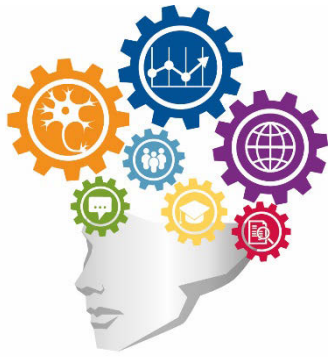


Vital Health Research Need for the Federal Vital Statistics System Health

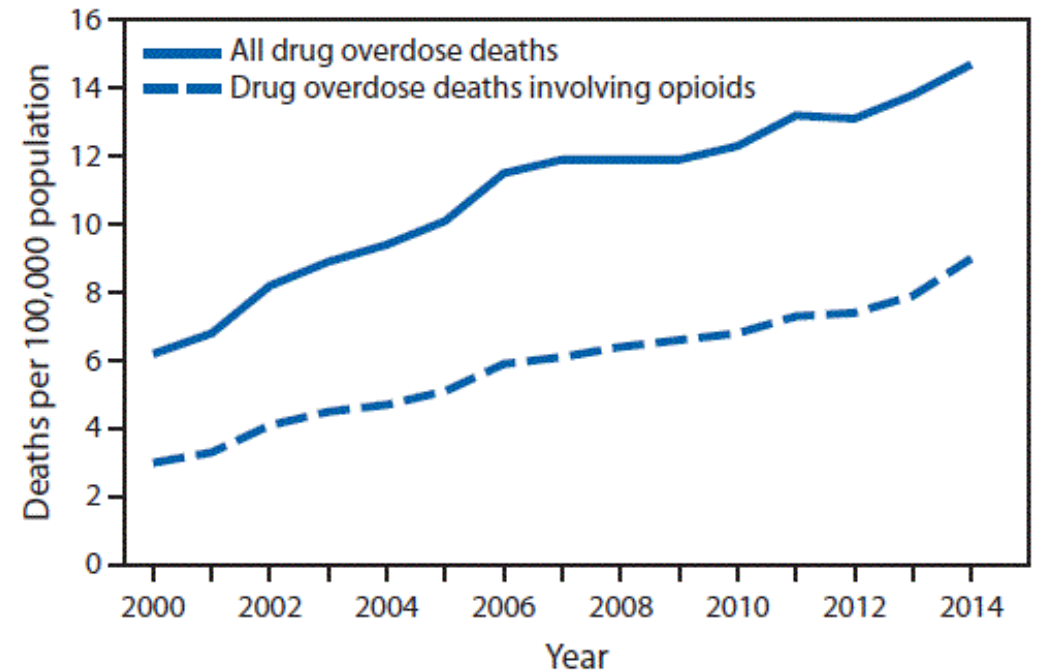


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Critical Need for Rapid and Ongoing Access to Mortality Trends

- Timely and quality death certificate data serve as an early warning system for causes of death in the United States
- Opioid Overdose Deaths as an example

NIH and the research community depend on NVHS Reports and MMWRs, among other sources, to identify areas of research priority



Rose et al., MMWR, 2016,64(50);1378-82

Example of Population Health Research from a Nobel Laureate using Vital Statistic Death Data

PNAS PNAS PNAS

Rising morbidity and mortality in midlife among white non-Hispanic Americans in the 21st century

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Contributed by Angus Deaton, September 17, 2015 (sent for review August 22, 2015; reviewed by David Cutler, Jon Skinner, and David Weir)

This paper documents a marked increase in the all-cause mortality of middle-aged white non-Hispanic men and women in the United States between 1999 and 2013. This change reversed decades of progress in mortality and was unique to the United States; no other rich country saw a similar turnaround. The midlife mortality reversal was confined to white non-Hispanics; black non-Hispanics and Hispanics at midlife, and those aged 65 and above in every racial and ethnic group, continued to see mortality rates fall. This increase for whites was largely accounted for by increasing death rates from drug and alcohol poisonings, suicide, and chronic liver diseases and cirrhosis. Although all education groups saw increases in mortality from suicide and poisonings, and an overall increase in external cause mortality, those with less education saw the most marked increases. Rising midlife mortality rates of white non-Hispanics were paralleled by increases in midlife morbidity. Self-reported declines in health, mental health, and ability to conduct activities of daily living, and increases in chronic pain and inability to work, as well as clinically measured deteriorations in liver function, all point to growing distress in this population. We comment on potential economic causes and consequences of this deterioration.

midlife mortality | morbidity | US white non-Hispanics

the United Kingdom (UK), Canada (CAN), Australia (AUS), and Sweden (SWE). The comparison is similar for other Organisation for Economic Co-operation and Development countries.

Fig. 1 shows a cessation and reversal of the decline in midlife mortality for US white non-Hispanics after 1998. From 1978 to 1998, the mortality rate for US whites aged 45–54 fell by 2% per year on average, which matched the average rate of decline in the six countries shown, and the average over all other industrialized countries. After 1998, other rich countries' mortality rates continued to decline by 2% a year. In contrast, US white non-Hispanic mortality rose by half a percent a year. No other rich country saw a similar turnaround. The mortality reversal was confined to white non-Hispanics; Hispanic Americans had mortality declines indistinguishable from the British (1.8% per year), and black non-Hispanic mortality for ages 45–54 declined by 2.6% per year over the period.

For deaths before 1989, information on Hispanic origin is not available, but we can calculate lives lost among all whites. For those aged 45–54, if the white mortality rate had held at its 1998 value, 96,000 deaths would have been avoided from 1999 to 2013, 7,000 in 2013 alone. If it had continued to fall at its previous (1979–1998) rate of decline of 1.8% per year, 488,500 deaths would have been

Linking NIH-Supported Epidemiologic Research to Deaths

- NIH supports numerous health surveillance studies, longitudinal cohorts, and clinical registries
- These epidemiologic studies are critical not only for documenting incidence and prevalence of diseases and health risk factors (e.g., smoking, obesity) but also for assessing predictors or moderators of these risk factors, morbidities, and mortalities, and for exploring factors that mediate the relationships between morbidity and mortality.
- Linking the various health data collected in these studies (e.g., genetics, behavioral, environmental) to death requires linking these data to the National Death Index

A Few Examples of NIH-supported Epidemiology Projects that Utilize Death Data

- NCI SEER (Surveillance, Epidemiology and End Results) Program (<https://seer.cancer.gov>)
- NIDA Monitoring the Future (<https://www.drugabuse.gov/related-topics/trends-statistics/monitoring-future>)
- NIAAA National Epidemiologic Survey on Alcohol and Related Conditions (NESARC) (<https://www.niaaa.nih.gov/research/nesarc-iii>)
- NIDDK Chronic Kidney Disease in Children (<https://statepi.jhsph.edu/ckid/>)
- NIA Epidemiology Projects:
 - Health and Retirement Survey (<http://hrsonline.isr.umich.edu>)
 - Midlife in the United States (MIDUS) (<http://midus.wisc.edu>)
 - National Health and Aging Trends Study (NHATS) (<http://www.nhats.org>)
 - National Long Term Care Survey (<http://www.nltcs.aas.duke.edu>)
- NICHD Add Health Study (<http://www.cpc.unc.edu/projects/addhealth>)
- NHLBI Epidemiology Projects:
 - Atherosclerosis Risk in Communities Study (ARIC) (<http://www2.csc.unc.edu/aric/>)
 - Coronary Artery Risk Development in Young Adults Study (CARDIA) (<http://www.cardia.dopm.uab.edu>)
 - Cardiovascular Health Study (<https://chs-nhlbi.org>)
 - Framingham Heart Study (<http://www.framinghamheartstudy.org>)
 - Hispanic Community Health Study/Study of Latinos (<https://sites.csc.unc.edu/hchs/>)
 - Jackson Heart Study (<https://www.jacksonheartstudy.org>)
 - Multi-Ethnic Study of Atherosclerosis (MESA) (<https://www.mesa-nhlbi.org>)
 - Strong Heart Study (<https://www.ncbi.nlm.nih.gov/pubmed/2260546>)
 - Genetic of Coronary Artery Disease in Alaska Natives (GOCADAN)
- Emerging Databases (Large Scale Cohort Studies in initial phases of data collection):
 - Adolescent Brain and Cognitive Development (ABCD) (<https://abcdstudy.org>)
 - All of Us (Precision Medicine Initiative) (<https://allofus.nih.gov>)
 - Environmental Influences of Child Health Outcomes (ECHO) (<https://www.nih.gov/echo>)

Example of the Importance of Quality Death Certificate Data: Cancer Survival Estimates

- Cancer survival estimation is essential for assessing prognosis
- Interest is in "net survival" – probability of surviving death in the absence of other causes
- If a reliable cause of death is available, cause-specific survival can be determined; otherwise, net survival is estimated from actuarial life tables

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ARTICLE |

Improved Estimates of Cancer-Specific Survival Rates From Population-Based Data

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Manuscript received January 8, 2010; revised August 20, 2010; accepted August 25, 2010.

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Linking NIH-Supported Clinical Trials Research to Deaths

- NIH supports a range of clinical trials that study the effects of various treatments on preventing and treating diseases (in FY16, NIH awarded funding for over 1000 clinical trials grants)
- Death is the primary outcome in a significant proportion of the clinical trials that NIH funds
- Even in those studies that use “surrogate endpoints” as their primary outcome and do not evaluate death as an outcome, there remains a need to track deaths for monitoring serious adverse events in these studies

How Do Researchers Know that Study Participants have Died During the Trial?

- For participants who die during hospitalization or under medical care, the medical record documents the death
 - Clinical studies commonly access these death event data from medical records of *the systems the study is conducted in or systems that the study knows the patient uses*
 - If the patient dies in a different healthcare system (e.g., emergency care takes the patient to a different hospital, patient is out of network in another state), the research team is unaware that the participant died
- For study participants who die somewhere other than in the hospital system where the study is conducted, the research team becomes aware of the participant's death only when the team attempts to contact the participant for follow-up and learns from surviving family member that the participant died sometime since the last contact.
- And in some cases, the participant or other contacts can no longer be contacted or located – their outcome including if they died, are impossible to determine without an independent source of death events

Why the National Death Index is so Important to Health Research

- Even with variations in reporting quality and timeliness, death certificates remain the only method to verify death, the date of death, and the cause of death. Otherwise, we are relying on either medical record information if available or the self-report of surviving relatives.
- Participants travelling or moving as well as multisite studies being conducted in multiple states requires a single, integrated death file that covers the United States
- Because participants often travel or move during the course of studies, particularly longer-term studies lasting a decade or more, researchers cannot rely on the death data from a single state
- The National Death Index (NDI) is crucial for these research purposes.
- The Social Security Death Master File is helpful, but the files available to researchers are incomplete

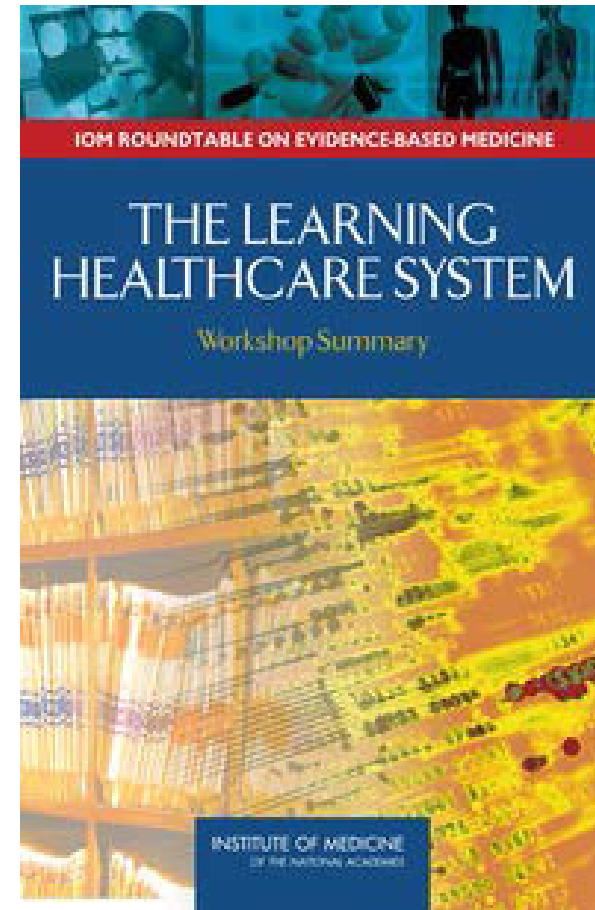
Invitational Meeting on Access to Death Records to Support Health Research

The Keck Center of the National Academies
Washington, DC
September 30, 2014

- Why not use the Social Security Administration's Death Master File (DMF instead)?
 - Prior to 2011, researchers had access to the full file with unlimited searches
 - Access was both cheaper and faster than the NDI
 - But SSA's agreement with states prohibit public release of state-owned data
 - Since Nov, 2011, SSA has omitted state data

Integrating of NDI with health system data to achieve a “learning healthcare system”

- Healthcare systems increasingly gathering research data on their outcomes to make rapid and responsive modifications to their practices and procedures
- One critical outcome is mortality, but unless the death occurs while the patient is in the healthcare system, the system has no information on this event.



And NIH-supported Research Relies on More than Death Data from the Vital Statistics System

- Births
 - Teenage pregnancy, including determinants and health consequences
 - Reproductive rates and studies of factors that influence reproduction
- Marriages, Births, and Adoptions
 - National Survey of Family Growth (NICHD support to NCHS)