Unpaid Carers in Liverpool and Wirral:

Statistical Analysis Plan

Networked Data Lab Liverpool CCG, Wirral CCG, Liverpool City Council and Wirral Council

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V2: 17/06/2022

On behalf of and for consultation with:

Liverpool and Wirral Networked Data Lab and Project Partners

1. **Background:**

The care burden for adults with long-term conditions or disabilities is largely taken up by family and friends, amounting to 7-13 million unpaid carers in England. While around 17% of people aged 16 and over reported having a caring role, (Health Survey of England 2019), the hesitance of many to self-identify as a carer means this proportion is certainly higher. The very low engagement in services for cares has resulted in a lack of evidence about the true impacts of caring roles.

Caring roles often have detrimental effects on carers’ physical and mental health, including on quality of sleep and ability to look after their own health and personal wellbeing. Carers can experience social isolation and difficulties in accessing care services. Detrimental effects of caring are disproportionately higher for already marginalised groups[[1]](#footnote-1).

The pandemic led to disruptions in formal care services, which meant that the care burden has increased for 70% of carers[[2]](#footnote-2) . The Carers Trust reports that mental health has declined for 40% of young carers and 59% of young adult carers.

Many people with caring roles do not seek supporting services available to them. Demand for unpaid care is expected to have doubled in the period 2008-2038, leading to a shortfall of 2.3 million carers for adults aged 65 and over[[3]](#footnote-3). Carers themselves often have long-term and complex conditions. In 2011, 1.3 million (14%) people aged 65 and over in England and Wales provided unpaid care. People aged 85 and over are more likely to care for someone with multiple needs, often including dementia. 72% of those who receive carer’s allowance are women. 12% of women working full-time provide unpaid care[[4]](#footnote-4) [[5]](#footnote-5).

The Care Act 2014 placed a duty on local authorities to identify, assess and meet carers’ needs, placing them on the same legal footing as those they are caring for. However, the appears to be a wide gap between what is offered to carers and the take-up of support. For example, only around 1.5 million adults are currently in receipt of means-tested Carers’ Allowance.

1. **Aims**

Our research will seek to understand how the unpaid care burden affects the vulnerability of carers in terms of their health and well-being. We aim to achieve this by measuring the intensity of unpaid care at the household level, and assessing the level of support provided to carers. We will measure the care burden relative to local contexts, such as small-area deprivations, to help service providers in reaching the most vulnerable.

The health of carers – including those registered with a GP either with or without ASC support – will be measured against the onset of conditions after being registered as a carer. We will also seek to understand how the duration from registration to ASC intervention might impact on carers’ health. Carers’ well-being will be measured against the level of ASC support they have receive, relative to the levels of deprivation they experience in their local areas.

Our analysis will compare population segments that have caring responsibilities and their needs between groups of carers and the overall population of Liverpool and Wirral. As we able to identify carers’ households, we can also analyse the intensity of health needs in those households. For example, carers of people living at home with dementia, or carers of children with disabilities.

This will not only have a social benefit to the system but can also be seen in terms of an economic benefit. NHS England in Commissioning for Carers reports that for every £1 invested this could equate to a saving of almost £4 in services. However, recent local analysis completed established a ratio of £1 to £3 for Liverpool. Estimate suggest that carers support an equivalent £244 per week per person commissioned service.

1. **Defining the population, outcomes, and explanatory factors**

**Population Cohort**

Linked data for all individuals who are either registered with a GP as a carer, or are known to Adult Social Care as carer. The number of carers in Liverpool and Wirral can be estimated form various sources as outlined below:

* 2011 census puts about 10% of the population as unpaid carers, so circa 50,000 (Liverpool).  Wirral 320k resident population @10% =  32,000.Actual number on the census 40,340 (Source: ONS QS301EW – Provision of Unpaid Care)
  + Updated 2021 census is expected over the next few months
* We have the GP registered cohort circa 22,000 (Liverpool)  5,237 (Emis 24/06/2022)
  + Of which circa 14000 (Liverpool) are confirmed via the vaccination work (carers centre has been reviewing this cohort) No review in Wirral has taken place.
* Local authority has around 12,000 (Liverpool) flagged carers on the system  (5,127 main+2,833 informal) =7,960
  + Of which circa 3,800 (Liverpool) are confirmed Need definition of what is confirmed
  + Of which circa 2,000 (Liverpool) get direct/indirect commissioned support, so our “crisis point” cases. 1,473 Salt Return (n = persons)
  + We also have quality of life and user experience surveys for about 15% (Liverpool) of this carer base from Dec 2021.  981 returns,  (981/7960) = 12% survey return

**Outcomes**

Outcomes we will consider are:

* Carers rates (i.e. per population)
* Percentage of all carers (i.e. GP and social care registered) receiving LA support, by type of support.
* Prevalence of diagnoses - comparisons between carers and non-carers
* Prescribing of medication (antidepressants)
* Rates of service use (community/ mental health / secondary care, A&E)- comparisons between carers and non-carers
* Rates of caring intensity and types of household health need: measured by the number carers’ household members with conditions and multi-morbidity.
* Distribution of household health and social care needs between households with carers / and households without carers

**Explanatory factors**

* Age
* Sex
* Deprivation
* Ethnicity
* Diagnoses of carers
* Diagnoses of other household members

1. **Data Sources**

Datasets below will be linked using a pseudonymised key between the council and the CCG. Number of records with an NHS number stands at 96%. Through a batch tracing exercise, it may be possible to increase this number. In Wirral,similar to Liverpool, we will try and link Health & Social care data by utilising social care data flowing via DSCRO

**NHS**

* Primary care data
* Secondary care data (SUS)
* MHDS
* CSDS

**LA Adult Social Care**

* Adults using social care services
* People assessed for carers support
* Contact with carer services
* Carer survey results

**Open data – linked to LSOAs**

* Indices of deprivation
* Census 2021 data (unpaid care) available from early summer (this is in case we receive data in time to fit with the analysis timeline which is dictated by the Health Foundation schedule)

1. **Analytical design**

The study will aim to conduct analysis that provides insight into the following three research questions, resulting in nine metrics, itemised below.

**Q1: What small-area characteristics impact on unpaid carers’ health?**

* Distributions of carers by gender, age, ethnicity, relative to multiple deprivations
* Distributions of carers from Census 2021
* Distributions of carers receiving / not receiving support

**Q2: How is carers’ health affected by the intensity of household rates?**

* Rates of adult household members with LTCs, multi-morbidity, or dementia, or child household members with disabilities
* Carers’ health rates relative to the intensity of household rates
* Correlations of carers’ health rates to dementia rates

**Q3: Where are the gaps in ASC support relative to carers’ health rates?**

* Health rates comparing carers who received / did not receive ASC support
* Health rates among carers who did not receive support relative to household rates
* Health rates among carers relative to the delay in receiving ASC support

**Governance**

Data: This study will use the pseudonymised routinely collected health record that are collected for commissioning purposes and stored securely on Arden & GEM CSU and Wirral CCG servers. Both Liverpool and Wirral CCG data is pseudonymised by DSCRO, before being made available to authorised users. Our legal basis for the use of the data is covered by commissioning purposes, which means that everything Liverpool and Wirral CCG receive via NHS Digital (SUS, CSDS, MHSDS) is already covered in their DARS, and place-specific local data (e.g. some primary care elements) is covered by our own local agreements.

Project: For project management, we have an NDL analytical group with all analytical team members. This group meets fortnightly and it is chaired by a project manager who oversees the link of this theme with the other ones. When it is relevant, this group hosts subject matter experts from commissioning or provider organisations. It feeds into a smaller group of theme leads and informs public advisors when applicable

**5 Impacts**

The research findings will potentially help in targeting carers for access to the new Carer Passport, which was developed and launched across 13 Trusts across Cheshire and Merseyside in November 2021. The passport was coproduced with carer organisations, carers and the cared for as equal partners to make a sustained and meaningful difference to carer and patient experience. The collaboration ensures that the passport will be consistently recognised and implemented across the regional footprint and highlights the value of carers and ensure that they are recognised and supported in their role.

**Stakeholder engagement statements**

**Carers’ Lead, Wirral Council:**

“This piece of research is the most comprehensive analysis of information that we hold on Carers who are known to services to date.  People with an unpaid caring role come from all backgrounds and the care that they provide cuts across all categories of adults with ill-health, long-term conditions, disabilities and people needing care because of their age, more in-depth understanding of the current position will inform the strategic development of services for Carers and the people they care for.  The information will be valuable not only to the local authority but other local system partners and stakeholders, it will form part of the Wirral JSNA , so that it accessible to anyone who is looking to develop targeted, evidence-based support for the Carer and the cared for.”

**Commissioming and Contracts Manager, Liverpool City Region:**

“This research will provide a greater insight into the caring journey particularly how, when and why the negative impacts of caring occur. Understanding this will inform a more efficient and effective whole system response to the early identification of carers and the preventative interventions required at place.”

**Timeline**

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| Expected date for data access in place | September 2022 |
| Data linkage and cleaning | 14 November 2022 |
| Interim results | January 2023 |
| Final results | February 2023 |
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1. https://www.carersuk.org/images/Facts\_about\_Carers\_2019.pdf [↑](#footnote-ref-1)
2. https://blog.ukdataservice.ac.uk/unpaid-caring-during-covid19/ [↑](#footnote-ref-2)
3. https://www.lse.ac.uk/cpec/assets/documents/Economics-of-caring-2018.pdf [↑](#footnote-ref-3)
4. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/articles/fullstorythegendergapinunpaidcareprovisionisthereanimpactonhealthandeconomicposition/2013-05-16 [↑](#footnote-ref-4)
5. https://www.carersuk.org/news-and-campaigns/features/10-facts-about-women-and-caring-in-the-uk-on-international-women-s-day [↑](#footnote-ref-5)