



Administrative Data  
Research Centre  
Scotland

Edinburgh Napier  
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An ESRC Data  
Investment

# Linking Scotland's census: enabling policy through innovative research

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Scotland

Better Knowledge

Better Society

# Overview

- ▶ ADRC-S
- ▶ The strengths of the decennial census
- ▶ Benefits of linking census to administrative records
- ▶ Examples of ADRC-S projects using census data
- ▶ *Care in the last days of life* – an exemplar project



# ADRC-S

## ▶ Phase 1 (2013-2018)

- ▷ Facilitating and enabling researchers to use administrative data
- ▷ Moving forward exemplar projects

## ▶ Phase 2 (2018-2021)

- ▷ Strategic Impact Programmes (SIPs)



# Why use census data?

- ▶ Largely complete
- ▶ 100% coverage of population (almost)
  - ▷ Minority groups
  - ▷ Small areas
- ▶ Key questions
  - ▷ Individual level socio-economic status
  - ▷ Informal care
  - ▷ Health




# Why link to census data?

- ▶ Supplement census data
  - ▷ Receipt of benefits
  - ▷ Hospitalisations
  - ▷ Prescribing records
- ▶ Create subsets
  - ▷ Minority groups
  - ▷ Small areas
- ▶ Answer key research questions with longitudinal data
  - ▷ Survival/ time to event analysis



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[Publications and impact](#)
[Thematic partnerships](#)
[Policies and procedures](#)
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- ▶ Academic publications
- ▶ Guides
- ▶ Conference
- ▶ Data Points Podcasts
- ▶ Hear the experts
- ▶ Sharing knowledge
- ▶ ADRN blog
- ▶ Newsletters



## Predictors of mental ill-health and its determinants in mothers caring for a son or daughter with intellectual disabilities at different stages of the caregiving trajectory including post caregiving

**Research Overview**

There is some evidence suggesting that mothers may be more likely than other carers to experience depression and anxiety. However, there is a lack of research in this area. It is therefore important to investigate how often mental health problems are experienced by mothers caring for a child, adult or older adult with intellectual disabilities or after a son or daughter with intellectual disabilities has died, and additionally, to compare this with the experience of similar women who do not have this type of caring role. It is also important to identify possible reasons for mental ill-health (e.g. living circumstances, child's health), so these can be addressed.

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**Benefit**

To identify what guidance services are required to ensure appropriate support mechanisms are put in place at the time when it is most needed.

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Lead research – Debbie Kinnear (University of Glasgow)



## Understanding the interplay of geography and demographic characteristics in the diagnosis of six-common cancers: The NASCAR-CENSUS project

### Research overview

When people develop cancer those that live in rural areas seems to suffer from more ill-health and have less chance of surviving than those that live in cities. This is the case in Scotland and has also been found in studies throughout the world. It is, however, not known why rural people with cancer do worse but there are several possibilities. It could be that they wait longer before contacting their GP. It could also be that, once they have contacted their GP the health service takes longer to diagnose them, and then they receive different treatment and follow-up than they would if they lived in the city.

To begin to explore why people in rural Scotland do worse with cancer we conducted the Northeast and Aberdeen Scottish Cancer and Residence Database (NASCAR) study. In the study detailed information was collected from over 12,000 people diagnosed with cancer in Northeast Scotland (including Orkney and Shetland) between 2007 and 2014. The results were surprising. We observed that people who lived on Orkney and Shetland or more than one hour's drive from Aberdeen were actually more likely to be diagnosed and treated quickly for their cancer than those living in the city. Despite this, they were still more likely to die within a year.

We are now trying to explain these findings. By linking the existing information we have to data from the national census we will be able to begin to try and explain what we have found. In particular we are interested to learn if peoples' access to transports, home circumstances and the type of work they do could be important. By linking our information to details from the census we will be able to answer these types of questions from our analyses.

Lead research – Peter Merchie (University of Aberdeen)





- ▶ Featured research
- ▶ Digital Economy Act
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## Featured research

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### Informal care in the last days of life: a data linkage study

#### Research overview

This study will bring together routinely collected data – from the Census and from death registrations – to better understand the household structure of people shortly before death. Household structure gives an indication of the availability of informal care – the care provided by others, such as family, which for many is an important component in enabling ongoing independent living. This will allow researchers to create a dataset of households shortly before the death of a household member, and to compare 2011 census data with 2001 to see if an increase in the proportion of deaths at home can be explained by changes in the availability of informal care. They will also be able to look at how household structures differ socially and geographically.

#### Benefit

To provide evidence that can inform the development of health and social care services, benefitting those who are caring as well as those in the final days of life.

Lead researchers – Iain Atherton and Anna Schneider (Edinburgh Napier University)







'Will these words be turned into actions?'

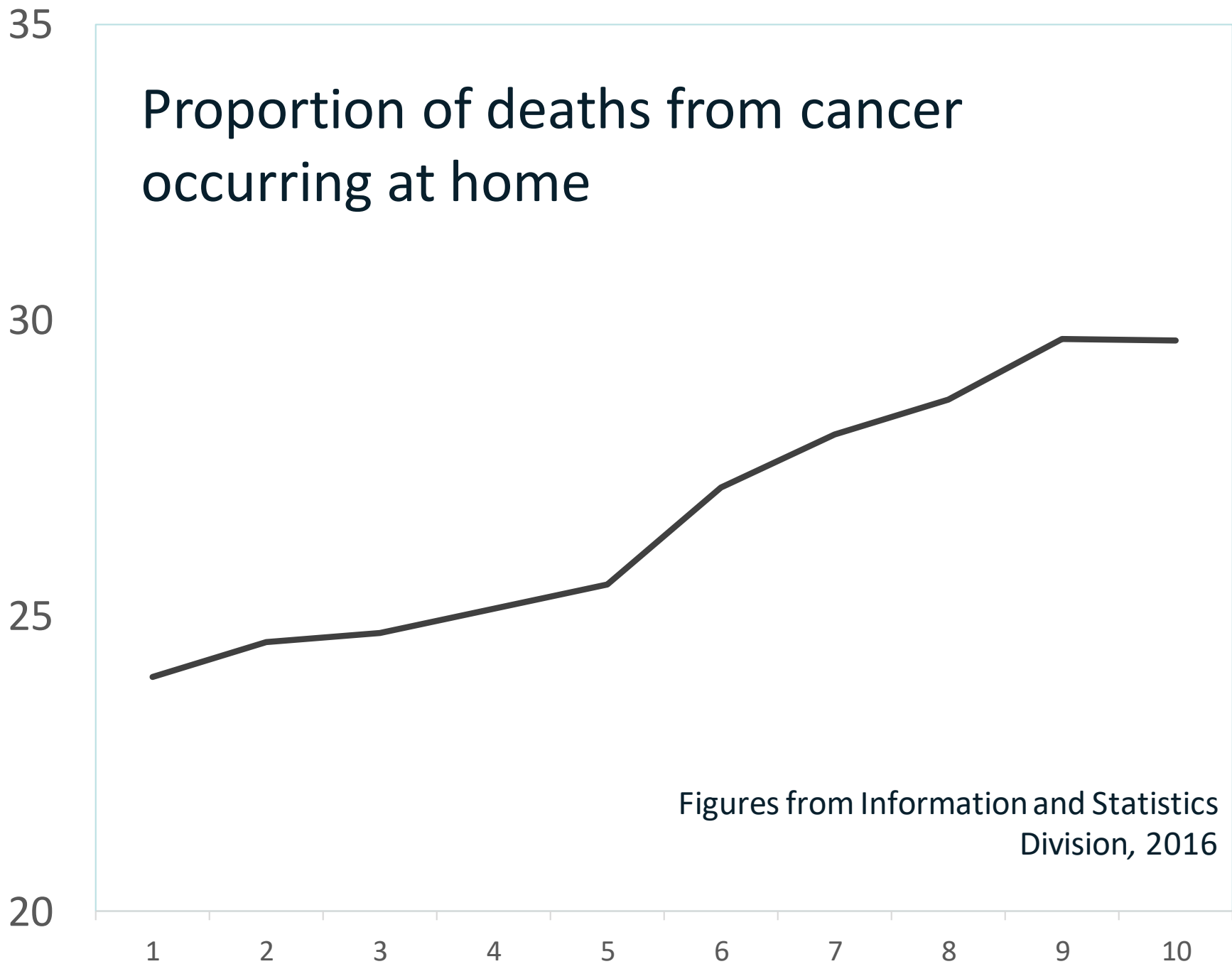
## REVIEWS AND REPORTS

# End-of-life care 'more important than ever' as deaths set to rise by 50,000

11 SEPTEMBER, 2018 | BY GEMMA MITCHELL



# Proportion of deaths from cancer occurring at home



Figures from Information and Statistics  
Division, 2016

# How to understand circumstances in the final days of life?

## ▶ Death records

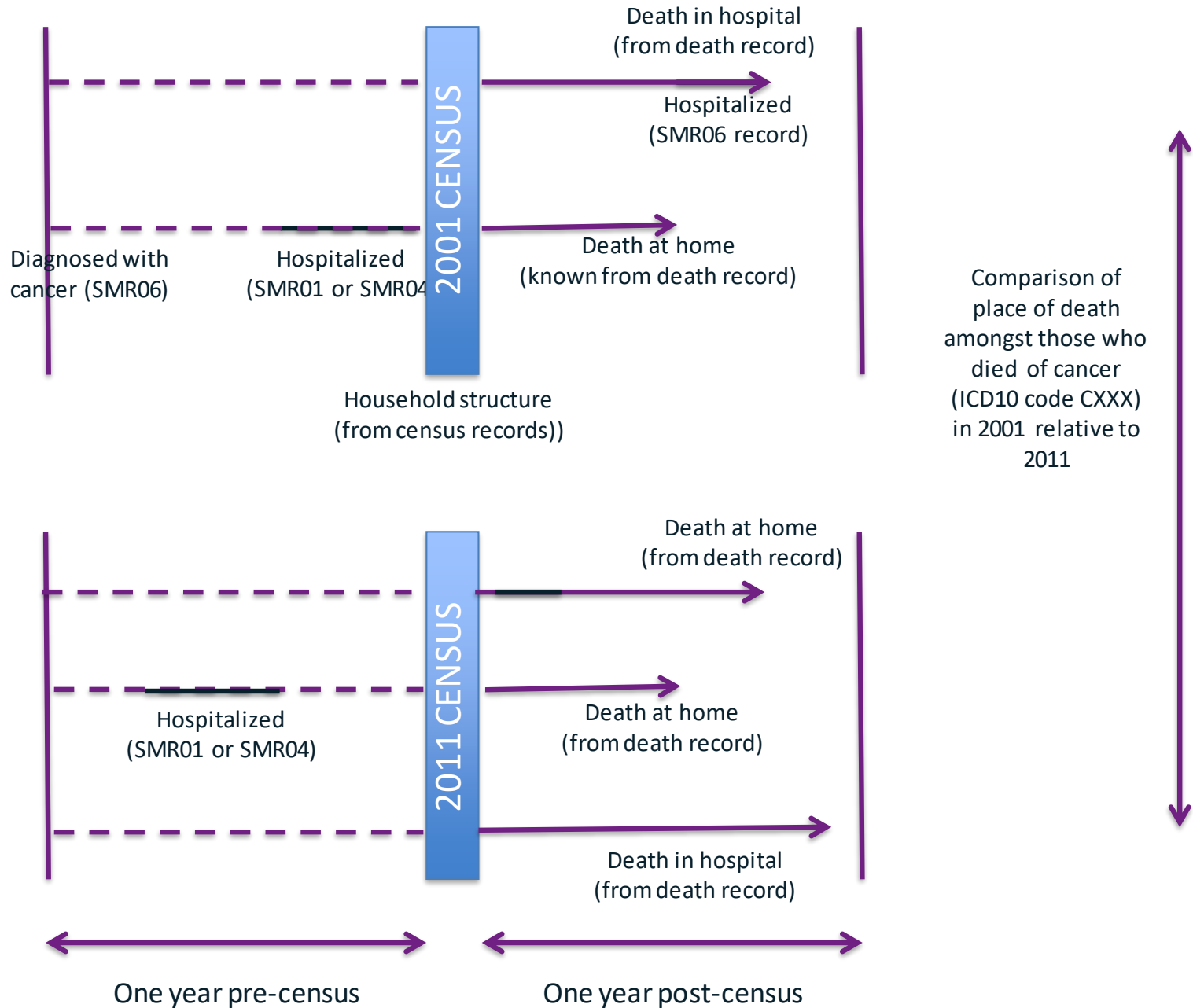
- ▷ Large numbers
- ▷ But very limited social data
- ▷ Snap shot at very end of life

## ▶ Surveys

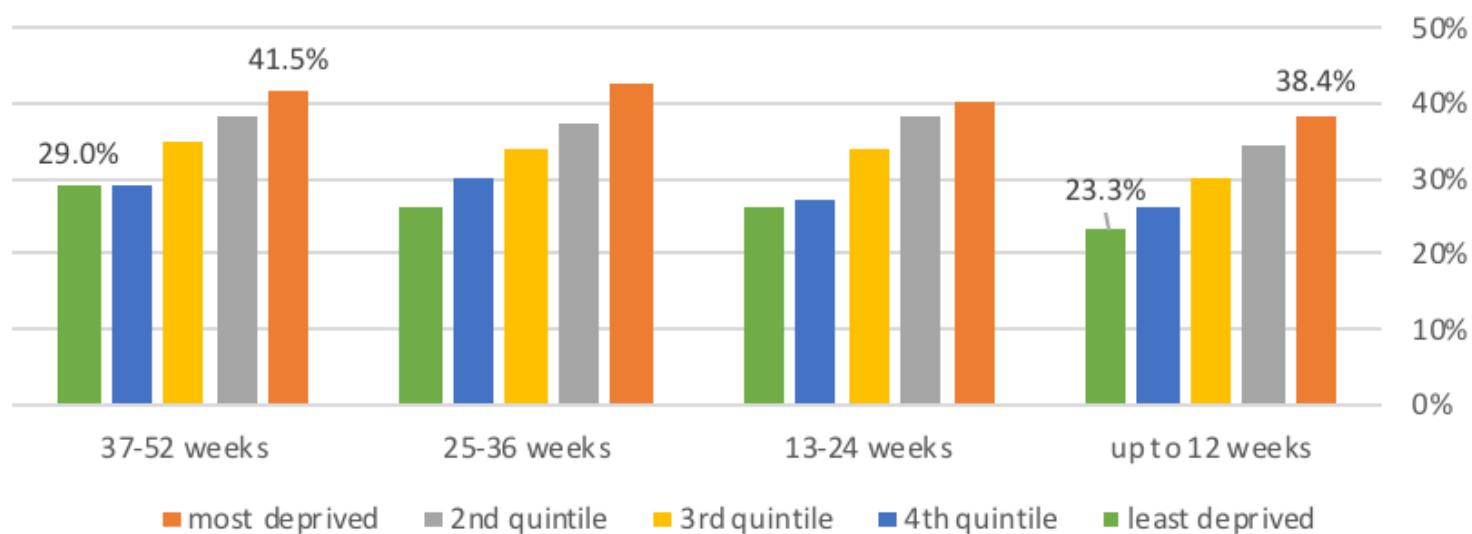
- ▷ Retrospective through carers (but small numbers and bias)
- ▷ Linkage to national surveys (numbers too small)



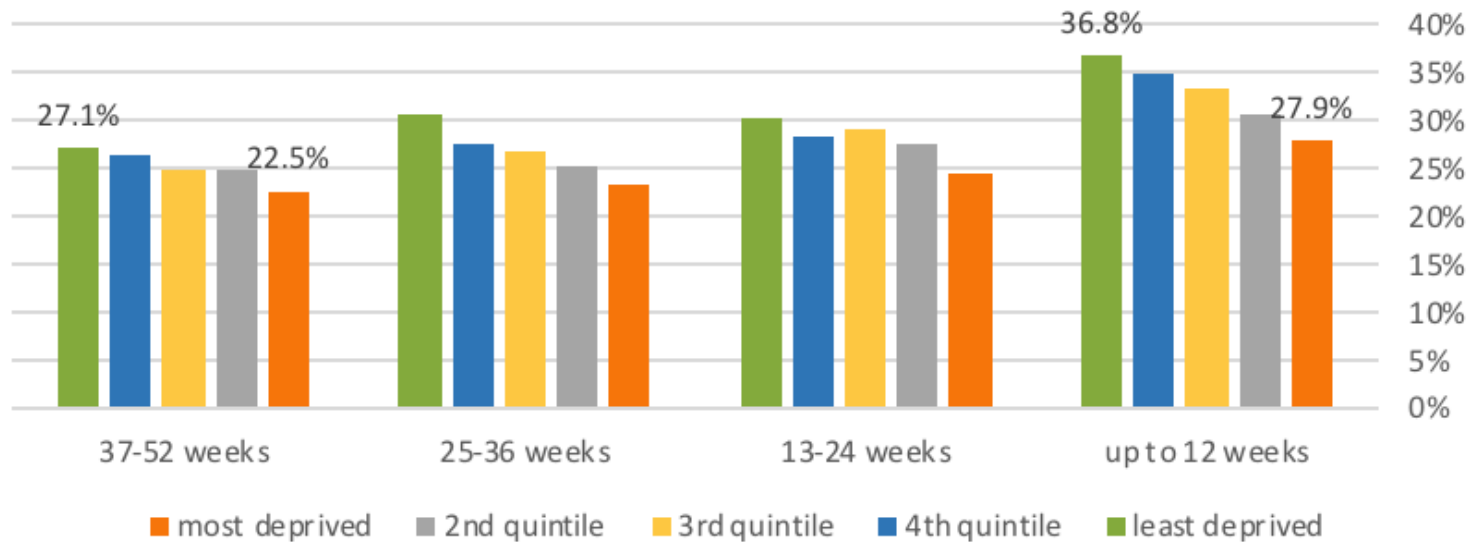
# Informal care in the last days of life: a data linkage study - Analysis plan



## Living alone by neighbourhood deprivation and time to death



## Living with informal carer by neighbourhood deprivation and time to death



# Summary

- ▶ Development of administrative data makes census *more* valuable
- ▶ Linkage of census to administrative sources enables analysis of minority groups
- ▶ And enables insights into previously unanswerable questions





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