Your healthwatch Leeds

Changing Home Care Engagement Panel Report

People in receipt of home care and their family members share their expertise.

August to October 2022

Name:

My home care journey

Your name is so that we can check everyone has completed the form … ntify you in any
with Leeds City Council. Please answer these questions … etur … t envelope b
you do not have a current experience of home care, p

1. What made you decide you or your loved one n ded extra support?

2. Who c … to arr

4. If y … somet … how

5. Have you or the person in receipt of care felt included in the decisions made about the care?

Do you have access to the care plan?

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Summary

Introduction

Leeds City Council is in the process of transforming home care services across the city. They wanted to hear from people who use home care and their family carers. We set up a virtual Changing Home Care Engagement Panel comprised of people who had recent experience of home care services. The aim of the panel was to bring the voice and expertise of those with lived experience to inform the transformation of home care services across the city towards a Community Health and Wellbeing Service. What is evident from feedback gained throughout this project is that key to the successful recommissioning of home care is also a need for improvement in the current Leeds City Council assessment process, as the two go hand in hand.

We opted for a home-based virtual engagement model to ensure that the meetings were as accessible as possible, particularly for people who would have needed assistance to attend an in-person meeting. We offered support in the form of trained 'buddies' to enable panel members to engage virtually from home. Buddies were able to provide equipment, Wi-Fi, and support to access virtual meetings for those who needed it.

We recruited 21 panel members, a mixture of those who used home care services and their family carers. Panel members were invited to a series of four virtual panel meetings which took place during September and October 2022. During the meetings, they were given the opportunity to share their views, experiences, and ideas on a variety of themes relating to how home care services may look in the future.

It should be noted that the panel comprised only a small sample of people in receipt of home care in Leeds and their family carers. As such, it may not truly represent the wider population of people receiving these services.

Key Findings

First contact

Some panel members didn't know where to go when they first needed help. Panel members also talked about the importance of building trust and confidence during that first contact, which could often be a quite scary and difficult process.

Assessment

There were mixed experiences of the assessment process; some panel members thought it was good, whilst others said it was slow and there had been poor communication with Leeds City Council, particularly where social workers changed frequently. Panel members were very clear that it was vital that any assessments and reviews of care should be person-centred. Our conversations with panel members from minority ethnic backgrounds showed that cultural and religious needs were not routinely considered during assessments and that it was often up to the person in receipt of care or their family to be proactive in terms of stating those needs.

Communication needs and preferences

This was a key theme that ran throughout. Not only were there examples of panel members' communication needs not being considered (as required under the Accessible Information Standard), but also due consideration was not always being given as to whether people had digital access. This applied to care plans, records, bills, and feedback and complaints mechanisms. Panel members were clear that having an alternative to digital was essential.

Involvement in care

There was variation in terms of how involved panel members felt they'd been in their care. In some cases, it depended on how proactive the individual had been in terms of making themselves heard. Not everyone said they had been involved in reviews of their care or had access to their care plan. With care records increasingly being kept digitally, some panel members who didn't have digital access felt that they were being excluded.

Personalised care

Panel members wanted flexibility in their care according to their needs which could vary day to day depending on what they were doing. They didn't want their lives to be controlled by the times of the care visits but by what they wanted to do. Younger panel members and those from different ethnic minorities talked about how they hadn't always felt that their needs were catered for in a person-centred way. Panel members said that having a small, consistent team of care workers helped to provide good quality, person-centred care.

Visit times

Panel members told us that care workers didn't always stay for their allocated time meaning that visits sometimes felt rushed and there was not always time to give the right care. There were also issues around care workers turning up early or late and not always notifying people that this was going to happen. Panel members said that they would like to be informed of this. There were also questions about why there are no care visits later than 10 pm to enable people to go out during the evening and to assist those who had care needs during the night. Panel members also said they wanted staff to have paid travel time and time to read their notes before each visit.

Communication

Panel members valued regular communication with care staff and managers, both on a day-to-day basis about practicalities, but also regular opportunities to check how things are going and to review their care. They said that they wanted clear information from the outset about what a care agency could and couldn't do as well as clear information about how to raise a concern. They also wanted access to rotas, and for staff to wear name badges so that they knew who was going to care for them.

Emotional and social support

Panel members wanted more social support built into their care, both in terms of companionship and support to get out into the community. Some panel members who were not able to get out without assistance were left feeling very isolated.

Health and care services working together

Panel members shared mixed experiences of how care workers had worked with other health professionals, most notably the district nurses. Where it had worked well, panel members reported there had been good communication between the care workers, the nurse, and the person in receipt of care. Some panel members didn't want care workers to carry out any of the current district nurse duties because they saw no need for it. Others said they would be okay with it if they had confidence in the quality of care provided by the care agency and the care workers had appropriate training. Having a consistent care team was also a factor in terms of how much some panel members said they would trust care workers to take on additional tasks.

Billing

Panel members said they wanted to receive regular bills that were itemised and timely. Billing delays and large arrears have caused stress and anxiety and made it difficult to check back on care actually received. They wanted bills in an accessible format (by post for those not online) and for it to be easier to resolve issues and suggested a dedicated billing helpline.

Pay and conditions

Panel members agreed that treating staff well, providing better pay and conditions, valuing them, and providing good training was absolutely integral to high quality as well as helping with staff recruitment and retention.

Training

Panel members wanted staff to be well-trained and have progression routes to make the profession attractive. They were not always happy with how training was delivered, saying that permission was not always sought with the client for on-the-job training and that it could feel intrusive. They wanted to see more training that involved people with lived experience.

Complaints and feedback

Panel members told us that complaints processes weren’t always clear or accessible. Whilst some said their care provider regularly sought feedback, others expressed concerns about making a complaint for fear of it compromising their care. Most panel members weren’t aware of the annual Leeds City Council survey but said that they would be happy to input into the design of any future survey if they felt that it would be taken seriously, and change would happen as a result. It was also important for panel members to be kept informed of any changes that happened as a result of their feedback.

Key recommendations / messages

For more detail on each of these recommendations, please go to page 77 of this report.

First contact

1. Raise awareness of home care services and how to access them so that people know where to get help when needed.

2. Make sure that people's first contact with Leeds City Council Adult Social Care is a good experience.

Assessment

3. Ensure that people and their families where appropriate are always actively involved in a comprehensive assessment and ongoing regular reviews of their needs and wishes.

4. Ensure that social work teams and home care agencies are routinely considering social and emotional needs alongside physical needs when carrying out assessments. These should always be reflected in care plans.

5. People should proactively be asked questions about their cultural and religious preferences and needs during any assessments and reviews.

6. Ensure that providers are following their obligations under the Accessible Information Standard.

7. Ensure that providers are also asking whether people want to receive information digitally and ensure that information is provided in a different format if people don't have sufficient digital access.

8. For self-funders who don't go through the Leeds City Council assessment process, there should be a clear accessible statement of what they can expect as a citizen of Leeds from any newly commissioned service.

Involvement in care

9. People should be involved in their own care on an ongoing basis including being involved in regular reviews of their care. Care plans should always be proactively provided in a format that is accessible to the individual (not assuming that a person has digital access).

Personalised care

10. Be aware of what ‘personalised care’ means in practice for people in receipt of care and ensure that the necessary things are in place to deliver it.

Visit times

11. Ensure that providers have flexibility around visit times according to people’s changing needs and that there is good communication with people when visit times have to change.

Communication

12. Make sure that providers routinely share relevant and clear information with people who use their services, to help them feel in control. As well as day-to-day information, this includes information such as the role and responsibilities of the care agency, rotas, and any changes in staffing and service provision.

13. Introduce a requirement for all care workers to wear name badges.

Emotional and social support

14. Make social interaction and supported access to the local community an integral part of any proposed community health and wellbeing service, where there are individually identified needs and outcomes.

15. Review the current availability of emotional and social support and companionship in all areas of Leeds for people who find it difficult to leave their homes without assistance. Where such support is not available, consider how these gaps will be filled.

Health and care services working together

16. If more co-ordinated working between health and care professionals is considered in any future plans, the following key factors should be in place to ensure that people in receipt of care get a good experience:
    - Good ongoing communication both between professionals and with the person in receipt of care.
    - Consistency and continuity of staff in care teams.
    - Relevant training of any staff taking on new roles.

Billing

17. Improve the current billing system by making sure that people get regular bills on at least a monthly basis in a format that is accessible to them.

18. Have a single point of contact for billing enquiries.

Pay and conditions

19. Improve the pay, conditions and career structure of care staff to attract and retain more people in the role. This includes things such as providing good training, supervision and support, manageable workloads and progression routes.

Training

20. Review training for all care staff and identify clear progression routes into the health and care sector.

21. Review the appropriateness of on-the-job and online training for practical skills.

22. Involve people with lived experience of home care in training.

23. Consider using the ideas generated by the ‘ideal care worker’ activity (session 2) in training to stimulate discussion about the skills, values and behaviours that are important in care work.

Complaints and feedback

24. Ensure that providers and / or Leeds City Council is asking people in receipt of home care and their family members for their feedback about the quality of the care, on at least an annual basis.

25. Monitor that care companies have clear accessible ways of dealing with complaints and concerns that are proactively shared with people in receipt of home care services and their family members. Also, ensure that care companies are routinely making people aware that they can also raise concerns directly with Leeds City Council.

Future involvement of people with lived experience.

26. Involve people in receipt of home care and their family carers in future opportunities to shape services, systems, communications and contract compliance, as well as consider their beneficial role in training.

Background

Leeds City Council is currently undertaking an ambitious programme of transforming home care services across the city towards a Community Health and Wellbeing Service. To ensure that the future provision for home care reflects the needs and views of people accessing home care, Leeds City Council wants people with an interest in home care to be at the heart of the process. To this end, they commissioned Healthwatch Leeds as an independent and impartial partner to recruit and support people to be part of a 'Changing Home Care Engagement panel' and undertake engagement activities on their behalf.

The aim of the panel was to support the transformation of home care and contribute to the following outcomes:

- A fit-for-purpose Community Health and Well Being Service that meets the needs of people living in Leeds.
- People will feel like they have been respected partners throughout this process and that their views have been taken into account.

The requirements from Leeds City Council were that the Changing Home Care Engagement Panel should:

- Reflect on the diversity of the city and be open to anyone who has recent experience of home care, whether they are funded by the Council or on a direct payment, and those who may need to use home care services in the future. It could also include family carers of people who use or have used home care services in the recent past.
- Have a minimum of 15 active members.
- Be diverse and inclusive of those with protected characteristics. In particular, it should include people from different areas of Leeds and people from minority ethnic communities.

What we did

Recruitment

In total, we recruited 21 panel members between August and September 2022. Not all of them were able to come to all the meetings, but for continuity, we asked people to commit to attending at least two of them. One panel member who was working opted to contribute outside of the meetings by answering the questions that we sent them in the post. 4 panel members out of the project at various points throughout the process due to their personal circumstances.

Of the 21 panel members, 12 were currently in receipt of home care. The remaining 9 were family carers of someone currently in receipt of home care, or who had been in the recent past. 7 panel members required the support of a buddy (see below). A third (7) of the panel members were from a minority ethnic community.

The panel also included both working-age and older people, and people with visual impairments, hearing impairments, long-term conditions and disabilities. Through initial discussions with all panel members, before the meetings commenced, we were able to find ways of making adjustments to make sure that meetings were accessible, and that everyone could participate fully in a way they were comfortable with.

We knew from previous experience that many people in receipt of home care would find it difficult to get out of the house to attend face-to-face meetings without support from carers. For this reason, we opted for a home-based virtual engagement model whereby panel members, if they needed it, were supported to engage virtually from home. Support was provided by a team of buddies comprising staff members and experienced volunteers, all of whom were trained in Safeguarding Adults and thoroughly briefed on their role before the panel meetings. All buddies also had a valid enhanced DBS check.

For more information about how we recruited panel members and for more details about the role of the buddies, see Appendix 1.

Conducting the panel meetings

The panel meetings were planned jointly between Leeds City Council and Healthwatch Leeds, and were held virtually via Zoom on the following dates:

Date and time	Content of meeting
Monday 26th September 2022 10 am to 11.30 am	Introducing the project, focusing on people's understanding of home care services as well as their current and past experiences of it.
Monday 3rd October 2022 2 pm to 3.30 pm	"My ideal service" – including "My ideal care worker", "My ideal day supported by care workers" and "My ideal home care agency".
Monday 10th October 2022 10 am to 11.30 am	How Leeds City Council works with care providers to ensure quality.
Monday 24th October 2022 2 pm to 3.30 pm	Proposals for the future

Meetings were facilitated by two members of Healthwatch Leeds staff and a note-taker. They were interactive and contained a mix of whole group, small group and individual activities to encourage discussion about different aspects of future home care. Meetings were also attended by representatives from Leeds City Council Adults and Health Commissioning Team.

Individual phone calls

In addition to the group sessions, we also made individual phone calls to six panel members who were from Black and Minority Ethnic communities to ask them about their views and experiences of how home care services could be more culturally sensitive.

What we found

Introduction

We have written up the main findings of each of the four sessions with panel members as well as the individual phone conversations about culturally sensitive services. In addition to what was discussed in the sessions, we have also included any comments we received from panel members via buddies, individual phone conversations or by email or post. To make the report more cohesive, where comments made in a particular session related more to the themes of a different session, we have moved them into the write-up of that session.

Session 1: Current understanding of home care and journey so far

Date: Monday 26th September 2022 10 am to 11.30 am
Number who committed to attend the session: 14.
Number actually attending the session: 12.
Apologies: 2

Activity 1 – What does home care mean to me?

Panel members were asked to write words and phrases on a whiteboard to capture what home care meant to them. The image on the next page captures people's contributions.

What does home care mean to me?

- Getting looked after
- Carers not valued, big turnover of staff
- Valuable, important, sociable
- Person-centred approach, personal 1:1 care
- Individualised support, encouragement
- A change of face, having social interaction
- Important that they understand my son's communication which takes time.
- Knowing mum is eating regularly and not forgetting her personal care
- Helps me to live my life and gets me out of bed
- Assistance with the tasks of normal daily living
- No support for care staff, underpaid
- Don't stay for the full half hour. They go after 15 mins
- Having to go to bed too early which restricts my son's life
- Good company. They bring outdoors in.
- I think home care is good. We go out every Monday, Weds and Friday.
- A chance to step back from caring responsibilities
- Enabling people to stay at home instead of going into a care home.
- Knowledge of person's conditions
- Staff retention. Unable to build relationship and unfamiliar
- Undervalued, rushed carers, poorly paid

Activity 2: Home care journey

Prior to the session, panel members were sent a worksheet (see Appendix 2) to complete about their home care journey. It asked a series of questions which are discussed in more detail below. 11 panel members completed the worksheet and returned it to us. During the session, panel members were split into three small, facilitated groups to have a discussion in more depth about four of the questions from the worksheet (questions 1, 4, 5 and 6). During the discussion, people were asked to think about what went well, what didn't go so well, how their wishes and needs were / weren't taken into consideration and any barriers they might have experienced (for example relating to culture, language, age, lifestyle, etc.)

1. Before receiving home care what made you or your loved one decide you needed extra support?

There were a variety of responses to this question:

- Some panel members had needed support since birth because of their disability or health condition, whilst others had become disabled following an accident in later life.
- Some had said that they had recognised that they needed extra support because of deterioration of a health condition or decline in mobility.
- Some had said that family members were no longer able to provide the care that was needed.
- In some cases, family members had been the ones to recognise that more support was needed (for example where the person had dementia).

"I need extra help with technology and support out in the community."

"I was approximately 30 when my mum became ill, [so she] was no longer able to care for me."

2. Who did you speak to, to arrange the care?

Around half of the panel members said that their care had been arranged when they or their relative was in hospital, either by an occupational therapist, social worker or following discharge to the reablement service. Others said they had spoken to a social worker to arrange the care. There were a couple of panel members who had arranged the care via other routes such as a rehabilitation centre they were staying in, or by going directly to a care agency to set up a private arrangement.

3. How were the care needs assessed?

Panel members said that their care needs had been assessed by the following people:

- Care manager / co-ordinator from a home care company
- Social worker
- Occupational therapist who assessed them during home visits
- Community matron
- Skills reablement team

4. How was the assessment process?

During group discussions in the session, it was apparent that there had been a variety of experience regarding panel members' experience of assessment.

What went well?

In one of the three small groups there was agreement that the process of 'setting up' home care for either themselves or a loved had been an easy process. They felt that agencies had communicated with them, and that they were able to work together to determine what care was best for the individual. There was consensus that if people wanted anything to change, they could request it and changes would generally be made promptly.

> **"It was before Covid, the social worker sorted it all out for me, I have no complaints."**

> **"When mum was financing her own care, it was easy to approach a private agency and make my own arrangements."**

> **"We had a copy of the care plan at home, and we did need to amend it but that was an easy process".**

What didn't go so well?

Feedback from the other two groups as well as feedback received via email and from buddies suggested some panel members' experience of assessment had not been so good. The key themes were around difficulty navigating the process, knowing what options were available or what they were entitled to, and the process being very slow. One panel member said that initially they didn't know where to go, or who to ask for help.

> **"After diagnosis of dementia there was no follow up or anyone to speak to."**

> **"The process is not easy and would prove difficult for someone with no family to check and investigate options provided."**

5 panel members said that trying to get help via Leeds City Council Adult Social Care had been very difficult because it had been slow, and communication had been difficult. One panel member described how they had been told by Leeds City Council that they hadn't received emails resulting in delays in getting their relative's care in place.

“The problems with Leeds Social Services getting and sourcing the care (which was incredible by the way) was horrific particularly when under extreme carer stress. This was caused by the issues I had with social services been passed from pillar to post. I latterly secured Continuing Healthcare funding as [my relative] was so ill which wasn't recognised by Social Services.”

“When mum was in hospital after breaking her hip, I was told that there was “no care” available and that there was a massive waiting list. I wanted to get it sorted so I approached a private agency myself and they had space, but because it was going to be funded by Leeds City Council, we still had to wait our turn as there was a queue of people waiting to be assessed. Result was delay in getting care and mum stuck in hospital until we could get things sorted.”

One panel member described a change in social worker every couple of months which had meant having to explain things again and again resulting in differing interpretations and understanding of individual needs. Another described their experience of losing their social worker once they “perceive you as being settled”. This was problematic when new issues arose meaning that they had to start again with a new social worker who knew none of their history. Others mentioned problems with communication, such as when a change to care was requested and promised but then not implemented.

“Everyone promises, but along the way things slip.”

> **“I wanted to change my visits from four times a day to three times a day, but the social worker said it wasn’t possible but didn’t explain why.”**

During the discussions, one panel member relayed their experience of long hospital stays. They said that they found out during one hospital stay that if they were in hospital for more than 21 days then the contract with their existing care company would cease and they would be at risk of being allocated a different provider once discharged. On that occasion they managed to get their care reinstated with the same care company. However, following their most recent hospital stay, they were no longer able to keep on with their previous care company and was allocated a new one which they said was not as good.

5. Are / were you or the person in receipt of care included in the decisions that are / were made about the care?

> **“It is really important that the family have a big input in the persons care, we know that person better than anyone.”**

The responses from the majority of the completed ‘my home care journey’ worksheets indicated that people felt as though they had generally been involved and included in decisions that were made about their or their relative’s care. However, a couple of people did say that they’d had to be very proactive in terms of making sure that they had been included in decisions. The group discussions during the session gave a more varied picture, with more people saying that they weren’t always involved in decisions about their care.

What went well?

> “They were really good and respectful; I can’t really complain but just frustrating that it was different people and having to explain everything all the time”.

> “The last social worker mum had, we spent a lot of time on the phone, and she wanted to understand my mum and her thoughts… helped us work together”.

> “We initially didn’t agree with the suggested timings for visits, but we worked with the consultant to decide on the best times, and we got what we wanted”

What didn’t go so well?

Some panel members gave examples of when they felt that they hadn’t been involved in decisions about their own care:

> “When I was in hospital, they drew up a care plan that said it involved me and that I’d agreed to the care package, but I’d never agreed to it and it hadn’t involved me.”

> “That’s actually a fraudulent document, I’ve never agreed to anything, and those statements aren’t from me.” [regarding timings in person’s care plan]

Some panel members expressed that as family members, they were not really involved in making decisions about their relative's care.

> **"The care workers think they know what's best for my mum because they look after her."**

> **"My father-in-law was assessed by the consultant, and it was very fast – just didn't get to talk to the home care company before they started visiting".**

One panel member whose child received care talked about the change in how much they were involved once their child reached the age of 18 when as a parent they felt they were no longer involved in decisions about their child's care. This was despite them feeling that their child was not able to make their own decisions.

Some panel members expressed worries about everything going online. Two panel members from one of the small group discussions said they didn't know they could request a paper copy of their care plan. One of them commented that even if they did request it, they were unsure as to whether they would actually receive it.

> **"Care plans are all on apps and phones. My carers have told me that paper plans have been abolished but I'm not good with technology".**

One panel member wasn't even aware that they had a care plan.

> **"I'm not sure if I have a care plan anywhere".**

6. If you had an issue and wanted to change something about the care, what would you do? (If this has happened in the past, what happened and how was it resolved?)

The majority of panel members knew that they could either talk to their care agency or their social worker / Leeds City Council Adult Social Care if they wanted to change something about their care. During the group discussions, panel members shared their views and experiences of raising concerns or making a complaint. There was a general worry amongst panel members about speaking up if they felt like something was really wrong with their care.

> **"We have a fear of speaking out about any problems because we are worried that they will pull out and abandon us, but we need this care (…) they tell us they don't like being criticised and it makes you feel vulnerable".**

One panel member said they had been threatened in the past with having their care taken away. Another said that they had had their complaint "turned around on them" and that the care company had withdrawn their services following a complaint.

> **"[I was told] I couldn't be provided with care anymore because I'd bullied this member of staff, whereas actually I'd just complained… At the time, I didn't have the energy to take it further…It left me feeling really down and I felt I had nowhere else to go."**

A couple of panel members described making a complaint and being told that "no one else has complained", thereby effectively shifting the blame onto the complainant.

Several panel members raised the issue that complaints processes weren't always clear or easy to access, especially for people who aren't online, or who can't easily get to a post box.

7. Do you have access to the care plan?

Just over half of the completed worksheets indicated that panel members had access to their own or their relative's care plan. Two panel members said that they received copies of care plans but noted that they were not always very thorough or up to date regarding their relative's needs. Three panel members (all in receipt of home care themselves) said that they didn't have access to their care plan.

> **"No. The care plan is in [care company]'s office as it's confidential."**
>
> **"No, as it is now on each carer's mobile."**

8. Is the care reviewed at least once a year?

Most panel members said that their or their relative's care was reviewed at least once a year. One panel member said it wasn't and that they thought it was only reviewed if and when they asked for a change. One panel member said the process wasn't clear and another said their care hadn't been reviewed yet but that they'd only been in receipt of care with their present company for around 6 months.

9. Are you or your loved one supported to access the local community?

Around half of the returned worksheets indicated that people weren't supported to access the local community.

> **"I'm not aware of what is available."**

Of those who said they or their relative were supported to go out, comments indicated that this was made possible by a variety of means including support from family, one of the Neighbourhood Networks or from a personal assistant.

> **"Alongside my care I also have a PA that is paid through personal budgets."**

Other themes raised during the session

Timings of visits

One of the recurring themes from this session was the general feeling that visits from care workers often felt rushed and that care workers weren't always there for the full allocated time. Panel members were unhappy with this, because it meant they weren't getting the full amount of time that the care agency was being paid for. Some were also dissatisfied with the amount of care given during that slot due to it being cut short.

> **"I asked whether they could wash my hair and they said, 'We don't have time, we'll do that tomorrow'… but it isn't always the same carer the next day".**

There was some uncertainty amongst panel members about whether travelling time was part of their time allocated for care. Some people said they had been told that this was the case, Leeds City Council confirmed that travel time is included in the fee that care providers are paid and shouldn't be taken out of people's time allocated for care.

> **"They are expected to leave me at 8:30am but are meant to be at their next client at 8:30am so I never get the full time."**

Panel members also said that it was a common experience for care workers to turn up early or late and that if they query it then they are told that there is a "window" 30 minutes either side of their allocated time slot where they have to be in, in case the care workers arrive. Panel members said that often the care workers didn't call to say if they were going to be early or late.

“I’ve come back early from being out with my friends and then they’ve turned up late and haven’t let me know. I could have been out enjoying myself.”

[in the middle of this Changing home care engagement panel session] “The carers have just walked in 45 minutes earlier than they were meant to… they are making me lunch but I’m not ready for it yet”.

One panel member talked about the lack of choice they had about the time they go to bed.

“I was always brought up to be independent as I can but now, I get put to bed at 8pm when there’s still children playing out.”

Quality of care

Panel members were on the whole satisfied with the quality of care but did acknowledge that there was variation depending on individual care workers.

“80-90% of the time the quality is good but they’re working under much worse conditions.”

“There are good carers and those who are not so good. It’s not their fault, they’re out of their depth.”

> **“Some carers are very good and do the job well. Some need to be told and reminded.”**

Staffing

When talking about their experiences of home care, panel members frequently mentioned the following issues relating to staff. These are explored more fully in the notes from session 2:

- High turnover of staff. One panel member talked of having lots of different care workers including trainees who were inexperienced and made her feel vulnerable when they were lifting her in the hoist.
- Poor working conditions - low pay and long hours worked by staff.
- Difficulty communicating with care workers with low levels of English.
- Need for better communication.

> **“It’s not just people coming in and out, but the agencies need to remember they’re coming to do very personal things. We deserve to at least know who is coming to do it”.**

Session 2: My ideal service

Date: Monday 3rd October 2022 2 pm to 3.30 pm
Number who committed to attend the session: 16.
Number actually attending the session: 14.
Apologies: 2

The focus of this session was to encourage panel members to think about what different aspects of a home care service could look like an ideal world. We wanted to get a sense of the things that were most important to them. We asked panel members to think about their culture, religion, age, language, skills, lifestyle, hobbies, and how an ideal service might help them with these different aspects of their lives. We also asked them to think about their own and staff's values, skills, knowledge and experience and how they could contribute to an ideal service.

Activity 1: My ideal care worker

For this activity we showed the outline of a person on a virtual white board and asked panel members to write down what qualities, skills, values, knowledge and experience they thought an ideal care worker should have. You can see people's contributions in the image on the next page.

One thing that was discussed following this activity was how people felt isolated, excluded and worried when care workers spoke to each other in a different language during a care visit. Panel members said that this was becoming more of an issue with the increase in workers coming from overseas to fill the labour shortage.

My ideal care worker

Respect for property and posessions

Empathy and compassion

Not making assumptions about what want might not seem a good idea for them but does for me

Good communicator, respectable.

Well briefed on the individual and routine. Person centred care

Deliver the tailored centred care thats promised

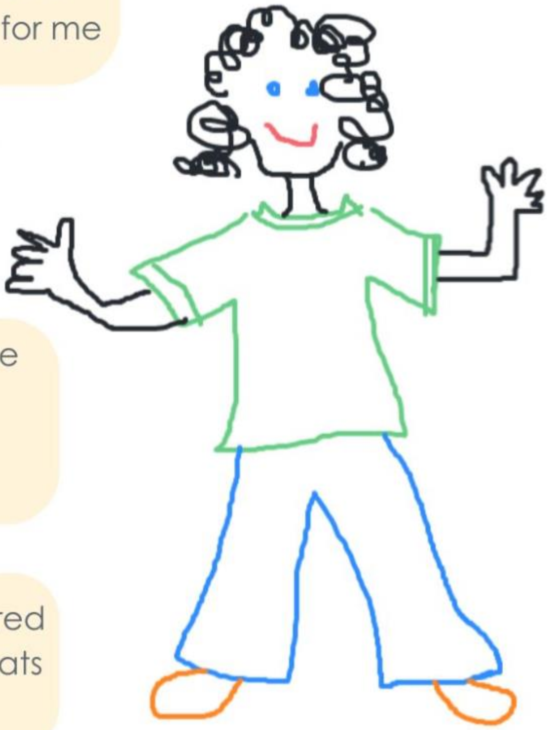
Happy, smiley, chatty, interesting, kind, well trained, good uns.

Take interest in what the person wants to do

Know what they are doing

Kind, happy, friendly, non judgemental, professional, confidentiality.

Name badges



Have respect and be culturally and religiously aware.

Be punctual and have enough time to do job and read notes.

Understanding needs and dignity

Being able to have a conversation

Listen to what you are saying to them about care

Trained to a level in basic skills like moving and handling

Have an interest in caring for people

Speak English that my elderly mum can understand

Carers uniform should identify the company

Be the right person for the job

Well trained, well motivated, respected and paid well. Decent working conditions.

Not complain about their jobs. I know it's hard but I don't need to hear this, I like them and it bothers me that they feel like this.

Activity 2: My ideal care agency

In small groups, we asked panel members to think about what would make a good care agency by asking them the questions below. We suggested thinking about things like the values of the care agency, how they operate, and what they do.

1. How would you like the care agency to contact you?

> **“There needs to be two-way communication, get everyone on board.”**

A recurring theme from this discussion was the importance of good communication in terms of building good relationships between:

- Staff and the people in receipt of home care.
- Staff and relatives of people in receipt of home care where they are involved in their care and there is consent in place to share information.
- Frontline care staff and the office staff and managers.

One panel member gave the example of when care workers are running late, saying they should call the office who should then call the client to let them know. Or alternatively, the care worker should call the client directly because the office doesn’t always answer. One panel member mentioned that this process already happens and that it helps them to be understanding of the situation.

> **“I’ve had it before where carers haven’t turned up and I’ve been ringing the office for 20 minutes to find out what’s wrong and no-one answers, no-one called me. When the carers finally arrive 20 minutes late, all they say is “sorry I’m late.”**

> **“Its common courtesy to let people know if you are going to be late.”**

Someone suggested that in an ideal world, the care agency would ring every so often to see how things were going. A couple of panel members mentioned that they currently have regular meetings / calls to discuss this and that this works well for them. One panel member mentioned that sometimes their care co-ordinator will come and do personal care (to cover sickness or holidays) which gives them the opportunity to raise any issues. They said they would like the opportunity for conversations like this to happen more often.

> **“The co-ordinators are helpful and point us in the right direction if we need further support”.**

Two relatives described the good communication they had with their care agency:

> **“I had a good relationship with one agency, the care worker would call after each visit to let me know if I needed to order anything, or for example make a GP appointment for my mum”.**

> **“They had an app on their phone, where they would detail what they were doing and that would get sent straight to us with all details of what went on each visit.”**

Someone made the following suggestion to improve the consistency of communication between relatives and care staff.

> **“Currently I leave notes about my Mum for the care staff – ideally would prefer to communicate via email or it would be good if both care staff and loved ones could communicate via the ‘booklet’ carers fill in after they visit”.**

2. What kind of information would you want from the care agency?

Panel members made the following suggestions:

- Information about the company through the post on a quarterly basis.
- Clear accessible information in different formats (i.e., not just a weblink) about how to raise a concern or put in a complaint both to the care company and to Leeds City Council.
- Staff should wear name badges so that people know the names of the people who are providing them with care.

> **“Introduce new staff and include a picture so if they turn up, I know a little about them.”**

- Clear information about what care workers can and can’t help with.

> **“Clients need Leeds City Council guidelines on what carers can and can’t do, I hear “we are not allowed” a lot.”**

3. How would the care agency treat their staff?

> **“Carers attitudes are reflected by how the agency is treating them.”**

The key message coming out of these discussions was that treating staff well, providing better pay and conditions, valuing staff and providing good training was absolutely integral to high quality care. They also felt that this would help with the ongoing issue of staff retention which resulted for many in different care workers all the time and a resulting lack of continuity of care. Panel members said that if staff were treated well, it would have a direct knock-on effect to how they felt about the work. One panel member suggested the importance of having a “strong, understanding management team.”

> **“If they look after their staff and respect staff, staff will have more respect for the management.”**

> **“I can see my care worker is content and she enjoys doing her job. One time she asked to do a double shift, but the agency refused her request and told her she needed a rest day.”**

Pay and conditions

Everyone was in agreement that care staff needed to be paid a decent wage, with some saying that they should be paid a salary rather than just for the hours they were delivering care. One panel member also suggested offering other incentives such as wellbeing days, paid training, or massage vouchers to reward and retain staff.

> **“Carers need paying more… it’s more skilled than people realise.”**

Panel members felt that care workers should be paid travel time and fuel costs that actually covered the cost of fuel. There was also acknowledgement of the pressures that care workers are under, working long hours, sometimes with “too many clients”, and often doing overtime to cover staff sickness.

> **“In an ideal world, carers should see fewer people throughout the day – not only does this relieve pressure on them, but also improves the standard of care.”**

One panel member reported that care workers were sometimes expected to walk between calls in all weathers, and that they were concerned about the way they were being treated.

> **“I’ve had carers shelter in my porch from the rain before. When I asked them if none of them drove, they said they had to wait for a driver, but that there was no allocated driver today.”**

They also commented on what they'd heard about the care workers' pay and working conditions:

> **"My current provider pays their staff £10.50 per hour. However, if a call is only 30 minutes duration, the care staff who work for this provider, have said that they are only paid £5.25 for the call. Clearly, I can only take this at face value, BUT if this is true then this is in my opinion pure "Gig" economy working conditions!"**

Recruitment, induction, and training

Panel members talked about being more selective in recruitment so that better staff were employed from the outset, but also acknowledged that attracting the right staff was linked to better pay and conditions.

There was a lot of discussion about training, with panel members emphasizing the need for people to be well-trained. One panel member suggested having a minimum level of training for all care stuff such as NVQ Level 2 or 3, and having clearly identified progression routes into the health and care sector. One panel member shared their experience of having a lot of inexperienced trainee care staff who made her feel vulnerable when they were lifting her in the hoist.

Specific training suggested was around:

- Basic skills like moving and handling, hygiene practices and how to use equipment.
- Working with younger people
- Specific disabilities or health conditions (e.g., brain injury, Parkinson's, Multiple Sclerosis)
- The various types of dementia
- Pressure sore care
- Cultural awareness

> **“There needs to be sufficient PPE provided to staff, and training to ensure good hygiene practices. I often have to remind my carers to wash their hands.”**

> **“A lot of the care companies are designed for the elderly patients and don’t meet my needs. I’m in a wheelchair and care workers do not know how to use my equipment. If they can’t care for my needs, it’s putting me in danger.”**

Some panel members talked about on-the-job training and the need to review whether this was the best way to train people because they felt that it could be intrusive and also put extra pressure on care staff. Others expressed a strong view that practical training such as how to use a hoist should be done in person in a classroom and not online. Another panel member suggested the possibility of scenario-based training.

> **“They are thinking about too many things at once – helping the client and training someone. It also then means people might not get trained properly.”**

Two panel members independently fed back that there had been occasions where trainees had turned up with regular care workers without asking the client’s permission. In one of the cases, it had been distressing for the client who had advanced dementia and didn’t know what was happening when “six staff turned up to learn how to use the hoist”.

Several panel members suggested that it would be good to get people with lived experience of home care involved in training for home care staff. They felt it would give staff an insight into what is important to them and how it can feel to receive both good and bad care.

> **"I think it would be great to get some of the service users to talk to groups of practitioners, do a training video or be involved in policy making."**

Panel members also suggested that probationary periods and spot-checking new staff was vital to check the quality of care and to identify any support and training required. One panel member felt that it would be really effective if people with lived experience also had a role in this.

Several panel members also mentioned the importance of staff routinely having the time to read information about the person they are going to see prior to each visit. They said this helped workers to connect with them and provide better quality care.

4. How would they plan their staffing rotas? How would they plan your care?

> **"I'd like the care agency to follow the five fundamental requirements for CQC [Care Quality Commission] standards. Things like dignity and respect, compassion, be inclusive and responsive and person-centred."**

Assessment

Panel members talked about the need for a thorough person-centred initial assessment to be carried out by the care agency, including someone's preferences and choices. People talked about the importance of really listening to a person's preferences and what needs to be done.

"Care needs to be delivered around the person."

Rotas

Throughout the sessions, panel members talked about the difficulties around constantly changing staff and the importance of having a team of regular care workers who could get to know you.

> **“Mum got confused with how many different care workers were visiting her a day.”**

Panel members agreed that the care agency should routinely share staffing rotas with them to let the client know who would be attending. They were understanding that there may be some staffing changes within reason, but that it was important that people had a least a rough idea of who would be going. Panel members felt that where possible the agency should also communicate any changes, especially if new workers were attending or the agency wanted trainees to attend for on the job training.

Care plans

Panel members discussed their own experience of care plans which was variable:

> **“I have a copy of my care plan left in the house that I can read. It does change each month though, so I can’t see previous months.”**

> **“I have a copy of my care plan and there’s a section next to their notes where I can write down any comments of my own if I don’t agree with something, or I want to add something.”**

A couple of panel members mentioned that they have never seen their care plan.

> **“I’ve never heard of this care plan. I’m not involved in any reviews of my care.”**

One panel member who is blind told us that they couldn’t read their care plan. No alternative format had been provided and nobody had offered to read through it with them.

Processes

One panel member mentioned the importance of risks assessments being done and health and safety procedures being followed which they felt didn’t always happen when they should.

Activity 3: An ideal day supported by care workers

In small groups we asked panel members to think about what an ideal day supported by care workers would look like, by using the following prompt questions. Following the session, we also asked them to individually think about their ideal day by completing a worksheet (see Appendix 3) that we had posted out to them. We received 8 completed worksheets back.

1. What kinds of things would care workers help you with? Is it important for example for you to be able to access the community with support from a care worker and how?

As in previous discussions, panel members stressed the importance of regular consistent care workers who they got on well with and trusted; who arrived promptly but were flexible; and who were experienced and respectful.

What came across really strongly was that as well as help with all the practical tasks (e.g., getting up / going to bed, personal care, preparing food), panel members stressed how much they would value just having a bit of emotional and social support and companionship.

Access to the community

The majority of panel members expressed how much they would like to be able to get out of the house. The majority of the panel members or the person they cared for were unable to go out without assistance.

> **"I would love for someone to take me to a park."**

“An adventurous journey going out into the community, (e.g. on the bus, to a park, have some lunch) with a carer you could trust. I wouldn’t want to go out with just anyone. You don’t have to be best friends but it’s important that you have a bit of friendship with them so that it’s interesting for both, not just the client. It’s important that they have some understanding of your needs and likes, and you don’t just have someone pushing you along.”

“I would like to have a wheel out, but I haven’t been able to get out for six months.”

“I’m actually trapped, I’ve seen what it’s like to be disabled in the 20th century.”

“Would love to go to bingo.”

“Access to the community would be wonderful, I am self-funded and cannot afford any extra care or the social care stuff, such as transport to take me to a local group in the community. In reality the access bus doesn’t work, they can’t do the times I would like.”

“I would like my carer to take me wherever I like.”

Emotional and social support and companionship
Everyone also stressed the importance of emotional support and companionship – someone to come in just for a chat, to "have a laugh", read or watch TV with them. Some panel members described how their circumstances had led to them becoming very isolated, particularly if they did not have family living nearby.

> **"Someone to have a cuppa and a chat as well as provide care. Companionship Is important if client isn't seeing a human being all day. It's nice to see a different face, have different conversations, not just talking about my illnesses or my care."**

> **"Sometimes I'm very anxious so need help to feel calm… someone I can call [at night] other than my daughter if I am anxious. Person will need knowledge of me which my daughter could provide. I get a bit confused at night."**

> **"In summer, someone with time to get me out to the garden and sit with me."**

> **"Have someone to bake for me so I can watch them bake – when I was able to, I would love to bake."**

A couple of panel members suggested that time needed to be built in specifically for this purpose.

“Although the evening call was 30mins it often worked out as only 10 or 5 and then they left. It would have been nice to spend that time chatting to individuals.”

“Can time be agreed for a 10-minute sit down chat, so the carer is actively listening? Could that be built into client's hours? Last night my mum was upset, and the carers sat and chatted with her for a while which really helped her.”

Flexibility

“My life is controlled by time.”

Several panel members talked about the need for flexibility and how whilst it was important for care workers to maintain a routine, it was also important to also work around the needs of the individual (for example, when they have appointments or social engagements) and take a person-centred approach.

“In an ideal world, mum would be able to get up when she feels ready to”.

“It’s important that my carers do what I want to do, not what they think I want to do.”

One panel member gave the following example about the lack of flexibility they currently experience.

> **“I’ve had numerous occasions where I’ve struggled with getting a taxi and had to sleep in my chair because the carers have stayed, they’ve done their quarter of an hour afterwards, and then left.”**

Panel members also said that they wanted care workers to be proactive, use their initiative and see a job when it needed doing.

> **“I would like carers to notice when things are needed to buy for my personal care.”**

When people’s needs don’t fit in a box

> **“Do not assume we are all the same.”**

Personalised care was really important to panel members, especially for those who felt they didn’t fit into the typical profile of an older person in need of care.

One of the panel members was a younger blind person who needed help with caring for her baby and cooking meals. She didn’t want her food cooked for her but wanted help to cook it herself. For her, her ideal day would involve people having enough time to help facilitate her independence.

> **“Social services don’t give enough time to ‘facilitate’. I want to cook not be fed!’”**

There were also younger people on the panel who felt that their social needs were not considered or catered for in their care package. One panel member felt strongly that current arrangements made it very difficult for them to have any kind of social life.

> **"What about those of us who have a 'non-disabled' life that want to go out with friends? My care gets delivered at 8.30pm, 60 year old, 8.30pm - put to bed, children are still playing out. Who does that cater for?"**

2. How would the support be delivered?

A couple of panel members mentioned the idea of 'support workers' to deliver the more social and emotional elements of support. One panel member said that they used to be a care manager for people with learning disabilities where there were support workers who focused on the more social side of the support. She gave the example of one client whose support worker would sit and watch Coronation Street with him because that's what he enjoyed doing.

> **"Create a role that encompasses carer and support worker."**

Another panel member suggested care agencies could work with local organisations to support people in their homes.

Session 3: How Leeds City Council works with care providers to ensure quality.

Date: Monday 10th October 2022 10 am to 11.30 am
Number who committed to attend the session: 16.
Number actually attending the session: 14.
Apologies: 2

Activity 1: Future billing

This was a whole group discussion where we prompted discussion with the following questions.

1. If you are billed, or you were to be billed, how would you like to be billed? How often? What would it look like? Would you like it to be itemised?

Itemised
Panel members agreed that it was important that bills were itemised so that they could check that they were getting charged for the actual care received because companies don't always stick to the contracted hours and "mistakes are often made".

One panel member shared a positive experience of all their current bills being itemised.

> **"Care is itemised with the time they arrive… we have a folder at home where they log all the care, and they have a login and logout system on their phones."**

Regular and timely

There was consensus that panel members wanted bills to arrive promptly and regularly (e.g., fortnightly or monthly) as this would make it easier to cross check bills against care actually received. There was a strong consensus that people shouldn't be several months in arrears because it caused unnecessary stress and anxiety. Three panel members in the group reported recent experiences where they had not received a bill for over four months.

One panel member described how the length of time made it difficult to keep track of the amount of care received in case they wanted to dispute what they'd been charged. Conversely one panel member who received monthly billing said they were happy with that system as it meant they could easily cross check against their own notes of the times that care was actually provided.

> **"It's been 17 weeks since I last had an invoice – this amounts to around £8000 for me to pay as a self-funder… There's a lot of anxiety about it."**

One panel member told us that Leeds City Council staff had explained to them that they would always be 12 weeks in arrears due to the time taken for the care agency send hours through to Leeds City Council, and for them to produce and send the invoice to the client. One panel member described the current system as a "Nightmare" because of how long it took. They asked, "How can we avoid that?"

One panel member questioned why as a self-funder the care company still had to follow the same system, rather than send the invoice directly to the client as this would be more efficient and save a lot of time.

Accessible

It was clear from discussions that there wasn't a consistently good understanding of how the current billing system works (e.g.: whether bills cover staff travel time; why Telecare is no longer charged on the invoice).

One panel member who described the system as “too longwinded” recounted getting two types of invoices, including one stating when the money would come out of their bank account.

Panel members said they wanted bills that were concise and easy to understand, and that it was also important that any system needed to be accessible to people who aren’t online.

> **“I want bills on paper and at least every fortnight.”**

Easy to resolve any issues

Panel members wanted a system where it would be easy to resolve any billing issues.

> **“Leeds City Council need to have a dedicated helpline to respond to these queries and also accept what the client is saying.”**

Panel members described the current system where they had to repeatedly ring up to chase bills, or be continually passed between the care company, Leeds City Council and social workers when trying to resolve any billing issues.

> **“It’s stressful as you get passed from person to person when sorting the payments.”**

> **“It’s enough sorting out my mum’s care without finding time to chase up the Council.”**

2. **Would you be happy with a bill where you paid a fixed amount each month based on an estimate of your monthly care cost (like a gas bill) and Leeds City Council would then reconcile it to the amount of care you had actually received?**

There was a general agreement from panel members that they thought this was a good idea.

Panel members said they would need to feel reassured that when care staff don't do their contracted hours, that this will be reflected in the bill.

Activity 2: Ensuring quality

Following a talk from the Leeds City Council contracts team explaining how they monitor home care providers, panel members broke into three small groups and discussed the following questions.

1. **From your own perspective, what kinds of things would you want LCC to check?**

The most important thing that panel members felt Leeds City Council should be checking was the quality of care.

> **"When they [Leeds City Council] are choosing these care companies, how are they monitoring the quality and attitudes of individual workers? Are they looking at how compassionate they are towards their clientele?"**

2. **Currently there is an annual survey from LCC that goes out to a sample of people in receipt of home care. Do you think it would be good to have the opportunity to feed into the kinds of question this survey is asking?**

There was a general feeling that surveys are all well and good, but change is the thing that matters. They felt that more work needs to be done to make sure (a) change happens as a result of feedback and (b) people are told what is or isn't changing as a result of their feedback.

Some panel members said that if they were confident that this would happen, then they would be willing to give their time to feed into survey design.

> **“If the survey isn't person-centred then it just feels like it's a lip service process. I think that the idea of clients coming up with survey questions is good.”**

Some of the things they thought it might be good to ask people in receipt of services or their family carers were:

- Any observations about the level of stress staff are under.
- “Do you feel you are getting value for money?”
- An option in the survey to include the name of the care provider.

It was also suggested that it needs to be made very clear who the survey is coming from. One panel member said they sometimes get confused as to whether communication is from the care provider or from Leeds City Council.

Discussion about the survey led into a wider discussion about making communication accessible and the importance of find finding out from people how they would like to be communicated with and ensure this it is recorded in their care plan.

> **“A survey will not work for everyone. My mum had dementia and she would have thrown it away”.**

Panel members said it was important to have try different methods for people to give feedback. For example, some panel members said they would like to give feedback by phone if they did not have digital access. Others may find it difficult to write or get out to post a completed survey. Another suggestion was an online forum (like the panel meetings).

There also followed a discussion about who to send the survey to. One panel member shared an experience of receiving a letter about her care addressed to her sister and her friend (both next of kin) at her address but that didn't include her name.

> **"Leeds City Council should not assume that services users are incapable in making choices and decisions about their own care".**

Panel members suggested that it would be useful to address letters to both the person receiving care and any person who has Power of Attorney or who is involved in their care. One family carer expressed frustration that they had to prove and provide evidence that they were next of kin every time they got in touch with Leeds City Council regarding their relative's care, and wondered if there was a system (e.g., using a centrally recorded password) to make this easier.

3. Have you had the opportunity to feedback to individual care companies? (NB this was a prompt question only asked in one small breakout group)

The response to this question was mixed, due to the fact that panel members were talking about a range of different care companies.

- One panel member spoke of having a positive experience feeding back to the area manager of the care company.
- Two panel members said their current company asks for feedback but their previous one did not.
- One family carer said their relative's care company doesn't regularly ask for feedback but that they did listen to the person receiving care when they expressed what they wanted.

There was consensus that it would be good to have an easy way to log concerns (not necessarily formal complaints) with Leeds City Council, as it's important for them to have an overview of all care providers.

Both care providers and Leeds City Council complaints systems also need to be transparent and easily accessible to everyone, including people who aren’t online.

> **“If you make a complaint to the care provider and nothing happens, you should be able to go to Leeds City Council.”**

Session 4: Proposals for the future

Date: Monday 24th October 2022 2 pm to 3.30 pm
Number who committed to attend the session: 15.
Number actually attending the session: 12.
Apologies: 3

Activity 1: Discussion about future proposals.

Leeds City Council commissioners gave an overview of their vision of future home care in response to feedback that has been shared so far during the sessions. This was received well by panel members who overall welcomed the future plans.

The following points were raised during a discussion about the proposals:

Mixed opinions on staff wearing uniform.

Although most panel members didn’t express a strong view about whether or not staff wore uniform, a couple of panel members raised the issue that they didn’t want everyone knowing that they needed care and would prefer care workers to dress more casually.

> **“Mum was put off outings with carers in the past as they wear a uniform, and she thinks this brings attention to her and she feels embarrassed that she needs carers.”**

In contrast, one panel member said that they really liked staff wearing uniform, because it made them smart and identifiable, and liked the fact that neighbours knew that care workers were coming in and out. Following the session, someone suggested that care agencies should ask people’s preferences on this matter and where possible respect it. They suggested that where people weren’t comfortable with uniforms, they could ask care workers to wear a cardigan or coat over their uniform which they could then take once inside the client’s home.

Is there any home care available during the night?
There was some discussion around the fact that agencies only provide care up until 10pm at the latest. Some panel members felt that there was a need for night care workers, particularly where people were incontinent. One panel member said that as part of their support plan they were able to call NHS staff during the night for this purpose but that they weren't always able to come out, resulting in them not being cleaned and changed until the next morning. Another panel member said that if her mother had continence needs during the night, that because of her dementia, she was not always able to call either her daughter or Telecare for help.

A small, consistent team is appreciated.
Several panel members mentioned that their most recent care teams were good because they have stayed quite static, with small teams, low staff turnover and good communication. One panel member whose relative has dementia said it was really important to have consistency in care workers because they are able to notice when things change.
"Sometimes my mum's carers, because she has quite a lot of different ones, they don't actually notice changes in mum and that is really important."
Limited choice if you want to change care provider.
One panel member said they only recently found out via a letter that they could ask for a change in provider if they weren't happy with their current arrangement. There then followed a discussion around limited choice of providers in some areas.

> **"Why is there less choice of providers in LS21?"**

Care being provided more locally

> **“It would be good if they get a set area instead of having to travel everywhere and rush around and not get paid for travel time.”**

Although panel members appreciated the positive aspects of care being delivered more locally, one panel member expressed worries that that if the areas covered become smaller, that people might be rushed or ‘fitted in’ to enable the care agency to ‘finish’ the work in a particular area. There were some concerns that this would affect the already limited input that people had into the choice of times in their daily schedule.

Personal safety of care workers.

Panel members were concerned about care workers keeping safe if they were walking between calls more, especially in winter when it gets dark earlier. Panel members wanted to know whether care workers would be provided with personal safety alarms and whether there would be a procedure to make sure they were safe after each call.

Challenge of making care truly ‘personalised’.

One panel member talked about the term ‘person-centred care’ and the constant move towards a more personalised approach to providing care. They shared some of their current experiences to highlight what they felt was a lack of personalisation in their current care.

> **"I don't get the opportunity to do any of my personal care myself apart from washing my hands and my face… There's nothing for people like me who want to go out with friends for a meal…. I have to give them a months' notice to request it [staying out until 9.30pm at the latest]. I had to come away from a 21st birthday party for a very close friend because I had to go to bed at 10pm…Where's the independence in all that?"**

This person felt strongly that the service she had previously received from personal assistants via direct payments had been much more person-centred than what was available from her current care agency.

Activity 2: How could other health and care services work together with home care workers better to meet your needs?

In small groups, we asked panel members to think about this question in terms of different professionals they see for help with their health and care. They shared their current experiences and thoughts about whether it would be better for them if things could be done differently in the future.

One panel member shared an experience where their care workers had previously been able to change dressings on their pressure sore seven days a week.

> **"Suddenly they were told not to do it [change my dressing] because they hadn't been trained in it."**

This person explained that they now have to rely on the district nurse only being able to come out three times a week to change the dressing but feels that this is unsatisfactory because the dressing gets dirty. They felt it would make a difference if care workers could be trained to do it for her daily and would feel alright with them doing some low-level tasks like this, as long as they had the relevant training.

Another panel member said they “feel happier with the district nurse” doing dressings but recognised that this meant that they would sometimes have to wait longer.

Two panel members shared their experience of their care workers currently working really well alongside the district nurses. They felt there was good communication between the care workers and nurses, with each team keeping the other up to date with what they were doing. They also noted that both the nurses and care workers were good at recognising when something wasn’t quite right with them and letting the other one know. One of these panel members said that they didn’t think that care workers should be doing tasks currently done by the district nurses as the roles are distinct and, in their case, the current arrangement works really well.

One panel member raised concerns about communication between the district nurses and the care workers. They were worried that with having so many different care workers, coupled with complicated instructions on how to keep the dressings clean and perform moving and handling safely, that the messages would get lost.

> **“How can it work with so many care workers?”**

> **“She [the district nurse] gave me five sheets of paper – it was so complicated. I’d need to train as a nurse to understand all the dos and don’ts.”**

A couple of panel members said that it would depend on the quality of the care company as to whether or not they would trust the staff to take on the duties of other health professionals. One mentioned that they would feel comfortable having care workers doing some tasks like changing a leg bag but didn't believe their current care team would be capable of doing it.

Another panel member said that they had experience of three different care companies, one "appalling", one "average" and one "amazing." Whilst they would have trusted staff from the "amazing" company staff to take on such additional tasks, they wouldn't have felt the same about the "appalling" one. They went on to say how communication had been a key factor with the good company and described a WhatsApp group where care workers could share useful info about clients. For example, if the person receiving care had a pressure sore, the next care worker that visited could be notified and would be able to check on it. They would also text a family member if there were any concerns or for general feedback.

> **"If the standard of training was good and the same across all care agencies / staff then in theory every carer would have the same ability, skills and knowledge. Then you would have more confidence in there being a cross-over in some duties."**

One panel member said that their care workers already do some of the tasks usually carried out by a district nurse due to a prior agreement and they feel that this works well. They said that the care workers provide preventative care that the district nurse would normally do, and if the care workers are concerned about anything they tell them to get in touch with the nurse. This person said that they didn't like waiting for district nurses as they never knew when they were going to arrive, and this impacted on other commitments they had during the day. Conversely, panel members also talked about how the timing of care visits can impact the service they receive from other health professionals.

> **“The agency needs to recognise that people have other commitments and appointments. Sometimes the carers running late has impacted another appointment I have with the district nurses.”**

One panel member gave an example of how their mother’s GP worked well with family to ensure a minimal stay in hospital:

> **“Recently my mum wasn’t very well, and the doctor said she had to go to A&E and said they would admit her, and I said, ‘Well I’m not prepared for my mum to sit in A&E until a bed is available. What I’d like you to do is as soon as a bed is available, let us know and send an ambulance to take my mum to the hospital.’ And that’s what happened, and mum went straight into a bed. And because mum has got a good package of care and because they’ve got a ‘virtual fragility team’ now, they were happy for my mum to come out the same day. And that worked quite well, and she didn’t have to stay in.”**

Individual interviews: Delivering a culturally sensitive service

We spoke to six panel members from minority ethnic backgrounds by phone about how they thought home care services could be delivered in a more culturally sensitive way. We asked them about current and past experiences, what had worked well, and what could have been better. We asked them to think about things like assessment of needs, communication and language, delivery of care, customs and culture, food and religion. We have grouped their feedback into the different themes below.

Assessment

There was a mixed response as to whether people were asked about cultural and religious needs during care assessments. Several panel members said that the assessment was more focused on times of visits and tasks that needed doing.

> **"It was a very loose presentation about what we [the care company] could be offering you".**

> **"When the care was set up from hospital, the consultant arranged it. I don't think anything was discussed about his cultural and religious needs, just the times they would come."**

A couple of panel members shared positive experiences:

> **"They asked about the cultural needs, and actually listened to the needs of the person."**

> **"Social worker was an absolute delight – assessment and care plan were thorough as requested including points about culture and religion."**

Two panel members said that although the care agency hadn't asked about cultural needs, they had taken them into consideration, but that this had been reliant on proactive family members talking to the care agency about what they wanted to happen. They felt strongly that care agencies should be asking these questions routinely, and that this is particularly important when someone has dementia, as sometimes they may not be able to articulate their wishes.

> **"When someone has dementia it's even more important to ask these questions and involve family because you don't have a voice at the latter stages. My mum can't speak so she can't tell the carers what she wants."**

Gender preferences

> **"Having respect to someone's gender preference is incredibly important."**

One of the key issues raised by almost everyone we spoke to was the importance of respecting gender preferences, with the majority saying that the care worker(s) providing personal care had to be of the same gender as themselves. This was relevant for people from both Asian and Caribbean cultures.

> **“He wasn’t very comfortable with a female carer. A lot of the carers were female so you couldn’t really get round that. My aunty has dementia and if she needed home care, there would be absolutely no way that she would be comfortable with a male giving care”.**

One panel member gave an example of how they’d worked with the agency to find a way that they could feel comfortable about having a male and female care worker attending together.

> **“The female carer attends to her personal needs…. he [the male carer] leaves the room and does other task in the kitchen such as washing dishes and preparing light lunches… My mum has built a very good relationship with the male carer, and he is very aware of his boundaries and is respectful of our culture and religion.”**

There were a couple of examples given where care workers of different genders had been sent without prior communication with the person in receipt of care.

One panel member whose mother had dementia described an incident where despite female care workers being requested, the agency didn’t communicate with them prior to sending a male care worker.

> **“Once I got to the house to see they’d sent a male carer to do personal care with my mum. He’d phoned the office to say my mum wouldn’t play ball. No-one had spoken to us beforehand to ask if this was ok. Within the Caribbean background that is absolutely a ‘No, No’ to have a man doing personal care.”**

Food

Half of the panel members we spoke to relied on family members to cook.

> **“My mum used to have particular Caribbean food that she would like that we’d prepare and leave in the fridge for her… It was often overlooked, and they’d give her something like a couple of jam sandwiches instead. “It was very important that my mum had Caribbean food - if she didn’t, she wouldn’t eat at all.”**

They said that if their family weren’t able to cook for them, it would be important that care workers knew how to cook culturally appropriate food.

> **“If the food provided to me wasn’t culturally appropriate, I would feel like a statistic, I would feel annoyed and patronised and that the service provision was an extremely token gesture.”**

One panel member said that the care workers would usually make a vegetarian sandwich but would also go out and buy a curry for them if they asked them.

Another panel member who was blind had had varying experiences around food from two different agencies. With one agency they described a time when a care worker had prepared a chicken dish for them that wasn't cooked according to their instructions, and this left them with doubts about whether or not the chicken had come from a halal butcher. With their current agency, they are assisted to cook the food they like and have no doubt that if they wanted to cook for an occasion such as Eid, that the care worker would go to an Asian butcher and purchase halal meat and other cultural ingredients.

One panel member said that cultural food and preferences weren't really touched on when care needs were assessed.

> **"In terms of food, they just asked things like, 'Does she like eggs, fish?' etc, but they didn't ask about any Caribbean options."**

A couple of panel members also mentioned that 'Meals on wheels' were suggested as an option but that they didn't seem to offer culturally appropriate food.

Hygiene

> **"Being aware of Muslim hygiene is incredibly important. There is a set of rules that is appropriate and acceptable for eating and drinking."**

Two panel members, both from the Muslim community spoke about the importance of hygiene and cleanliness in their culture. The following were all mentioned as important to them:

- Removal of shoes when entering the house
- Personal bodily hygiene of care workers is important when delivering personal care in someone's personal space.
- Good continence care

> **"It's important that they don't clean my catheter bag in the basin because the family do their ablutions (washing before praying) in the bathroom basin".**

> **"If I were to have a bath, I would have a shower first, to have a rinse down so I'm not sitting in dirty water."**

Language

One panel member told us about the language barriers faced by their relative:

> **"With my mum being from Caribbean background, no-one would understand what she was saying. My mum would complain, and one of the ladies would say, 'What did she say? What did she mean by that?' So, in the end me or my sister would have to be there to translate what she was saying, which was very hard because every time someone came, we would have to be there as well. My sister felt that she was one of the carers herself. She was actually even rostered into the care plan."**

Another panel member talked about language use and that when her care workers used terms such as "Bedbound" or "wheelchair bound" she found this really offensive as she said she is not 'bound' to her wheelchair or bed.

> **"When I challenge them on it, they told me they're told these terms in their training."**

Activities and interests

One panel member told us how it was really important for their mother to attend a day centre three times a week where she'd meet with other people from her community, get Caribbean food, sing old folk songs from the Caribbean and go to weekly prayer meetings.

> **"Being very Christian she appreciated going [to the day centre] because they would have Caribbean prayers from when she was a little girl."**

The prayer meetings were particularly important because she had been a regular church attender.

> **"We as a family used to take her to church but the deeper the dementia got it became more difficult, so the only religious communication was at the day centre."**

They described how the care agency had initially said they could take her to the day centre, but then pulled out which meant that she was then dependent on her family to take her. This meant that she wasn't able to go as often because of family member's work commitments.

> **“First the carers said they could accommodate getting mum there and back. And then after a few weeks they said they couldn’t do it. It was like they were overpromising to get you through the door.”**

Stigma and assumptions about receiving care

One panel member talked about the stigma around receiving care from an agency in some communities, explaining that people make assumptions that the family don’t want to care for the person anymore.

Another panel member mentioned that their loved one was quite fearful about the prospect of receiving care from people who weren’t family.

> **“I couldn’t care for my parents any longer so suggested we get carers. My parents felt uncomfortable and unsafe at the thought of someone coming to their home. They had heard stories about carers stealing, abusing people etc. I explained to my parents that carers are checked and trained, and after a lot of persuasion parents agreed to receiving care.”**

Another panel member who had been blind since birth and had previously been supported by in the family home, wanted to move out to be more independent. They said that it had initially been difficult to prove to Leeds City Council Adult Social Care how much care they needed and felt like they were constantly fighting for their rights. They said that this got easier once they had a baby and feels that they now get the care they need.

> **“Services shouldn’t assume that Asian families will always care for their loved ones. They need to understand that the person receiving care might not want to be cared for by their family members.”**

Cultural background / knowledge of care workers

There was consensus amongst panel members that it was helpful to have a diverse workforce to help with understanding of different cultural needs.

> **“We did get some workers that were Muslim. It helped in certain aspects like being familiar with our culture... For example, being a Muslim, he [my father] had to shave hair under his arms and in the pubic area within 40 days. My husband and a male carer did it.”**

> **“They know, they are from different cultures too, Hong Kong, Africa, Asia, they understand.”**

> **“It was a struggle because we ended up having two care providers that we had to change because they couldn’t cater for her cultural needs. They didn’t have a diverse workforce and I think that affected their understanding of my mum’s cultural needs. [The third care company] was a local company and was based in the community where my mum lived, and they were actually very accommodating. They had a wide range of different nationalities on their books as carers. My mum used to have two carers, maybe one from a Caribbean background, one English. Always a decent mix… When they came in, they used to call her ‘Aunty’.”**

There was also acknowledgement that panel members who weren’t from the same cultural background were also capable of meeting people’s cultural needs but that it was a question of making themselves interested in and aware of different cultures.

> **“My care worker is from a different cultural background [to me] but has a broad understanding of other cultures too.”**

Consistency and small teams of care workers

Several panel members mentioned that one of the things that worked well in terms of understanding and meeting cultural needs (as well as providing good care in general) was having a small core team of care workers who knew the person receiving care well.

> **“She had a core number that used to go. About six carers that used to go regular. In regard to personal care, there was only a couple that she would trust so having regular carers was really important.”**

Conversely, panel members were more likely to have poor experiences when there was a constant rotation of staff. One panel member described the impact on her of this:

> **“The girls who were going to be doing my shower kept changing. I wasn’t comfortable having a shower with new girls. It felt like I was having to re-expose myself physically to another woman every second day.”**

Importance of having respect for personal preferences, being open and asking questions.

> **“I’ve had the good fortune of meeting some really good carers who actively listen. For me to have my values listened to respected and heard is intensely important.”**

Panel members said that it was really important for staff to proactively ask them about their cultural preferences, make sure all staff are aware of these and respect them. They also felt it was important for care staff to be open and ask questions if they are not sure about anything.

What could be better?

Panel members came up with the following suggestions as to what could be done to make services more culturally sensitive:

- People should proactively be asked questions about their cultural and religious preferences during any assessments and review.

> **“The provider should find out what that person eats, what religion they are, how would they like to be looked after, do they have any preference in someone who is same cultural background to them? They should address the issue and say for example, ‘We have four carers that are of this particular ethnicity, in terms of meeting your cultural needs, would you prefer to be cared for by then or would you prefer someone from different background / community?’”**

- Staff should be trained or have awareness raising around different cultures and the importance of listening, being open and asking questions about people’s personal preferences. Training should cover cultures, customs, and religions, and how to cook basic cultural food. The training could involve people from different cultures who access home care services.

> **“Training could involve people like me who have lived experience of home care who happen to be from a different culture. Would there be financial incentives for people to get involved in things like that, to recognise the skills and expertise they bring?”**

- Training should be delivered from the social model of disability recognising the importance of language. It should encourage terms such as “impairment” instead of “disability”, “Wheelchair user” instead of “wheelchair bound”.

- From the outset, Leeds City Council could provide families with more options, so that they have a better-informed choice. E.g., are there any providers from their own community with a more diverse workforce that can be offered?

> **"The family that are requiring the care should also find out from the providers if there is any cultural help they can get. Has the care provider got someone who can meet the cultural needs of the person receiving care?"**

- Agencies should let people know how care workers are vetted and the training they have received to help them have trust and confidence in the care offered.

Contacting Leeds City Council Adult Social Care

We also asked panel members about their experiences of contacting Leeds City Council whilst arranging and receiving their home care support. Their experiences were very variable.

One panel member talked about how difficult it was finding out where to turn to for help:

> **"It was difficult at first, and it was word of mouth that we heard about it from people in the community who had been through it. Luckily for us, my sister had worked the Citizen's Advice Bureau, but even she, who was someone from the system, found it difficult."**

Others talked about the importance of first contact and how it can set the tone and reassure someone that help is on the way. Someone said that agreeing a call back within a time frame can help relieve anxiety.

> **“The person on the phone could hear in my tone that I was desperate. I could tell she cared and was genuine, she immediately said, ‘Let me see if anyone is available to help.’”**

> **“My social worker is very good, if she can’t ring me immediately, she lets me know when she can.”**

One panel member who contacted Leeds City Council to query fees, said they didn’t really feel that the issue got resolved.

> **“It’s been very hotchpotch… It felt like they just had their script and stuck to that.”**

Another panel member described how they felt the help from their social worker in terms of finding a new care agency was limited.

> **“I was fed up with the previous agencies so wanted to change. Although my social worker had recommended a couple of agencies, she couldn’t help any further. I went onto Google, and I found my agency myself.”**

One panel member whose relative was in receipt of palliative care had a positive experience:

> **“I can’t really grumble…We asked for a night sitter, and someone came and sat for two nights…If we called them during the night someone would come out.”**

Our messages and recommendations

First contact

1. **Raise awareness of home care services and how to access them so that people know where they can go when they need help.**
    - Find opportunities to build better links with communities, Neighbourhood Networks and other community organisations to increase awareness.
    - Consider how general information about Leeds City Council Adult Social Care is currently shared with the general public and how this could be improved.

2. **Make sure that people's first contact with Leeds City Council Adult Social Care is a good experience.**
    - Inspire trust and confidence (e.g. reassurance, good clear information, keeping them in the loop) at a time when people may be feeling worried or stressed about needing more help.
    - Make sure that people are made aware of all the options available to them from the outset.

Assessment

3. **Ensure that people and their families where appropriate are always actively involved in a comprehensive assessment and ongoing regular reviews of their needs and wishes.** All care plans should have input from people in receipt of their care and families where appropriate and be shared with people in a format appropriate to their needs (whether someone has digital access should always be considered).

4. **Ensure that social work teams and home care agencies are routinely considering social and emotional needs alongside physical needs when carrying out assessments.** Ensure that these needs are reflected in care plans with time allocated to simple things like 'having a chat' or taking person into their garden.

5. **People should proactively be asked questions about their cultural and religious preferences and needs during any assessments and review.** Things that should be considered should include personal care, food, customs, religious, social and community activities and gender / cultural preferences of staff.

6. **Ensure that providers are following their obligations under the Accessible Information Standard.** Ensure that they are:
    - Asking all people using their services about any communication needs and preferences.
    - Recording those communication needs.
    - Routinely acting on those communication needs by providing information in formats that are accessible to people.

7. **Ensure that providers are also asking whether people want to receive information digitally and ensure that information is provided in a different format if people don't have sufficient digital access.**

8. **For self-funders who don't go through the Leeds City Council assessment process, there should be a clear accessible statement of what they can expect as a citizen of Leeds from any newly commissioned service**.

Involvement in care

9. **People should be involved in their own care on an ongoing basis.** Everyone in receipt of home care, and their family carers where appropriate should always have the opportunity to be involved in regular reviews of their care. Care plans should always be pro-actively provided in a format that is accessible to the individual (not assuming that a person has digital access).

Personalised care

10. **Be aware of what 'personalised care' means in practice for people in receipt of care.** Where this is a key aim of any service, it is important that the necessary things are in place to ensure that it can happen in a meaningful way. This may mean a culture change for some providers, getting used to delivering to in a way that focuses more on personal outcomes for people than on tasks that need doing. What training, supervision and support will be needed to ensure truly personalised care? And how will this be monitored

Visit times

11. **Ensure that providers have flexibility around visit times according to people's changing needs and also that there is good communication with people when visit times have to change.**
    - Monitor providers more closely to ensure that people are getting the full time they have been allocated where this is needed.
    - Ensure that care providers are calling clients to inform them if there are any changes.
    - Consider the need for nighttime visits for those who require care in the late evening or during the night. The current 10 pm cut off impacts those who want to socialise in the evening and / or those who experience incontinence.

Communication

12. **Make sure that providers routinely share relevant and clear information with people who use their services, to help them feel in control.** As well as day to day information, this includes information such as the role and responsibilities of the care agency, rotas, and any changes in staffing and service provision.

13. **Introduce a requirement for all care workers to wear name badges.**

Emotional and social support

14. **Make social interaction and supported access to the local community an integral part of any proposed community health and wellbeing service, where there are individually identified needs and outcomes.**

15. **Review the availability of emotional and social support and companionship in all areas of Leeds for people who find it difficult to leave their home without assistance.** Where there are gaps, consider the resulting impact on people's emotional wellbeing and feelings of isolation. How can these social needs be met? For example, could they be through allocation of hours in existing care packages or with newly commissioned services?

    Ensure that where social and emotional support is available in a locality that care agencies are proactively identifying and referring people in need of social support to relevant schemes and support such as from Neighbourhood Networks.

Health and care services working together

16. If more co-ordinated working between health and care professionals is considered in any future plans, the following key factors should be in place to ensure that people in receipt of care get a good experience:
    - Good ongoing communication both between professionals and with the person in receipt of care.
    - Consistency and continuity of staff in care teams.
    - Relevant training of any staff taking on new roles.

Billing

17. **Improve the current billing system by making sure that people get regular bills on at least a monthly basis.** Reduce the time between receipt of care and receiving a bill and make people aware of the options and implications around different ways of charging.

18. **Have a single point of contact for billing enquiries** so that people don't have to get passed between their provider, Leeds City Council and the social worker.

Pay and conditions

19. **Improve the pay, conditions and career structure of care staff to attract and retain more people in the role.**
    - Salaried staff rather than just paying for time spent doing care visits.
    - Paid travel time and fuel costs covered.
    - Looking after staff, providing good training, supervision and support and manageable workloads.
    - Make care work an attractive profession for people by providing good career structure and progression routes.

Training

20. **Review training for all care staff and identify clear progression routes into the health and care sector.** Training that was suggested as being important by panel members was in:
    - Basic skills like moving and handling, hygiene practices and how to use equipment.
    - Working with younger people
    - Specific disabilities or health conditions (e.g., brain injury, Parkinson’s, Multiple Sclerosis)
    - The various types of dementia
    - Pressure sore care
    - Cultural awareness

21. **Review the appropriateness of on-the-job and online training for practical skills.**
    - Consider the impact that on-the-job training has on people in receipt of care and whether there are alternative ways of delivering in person training.
    - Produce some guidelines for any on-the-job training to ensure the feelings of the person in receipt of care are considered. For example, ask the person in receipt of care (and / or their family member if appropriate) for permission to do the training and limit the number of trainees present in a person’s home at any one time.

22. **Involve people with lived experience of home care in training.** This would help give people a unique insight into what is important to them and how it can feel to receive both good and bad care.

23. **Consider using the ideas generated by the 'ideal care worker' activity (session 2) in training to stimulate discussion about the skills, values and behaviours that are important in care work.**

Complaints and feedback

24. **Ensure that providers and / or Leeds City Council is asking people in receipt of home care and their family members for their feedback about the quality of the care, on at least an annual basis.** We recommend that any feedback mechanisms should:
    - Involve people with lived experience in their design.
    - Enable people to identify the care provider.
    - Enable people to complete any surveys or feedback forms anonymously.
    - Be part of and feed directly into any contract monitoring and reviews. (e.g., talk to service users as part of regular monitoring).
    - Enable people the opportunity to feed back in different ways according to their communication needs (e.g., by telephone, online or by post)
    - Feedback to people the findings of any surveys and any changes that happened as a result of what people shared.

25. **Monitor that care companies have clear accessible ways of dealing with complaints and concerns that are proactively shared with people in receipt of home care services and their family members.** Also ensure that care companies are routinely making people aware that they can also raise concerns directly with Leeds City Council. Include a question about people's experience of raising concerns the annual survey that goes out to people in receipt of home care services.

Future involvement of people with lived experience.

26. **Consider harnessing the enthusiasm and expertise of the home care panel participants as well as other people in receipt of home care and their family carers to:**
    - Be involved in future opportunities to shape services, systems, policy and public-facing communications.
    - Be involved in monitoring processes and contract compliance (this could be similar to the ‘experts by experience’ model used by the Care Quality Commission) to ensure that people using services have more systematic ways to feed into care provider reviews.
    - Have a role to play in training of care staff (see section on training above). We believe that the expertise and insight gained from any such roles should be properly rewarded with payment or financial incentives.

Commissioner Response

“Leeds City Council would like to thank everyone who took part in the Changing Home Care Engagement panel for giving their time and sharing their views and experiences so openly and honestly. Hearing from people who are using services and family carers is vital for us to fully understand what’s working well and what isn’t working quite so well, both with our internal council processes and our home care providers. The comments made have helped to confirm to us what’s important to people and where things need to change. It was also good to hear the positive experiences of some panel members and we want to make sure this is replicated across the city.

The council recognises that home care is currently too rigid and focusses too much on tasks and timings, so we want services to be more flexible, and delivered in a way that keeps people as well and independent as possible, as well as finding ways of keeping people connected to their community where appropriate. Where people need to pay towards their care, we want our billing processes to be as straightforward as possible.

We want people to know how to access support when they need it, and that they and their carers’, are involved at every step in the planning and reviewing of their own care. The discussion around the use of technology in care tracking, communication and tech enabled care was very interesting with differing views on the benefits, and concerns raised about digital inclusion and access. It’s something we’re taking away to reflect on how we ensure effective communication with residents, through various ways, including, but not limited to, digital means. We are also considering how technology may be used to enhance the care and support provided to residents.

We also share the views of the panel that staff should be valued, well trained, and paid appropriately with good terms and conditions of employment and opportunities for development and career progression. We will continue to work with all our partners to highlight the crucial and valuable role that care workers play in supporting people to live independently, and to help improve the pay and terms and conditions of care workers'.

Finally, we would like to thank our Healthwatch colleagues for facilitating the sessions and producing this report. The Changing Home Care Engagement panel is one of a number of ways the council is engaging with residents and partners to shape how care and support is arranged and delivered in the future. We will consider all the recommendations and points made in this report and use them to feed into these wider discussions and plans."

Caroline Baria, Deputy Director, Integrated Commissioning

Next Steps

The report will be shared with Leeds City Council as the commissioners of home care services.

We will agree with them the next steps to be taken in response to our recommendations and work with them to ensure any agreed actions are followed through and implemented. We plan to have a follow up meeting with panel members in Spring 2023 to feed back any progress made in terms of their feedback and our recommendations. We are also hoping to involve panel members in the procurement of home care services in summer 2023 which will be informed by the findings and recommendations in this report.

The report will also be published on the Healthwatch Leeds website.

Thank you

This report has been written by Harriet Wright with support from Parveen Ayub, Community Project Workers at Healthwatch Leeds.

We would like to say a big thank you to all the Home Care Engagement Panel members who shared so honestly and constructively their personal experiences and ideas for the future. We'd also like to thank Louise Morgan and Enya Cooper from Leeds City Council for collaborating with us to design the sessions and help us to ensure that the project ran smoothly and efficiently.

And last but not least, a huge thanks to all our staff and volunteer buddies who helped to support panel members to access the online meetings: Janet Onslow, Val Hewison, Greta Landi, Denise Wall, Jonathan Phillips, Craig McKenna, Hannah Davies, Tatum Yip, Anna Chippindale, and Gemma O'Connell.

Appendix 1: Methodology

Recruitment of panel members

During August 2022, we advertised for panel members by producing two different flyers – one targeted at people from Black, Asian and Minority Ethnic communities, and one targeted at people living in rural and West Leeds communities. The flyers included details about the support we were able to offer such as interpreters and buddies to support people who didn't have digital access (see below). An incentive of a £20 supermarket voucher per meeting attended was also offered. This was in recognition of the significant contribution and commitment we were asking people to make and to encourage people to take part.

The flyers were shared with the following groups / individuals:

- A targeted letter that was sent out by Leeds City Council on our behalf to approximately 800 people currently in receipt of home care.
- The neighbourhood networks and GP surgeries in Armley, Bramley and Wortley.
- Leeds Centre for Independent Living
- Carers Leeds
- Community groups working with people from ethnic minorities such as Leeds Black Elders, Touchstone, and Feel Good Factor.
- Leeds Care Provider e-bulletin.
- All home care agencies via their commissioners.
- People who had attended the recent focus group run by Leeds City Council for family carers of people in receipt of home care.
- Our own People's Voices List of people who have been involved in one or more of our engagement activities in the past.

Role of ‘buddies’

The buddies’ role was to meet with their panel member prior to, during and after each meeting that they wished to participate in. This way they were able to:

- Spend some time with the panel member prior to a meeting going through what was going to be discussed at the meeting and build confidence to participate.
- Provide the IT equipment to participate, explain how virtual meetings work if the panel member is new to this kind of engagement, and support them with digital access.
- Help them to express themselves and speak on their behalf if that is what they wish.
- Debrief after meetings with next steps, any questions and provide an opportunity to give feedback about how they felt the meeting went.

Appendix 2: My home care journey worksheet

Name: ____________

My home care journey

Your name is so that we can check everyone has completed the form. We won't identify you in any comments we share with Leeds City Council. Please answer these questions and return to us in the Freepost envelope by 18th September. If you do not have a current experience of home care, please answer the questions relating to your past experience.

1. What made you decide you or your loved one needed extra support?
2. Who did you speak to, to arrange the care?
3. How were the care needs assessed?
4. If you wanted to change something about the care, how would you do this?
5. Have you or the person in receipt of care felt included in the decisions made about the care?
6. Do you have access to the care plan?
7. Is the care reviewed at least once a year?
8. Are you or your loved one supported to access the local community?

Please turn over if you need more room to write

Use this side if you need more space for your answers

1.

2.

3.

4.

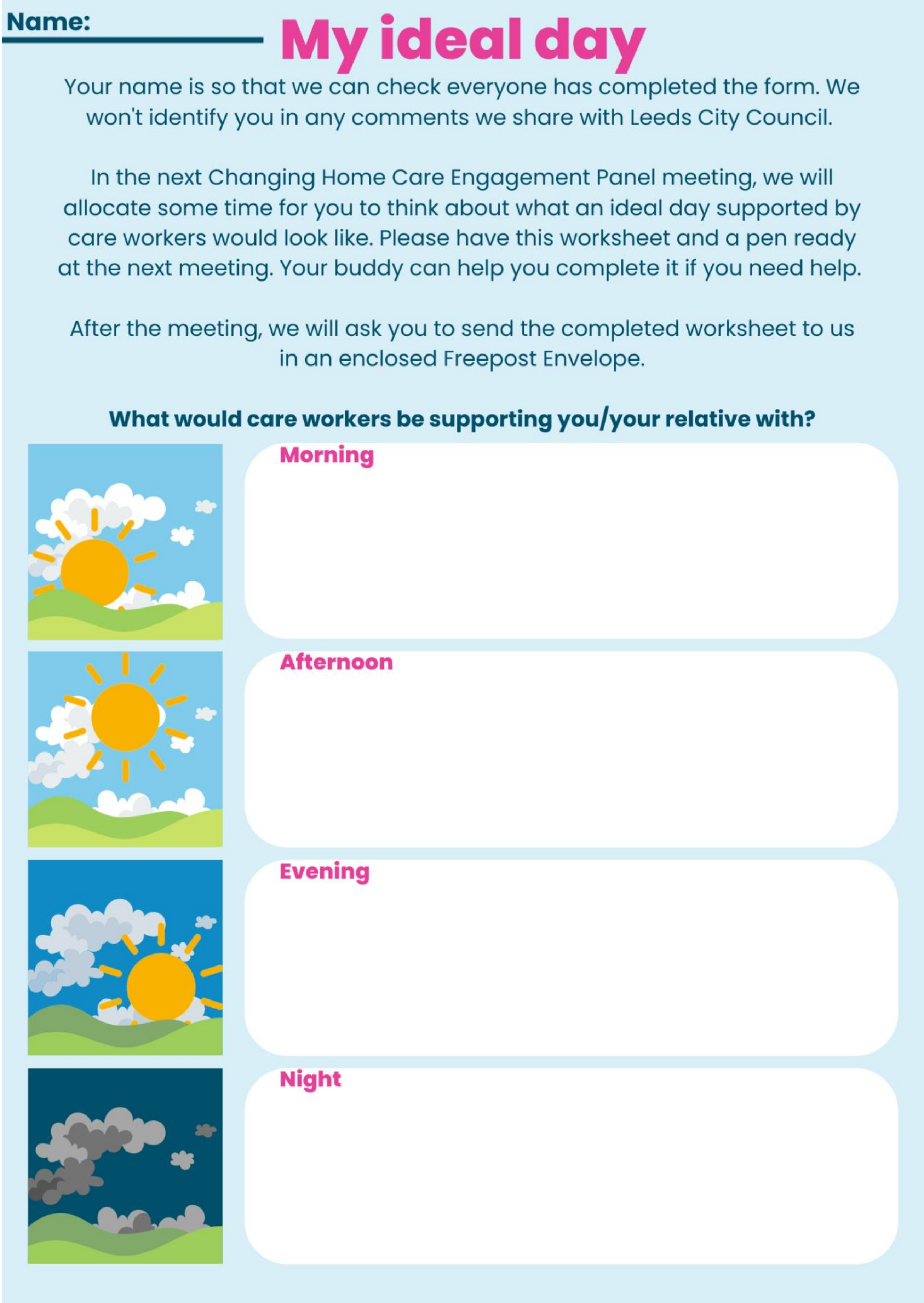
5.

6.

7.

8.

Appendix 3: My ideal day worksheet



Name:

My ideal day

Your name is so that we can check everyone has completed the form. We won't identify you in any comments we share with Leeds City Council.

In the next Changing Home Care Engagement Panel meeting, we will allocate some time for you to think about what an ideal day supported by care workers would look like. Please have this worksheet and a pen ready at the next meeting. Your buddy can help you complete it if you need help.

After the meeting, we will ask you to send the completed worksheet to us in an enclosed Freepost Envelope.

What would care workers be supporting you/your relative with?

Morning

Afternoon

Evening

Night

Your
healthwatch
Leeds

Healthwatch Leeds
The Old Fire Station
Gipton Approach
Gipton
Leeds
LS9 6NL
www.healthwatchleeds.co.uk
t: 0113 898 0035
m: 07717 309 843
e: info@healthawtchleeds.co.uk
@HWLeeds
Facebook.com/Healthwatch.leeds/