Evaluation of the Leeds Neighbourhood Networks

Towards an understanding of their contribution to health and care costs and resources

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Acknowledgements

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Introduction

This report explores the population health profile of older people[1] who access **community-based support** and the extent to which they make use of various health and care system resources. It focuses on the work of the **Leeds Neighbourhood Networks (LNNs)**, who support older people to live independently and participate in their communities through a range of activities and services that are provided at a neighbourhood level.

The study that informs this report set-out to **better understand how different types of data could be used to evaluate the costs, benefits and value for money of the LNNs** in relation to the health and social care system in Leeds. It forms part of a broader evaluation of the LNNs undertaken by the Centre for Regional Economic and Social Research (CRESR) at Sheffield Hallam University on behalf of a partnership between the Centre for Ageing Better (Ageing Better), Leeds City Council (LCC) and Leeds Older People's Forum (LOPF). The partnership was established in October 2017 to enable Leeds to adopt evidence-based practice, pilot innovative approaches, and generate new evidence that can be shared locally, regionally, nationally and internationally. The evaluation commenced in September 2019 and will conclude in 2023[2]. It has the broad aim of improving the evidence base about community-based approaches to supporting older people, including how initiatives like the LNNs contribute to outcomes and support local and national policy priorities in health and social care.

The evidence presented in this report draws on two main sources of data:

1. A pilot cohort of 148 members from one LNN whose records were pseudonymised then linked to the Leeds Data Model (LDM). LDM is an analytical resource to support Population Health Management and healthcare system planning. It contains health and social care data from organisations including hospitals, GP practices, urgent care including 111 and ambulance, community and mental health, maternity, adult social care and population data. The variables used in this report include demographics, health status, and health and care usage and indicative costs.

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[1] The term 'older people' is applied loosely throughout this report. The LNNs do not have strictly defined age criteria but in 2018 it was estimated that 99 per cent of LNN members were aged 60 or over. 23 per cent were aged 60-69, 33 per cent were aged 70-79, 35 per cent were aged 80-89, and 8 per cent were aged 90 or over.

[2] More information about the LNN Evaluation is available here: https://www.ageing-better.org.uk/our-work/leeds-neighbourhood-network

2. Evidenced-based costed hypothetical vignettes of two LNN members. Although not 'real' LNN members, the vignettes have been developed from interviews undertaken for the 'Healthy Ageing' thematic evaluation report [3] in 2022 to illustrate some of the common characteristics, experiences and outcomes of LNN members identified during the evaluation. The vignettes have been costed using existing evidence about health and social care costs associated with older people experiencing loneliness and dementia.

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[3] Dayson, C., Gilbertson, J., Chambers, J., Ellis-Paine, A., & Kara, H. (2022). *How community organisations contribute to healthy ageing*. Centre for Ageing Better.

An Overview of the Leeds Data Model

2

The Leeds Data Model (LDM) is an analytical resource used across the Leeds Health and Care system. It supports Population Health Management and healthcare system planning. The data in it is pseudonymised so individuals cannot be re-identified, and it includes health and social care data from organisations including hospitals, GP practices, urgent care including 111 and ambulance, community and mental health, maternity, and adult social care. There is interest in Leeds and more widely about how integrated datasets such the LDM can be used to understand and evaluate the costs, benefits and value for money of community-based organisations whose work supports the priorities of the health and care system.

This chapter provides and overview of the LDM model and the process for accessing and analysing the data.

2.1. Key Variables in the Leeds Data Model

LDM data was provided in July 2022. Table 2.1 provides an overview of the key variables in the LDM that were provided for this pilot study. Together, these variables provide a generalised annual picture of an individual's engagement with the healthcare system. They can be analysed at the population level or segmented into categories of interest and compared with different population groups.

Table 2.1: Overview of LDM variables

Demographics	Health status	Health and care usage*	
Age	Frailty score (EFI)	Total number of episodes	Total cost of episodes
Gender	No of long-term health conditions	Primary care episodes	Primary care costs
Ethnicity	Population Health Management (PHM) cohort	Urgent care episodes	Urgent care costs
IMD decile	Complexity of need	Community care episodes	Community care costs
		In-patient episodes	In-patient costs

*Note that each health and care usage category included a number of component parts. For this study these were analysed at various aggregate levels.

For the demographic and health status variables the latest data for 2021-22 was provided. For the health and care usage variables data for the years 2018-19, 2019-20 and 2020-21 was provided to enable an exploration of trends over time.

2.2. Identifying LNN members the Leeds Data Model

LNN membership and other forms of LNN participation are not routinely included in the LDM. As such, a process was developed with the LDM team to pseudonymise, link and access the data. To ease the resource burden and capture key learning, one LNN was selected in 2019 to take part in a pilot.

Stage 1: Collecting NHS Numbers and Consent.

NHS Numbers enable data from different sources to be linked across the health and care system. The pilot LNN was asked to collect NHS numbers from as many members as possible across a range of activities and services. An form of words for obtaining consent from LNN members for their data to be accessed anonymously was agreed with the LDM team who then secured the necessary Information Governance approvals from the NHS.

In total, 148 NHS numbers were collected by the pilot LNN during 2019 and shared with the LDM team. The pilot LNN reported that the request for NHS numbers had a very mixed response from members. Some people refused, some people couldn't find their NHS number, while others were happy share their NHS number and provide consent. The LNN reported that the process didn't feel too onerous, and they still try to collect NHS numbers from their members.

Stage 2: Data linkage

The NHS numbers were pseudonymised by the Data Service for Commissioners Regional Office (DSCRO) to enable the LDM team to identify the 148 LNN members within the LDM dataset so that their data could be extracted for analysis.

Stage 3: Data analysis

The LDM Team identified key variables for analysis in consultation with the Evaluation Team (as outlined in table 2.1). For the demographic and health status variables they provided aggregate data for the LNN cohort cross-tabulated for comparison with the Leeds population aged 64 and over. For the health and care usage variables they provided anonymised individual level data on the number and cost of various types of health and care use categories for the years 2018-19, 2019-20 and 2020-21. These data were shared with the Evaluation Team for further analysis and interpretation.

2.3. Limitations and challenges of the Leeds Data Model data

It is important to note a number of challenges associated with using these LDM data for this pilot study and more generally.

- First, a typical pre/post intervention study, whereby a pre-intervention baseline measure is compared with a post-intervention measure, was not possible. As other LNN evaluation reports have demonstrated, the LNN membership model means that older people join a network at different points in time and access a range of different interventions over an extended time period. For the LNN members included in this pilot start dates and information about the types of support accessed at different time points was not available. As such, the data

represents a snapshot of a point in time through which it is difficult to fully understand changes or what has caused them.

- Second, as our data is for a sample of members from one pilot LNN, it is unlikely to be representative of LNN membership as a whole. For example, the pilot cohort has a higher proportion of members aged over 80 than the LNN membership as a whole but is broadly representative by gender. The LNN is also based in relatively healthy and economically prosperous area of Leeds, with several pockets of more severe deprivation. Frailty and under 75 mortality rates in this area are generally very good, and life expectancy is also very high. These differences mean that a larger sample of LNNs and their members would need to be included for the findings to be considered generalisable to a wider population.

- Third, whilst the comparison with the Leeds population aged 64 and over is useful, it is not a true counterfactual as there is no record of other non-LNN community-based activities that might have been accessed by people in either group.

- Finally, the COVID-19 pandemic occurred during the period covered by the LDM data. This means that COVID-19 related admissions are present in the health and care usage data for 2020-21 which may mask other underlying trends.

Despite these limitations these data provide a novel and useful resource through which to explore the health profiles and health and care usage patterns of LNN members. The analysis presented in the report provides an illustration of how these data could be used for future evaluation of and research into the LNN and their contribution to health and care priorities.

Leeds Data Model Analysis: Key Findings

<div style="text-align: right">3</div>

This chapter presents the key findings from our analysis of the Leeds Data Model variables for a cohort of 148 members from one pilot LNN. Appendix 1 provides a detailed overview of the data covering demographic characteristics, various aspects of health status, and health and care usage and costs.

3.1. Demographic characteristics

The demographic data confirms what we have previously reported about LNN members:

- **They tend to be older:** 70 per cent of the cohort were aged 80 or older compared to only 26 per cent of the Leeds population aged over 64.

- **They are more likely to be female:** 75 per cent were female compared to 54 per cent of the Leeds population aged over 64.

- **They cater for a higher proportion of people from White ethnic backgrounds:** 99 per cent were White compared to 91 per cent of the Leeds population aged over 64 (although it should be noted that the pilot LNN is based in a predominantly White area of the city).

The data also show that this LNN caters for older people from a **cross-section of economic backgrounds**, including people in the poorest and wealthiest communities according to the Indices of Multiple Deprivation (IMD): 14 per cent were from the poorest 30 per cent of communities compared to 30 per cent of the Leeds population aged over 64; 55 per cent were from the most prosperous 30 per cent of communities compared to 31 per cent of the Leeds population aged 64 and over.

This finding about economic backgrounds is quite surprising as previous research undertaken during this evaluation has suggested that LNN's are very effective at engaging older people in economically deprived areas of the city. Further investigation is needed to fully understand this discrepancy, but it may reflect a number of factors:

- The pilot LNN is based in a part of Leeds that does include a number of more prosperous communities.

- There may be some bias in who is willing and able to provide their NHS number. It could be that older people from more prosperous backgrounds are better able to locate their NHS number and more willing to trust that it will be used in a safe and secure way.

Understanding potential biases in the data will be important if the LDM is to be used as a tool to evaluate the LNNs on a broader basis in the future.

3.2. Health Status

The data on the health status of LNN members provides **new insights into who the LNNs are supporting** in the community. A previous LNN evaluation report has highlighted how the LNNs are able to prevent, reduce and delay the need for reactive health and care services, and these data further highlight how LNN members are distributed across the healthy ageing spectrum[4].

a. *Electronic Frailty Index score*

The Electronic Frailty Index (EFI) uses the information within the electronic primary health care record to identify populations of people aged 65 and over who may be living with varying degrees of frailty. When applied to a local population it provides the opportunity to predict who may be at greatest risk of adverse outcomes in primary care as a result of their underlying vulnerability. It records and a 'cumulative deficit' model to measure frailty based on the accumulation of a range of deficits. These deficits include clinical signs (e.g., tremor), symptoms (e.g., vision problems), diseases, disabilities and abnormal test values[5].

EFI is presented a score between 0-1 based on the number of deficits present out of a possible total of 36, with the higher scores indicating the increasing possibility of a person living with frailty and hence vulnerability to adverse outcomes. The scores are then categorised into levels of severity, with 0–0.12 meaning 'fit'; >0.12–0.24 meaning 'mild frailty'; >0.24–0.36 meaning 'moderate frailty' and above 0.36 meaning 'severely frail'. Figure 3.1 presents the range of EFI scores in the LNN cohort compared with the Leeds 64+ population.

This shows that **levels of frailty amongst the LNN cohort were broadly similar to the wider population**. 85 per cent were 'fit' or had 'mild frailty' compared with 83 per cent of the wider population, eight per cent were 'moderately frail' compared with 12 per cent of the wider population, and seven per cent were 'severely frail' compared to 6 per cent of the wider population.

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[4] Dayson, C., Gilbertson, J., Chambers, J., Ellis-Paine, A., & Kara, H. (2022). How community organisations contribute to healthy ageing. Centre for Ageing Better.
[5] For more information see Clegg, A, et al. (2017). Development and validation of an electronic frailty index using routine primary care electronic health record data, Age and Ageing, 45, 3, 353–360, https://doi.org/10.1093/ageing/afw039

Figure 3.1: EFI score for the LNN cohort compared with the Leeds 64+ population
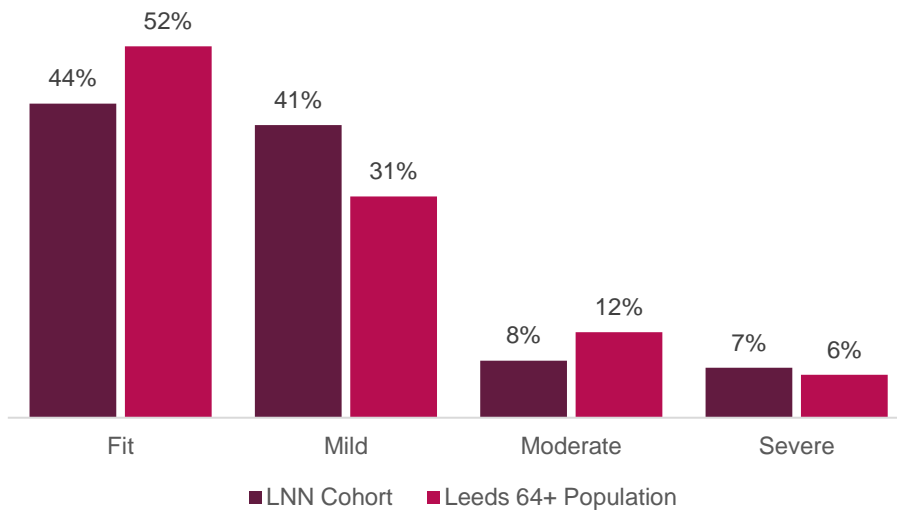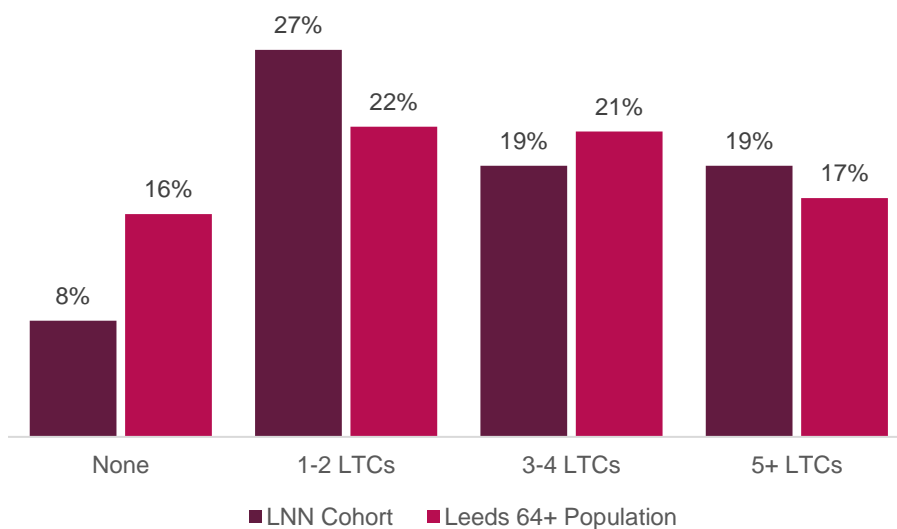

Source: Leeds Data Model, June 2022.
Base: LNN Cohort, 148; Leeds 64+ Population, 143,418

b. Number of long-term health conditions (LTCs)

The LDM records the total number of diagnosed LTCs for each individual. Figure 3.2 presents the number of LTCs amongst the LNN cohort compared with the Leeds 64+ population.

Figure 3.2: Number of LTCs amongst the LNN cohort compared with the Leeds 64+ population

Source: Leeds Data Model, June 2022.
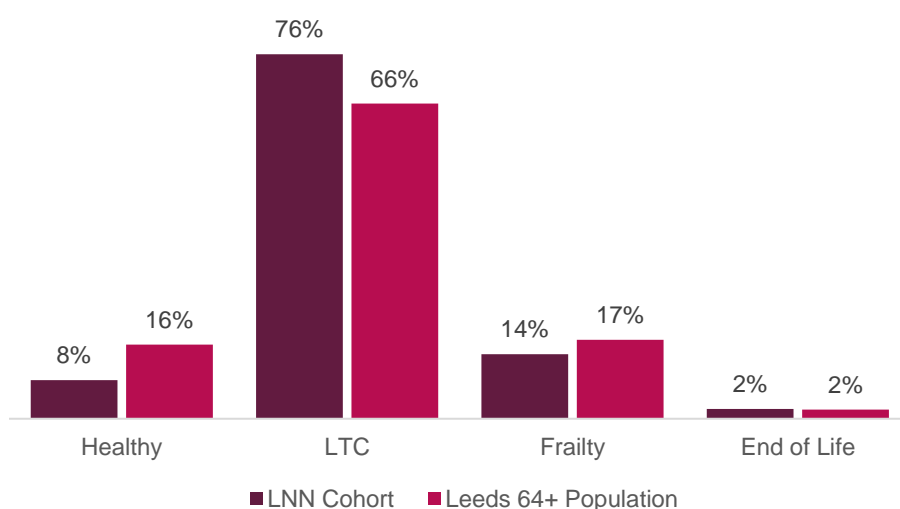Base: LNN Cohort, 148; Leeds 64+ Population, 143,418

This shows that **members of pilot LNN tended to have more LTCs than the wider population**, but that the difference was not that large. Eight per cent of the LNN cohort had no LTCs compared with 16 per cent of the wider population, 27 per cent had one or two LTCs compared with 22 per cent of the wider population, 19 per cent had three

or four LTCs compared with 21 per cent of the wider population, and 19 per cent had more than five LTCs compared with 17 per cent of the wider population.

c.   Public Health Management (PHM) cohort

The PHM process segments the Leeds population according to levels of assessed health functioning and stage of healthy ageing to aid the targeting of health and care services. Four categories are used: 'healthy', to indicate a high level of functioning; 'LTC', to indicate the prevalence of at least one health condition that may affect frailty in the longer term; 'frailty', to indicate decreased functioning that is considered to be of concern with regard to functioning; and 'end of life', to indicate cases where functioning has reduced to the extent that an individual is included on the palliative care register. These categories are recorded in the LDM. Figure 3.3 presents the distribution of these PHM categories across the LNN cohort compared with the Leeds 64+ population.

Figure 3.3: PHM categories of the LNN cohort compared with the Leeds 64+ population

Source: Leeds Data Model, June 2022.
Base: LNN Cohort, 148; Leeds 64+ Population, 143,418

This shows that the **largest proportion of LNN members (76 per cent) fall into the LTC category** and that they support a higher proportion of older people in this category than is present in the wider population (66 per cent). It also shows that **there are a smaller but significant proportion of LNN members in the frailty category** (14 per cent) but that this is slightly lower than the wider population (17 per cent).

d.   Overall assessment of the complexity of health and care needs

Overall, these data about the health status of LNN members support findings from previous LNN evaluation reports that **a significant volume of LNN's work is targeted at prevention for older people experiencing the onset of LTCs and/or mild frailty** many of whose health and care needs can be met in non-clinical settings. This can in turn contribute to delaying the onset in severity and complexity and reduce the need for acute care. But it also supports the finding that LNNs do also support a small number of members with more complex needs for whom LNNs are able supplement the clinical care they receive. Growing community-based support for older people with moderate and more complex frailty is a key aim of the health and care system and this

evidence suggests that LNNs do have capacity to support these individuals if appropriately resourced to do so.
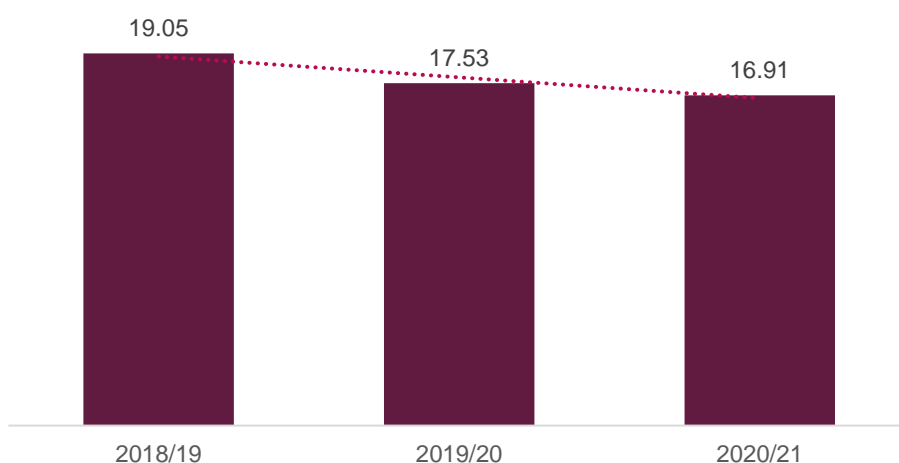
3.3. Health and care usage and costs

The LDM includes annualised data about health and care usage and costs at the individual level. Categories covered include primary care, urgent care (such as Accident and Emergency), community care and in-patient secondary care (planned and unplanned). For each category the number of episodes per year is provided along with the cost of those episodes. A figure for the total number and costs of all health and care episodes is also provided. This analysis covers data for the years 2018-19, 2019-20 and 2020-21 to enable an exploration of trends over a short period of time (i.e., the three years following the initial collection of the NHS numbers by the pilot LNN).

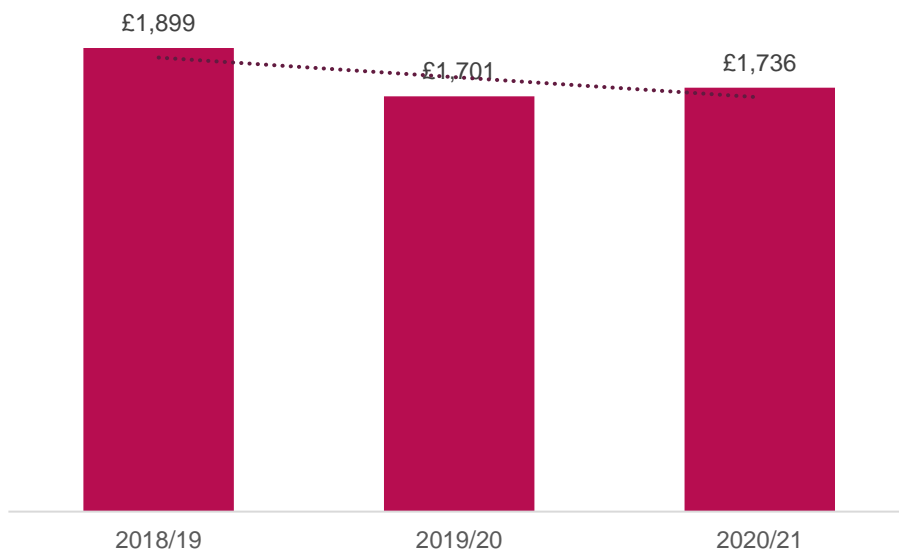### a. Total health and care usage and costs

Figure 3.5a provides a figure for the average (mean) number of all health and care episodes per year for the LNN cohort. Figure 3.5b provides a figure for the average (mean) cost of all health and care episodes per year for the LNN cohort. The charts show **a small reduction in the total number and cost of all health and care episodes** over time. The average number of episodes reduced from 19.05 per year to 16.91 per year whilst the average cost reduced from £1,899 per year to £1,736 per year. Whilst it is not possible with these data to determine the extent to which these reductions are linked to engagement with the pilot LNN, it is positive that they have not increased at all, which supports the wider evaluation finding that **LNN membership can help limit deterioration in functional ability in older people** who my otherwise have experienced a decline.

Figure 3.5a: Average (mean) number of all health and care episodes for the LNN cohort 2018/19-2020/21

Source: Leeds Data Model, June 2022.
Base: LNN Cohort, 148

Figure 3.5b: Average (mean) cost of all health and care episodes for the LNN cohort 2018/19-2020/21

£1,899

£1,701

£1,736

2018/19   2019/20   2020/21

Source: Leeds Data Model, June 2022.
Base: LNN Cohort, 148

b. *Primary care (GP) usage and costs*

Figure 3.6a provides a figure for the average (mean) number of primary care episodes per year for the LNN cohort. Figure 3.6b provides a figure for the average (mean) cost of primary care episodes per year for the LNN cohort.

Figure 3.6a: Average (mean) number of primary care episodes for the LNN cohort 2018/19-2020/21

10.45

9.75

7.6

2018/19   2019/20   2020/21

Source: Leeds Data Model, June 2022.
Base: LNN Cohort, 148

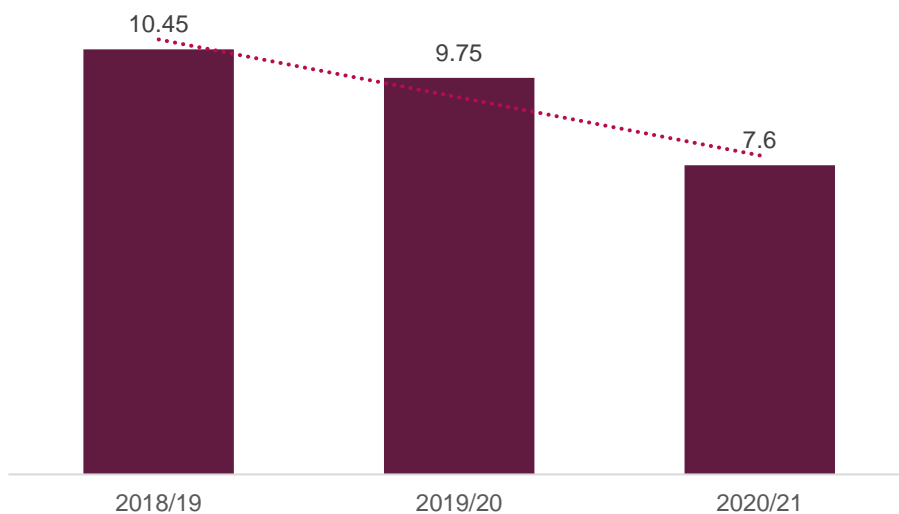**Figure 3.6b: Average (mean) cost of primary care episodes for the LNN cohort 2018/19-2020/21**
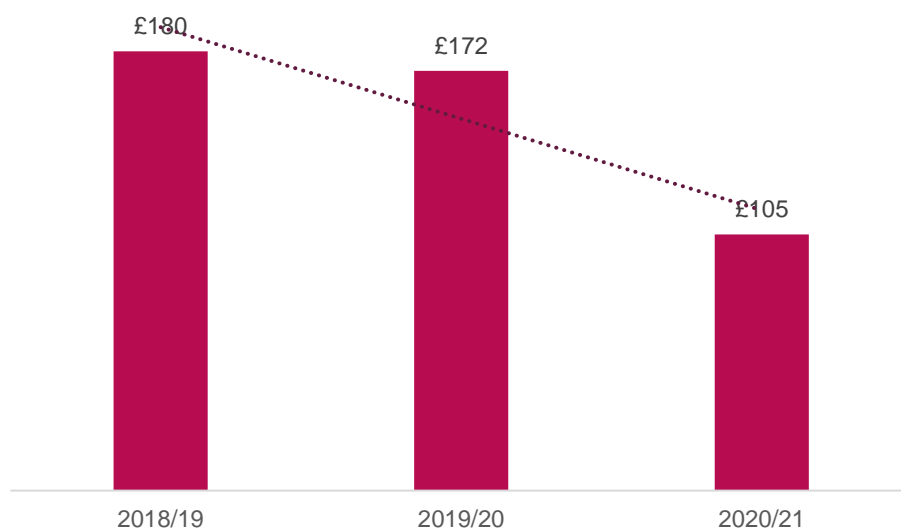
Source: Leeds Data Model, June 2022.
Base: LNN Cohort, 148

These show **a reduction in the total number and cost of primary care (GP) episodes over time.** The average number of episodes reduced from 10.45 per year to 7.6 per year whilst the average cost reduced from £180 per year to £105 per year. Similar to the overall number and cost of health and care episodes it is not possible to determine the extent to which these reductions are linked to engagement with the pilot LNN. Again, however, the fact that they have not increased at all is positive and supports the wider evaluation finding that **LNN membership can help sustain positive health and wellbeing** and prevent declines.

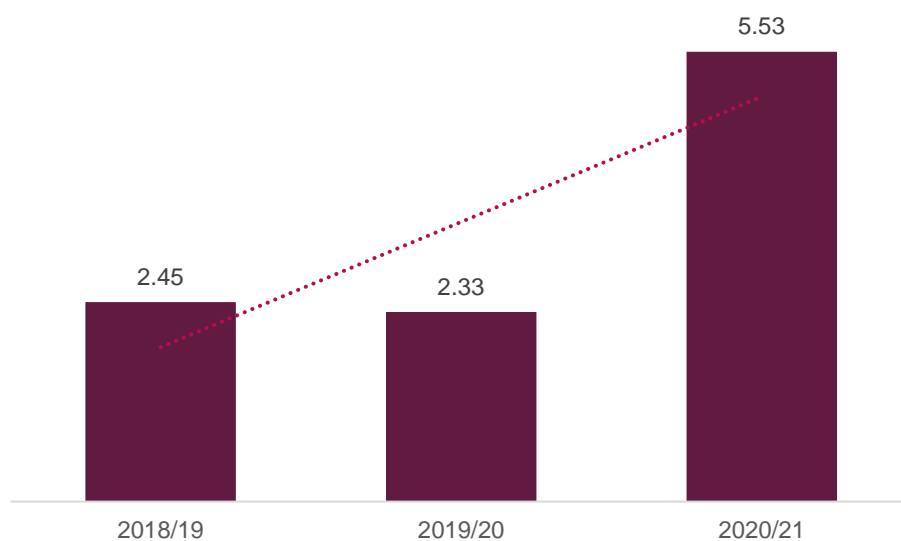### c.   *Community care usage and costs*

Figure 3.7a provides a figure for the average (mean) number of community care episodes per year for the LNN cohort. Figure 3.7b provides a figure for the average (mean) cost of community care episodes per year for the LNN cohort. These show an **increase in the total number of community care episodes but a reduction in cost over time**. The average number of episodes increased from 2.45 per year to 5.53 per year whilst the average cost reduced from £266 per year to £206 per year. The reasons behind these differences are not entirely clear. However, **they may be linked to the COVID-19 pandemic**, during which more people may have needed community level support, but in ways that were less resource intensive. For example, support to collect medicines and food deliveries, as opposed to personal care and direct assistance in the home.

Figure 3.7a: Average (mean) number of community care episodes for the LNN cohort 2018/19-2020/21

Figure 3.7b: Average (mean) cost of community care episodes for the LNN cohort 2018/19-2020/21
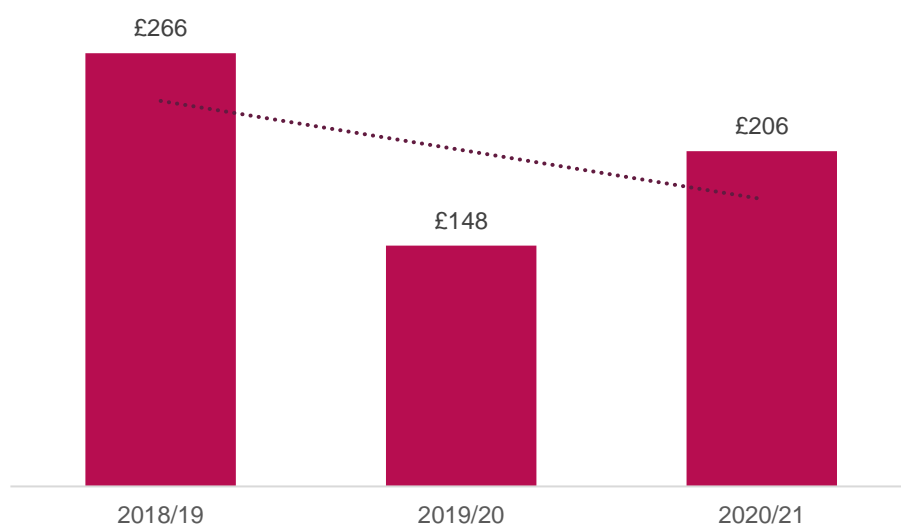
d. Urgent care usage and costs

Figure 3.8a provides a figure for the average (mean) number of urgent care episodes per year for the LNN cohort. Figure 3.8b provides a figure for the average (mean) cost of urgent care episodes per year for the LNN cohort.

Figure 3.8a: Average (mean) number of urgent care episodes for the LNN cohort 2018/19-2020/21

Source: Leeds Data Model, June 2022.
Base: LNN Cohort, 148

Figure 3.8b: Average (mean) cost of urgent care episodes for the LNN cohort 2018/19-2020/21
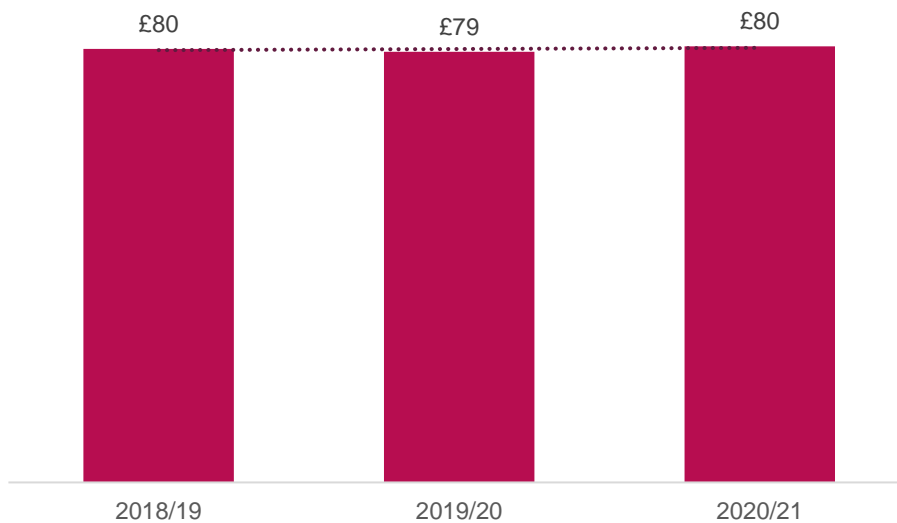
Source: Leeds Data Model, June 2022.
Base: LNN Cohort, 148

These show that **the total number of urgent care episodes reduced over time but that costs remained broadly the same**. The average number of episodes reduced from 0.89 per year to 0.74 per year whilst the average cost stayed at around £80 per year. It is also important to note that **the overall number and cost of episodes was relatively low**. These variations appear to be driven by a small number of people requiring costly interventions. Whilst we cannot be sure **it could be linked to extended stays related to COVID-19**.

e. *In-patient care (non-elective) usage and costs*

Figure 3.9a provides a figure for the average (mean) number of non-elective in-patient care episodes per year for the LNN cohort. Figure 3.9b provides a figure for the average (mean) cost of non-elective in-patient care episodes per year for the LNN cohort. These show a **reduction in the total number of community care episodes but an increase in cost over time**. The average number of episodes reduced from 0.33 per year to 0.28 per year whilst the average cost increase from £460 per year to £977 per year. Similar to urgent care, these **variations appear to be driven by a small number of people requiring costly in-patient stays**, possibly related to COVID-19.

Figure 3.9a: Average (mean) number of non-elective in-patient care episodes for the LNN cohort 2018/19-2020/21
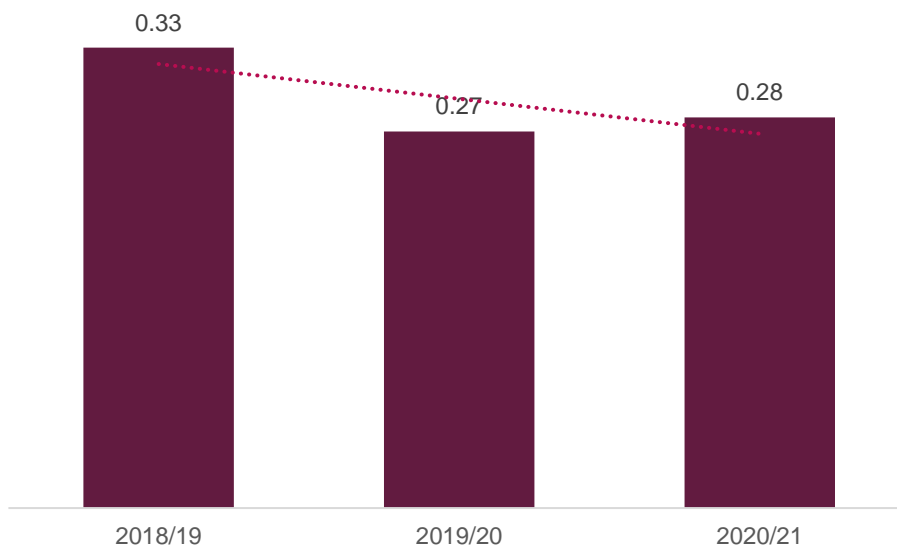
Source: Leeds Data Model, June 2022.
Base: LNN Cohort, 148

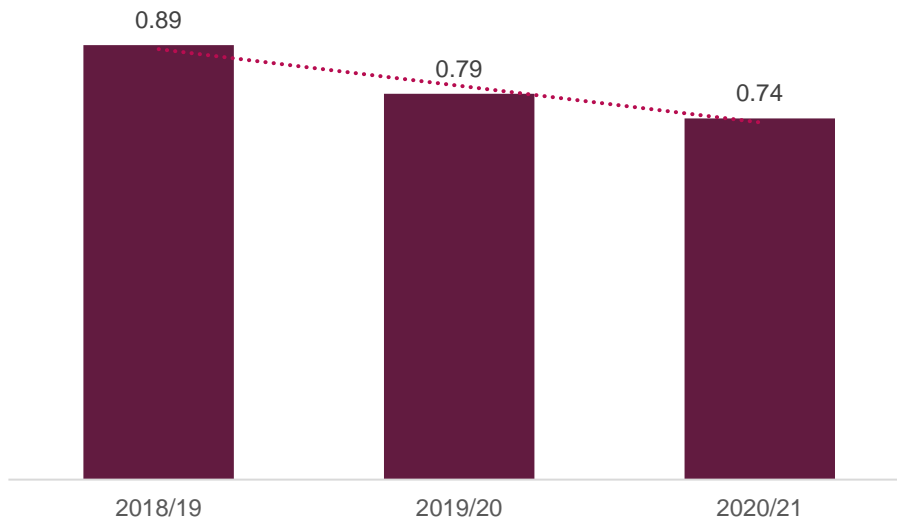**Figure 3.9b: Average (mean) cost of non-elective in-patient care episodes for the LNN cohort 2018/19-2020/21**
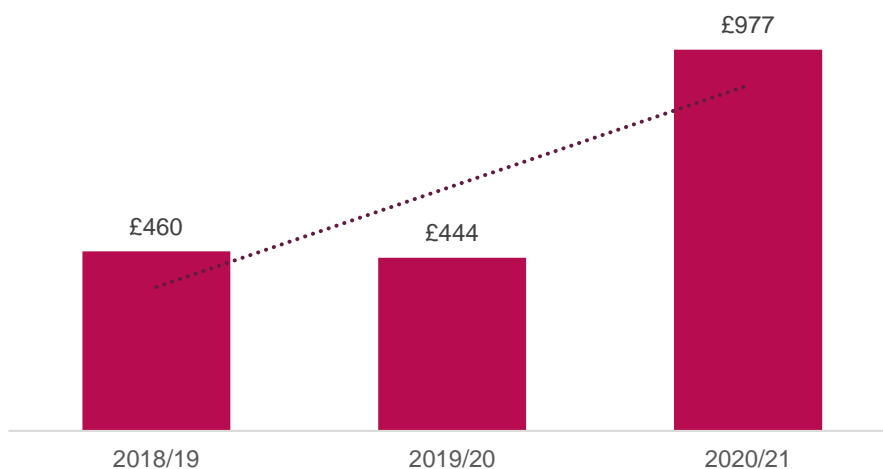
Source: Leeds Data Model, June 2022.
Base: LNN Cohort, 148

Qualitative vignettes

This chapter presents two detailed vignettes of LNN members to help illustrate the potential benefits to the health and care system of having well-resourced and sustainable LNNs active within Leeds. Although each vignette is not a 'real' LNN member, they have both been developed from our existing LNN evidence-base to illustrate some of the common characteristics, experiences and outcomes of LNN members. Similar to the 'health ageing' evaluation report, the 'prevent, delay, reduce' framework for understanding different stages of healthy ageing has been applied[6]. Each vignette draws on wider evidence about health and social care costs associated with older people experiencing loneliness and health conditions such as dementia.

4.1. Vignette 1: Hannah

Hannah is eighty-two. She is **a frail older person recently bereaved and living alone**. Hannah was struggling at home on her own and was referred to her LNN by her GP. Hannah has a son living over two hours away who has a family and a busy job. Although he visits as often as he can, he worries about her being on her own. He noticed that she wasn't coping so well after his Dad died and encouraged her to see her GP. Since his Mum was referred to the LNN, she seems much brighter, he doesn't worry about her quite as much as he knows she has support in place, that someone is looking out for her and there are people nearby she can rely on for help if she needs it.

a. Prevent

After seeing her GP Hannah was contacted by her local LNN to see what she needed and how they could help her. It was great that the person from the LNN could visit Hannah at home and check that she was okay and getting the things she needed and the benefits she was entitled to. Hannah started attending some of the activities the LNN offered including a lunch club and a chair-based exercise class. Hannah enjoyed meeting new people and felt so much better getting out. Hannah sometimes found it difficult to get out, so the LNN arranged for a befriender to call her once a week.

> *"I've had some really nice conversations, you know, it's been really friendly, you know, we've talked about lots of different things, and they've mentioned how they felt with things, and yes, it's been really good."*

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[6] Dayson, C., Gilbertson, J., Chambers, J., Ellis-Paine, A., & Kara, H. (2022). *How community organisations contribute to healthy ageing*. Centre for Ageing Better.

During the COVID-19 pandemic Hannah wasn't forgotten about and her befriender continued to call her every week and arranged for a volunteer to do some shopping for her. She looked forward to the calls, the volunteer delivering her shopping and having a chat at the door. The LNN sent Hannah activity packs and supplied her with an iPad showing her how to use it so she could stay connected with her son and some of her friends more easily.

> *"I think to me it's underlying some of the enormous value of this sort of having a volunteer who will come and do something for you often. You could see another face and you could have a little laugh... It's been amazing, piece of sharing as well and I think that sharing is just as valuable in difficult times, whether its Covid or whether one was having other problems and needed help…. That was just amazing I never had anybody volunteering to do anything for me before. I hadn't needed it, not the kind of person who never really liked asking for help."*

Hannah joined her LNN's book club via teleconference and started some activities they offered like knitting at home to keep her busy in the evenings. She especially liked knitting for good causes as she felt she was helping others too. The LNN provided her with assistance and delivered the books and materials she needed so she could take part in these activities.

> *"Thank you for giving me the opportunity to knit. I am enjoying it especially in the evenings when I have nothing to do. It feels really nice knowing I have done something for someone, and I enjoyed knitting the chicks as it has helped me with my depression otherwise, I would sit doing nothing."*

Since the pandemic Hannah still receives regular calls from her befriender and has continued taking part in her activities at home and remotely. She has managed to return to the lunch club occasionally. Her LNN is helping her get out and about again and return to normal after a difficult time. Getting advice on COVID-19 and the vaccinations has helped Hannah to make sense of all the information and provided much needed reassurance.

> *"We're moving to a confidence-building focus to help people understand that it's OK to go out now." (NN, staff member)*

Hannah's befriender can now take her out and they have managed a couple of walks together which is helping Hannah to get moving and enjoy a bit of exercise again.

b. Delay

When Hannah joined her local LNN, she benefited from a project that was running with local GPs and healthcare services aimed at helping people like her who were frail and struggling with their wellbeing. Hannah received lots of friendly advice and support about healthy eating, mobility, relaxation, and mindfulness which has helped with managing her health and resulted in her feeling healthier and more positive.

> *"With the eating part of it, again it's are they struggling to open things? How are they using their knives and forks? Are they not eating? Are they eating maybe too much as such? But yes, it's just kind of, each point has little things that will prompt us to maybe ask questions." (NN, staff member)*

> *"…and I was very struck by how friendly and sort of open and not like any of them blue hats, like a doctor's surgery you know."*

Hannah's befriender also checks on how she is getting on and mentioned that since she knows Hannah so well, she can often spot signs that something isn't right or if there are any concerns.

"Well she just, I would say she's probably keeping an eye on me, making sure I'm alright."

"… when you ring up, you ask how they are, have they had much to drink today with older people in hot weather you know. If it's very hot you can be asking those sort[s] of questions, … when you are doing the befriending face to face you can actually keep an eye on what they are looking like and if they are beginning to look very thin." (LNN, volunteer)

As well as having a friendly chat, Hannah knows that if there is anything she needs she can tell her befriender or contact the LNN herself. She knows the staff and volunteers there and feels confident they will help her.

"I think the main thing is knowing there's somebody out there, they're out there and they are so caring, keeping in touch with you once a week is I think is absolutely wonderful I do."

Hannah also has more information about other services and understands that her LNN can assist with accessing additional support should she need it.

"It's the reassurance of knowing that there is help there if you need it."

c.   Reduce

Hannah doesn't feel so lonely anymore and is managing much better. She says she doesn't have to bother her son or GP with her health worries so much these days as she has more knowledge about keeping well and knows she can contact her LNN to get more advice and support. Before, when Hannah was on her own and worrying about her health, she would sometimes contact her GP to make an appointment so that she could talk about her concerns.

Hannah recently had some official forms to fill in. Rather than call an impersonal helpline that would keep her waiting indefinitely she called her LNN to get help and they were able to assist her and complete the form with Hannah over the phone. Hannah feels much more able to deal with these things now that she can access help she trusts.

Hannah's son is much happier and isn't feeling so stressed about his Mum's health and care. He's seen a big improvement in his Mum's wellbeing since she joined her local LNN and feels reassured that she is being cared for. He can also contact the LNN if he has any concerns about his Mum and knows that these issues will be followed up.

"I know that they will say to me, or they will say to their friends, at least we don't have to worry about mum, you know for this and this and this because they've got this wonderful organisation [in name] and I think that's been a great help ..." (NN staff member)

d.   What Hannah's story tells us

Hannah's health and wellbeing is adversely affected by frailty and bereavement, and she is becoming increasingly lonely and socially isolated. **Without the NN's intervention it is likely that Hannah's circumstances would have deteriorated**. Hannah's story demonstrates the importance of the work that LNNs do around **primary prevention** and shows how this activity contributes to other outcomes. Increasing social contact and connectedness, improving mental health and wellbeing, and promoting independence are key to developing the basis from which other outcomes occur. This foundation offers opportunities for secondary prevention when

necessary, and as appropriate, supporting better management of long-term conditions which in turn can help **delay** deterioration. By supporting people in this way LNNs can help to **reduce** the burden on families and relieve pressure on acute services.

Some of the benefits of LNNs' work can be valued by looking at the costs of loneliness:

- **Severe loneliness** adversely effects health[7] [8] and **the negative impact on each afflicted person is estimated to total around £9,900 per year** with the greatest impact on wellbeing (£9,537)[9].

- Another estimate[10] of the impact on health care costs suggests **that an individual aged of over sixty-five who feels lonely most of the time could require £6,000 in additional healthcare costs** (including GP visits, hospital admissions, emergency services and other types of outpatient care including treatment for depression, treatment for coronary heart disease, treatment for stroke and services and support for people living with dementia) **over 10 years, averaging at £600 per year** (2015 prices). This amounts to £672 in 2019 prices. This review and modelling of loneliness studies suggests that majority of savings (59 per cent) are due to the avoidance of unplanned hospital admissions, with further substantive savings (16 per cent) from the avoidance of excess GP consultations. Most of the remaining costs averted (22 per cent) are accounted for in the delay in the use of dementia services.

It is probable that these assessments are conservative and further research is needed to improve estimates of health impacts[11]. This vignette and the figures used are indicative and only cover certain aspects of LNN work, meaning there are likely to be other benefits and cost savings than those identified in Hannah's example.

4.2. Vignette 2: Gordon

Gordon is seventy-three. He lives with his wife Anne and has two grown up children and five grandchildren who live in Scotland and the north-east. **Gordon suffers with depression and over the last year has experienced worsening problems with his memory**. Gordon has not been going out much or enjoying his usual activities. Recently, Gordon was **diagnosed with early-stage dementia and his mental health problems deteriorated**. Anne is finding caring for Gordon more difficult and is struggling to give Gordon the support he needs. She contacted the memory support service in Leeds and was assisted by a memory support worker who referred Gordon to his local LNN.

Since joining the LNN Gordon has been able to enjoy some social activities. Both Gordon and his wife have benefited from having more information and advice and support. Anne is feeling more positive about caring for Gordon and has seen a big improvement in his mood and outlook. Having help from the local LNN means that she

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[7] Courtin, E, and Knapp, M (2017) Social isolation, loneliness and health in old age: a scoping review. *Health and Social Care in the Community* 25 (3), 799–812

[8] Lee S L, Pearce E, Ajnakina O, Johnson S, Lewis G, Mann F, Pitman A, Solmi F, Sommerland A, Steptoe A, Tymoszuk U and Lewis G (2020) The association between loneliness and depressive symptoms among adults aged 50 years and older: a 12-year population-based cohort study. *The Lancet Psychiatry*, 8 (1), 48-5.

[9] Peytrignet, S, Garforth-Bles, S and Keohane, K (2020) *Loneliness monetisation report: Analysis for the Department for Digital, Culture, Media & Sport*, Simetrica Jacobs

[10] McDaid, D., Park, A.-L. & Fernandez, J.-L. 2016. Reconnections Evaluation Interim Report, London, Social Finance. Also see McDaid, D, Bauer, A and Park, A (2017) *Making the case for investing in actions to prevent and/or tackle loneliness: a systematic review*. Briefing paper. London School of Economics. Personal Social Services Research Unit

[11] Peytrignet, S, Garforth-Bles, S and Keohane, K (2020) *Loneliness monetisation report: Analysis for the Department for Digital, Culture, Media & Sport*, Simetrica Jacobs

can take a break from time to time too. Gordon's son and daughter were worried about how their mum would cope with their dad's illness. Since the LNN's involvement the situation has improved, and they feel much less worried.

a. Prevent

On meeting Gordon and Anne, the memory support worker was able to refer Gordon to his local LNN. Part of Gordon's problem was a lack of social interaction and support which was making him feel depressed.

> "it's people that are lonely, they're isolated, they're not getting out much, the purpose behind a referral with their consent is to expand their social networks, so they've got additional support in the community and also to give them extra mental and cognitive stimulation. So it's very much around social support." (Memory support worker)

The LNN runs activities including a lunch club and an arts and craft club that Gordon attends. With support Gordon enjoys getting out and taking part in activities. Having some social interaction benefits his mental wellbeing as he isn't stuck at home all the time. Some activities incorporate elements of reminiscence and talking about the past. Gordon likes reminiscing about his life and past events and this mental stimulation helps with his memory loss.

> "And then a few weeks ago we talked about the cinema in Leeds, we have talked about people's pets, and they can bring photos as well…. They are sharing parts of their life and it's really lovely and it's really reciprocal…. it brings up happy memories, you know, I think it connects people, it brings a sense of connection. [It] also gets the mind working as well." (NN staff)

Gordon and Anne are now looking forward to going on some of the upcoming trips that the LNN is arranging. Going on an organised trip with people they know feels less daunting and means that they can start to enjoy activities together again, something which they haven't been doing so much lately.

b. Delay

When Gordon was referred to the memory support worker, she told him and Anne about events that their local LNN ran on dementia. Gordon and Anne went along to an event to find out more. They were able to get advice and speak to a range of healthcare professionals who identified avenues for support that could help. The event was informal and friendly, enabling Anne and Gordon to talk openly about issues with health professionals and LNN staff and volunteers.

Gordon and Anne also go along to the memory support group and the carers support group run by their local LNN that members, family, and carers can attend together. The groups are a useful source of information and advice and provide help with coping strategies. Meeting people in a similar situation sharing experiences and having peer support has made a big difference to them both.

> ".. the importance of peer support, people that's you know, got similar lived experience of certain conditions whatever those conditions are and having less, less reliance I suppose on a health and care system and more of a nudge towards kind of peer support and kind of community and community connections really." (NN stakeholder)

c. *Reduce*

The support Gordon and Anne get from their LNN has not only benefited Gordon but has also helped Anne with caring for him and reduced the stress she was feeling about the situation. She knows a lot more about Gordon's condition and has information about additional help and support. She can discuss issues with people at the support groups or can contact people at the LNN if she has any concerns.

When Gordon attends the lunch club or the craft club, Anne gets some time to herself and can do the shopping or go out with friends. Some of the LNN members at the carers club have befrienders who visit once a week which helps to give their carers a bit of respite and this is something that might help Anne and Gordon too.

> *"And another aspect can be where somebody has got dementia or disabilities and their partner is a carer, actually go in and spending an hour or so just to chat with the member, actually gives a respite to the person who is a carer for them." (NN volunteer)*

d. *What Gordon's story tells us*

Gordon's membership of his local LNN has not only **improved his social connections and wellbeing** but has **had a wider impact on his family, reducing the burden and stress on his wife** and providing a sense of reassurance for his son and daughter who live further away. They were really worried about how their Mum would cope with things but are much happier now that their parents are being supported.

Supporting members and their carers together is important. Involvement in the LNN not only enables Gordon to socialise and remain as independent and healthy as possible but it helps Anne to make time for herself, so she feels better able to **cope with her caring role**. Through their local LNN Gordon and Anne have **access to information and peer support which will reduce their reliance on the health and social care system,** now and in the future.

Some of the benefits of LNNs work can be valued by looking at the costs of dementia:

- The Alzheimer's Society estimates that in the UK **the average annual cost per person with dementia works out at £32,250**. Around two-thirds of this cost is met by people with dementia and their families, either in unpaid care or in paying for private social care. Due to the complexity of **dementia care costs are on average 15 per cent more than standard social care**, with some costs up to 40 per cent higher[12].

- Other estimates suggest that the **average annual costs to health and social care of mild, moderate and severe dementia are £24,400, £27,450 and £46,050, respectively** at 2015 prices[13].

- Dementia Memory Services have been estimated to have an average annual cost per client of £1,325[14].

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[12] How much does dementia care cost? | Alzheimer's Society (alzheimers.org.uk)
[13] Wittenberg, R., Knapp, M., Hu, B., Comas-Herrera, A., King, D., Rehill, A., Shi, C., Banerjee, S., Patel, A., Jagger, C. & Kingston, A. (2018) The costs of dementia in England, Research Article, Geriatric Psychiatry, DOI: 10.1002/gps.5113.
[14] Unit Costs of Health and Social Care 2020 (pssru.ac.uk)

- A review of **supporting caregivers** suggests that it **is an effective strategy which often improves the wellbeing of the carer and the care recipient** and results in additional benefits for society[15].

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[15] Vandepitte, Sophie et al. 'Effectiveness of Supporting Informal Caregivers of People with Dementia: A Systematic Review of Randomized and Non-Randomized Controlled Trials'. 1 Jan. 2016: 929 – 965.

5

Conclusion and recommendations

This report has explored the population health profile of older people who access community-based support through the Leeds Neighbourhood Networks (LNN) and examined the extent to which they make use of various health and care system resources. Although the analysis is based on a small pilot study using Leeds Data Model (LDM) data and two case study vignettes, the report has provided some novel insights into LNN members' health status, their engagement with the health and care system, and the likely costs and benefits. These findings have important implications for how we understand the value for money of investment in community-based models of support such as the LNN.

5.1. Key Findings

The LDM pilot confirms what we have previously reported about the characteristics of LNN members: they tend to be **older**, are **more likely to be female**, and they cater for a **higher proportion of people from White ethnic backgrounds**. It also indicates that the LNN caters for older people from a cross-section of economic backgrounds, including people in the poorest and wealthiest communities.

In terms of population health, the LDM analysis supports findings from previous LNN evaluation reports about how much of the LNNs work is **targeted at prevention for older people experiencing the onset of LTCs and/or mild frailty.** In many cases these are people whose health and care needs can be met in non-clinical settings, and community-based organisations such as the **LNNs can contribute to delaying the onset in severity and complexity, potentially reducing the need for acute care**.

The LDM data also shows that **LNNs do also support a small number of members with multiple LTCs and more severe frailty**. For these older people support from an LNNs complements and supplements the clinical care they receive. Given that growing the number of older people with more severe frailty accessing LNNs is a key ambition for the health and care system over the next few years, this evidence suggests that LNNs do have capacity to support these individuals if appropriately resourced to do so.

The data on health and care costs and episodes is more complicated to interpret at least in part because the first 12 months of COVID-19 pandemic is covered within the data. Overall, the data illustrates a **'steady state' for the LNN members covered**: the overall number and cost of the health and care episodes remained relatively static between 2018/19 and 2020/21, with a very small reduction recorded. Whilst it is not possible to determine the extent to which this reduction is linked to LNN engagement

with, it is positive sign that they have not increased at all. This supports the wider evaluation finding that **LNN membership can help limit deterioration in functional ability for older people** who my otherwise have experienced a decline.

The costed vignettes demonstrate how **LNN membership can be associated with real financial benefits for the health and social care system**. Preventing loneliness for one older person such as Hannah can be worth almost £10,000 in terms of individual wellbeing benefits and save almost £6,000 in additional healthcare costs over a 10-year period. Supporting dementia sufferers and their carers like Gordon can also confer a wide range of financial benefits. Dementia care is costly - the average annual costs to health and social care of dementia are between £24,400 (mild) and £46,050 (severe) – so the work LNNs do delay the onset in severity can be hugely beneficial.

5.2. Recommendations for future evaluation

The pilot analysis presented in this report demonstrates how the value for money of health and care system investment in the LNNs could be monitored and evaluated using data from the LDM alongside other sources of evidence. The following recommendations have been produced to aid health and social care commissioners and data analysts in Leeds (and other areas with a similar data infrastructure) undertake more extensive evaluation in the future. It is important to note that data from the LDM about LNN members should not be analysed in isolation. Qualitative research and case studies provide important contextual evidence that should be used to interpret quantitative insights.

a. Make collecting NHS numbers routine practice for all LNNs

If each LNN collected NHS numbers from all of their members on a routine basis (i.e., upon first joining) it would enable this type of analysis to be replicated for the LNN as a whole. To enable NHS numbers to be linked to the LDM a common approach to gaining consent would need to be developed and agreed with the LDM team and other key Information Governance stakeholders.

b. Develop a routine 'minimum data set' for LNNs that can be linked to LDM data

In conjunction with NHS numbers a routine 'minimum data set' should be developed that stipulates the information LNNs are expected record on each of their members. This should be limited to data that is not available in the LDM but would support evaluation. It should include, although not be limited to: month and year of first engagement with the LNN, frequency of engagement (weekly, monthly, less often etc), activities accessed (using a common typology – see previous evaluation reports for an example), and any volunteering involvement. These fields should be non-disclosive to preserve anonymity at all times.

c. Undertake regular descriptive analysis of LDM data

Implementing recommendation A would enable regular analysis of LDM data for LNN members to be undertaken. This could replicate the analysis presented in this report but also enhance it by presenting data for the LNN as a whole to better understand their contribution to population health priorities and track how this changes over time. Implementing recommendation B would enable more granular analysis to be undertaken, for example comparing the profiles of LNN members with different health states, accessing different types of activities and with different start dates.

d. *Undertake more complex statistical analysis*

The implementation of recommendations A and B would also provide a platform for more complex statistical analysis to be undertaken. For example, exploring individual-level longitudinal changes in population health measures and health and care episodes and costs. Exploring how LNN members change over time compared a statistically matched comparison group, or the wider Leeds population aged over 64, would significantly enhance understanding of the outcomes, impacts and value for money of investment in the LNN.

We recognise there will be resource implications associated with implementing these recommendations which will need to be weighed against other competing analytical priorities within the health and care system. In this context, it is worth noting that these recommendations could also be applied to other types of VCSE organisations whose work is commissioned by or supports the objectives of the health and care system.

Appendix 1: Leeds Data Model Data Overview

A1. Demographic Characteristics

a. Age

Age Category	LNN Cohort		Leeds 64+ Population	
	Count	Per cent	Count	Per cent
60 to 64	1	0.7	8,274	5.8
65 to 69	5	3.4	35,862	25.0
70 to 74	23	15.5	34,766	24.2
75 to 79	16	10.8	26,699	18.6
80 to 84	38	25.7	18,163	12.7
85 to 89	34	23.0	12,367	8.6
90 to 94	22	14.9	5,570	3.9
95+	9	6.1	1,717	1.2
Total	**148**		**143,418**	

b. Gender

Gender	LNN Cohort		Leeds 64+ Population	
	Count	Per cent	Count	Per cent
Female	111	75.0	77,140	53.8
Male	37	25.0	66,278	46.2
Total	**148**		**143,418**	

c. Ethnicity

Ethnicity	LNN Cohort		Leeds 64+ Population	
	Count	Per cent	Count	Per cent
White Background	147	99.3	130,668	91.1
Asian Background	1	0.7	4,838	3.4
Unknown	0	0.0	4,130	2.9
Black Background	0	0.0	1,836	1.3
Chinese & Other Background	0	0.0	1,185	0.8
Mixed Background	0	0.0	761	0.5
Total	**148**		**143,418**	

d. Indices of Multiple Deprivation

IMD Decile	LNN Cohort		Leeds 64+ Population	
	Count	Per cent	Count	Per cent
1	9	6.1	22,212	15.5
2	11	7.4	10,087	7.0
3	0	0.0	10,519	7.3
4	0	0.0	5,058	3.5
5	20	13.5	12,205	8.5
6	2	1.4	12,710	8.9
7	22	14.9	18,564	12.9
8	6	4.1	14,082	9.8
9	28	18.9	15,955	11.1
10	48	32.4	13,753	9.6
-	2	1.4	8,273	5.8
Total	**148**		**143,418**	

A2. Health status

a. Electronic Frailty Index Score

No of frailties	LNN Cohort		Leeds 64+ Population	
	Count	Per cent	Count	Per cent
0	3	2.0	9,236	6.4
1	11	7.4	13,723	9.6
2	13	8.8	16,862	11.8
3	17	11.5	17,740	12.4
4	21	14.2	16,475	11.5
5	19	12.8	14,368	10.0
6	17	11.5	12,050	8.4
7	18	12.2	9,785	6.8
8	7	4.7	7,635	5.3
9	4	2.7	6,069	4.2
10	4	2.7	4,770	3.3
11	2	1.4	3,683	2.6
12	2	1.4	2,895	2.0
13	5	3.4	2,341	1.6
14	0	0.0	1,751	1.2
15	2	1.4	1,281	0.9
16	2	1.4	907	0.6
17	0	0.0	666	0.5
18	0	0.0	449	0.3
19	1	0.7	309	0.2
20	0	0.0	167	0.1
21	0	0.0	127	0.1
22	0	0.0	63	0.0
23	0	0.0	31	0.0
24	0	0.0	17	0.0
25	0	0.0	13	0.0
26	0	0.0	4	0.0
27	0	0.0	1	0.0
Total	**148**		**143,418**	

b. Number of recorded long-term health conditions (LTCs)

No of LTCs	LNN Cohort		Leeds 64+ Population	
	Count	Per cent	Count	Per cent
0	12	8.1	22,305	15.6
1	40	27.0	31,058	21.7
2	28	18.9	30,570	21.3
3	28	18.9	23,908	16.7
4	16	10.8	15,905	11.1
5	16	10.8	9,676	6.7
6	5	3.4	5,262	3.7
7	1	0.7	2,619	1.8
8	1	0.7	1,316	0.9
9	1	0.7	521	0.4
10	0	0.0	211	0.1
11	0	0.0	47	0.0
12	0	0.0	17	0.0
13	0	0.0	2	0.0
14	0	0.0	1	0.0
Total	**148**		**143,418**	

c. Public Health Management (PHM) cohort

PHM Cohort	LNN Cohort		Leeds 64+ Population	
	Count	Per cent	Count	Per cent
Healthy	12	8.1	22,256	15.5
LTC	113	76.4	94,674	66.0
Frailty	20	13.5	23,756	16.6
End of Life	3	2.0	2,732	1.9
Total	**148**		**143,418**	

d. Complexity of health and care needs

Complexity	LNN Cohort		Leeds 64+ Population	
	Count	Per cent	Count	Per cent
Low complexity	52	35.1	9996	7.0
Middle complexity	88	59.5	80,059	55.8
High complexity	8	5.4	53,363	37.2
Total	**148**		**143,418**	

A3. Health and care usage and costs for LNN cohort

	2018/19	2019/20	2020/21
Total:			
Mean cost	£1,898.71	£1,700.80	£1,735.92
Mean activity	19.05	17.53	16.91
GP:			
Mean cost	£180.21	£172.46	£105.30
Mean activity	10.45	9.75	7.60
Urgent care:			
Mean cost	£79.94	£79.38	£80.37
Mean activity	0.89	0.79	0.74
Community care:			
Mean cost	£266.26	£147.98	£206.00
Mean activity	2.45	2.33	5.53
Outpatient:			
Mean cost	£404.60	£399.91	£193.09
Mean activity	4.06	3.91	2.51
All inpatient:			
Mean cost	£967.70	£901.07	£1,151.16
Mean activity	0.72	0.57	0.45
Non-elective inpatient:			
Mean cost	£459.78	£444.10	£976.66
Mean activity	0.33	0.27	0.28

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