Health Status and Later Life Diseases: ELCS Study and the Utah Population Database

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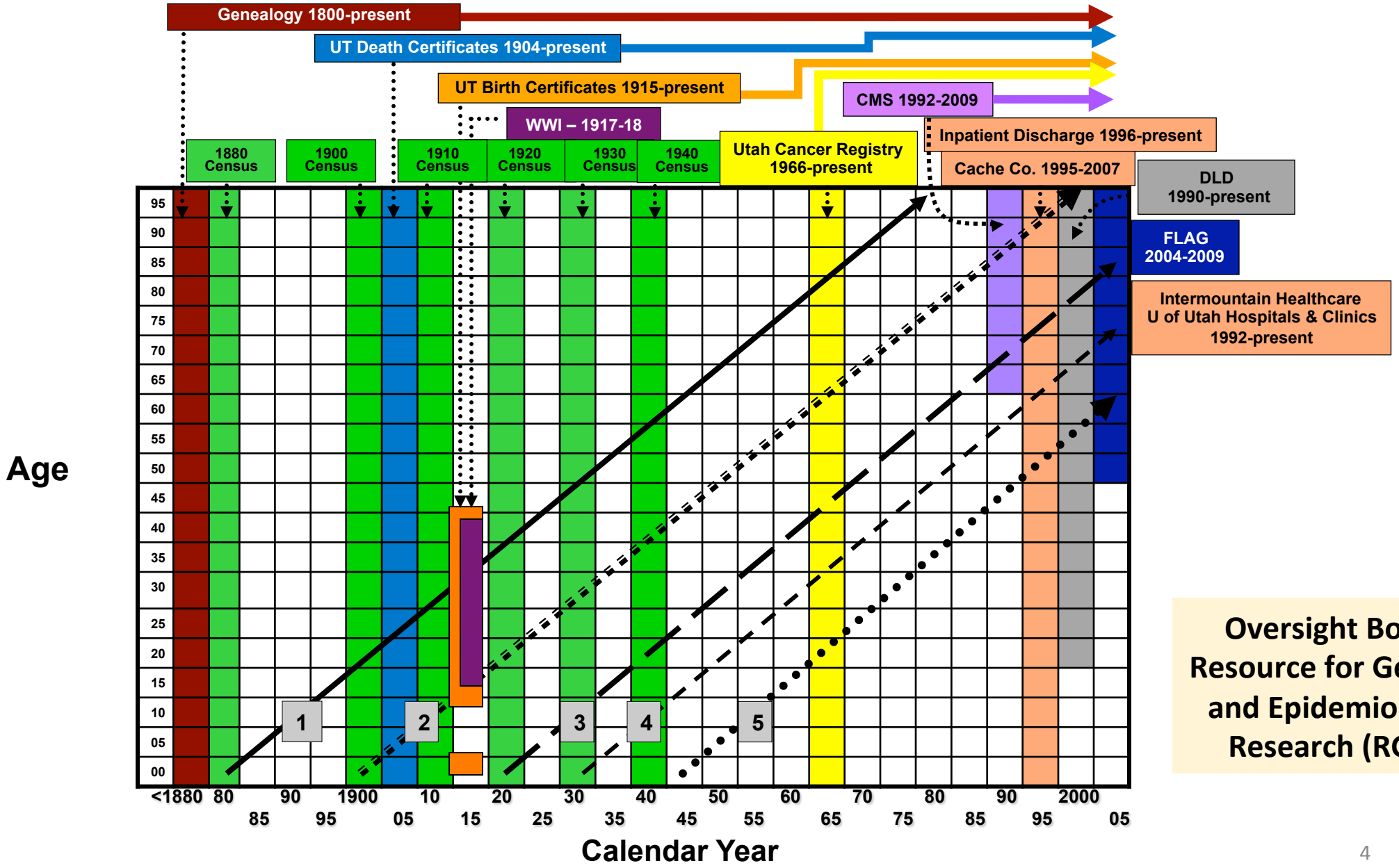
What are the research questions you study?

Early Life Conditions, Survival, and Health(ELCS):
A Pedigree-Based Population Study

- Test hypotheses about the association between earlier life conditions (ELCs) and later life health and survival.
- Provide insights into the importance of early influences and identify at-risk sub-populations.
- Improve our understanding of health disparities that may arise early in life and help guide health interventions and surveillance strategies.

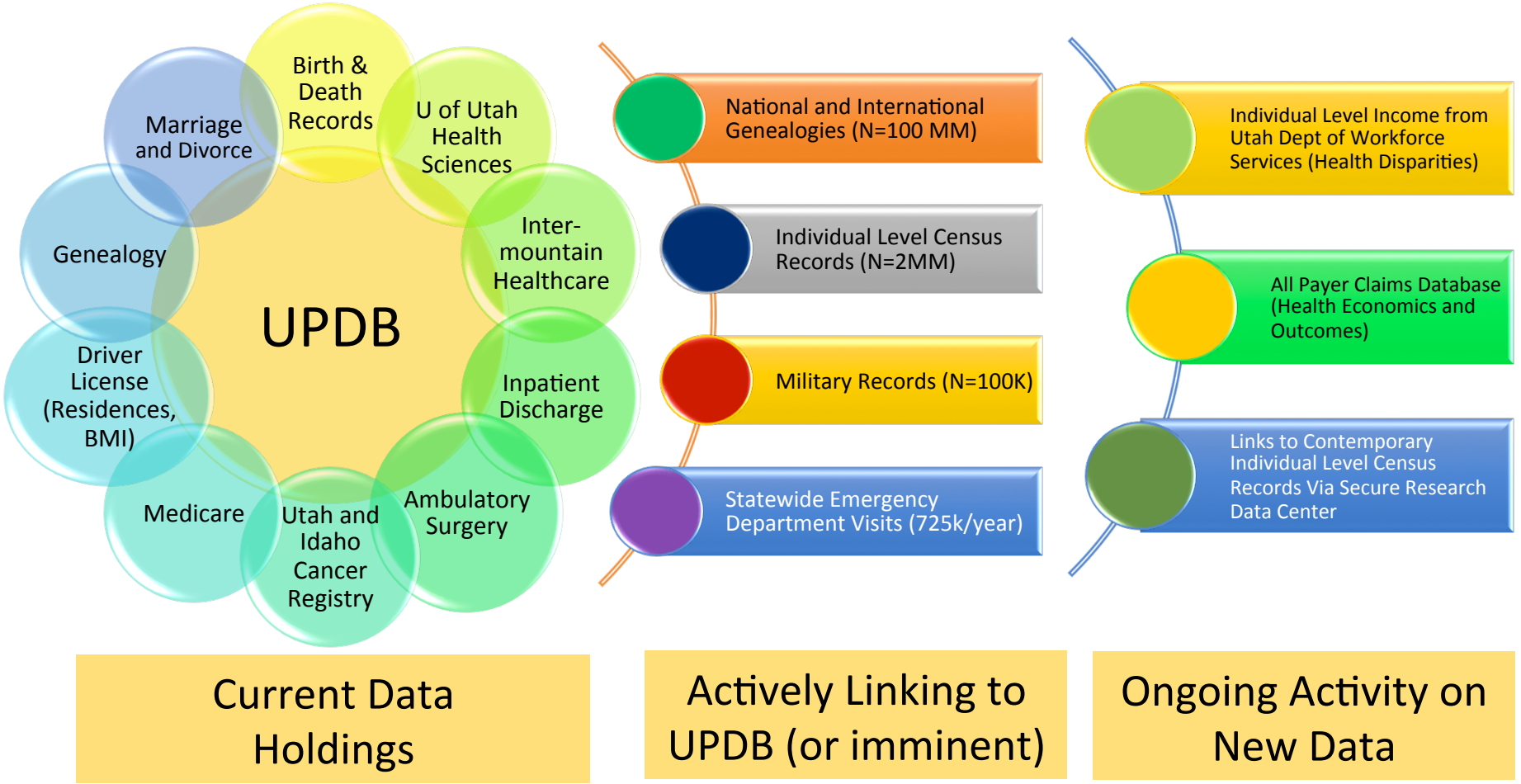
What data, including administrative data, do you now use in that research?

Lexis Diagram of Data Sets for Early Life Conditions and Later-Life Health

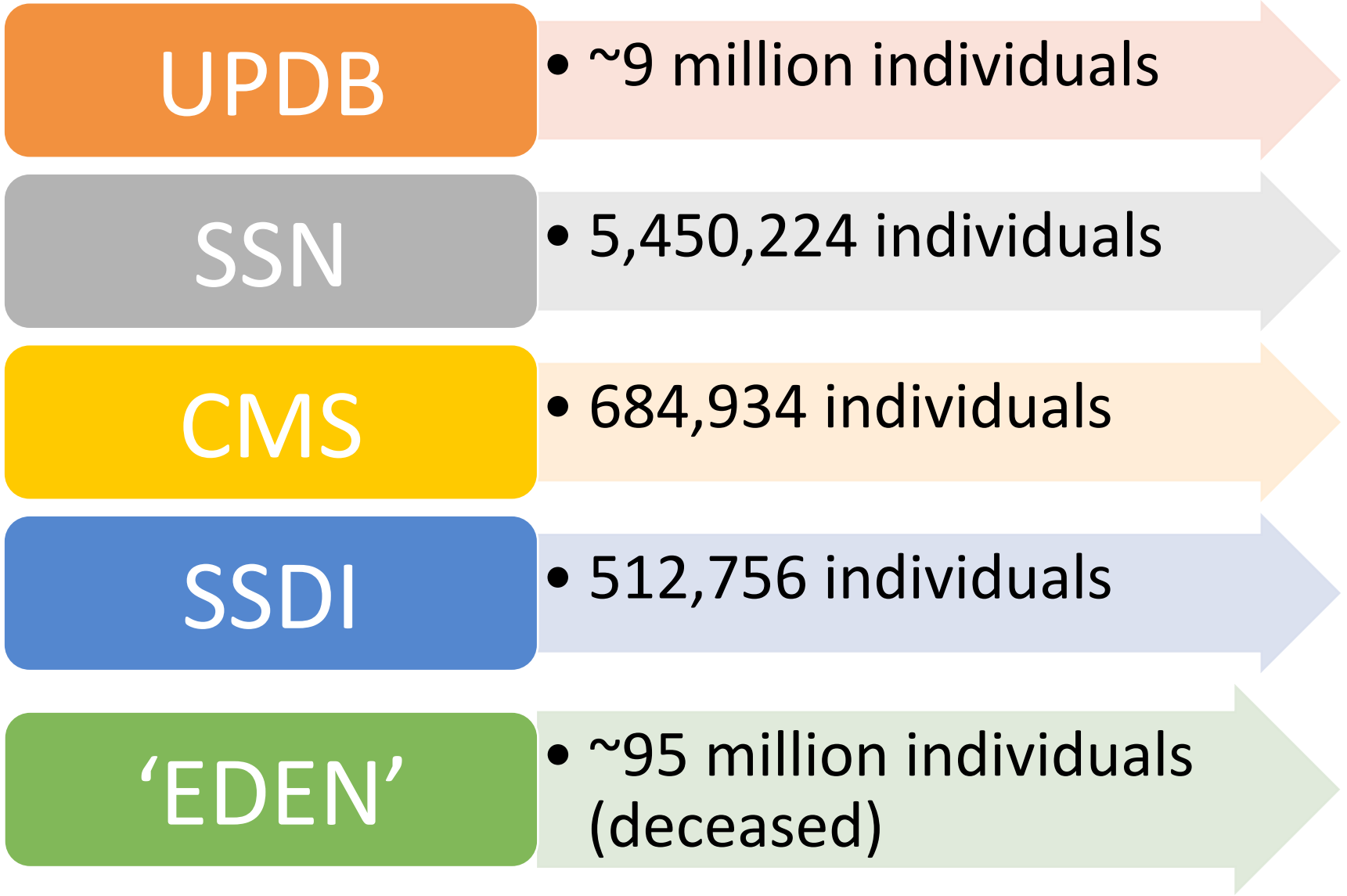


Oversight Body: Resource for Genetic and Epidemiologic Research (RGE)

UPDB – Current And Planned Data Sources



Selected Counts

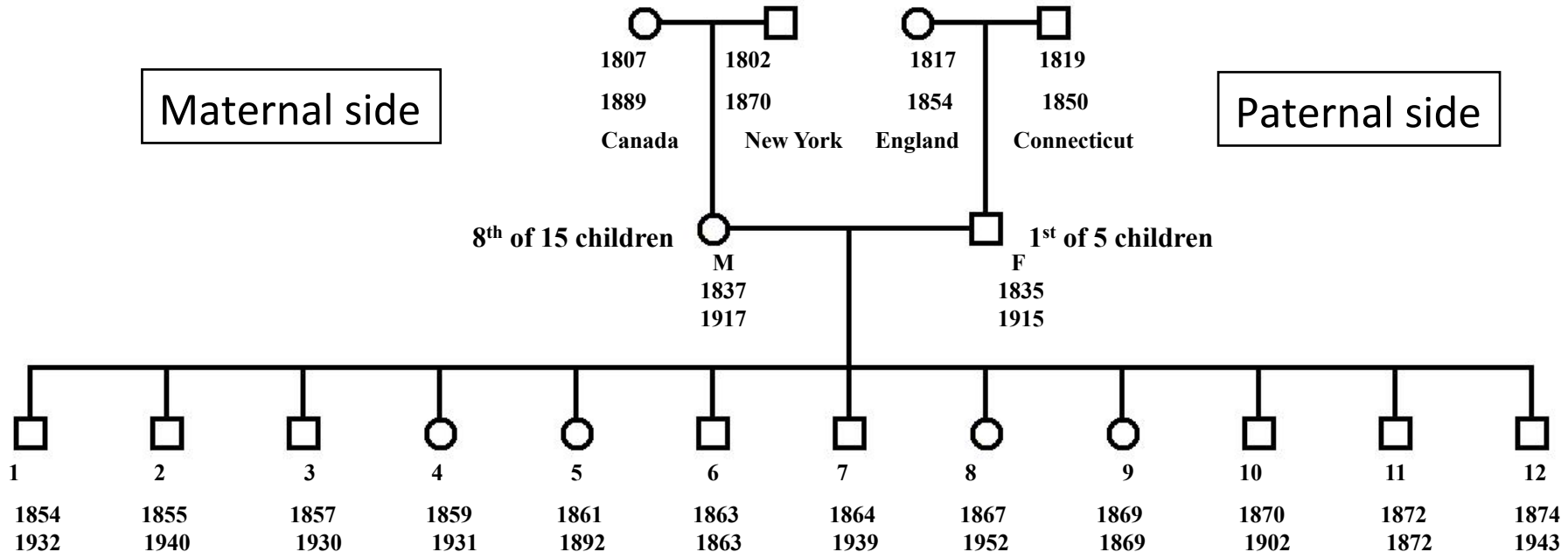


Utah Family, Circa 1900

Father (F), Mother (M) and children by birth order

Married 1853, 12 children, 3 infant deaths

Utah Family in UPDB



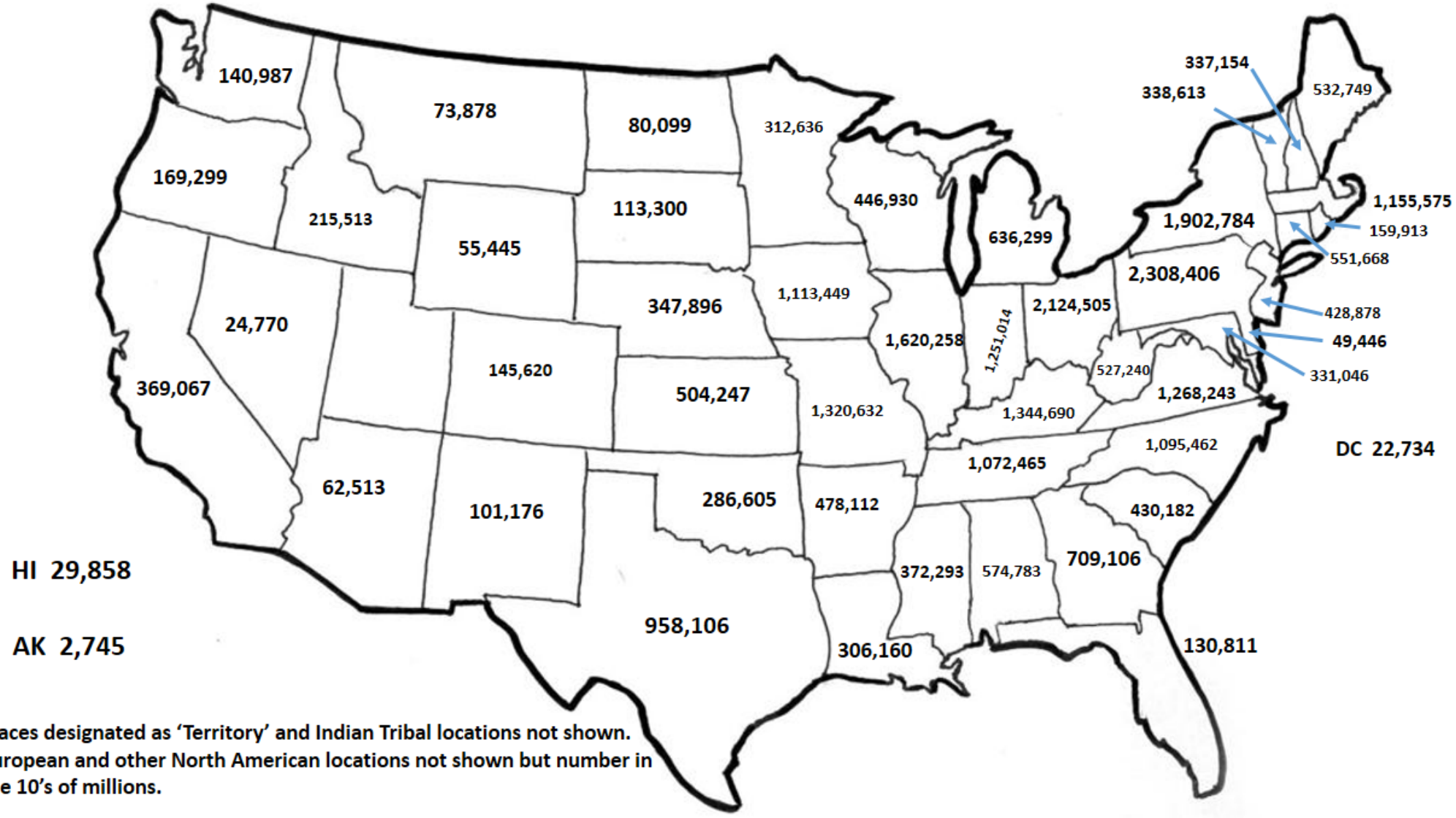
Spans 11 generations from 1807 to 2015

Couple (in picture): **7,565 descendants (6,793 living; 92% BC)**

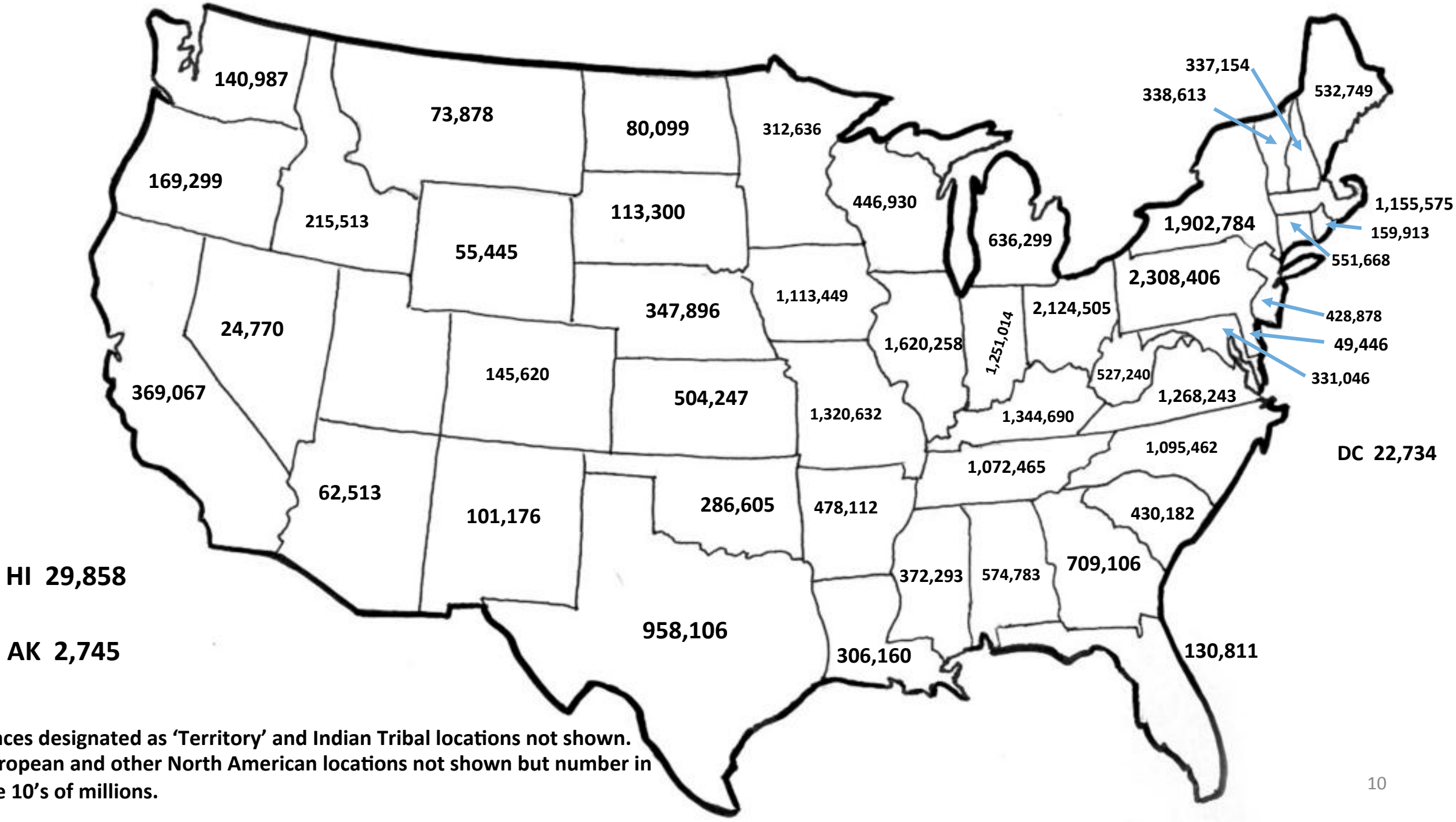
Paternal side: **11,944 descendants (10,617 living; 83% BC)**
15% have genealogies from original set

Maternal side: **33,607 descendants(29,936 living; 89% BC)**
17% have genealogies from original set

Counts of Individuals Related to Persons in Utah. Source: UPDB and the EDEN Data



Places designated as 'Territory' and Indian Tribal locations not shown. European and other North American locations not shown but number in the 10's of millions.



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What are the limitations of these data?

Migration

- Drivers License

Cancer Incidence

- SEER
  - 30% of US
- State Cancer Registries

CMS - Medicare

- Challenges in Usage

Reluctant Agencies

- Workforce Services
- Department of Education
  - Advantage of birth certificates

How would access to an intergenerational panel improve the quality of your research?

Generalizability and Sample Size

- Genetic Risk
  - Family History
  - Medical
- SES/SOCMOB

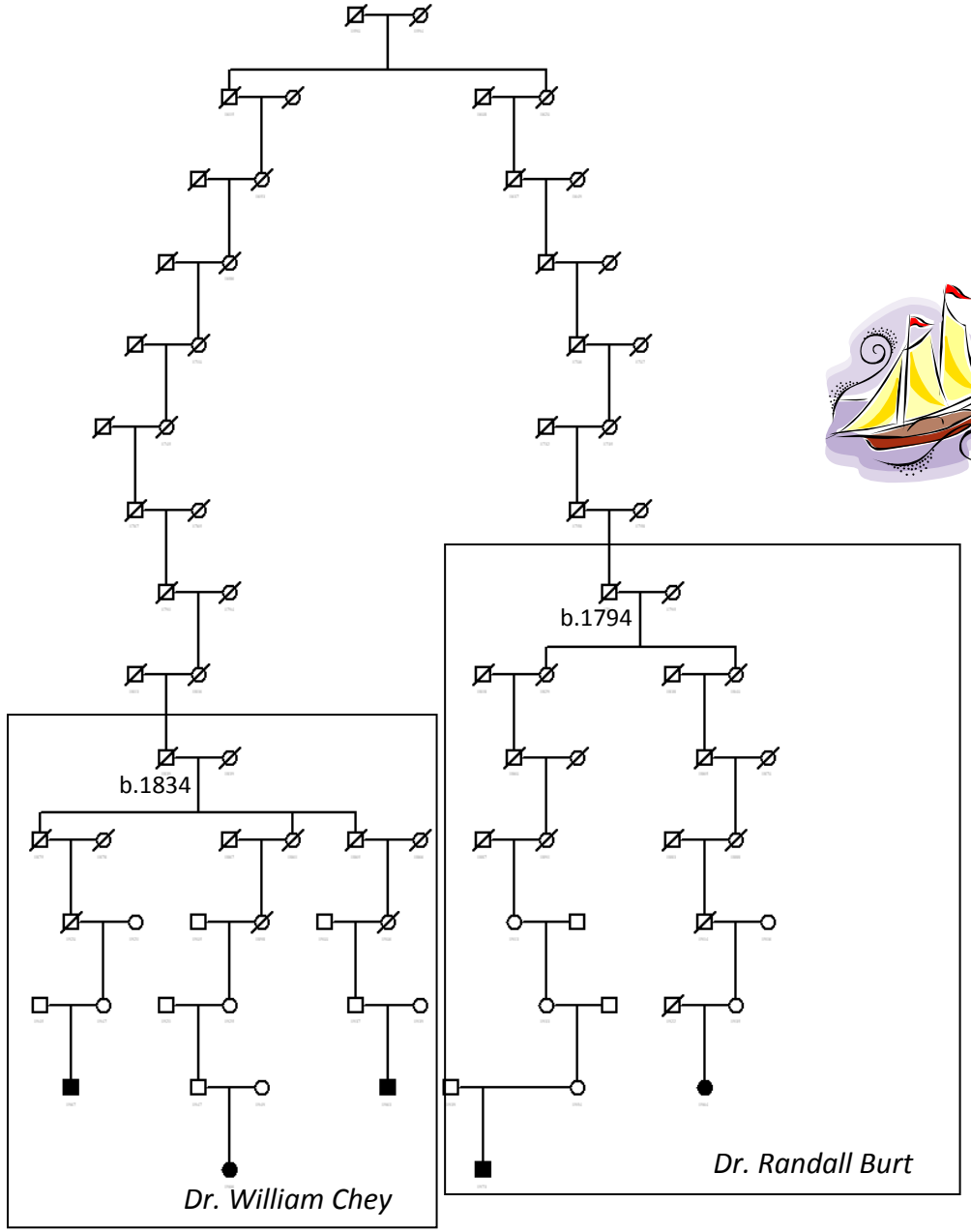
Natural Experiments

- Utah
  - Nevada Test Site
  - Air Quality
  - Missionary Age

Historical Geocoded Data

- Exposures in the past
- Family Enclaves

American founder for AFAP APCdelAT(426-427)



1615, St. Nicholas, Somerset, England: founders married

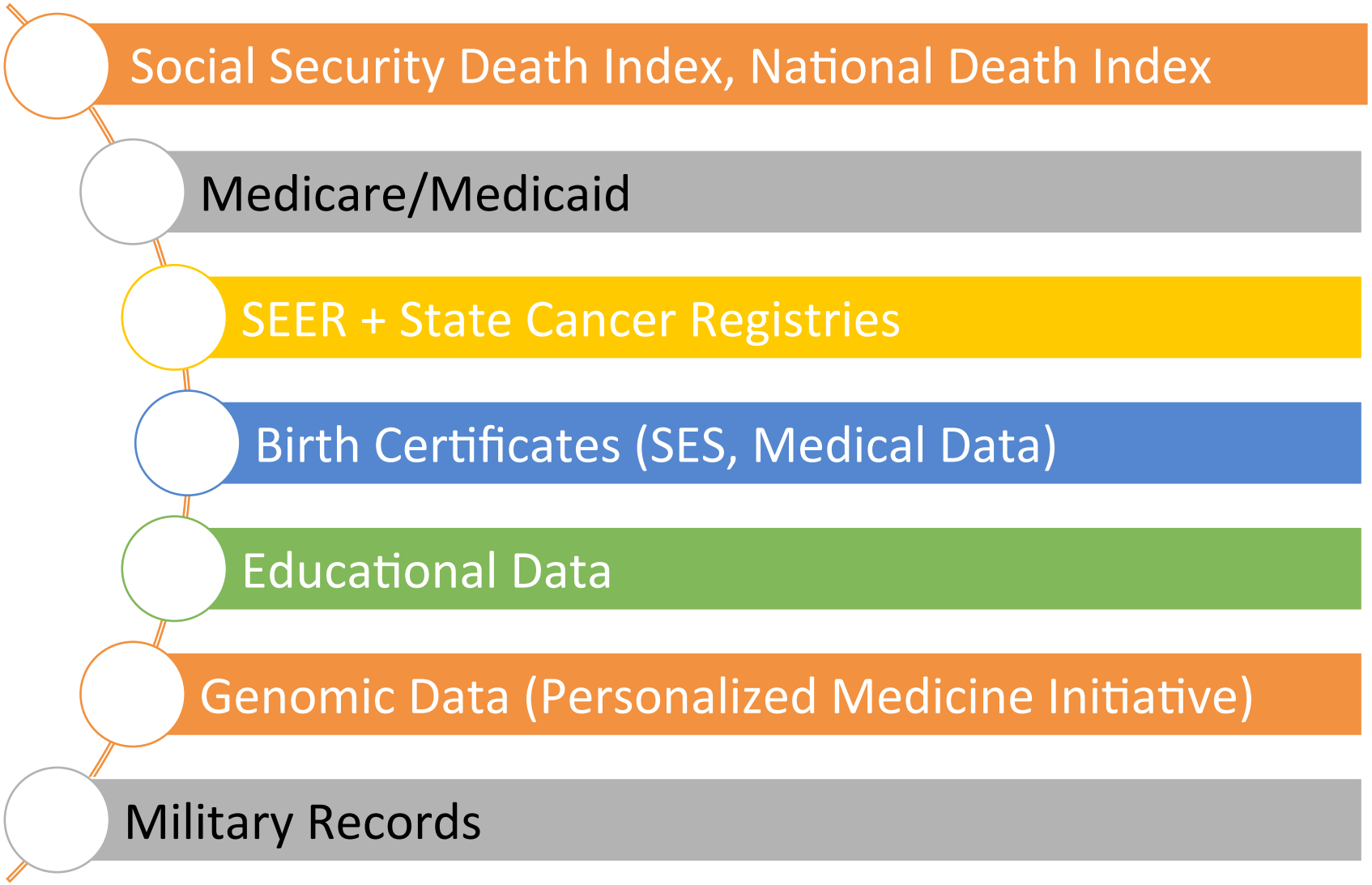
1624 -1640 Family emigrated to Weymouth, Norfolk, Massachusetts

Neklason DW, Clin Gastro & Hep 2008;6:46–52

K439
New York family

K353
Utah family

Linkage to which administrative data would be most important for your research?



How would this intergenerational panel with linked administrative data improve the evidence base in assessing longer-term impacts of policy on key outcomes in your research area?

State-Level/Time – Specific Data	• Policy changes (including medical recommendations) as experiments that extend to descendants
Family-Level Data	• Genetic relationships for family-based models and effect of social mobility on descendant health
Migration	• Health differences among ancestors and descendants as a function of selective migration
PIKs	• PIK'd old census records to health outcomes from various health data sources for better assessments of intergenerational effects

What access/barriers to use do you foresee?