

DE-IDENTIFICATION Project Overview

## Project Tycho¹

## Project showcases power of de-identified data.



Snapshot of measles elimination in the United States. Weekly incidence rates per 100,000 population are shown for the entire country in the black graph at the top of the panel, along with the total numbers of cases of the disease. In the colored graph, weekly incidence rates per 100,000 population are shown for states, grouped according to the epidemiologic region. The year of vaccine licensure is indicated by a vertical pink line.

## First step was digitizing data.

University of Pittsburgh's Graduate School of Public Health began this research by gathering public health reports of disease as far back as the $19^{\text {th }}$ century, from 1888 to 2013 . The report covers 56 infectious diseases, including polio, measles, rubella, mumps, hepatitis A, diphtheria and pertussis, with much of the reporting coming from the Center for Disease Control and Prevention's weekly morbidity reports. After Digital Divide, which provides jobs and training to young adults in Cambodia, Laos and Kenya, digitized 88 million reports of individual cases of disease, researchers sorted and standardized the data, making it computable.

## Researchers aggregated individual disease reports to assess vaccine effect.

Researchers examined the disease reports before and after the time when the vaccine became licensed. Above in the heat map reflecting disease reporting for measles, the vertical pink line reflects that the vaccine became licensed in 1963. The research team estimated the number of prevented cases from the decline in disease reports after the introduction of the measles vaccination, and extrapolated the numbers of cases that would have occurred in the absence of a vaccine to the increased population. This analysis occurred with all of the diseases studied.

## Data's impact is enormous.

The data reflect the abrupt impact that vaccine licensure had on the spread of disease. Researchers estimate that vaccine introduction "helped prevent 100 million cases of serious childhood disease." One of the study's scientists noted that this study should inform the debate on childhood vaccination. As some parents have refused to vaccinate their children, certain diseases, such as measles and pertussis which were once thought to be eliminated, have surged. Scientists hope that this study spurs conversation about vaccine efficacy.

It is anticipated that this huge store of data will help public health officials and scientists better fight future outbreaks of disease. The additional detail with regard to date, location, demographics, weather and climate has the potential to assist epidemiologists in predicting outbreaks. Given the open access model to the data, epidemiologists wonder what patterns and insights about health are yet to be discovered. Individuals may also access the database to see the impact of disease on their community. Project Tycho "brings epidemiology to a hometown level."

## SUPPORTERS



Robert Wood Johnson Foundation

[^0]1. Willem G. van Panhuis, John Grefenstette, Su Yon Jung, Nian Shong Chok, Anne Cross, Heather Eng, Bruce Y Lee, Vladimir Zadorozhny, Shawn Brown, Derek Cummings, Donald S. Burke. Contagious Diseases in the United States from 1888 to the Present. NEJM 2013; 369(22): 2152-2158. University of Pittsburgh. () Project Tycho: Data for Health. Retrieved from http://www.tycho.pitt.edu; Lohr, S. (2013, Nov. 27). The Vaccination Effect: 100 Million Cases of Contagious Disease Prevented. The New York Times. Retrieved from https://bits.blogs.nytimes.com/2013/11/27/the-vaccination-effect-100-million-cases-of-contagious-disease-prevented/? r=0 . Dennis, B. (2013, Nov. 27). Researchers at University of Pittsburgh Create Digital Database of Infectious Diseases. The Washington Post. Retrieved from
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[^0]:    This document was developed by Sallie Milam, JD, CIPP/US/G, Deputy Director, Network for Public Health Law - Mid-States Region Office, and reviewed by Denise Chrysler, JD, Director, Network for Public Health Law - Mid-States Region Office. The Network for Public Health Law provides information and technical assistance on issues related to public health. The legal information and assistance provided in this document does not constitute legal advice or legal representation. For legal advice, please consult specific legal counsel.

