项前瞻性研究（单项研究样本量为50至568；总样本量为5499）招募了遭受伤害（46%），灾难（24%），暴力（13%），交通事故（10%）或其他急性事件的儿童。参与者97%为学龄儿童或青少年，60%为男性，约一半为少数民族。使用来自22种测量的统一化数据发现，24%的参与者在事件发生1个月后报告了严重的创伤应激。其他常见评估结果包括抑郁（19个研究），内化/外化症状（19）和父母心理健康水平（19）。研究涉及2至5次评估；80%的参与者至少保留参与2次的评估。在研究水平上，更高的保留率与更多次计划评估有关。在参与者水平上，青少年，少数民族青年以及社会经济地位较低的人保留率较低。

**结论:** 本项目证明了将创伤性应激研究数据汇总并重新使用的可行性和价值。作为一项不断进行的研究资源，此档案库可以促进'FAIR'数据的使用并有助于综合分析，以加深对儿童创伤应激的理解。

and making these data available for re-use.

## 1. Introduction

Childhood exposure to acute single-incident trauma is unfortunately common: injury, violence, disasters, traffic accidents, and other potentially traumatic events affect tens of millions of children each year around the world (Children in a Changing Climate Coalition, 2013; UNICEF, 2014; World Health Organization [WHO], 2008). Trauma-exposed children exhibit wide variation in psychological adaptation and outcomes. While many recover well, a significant minority develop psychological sequelae with substantial impact on their health, functioning, and development (Costello, Erkanli, Fairbank, & Angold, 2002; Furr, Comer, Edmunds, & Kendall, 2010; Kahana, Feeny, Youngstrom, & Drotar, 2006). In addition to symptoms of posttraumatic stress disorder (PTSD; i.e. re-experiencing, avoidance, cognitive/mood alterations, and hyperarousal), sequelae of acute trauma exposure include new or worsened symptoms of depression or anxiety, and decreased health-related quality of life (Fowler, Tompsett, Braciszewski, Jacques-Tiura, & Baltes, 2009; Han et al., 2011; Pailler,

Kassam-Adams, Datner, & Fein, 2007). A better understanding of the processes through which children recover after acute trauma is only possible with studies that enrol cohorts of trauma-exposed children and follow them over time. ('Acute trauma' refers to specific potentially traumatic incidents such as violence, injury, or disaster, in contrast to potentially traumatic experiences characterized by chronic exposure, such as maltreatment, abuse, or living in a conflict area.)

There is a rich literature on traumatic stress and related sequelae in children after acute events. Historically, many studies were cross-sectional, evaluating PTSD and other outcomes at a single assessment point many months or years post-trauma, with risk or protective factors examined via retrospective report. In the last several decades, a growing number of prospective studies identified children soon after acute trauma exposure (within days or a few months) and prospectively tracked risk and protective factors and trauma responses over time. This body of research has advanced our understanding of

child traumatic stress, but presents some limitations. Because of the considerable resources required for prospective recruitment and follow-up, many samples are relatively small, limiting both power and generalizability. Comparing results across studies can be challenging due to variations in measures and assessment timing.

Meta-analyses (Alisic et al., 2014; Cox, Kenardy, & Hendrikz 2008; Furr et al., 2010; Hiller et al., 2016; Kahana et al., 2006; Trickey et al., 2012; WHO, 2008) and systematic reviews (Wang, Chan, & Ho, 2013) provide valuable syntheses of aggregate research results across studies, but it has rarely been possible to combine item-level data across studies to conduct analyses at the individual participant level. Integrative data analysis of pooled, harmonized participant-level data ‘makes efficient use of limited resources in the pursuit of a cumulative science’ (Curran & Hussong, 2009). Increasingly, research funders encourage or require open science practices, including data sharing (making data available for re-use, ideally by depositing them in an established data archive) (National Institutes of Health, 2003; Organization for Economic Co-operation and Development, 2007; 2011). However, emerging standards for data stewardship recognize that simply archiving or sharing datasets is not enough. The ‘FAIR’ data principles state that data should be Findable, Accessible, Interoperable, and Re-usable. (Wilkinson et al., 2016) Re-use in integrative cross-study analyses requires consistent application of metadata (information about the data) as well as careful attention to data harmonization, with well-informed decisions by subject matter experts regarding harmonization algorithms to support secondary analyses.

We created the Prospective studies of Acute Child Trauma and Recovery (PACT/R) Data Archive to help address challenges of data stewardship in the traumatic stress field. The overarching goal is to enable researchers to better examine the nature and course of children’s responses to acute trauma exposure by combining data from multiple studies. The objectives of the current paper are to (a) describe creation of the PACT/R Data Archive including methods for standardizing or harmonizing key variables; (b) describe study- and participant-level variables across the first 30 studies in the Archive, including an estimate of the prevalence of significant PTSD symptoms (PTSS); and (c) examine retention to follow-up in these prospective studies and potential study- and participant-level correlates of retention. We also hope this paper will encourage discussion of the value of data sharing, curation, and preservation to advance open and reproducible practices and build cumulative science in the traumatic stress field.

## 2. Method

### 2.1. Overview of data archive

In 2009, our collaborative international team initiated a data archive as part of a larger project investigating predictors of posttraumatic stress in children. In 2017, additional funding allowed the archive to expand and better support findability, accessibility, and re-use of these data. Inclusion criteria for datasets in the PACT/R Archive are: (a) Study conducted with appropriate ethics approval; (b) Study participants (children or adolescents, under age 21 at time of enrolment) identified based on exposure to an acute potentially traumatic event; and (c) Data collected prospectively, at a minimum of two time points, beginning within 6 months of the event. Studies are excluded if participants were identified based on symptoms or treatment-seeking (rather than trauma exposure).

### 2.2. Ethical issues in creation and use of the data archive

The Archive includes de-identified, anonymized data from studies conducted with appropriate ethics approval. The Institutional Review Board (IRB) of The Children’s Hospital of Philadelphia determined that the operation of the archive does not constitute human subjects research because all data are de-identified. Depending on local regulations, submitting a de-identified dataset to the archive may or may not require ethics approval by the investigator’s institution.

### 2.3. Data submission by original investigators

Investigators provide de-identified/anonymized datasets, information on study design and ethics approval, and a data dictionary. Datasets include participant-level data regarding: (a) demographics, (b) exposure to a potentially traumatic index event, (c) posttraumatic stress symptoms, (d) other variables assessed in the study, and (e) if available, the actual timing (in days post-event) of each participant’s assessment at each study assessment point.

### 2.4. Using data from the PACT/R archive

PACT/R data are not fully ‘open’ but are accessible to qualified investigators. Researchers requesting data from the Archive specify the data elements requested, research questions to be addressed, and intended products/uses. Even though all data are de-identified, requestors must agree to maintain data securely and not re-release data to others. Approval of data requests is determined by the PACT/R Steering Committee consisting of 3 to 5 investigators who have contributed data.

## 2.5. Data standardization and harmonization

We have found it useful to distinguish between ‘standardizing’ versus ‘harmonizing’ variables drawn from multiple studies. Here we define ‘standardizing’ as establishing common variable names and response values for essentially identical data points collected in different studies (e.g. child age in years, values assigned to item responses within an established measure). We define ‘harmonizing’ as the process of deriving a new common variable from existing data that measured the same or similar constructs (e.g. educational level as defined in different countries, or intrusive thoughts about a traumatic event as assessed by different PTSD symptom measures).

### 2.5.1. Standard variable names and coding

We established variable naming conventions for key demographic, event, and symptom measure variables; these standard variable names are applied to each dataset upon submission. (The data dictionary, updated periodically, is available at the PACT/R website.) We also examine item numbering and response coding, and recode if necessary to align all datasets with standard values for an established measure (e.g. if a study coded item responses as 1–2–3 when standard values for that measure are 0–1–2).

### 2.5.2. Timing of assessment

Future re-use of these datasets will require flexibility in how the timing of each assessment is considered. We, therefore, provide common information across datasets about assessment timing at both the study and the participant level. At the study level, we defined standard ‘time buckets’ and indicate these in standard variable names: e.g. data collected at the nominal ‘3-month’ follow-up in a given study have variable names starting with ‘t6’, as the ‘t6’ time bucket denotes from 3 months to less than 6 months post-trauma. At the participant level, we provide a means to harmonize data based on the actual number of days post-trauma for each participant’s assessment (e.g. a specific child’s intended ‘3-month’ follow-up may actually have taken place at 112 days). In the Archive, 25 of 30 current datasets provide this information directly; in an additional 3 datasets, it can be reliably estimated (i.e. research measures administered on the same day to groups of children in classrooms). We created templates for recoding item-level data to denote the participant’s ‘true time’ of assessment, facilitating selection or grouping of participants for analysis based on assessment time for a key variable.

### 2.5.3. Demographic data

We created standard or harmonized demographic variables at the participant level. For child sex and

age, this generally required a straightforward renaming of variables and ensuring common coding of values (as noted above). However, variables for socioeconomic status (SES) and race/ethnicity pose different challenges. The most common SES variable across studies was parent education level. Given the wide variation in educational systems across countries, we identified an internationally recognized standard for education level (UNESCO, 2006) with which to create a harmonized parent education variable. In contrast, because race/ethnicity is largely socially constructed and categorized differently across countries (Aspinall, 2007), it was not possible to create a harmonized cross-national coding scheme for race/ethnicity. Instead, we retained standard race/ethnicity coding for each country within a single variable. As just one approach to integrating cross-national ethnicity data, we derived a new harmonized variable denoting whether a child was of racial/ethnic minority status within their country of residence. Future investigators may elect to use the country-based race/ethnicity coding in other ways.

## 2.6. Harmonization of multi-item measures

Harmonization of child PTSD symptom measures illustrates an approach that can be applied to other multi-item measures to facilitate cross-study analyses. In these 30 datasets, PTSD symptom measures fell into three broad types: (1) standardized child interviews assessing DSM-IV or DSM-5 diagnostic criteria; (2) self-report checklists yielding information on DSM-IV or DSM-5 symptom criteria; and (3) self-report checklists yielding a severity score with a validated cut-off for significant symptoms. Most of the 30 datasets assessed PTSD in relation to DSM-IV criteria, a few in relation to DSM-III-R, and only the most recent in relation to DSM-5. Child PTSD symptoms were sometimes also assessed via parent proxy report, especially for younger child participants.

Harmonization algorithms can be applied to any of these types of measures, utilizing information at the level of an overall scale, a subscale, or individual symptom items. Our initial approach was to create common, dichotomized variables at the scale and item level. Future investigators may wish to apply other approaches to harmonization of these data, such as rescaling or ‘binning’ to achieve common item response scales across different measures (Bainter & Curran, 2015; Fried et al., 2018), or using latent variable approaches to build measurement models (Hussong, Curran, & Bauer, 2013). The choice of harmonization approach should fit the research questions being addressed.

At the scale level, we harmonized across PTSD symptom measures by scoring each measure for the presence/absence of a specific type of PTSD symptom

outcome, i.e. meeting diagnostic criteria, or having clinically significant PTSD symptoms. Future investigators should select harmonized outcome variables based on the research question and the availability of data to derive that outcome. For example, one can derive a dichotomous outcome for presence/absence of significant PTSD symptoms from all 30 datasets currently in the Archive (including those where it is not possible to determine diagnostic status) using established rules for symptom counts or validated cut-offs. This was our approach in the current analyses.

We have reported elsewhere on item-level harmonization for traumatic stress symptoms in an earlier subset of datasets in the Archive (Kassam-Adams et al., 2012). Briefly, we reviewed available items from all traumatic stress measures utilized in any dataset, and used an expert panel to arrive at consensus regarding which items (a) adequately represented each target symptom (i.e. as defined in a DSM-IV or DSM-5 symptom criterion) and (b) were sufficiently congruent in wording to be combined for cross-study analyses. Item ratings were dichotomized using each measure's standard scoring rules for symptom presence, or expert consensus when no rule was available, to derive a new harmonized cross-study variable.

## 2.7. Data analyses

We conducted descriptive analyses of study-level characteristics and participant-level demographic and trauma characteristics. To estimate PTSD symptom outcomes for participants across studies, we selected the first PTSD assessment for each child conducted more than 1 month post-trauma. If more than one PTSD symptom measure was available for a participant at that time point, we used the best available measure, prioritizing type of measure in the following order: standardized interview, checklist with all DSM-IV symptoms, checklist with some DSM-IV symptoms, non-standardized clinical interview. We prioritized child-informant measures (available in 29 of 30 studies) over parent-report measures. We examined rates of retention (participants completing at least two assessments) in these prospective studies, and used Chi square analyses or ANOVA, as appropriate, to explore several study-level and participant-level variables potentially associated with retention.

## 3. Results

The PACT/R Archive continues to grow as we receive additional datasets. Results presented here are based on the first 30 datasets included in the Archive.

### 3.1. Study and participant characteristics

Table 1 presents study-level characteristics: type(s) of acute trauma exposure, age range of child participants, country, sample size at baseline, number/timing of planned research assessments. Sample size ranges from 50 to 568 (mean = 183.3, median = 133). Participants were recruited in emergency departments (13 studies), inpatient medical (hospital) settings (19 studies), outpatient medical settings (3 studies), schools (4 studies – all post-disaster), and/or social service agencies (1 study). Languages of assessment include English (27 studies), German (2 studies), Spanish (2 studies), and Turkish (1 study).

Table 2 presents the number of studies (and the number of individual participants) in which several key demographic or trauma variables were assessed. All studies recorded child age, gender, and primary trauma type, and nearly all recorded race/ethnicity (thus participant-level data is rarely missing for these variables). Study-level variation is more evident in the availability of data regarding parent education and prior trauma exposure. Table 2 also presents descriptive results of participant-level data, from pooled analyses across all datasets, for demographics, trauma type, and prior trauma. Among children for whom these were assessed, 50.1% were of minority ethnicity, 20.7% had parents who did not complete secondary education, and 54.7% reported prior trauma exposure.

### 3.2. Assessment of post-trauma adaptation and recovery

Across the 30 studies, 22 different measures were used to assess children's posttraumatic stress symptoms; 17 measures with the child as informant and 5 with the parent as informant. Many studies used more than one measure or informant, e.g. 11 studies used both parent proxy-report and child self-report. With the child as informant, 12 studies used standardized interviews, one used a non-standardized clinical interview, and 26 used questionnaires/checklists. With regard to timing, 21 studies assessed child traumatic stress within 1 month of the index event, and all 30 studies assessed these symptoms one to 6 months post-event.

As one indicator of the traumatic stress responses reported by trauma-exposed children in these 30 studies, we identified the first PTSD symptom assessment conducted 1 month or more post-trauma for each participant and derived a harmonized variable for the presence of significant PTSD symptoms at that assessment. Across all datasets, 4510 (82.0%) participants had data regarding at least one PTSD symptom assessment 1 month or more post-trauma. If more than one PTSS assessment was available, we used the first available post-30-day assessment for

**Table 1.** Study characteristics for the first 30 PACT/R Data Archive datasets.

PACT/R dataset number	Type(s) of acute trauma exposure (index event)	Age range (years)	Country	Year(s) <sup>a</sup>	N in dataset	Number of assessments	Assessment timing <sup>b</sup>						
							< 24 hr	1 day-1 mo	1-3 mo	3-6 mo	6-12 mo	≥ 12 mo	
1001	Injury/RTA (Kassam-Adams & Winston, 2004)	8-17	US	1999-2001	243	3		X X				X	
1002	Injury/RTA (Feinberg, 2004)	5-7	US	1999-2001	122	3		X X				X	
1003	Injury/Medical (Kassam-Adams, 2006)	8-17	US	2002-2004	176	2		X		X			
1004	Violence (Fein et al., 2002)	8-18	US	1999-2000	185	5	X	X					X
1005	Injury (Kassam-Adams, Bakker, Marsac, Fein, & Winston, 2015)	8-17	US	2003	262	2	X	X					
1006	Injury/Medical/Violence/RTA (Kassam-Adams et al., 2013)	8-17	US	2007-2010	447	2	X	X				X	
1007	Injury (Kassam-Adams et al., 2011)	8-17	US	2007-2008	131	3	X	X					
1008	Injury (Marsac, Donlon, Winston, & Kassam-Adams, 2013)	8-17	US	2005	120	3	X	X					
1009	Violence (Pailler et al., 2007)	8-17	US	2001-2003	392	2	X	X				X	
1010	Injury (Le Brocque, Hendrikz, & Kenardy, 2010)	7-16	AUS	2000-2002	151	4	X	X				X	X
1012	Injury (Kenardy, Thompson, Le Brocque, & Olsson, 2008)	7-15	AUS	2003-2004	104	3	X	X				X	X
1013	Injury (Kenardy et al., 2012)	6-14	AUS	2004-2006	205	5	X	X		X		X	X
1014	Injury (Cox & Kenardy, 2010)	7-16	AUS	2007	63	3	X	X				X	X
1018	Injury (Nugent, Christopher, & Delahanty, 2006)	8-18	US	2001-2003	85	3	X	X		X			
1019	Injury (Ostrowski, Christopher, van Dulmen, & Delahanty, 2007)	8-18	US	2003-2004	61	3	X	X		X			
1020	Violence/RTA (Meiser-Stedman, Yule, Smith, Glucksman, & Dalgleish, 2005)	10-16	UK	2001-2002	103	3	X	X		X		X	
1021	RTA (Meiser-Stedman, Smith, Glucksman, Yule, & Dalgleish, 2008)	2-10	UK	2004-2005	113	3	X	X				X	
1022	Injury/Medical/Violence/RTA (Nixon, Ellis, Nehmy, & Ball, 2010)	7-17	AUS	2004-2006	135	3	X	X		X		X	
1023	RTA (Zehnder, Meuli, & Landolt, 2010)	7-16	SUI	2004-2007	50	3	X	X		X		X	
1025	Injury/RTA/Violence (Zatzick et al., 2006)	12-18	US	2002-2003	108	4	X	X		X		X	
1026	Injury (Alisic et al., 2015)	3-16	AUS	2013-2014	85	3	X	X		X		X	
1027	Disaster (hurricane) (La Greca, Silverman, Verman, & Prinstein, 1996)	7-12	US	1992	568	3	X	X		X		XX	
1028	Disaster (hurricane) (La Greca, Silverman, & Wasserstein, 1998)	9-12	US	1992	156	3	X	X		X		X	
1031	Disaster (earthquake) (Eksi et al., 2007)	9-16	TUR	1999	160	2	X	X		X		X	
1032	RTA/Injury (de Haan, Tutus, Goldbeck, Rosner, & Landolt, 2019)	7-18	SUI	2016-2018	130	3	X	X		X		X	
1034	Injury (O'Connor et al., 2012)	13-17	US	2007-2008	230	5	X	X		X		XXX	
1035	Disaster (hurricane) (Self-Brown, Lai, Thompson, McGill, & Kelley, 2013)	8-16	US	2005	426	4	X	X		X		XXX	
1036	Injury (Marsac et al., 2017)	8-17	US	2012-2014	101	3	X	X		X		X	
1037	Injury/RTA/Violence/Medical (Meiser-Stedman et al., 2017)	8-17	UK	2010-2013	260	3	X	X		X		X	
1038	Injury/RTA/Violence/Medical Halligan (Hiller et al., 2018)	6-13	UK	2014-2015	127	3	X	X		X		X	
	<b>Total for combined 30 datasets</b>	<b>2-18</b>		<b>1992-2018</b>	<b>5499</b>	<b>2-5</b>							

<sup>a</sup>Calendar year(s) in which index trauma occurred; <sup>b</sup>Time categories are mutually exclusive, i.e. '1-3 mo' denotes at least 1 month but less than 3 months; multiple Xs denote multiple assessment points within one time category. RTA = Road traffic accident; Medical = Acute medical event other than injury; US = United States; AUS = Australia; UK = United Kingdom; SUI = Switzerland; TUR = Turkey.

**Table 2.** Participant-level data from the first 30 PACT/R Data Archive datasets: Primary trauma type (index event), demographic characteristics, and prior trauma exposure.

	Frequency N (%)	Number of studies and number (percent) of participants in which this was assessed
Primary trauma type (index event) for child		30 studies
Unintentional injury	2545 (46.3%)	5499 participants (100%)
Disaster	1310 (23.8%)	
Interpersonal violence	735 (13.4%)	
Road traffic accident	573 (10.4%)	
Acute medical event	136 (2.5%)	
Missing	165 (3.0%)	
Child age (in years)		30 studies
2–5	84 (1.5%)	5499 participants (100%)
6–12	3124 (56.8%)	
13–18	2215 (40.3%)	
Missing	76 (1.4%)	
Child gender		30 studies
Male	3275 (59.6%)	5499 participants (100%)
Female	2217 (40.3%)	
Missing	7 (0.1%)	
Child is of minority race/ethnicity in country of residence		28 studies
Yes	2494 (45.4%)	5231 participants (95.1%)
No	2487 (45.2%)	
Missing	250 (4.5%)	
Not assessed in study	268 (4.9%)	
Parental education level		16 studies
Did not complete secondary education	511 (9.3%)	3145 participants (57.2%)
Completed secondary education	1952 (35.5%)	
Missing	682 (12.4%)	
Not assessed in study	2354 (42.8%)	
Child has prior trauma exposure		17 studies
Yes	1265 (23.0%)	2502 (45.5%)
No	1046 (19.0%)	
Missing	191 (3.5%)	
Not assessed in study	2997 (54.5%)	

that participant. Time from index event to this assessment ranged from 31 to 760 days (median = 90 days); the vast majority (86%) were within 6 months, and nearly all (98%) within 1 year. Significant PTSS was present for 1061 of these 4510 child participants, for a prevalence rate of 23.5% (95% CI: 22.3–24.8%).

Beyond posttraumatic stress, other child mental health outcomes assessed in these 30 studies included depression symptoms (19 studies), anxiety symptoms (10 studies), and broad assessments of internalizing and externalizing symptoms (19 studies). Parents' own mental health outcomes were assessed in 20 studies, including parents' traumatic stress (20 studies), depression (14 studies), and anxiety (10 studies). The range of other variables available across multiple datasets in the PACT/R Archive continues to evolve as new datasets are added. These include physiological variables (e.g. heart rate, cortisol levels), cognitive variables (e.g. trauma-related cognitive appraisals, memory processes), and other information on post-trauma adaptation (e.g. child coping strategies, help-seeking), and health-related quality of life.

### 3.3. Retention to follow-up

Across these 30 studies, the number of planned assessment points ranged from 2 to 5. We defined retention as a participant's completion of at least two assessments. At the study level, rates of retention ranged from 47.0%

to 100%. At the participant level, 4406 of 5499 (80.1%) children were retained for two or more assessments.

We examined the potential association of study design characteristics with retention. Only two studies had retention rates under 50%: a study in which research assessments were added to a programmatic effort to reach violently injured youth over time (Dataset 1004 (Fein et al., 2002)), and a study with Turkish earthquake survivors that attempted follow-up only with those who exhibited significant PTSD symptoms at the initial assessment (Dataset 1031 (Eksi et al., 2007)). We used ANOVA to compare mean study-level retention rates by type of recruitment site, timing of recruitment after the index event, and the number of planned assessments. We found no difference in study-level retention rate based on recruitment site or timing of recruitment: pre-event (1 study), within 24 h (6 studies), within the first month post-event (19 studies), or later than a month post-event (4 studies). Not surprisingly, studies with more planned assessment points were more likely to retain participants across at least 2 research assessments: mean retention = 68.0% in studies with 2 planned assessments, 84.8% in those with 3 planned assessments, and 86.7% in those with 4 or more planned assessments (ANOVA:  $F = 3.53$ ,  $df 2$ ,  $p = .04$ ).

Using participant-level data, we examined the potential association of demographic characteristics, type of index trauma, or prior trauma exposure with



retention. In pooled cross-study analyses we found no difference in retention based on child gender or prior trauma. We did observe differences based on child age, minority ethnicity, parental education, and type of index trauma. Retention rates were somewhat lower in adolescents (age 13 to 18) than in school-age children (age 6 to 12): (75.9% vs 82.9%;  $X^2 = 40.146$ ,  $df = 1$ ,  $p < .0001$ ). Among the small number ( $N = 84$ ) of young children (age 2 to 5) in the Archive, 89.3% were retained for two or more assessments. Retention was lower among children of minority ethnicity compared to non-minority children (74.4% vs 87.7%;  $X^2 = 143.453$ ,  $df = 1$ ,  $p < .0001$ ), and among children whose parents had not completed secondary education (75.2% vs 90.1%;  $X^2 = 79.593$ ,  $df = 1$ ,  $p < .0001$ ). Retention rates were higher among children whose index trauma was a disaster (84.6%), an unintentional injury (84.3%), or a road traffic accident requiring medical attention (82.1%), and lower among children whose index trauma was an acute medical event (66.2%) or interpersonal violence (61.9%) ( $X^2 = 211.424$ ,  $df = 4$ ,  $p < .0001$ ).

## 4. Discussion

The development of the PACT/R Data Archive demonstrates the feasibility and value of bringing together traumatic stress research data and making it available for re-use. The Archive now includes datasets from more than 30 studies conducted by 15 research teams in 5 countries, ranging from recently completed studies to studies conducted several decades ago. The project has created a sustainable framework for standard variable names, metadata, and harmonization algorithms, and has already enabled new analyses of these data by investigators around the world.

This Archive has begun to address an important gap. To our knowledge, there is no other data repository with substantial numbers of datasets bearing on child acute trauma and recovery in non-treatment-seeking populations. Given the worldwide prevalence of acute trauma exposure for children, and the public health importance of understanding children's responses to this exposure, this is a much-needed resource. Indeed, there are only a few existing data resources focused on any area of child trauma (Cornell University; Steinberg et al., 2014). In addition to future data, there is some urgency to preserving the rich legacy of past child trauma research; several datasets contributed to the Archive were previously in outdated storage media, at risk for not being retrievable.

The utility of this research resource is already in evidence. To date, the PACT/R Archive has fulfilled data requests from investigators in North America, Europe, and Australia, resulting in two peer-reviewed publications (Kassam-Adams et al., 2012; Lenferink

et al., 2020), others in preparation or under review, and two completed doctoral theses (Vibhakar, 2018; Walker, 2018). These projects demonstrate the potential impact of this growing set of accessible, harmonized child trauma data to enable novel analyses utilizing large sample sizes.

### 4.1. Lessons from the PACT/R archive about prospective child trauma study methods

#### 4.1.1. Demographic and trauma characteristics

The 30 current datasets include data from a wide range of school-age children and adolescents; data on children under six are limited. The higher proportion of boys versus girls in these datasets is driven primarily by studies focused on injury or interpersonal violence, reflecting gender-based exposure rates (WHO, 2008). There is economic and ethnic diversity among participants, with approximately half of minority ethnicity and one in five of lower socioeconomic status. Key demographic and trauma characteristics (age, gender, ethnicity, trauma type) were assessed nearly universally and can thus be used as predictors or covariates in analyses using Archive data. There is more cross-study variation in assessing other characteristics (socioeconomic status, prior trauma exposure) that could be useful in many analyses. This variation suggests that the field might benefit from converging on a core set of common data elements for future child trauma studies.

#### 4.1.2. Assessment of traumatic stress and other outcomes

The most striking finding about PTSS assessment is the sheer number of different measures used across studies. The child trauma field has not converged on a gold standard measure for traumatic stress. Beyond PTSS, the most commonly assessed outcomes were child depression, internalizing/externalizing symptoms, and parent traumatic stress. Variation in assessment of outcomes, as well as potential risk/protective factors and mechanisms, indicates another area for fruitful discussion of common data elements for future studies.

The PACT/R Archive makes it possible to estimate prevalence from individual participant data in a large cross-study pooled sample, complementing results of meta-analyses which rely on aggregate study-level data. The rate of significant PTSS at 1 month or more post-trauma was 23.5% (95% CI: 22.3–24.8%) amongst 4510 trauma-exposed children across 30 datasets. We can compare this with results of recent meta-analyses. Alisic et al. (2014) conducted a meta-analysis of 43 studies (total  $N = 3563$ ) enrolling children with any trauma type (not limited to acute trauma), deriving a pooled estimate of 15.9% (95% CI: 11.5–21.5%) with full PTSD at the first eligible study wave after 1 month (Alisic et al., 2014). Hiller

et al. (2016) conducted a meta-analysis of 28 studies (total  $N = 3910$ ) of children exposed to any discrete traumatic event, deriving pooled estimates of significant PTSS at a number of time points: 21% (95% CI: 16–28%) at 1 month and 15% (95% CI: 10–22%) at 3 months post-trauma (Hiller et al., 2016).

#### 4.1.3. Recruitment and retention

An impressive 80% of children were retained for repeated assessment across these datasets – crucial for understanding PTSS development over time. Retention rates were high across all demographic groups, and did not vary by recruitment site or timing. The disparity in retention based on minority ethnicity or lower socioeconomic status emphasizes the ongoing need for careful attention to retaining these groups. One methodological note is the importance of recording participant-level data on assessment timing – key information for many research questions and analytical approaches.

#### 4.2. Conclusions and implications for future work

It is important to note some limitations. While the Archive has extensive information on study measures and variables, it is not always possible to collect copies of the original questionnaire documents or data processing scripts from each study. Regarding study characteristics summarized here, despite the large number of datasets, they may not be representative of all prospective child trauma studies. With more universal data sharing and harmonization, future analyses will be better able to characterize the state of the field. These data represent a large number of trauma-exposed children, but geographic distribution (mostly industrialized countries), demographic characteristics (few younger children), and trauma types must be taken into account when using these data to understand child trauma responses. Continuing to expand geographic, age, and other diversity of trauma-exposed children represented in the Archive is an important goal.

In conclusion, the PACT/R Data Archive project makes item-level, participant-level data available for integrated cross-study analyses that could address a range of research questions, including examining causal models, risk/protective factors, and trajectories of post-trauma recovery. Further information about the Archive is available at [www.childtraumadata.org](http://www.childtraumadata.org), including how to contribute or request data; and information on variables, measures, and harmonization algorithms.

It is rare in the child trauma field to have the opportunity to collect or analyse ‘big data’. This project reflects the rich potential of the ‘long tail’ data (Ferguson, Nielson, Cragin, Bandrowski, & Martone, 2014) that our field has in abundance, i.e. combining data from many smaller research studies to enable new analyses and insights. The Global Collaboration on

Traumatic Stress recently adopted the theme of ‘Making Traumatic Stress Research Data “FAIR”’. The PACT/R project exemplifies one approach to addressing this goal, and has already helped to make prospective child trauma data more findable, accessible, and re-usable. Data sharing, preservation, and re-use advance more robust science, and ultimately support a strong empirical foundation for effective intervention to help children exposed to acute trauma.

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#### Data availability

The data that support the findings of this study are available upon request from the PACT/R Data Archive. <https://childtraumadata.org/use-pactr-data>

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