

# Disaster Research Response (DR2): A Platform for Collaboration



**Richard Kwok, PhD**

August 2, 2022

Symposium on Pediatric Disaster Science

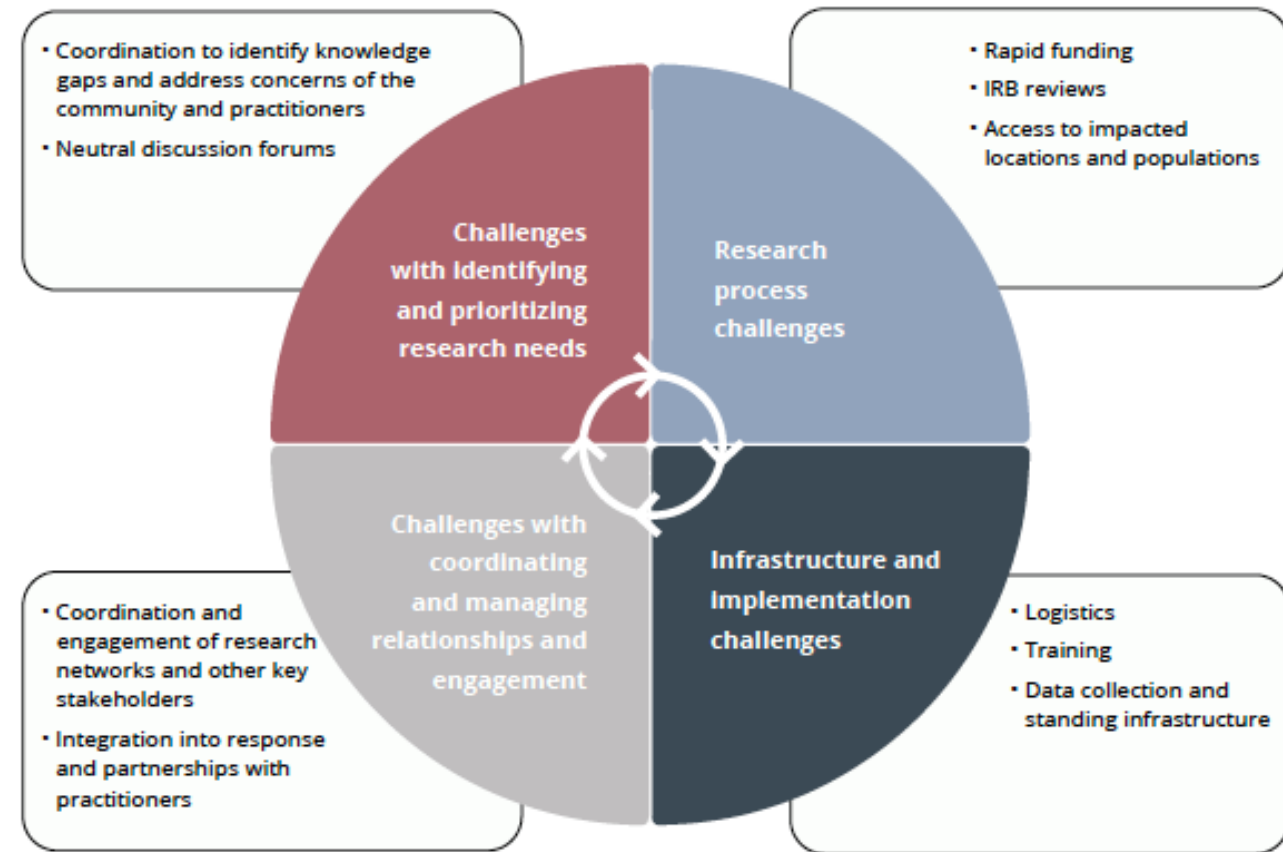
National Academies of Science, Engineering, and Medicine

Washington, DC

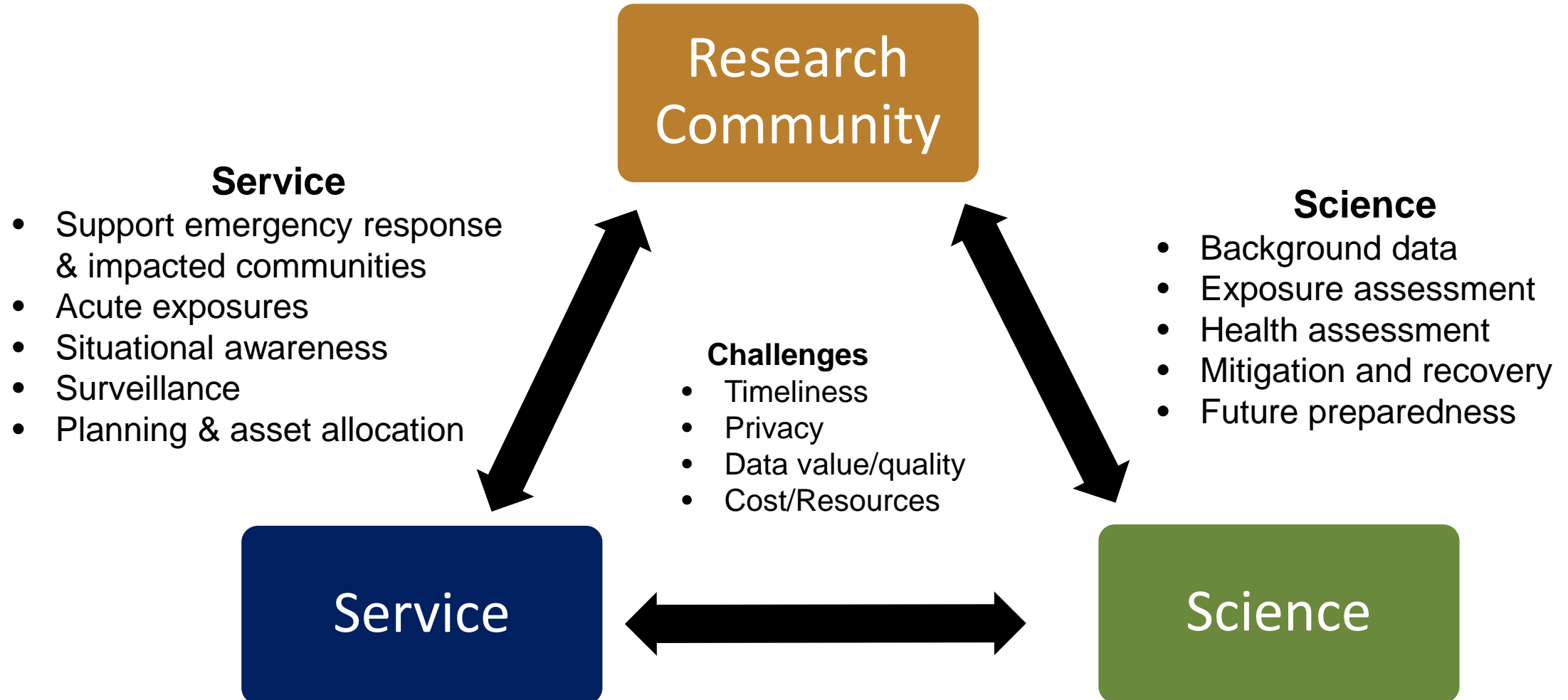
## NIH Disaster Research Response (DR2) Program (started in FY 2014)

### *Overcoming the Challenges for Timely Data Collection and Research*

- Advance ability to rapidly identify **data gaps** and **research priorities**
- Improved **processes** to support data collection and management (IRB, funding, )
- Access to **data collection tools** and **training** for researchers with diverse partners
- **Facilitating engagement** between agencies, academia, workers, and communities
- **Integration** into planning and emergency response system



## Academic DR2 Responses: Strengthening Capacity for Service & Science



## NIEHS DR2 Centers & Grantees Group/Network (started Dec 2019)

*Engage & elevate NIEHS Grantee Community and partners to contribute expertise, experience, and research to the nation and globally*

### Objectives

- Highlighting value of EHS
- Info sharing
- Fostering collaborations
- Improving resources
- Improving disaster research
- Helping communities!

**Developing an Environmental Health Sciences COVID-19 Research Agenda: Results from the NIEHS Disaster Research Response (DR2) Work Group's Modified Delphi Method**

Nicole A. Errett <sup>1,\*</sup>, Marilyn Howarth <sup>2</sup>, Kimberley Shoaf <sup>3</sup>, Megan Couture <sup>4</sup>, Steven Ramsey <sup>4</sup>, Richard Rosselli <sup>4</sup>, Sara Webb <sup>4</sup>, April Bennett <sup>5</sup> and Aubrey Miller <sup>6</sup>

### NIEHS US Research and Training Centers

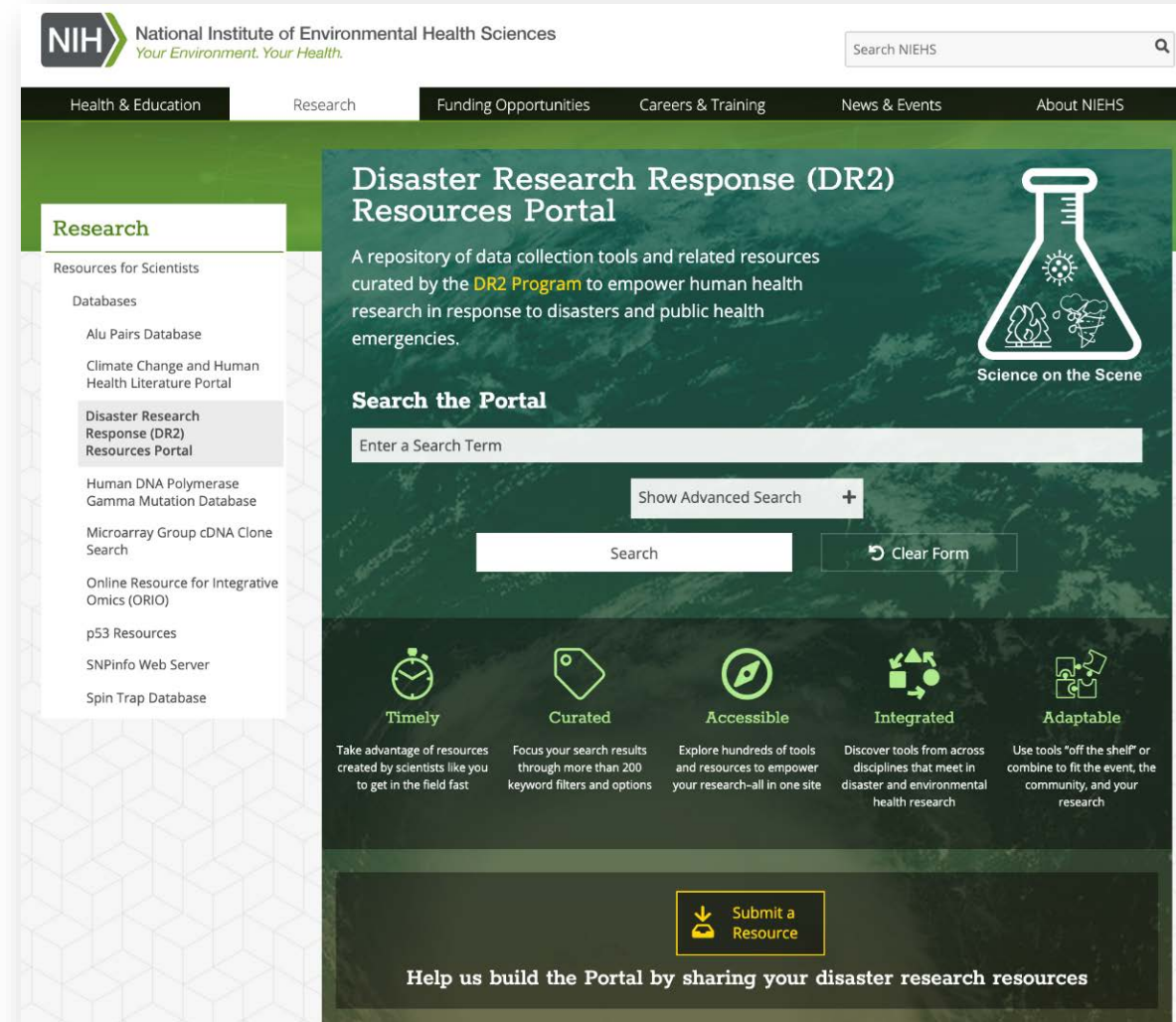


Updated: Aug 2020

## DR2 Resources Portal

*Increase speed and quality of epidemiologic and clinical research & Promote standard measures, replication, cross comparisons*

- Over 500 resources, all publicly available
  - Questionnaires
  - Surveys
  - Protocols
  - Guidance documents
- Search tools are simple and intuitive.
- Metadata (e.g., languages, populations, length and time, ease of use, contact info)
- Online Submission of Resources

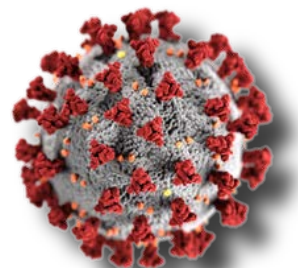




## The DR2 Resources: Empowering the NIH DR2 Response to COVID-19

- ***April 2020 NIEHS asked to host NIH COVID-19 Survey Instruments***
- *Need for access to rapidly evolving survey items by researchers*
- *Need to maximize comparisons across datasets or studies, and facilitate data integration and harmonization*

***NIH funding opportunities encourage use of DR2 survey items***



- Over 130 Survey Tools for COVID
- Data Dictionaries
- Common Data Elements (CDEs)
- REDCap Data Management



**FAIR Data Principles (Source:  
National Institute of Environmental  
Health Sciences)**

Enter a Search Term

FILTER BY
FILTER CRITERIA

☐ Administered By

☐ Administration Mode

☐ Administration/Completion Time

☐ Availability

☐ Common Data Elements Used

☐ Ease of Use

☐ Electronic Data Capture (EDC)

☐ Flesch-Kincaid Reading Level

☐ Language

☐ Number of Survey Questions

☐ Resource Type

☐ Study Population

☐ Event Type

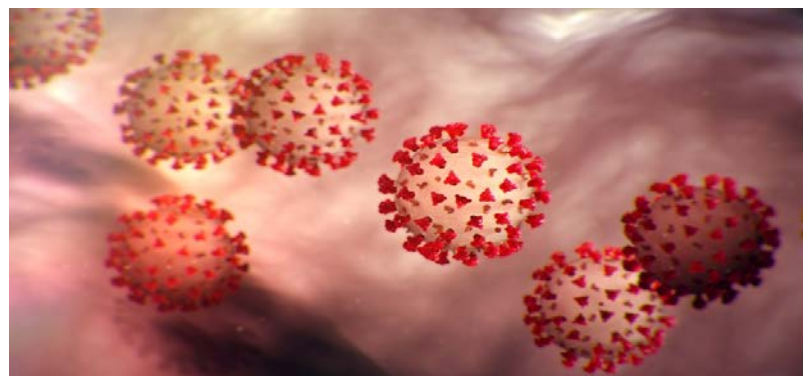
☐ Exposure Agent

# DR2 New Search Engines and Topic Areas

COVID Tool Main Topics for quick access by interest area:

MAIN TOPICS	
Diagnosis, Status, Treatment, Recovery	Symptoms
Comorbidities	Demographics
Mental Health	Environmental Factors
Travel History	Personal & Family Impacts
Risk Reduction Behaviors	Perceptions
Government Support	Community Impacts
Other	PASC / Long COVID

# Intake Form and Meta Data



## Promoting Data Harmonization to Accelerate COVID-19 Pregnancy Research

Post-Acute Sequelae of SARS-CoV-2 Infection and Vaccine  
Attitudes Working Group Addendum

## Disaster Research Response (DR2) Resources Portal

### Resource Submission Form



To suggest a resource (survey, study protocol, data dictionary, or other associated material) for inclusion in the Disaster Research Response (DR2) Resources Portal repository, please fill out the form below as completely as possible. Your suggestion will be reviewed for appropriateness for inclusion. Additional information on field/option criteria can be found in the [DR2 Criteria Document](#).

By submitting this information, you are indicating that you are authorized to make this information publicly available on the [DR2 Resources Portal](#). Thank you for helping to build the repository!

All required fields have the word (Required) after the label.

#### Resource Description

**Title (Required)**

Title of the Resource. Do not begin the title with "A, An, or The."

**Subtitle**

Subtitle of the Resource. Do not include subtitles in the main title field.

**URL (Required)**

The online location of the Resource. If the Resource is not currently available online, please indicate below and upload a file of the Resource at the end of this form (.doc, .pdf, .xls, etc.). Related Resources can also be uploaded at the end of this form.

☐ URL unavailable

**Resource Type (Required)**

Select One



**Description (Required)**

Please provide a brief summary (maximum of 1,000 characters) describing the Resource. In particular, include information not covered by other fields in this form (e.g., major modules, study design, past use, IRB status, etc). For an example description, see [Fordham University's Coronavirus Victimization Distress Scale](#)



# Recommendations for Common Data Elements for COVID-19 Studies Including Pediatric Participants

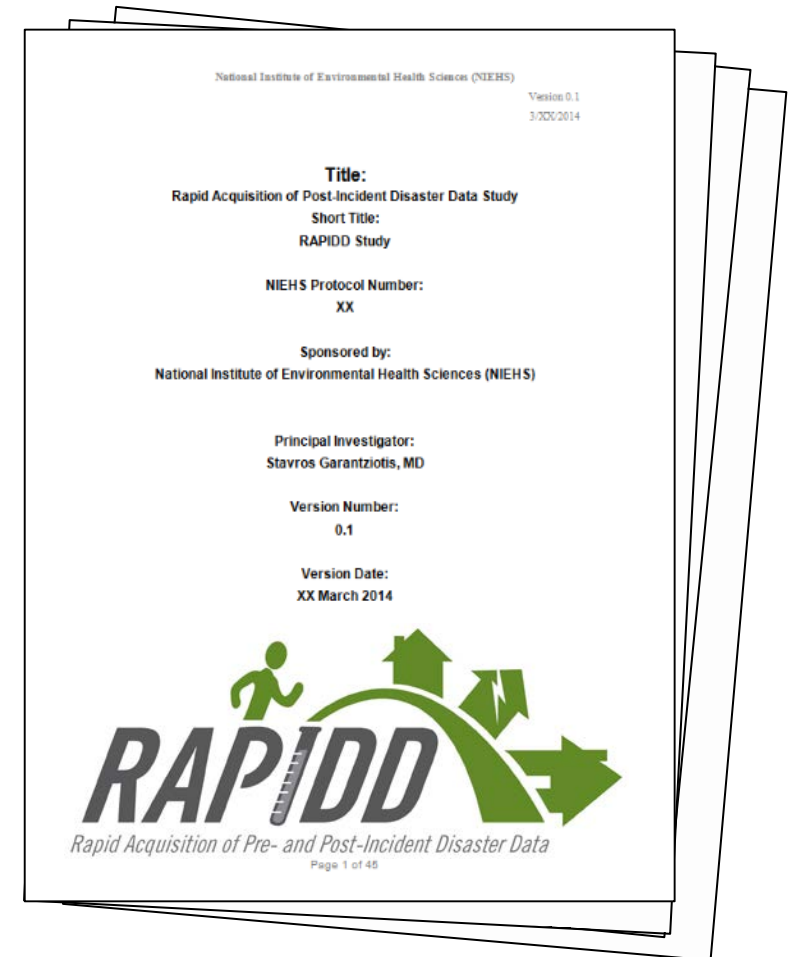
Promoting Data Harmonization to Accelerate COVID-19 Pediatric Research

URL:	<a href="https://www.niehs.nih.gov/research/programs/disaster/database/promoting_data_harmonization_to_accelerate_covid_19_pediatric_research_508.pdf">https://www.niehs.nih.gov/research/programs/disaster/database/promoting_data_harmonization_to_accelerate_covid_19_pediatric_research_508.pdf</a> 
Resource Type:	Guideline
Related Resources:	<a href="#">See list of available resources</a>
Source:	Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)
Contact:	<a href="#">Robert Tamburro</a> 
Availability:	Publicly Available, No Cost
Common Data Elements:	Yes (RADx CDEs, CONNECTS NHLBI Common Data Elements, Pregnancy CDEs, Clinical Data Coordination Group (Project 5) CDEs, NIH CDE Repository CDC COVID-19 Community survey question bank, RADxUP)
Date Published:	07/08/2021
Date Record Updated:	11/29/2021
Description:	We present a battery of recommended biomedical and psychosocial common data elements (CDEs) and measures that, when combined across datasets,

Additional Descriptors	
Administered By:	Medical Professional, Parent/Teacher, Researcher/Professional Interviewer, Self, Trained Non-Expert
Administration Mode:	In-Person Interview, Online/Mobile App, Paper/Written, Phone Interview
Administration/Completion Time:	60+
Ease of Use:	Moderate
Electronic Data Capture (EDC):	RedCap
Language:	English
Number of Survey Questions :	75-99
Resource Type:	Guideline
Study Population:	Age <ul style="list-style-type: none"><li>Age: Child<ul style="list-style-type: none"><li>Children: Infant, Adolescent/Teen</li></ul></li></ul>
Event Type:	Infectious Disease Outbreak
Exposure Agent:	Biological/Infectious Agent <ul style="list-style-type: none"><li>Biological/Infectious Agent: Virus<ul style="list-style-type: none"><li>Virus: SARS-CoV-2, SARS-CoV-1, MERS</li></ul></li></ul>
Health Impact/Organ System:	Circulatory/Cardiovascular, Developmental, Diabetes/Obesity, Digestive/Excretory, Endocrine, Hepatic, Immune/Lymphatic, Malnutrition/Food Insecurity, Mental Health/Well-Being, Morbidity/Mortality, Neurological/Nervous System, Renal/Urinary, Respiratory, Skeletal <ul style="list-style-type: none"><li>Developmental: Birth Outcomes, Cognitive/Neurological/Psychological Disorder</li></ul>
Special Topics:	Community Impacts, Comorbidities, Demographics, Diagnosis/Status/Treatment/Recovery, Domestic Violence/Family Impacts, Illicit Drug Use/Substance Abuse, Lifestyle/Quality of Life, Perceptions, Preparedness, Risk Reduction Behaviors, Social Determinants of Health, Social Support/Resilience, Symptoms <ul style="list-style-type: none"><li>Risk Reduction Behaviors: Vaccine-related</li></ul>
Funding Source:	National Institutes of Health

# NIEHS Emergency Research Protocol: Rapid Acquisition Pre/Post Incident Disaster Data (RAPIDD). Initial Release 2015

- NIEHS IRB pre-approved protocol (2015)
- Standardized methodology using established instruments
- Collect *scalable* questionnaire data and biological specimens
- Appendices enable quick modification for amendments
- Adopted by NIEHS funded centers
  - University of Iowa, University Texas-Medical Branch, Oregon State University



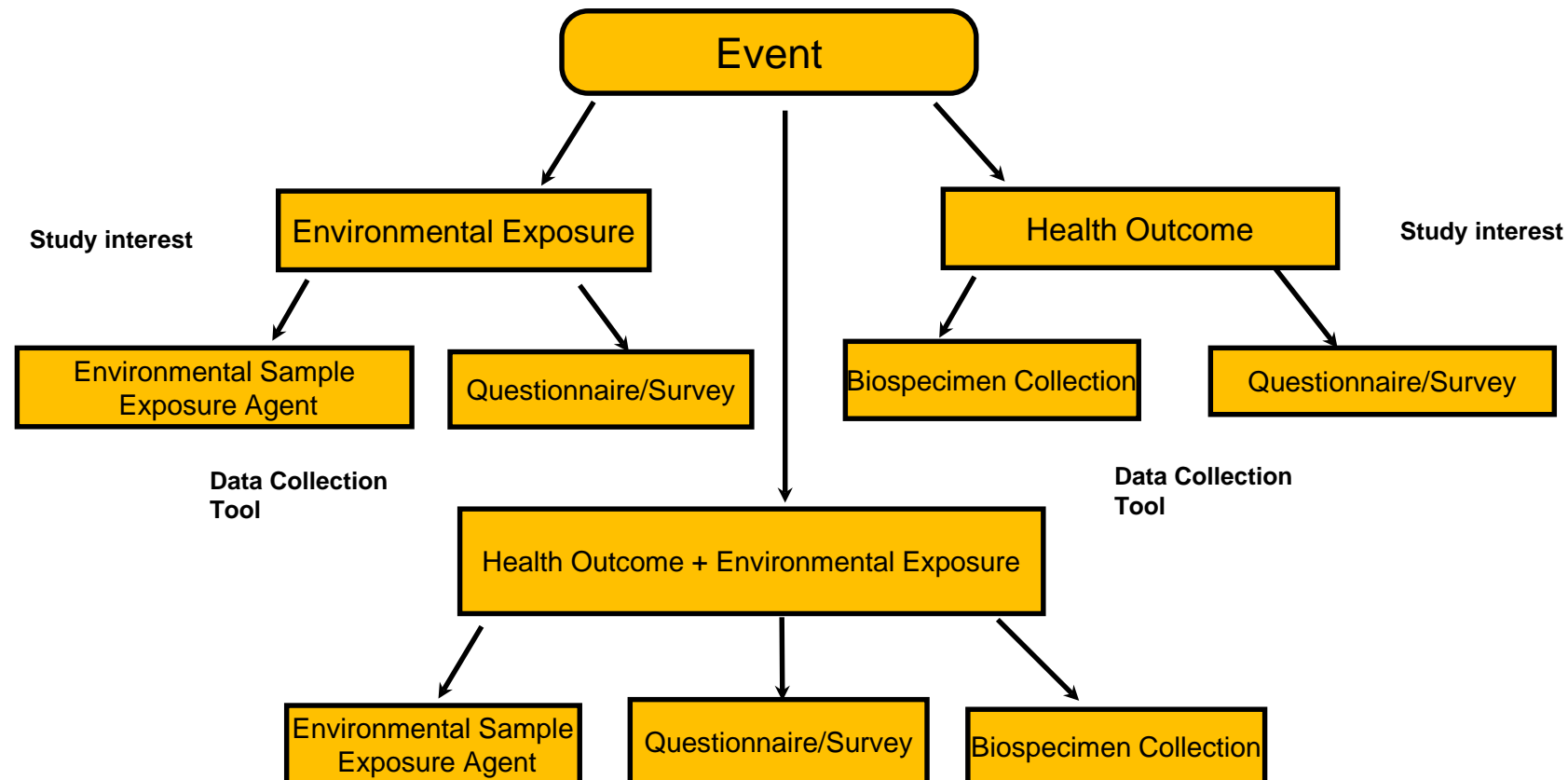
## Moving Towards the DR2 Café Vision



# RAPIDD 2.0

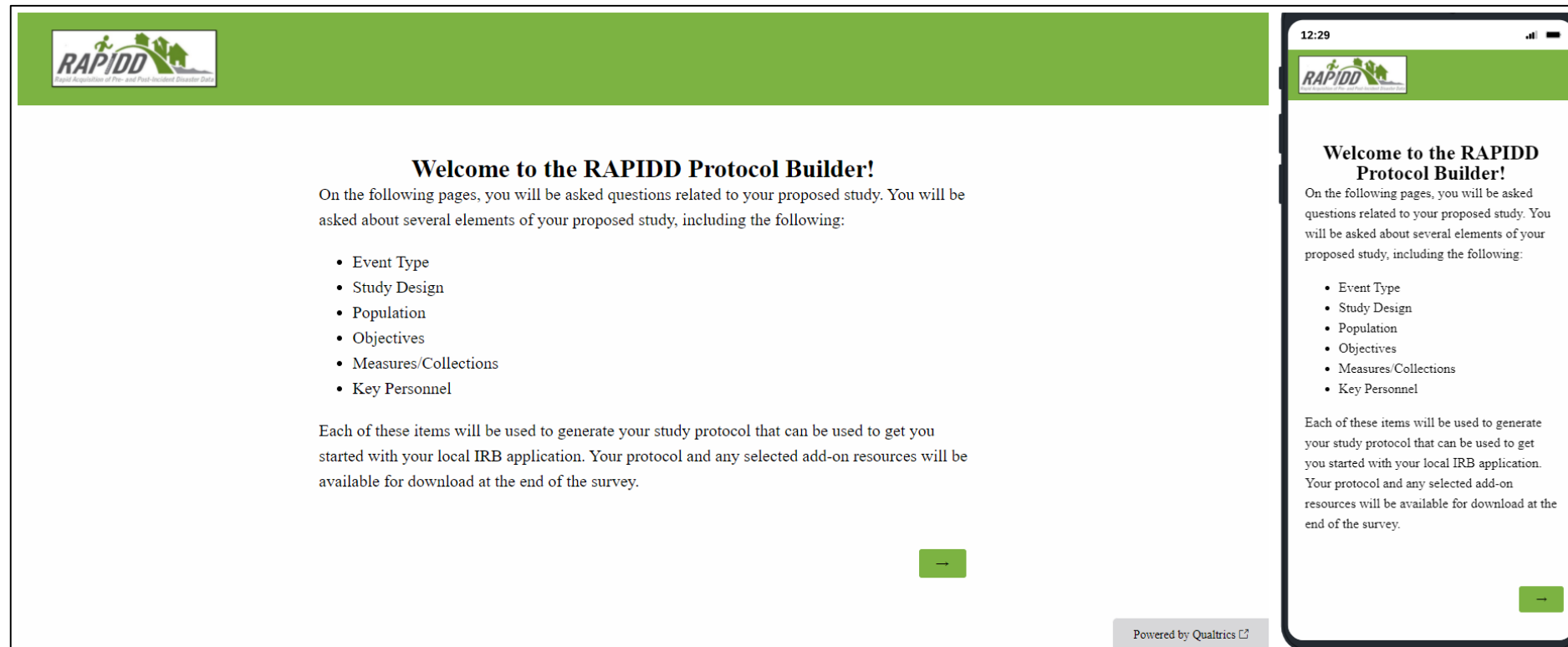
## User Workflow

1. Investigator selects the event
2. Investigator selects study interest
3. Based on study interest, investigator selects data collection tool



## RAPIDD 2.0 Protocol Builder Concept

- Comprised of user inputs and approved protocol text from various sources
- Generates an output file consisting of protocol language, procedural guides, and informed consent forms





## RAPIDD Protocol Builder Concept

- Enables quick access to DR2 resources based on user's research interests and inputs

12:29

**RAPIDD**  
Your Environment. Your Health.

The following Institutional Review Board (IRB) will be overseeing this study:

Which event type(s) is your research related to?

☐ Chemical Contamination Release Event

☐ Drought

☐ Earthquake

☐ Flood

☐ Hurricane

☐ Infectious Disease Outbreak

☐ Large Scale Violence/Terrorism

☐ Tornado/Windstorm

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**RAPIDD**  
Your Environment. Your Health.

Which, if any, specific exposures are you interested in studying?

☐ Air Pollutant (e.g. CO<sub>2</sub>, PM, PAHs)

☐ Allergens

☐ Asbestos

☐ Bacteria

☐ Metal

☐ Mold/Fungus

☐ Nanomaterial

☐ Pesticide/Herbicide/Fungicide

☐ Radiological Agent

☐ Virus

☐ None of the above/Not applicable to my study

12:29

**RAPIDD**  
Your Environment. Your Health.

Below you will find links to surveys/questionnaires from the [DR2 Resources Portal](#) that have been used to study the impacts of Hurricanes. (Note: Links will open in a new window) Please carefully review the resources at the links provided and select those that you would like to include in your study. Your selections will appear later on in the survey.

Hurricane

☐ [Disaster Adaptation and Resilience Scale \(DARS\)](#)

☐ [Hurricane Maria Household Mortality Survey](#)

☐ [Texas Flood Registry](#)

☐ [NIOSH Respirator Use Questionnaire](#)

☐ [Hurricane Assessment and Referral Tool for Children and Adolescents](#)

☐ [WTC Health Registry Hurricane Sandy Survey](#)

☐ [Hurricane Sandy Assessment Survey](#)

# IRB: Improving Integration & Timeliness



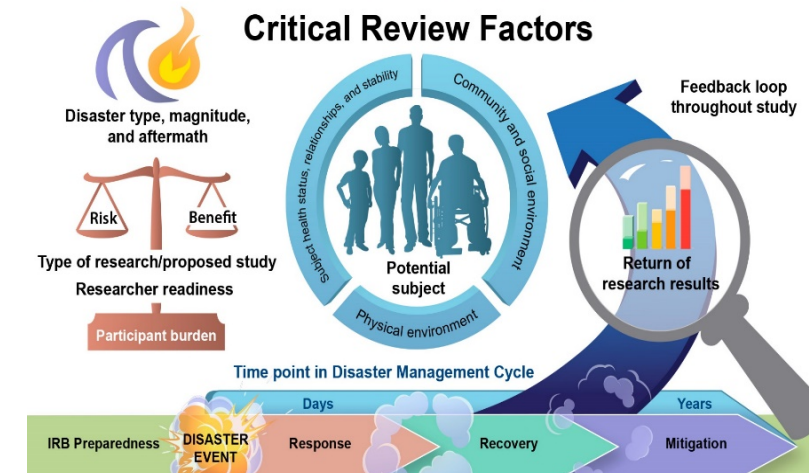
- **Training based on NIEHS published recommendations and best practices for IRB review of disaster related protocols**
  - Ethical Considerations in Disaster Research: A Practical Approach to Guide IRB Decision-Making
- **Training Workshops & Mock IRB Reviews**
  - Training for IRB members and field testing of training tools
    - UTMB Texas City clinical exercise 2017

**Conducting Science in Disasters: Recommendations from the NIEHS Working Group for Special IRB Considerations in the Review of Disaster Related Research**

Joan P. Packenham,<sup>1</sup> Richard T. Rosselli,<sup>2</sup> Steve K. Ramsey,<sup>2</sup> Holly A. Taylor,<sup>3,4</sup> Alice Fothergill,<sup>5</sup> Julia Slutsmann,<sup>6,7\*</sup> and Aubrey Miller<sup>8</sup>



## Disaster Research Review Considerations Continuum





# Thank You!

Google NIH DR2

