

Can you tell we care?

Identifying unpaid carers using local authority and GP records

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Key points

- There are at least 5.7 million unpaid carers in the UK, and they play a vital role in our society. To help them perform their roles and protect their health and wellbeing, they need support from the NHS and social care services. This can range from health checks, social prescribing and community support services to breaks and practical and financial support.
- To provide well-targeted support, the NHS and local authorities need to know about the unpaid carers in their populations.
- In this [Networked Data Lab](#) study, we look at how many carers were known to GPs and local authorities in four areas of England and Wales (Leeds, Liverpool and Wirral, Neath Port Talbot and Swansea) between 2016 and 2021. We found that:
 - data held by GPs and local authorities identified at most between 11% and 26% of unpaid carers compared to the census
 - GP sources identified up to 15 times more carers than local authority sources
 - local authority data tended to identify more older carers than GP data
 - less than 7% of carers identified were found in both GP and local authority data.
- The under-recording of carers means that local authorities cannot properly understand need in their area and thus target support to those who need it most. Without more complete data, GPs may not be able to provide proactive support to keep carers both physically and mentally well. Nor can national policymakers reliably assess the degree of unmet need. This under-recording of carers also raises questions about how well integrated care bodies understand the health needs of their populations.
- National policymakers, local NHS and social care bodies and GPs all have a part to play in improving the identification of, and recording of data on, unpaid carers. Approaches could include the use of incentives, training and guidance.
- Better data and identification are a start, but to fully support carers, the NHS and social care need adequate resources and to appropriately prioritise carer support, reflecting the value of their work.

1. Introduction: why carer support matters

Unpaid carers make up 9% of the UK population, according to Census 2021 data and Office for National Statistics census data for Scotland and Northern Ireland. This may be a considerable underestimate; results from other nationally representative surveys put the figure at 16% to 19%. Our [previous analysis](#) discusses the reasons for such variation in the estimates, however we know there are at least 5.7 million unpaid carers and possibly many more.

Carers play a vital role for the people they care for and in wider society by bridging gaps in state funded support, thereby reducing pressure on health and care services. Many carers derive pride and satisfaction from their roles, but caring can also have a [personal and financial cost](#).

Too often, carers do not receive the support they need – either from social care or health services. Evidence also suggests that carers can neglect their own health and are more likely to report a long-term condition, disability or illness than non-carers. If a carer becomes unwell and can no longer provide care, or if caring relationships break down, the needs of the cared-for person can quickly turn into a crisis. This may require the cared-for person to present to primary or secondary care and/or require the involvement of emergency duty teams. Improving carers' access to timely support is therefore important to improve outcomes in population health and health care, tackle inequalities, enhance NHS productivity and support broader social and economic development.

Despite recognition of these issues and numerous policy commitments over the past decade to increase support for unpaid carers, we have very little information about how many carers are known to local services. Carer identification matters, because it is the first step towards the NHS and local authorities being able to provide well-targeted support.

In this long read, we present analysis from the Health Foundation's [Networked Data Lab](#) (NDL), a collaborative network of analytical teams from across the UK established to use local expertise, patient and public experience and unique linked datasets to produce new insights into major challenges in health and care. For the past year, the NDL has focused on unpaid carers. Analytical teams in five areas of England and Wales piloted linking health and local authority electronic records to provide the best possible view of their local unpaid carer populations and the types of support they access from local services. This report describes what they found. In the final section, we discuss the implications of the findings for four different groups with responsibility to unpaid carers: local authorities, general practices, integrated care bodies and national policymakers. We also set out recommendations for other analysts working with electronic records on unpaid care.

Box 1: What data did we use, and how?

As part of the NDL programme, four local authorities provided data from their carer assessments and case management systems that capture carers deemed eligible for support (such as respite care or direct payments) from the council:

- Leeds
- Liverpool and Wirral (combined into one area for the purpose of this analysis)
- Neath Port Talbot
- Swansea

These areas were also able to provide GP records, through the involvement of the NHS in our research programme. A fifth area, North West London, also took part in this pilot but only provided GP data.

Teams in each area then linked their individual-level data using NHS numbers and, if those were missing, probabilistic algorithms dependent on other personal information. This data linkage enabled sites to identify which unpaid carers were interacting with their GPs and/or local authorities – as well as the pathways they navigated through different health and social care services.

Obtaining this local authority data, understanding it and working through information governance procedures was not straightforward. The NDL teams were constrained by each local authority having a different service delivery model. This affected which datasets they could obtain and the temporal data coverage for each area. Leeds, Liverpool and Wirral were able to provide data covering the entirety of 2016 to 2021. Neath Port Talbot provided data from July 2017 to June 2022, whereas Swansea provided from March 2021 to June 2022.

Benefits data was outside the remit of this work.

A more detailed explanation of our data sources and analytical methods is set out in our [Technical Appendix](#).

2. Improving support for carers requires better data

Population-level data collections like the census and surveys such as [Understanding Society](#) provide estimates of the number of unpaid carers, their demographic characteristics and how many hours of care they provide per week. These data sources are vital to track changes in the carer population and inform national long-term planning and resource allocation. For example, Census 2021 results suggest that need [may be increasingly concentrated among people providing high-intensity care](#), meaning that the scarce available funding must be allocated more effectively to support this group.

Survey data can also be useful to examine geographical variations and inform the development of local support for carers. For example, our [previous analysis](#) of the 2021 census found large variation between local authorities in the percentage of people providing unpaid care, with the highest rates in Northern Ireland, Wales and the north of England. Although such surveys are useful, local areas need individual-level datasets to identify residents providing care and target interventions at those who need them.

Local authorities can identify some unpaid carers through their stored carer assessments and case management systems. Similarly, Care Quality Commission guidance encourages GPs to keep electronic records of their patients who are unpaid carers in order to support them in maintaining their own health and the health of the person (or people) they care for.

Identifying carers in routinely collected data is notoriously difficult, as made clear during the [drive to find and vaccinate carers](#) in the early days of the COVID-19 vaccination programme. A commonly used approach involves clinical code flags in primary care data (eg 'is a carer'/'has a carer'). The Health Foundation has also trialled [experimental methods](#) to identify carers in data. But there is largely untapped potential in using wider local authority datasets (related to, for example, carer assessments or allowances) to enable a more complete view of the unpaid carer population.

Linking existing individual-level GP and local authority databases should, in theory, provide the best possible view of the carer population. In the next section, we report the experiences of NDL teams in four geographical areas of England and Wales trying to do just that.]

3. What we learned from identifying unpaid carers using linked records

Electronic records underestimate the total number of carers by a wide margin

The number of unpaid carers identified in local authority and GP records is substantially lower than identified in the census, as shown in Figure 1. These counts show that in the NDL pilot areas, only a small minority of unpaid carers (between 1% and 11.5% depending on the area and year) can be identified in GP and local authority electronic records each year. This may mean that only a small percentage of carers are known to local services, and even fewer will receive support.

Using linked data over the entire data-availability period, we were only able to identify between 11% (Neath Port Talbot) and 26% (Leeds) of the unpaid carers identified in the 2021 Census. We used a long look-back period on our electronic records, covering just over 5 years before the census, to cast a wide net that likely captures many carers not identified by the census. Comparing these two quantities relies on the assumption that those identified as carers from 2016 onwards remained carers and living in the same area when the census took place in 2021.

Figure 1

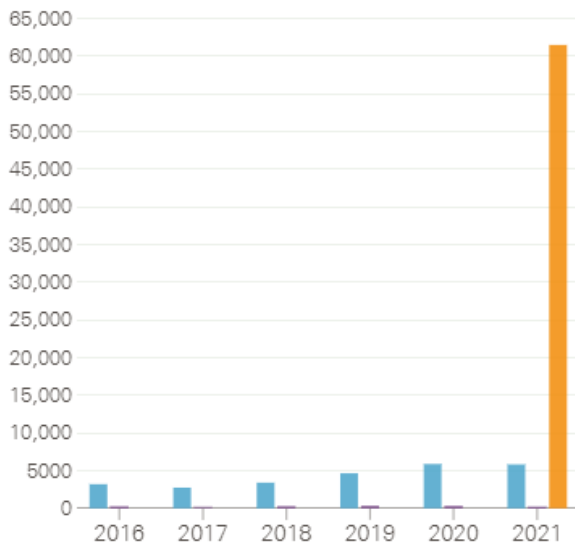
GP and local authority electronic records only identify a small number of unpaid carers

Number of unpaid carers identified each year, as a proportion of carers identified in the 2021 Census

■ GP records ■ Local authority records ■ 2021 Census

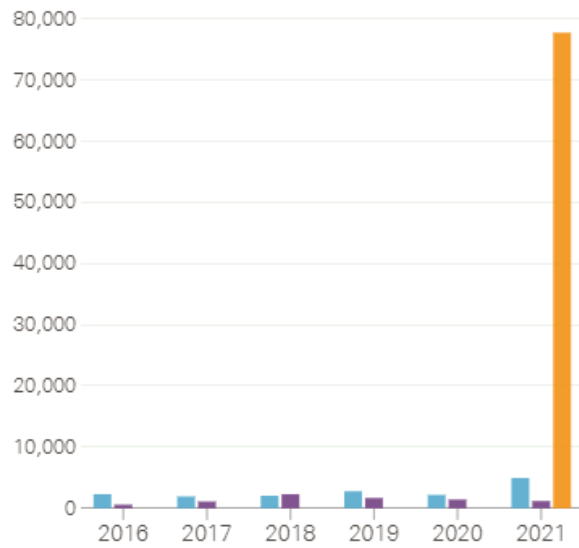
Leeds

Number of carers identified



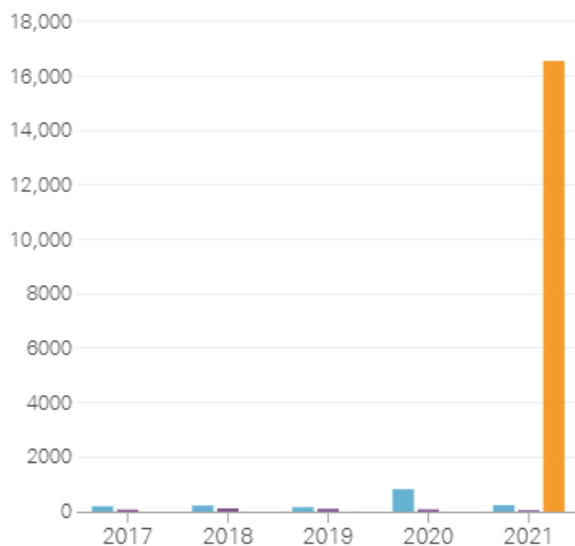
Liverpool and Wirral

Number of carers identified



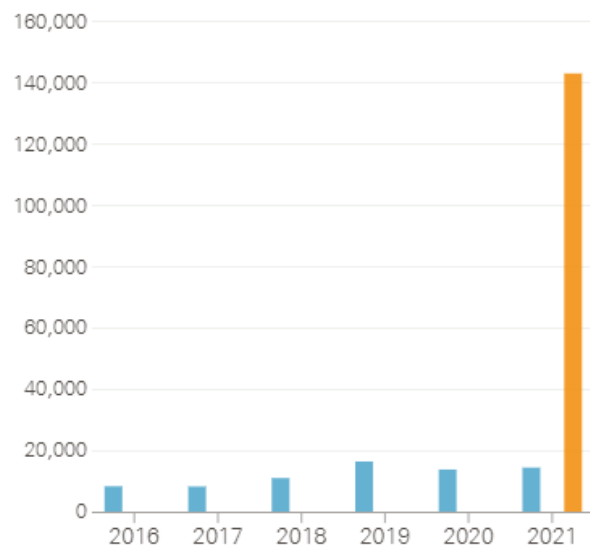
Neath Port Talbot

Number of carers identified



North West London

Number of carers identified



GP records identify many more carers than local authority records – and very few appear in both

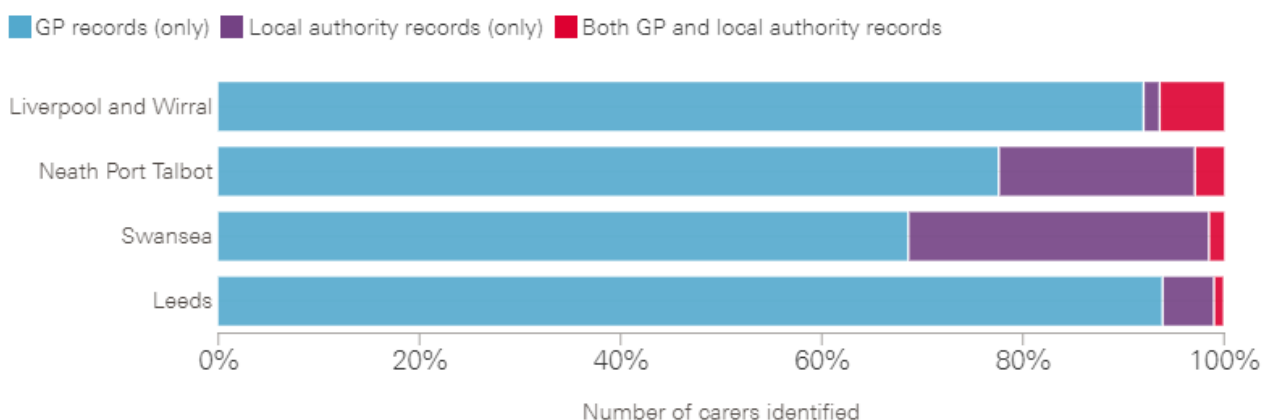
GP records consistently identify more carers than local authority sources. Figure 2 shows the number of carers identified by each source (and the degree of overlap) over the entire data-availability period. In each pilot area, the size of the GP cohort was larger than the local authority cohort, identifying up to 15 times as many carers.

Our novel data linkages, enabled by our NDL partners, showed us whether the same people were being identified by each data source. We found surprisingly little overlap between these two sources (under 7% in each of our pilot areas), implying that unpaid carers who are recorded by their GPs are a different group from those appearing in local authority records related to carer support. This may be due to different impetuses for carers coming forward and identifying with each service and/or a lack of data sharing and signposting between primary and social care. There may be many reasons underpinning a siloed approach to carer support, from legal barriers to sharing data to poor integration at a strategic level.

Figure 2

GPs and local authorities tend not to identify the same carers

Percentage of unpaid carers identified by each data source, as a proportion of all carers identified in electronic records over the study period



Carers identified in local authority records tend to be older than those identified by GPs

Figure 3 shows the age breakdown of carers identified by local authority and GP records compared to those identified by the census. We found that unpaid carers identified in local authority records were, on average, older than those in GP records or the census – possibly owing to older carers having more support needs, making them eligible and therefore more likely to reach out to their local authority for support. Indeed, [research by Carers UK](#) shows that older adults, who are often caring for a partner, face a specific set of challenges, as they are more likely to be supporting someone with mobility issues or dementia and may also be managing their own health conditions.

Figure 3

Unpaid carers identified in GP records were younger than those identified through local authority records

Percentage of unpaid carers in each age group by identification source



Another explanation may be the interplay between GP recording behaviours, COVID-19 vaccine priority groups and age. When the first COVID-19 vaccine was approved in December 2020, the Joint Committee on Vaccination and Immunisation drew up **priority groups** ranked by risk. The first five included people older than 65 years of age and residents of care homes, regardless of whether they were unpaid carers. The sixth was at-risk adults aged 16 to 65 years, including unpaid carers. Therefore, younger carers had greater incentive to register their caring status with GPs for the purposes of COVID-19 vaccination access. This may explain in part the increase in the number of carers identified by GPs in some areas in 2020 and 2021 (Figure 1).

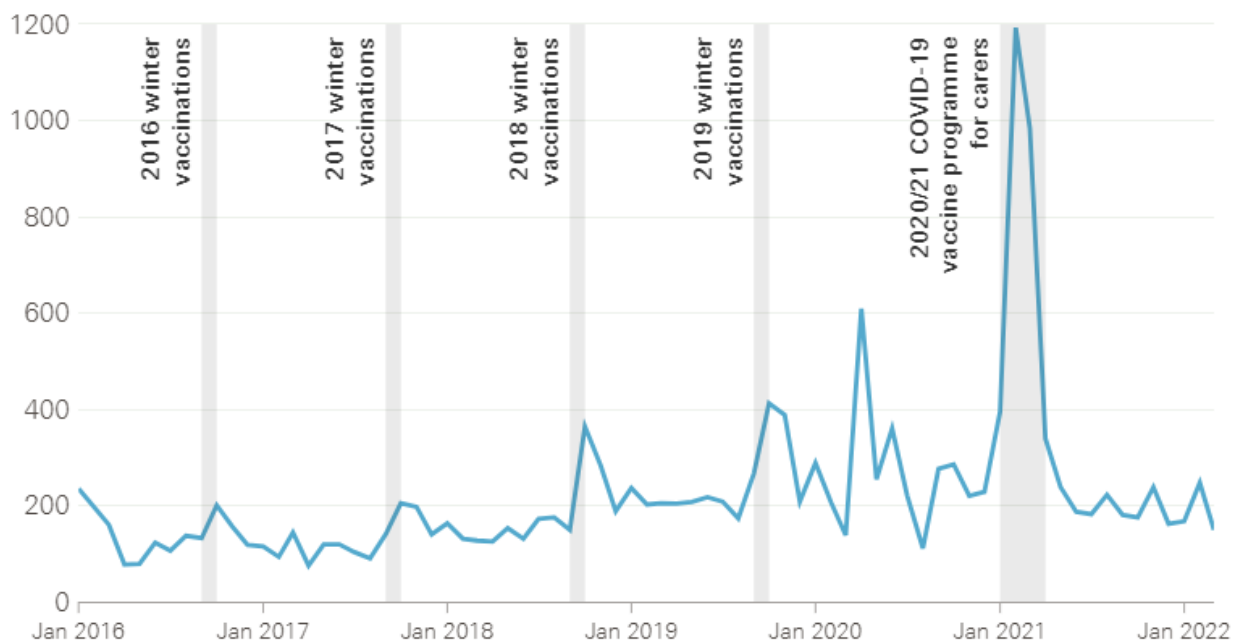
4. Case study: Identifying unpaid carers through GP vaccination programmes in Leeds

GP identification of carers is intrinsically linked to annual vaccination programmes. Each autumn and winter, unpaid carers are eligible for **free flu vaccines** to protect both themselves and those they care for. These are usually only freely available for working-age adults with certain health conditions or who are pregnant. Our Networked Data Lab partner in Leeds counted the number of GP carer registrations in the area using clinical codes and found that GPs identified more carers during periods when they offered flu and COVID-19 vaccines.

Figure 4

In Leeds, more carers were identified by GPs during winter and COVID-19 vaccination programmes

Number of unpaid carers identified each month by GPs



5. Local authority data challenges: lessons for integrating health and social care

Our NDL partners initially set out to include around 20 local authorities in their research to help answer questions on local authority support for carers. They intended to report, for example, the number of carers requesting local authority support, the proportion of applicants receiving various support packages and the time between successful requests and service delivery. They planned to produce these statistics for different demographic and socioeconomic groups in order to uncover any existing inequities in the delivery of carer support.

Unfortunately, it was not possible to include all the local authorities that initially expressed interest, nor to answer all these questions. Most of the NDL partner sites faced challenges obtaining data on carers despite the local expertise and dedicated project funding and staff time that should have facilitated access and linkage. Where linked data were eventually obtained, poor quality and missing data hampered our partners' ability to answer the intended research questions. Based on these experiences, we share here insights and recommendations for analysts and local system leaders seeking to analyse carer support.

Recommendations for obtaining local authority data on carer support

- **Engage with data holders early in the process and sustain this engagement throughout the project.** To ensure a high level of engagement, you should articulate the real-world problems data holders could help solve by taking part in the research. It also helps to show that your research has support from decision makers in government and carers' groups. Engagement can be sustained through regular touchpoints with your local authority stakeholders, showing them how the analysis is progressing and allowing them to shape the direction of the project in real time.
- **Start with the highest-possible number of local authorities.** Reach out to all local authorities within your integrated care board or geographical boundaries. Based on our experience, it is not unusual for local authorities to drop out of the process after it has begun. This may be due to a lack of resources, changes in staff or data limitations. For example, some local authorities may realise that their number of carer assessments is too low to enable meaningful analysis or that the risk of being able to identify an individual from the data is too high.
- **Start with minimal data requirements.** This will help maximise the number of local authority partners taking part. For example, set the minimum requirements to only carers' personal information and assessment dates. Avoid asking for variables that your local authority partners may not have access to.

- **Timing matters.** Local authority deadlines to submit government returns on unpaid carers can get in the way their participation in the analysis, as can deadlines for other large-scale updates to data infrastructure. In 2023, these deadlines were in June but may be different for subsequent years.
- **Make sure you can provide legal support.** Local authorities might need legal guidance during the information governance process, for example to draft data-sharing agreements. If this is a local authority's first time sharing data on carers, offer them data-sharing agreement templates. We have uploaded a [data-sharing agreement template](#) for new users to draw from, courtesy of the West Yorkshire integrated care board. They can also reach out to other local authorities with experience sharing data for informal support.
- **Explore the data before developing your research questions.** It may be possible to access a data extract before submitting a research proposal. If you can, take this opportunity to assess the feasibility of your research questions. The content of carer assessment and local authority support datasets can sometimes fall short of what is suggested by metadata files or dataset descriptions. In some cases, the information governance challenges may not be worth the data you receive.

Recommendations for working with local authority data on carer support

- **Draw a diagram of carer pathways through the system.** Each carer who requests support has a pathway through the system that takes them from reaching out to referral, assessment, development of a support plan, delivery and review. Without understanding these pathways, it can be very difficult to interpret each data point and accurately compute metrics such as wait times for services. In addition, there are often inconsistencies in how adult social care systems administer each point in the pathway, adding further complexity to these metrics.
- **Involve carers in your research.** People who have interacted with carer services first-hand provide invaluable information on their own pathways through the social care system, and their feedback should be interpreted alongside the perspectives of service providers. Not only will listening to carers help you understand the data, it will also help you interpret the findings.
- **Reach out to those who extracted and processed the data.** They should be able to answer questions on how carer services are delivered and data are collected. Because data extracts on carer support do not often come with a detailed guide, it is easy to misinterpret the data. Human connections matter.
- **Look out for possible biases in the data.** Carers' demographics are not always recorded at the same stage of the pathway. In some cases, they are recorded when the carer asks for support. In others, they are only recorded when a carer receives support. This could result in data biases, with carers further along their pathway being more likely to have complete data.

- **Populate missing NHS numbers.** NHS numbers are often missing from local authority data on carers because they are not needed by adult social care teams to deliver services. This can make linking health and social care data more complex, because it requires resorting to probabilistic linkage methods using other personal information (such as name and address).
- **Bring together data on carer assessments and support delivery.** The outcome of a carer assessment (whether it resulted in support or not) may be stored separately from the assessment itself. This is because some local authorities subcontract the assessments to a third party but deliver the support themselves.
- **Take caution when aggregating data from different local authorities.** There is a lack of common data standards between local authorities due to local differences in IT systems, subcontracting arrangements and varying carer pathways through the system. The types of services offered and eligibility criteria can vary even between neighbouring local authorities.

6. Implications for policy and practice

The novel analyses we undertook quantify, for the first time, the massive under-recording of unpaid carers in GP and local authority datasets. In the four areas that piloted this data linkage, electronic records identified only a small fraction of the true population of unpaid carers. Taking the most generous approach possible – combining both datasets and looking over a 5-year period – we were still only able to identify between 11% and 26% of carers compared with the Census 2021. Given that other nationally representative surveys estimate the total number of carers to be around twice the figure suggested by the 2021 census, the true level of under-identification may in fact be even higher.

Taken together with the insights from the process of linking and analysing GP and local authority datasets, these results are pertinent to several groups with responsibility for unpaid carers.

Local authorities

The extent of the undercounting of carers in local authority data in the NDL areas indicates that the gaps may not simply reflect a lack of need for support. According to the 2021 census, carers providing care at the highest intensity (50+ hours per week) account for more than 30% of the total carer population. Yet the ascertainment of carers in local authority data did not exceed 3% in any area. Without knowing who the unpaid carers in their population are, local authorities cannot understand the needs of this important group that they have a legal duty to support under [the Care Act 2014](#).

In the context of the current budgetary pressures and funding constraints facing local authorities, there is a question about whether councils would be able to support more carers even if they could identify them. Yet an approach that relies on people coming forward for carer assessments is likely to paint both an inaccurate and biased picture of the local need and is therefore an inadequate basis for commissioners and services to build appropriate support offers.

Having a better grasp of the total carer population would allow social care services to design and deliver more equitable services, target specific interventions at particular groups of carers and better manage the overall demand for services, thereby ensuring that support is provided where the need and benefit are greatest. In many cases, valuable support (for example, access to peer support groups) can be provided at relatively low cost.

GP practices

GPs play a crucial role identifying and supporting carers due to their longstanding relationships with patients. However, our analysis shows a significant undercounting of carers, with GP records capturing only 10% to 28% of the carers indicated by the 2021 census. This under-recognition poses a barrier to carers receiving proper support for their physical and mental health and hinders referral to other support services.

Primary care professionals can make a significant **difference to carers' health and wellbeing**, for example by actively screening for risks like depression and high blood pressure, as well as potentially reduce demand on services and prescribing costs in the long run.

Providing support for carers means that those being cared for may also be healthier and happier and experience benefits such as improved confidence and trust in their carer, reduced anxiety and feelings of guilt and reassurance that their carer will continue caring for them. Furthermore, it facilitates better care planning, particularly for people with long-term conditions, people receiving palliative care and elderly and vulnerable people. Ultimately, prioritising carer health not only benefits those directly involved but also contributes to more efficient health care services, reducing unnecessary hospital admissions and associated costs.

Integrated care bodies

Carers must navigate some of the most complex pathways across various sectors (health care, social care, voluntary sector) to access care and support. Their experiences highlight the pressing need for better integration of both services and datasets.

In England, integrated care systems are key emerging forces in supporting unpaid carers, and relationships between integrated care bodies and their local authority (or authorities) are likely to grow in significance. There are strong aspirations around using linked data to support integration, which will require bringing together data from GPs, local authorities and other organisations. In the longer term, this may be done through the creation of regional secure data environments, but in the shorter term, systems will rely on **obtaining local authority data and making linkages locally** to use this data for population segmentation, risk stratification and population health management. The NDL's experience trying to do this for unpaid carers surfaced several challenges that may provide useful lessons for integrated care systems as they progress towards this aim.

One of the key drivers for better integration is to improve population health and health care. Proactively supporting carers through an integrated, population health-management approach could enable them to stay well and provide essential care for longer, reducing rates of carer breakdown and costly late-stage interventions. This approach also has the potential to release savings that can be reinvested in health services. Another driver for integration is to tackle inequalities in outcomes, experiences and access. There is clear evidence that caring responsibilities are linked to inequalities and are more concentrated in **areas of England and Wales with higher deprivation**.

National policymakers

The **value of carers** to both the health and care system and the wider economy is greater than ever, and the importance of supporting this group is recognised in national policy. These findings provide quantitative evidence for national policymakers about the likely scale of unmet need.

Increasing the availability of support could help more unpaid carers live healthy lives, access breaks and balance caring with other responsibilities, saving the government money in the long run. This is particularly relevant in the context of current concerns about the number of working-age people dropping out of the labour market due to caring responsibilities, the annual cost of which is estimated at £2.9bn in benefit payments and lost tax revenues. Therefore, as well as relying on unpaid carers to prop up the health and social care systems, the government has an economic interest in supporting working-age carers to remain in the workforce.

7. The way forward

Support for carers matters more than ever. As local authority-funded social care has failed to keep up with **demand**, the need for unpaid carers has increased. Mounting pressure in the NHS to discharge patients from hospital may also be leading to carers supporting relatives and friends with more complex needs, exacerbating their need for support.

As a starting point, data is vital to improve carer support. High-quality data relies on comprehensive identification and high-quality recording to improve the figures we saw in our pilot analyses, as well as mechanisms for linking and sharing data between local health and social care services (with appropriate consent). Having individual-level data on the carer population, ideally linking the carer and the cared-for person, would also help fill important evidence gaps on how to best support different groups of carers.

There are several ways that the recording of unpaid carers by local services could be improved. These range from promoting existing guidance, such as NHS England's **quality markers framework** and **guidance on GP coding**, to carer awareness training, to developing mechanisms for data sharing between local services.

In England, the development of **shared care records** presents an opportunity to enable access and cooperation across health and social care organisations (social services, GPs, hospital discharge teams, virtual wards, continuing health care, community teams), allowing carers to register once across multiple organisations and share and update records and contingency plans electronically. To successfully implement this, integrated care bodies will need clear data standards that set out the purpose of sharing unpaid carer data and clarify the roles and responsibilities of all parties involved.

National policymakers could consider using positive national drivers, such as incentives or targets for carer identification, to encourage the recording and sharing of data on unpaid carers. The Department for Health and Social Care's **operational framework for local authorities** introduces a new duty for the Care Quality Commission to assess the performance of local authorities' adult social care functions, which may provide a key incentive for improved data collection and sharing. There are also avenues for national policymakers to shape the collection and sharing of data on unpaid carers, as outlined in the **department's roadmap for better data for adult social care**.

Better data and identification are a start, but to fully support carers, the NHS and social care need adequate resources and for carer support to be appropriately prioritised, reflecting the value of their work.

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Box 3: Acknowledgments

We are grateful to the members of the public who took the time to review and help improve this work, including Saroj, Naseem Akram and John Curtin.

Thanks also go to the public advisers who supported NDL partners with communication and engagement with the public: Claire Morgan (Carers Wales), Tim Banks (Carers Trust Wales) Digital and Health Care Wales' Patients and Public Assurance Group, Swansea University's SAIL Consumer Panel, Patricia McKinney, Lilla Tan (Leeds Involving People), Malachi Gooding (Leeds Involving People), Royal Borough of Kensington and Chelsea Carers Forum and Carers Network, Liverpool City Council Future in Mind team, The Brain Charity and Liverpool Chinese Wellbeing Centre.

This work would not have been possible without the support of many individuals within the participating local authorities who provided both data and expert insight. Particular thanks go to the Leeds Adult Social Care team (Ian Brooke-Mawson, Rob Wood, Diane Wrigglesworth and Ben Grant), Neath Port Talbot local authority (Ian Rees, Marianne Matthews), Swansea local authority (Catherine Stallard, Andrew Fung, Rachel Thomas, Michelle Glen), Denbighshire local authority (Alison Hay, Dyfan Barr, Michael Langford) and Gwynedd local authority (Linda Evans, Dave Roberts, Mark Parry, Rhodri Owain Lloyd).

Thanks to Catherine Foster and Giles Greene from Public Health Wales and Sarah Houston and Sian Simpson from Imperial College Health Partners for their support.

We would also like to thank Fiona Grimm, Kathryn Marszalek, Lucinda Allen and Hugh Alderwick for their contributions and comments on earlier drafts, as well as Zoe Ruziczka and Chamut Kifetew for managing the overall NDL programme at the Health Foundation.

This work uses data provided by patients and service users and collected by health and social care services as part of their care and support.

A detailed explanation of our data sources and analytical methods can be found in our [Technical Appendix](#).

8. Supporting information

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This long read was published originally on 8 November 2023 at the following address:

www.health.org.uk/publications/long-reads/can-you-tell-we-care