Enhancing Health Data (EHealth) Initiative at the U.S. Census Bureau

National Association of Health Data Organizations 34th Annual Meeting

11/7/2019
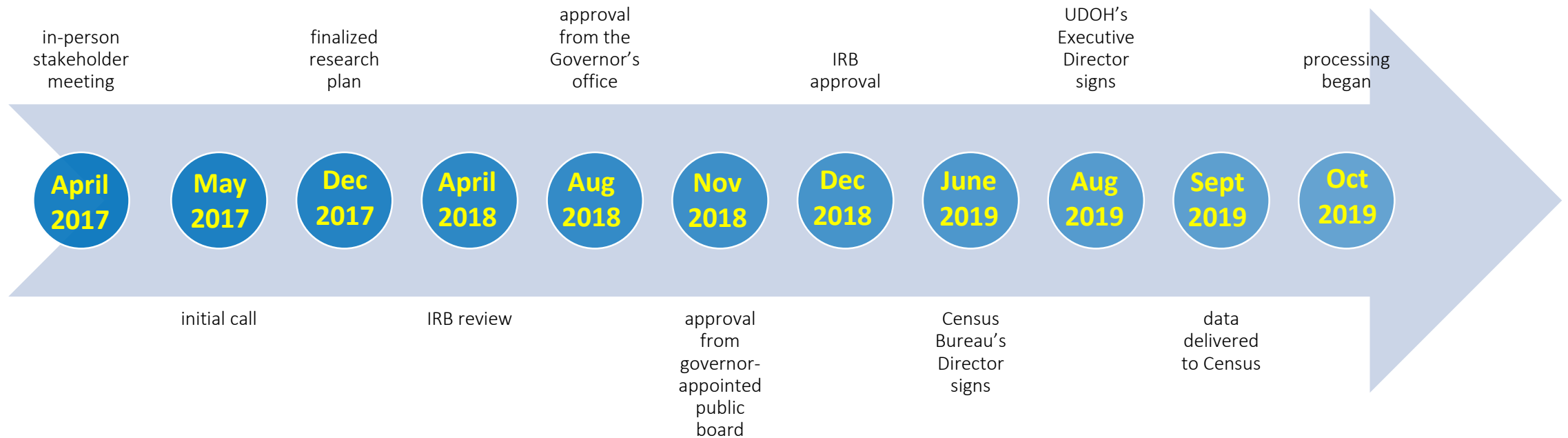
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Background

- Enhancing Health Data (EHealth) Initiative began in 2017

- Internally funded for 3 years from the innovation fund, extended through October 2020

- Objectives:

  - explore how existing data could be used in new ways to support insights into the social determinants of health

  - develop working relationships and obtain clinical health data from stakeholders

  - process and link health data to Census-maintained datasets

  - increase institutional knowledge pertaining to an emerging data source

  - assess organizational strengths, weaknesses, costs, and opportunities to obtain and process health data

United States Census Bureau

U.S. Department of Commerce
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UDOH-Census Partnership

- Link Utah's Department of Health (UDOH) emergency department (ED) encounters data from 2013-2017 to American Community Survey (ACS) from 2001-2017

- Aim 1: Examine social determinants of ED utilizations in Utah in order to reduce preventable and avoidable ED visits

  - in particular, examine the link between demographic, social, economic, and housing factors from ACS and ED visits

- Aim 2: Evaluate the ED data by making comparisons to the National Hospital Ambulatory Medical Care Survey (NHAMCS) data files

Partnership timeline so far

Above timeline					
in-person stakeholder meeting	finalized research plan	approval from the Governor's office	IRB approval	UDOH's Executive Director signs	processing began

Timeline milestones:
April 2017 · May 2017 · Dec 2017 · April 2018 · Aug 2018 · Nov 2018 · Dec 2018 · June 2019 · Aug 2019 · Sept 2019 · Oct 2019

Below timeline				
initial call	IRB review	approval from governor-appointed public board	Census Bureau's Director signs	data delivered to Census

Lessons learned and looking ahead

- Things to consider: data sensitivity, data security, access to the linked data, benefits to both sides, balancing benefits vs. risks

- Lessons learned: narrow scope initially to build trust and demonstrate benefits, flexibility in study design, strong benefits to both parties, regular communication

- Demonstrate value by completing initial set of use cases

- Continue to engage with other stakeholders and research community

- Make linked data available at Federal Statistical Research Data Centers for approved research projects and to approved researchers

- Partner with other federal statistical agencies such as the National Center for Health Statistics

Contact info

Thank you!

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