Better **Knowledge**
Better **Society**

9 October 2015

Opportunities to Promote Data
Sharing
UCL and the YODA Project

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Research Centre
England**

An ESRC Data
Investment

Overview

- Administrative Data Research Network (ADRN)
  - Administrative Data Research Centre for England (ADRC-E)

- University of Southampton & University College London secure lab facilities
  - Safe environment

Administrative data research

▶ Uses data collected primarily for administrative purposes, usually when delivering a service – not for research

▷ Eg data from government departments, national statistical agencies, but also interest in large surveys, and especially linked data

▶ Both substantive and methodological

▶ Answering the same fundamental social science questions with data not accessible by other means

▶ Record-level data enabling exploration of record-level relationships

▶ Not necessarily "Big Data"

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Big Data Investment: Capital funding

9 April 2013

The Economic and Social Research Council is delighted to announce new funding of £64 million to be invested in Big Data.

This forms part of the Chancellor of the Exchequer's announcement of capital funding for the eight Great British technologies in his Autumn Statement detailing an additional £600m for science, research and innovation.

The investment will support the development of innovative technologies and strengthen the UK's competitive advantage in Big Data. The ESRC investment is:

Administrative Data Research Network - £34 million

The UK has the potential to achieve world leadership in the use for research of de-identified administrative data, routinely collected by government departments and other agencies. Such data, made accessible for research in ways that prevent the identification of individuals, will provide a robust evidence-base to inform research, and policy development, implementation and evaluation. This entails not just the development of a safe, secure and efficient system for linking, managing and analysing administrative data, founded on secure technologies, but on trust between data providers, researchers and all other interested parties. In addition to linking administrative data together across government departments, value can also be gained from linking administrative data to other studies, including on-going longitudinal and other surveys.

Noticeboard

- ▶ Wave 4 of Understanding Society is now available (UK Data Service)
- ▶ ESRC Celebrating Impact Prize 2015
- ▶ Changing World – photographic competition 2015
- ▶ Call for papers: CLS conference 2015 (external website)
- ▶ Job opportunity: Director of CLOSER (external website)
- ▶ NCRM research commissioning consultation (external website)

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▶ Phase 2: business and local government data
▶ Phase 3: civil society data

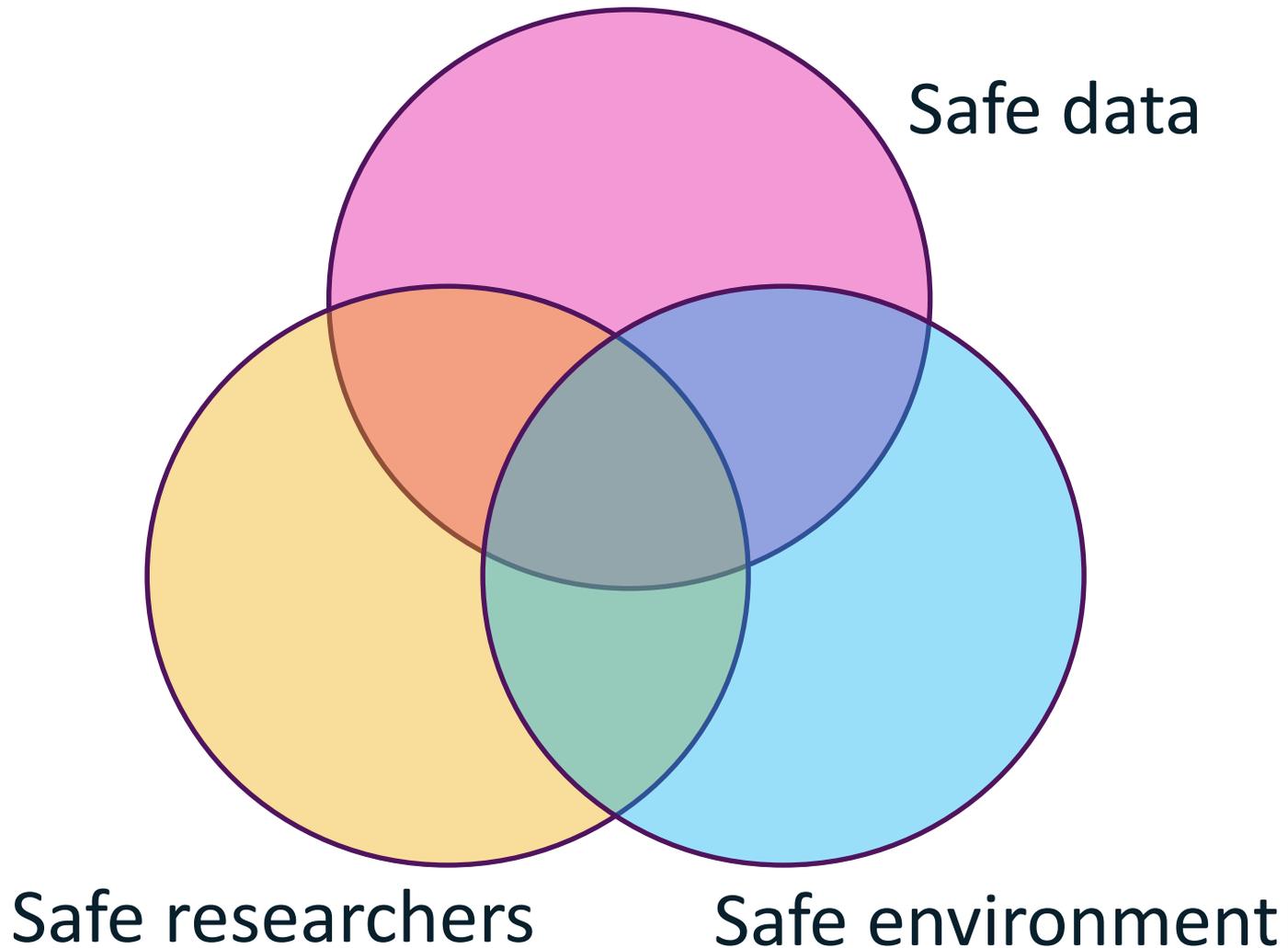# Administrative Data Research Network (ADRN)

▶ Four Administrative Data Research Centres (ADRCs)

▶ Administrative Data Service (ADS) – coordinates ADRN; central point of entry for researcher; key role in public engagement, outreach, policies and procedures, website

▶ Each ADRC is a partnership between academic institution(s) and national statistical organisation
  ▷ Centres are data processors, not data controllers

▶ Vision: to benefit society and quality of life through intelligent social research

What are we trying to achieve?

Safe data

Safe researchers

Safe environment

ADRN

- ▶ Safe people, data and environments
  - ▷ Integrated policies, governance and accreditation
  - ▷ Board reports to UK Statistics Authority; Approvals Panel includes lay members; citizen panel/s being set up...
- ▶ Support service, data scientists, trusted data-linkage partner organizations
- ▶ Research agenda including both substantive and methodological projects
  - ▷ Aiming to improve methods and provide demonstrators for others to follow
  - ▷ Examples include improved linkage methods; data quality measures; education outcomes, environment and health

Current situation

▶ ADRN contracts awarded October 2013

▶ Secure labs built, policies and protocols agreed, staff in post, boards and panels established

▶ ADRN open for project enquiries November 2014: around 50 enquiries received, of which over 20 are now approved projects

▶ Early applications include ADRN co-investigators and PhD students - to test processes

▶ New research proposals: new ethical and practical debates (paradata, non-response)

▷ Implications for ethics committees

▶ Data provision, sustainability, archiving…??

Who can use ADRN resources?

You need to:

▶ Be from academia, the public sector or a research organisation that's eligible for Research Councils UK funding

▶ Be capable of carrying out the research either independently or under the direction of an appropriate supervisor or lead investigator

▶ Attend accreditation training, and sign up to terms of use and breaches policy

What is an ADRN project? (1)

Each project must:

▶ Be non-commercial research

▶ Be feasible, viable, ethical and have clear potential public benefit (ESRC Framework for Research Ethics)

▶ Make a case for using administrative data to carry out the research

▶ Show that the linked administrative data can only be accessed through ADRN, rather than alternative safe settings

▶ Not be research which a government department or agency would carry out as part of its normal operations

▶ Make its results public through ADRN website

What is an ADRN project? (2)

New test questions:

- Is the main outcome of interest economic or social in nature?

- Is a significant factor that is being examined as causally important economic or social in character?

- Is the use of social and economic variables simple for characterisation, to produce matched samples?

What is an ADRN project? (3)

Examples:
- Impact of asthma on a child's school attendance and achievement
- Measurement of unmet health need in a health economics study
- Non-randomised follow-up on survival after different types of surgeries where a measure of poverty was used to match groups
- Study of different compliance to drug therapies between different social groups where the research question really focused on different in health outcomes between different social groups
- Study of transport-related pollution and is impact on the risk of developing heart disease

What is NOT an ADRN project?

A study where there is no evidence of any social or economic science in the proposal eg a long-term impact study of drug X on survival follow-up of RCT where the follow-up is entirely in terms of an individual's health

How does it work? (short version, 1)

▶ Researcher approaches ADS with initial enquiry

▶ Researcher submits proposal to ADS and appropriate ethics committee

▶ ADS (with ADRC support) conducts privacy impact and project feasibility assessments

▶ All evidence goes to Approvals Panel

If approved:

▶ ADS negotiates data access with data owners

▶ Researchers undergo training to become accredited to use ADRN facilities (national harmonisation)

How does it work? (short version, 2)

▶ Data transferred from suppliers to trusted linkage partner (eg dedicated unit within Office for National Statistics)

▶ Linked, de-identified data released to ADRC safe setting (secure lab) and accredited researcher is granted controlled access

▶ Analysis takes place within safe setting, supported by ADRC staff

▶ Outputs vetted and approved

▶ At end of project data destroyed, documentation and syntax retained

▶ Plain-English summaries of research published

ADRN Projects include:

- Evaluating linkage between children's health, education and social care data: Pre-term birth sub-study
- Patterns of energy consumption using Living Costs and Food Survey 2012 & Understanding Society 2011/2012 & Dept Energy & Climate Change's National Energy Efficiency Data 2011/2012 energy consumption data
- Water demand analysis using Affinity Metered Water Sample 2011 (n=5,000) & 2011 Census household microdata

Early results (1)

- McGrath-Lone et al.

- Barriers to exploring the educational outcomes of children who are looked after in England, using administrative data

- Potential effects of being in care during early childhood cannot be explored using linked data from the National Pupil Database and the Children Looked After dataset because of coverage and quality issues

- Finding has been shared with the data owners and will allow them to make informed decisions about their data collection and specification of shared datasets

Early results (2)

- Moore, Durrant & Smith
- Combining survey data, paradata and administrative data to investigate the optimisation of government survey data collection given survey non-response, including whether findings can be generalised across different surveys
- This involves computing the maximum no. of face-to-face calls any sampled household should receive to minimise collection costs without compromising survey data quality

Note!

- Time
  - Application
  - Negotiation
- Dataset specification
- Free to researcher

- Open Data vs open data
- ADRN is NOT a data repository
- Safepods/safeshare

University of Southampton & UCL secure lab facilities

▶ **Description**
  ▷ Physical security
  ▷ IT security
  ▷ Policies and procedures

▶ **Accreditation**

▶ **Researcher support**

Opportunities?

► Re-use clinical trials data by linking them with administrative data to answer research questions

► Make the data available to other researchers for them to link to administrative data to answer research questions

► Store data in secure lab facilities to make them available for research

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