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# The Challenges of Administrative Data Linkage for Longitudinal Studies of Ageing

Event CLOSER Conference Preparing for the future III: Tackling key challenges facing longitudinal population studies in a post-COVID world

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# Linking Longitudinal Studies of Ageing with Administrative Data

- ESRC Centre for Population Change project
- Survey of 14 longitudinal Health and Retirement Studies across the world
- Conducted June 2020 - June 2021
- Focus: benefits/challenges, application / approval / access processes, linkage mechanisms, linked data use & impact

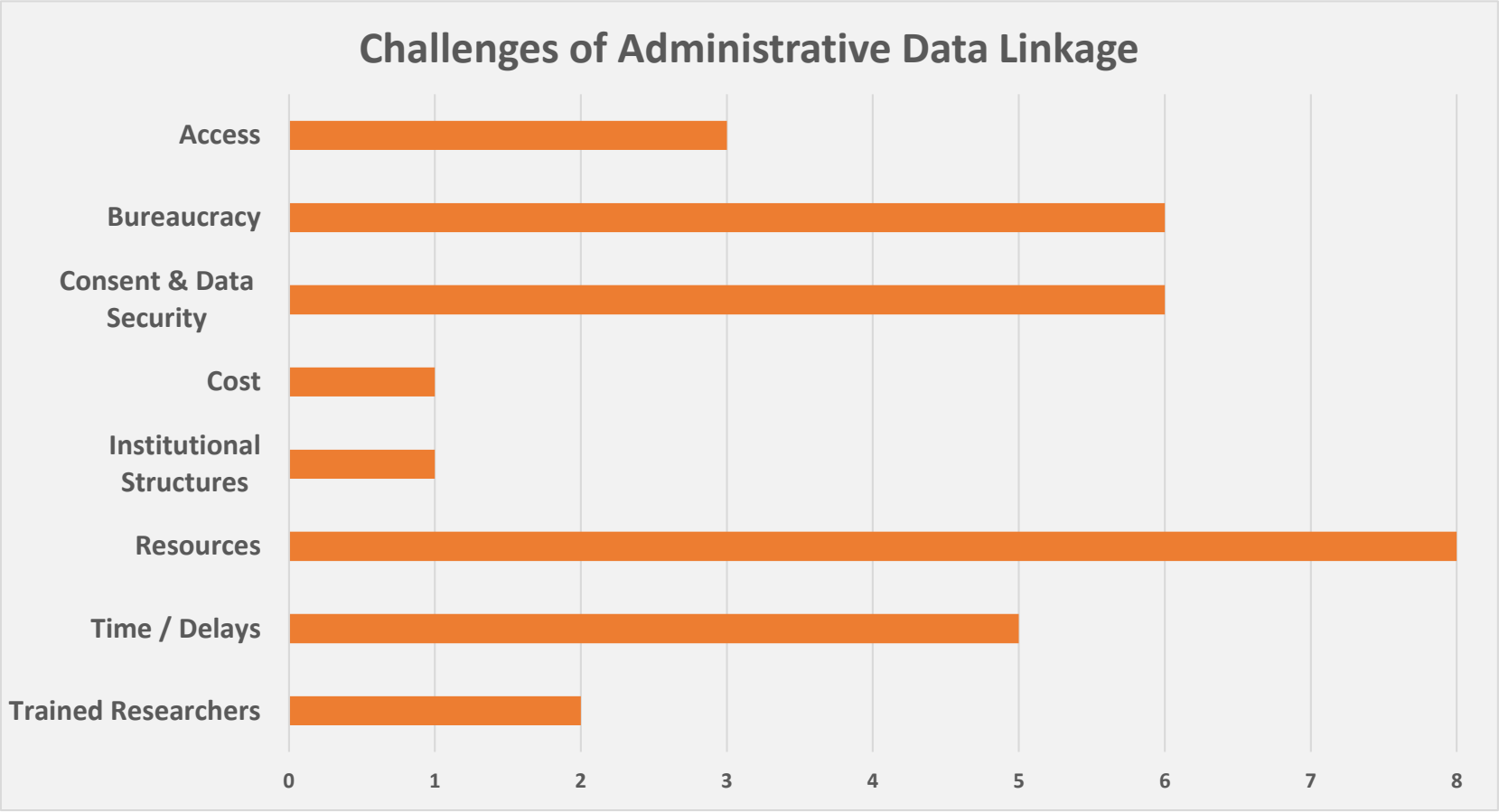
# Participating Studies

| Individual & Contextual Linkages | Individual Linkages | Contextual Linkages | No Linkage |
|---|---|---|---|
| English Longitudinal Study of Ageing (ELSA) | Costa Rican Longevity & Healthy Aging Study (CRELES) | Mexican Health and Aging Study (MHAS) | The Brazilian Longitudinal Study of Aging (ELSI) |
| Health & Retirement Survey (HRS) | The Health and Aging Study in Africa (HAALSI) | | Health, Aging, and Retirement in Thailand (HART) |
| Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA) | Healthy Ageing in Scotland (HAGIS) | | Longitudinal Aging Study in India (LASI) |
| The Irish Longitudinal Study on Ageing (TILDA) | Japanese Study on Aging & Retirement (JSTAR) | | Malaysia Ageing and Retirement Survey (MARS) |
| | Survey of Health, Ageing & Retirement in Europe (SHARE) | | |

# Linkage Landscape

- Linkage was intermittent, fragmented administrative data infrastructures, multiple owners and controllers
- Most studies were reliant on respondent consent to undertake linkage
- Health and mortality records most often linked data type

# Linkage Challenges



# Bureaucracy: Application & Approval Processes

- Critically dependent on building relationships with institutional data controllers and establishing trust
- Inextricably bound up with ethical and legal data protection and security requirements
- Length of time taken to build relationships and navigate the application/approval process varied between 2 and 10 years

# Consent & Data Security [1]

- Safeguarding of respondent confidentiality of paramount concern to data controllers
- Respondent consent for linkage regarded a major challenge
  - Low consent rates can reduce linked sample size
- Trust is key, low levels of trust in govt & institutions -> low consent rate

# Consent & Data Security [2]

- Transparency key to respondent buy-in, leading to political buy-in
- Potential trade-off between participant and wider public advocacy with increased number of linkages
- Respondent consent not strictly necessary under GDPR

# Resources - Linkage Processing

- Availability of resources most cited challenge
- Issues: linked data sample size, bias/reduced representativeness, cleaning, rendering and coding, assessing data quality
- Ease of post-approval access dependent on admin data infrastructures
- Incomplete/inaccurate/missing study data could make record matching problematic
- Scarcity of appropriately skilled researchers

# Infrastructure & Access

- Need to navigate fragmented, piecemeal administrative data infrastructures
- Linkage keys tended to be dataset-specific as usually no common, unique ID numbers
- Access varied from remote, secure terminals to Safe Haven sites

# Recommendations [1]

1. Respondent consent should be sought at the outset, either prior to or at same time as approach to data controllers
2. Studies should investigate whether or not consent strictly necessary given their specific data protection and ethical requirements
3. Pooling & sharing of expertise by HRS family
4. Studies should monitor outputs from linked data and their impact, to build and support the case for future linkage

# Recommendation [2]

1. Establishment of a single ID number to enable linkage across administrative datasets: employment, tax, benefit, health, education records.
2. Development of infrastructure to centrally manage administrative datasets, to overcome fragmented nature of most systems and streamline access

3. Real time linkage to cross-linked databases on an as-needed, live basis

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