

#NetworkeddataLab

Engagement Evaluation Report

Topic 3 – Unpaid Carers

Author: Helen Butters

Date: May 2023

Context

The [Networked Data Lab](#) (NDL) is led by the Health Foundation and is a collaborative network of advanced analytical teams across the UK working together on shared challenges and promoting the use of analytics in improving health and social care. The Leeds Office of the Integrated Care Board (ICB) and Leeds City Council (LCC) are, together, one of five partners across the country who successfully bid to take part in the initiative.

The project looks at how partners can work together to use data to improve health and care in the UK, against the backdrop of widening health and care inequalities. It is doing this by identifying and analysing six topic specific data sets. The first data set focused on COVID and its effect on shielded patients (also referred to as “clinically extremely vulnerable”) who are the ones deemed the most at risk of becoming seriously ill from COVID. The second investigated mental health services and their use by children and young people and the third is examining the experiences of unpaid carers.

Healthcare data sets include vast amounts of medical data, various measurements, financial data, statistical data, demographics of specific populations, all gathered from various health and social care data sources. These complex data sets of information are not necessarily useful by themselves; they require linking together followed by appropriate and robust analysis to fulfil their potential to guide improvements in service delivery.

What is linked data? Linked data sets combine information from different organisations and sources to expand the items of information held on individuals. Working in this way enables us to better understand the health of our population and how they use services. This combined data enables us to plan and resource health and care for different populations. For example, dataset A might tell us lots of clinical information about people who are unpaid carers, dataset B gives us information about how these people want to access services, dataset C tells us about how being a carer affects people from BAME backgrounds. By combining these datasets, we have a better understanding of how to support unpaid carers. We can use the insight to design and pay for services for this specific population.

Patient and Public Involvement and Experience (PPIE)

An important part of the NDL is involving patients and the public in the project. This will ensure that:

- Data is used in a legitimate and transparent way.
- We recognise patients, carers and the public as stakeholders with rights, and responsibilities, for publicly funded services, research and education.
- We don't make assumptions about people's experiences of health and care.
- We focus on reducing health inequalities.

What does good PPIE analytics look like?

Using PPIE in conjunction with data analytics is a new concept, one designed to improve data quality and the analysis process. Good PPIE analytics bridges the gap between the researching team and the public. This means that data analysis doesn't isolate the public group the research is trying to help, which helps us to keep patients at the centre of our research.

Good PPIE analytics is also entirely collaborative. Interpretation of data and the presentation of information involves public voices. This means the drivers of how to use data is done by a range of stakeholders, instead of only our analytical teams. By involving the public with data interpretation, this can anchor the process to the public interest. By involving the public with the data presentation development, the team can produce accurate and digestible messages.

In all, good PPIE analytics is the heart of the NDL pilot project, and it can improve our data, analysis process and information dissemination. For us, this can lead to robust decisions made in the best interest of the Leeds population.

How have patient's and public feedback shaped decision making?

Firstly, an insight report was created looking at what we already knew across the city about unpaid carers. This information influenced and shortlisted the analysts' areas of interest together with the available data. The analytical team looked at:

- Registration (who registers where are the gaps?)
- Carers Assessment pathway

A task and finish group of 17 diverse unpaid carers with lived experience and interested stakeholders was set up to steer topic 3 with engagement at the heart. Membership of the group included the data scientists, Integrated Care Board (ICB) in Leeds volunteer, unpaid carers from diverse backgrounds, Carers Leeds, the commissioning programme lead for unpaid carers, Leeds Involving People (LIP). The group met eight times during the life of the project and helped:

- Inform the design of the research study
- Clarify the research questions and affirm their importance
- Steer the project throughout the research process

- Assist the research team in developing themes from data
- Consult and check their understanding of the data interpretation in the same way as the research team.

What mattered to the unpaid carers from the results?

- Low numbers of people registering with their GP: do we need a consistent offer of benefits from GP practices?
- Agreed GP should be the focal point of registering as 95% of carers are registered with a GP: there are health benefits for registering, i.e., early vaccination and signposting.
- Unpaid carers don't look after their own health needs: do GPs need to offer an annual health check?
- Low number of people being referred for a carers assessment
- Low numbers of people being successful in getting a carers assessment
- Confusion over the system: if English speaking people are confused where does that leave people for whom English is not their first language. Work is being done to raise awareness with GP practices, but do we need to raise awareness with people "on the street"?
- People would value a carers road map
- Make sure interpreters are used to explain to carers the road map (this could be translated into most popular languages)
- More awareness around carers assessment: do all GP practices have the same processes of informing people of the carers assessment and details to contact Carers Leeds once they register?

Additional surveys and one to one interviews were carried out with the gypsy and traveller (G&T) and older communities seeking their experience of being an unpaid carer. Feedback reflected comments from the task and finish group in that people felt their physical and mental health had been affected by caring. Members of the G&T community told us that they found it intimidating to approach services so very much used their own community to care. Following this comment, Steve from Carers Leeds visited the G&T community in their own environment to talk, listen and give advice. By doing this it is hoped that Adult Social Care (ASC) would be less intimidating to them and more personalised with a known face to approach in the future.

Additional referrals signposted at the interviews included the following:

1. Mother with undiagnosed Autistic boy (did not want to disclose her carer needs within her community) was effectively signposted for an autism diagnosis by LIP staff on the day. The child is home schooled therefore had fallen through the gaps in provision.
2. Several questions to Steve were asked by the group in a group setting at first and then three asked for one-to-one follow-up appointments on the day with Steve. Questions included adaptations for trailers/static homes, questions in relation to supporting family members when the carer for person has additional health inequality issues, support for carers who were supporting non-relatives who were on their site, carer support away from

the community, one had heard rumours of re-decorating and discussed with Steve if she would be eligible.

3. Steve was able to arrange additional follow-up appointments at the Leeds Gypsy and Traveller Exchange (GATE) so he could engage with people on a one-to-one basis in their environment as opposed to assuming that the carer would be able to go to Carers Leeds for impartial advice and support.

4. Leeds Involving People was invited to access two Leeds traveller sites with support from GATE, to share information and feedback on the topic when NDL reports and action lists have been completed.

5. All unpaid carers that were interviewed were not already accessing support through Carers Leeds.

6. LIP will be doing follow-up engagement in the G&T and OPAL communities to present the findings of the NDL project in a straightforward 'you said, we did' format.

What difference has PPIE made to the project?

Involving PPIE within the project has created several positive benefits. We were wanting to understand the unmet needs for unpaid carers: Building on intelligence and better understanding the support needed, the start of that process is to get people registered. At every meeting we asked someone with lived experience to tell their story of a particular theme the analysts were working on to enrich the data sets. The unpaid carers reflected many of the findings of the analytics and brought them to life with further discussion and recommendations which will be presented to local and national decision makers. An example of where the lived experience matched the data was around unpaid carers not looking after their own health as much as people who did not have caring duties. The project has also had a positive impact on the G&T community and we have been able to provide them with information to help them care as well as build up relationships with important stakeholders. The task and finish group members bonded and supported each other during the project and have expressed an interest to keep in touch.

Quotes from the team

"From an analytical perspective, it has been challenging to understand the support for unpaid carers in Leeds, so the lived experience of carers and know-how of service providers has been invaluable in building a clearer picture when data is scarce".

Alex Brownrigg – Data Scientist

"The NDL project on unpaid carers in Leeds involved a diverse group of people with lived experience from the outset. Their contribution was highly valued, and their perspective gave the data analysts valuable context on the topic, a collaborative model with people's voices definitely being heard".

Patricia McKinney – ICB Volunteer

“Remarked that she’s grateful to hear all the stories, and that she’s hopeful that the collection of information will be used to develop services going forward and that hearing other’s stories has added context to some of her own experiences as a carer.” –

Task and Finish Group Member, describing how the meeting has benefitted her in her own understanding of what it is to be an unpaid carer.

“Thinks that we’re getting to the meat of it now. We’re hearing a lot more useful data and generating ideas that might be useful to carers.”

Group Member, giving feedback on experience of discussion in the meeting.

Key Learnings for PPIE

- Having a task and finish group which included 17 people with lived experience and professionals worked well rather than having two separate groups. Having decision makers listening to people’s lived experience is powerful. The professionals were also able to answer questions and signpost.
- We knew that certain groups would not feel comfortable attending a virtual group so we met with groups of older people and 9 members of the gypsy and traveller community in their own environments.
- We also put together two surveys to seek more information which enhanced the data sets.

Main headlines from the Networked Data Lab analytics on unpaid carers

Background

Network Data Lab in Leeds has conducted research to establish gaps in the knowledge of the Leeds population regarding the needs of unpaid carers and the utilisation of services by unpaid carers. This paper pulls together the main headlines of 2 pieces of analytics.

1. Registered carers
2. Carers assessment pathway

Original Questions to look at:

1. Health outcomes of unpaid carers
2. Impact of carers accessing council services
3. How are support services being used?
4. Are all carers aware of services and receiving them?

Additional questions

1. Are services aware of carers?
2. Do they document them?
3. What are the reasons for people not caring?
4. What is the impact of providing care on a persons finances?

What outcomes are we wanting to achieve from this project?

We are wanting to understand the unmet needs for unpaid carers: Building on intelligence and better understanding the support needed. The start of that process is to get people registered.

What did we find out about identifying registered carers using GP data?

The headlines

- 65,000 unpaid carers in Leeds (source 2021 census)
- Needs of unpaid carers are complex with 83% reporting a negative impact of caring on their physical health – 87% impact on their mental health

- Out of 65K only 19K have informed their GP – rise in 2020 – covid
- More females than males registered
- No trend observed with deprivation, people who live in the most deprived areas are roughly as likely to tell their GP they are carers as those who live in less deprived areas
- People in deprived areas are more likely to have poorer outcomes so we assume that people from these areas would be more likely to care for someone but this is not seen in the registration numbers -potentially pointing to a lack of registration among areas of higher deprivation.
- Carers who speak English as first language is 85%
- Non English is 5% - does this mean that non English are not registering and making themselves known?
- We know that most carer registrations come from older age groups – typical persona white British retired woman

Pre-covid

- People from less deprived areas seem to register in the autumn – driven by the flu jab
- Base number increases seasonally

Discussion and conclusion

- This work has looked at registration rates by GP practices and secondary care interactions
- Registered carer rates have been increasing between 2016 – 2021 with a sharp increase in 2020 linked to the pandemic
- Carers often do not look after their own health. Early data analysis shows that unpaid carers could have more significant health characteristics to people who are 10 – 15 years older than themselves. This information was also reflected in conversations with the task and finish group
- Registration rates are unequal across demographics – men around 40 – 50% less likely than women
- Younger people (18-39) 10-20 times less likely than retirement age
- Non-english speakers 10-40% less likely than English speakers
- Chinese and Black, Black British less likely than white British to register
- Indian and Pakistani are more likely than white British to register as carers
- Retired British women are more likely to register as carers as opposed to
 - Non-English speakers
 - Men
 - Chinese and African
 - People who live in deprived areas
 - Working age across the age range

Dates

- Spikes in Autumn and then during covid
- Retirement age has a large increase in registrations
- Beginning of pandemic whilst working age patients had increased registrations and the onset of the vaccination programme

- Clear trend that during periods of increased call for carer registration the numbers increased greatly
- These drives are successful– these drives seem more effective in areas of lower deprivation where interactions with GPs are more routine – should more comms or engagement benefit these drives?

Health Needs

- Carers tend to have poorer health outcomes from non-carers – they put off their health needs
- Carers have a similar rate to non-carer for elective care but have a higher rate of attendance in A&E in most age bands. More women are attending A&E

NDL Adult Social Care Data – Support for unpaid carers

It should be noted that the interpretation of analysis was limited by small numbers of carers and cannot be considered representative of the carer population in Leeds.

The 2021 Census identified approximately 65,000 unpaid carers in Leeds. Services such as home care, sitting services and direct payments can be provided for unpaid carers through assessment by Adult Social Care (ASC). Between 1/1/2016 and 31/12/2021 there were 1,977 referrals for a carer assessment from a maximum of 1,361 known individuals.

How it currently works

Typically, unpaid carers looking to access support contact the social services in Leeds (the local authority – LA) and can be signposted to sources of community services (mainly Carers Leeds) or, if they are eligible, referred for a carers assessment. A joint carers assessment can also provide indirect support (such as respite) as part of a wider package of care for an adult social care service user. These contacts are recorded through the CIS case management system and flow into the Leeds Data Model (LDM).

Analysis presented here shows;

- 1) Only 2.1% of carers in Leeds have been assessed for support through the Local Authority (LA).
- 2) 67% percent of carers are female, compared to 31% male (with 2% unspecified gender).
- 3) On average, 225 carer assessments take place each year.
- 4) 38% of those carers who have a carer assessment receive a support plan to provide services.
- 5) It is impossible to determine the total number of carers seeking support from the data available. Only carers referred for a carer assessment were included here.

Key analysis

There was a wide representation of unpaid carers aged 18 to 99 from across Leeds. Females, between the age of 50-59, living in the most deprived areas (IMD decile 1) typically had the most carers assessments.

Gender and age

Between 2016 and 2021 Leeds had an average of 320,896 (51.5%) females and 301,769 (48.5%) males over 18. In contrast, 68% of carers were female and 31% were male. This imbalance was greatest in the lowest age band (18-29) and generally reduced as age increased.

Demographics and age

Younger age bands were dominated by carers from the most deprived areas (IMD decile 1). There was an increasing proportion of carers from more affluent areas as their age increased. This is also observed in the underlying population, but to a lesser extent.

The patterns identified above were consistent across each year of the study, but yearly breakdowns suffered from low sample sizes. Similarly, data was stated as percentage of the population with caring responsibilities, but again, it was difficult to draw conclusions with such low numbers.

Looking at the pathway

The pathway from carer assessment to service provision is variable depending on carer circumstances. Multiple conversations may occur before a support plan is issued and decisions are not well documented. Poor understanding of assessment pathways makes it difficult to estimate time from referral to service provision.

Inequities in service provision

Between 2016 and 2021, 533 (39.5%) of 1,350 carers who were referred for a carers assessment received support. The criterion for carer support is independent of age, gender, financial status and other demographic information and this is consistent with the analysis conducted here. However, considering such small numbers of overall referrals, it is surprising that approximately 60% of unpaid carers do not meet the criteria for support.

Ultimately, only 0.82% of the estimated carers, or 0.086% of the population in Leeds receive carer support.

Unpaid Carers Task & Finish Group Feedback

Key themes that mattered to the group from the analysis

- Low numbers of people registering with their GP – Do we need a consistent offer of benefits from GP practices?
- Agreed GP should be the focal point of registering as 95% of carers are registered with a GP: there are health benefits for registering, i.e. early vaccination and signposting.
- Un-paid carers don't look after their own health needs – Do GPs need to offer an annual health check?
- Low number of people being referred for a carers assessment

- Low numbers of people being successful in getting a carers assessment
- Confusion over the system – if English speaking people are confused where does that leave people who English is not their first language. – work is being done to raise awareness with GP practices, but do we need to raise awareness with people on the street?
- People need a carers road map
- Make sure interpreters are used to explain to carers the road map (this could be translated into most popular languages)
- More awareness around carers assessment – do all GP practices have the same processes of informing people of the carers assessment and details to contact carers Leeds once they register?