Opportunities to Increase Stability and Usefulness of the Vital Statistics System for Health Research

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Timeliness of Obtaining Death Data

- The time from study completion to publication is two years or longer.

- Although there are many factors that contribute to this publication lag, the lag time to get death certificate data is one contributor

- When a participant is unreachable, being able to check death status on a case-by-case basis would allow for a more rapid resolution of follow-up status, and any signs from these deaths that would suggest a yet undetected serious adverse event.

- Opportunity:
  - Electronic Data Registration System (EDRS) utilized by all states and localities to facilitate data entry
  - A common and shared EDRS
  - Note that births are reported almost entirely via electronic system

Revising Cost Structure and Support

- NDI currently charges per death certificate obtained
  - States rely on these revenues to support their vital statistics role, some of them entirely
  - Given current computerized systems, costs to provide these certificates are more fixed (upfront) than variable (per service)
  - Fees per death certificate can be expensive for large epidemiologic studies that make thousands of data requests to NDI

- Opportunity
  - Vital statistics are a critical national health research need, and greater cost sharing between federal and state support should be considered
  - Note that in the current cost structure, the fees per certificate are paid predominately by the federal government anyway, just through research grants to investigators who use these funds to pay the fees to NDI to access the data
  - Consider a volume discount fee structure with higher rates for smaller studies and lower rates for larger studies

Streamlined process for linking NDI and health research data

- Current Process:
  - Researchers send a list with personal identifiers
  - NDI sends back candidate matches (one to many) based on probabilistic matching (but not the full dataset for each potential match)
  - Research team reviews and determines best match

- Many, including AHA, have recommended improved linkages

- Opportunity to Improve Linkages
  - Provide a protected API or data enclave that would let researchers enter personally identifiable information and retrieve immediately from NDI a full dataset of probabilistic matches to view
  - Researchers select the best fit to their participant and retrieve only the selected dataset to link to their database
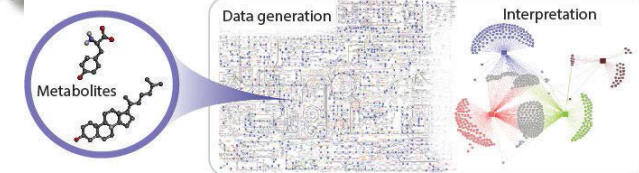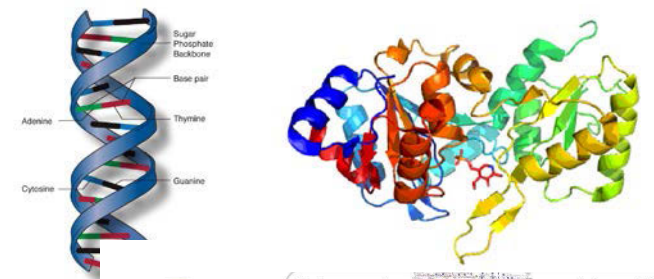
. . But Let's Think Big -
A National Health Surveillance System
Others Have It; Why Not Us?
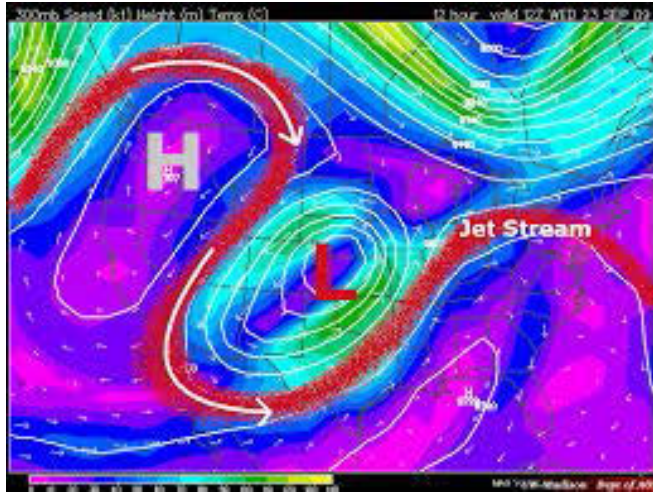
Integrated, comprehensive national (international) surveillance systems that generate temporally dense data and provide easy data access, not only to researchers but to consumers as well
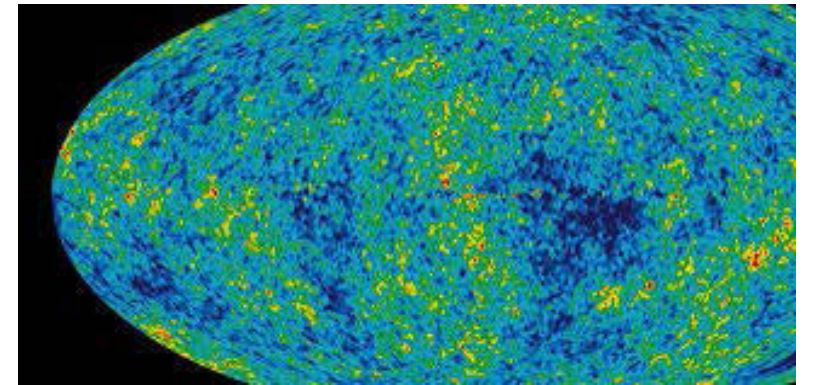
Our Fragmented, Disconnected Health Surveillance System

Brief Vision for a National Health Surveillance System

- Monitor the health of the U.S. population from birth to death

- Unique health ID for every individual

- Electronic Health Records that link to each other and to related data sets

- Increasing integration of protected genetic data with EHRs

- Core basic survey data obtained on all, more in depth or time intensive data from representative subsets

- Ability of participants to donate data, especially non-traditional data (e.g., activity trackers, heart rate monitors, location data from phone)

- Invitations to engage in clinical studies and trials

- All integrated and accessible from a data enclave that allows researchers, public health officials, and the public to track the health of the nation in real time