

# Chapter 2.4

## Databases and Registers as Tools for Disaster Epidemiology

Philip J. Schluter  
Hyun Min Kim

# Learning objectives

To understand the three major types of database and register available to disaster epidemiology researchers, and their associated strengths and weakness by:

- Characterizing the salient differentiating features of these database and register types.
- Providing case studies and examples to illustrate these and their usage.
- Highlighting the strengths and weaknesses of each, and providing a global overview.

# Introduction (1)

**Exposome:** “totality of human environmental exposures” or all the non-genetic exposures which shape individuals’ life-course trajectories.

- Quantifying this concept is difficult in the context of Health EDRM, when people may be exposed to the risks or consequences of emergencies and disasters.
- Exposure begins **before birth** and includes insults from **many sources**.
- Genetics accounts for only about 10% of diseases, while the remaining causes appear to be from life histories and environment.



## Introduction (2)

Databases and registers are used to understand the exposome and a person's life-course trajectory by measuring **factors**, **exposures**, and their **effects**.

- Researchers now use databases and registries more because of their **rapid evolution**, **availability**, and the **ability to link to other information sources**.

### Three major types of database and register:

- Ongoing population-based databases and registers.
- Pre-existing subpopulation databases and registers.
- Post-disaster databases and registers.



# Ongoing Population-Based Databases & Registers (1)

Vast amounts of data are produced daily and are collected and archived more frequently and routinely from a growing variety of sources. For instance, New Zealand's **Integrated Data Infrastructure (IDI)** is a large national research database holding microdata about all New Zealand people and households, which

- Links data from health, education, justice, income/work, population, etc.
- Provides a **holistic** detailed baseline account and history of individuals who might be in an emergency- and disaster-affected region.
- **Prospectively** collects the data and provides complete population coverage.



## Ongoing Population-Based Databases & Registers (2)

Estonia now has a nationwide digit ecosystem that includes integrated data from different healthcare providers to create a common record for every patient, and patient registries with complete nationwide coverage and individual-level linkage potential have existed in:

- Finland since 1969
- Denmark since 1978
- Sweden since 1987
- Iceland since 1999
- Norway since 2008



# Ongoing Population-Based Databases & Registers: Limitations (1)

## Limitations:

- Limited by the **scope** and **quality of data** that are collected.
- Administrative data typically **lack important qualitative information** because these are collected by government agencies for registration, transaction, monitoring and record-keeping purposes, rather than for research.



## Ongoing Population-Based Databases & Registers: Limitations (2)

Routine databases and registers are often not designed for specific disaster research purposes. Sometimes they can absorb considerable resources for very few scientific gains.

The precise exposures or confounders that researchers wish to explore are often absent from these databases.

The **RE**porting of studies **C**onducted using **O**bservational **R**outinely collected health **D**ata (**RECORD**) statement should aid transparency and improve research reporting.



**Case study 2.4.1:** *Measuring the impact of integrated health system changes on emergency department attendances and acute admission, precipitated by an earthquake (1)*

Hospital systems routinely collect data on emergency department (ED) attendees and acute admissions, which are costly and often preventable.

The Canterbury District Health Board shifted to an integrated person-centered healthcare model.

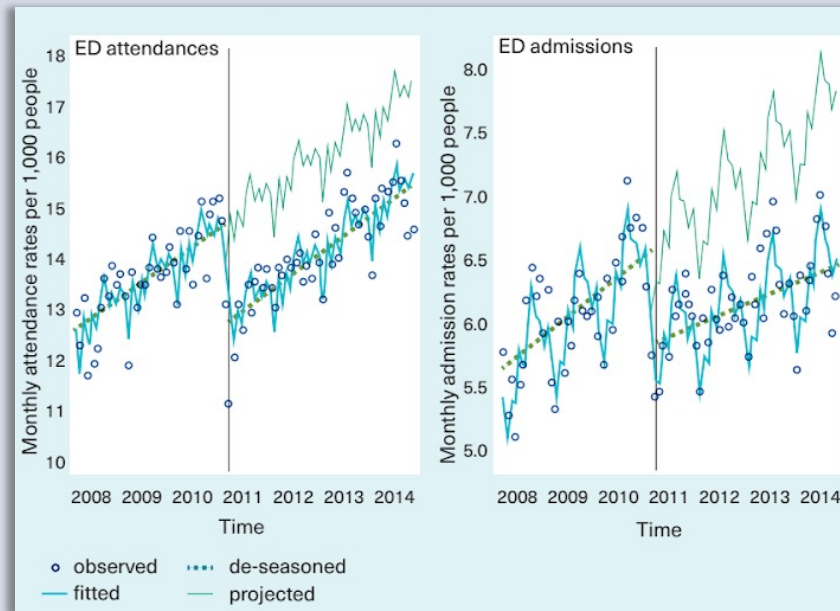
The 2010-2011 Christchurch earthquakes and aftershock series compromised infrastructure and disrupted services, causing the new healthcare delivery model to be rapidly implemented.

By interrogating the routinely collected ED attendance and admission records for Christchurch Hospital (the single tertiary hospital in the region serving approximately 500,000 people), one important component of the earthquake impact and change in service delivery model could be measured.



## Case study 2.4.1: Measuring the impact of integrated health system changes on emergency department attendances and acute admission, precipitated by an earthquake (2)

Figure 2.4.1 Scatter plots of observed Canterbury District Health Board standardized monthly Emergency Department attendance and admission rates per 1000 people.



The findings show that after the earthquake, the Canterbury District Health Board's integrated health systems transformations resulted in a dramatic and sustained reduction in ED attendances and acute hospital admissions.

## Pre-Existing Sub-Population Databases and Registers

Pre-existing cohort or longitudinal studies that were already being conducted in an area affected by a disaster often contain **pre-event information** from multiple health, social and environmental domains.

Participants in these studies commonly have their data augmented by information collected from other sources.

For example, the *Avon Longitudinal Study of Children and Parents* was established to understand how genetic and environmental characteristics influence health and development in parents and children.

**Case study 2.4.2:** *Understanding the role of peri-traumatic stress and disruption distress in predicting symptoms of major depression following exposure to a disaster caused by a natural hazard (1)*

- The study followed 1265 children born in 1977, from birth to 35 years of age.
- During the 2010-2011 Christchurch earthquakes, participants were 34 years old.
- Just over 50% of them were exposed to the earthquakes while the remainder were unexposed.

When examining the link of the earthquakes to symptoms of depression, participants who were exposed to the earthquakes were interviewed about their experiences of them.



**Case study 2.4.2:** *Understanding the role of peri-traumatic stress and disruption distress in predicting symptoms of major depression following exposure to a disaster caused by a natural hazard (2)*

The study found that peri-traumatic stress is an under-recognized predictor of major depressive disorder following a disaster caused by a natural hazard.

Thus, pre-event data, combined with the different earthquake exposure levels, allowed the researchers to understand the various impacts of this disaster.



# Pre-Existing Sub-Population Databases and Registers: Advantages and Limitations

Advantages: **In-depth data** on sub-population readily available. These are often **ecologically valid** and reliable in these populations.

Limitations: Pre-disaster information **not purposefully collected** so may not be relevant for studying HEDRM.



# Post-disaster Databases and Registers

Post-disaster databases and registers are needed to understand the health impacts and service gaps on a population **following an emergency**.

They are **flexible** and **tailored** to the specific needs of the population/situation.





**Case study 2.4.3:** *World Trade Center Health Registry and the longitudinal determinants of depression among World Trade Center Health Registry enrollees, 14 to 15 years after the 9/11 attacks (1)*

The World Trade Center Health Registry contains health data on the survivors of the 9/11 attacks on the World Trade Center towers.

The registry was established post-disaster and involved survivors of the attacks who participated voluntarily by completing health surveys over many years.

The results of these surveys help determine the extent to which physical and mental health conditions persisted among the survivors, and whether any new symptoms and conditions emerged.





**Case study 2.4.3:** *World Trade Center Health Registry and the longitudinal determinants of depression among World Trade Center Health Registry enrollees, 14 to 15 years after the 9/11 attacks (2)*

Another goal of the registry is to identify and help address gaps in physical and mental health treatment.

For example, a study by Jacobson and colleagues (2018) found substantial burden of depression in a trauma exposed population 14 to 15 years after the disaster, especially among those with PTSD.



# Post-disaster Databases and Registers: Limitations

## Limitations

- Pre-disaster information must be retrieved **retrospectively**, which can lead to **selection bias** and **information bias**.
- **Practical** and **ethical issues** arise because of the possibility of interference with emergency response, participant safety/sensitivity and informed consent.



# Conclusions (1)

Major register types	
Strengths	Weaknesses
<b>Ongoing population-based databases and registers:</b>	
<p>Cost: usually relatively inexpensive;</p> <p>Coverage: usually population wide;</p> <p>Predisaster information available;</p> <p>Time: relatively quick to undertake.</p>	<p>Not designed for disaster research;</p> <p>Important instruments or variables may be missing or have poor psychometric properties;</p> <p>Database linking may be difficult or impossible;</p> <p>Selection bias may mean that those missing from the register are importantly different from those included;</p> <p>Data are often aggregated or grouped in ways that lead to findings suffering from the ecological fallacy;</p> <p>Big Data datasets require data storage systems, computation capacity and performance, and analytical techniques that are (currently) often beyond the scope of many individual researchers.</p>

Disaster epidemiology researchers are able to use a variety of health-related databases and registers when studying topics of relevance to Health EDRM.

Each type of database and register has its own strengths and weaknesses, as shown in the tables.

# Conclusions (2)

Strengths	Weaknesses	Strengths	Weaknesses
<b>Pre-existing sub-population databases and registers:</b>		<b>Post-disaster database and registers:</b>	
<p>Cost: potentially inexpensive if 'added-on' to an existing study;</p> <p>Predisaster information available</p> <p>Typically cover subject matter in-depth;</p> <p>Capability to augment with qualitative information;</p> <p>Instruments normally designed for research purposes and often tested for psychometric properties and reliability.</p>	<p>Not originally designed for disaster research, so may miss important factors or exposures;</p> <p>Recruitment or retention to the existing study may limit the external validity of finding;</p> <p>Study participant sample size may lack statistical power.</p>	<p>Designed and tailored for disaster and population of interest.</p>	<p>Cost: usually expensive;</p> <p>Predisaster information is limited;</p> <p>Potentially time consuming and resource or expertise intensive;</p> <p>Timely collection of data may be unethical;</p> <p>If a multi-agency, multi-sector research collaboration then competing interests may exist and hamper the scope.</p>

# Key messages (1)

- There are multiple and continuously growing sources of data available for disaster epidemiology research. Knowledge of the exposome can be extended and developed by using and linking these data and exploring how emergencies/disasters affect people's likelihood of mortality, morbidity, and life-course trajectories.
- The expediency of using routinely collected data is often offset of the coverage, depth, and quality of the variables available to researchers. This often requires initiation of a post-disaster study, that is both specifically and contextually relevant to the disaster and the population affected.



# Key messages (2)

- As increasingly richer and better-quality data are collected, Big Data, machine learning and data science are likely to play an increasingly important role in disaster epidemiology research.
- However, possible avenues to augment these quantitative data with qualitative information still need to be explored.

## Further readings

Kreis IA, Busby A, Leonardi G, Meara J, Murray V, editors. *Essentials of Environmental Epidemiology for Health Protection: A Handbook for Field Professionals*. Oxford, United Kingdom: Oxford University Press. 2013.

This introductory handbook is designed for front-line public health researchers and describes various tools for assessing and scoping environmental health questions after disasters, including health registers.

Webb P, Bain C, Page A, editors, *Essential Epidemiology: An Introduction for Students and Health Professionals* (4<sup>th</sup> edition). Cambridge, United Kingdom: Cambridge University Press. 2020.

This introductory textbook provides an adequate description of how the impact of disasters and other significant health events is important for responding to a specific event and planning for future events.

## References (1)

- This chapter:** Schluter PJ, Kim HM. Databases and Registers as Tools for Disaster Epidemiology **Exposome and Exposomics**. 2014 <https://www.cdc.gov/niosh/topics/exposome/default.html>
- Integrated Data Infrastructure** 2018. <https://www.stats.govt.nz/integrated-data/integrated-datainfrastructure>
- Databases and registers: useful tools for research, no studies.** Rheumatology International. 2014;34(4): 447-52.
- The role of administrative data in the big data revolution in social science research.** Social Science Research. 2016;59: 1-12.
- The Danish National Patient Registry: a review of content , data quality, and research potential.** Clinical Epidemiology. 2015;7: 449-90.
- The RECORD statement.** PLoS Medicine. 2015;12(10): e1001885.



## References (2)

**Integrated health system changes, accelerated due to an earthquake, on emergency department attendances and acute admissions: a Bayesian change-point analysis.** BMJ Open. 2016;6(5): e010709.

**Avon Longitudinal Study of Parents and Children: ALSPAC mothers cohort.** International Journal of Epidemiology. 2013;42(1): 97-110.

**Peri-traumatic stress and disruption distress in predicting symptoms of major depression following exposure to a natural disaster.** Australian and New Zealand Journal of Psychiatry. 2017;51(7): 711-8.

**World Trade Center Health Registry.** 2019 <https://www1.nyc.gov/site/g11health/about/wtc-health-registry.page>

**Longitudinal determinants of depression among World Trade Center Health Registry enrollees, 14-15 years after the 9/11 attacks.** Journal of Affective Disorders. 2018;229:483-90.

# Contact information

## **Dr. Hyun Min Kim**

Biostatistician / Research Fellow

Biostatistics Group

Dean's Department

University of Otago Wellington

Wellington, New Zealand

**[alice.kim@otago.ac.nz](mailto:alice.kim@otago.ac.nz)**

