Using routine data in research: conquering challenges and thriving
Using Social Care Administrative Data

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The Changing Landscape

• Changes since I started my PhD in 2013

• 6-years of child level data on children looked after for the whole of Wales (1st April 2008 to 31st March 2014) (n=69,960).

• Used a single dataset (SSDA903). Still interesting stuff to be done with single datasets or aggregate data, see for example Hodges (2020) Children looked after in Wales: Trends

• 12 variables (but analysis by 22 LAs, 6-years, deprivation….)

• Predominantly descriptive statistics….but, not even that had been previously done

• Things have changed significantly in the intervening 10 years
The Changing Landscape

• The last decade has seen substantial changes to the use of administrative data and data linkage in the field of social care (predominantly in relation to children’s data)

• Social care data in SAIL (CRCS/Children in Need and CLA) and the development of ECHILoD in England

• Review of UK social care data linkage studies in 2021 (Allnatt et al. 2022) identified 25 studies, with the vast majority (18) being conducted using only English data - HUGE opportunities and more being done all the time

• Research ready datasets and publication of data profiles


• Not just linked data - National Social Care Data Portal
Opportunities

• Still relatively underutilised in social care

• Developing advanced methodological skills and expertise

• Linking opportunities - Education, Health, SHRN, 2021 Census, youth offending, court data…..

• Opportunities to come – workforce, adult social care data

• Routinely collected free text data, not just statistical returns
Challenges

• Current lack of adult social care data in SAIL or analysis, although this is coming

• Data quality, although improving all the time – the 31st March ‘peak’

• Linkage of records for children under 4. Again, this is almost there

• Divergence of Wales from England and changes in Wales (largely shared definitions pre-2016) e.g., Children in Need and Children in Receipt of Care and Support

• ‘100% complete’, but some responses not helpful e.g., where children went when they leave care (a third of children went to ‘other’)

Research-Faculty@wales.nhs.uk

www.healthandcareresearchwales.org/faculty
Sources of Support

• SAIL

• CASCADE and CARE

• The Welsh Children’s Social Care and Family Justice Data Users Group (WCSCFJDUG) and the CSCDUG in England (https://cscdug.co.uk/)

• The newly developed Welsh Adult Social Care Data and Linked Data Research Group
Using Health Data
SAIL, NHS Digital, eDRIS, CPRD

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Why use routine health data?

Research Question

Methods
- Epidemiology
- Mixed Methods

InFORM Fellowship – people who call the ambulance service frequently

BE SURE – NIHR HS&DR, looking at injury presentation to emergency services by ethnicity
What data is available to you?

SAIL databank
- Data dictionaries
- Scoping support
- Cost £££
- SAIL Consumer Panel

Bring in your own data
Governance
- Information Governance Approval Panel
Data outside of Wales?

NHS Digital, electronic Data Research and Innovation Service (eDRIS), Clinical Practice Research Datalink (CPRD)

Governance
- HRA – IRAS
- Favourable ethics opinion
- Confidentiality Advisory Group (CAG)
- NHS Digital
- NHS Scotland - Health and Social Care - Public Benefit and Privacy Panel for (HSC-PBPP)
- electronic Research Application Portal (eRAP)

UKSERP Data Haven
Determinants of using linked data in research

• Don’t need to be a data analyst
• Do understand what data is available and how it is recorded
• Look for online training
• Look for people who can support you
• Be clear about the questions you are looking to answer
• Explore ways you want to report results
  - Descriptive statistics
  - Modelling of data
Thank you
Social care research in Wales in 2023

Jonathan Scourfield

Specialty co-lead for social care research
But let’s be more positive!

Social care research infrastructure in Wales

<table>
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<tr>
<th>Centre Name</th>
<th>Description</th>
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| Children’s Social Care Research and Development Centre (CASCADE) | • Founded **2014**  
  • Now largest such centre in UK |
| Centre for Adult Social Care Research (CARE) | |
| Centre for Ageing and Dementia Research (CADR) | |
| National Centre for Mental Health | |
Examples of ambitious studies

- High quality evaluations
- Data linkage studies
- Innovative qualitative research
- Innovative intervention research
- Social care economics
Essential supporting infrastructure

- Connections with practice (we need more!)
- Co-production of studies with people with lived experience of social care

Parents Research Advisory Group