Research prioritisation report: linked data research in adult social care

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**Authors: Tara Hughes, Amber Browne and Eleanor Johnson**

Introduction

The Administrative Data Research (ADR) Wales Social Care team, led by Social Care Wales, has run a priority-setting exercise on linked data research in adult social care. **This exercise was funded by ADR Wales.** It involved identifying the aspects of adult social care in Wales that should be examined using linked data research. This report sets out the results of this priority-setting exercise. It summarises feedback from participants on each of the top 10 priority themes, as well as their reflections and feedback on the priority-setting process. You can learn more about this process on our [help set research priorities](https://insightcollective.socialcare.wales/our-work/help-set-research-priorities/what-do-we-mean-by-research-priority-setting) page.

Linked data research

Administrative data is information that’s routinely collected by government and public services to carry out their work effectively. Administrative data that’s collected in different places can be linked to compare information from various areas of our lives. This is called linked data research.

Linking adult social care data from across Wales with administrative data from other sources, such as health or housing, can help us understand more about people’s needs and experiences. When we link data, it gives us a more complex and comprehensive picture at a population level than a single data set can provide.

Data that’s readily available to be linked is in electronic format with an identifier (for example, date of birth). It also meets appropriate governance requirements, such as consent for data to be used for research.

In linked data research, the data that’s used and linked together is held within an anonymised and secure databank. In Wales we have access to the Secure Anonymised Information Linkage Databank (SAIL). SAIL stores anonymised health and social care data about people in Wales.

Social Care Wales has a leadership role for social care in the ADR Wales 2022 to 2026 period, with funding from the Economic and Social Research Council (ESRC), via ADR Wales. Our agreed focus is adult social care research, since linked data for children’s social care research is more advanced in Wales.

Our approach to research priority setting

We completed this project after three previous research priority-setting exercises, which focused on [care and support for older adults](https://insightcollective.socialcare.wales/what-do-we-mean-by-research-priority-setting/care-and-support-for-older-adults), [family support services](https://insightcollective.socialcare.wales/what-do-we-mean-by-research-priority-setting/family-support-services), and [transitions from children’s to adults’ social care support](https://insightcollective.socialcare.wales/what-do-we-mean-by-research-priority-setting/transitions-from-childrens-to-adults-social-care-support). This exercise aimed to identify priorities for linked data research by working with organisations that routinely collect data, people with lived experience of care and support, social care practitioners, third sector partners, researchers and policy makers.

The priority setting exercise included several steps:

1. **Engagement activities**

A survey, online meetings and face to face conversations were carried out with operational and strategic social care staff, third sector colleagues and people accessing adult social care services. In these engagement activities we asked, ‘What adult social care do people in Wales need, now and in the future?’

1. **Analysis**

Data gathered during the engagement phase was separated into individual data points, analysed, and grouped into themes. This involved establishing where data was out of scope, such as if it didn’t relate to adult social care or if it couldn’t be explored using linked data research. This resulted in a shortlist of 15 themes.

1. **Consensus development workshop**

An online workshop took place with a group of 14 people. The group included five people with lived experience of accessing social care services and nine professional participants, who worked in operational or strategic roles across the adult social care sector. After discussing the 15 themes in small, facilitated groups, individuals were then asked to vote on their priority themes. This voting led to a final ‘top 10’ priority themes.

Read more about the priority setting process [here](https://insightcollective.socialcare.wales/what-do-we-mean-by-research-priority-setting/linked-data-research-in-adult-social-care).

Top 10 themes for linked data research within adult social care

This section of the report summarises the contributions and discussions that took place in relation to each of the top 10 priority themes. Some priorities received greater attention than others, so some summaries are longer in order to capture this.

The summaries in this report draw upon:

* responses to engagement activities, including suggestions from survey respondents, where people were asked to share what adult social care they felt people in Wales need
* notes from the consensus development workshop, which captured participants’ discussions about which of the initial list of 15 themes should be prioritised for future linked data research on adult social care.

*Hold the Ctrl button on each topic and click on the hand icon that appears to jump to each priority theme with further information.*

1. [Understand the impact of preventative and early intervention services (such as home adaptations or telecare) on the use of other health and social care provision](#_#1._Understand_the).
2. [Understand the needs of different groups to make sure future commissioning of social care services can respond to them. These groups include unpaid carers, neurodivergent people, people with learning disabilities, and young people with physical disabilities.](#_#2._Understand_the)
3. [Understand what factors impact the health and well-being of social care staff, and how these factors may also affect recruitment and retention.](#_#3._Understand_what)
4. [Forecast future demand and resource allocation for social care services, including housing with care and support and day services.](#_4._Forecast_future)
5. [Explore the relationship between social care funding and the quality and effectiveness of service provision.](#_#5._Explore_the)
6. [Understand the relationship between workforce-related factors - such as staffing levels, terms and conditions, training needs, language skills and other relevant skills - and the care and support provided.](#_#6._Understand_the)
7. [Understand how social care is provided across a person's lifetime and the relationship between social care provision and the overall health of people using care services.](#_ #7._Understand_how)
8. [Understand where health and social care services work together and how this impacts on people accessing care and support as well as the services involved.](#_#8._Understand_where)
9. [Understand the relationship between social isolation, loneliness and social care provision.](#_#9._Understand_the)
10. [Understand the impact of waiting times for social care provision on individuals who need care and support.](#_#10._Understand_the)

#1. Understand the impact of preventative and early intervention services (such as home adaptations or telecare) on the use of other health and social care provision.

Several suggestions that contributed to this theme emerged during the engagement activities. People thought that linked data research should focus on the effect of preventative and early intervention services. They also wanted research to focus on how these services would impact on individuals’ outcomes and wider health and social care services. Examples of these types of services were also provided, including direct payments, telecare, home adaptations, and strengths-based or place-based working.

In terms of prevention, survey respondents wanted linked data research to focus on interventions which delay or reduce the need for other health and social care services, manage the escalation of need, and promote personal independence.

In the workshop, all participants agreed on the importance of early intervention. Participants highlighted that early intervention improves individual outcomes and reduces long-term dependency on care services. They emphasised the need for a person-centred approach to prevention, where individuals and their families are actively involved in planning and decision-making.

Some participants also spoke about how preventative and early intervention services can promote independent living within the community. One participant described it as "key because it's about enabling independent living as much as possible".

Another participant shared that their own home adaptations helped them to maintain their independence. However, they also suggested that some home care providers had failed to communicate effectively with people using care services and their families. For this participant, poor communication was seen as a significant barrier to good preventative care.

Another participant described how properly implemented early intervention measures could reduce hospital stays and unplanned care, as well as preventing unnecessary transitions into care homes. Another participant noted that their team were currently working to understand the impact of early intervention, recognising that this is a critical area that needs further development and evidence to inform practice.

It's important to note that some participants in the workshop expressed concern that the examples provided within this priority theme were not representative of the wide range of services or approaches that could be investigated in future research looking at prevention. This includes considering self-advocacy services, day centres, and community initiatives.

**#2. Understand the needs of different groups to make sure future commissioning of social care services can respond to them. These groups include unpaid carers, neurodivergent people, people with learning** disabilities, and young people with physical disabilities.

Of our shortlist of 15 themes, this theme brought together the highest number of suggestions from our initial engagement activities. Many participants in these activities said that there is a need for linked data research to understand the needs of different groups, so that future services can be designed and delivered with their specific needs in mind. These groups include unpaid carers, neurodivergent people, people with learning disabilities, and young people with physical disabilities.

Several participants in the engagement activities mentioned specific services and types of support that might be required to respond to the needs of these different groups. For example, carers’ needs assessments, respite, and support for family carers were mentioned in relation to the needs of unpaid carers.

In the workshop, many participants emphasised the importance of equality, inclusion, and cultural competency in social care. Some participants highlighted that a lack of knowledge or understanding within social care services can mean that the needs of certain groups remain unmet. Others suggested that commissioning should be informed by the diverse lived experiences of unpaid carers, neurodivergent people, ethnic minority groups, and other under-represented groups.

One participant suggested how this area could be investigated: "We would really like researchers to look at this using evidence within the third sector."

Another participant with lived experience of providing care for a family member reported communication barriers in discussing care needs, particularly in terms of language. This participant also reported instances where there was a lack of cultural awareness on the part of social care workers, such as not removing shoes in individuals’ homes. There was strong support from many participants for a person-centred model of care that aligned with culturally appropriate care values, where the needs and preferences of people using care services are actively considered and respected.

Participants also noted that using linked data research to better understand the needs of different groups could provide the evidence needed to distribute resources more strategically and equitably. By identifying and addressing gaps, services could become more inclusive and responsive to the varied needs within communities.

#3. Understand what factors impact the health and well-being of social care staff, and how these factors may also affect recruitment and retention.

Participants in our initial engagement exercise reported high levels of staff sickness and difficulties in recruiting and retaining staff. They called for linked data research that would help to build an understanding of how to improve the health and well-being of social care staff, as well as supporting recruitment and retention.

Many participants in the workshop agreed that understanding the factors that impact on staff well-being is a priority, particularly in terms of the subsequent impact that poor well-being can have on recruitment and retention. The consensus was that staff well-being is crucial for maintaining high-quality social care, yet many participants described the current situation as challenging. Key issues reported by the workshop participants included low morale, emotional strain, and burnout. Good supervision was also proposed as a potential solution that linked data research may be able to explore.

One participant suggested that care companies often listen to staff complaints but fail to act, leaving workers feeling unheard and unsupported. They suggested that, when people leave, this can lead to remaining staff taking on additional tasks beyond their role. This in turn, creates more pressure that can negatively impact staff well-being and care quality. Participants also emphasised the need for better training to prepare workers for their roles. They felt that insufficient training can often leave staff feeling unprepared.

One participant suggested that low morale among staff is particularly common in local authority settings. They acknowledged that social workers needed to manage emotionally demanding situations, but that a lack of supervision could lead to poor mental health, burnout and compassion fatigue.

Many participants emphasised that better working conditions and fair wages are essential for maintaining the social care workforce. One participant stressed that low pay remains a critical barrier to recruitment and retention, stating: "The pay is not brilliant".

One participant said that care workers are often undervalued compared to health professionals. They noted that care workers felt left behind during the pandemic, reinforcing feelings of disempowerment.

#4. Forecast future demand and resource allocation for social care services, including housing with care and support and day services.

Some participants who took part in the engagement activities wanted linked data research to focus on projecting future demand on social care services. They felt this would aid decisions around workforce planning, policy development and strategic decision-making, budget allocation and service delivery. There was a strong focus on understanding the future demand for discrete services, such as adult day services, and housing with care and support.

In the workshop, many participants suggested that linked data research that focused on forecasting and planning for future care needs should be prioritised, particularly if it could be used to inform early intervention approaches. There was a consensus amongst participants that proactive planning would help make sure that services meet the growing needs of Wales’s ageing population and, in particular, the needs of individuals with learning disabilities as they grow older.

Many participants noted the high volume of referrals they encounter for their services, highlighting the challenge of managing demand without sufficient funding for development, particularly within mental health teams. Some participants described current approaches as reactive rather than proactive, despite ongoing efforts to forecast demand. One participant spoke about the impact that managing high demand for services had on her and her colleagues, saying: “We’re constantly firefighting”.

Several participants appreciated that theme number four specifically included housing and day services, which they said were often overlooked when planning. Workshop participants spoke about hard-working and committed social care staff, stressing that better planning would improve the terms and conditions for these workers. Others spoke about how better forecasting and planning would make social care more equitable and facilitate a more strategic approach to managing limited resources.

However, there were mixed views on whether this theme needed more research. Some participants felt that forecasting should already be an established practice, while some believed that improved data integration and a more strategic perspective would enhance long-term planning and reduce inequalities.

#5. Explore the relationship between social care funding and the quality and effectiveness of service provision.

Suggestions from participants involved in our engagement activities that related to this theme included:

* a need to assess the impact of long-term usage of social care packages on the health and well-being of people using care services
* the relationship between different types of service provision and outcomes for individuals
* the relationship between the funding provided to services and the quality and effectiveness of those services.

In the workshop, one participant expressed that there was a lack of clarity about funding allocations and spending within social care, which hindered the effective use of resources. Another participant said that there was a need to research existing social care funding models to determine whether they fit their intended purpose. Some participants questioned whether current financial structures effectively support people using care services or align with preventative approaches. Some participants also highlighted that it remains unclear what determines the quality and effectiveness of services, suggesting that this area requires further investigation.

However, other participants pointed out that there is a well-established evidence base around cost-effectiveness in social care. One participant noted that rather than continuing to explore funding itself, it would be more valuable if linked data research focused on maximising outcomes within existing financial limits. Another participant agreed that funding is critical, but argued that attention should be directed towards maximising efficiency and ensuring that interventions are appropriate and practical, rather than solely on reassessing funding models.

#6. Understand the relationship between workforce-related factors – such as staffing levels, terms and conditions, training needs, language skills and other relevant skills – and the care and support provided.

Suggestions from participants in the engagement activities covered a broad range of workforce-related issues. Suggestions also focused on how these issues impact not only on staff recruitment, retention and well-being but also on the health and well-being of individuals accessing care and support. Suggestions indicated the need to understand workforce capacity and skills shortages, the language skills of staff, and terms and conditions, specifically concerning pay.

In the workshop, many participants emphasised that workforce-related factors such as staffing levels, terms and conditions, training needs, and skills development significantly impact on the quality of care and support that is provided to people accessing social care. They highlighted how issues related to low pay, a lack of training, and inconsistent workforce standards also contributed to recruitment and retention challenges. One participant stated: "People who do the caring are not rewarded well".

One participant emphasised how low pay, poor working conditions and a lack of structured support all impact on recruitment and retention. They also spoke about the difficulties that some workers face when asking for additional support, which can leave them feeling unvalued and unheard.

Another participant raised concerns about a lack of training for social care staff, particularly in moving and handling individuals. They explained that many staff members lack adequate training but are expected to perform physically demanding or technical care tasks. They said that this gap in training often forces more experienced staff to train their colleagues on the job, which further increases their workload. They stressed that online training alone is insufficient for many hands-on caregiving tasks and called for structured, in-person training opportunities to ensure high-quality care.

Some participants noted that inconsistent workforce standards and unequal opportunities across local authorities make it challenging to maintain consistent care quality. During this discussion some participants called for national workforce planning, consistent pay structures, and more formalised professional development for care staff. One participant stressed that health and social care services cannot function effectively without the right people in the right roles and highlighted the importance of values-based recruitment alongside skills training.

#7. Understand how social care is provided across a person's lifetime and the relationship between social care provision and the overall health of people using care services.

People who took part in our engagement activities suggested that there was a need to use linked data research to better understand how social care is provided over a person’s lifetime, including at the end of life. They also expressed that there was a need to understand the overall health of people using care and support services, including morbidity and mortality rates amongst people accessing care and support.

In the workshop, there was consensus amongst many participants that social care requires dynamic and adaptable approaches that respond to changing needs. There was agreement that social care services must be flexible enough to adapt to individuals’ multifaceted needs and consider changing needs over time. One participant said: "There is no one size fits all".

There was consensus amongst many participants that there is a need to understand how care and support can be provided holistically and with continuity across life stages. One participant in the workshop stressed the need for those delivering care to understand how care needs change over time. They suggested that relying solely on a prescriptive, standardised model of care provision does not adequately meet the needs of individuals, whose circumstances often evolve.

One participant emphasised that reviewing the history of an individual’s condition and their past care use leads to a better understanding of what care provision is appropriate for that person today. However, they noted some of the systemic challenges with data sharing between health and social care systems, which often hinder timely and well-informed care decisions being made.

There was recognition amongst some participants that understanding care provision across people’s lifetimes could also have significant financial implications. One participant noted that better planning around lifetime needs could help reduce financial costs, particularly when addressing the requirements of people with learning disabilities. They pointed out that failing to provide early and consistent support can negatively impact individuals and families, increasing long-term demand on social care services.

#8. Understand where health and social care services work together and how this impacts on people accessing care and support as well as the services involved.

People involved in the engagement activities indicated several areas where there was a need to understand how health and social care services are working together. They were also interested in how this joint working might improve access to care and support as well as outcomes for individuals accessing services. Several examples of joint working between health and social care services were provided, including routine dental care and other health services provided in care homes and social care following hospital discharge. Participants indicated that barriers to effective joint working also need to be understood better to improve outcomes for those in need of care and support.

In the workshop, many participants emphasised that collaboration between health and social care services is essential to achieving person-centred care. However, there was a discussion about difficulties people using care services and professionals faced because of the disjointed nature of the current system. One participant said: "It's a complicated system that is hard to navigate".

There was consensus amongst some participants that better integration between sectors is necessary to make sure individuals have access to the right support. They highlighted the importance of streamlining processes and developing clearer pathways to reduce duplication and delays. They suggested joint assessments, pooled budgets, and involving the third sector as practical solutions to improve coordination. One participant stressed that transitions into and out of services are particularly problematic, often resulting in people "falling through the cracks".

One participant said that collaboration between local authorities and health boards remains inconsistent, particularly regarding data sharing and service planning. They pointed out that, despite having valuable resources like the SAIL Databank in Wales, there are still challenges in accessing and using local authority data.

Another participant noted that care workers are often undervalued compared to health professionals, which impacts on collaboration between teams. They called for shared responsibility and mutual respect when addressing an individual’s needs, focusing on working as a team rather than in isolated roles. Addressing systemic barriers, clarifying roles, and fostering integrated working relationships were also identified as essential to moving toward a more joined-up approach.

#9. Understand the relationship between social isolation, loneliness and social care provision.

Participants in our engagement activities suggested that linked data research is needed to understand loneliness and isolation, including potential causes of isolation and loneliness and their impact on social care provision.

In the workshop, many participants recognised social isolation and loneliness as research priority areas. They described them as a significant public health issue, particularly for individuals who have experienced bereavement, carers, and people with learning disabilities. They noted that social isolation contributes to poor mental health and can have an impact on mortality rates, highlighting the need for community support and more accessible ways for individuals to connect with others.

One participant explained that losing a loved one often creates a barrier to social engagement, making it more difficult for people to reach out and form connections. They also shared their personal experience of how social interaction was made even more challenging for their father because he was neurodivergent. They emphasised the importance of providing support that’s tailored for different groups.

Another participant stated that prioritising research in the area of loneliness and isolation could lead to better health outcomes and more effective public health interventions. They also noted that carers are especially vulnerable to isolation and that more targeted research is needed to understand how different groups experience and cope with loneliness.

Some participants felt that this area has already been addressed in existing research and suggested that resources might be better directed elsewhere. However, other participants said that more targeted studies are needed to understand how loneliness varies among different groups.

There was consensus amongst many participants that community-based solutions and social connection interventions could help mitigate loneliness, particularly as Wales’s ageing population is likely to mean an increased prevalence of isolation. Participants suggested that understanding this issue would help inform policy and prevent adverse health outcomes.

#10. Understand the impact of waiting times for social care provision on individuals who need care and support.

Participants in our engagement activities asked for linked data research to understand the impact of waiting times for social care provision on individuals. This included a need for information on how long people are waiting to access care and support and whether people’s health and well-being deteriorates during this waiting period.

In the workshop, participants suggested there is widespread recognition that waiting impacts on social care provision in all areas. One participant said: "Waiting times [are] essential to consider in any piece of work. The waiting list itself can cause distress". This participant suggested that psychological interventions could help minimise the emotional impact on those waiting for care.

Another participant stressed the importance of planning improvements carefully, noting that changes made to reduce waiting times could unintentionally increase staff workloads.

Some participants prioritised other themes, but did not dismiss the importance of waiting times as a priority. For example, one participant described waiting times as a "big problem", but said that addressing other research priorities first could naturally reduce waiting times by filling gaps in provision. They emphasised that faster access to care could help alleviate related challenges, but that improvements should also be balanced to avoid overburdening the system.

Reflections and feedback from the workshop participants

This section considers what the workshop participants told us about the linked data research priority-setting process, including feedback provided to us on an evaluation form sent to participants following the workshop.

**Overall reflections on the top 10 priority themes**

The priority themes were based on the original ideas gathered during the engagement activities and were developed in consultation with the project’s working group and data experts. Some participants in the workshop expressed concern that the examples used within the priority themes were not wholly representative of the services or approaches which should be investigated in future research activities. Some also said that they felt that the priority themes were too broad, could overlap or may already have sufficient or ongoing research available.

We’ll take this feedback on board for the next stage of this project, in which the priority themes will be used to create research questions. We’re confident that the process we went through has identified 10 priorities, which don’t yet have sufficient evidence to address them fully.

In the feedback form, all participants were happy with the final top 10 priority themes and said that they were pleased with the outcome of the workshop. They particularly enjoyed having the opportunity to discuss the themes with others, sharing knowledge and viewpoints. One participant said:

“Being given time to study the questions and themes, I was prepared with my answers for the questions. I was quite willing to listen to anyone else's point of view. The three themes that I felt really needed to be addressed, I really stuck to, I never changed. I was more flexible on the other seven themes.”

**Overall feedback on the final workshop**

In our final feedback form we asked participants what they thought of the workshop and how it was run. Overall, the workshop was a success, with lots of positive feedback from participants and the supporting staff involved. A public and professional involvement worker, who facilitated the involvement of people with lived experience of social care in the workshop, said:

"The workshop was thoughtfully designed to bring together individuals with lived experience, professionals, and practitioners to shape linked data research priorities in Wales... While attendees came from different backgrounds and brought different perspectives, there was a strong sense of mutual respect and equality shared across the group. The team at Social Care Wales were committed to ensuring inclusivity and accessibility, and they were a pleasure to work with."

Participants described the workshop as well run, respectful and interesting. All participants ‘strongly agreed’ that the workshop allowed them to contribute their views and opinions in a meaningful and respectful way. All participants also ‘strongly agreed’ that the workshop facilitators were fair and impartial, and that the process of determining the top 10 was fair and robust. One participant said:

“It was a well-run and interesting workshop, giving everyone a chance to say what they wanted to, in an environment that was friendly and helpful”.

Acknowledgements

The team would like to recognise the contributions of all those who have provided their insights and experiences to this priority setting exercise. The contributions and involvement of the workshop participants has added a wealth of knowledge and experience to the final priority themes for linked data research within adult social care. We would like to thank Alice Butler, from the Centre for Adult Social Care Research (CARE), who facilitated the involvement of members of the CARE Lived Experience Collective in the priority setting workshop. We would also like to thank the individuals who took part in our initial engagement activities.

We would also like to thank members of our working group, who gave up their time to discuss and advise on all aspects of the design and delivery of the project. The working group included representatives from local authorities, the third sector, Welsh Government, academia, and a member of the public.

Thanks to our participants sharing their views, perspectives and experiences, we’re confident that the top 10 themes reflect the needs of people who access and deliver social care services. And we’re confident that they can all be explored using linked data research.

*Image description: a screenshot of the online consensus building workshop*

The team would also like to thank Katherine Cowan, prioritisation specialist, who provided guidance and expert knowledge on consensus building throughout the process. Our other workshop facilitators, Gill Toms, Rhiannon Wright and Katie Jacobs, were also essential to making sure participants in the workshop felt at ease and able to express their opinions without judgement. Finally, the success of this priority setting exercise was also due to the hard work and commitment of the project team, including: Tara Hughes and Lynsey Cross (Swansea University) and Eleanor Johnson, Amber Browne, Emma Taylor-Collins, Elen Griffiths, Jeni Meyrick, Rhian Reynolds and Sarah Atkinson (Social Care Wales).

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Get in touch with the team by contacting research@socialcare.wales.