

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 ECHILD 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

Allnatt, G., Lee, A., Scourfield, J., Elliott, M., Broadhurst, K. and Griffiths, L. 2022. Data resource profile: children looked after administrative records in Wales. *International Journal of Population Data Science* 1(1)

Lee, A., Elliott, M., Scourfield, J., Bedston, S., Broadhurst, K., Ford, D. V. and Griffiths, L. J. 2022. Data resource: children receiving care and support and children in need, administrative records in Wales. *International Journal of Population Data Science* 7(1), article number: 8.

- Not just linked data - National Social Care Data Portal
(<https://www.socialcaredata.wales/dataset?c=11&p=1>)

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’)

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



CASCADE



But let's be more positive!

Social care research infrastructure in Wales

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



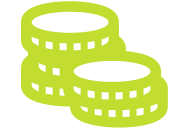
Data linkage studies



Innovative qualitative research



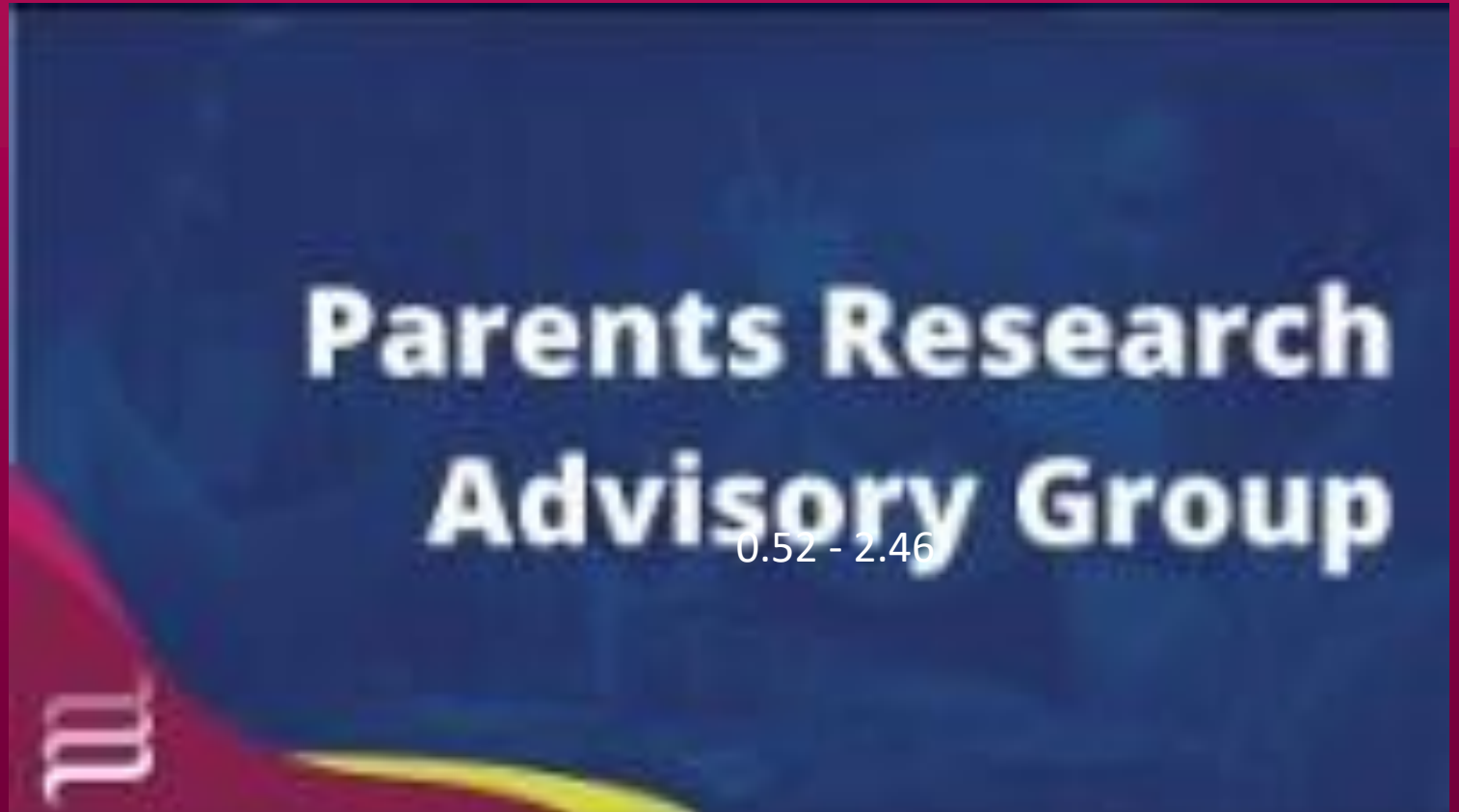
Innovative intervention research



Social care economics

Essential supporting infrastructure

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



CASCADE