ADULT SOCIAL CARE LINKED DATA RESEARCH WEBINAR

ADR Wales Social Care Team - December 2024

Economic and Social Research Council

Gofal Cymdeithasol Cymru
Social Care Wales

Welcome

- Introductions to the team.
- Overview of today's agenda.
- Join the Adult Social Care Linked Data Research Group for future activities contact tara.hughes@socialcare.wales for more info.
- Use our online forum on the Social Care Wales evidence community platform here: Social Care Wales Communities - Social Care Wales Communities
- Feel free to use the Q&A function throughout the webinar, we have opportunities to answer these at points throughout the webinar.

Ystadegau Gofal Cymdeithasol i Oedolion yng Nghymru

Adult Social Care Statistics in Wales

Joseph Wilton

Pennaeth Dadansoddi ac Arloesi / Head of Analysis and Innovation

Swyddfa Genedlaethol Gofal a Chymorth / National Office for Care and Support

Llywodraeth Cymru / Welsh Government

AnalysisAndInnovationTeam@gov.wales

Oedolion sy'n derbyn y cyfrifiad gofal a chymorth

Casgliad lefel unigol newydd o 2023-24

- Oedolion cymwys sydd â gofal a chymorth
- Blwyddyn gyntaf y casgliad ar gyfer 1 Ebrill 2023 i 31 Mawrth 2024
- Bydd y data yn cael ei ddychwelyd yn ddiweddarach yn y flwyddyn

Adults Receiving Care and Support Census

Llywodraeth Cymru
Welsh Government

New individual level collection from 2023-24

- Eligible adults who have care and support
- First year of collection for 1 April 2023 to 31 March 2024
- Data is due to be returned later in the year

Cefndir

- Yn dilyn ymgynghoriad ar y Cod Ymarfer newydd ynghylch Fframwaith Perfformiad a Gwella, ymrwymodd LIC i ddatblygu cyfrifiad newydd ar gyfer oedolion â chynllun gofal a chymorth.
- Mae'r datblygiad wedi ei seilio ar dystiolaeth o lwyddiant casgliadau data lefel unigol y plant.

Background

- Following a consultation on the new Code of Practice around a Performance and Improvement Framework, WG committed to developing a new census for adults with a care and support plan.
- The development has been based on evidence of the success of the children's individual level data collections.

Adrannau

1. Manylion craidd: Ar gyfer pob oedolyn cymwys

Gwybodaeth ddemograffig, dyddiadau dechrau a gorffen cynllunio, diogelu

2. Manylion gofal a chymorth: Ar gyfer oedolion â chynllun gweithredol ar 31 Mawrth

Preswylfa, math o ofal a chymorth, gofalwr, digwyddiadau

Sections

1. Core details: For all eligible adults

Demographic information, plan start and ends dates, safeguarding

2. Care and support details: For adults with an active plan on 31 March

Residence, type of care and support, carer, events

Manylion craidd

Dyddiad geni
Rhyw (nid rhyw ar enedigaeth)
Ethnigrwydd
Anabledd
Dyddiadau yn dechrau ac yn gorffen
Rhesymau dros gau cynlluniau
Diogelu
O 2024/25 – enw a chod post

Core details

Date of birth
Gender (not sex at birth)
Ethnicity
Disability
Dates of plan start and end
Reasons for plan closure
Safeguarding
From 2024/25 – name and postcode

Manylion gofal a chymorth

Preswylio

Diogelu presennol

Math o ofal a chymorth

Cyfrifoldebau gofalwr a gofal

Digwyddiadau (asesiadau, ailasesiadau ac adolygiadau)

Care and support details

Residence

Current safeguarding

Type of care and support

Carer and caring responsibilities

Events (assessments, re-assessments, and reviews)

Llywodraeth Cymru
Welsh Government

Diweddariadau a Diwygiadau

Mae Llywodraeth Cymru yn cyfarfod ag awdurdodau lleol yn rheolaidd i drafod newidiadau posibl.

Mae diwygiadau'n codi pan godir mater gyda:

- Adroddiad (gan awdurdod lleol)
- diffiniad (gan dimau polisi neu randdeiliaid)
- dilysu neu gysondeb (gan y tîm ystadegau mewnol)
- Cyflawnrwydd neu ddefnyddioldeb (gan unrhyw gyfranddaliwr)

Trafodir diwygiadau posibl gydag awdurdodau lleol a gwneir diweddariadau yn unol â'u hadborth

Updates and Revisions

Welsh Government meets local authorities on a regular basis to discuss potential changes.

Revisions arise when an issue is raised with:

- reporting (by a local authority)
- definition (by policy teams or stakeholders)
- validation or consistency (by internal statistics team)
- completeness or usefulness (by any stakeholder)

Potential revisions are discussed with a local authorities and updates made in line with their feedback

Gofalwyr di-dâl yn derbyn cyfrifiad cymorth

Unpaid carers receiving support census

Llywodraeth Cymru
Welsh Government

Casgliad lefel unigol newydd yn cael ei ddatblygu

- Gofalwyr di-dâl cymwys sydd wedi cael asesiad anghenion gofalwyr
- Mae blwyddyn gyntaf y casgliad wedi'i chynllunio ar gyfer 1 Ebrill 2025 i 31 Mawrth 2026
- Gwybodaeth ddemograffig, dyddiad digwyddiadau allweddol, math o gefnogaeth

New individual level collection in development

- Eligible unpaid carers who have had a carer's needs assessment
- First year of collection is planned for 1 April 2025 to 31 March 2026
- Demographic information, date of key events, type of support

Manylion craidd

Enw a chod post

Dyddiad geni

Rhyw (nid rhyw ar enedigaeth)

Ethnigrwydd

Diogelu

Core details

Name and postcode

Date of birth

Gender (not sex at birth)

Ethnicity

Safeguarding

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Darpariaethau a manylion cymorth

Manylion gofal a chymorth:

Preswylfa, math o ofal a chymorth, gofalwr, digwyddiadau

Provisions and support details

Care and support details:

Residence, type of care and support, carer, events

Llywodraeth Cymru
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Diolch am wrando!
Thank you for listening

Sorcha Egan
Llywodraeth Cymru
Welsh Government
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Any Questions?

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Centre for Adult Social Care Research
Canolfan Ymchwil Gofal Cymdeithasol i Oedolion

Sophie Wood, Fiona Lugg-Widger, Abigail Palmer

09/12/2024

@CAREResearch_W

www.careresearchwales.org

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Health and Care Research Wales

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Funded by Welsh Government

What are we about?

Funded by Health and Care Research Wales (2023 to 2028).

Bringing together adult social care research from across Cardiff University, providing:

- a critical mass of research staff working on allied topics,
- strong connections with the social care sector and other social care academics, and
- enhanced support for involving people with lived experience in social care research.

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What are we about?

Vision:

To be a leading research centre in adult social care that envisions a society where every individual with care and support needs receives person-led, dignified, compassionate and high-quality social care, promoting well-being and inclusion of adults of all backgrounds.

Mission statement:

CARE will generate high quality evidence about social care for adults, rooted in the experience of people who receive care and support and those who provide care, and based on the most rigorous research approaches suitable for the questions being addressed. **Our mission is to advance knowledge and understanding in the field of adult social care through multidisciplinary research and collaboration.**

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How are we going to use the ARCS?

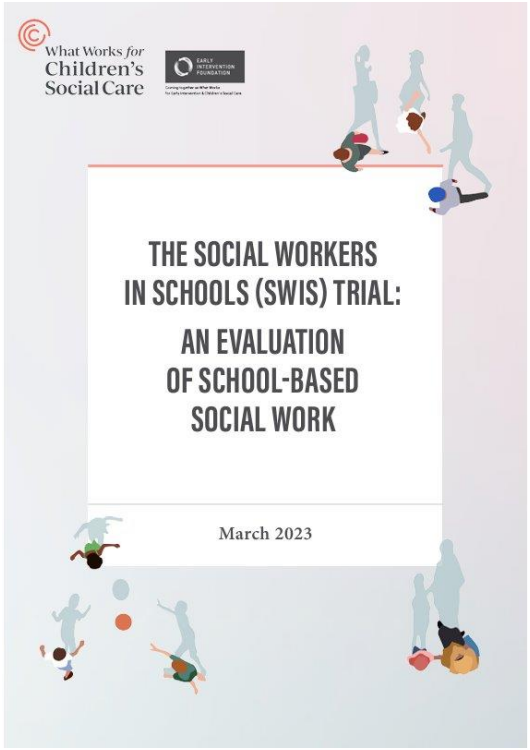
- New data set
- Data linkage – demographics, household, health, education, criminal justice
- History
- Outcomes
- Predictions
- **NIHR study: Recognising and responding to the abuse and mistreatment of people living with dementia within local authority adult safeguarding**

Working with routine social care data over the years…

Centre for Trials Research:
UK Clinical Research Collaboration (UKCRC) registered clinical trials unit

Nurse-led home-visitation programme for first-time mothers in reducing maltreatment and improving child health and development (BB:2-6): longer-term outcomes from a randomised cohort using data linkage

Michael Robling [1,2] Fiona V Lugg-Widger [1] Rebecca Cannings-John,[1] Lianna Angel,[1] Sue Channon,[1] Deborah Fitzsimmons,[3] Kerenza Hood,[1] Joyce Kenkre,[4] Gwenllian Moody,[1] Eleri Owen-Jones [1] Rhys D Pockett [3] Julia Sanders,[5] Jeremy Segrott [1,2] Thomas Slater [6]



Impact of the COVID-19 pandemic on domiciliary care workers in Wales, UK: a data linkage cohort study using the SAIL Databank

Rebecca Cannings-John [1] Simon Schoenbuchner,[1] Hywel Jones,[2] Fiona V Lugg-Widger [1] Ashley Akbari [3] Lucy Brookes-Howell,[1] Kerenza Hood,[1] Ann John [4,5] Daniel Rh Thomas [6,7] Hayley Prout,[1] Michael Robling [1]

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Adult social care linked administrative data

https://ar.inspiredpencil.com/pictures-2023/review-of-literature-images

UK Scoping Review

- Fourteen articles were included (national and local projects)
- Definitions for the adult social care population ranged
- One included unpaid carers
- One included the domiciliary care workforce.
- Linkage of datasets was slow, with challenges in the governance and linkage process.

Use of Linked Administrative Adult Social Care Data for Research: A Scoping Review of Existing UK Studies

Fiona Lugg-Widger ✉, Mia Sydenham, Rebecca Oatley, Jonathan Scourfield

The British Journal of Social Work, bcae151, https://doi.org/10.1093/bjsw/bcae151

Published: 26 September 2024 **Article history** ▾

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Opportunities for Wales

- Describing the population in more granularity
- Understand the health of the population
- Describe service provision across Wales
- Identify residential status

https://www.vecteezy.com/vector-art/11661513-wales-map-outline-vector-illustration-in-white-background

SAIL DATABANK

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Opportunities for Evaluations

Do home adaptation interventions help to reduce emergency fall admissions? A national longitudinal data-linkage study of 657,536 older adults living in Wales (UK) between 2010 and 2017

Joe Hollinghurst ✉, Helen Daniels, Richard Fry, Ashley Akbari, Sarah Rodgers, Alan Watkins, Sarah Hillcoat-Nallétamby, Neil Williams, Silviya Nikolova, David Meads ...
Show more

Age and Ageing, Volume 51, Issue 1, January 2022, afab201,
https://doi.org/10.1093/ageing/afab201

- Anonymised linkage over time
- Natural experiments of policy or local guideline changes

Need time for data to mature

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CARE Lab

Aim: To advance understanding of the adult population receiving local authority care and support, to inform service planning, evaluation and strategies to reduce inequalities

1. Analysis of stand-alone ARCS census
2. Stakeholder views on national and local trends
3. Analysis of linked data in SAIL Databank
4. Evaluation feasibility
5. Horizon scanning

https://creativemarket.com/Drum-magic/1385283-Coming-Soon-Announcement

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The London School of Economics and Political Science

Focus on adult safeguarding

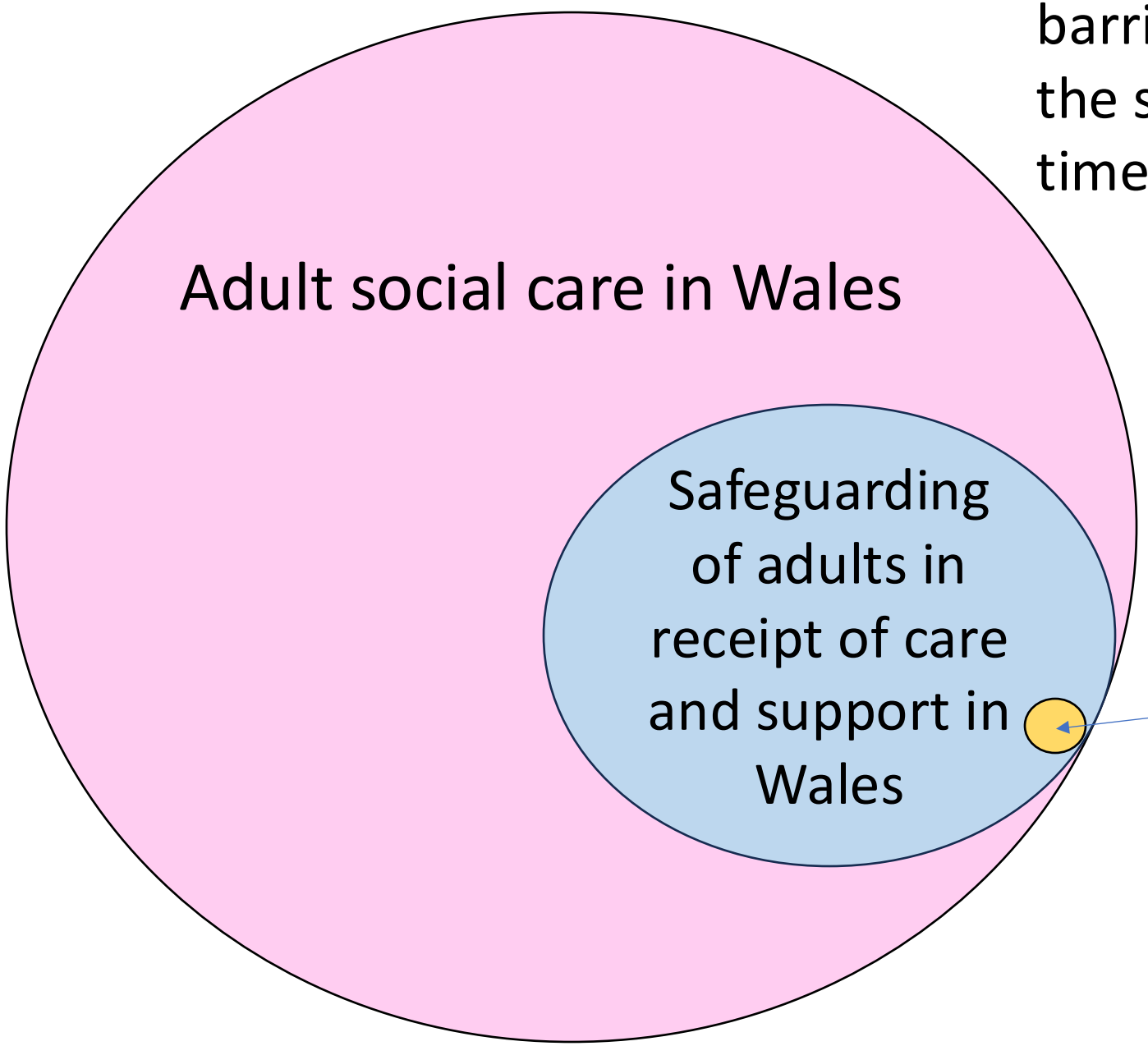
Abi Palmer

1st-year PhD student in CARE

PalmerAO@cardiff.ac.uk

This presentation will introduce:

- The topic of adult safeguarding inequalities
- An overview of PhD plans
- What ARCS could tell us about adult safeguarding inequalities



Inequalities in exposure to abuse, or, barriers and facilitators to going through the safeguarding process or to receiving timely, personalised support

Exploring the **variation and equality of access to safeguarding for at-risk adults in receipt of care and support in Wales**

Focus on adults who receive or are eligible for support from the social care system (everyone in ARCS census)

Snapshots of safeguarding inequalities

Characteristics of family members

Adult children who experience unemployment or addiction are more likely to abuse their elderly parents **(Naughton et al., 2012)**

Type of service / setting

Health workers are less likely to ask self harm patients about abuse in emergency settings where "there is typically no private room in which to talk." **(Knipe et al., 2024)**

Dementia

"It may be more difficult to reach a definitive outcome [about whether abuse occurred] in those cases involving an alleged victim with dementia **(Fyson & Kitson, 2012)**

Living in a deprived area

Higher levels of local deprivation associated with higher rates of safeguarding screening and protection **(Montgomery, Doyle, Bunting & Gleghorne, 2024)**

Intellectual disability

People with intellectual disabilities face disproportionate abuse risk compared to other disabled people **(Hollomotz, 2012)**

Clinicians may fail to recognize signs of abuse in people with learning disability due to "diagnostic overshadowing, and various knowledge gaps **(Harlow, 2022)**

Communication differences

Safeguarding leads viewed service users who struggled to communicate as a "hindrance" during abuse investigations **(Fyson & Kitson, 2012)**

Planned timeline

Present

Initial reading / exploring

Scoping review

ARCS analysis

Qualitative study

Identified potential variation in safeguarding practice from analysis of CIW reports

Explored local-level safeguarding data

Non-systematic literature search and reading

What is already known about inequalities in the adult safeguarding process **in the UK**?

Abuse, reporting, process, protection plans, personalisation, long-term outcomes

What are the characteristics of adults subject to safeguarding processes, by type of abuse, and of adults with protection plans, compared with those receiving care and support who have not been subject to safeguarding?

Informed by findings from these studies

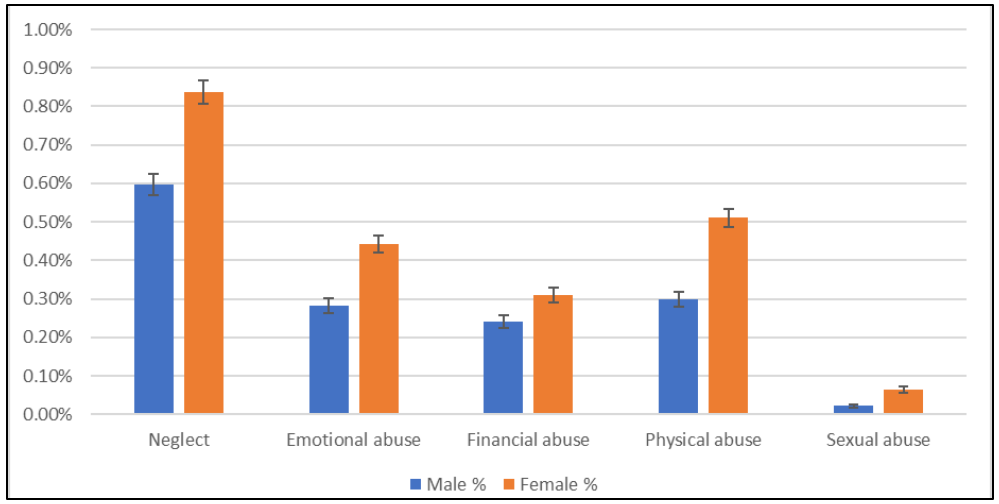
/ To answer questions that ARCS couldn't, or to expand on ARCS findings

More detailed safeguarding insights with ARCS

Local authority-level data:

- Not individual-level
- Not released since 2019
- Some ethnicity data missing
- BUT some indication of inequalities

% of men and women over 65 subject to safeguarding processes, by abuse type, in Wales



Limitations: Individual ages / distribution of ages unknown, so not able to estimate true proportions / risk for gender-age groups

ARCS data (individual level):

Caring responsibilities

Has a known carer

Age

Local authority

Gender

- Subject to safeguarding procedures? (y/n)
- Category of safeguarding (five categories)
- Active care and support protection plan on 31/3?

Ethnicity

Language

Disability / illness

Type of care and support

Type of residence

https://www.gov.wales/sites/default/files/statistics-and-research/2024-06/adults-receiving-care-and-support-census-2023-24.pdf

What inequalities can/cannot be identified from ARCS?

Characteristics of family members

Adult children who experience unemployment or addiction are more likely to abuse their elderly parents **(Naughton et al., 2012)**

Type of service / setting

Health workers are less likely to ask SH patients about abuse in emergency settings where "there is typically no private room in which to talk." **(Knipe et al., 2024)**

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In conclusion:

- Adult safeguarding inequalities could be about risk of abuse, likelihood of a referral, timeliness of process, accessibility of safeguarding investigations or services where safeguarding might be disclosed... and much more!
- The ‘safeguarding inequalities’ analysis of the ARCS census will follow on from a scoping review, as part of a PhD project
- We can use ARCS to learn about the characteristics of adults subject to safeguarding processes and with protection plans – looking at many intersecting demographic and other factors
- Initial readings indicate that people with dementia, communication differences, intellectual disabilities, or who live in a deprived location, have adult children who are unemployed or suffer from addiction, or who present in specific care settings (and potentially other groups) may be disadvantaged with regard to abuse and the safeguarding process (and gaps in knowledge are not yet known)

Fyson, R., & Kitson, D. (2012). Outcomes following adult safeguarding alerts: a critical analysis of key factors. The Journal of Adult Protection, 14(2), 93-103.

Harlow, E. (2022). Adults with learning disabilities' experiences of disclosing abuse, who access Community Learning Disabilities Teams, in Southeast England, UK (Doctoral dissertation, University of Essex).

Hollomotz, A. (2012). 'A lad tried to get hold of my boobs, so I kicked him': an examination of attempts by adults with learning difficulties to initiate their own safeguarding. Disability & Society, 27(1), 117-129.

Knipe, D., Gregory, A., Dangar, S., Woodhouse, T., Padmanathan, P., Kapur, N., ... & Derges, J. (2024). 'Once you've opened that can of worms': qualitative study to understand why liaison psychiatry staff are not asking about domestic abuse following self-harm. BJPsych Open, 10(6), e177.

Montgomery, L., Doyle, L., Bunting, L., & Gleghorne, N. (2024). Adult Safeguarding Inequalities in Northern Ireland: An Exploratory Study. The British Journal of Social Work, bcae064.

Naughton, C., Drennan, J., Lyons, I., Lafferty, A., Treacy, M., Phelan, A., ... & Delaney, L. (2012). Elder abuse and neglect in Ireland: results from a national prevalence survey. Age and ageing, 41(1), 98-103.

I am happy to answer any questions!

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Our website:

www.careresearchwales.org

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Gosod blaenoriaethau ymchwil

Data gofal cymdeithasol oedolion a gesglir yn rheolaidd

Lynsey Cross, Swyddog Ymchwil Gofal Cymdeithasol

Setting research priorities

Routinely collected adult social care data

Lynsey Cross, Social Care Research Officer

Noddir gan Lywodraeth Cymru
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Gofal cymdeithasol yn ADR Cymru

- Mae rhaglen gofal cymdeithasol Cymru Ymchwil Data Gweinyddol (ADR) yn cael ei harwain gan Ofal Cymdeithasol Cymru
- Mae gan Ofal Cymdeithasol Cymru gylch gwaith i hybu'r defnydd o dystiolaeth mewn gofal cymdeithasol yng Nghymru
- Bydd Gofal Cymdeithasol Cymru ac ADR Cymru yn hyrwyddo manteision ymchwil data cysylltiedig mewn gofal cymdeithasol oedolion a phartneriaid cymorth i rannu eu data er mwyn galluogi'r ymchwil sydd ei angen arnynt

Social care in ADR Wales

- Administrative Data Research (ADR) Wales social care programme is led by Social Care Wales
- Social Care Wales has a remit to promote the use of evidence in social care in Wales
- Social Care Wales and ADR Wales will promote the benefits of linked data research in adult social care and support partners to share their data to enable the research they need.

Pam rydym yn gosod blaenoriaethau ymchwil

- Credwn y dylid gwneud ymchwil ar bynciau sydd o bwys i bobl sy'n cyrchu a darparu gofal cymdeithasol
- Buom yn gweithio gyda Chynghrair James Lind (JLA) ar ddau ymarfer gosod blaenoriaethau blaenorol. Rydym wedi defnyddio'r rhain i lywio ein gwaith ac wedi'u rhannu â chyllidwyr ac ymchwilwyr
- Rydym bellach yn cynnal ymarfer gosod blaenoriaethau ar ddata gofal cymdeithasol oedolion a gesglir yn rheolaidd

Why we set research priorities

- We think research should be done on topics that matter to people accessing and delivering social care
- We worked with the James Lind Alliance (JLA) on two previous priority-setting exercises. We've used these to inform our work and shared them with funders and researchers
- We're now running a priority-setting exercise on routinely collected adult social care data

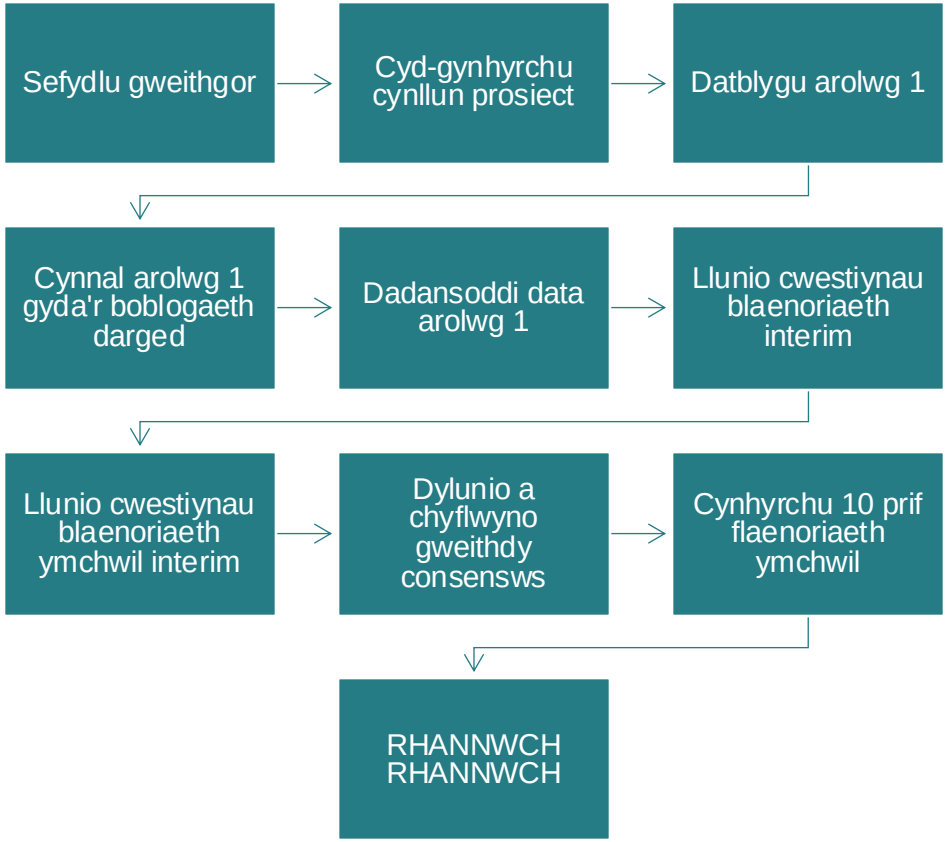
Ynglŷn â'r ymarfer gosod blaenoriaethau hwn

- Mae pobl sy'n cynllunio ac yn darparu gofal cymdeithasol eisoes yn casglu ac yn defnyddio data bob dydd i gefnogi eu gwaith
- Gallwn gysylltu'r data hwn â ffynonellau eraill o wybodaeth i weld lle mae bylchau neu dueddiadau – er enghraifft, i ddweud wrthym pa ofal sydd ei angen ar bobl mewn gwahanol rannau o Gymru
- Bydd yr ymarfer gosod blaenoriaethau hwn yn nodi'r '10 uchaf' cwestiwn ymchwil ar ofal cymdeithasol oedolion y mae angen i ni eu hateb gan ddefnyddio data cysylltiedig.
- Bydd hyn yn arwain ymchwil ar yr hyn sy'n bwysig i bobl mewn gofal cymdeithasol, gan helpu i wella canlyniadau

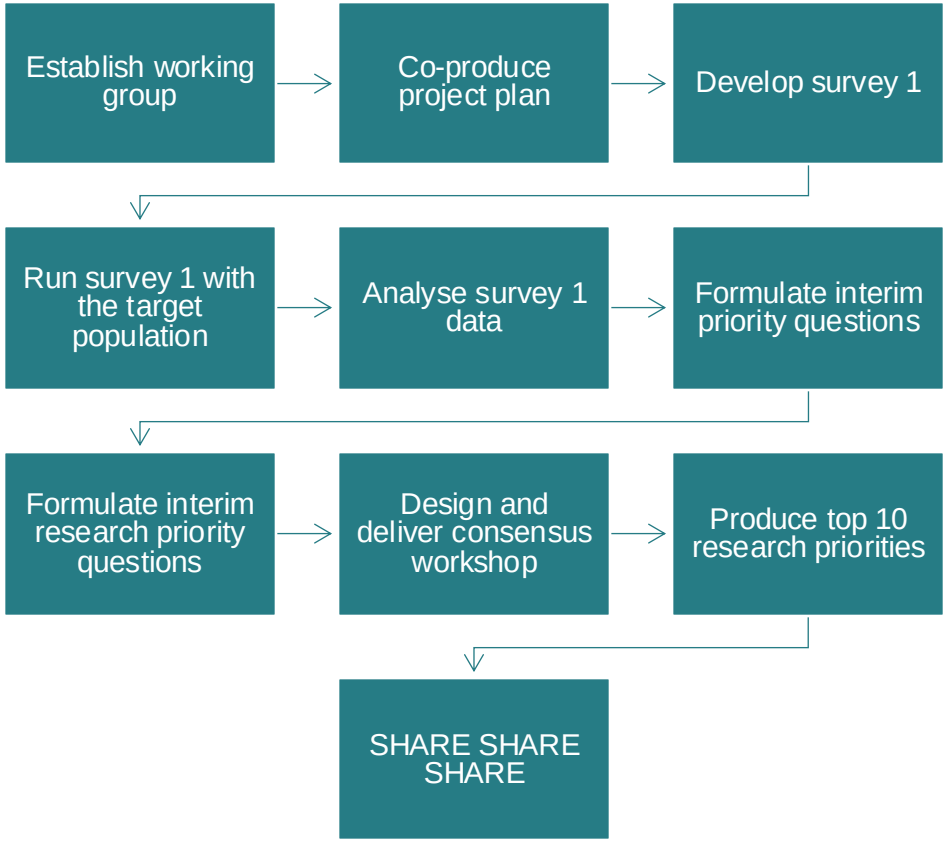
About this priority-setting exercise

- People planning and delivering social care already collect and use data everyday to support their work
- We can link this data to other sources of information to see where there are gaps or trends – for example, to tell us what care people need in different parts of Wales
- This priority-setting exercise will identify the 'top 10' research questions on adult social care we need to answer using linked data
- This will guide research on what matters to people in social care, helping improve outcomes

Ein hymagwedd



Our approach



Canfyddiadau interim

- Rhagfynegi ar gyfer y dyfodol: defnyddio data cysylltiedig i ragweld y galw yn y dyfodol a dyraniad adnoddau ar gyfer gwasanaethau gofal cymdeithasol.
- Deall mynychder amseroedd aros am ddarpariaeth gofal a'r canlyniadau i'r unigolyn a'r gwasanaethau dan sylw.
- Ymchwil sy'n cynnwys arloesi digidol a'r defnydd o dechnoleg o fewn darpariaeth gofal cymdeithasol oedolion.

Interim findings

- Forecasting for the future: using linked data to forecast the future demand and resource allocation for social care services.
- Understand the prevalence of waiting times for care provision and the outcomes for the individual and services involved.
- Research involving digital innovation and the use of technology within adult social care provision.

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Diolch

Thank you

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Final Questions

- We will be sending you all a feedback form and ways to stay in touch.
- We look forward to sharing future activities and events from the Adult Social Care Linked Data Research Group.