# Methodology

# Data and data linkage

## Identifying unpaid carers

Unpaid carers were anonymously identified using local authority (LA) carer assessment data and general practice (GP) data sources.

### Local authority data

Adult carers’ assessment data was obtained from three Welsh LAs: Neath Port Talbot, Swansea, and Denbighshire. This LA data was uploaded into the Secure Anonymised Information Linkage (SAIL) Databank Trusted Research Environment (TRE) as a Core Restricted data source, using the split file process with SAIL’s trusted third-party partner organisation Digital Health and Care Wales (DHCW) (1). The data items provided by each LA are listed in Appendix A.

### GP data

The Welsh Longitudinal General Practice (WLGP) data source is held within the SAIL Databank. Read codes used to identify unpaid carers in this data source are listed in Appendix B (2).

### Data linkage

Unpaid carer records were linked to anonymised individual-level, routinely-collected, population-scale electronic health record (EHR) and administrative data sources available within the SAIL Databank (3–5) (Appendix C) using an anonymised linkage field (ALF) to determine aspects of health and health-care services usage.

# Definitions

### Study period

The study period was defined per LA and reflected the date range of carers’ assessment data available[[1]](#footnote-1) (Table 1).

Table 1: Study period by LA.

|  |  |
| --- | --- |
| **Local Authority** | **Study period** |
| Neath Port Talbot (NPT) | 07/2017 - 05/2022 |
| Swansea | 04/2021 - 06/2022 |
| Denbighshire | 04/2020 – 03/2022 |

### Inclusion criteria

1. Aged 18 and above.
2. Have a valid sex code.
3. Have a valid week of birth (WOB).
4. Residing in the LA of interest.
5. Resident at a Welsh address for a full year prior to identification date.
6. Registered with a Welsh GP providing data to SAIL for a full year prior to identification date.
7. Probabilistic linkage match of 90% or above.

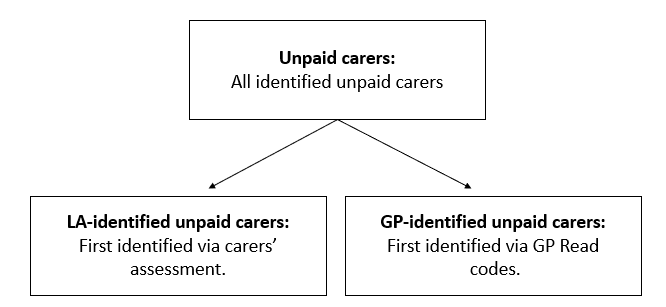
### Index date

The index date was defined as the earliest identification date as an unpaid carer within the study period where the inclusion criteria were met.

# Cohorts

### Unpaid carer cohorts

Three unpaid carer cohorts were created for each LA:



The sizes of the total cohorts for NPT, Swansea and Denbighshire were 2,024, 926 and 841, respectively. Table 2 shows the total number of unique LA records at each data processing step.

Table 2: Application of exclusion criteria for LA data. (\* Count for Swansea demographic criteria not met is included in identified earlier in GP)

|  |  |  |  |
| --- | --- | --- | --- |
|  | NPT | Swansea | Denbighshire |
| Initial records | 1,513 | 548 | 585 |
| Duplicate records | 576 | 0 | 135 |
| Linkage issues | 31 | 113 | 41 |
| Client assessment outside study period | 31 | *NA* | *NA* |
| Carer assessment outside study period | 340 | *NA* | *NA* |
| Demographic criteria not met | 22 | \* | 33 |
| Death before assessment | 0 | 0 | 0 |
| Not resident in Wales/not registered at a SAIL GP for 1 year prior to identification | 73 | 115 | 147 |
| Identified earlier in GP data | 27 | 39\* | 16 |
| LA-identified unpaid carers | 413 | 281 | 213 |

### Matched non-carers

A matching pool was created of individuals who were resident in the LAs of interest but were not identified in the unpaid carer cohort, nor able to be identified as an unpaid carer via Read codes during the two years prior to study start date. Using this pool and the R Library ‘Matchit’, a list of matches of non-carers for each unpaid carer on sex, age-group and local authority at study start date was generated (6). The index date of each unpaid carer was imputed to their matched non-carers as a pseudo-index date. The inclusion criteria were then re-applied to this list of matches based on the pseudo-index date, and a non-carer was selected at random from the remaining matches, resulting in a 1:1 exact match of carers and non-carers. We verified that the age and sex distribution of the unpaid carers and matched non-carers were similar using cross-tabulation functions in R (7).

# Measures

### Demographics

Demographic characteristics were defined as follows:

* Age group: Under 40 (i.e. 18-39), 40-49, 50-59, 60-69, 70-79, 80+.
* Sex: male, female.
* Welsh Index of Multiple Deprivation 2019 (WIMD) quintile (8): 1 (most deprived), 2, 3, 4, 5 (least deprived).
* Ethnic group (using methodology developed within SAIL Databank (9) and the 5 ONS Categories (10)): 1) Asian, Asian British or Asian Welsh, 2) Black, Black British, Black Welsh, Caribbean or African, 3) Mixed or Multiple ethnic groups, 4) White, 5) Other.

The age, sex, and deprivation quintiles were compared against the ONS 2020 mid-year estimates of adults aged 18 and above in the respective LAs to gain an understanding of the unpaid carers within the context of the local population (11). At the time of analysis, the full breakdown of 2021 mid-year estimates was not publicly available.

### Long-term conditions (LTCs)

LTCs were identified using Read codes in the WLGP data source. Conditions of interest were defined by version 1.1 of the Cambridge Multimorbidity Score (12,13). Read code alternatives of conditions listed in the Cambridge Multimorbidity Score were used (14,15). The look-back period for each condition was as defined by Cassell (13). The full list of LTCs used in the analysis can be found in Appendix D. Chronic painful conditions should be interpreted with caution as they rely on prescription codes for identification, and pain medications can be used for other purposes (12). Multimorbidity rates (defined as two or more conditions) and most common conditions per cohort were evaluated.

### Health Service Use

Health service use was determined over the year prior to index date. For ED attendances, inpatient admissions (both planned and emergency) and outpatient attendances, rates of the number of people with one or more attendances or admissions per 1,000 population were calculated. For GP interactions, the rate of interactions per person was calculated. Crude rates were compared between unpaid carers /non-carers and LA-identified/GP-identified using rate ratios and 95% confidence intervals. Additionally, age-sex standardised rates and rate ratios were calculated and compared for LA-identified and GP-identified using the ONS 2020 mid-year adult population estimates.

### Carer-client relationship (**Only included in feedback to Neath Port Talbot**)

Data on carer-client relationships was only available in NPT carers’ assessment data. Relationships were grouped into categories as described in Appendix E and evaluated as a proportion of all relationships. We also calculated the ratio of carers to clients and clients to carers.

# Statistical analysis

This analysis strictly observed the statistical disclosure control (SDC) criteria established by the SAIL Databank TRE and data providers, including the Office for National Statistics (ONS) (16,17).

Differences in distribution of sex and deprivation between the LA and GP carers cohorts were tested using Chi-square and Mann Whitney U tests. T-tests were used to determine statistical significance of differences in age between the LA and GP carers cohorts. Rate ratios and confidence intervals were used to test differences in multimorbidity and health service use.

# References

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# Appendices

# Appendix A: Unpaid carer data items by LA

|  |  |  |  |
| --- | --- | --- | --- |
| **LA\_Table 1: Identifiable data Item** | **Swansea** | **Neath Port Talbot** | **Denbighshire** |
| Carer ID | Yes | Yes | Yes |
| Carer first name | Yes | Yes | Yes |
| Carer surname | Yes | Yes | Yes |
| Carer address | Yes | Yes | Yes |
| Carer postcode | Yes | Yes | Yes |
| Carer date of birth | Yes | Yes | Yes |
| Carer NHS number | Yes | Yes | Yes |
| **LA\_Table 2: Identifiable data Item** | **Swansea** | **Neath Port Talbot** | **Denbighshire** |
| Care recipient ID | No | Yes | No |
| Care recipient first name | No | Yes | No |
| Care recipient surname | No | Yes | No |
| Care recipient address | No | Yes | No |
| Care recipient postcode | No | Yes | No |
| Care recipient date of birth | No | Yes | No |
| Care recipient NHS number | No | Yes | No |
| **LA\_Table 3: Non-identifiable data Item** | **Swansea** | **Neath Port Talbot** | **Denbighshire** |
| Carer ID\* | Yes | Yes | Yes |
| Care recipient ID | No | Yes | No |
| Carer relationship to recipient | No | Yes | No |
| First carer assessment date (as available in data) | Yes | Yes | Yes |
| Last carer assessment date | Yes | Yes | No |
| Number of carer assessments completed | Yes | Yes | No |

# Appendix B: Unpaid carer Read codes

|  |  |  |
| --- | --- | --- |
| **Row Number** | **Read Code** | **Description** |
| 1 | 918A. | Carer |
| 2 | 918A0 | Cares for a friend |
| 3 | 918A1 | Cares for a neighbour |
| 4 | 918A2 | Cares for a relative |
| 5 | 918G. | Is a carer |
| 6 | 918H. | Primary carer |
| 7 | 918W. | Carer of a person with learning disability |
| 8 | 918a. | Carer of a person with substance misuse |
| 9 | 918d. | Carer of a person with mental health problem |
| 10 | 918m. | Carer of a person with a terminal illness |
| 11 | 918t.00 | Carer from Black and minority ethnic group |
| 12 | 918Y. | Carer of a person with sensory impairment |
| 13 | 8IHE. | Carer health check declined |
| 14 | 8O7.. | Carer support |
| 15 | 918b. | Carer of a person with alcohol misuse |
| 16 | 8IEP. | Carer annual health check declined |
| 17 | 8BAr. | Carer health check completed |
| 18 | 13Wb. | Carer has sole parental responsibility |
| 19 | 9NSS. | Carer health check offered |
| 20 | 918J. | Carer - home telephone number |
| 21 | 9Ngw. | Carer does not understand care plan |
| 22 | 918W. | Carer of a person with learning disability |
| 23 | 918y. | Carer of person with dementia |
| 24 | 9Ngv. | Carer understands care plan |
| 25 | 918X. | Carer of a person with physical disability |
| 26 | 13VN. | Carer able to cope |
| 27 | 69DC. | Carer annual health check |
| 28 | 918M. | Carer - email address |
| 29 | 9180. | Carer’s details (also called 9180) |
| 30 | 69DE. | Carer health check |
| 31 | 918L. | Carer - mobile telephone number |
| 32 | 918K. | Carer - work telephone number |
| 33 | 388Q. | Carer strain index score |
| 34 | 9d46. | Carer |
| 35 | 918c. | Carer of a person with chronic disease |
| 36 | 8HkA. | Ref for GP carer’s assessment |
| 37 | 8Hkb. | Referral for social services carer's assessment |
| 38 | 13HH.00 | Looks after chronically sick relative |
| 39 | 13HH. | Looks after elderly dependent |
| 40 | 13HH.11 | Cares for mentally handicapped dependent |
| 41 | 13HH.12 | Looks after chronically sick father |
| 42 | 13HH.13 | Looks after chronically sick husband |
| 43 | 13HH.14 | Looks after chronically sick mother |
| 44 | 13HH.15 | Looks after chronically sick spouse |
| 45 | 13HH.16 | Looks after chronically sick wife |
| 46 | 13HH.18 | Looks after physically handicapped dependent |
| 47 | 13VP0. | Receiving carer allowance |
| 48 | 91800 | Details of informal carer |
| 49 | 918t. | Carer from Black and minority ethnic group |
| 50 | 9NSW | Assessment of needs offered to carer |
| 51 | 8IAk. | Referral to Princess Royal Trust carers centre declined |

# Appendix C: List of data sources used in SAIL

|  |  |  |
| --- | --- | --- |
| **Dataset** | **Description** | **Dated provision version** |
| Annual District Death Extract (ADDE) | From the Office for National Statistics (ONS) mortality register, containing data on all deaths in Wales within the study period | 01/07/2022 |
| Welsh Demographic Service Dataset (WDSD) | Contains linkable data on demographics of the Welsh population from the Census | 04/07/2022 |
| Wales Longitudinal General Practice (WLGP) | Patients’ GP events in Wales | 01/03/2022 |
| Emergency Department Data Set (EDDS) | All emergency department attendances in Wales | 01/06/2022 |
| Patient Episode Database for Wales (PEDW) | All inpatient admissions in Wales | 04/07/2022 |
| Out-Patient Database for Wales (OPDW) | All outpatient appointments in Wales | 01/05/2022 |

# Appendix D: List of Long-term conditions

Obtained from source: Table A3.2 in <https://www.cmaj.ca/content/cmaj/suppl/2020/01/28/192.5.E107.DC1/190757-res-3-at.pdf>. Original study(15).

|  |  |
| --- | --- |
| **ID** | **Morbidity** |
| **Morbidities based on Read code ever recorded** | |
| 1 | Alcohol Problems |
| 2 | Anorexia or bulimia |
| 3 | Atrial fibrillation |
| 4 | Blindness and low vision |
| 5 | Bronchiectasis |
| 6 | Chronic liver disease and viral hepatitis |
| 7 | Chronic sinusitis |
| 8 | COPD |
| 9 | Coronary heart disease |
| 10 | Dementia |
| 11 | Diabetes |
| 12 | Diverticular disease of intestine |
| 13 | Hearing loss |
| 14 | Heart failure |
| 15 | Hypertension |
| 16 | Inflammatory bowel disease |
| 17 | Learning disability |
| 18 | multiple sclerosis |
| 19 | Parkinson's disease |
| 20 | Peptic ulcer disease |
| 21 | Peripheral vascular disease |
| 22 | Prostate disorders |
| 23 | Psychoactive substance misuse (not alcohol) |
| 24 | Rheumatoid arthritis, other inflammatory polyarthropathies & systematic connective tissue disorders |
| 25 | Stroke & transient ischaemic attack |
| 26 | Thyroid disorders |
| **Morbidities based on prescription in last 12 months** | |
| 27 | Constipation (treated) |
| 28 | Migraine |
| **Morbidities based on combination of Read code ever recorded**  **and/or prescription in last 12 months** | |
| 29 | Epilepsy (currently treated) |
| 30 | Asthma (currently treated) |
| 31 | Irritable bowel syndrome |
| 32 | Psoriasis or eczema |
| **Morbidities otherwise defined** | |
| 33 | Anxiety & other neurotic, stress related & somatoform disorders OR depression |
| 34 | Cancer - [New] Diagnosis in last 5 years (excluding non-melanoma skin cancer) |
| 35 | Chronic kidney disease |
| 36 | Painful condition |
| 37 | Schizophrenia (and other non-organic psychosis) or bipolar disorder |

# Appendix E: Carer-Client Relationship Categories

|  |  |
| --- | --- |
| **Relationship Category** | **Relationships Included** |
| Partner | Married Partner  Unmarried Partner |
| Child | Daughter  Daughter-in-law  Son  Son-in-law |
| Parental | Father  Foster Parent  Mother  Parent’s Partner  Step-Parent |
| Sibling | Brother  Brother-in-law  Sister  Sister-in-law |
| Other | Extended Family (grandchild, cousin, niece or nephew)  Friend  Neighbour  Non-specified family member  Non-specific relationship |

1. For Neath Port Talbot, the data shared included all carers’ assessments completed within the defined study period which were also linked to client assessments completed within this period. Internal sensitivity analysis conducted by NPT indicated that approximately 50 carers assessments per year were completed where no linked client assessment was available. [↑](#footnote-ref-1)