



- My care at home -

People's experiences of home care in Suffolk



It's a personal thing, isn't it? And you're allowing somebody into your own personal house, your own space, to do a personal thing. And I think it's important to have that rapport, whereas, if it continually changes, it's like, a stranger suddenly come to do a personal thing.'

A home care service user



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ACKNOWLEDGEMENTS

Healthwatch Suffolk can only instigate change and improve the experience of health and social care in Suffolk if local people in Suffolk continue to take the time to share their views and experiences with us. We would therefore like to acknowledge and extend our gratitude to every person who responded to our survey and participated in our interviews. We give special thanks to those who agreed to be case studies.

We would also like to thank staff at Suffolk County Council, the Care Quality Commission (CQC) and ACE Anglia for their support in facilitating this research.

FOREWORD



By Mike Hennessey

(Corporate Director for Adult and Community Services at Suffolk County Council)

Suffolk County Council (SCC) is committed to ensuring that the delivery of care for the future is sustainable, affordable and meets peoples' individual needs.

In Suffolk we are facing significant challenges as the population of older people (65+ years), is predicted to increase by nearly 50% in the next 20 years from more than 173,000 to over 255,000. In addition, there are approximately 13,000 people living with dementia in Suffolk at present and this is also forecast to almost double to over 24,000. Most new cases are predicted to be in people aged 85+ years, who are also very likely to have care needs.

To help shape our plans for the future we want to hear the experiences from vulnerable adults in Suffolk, who are currently receiving care. The Healthwatch survey has provided an opportunity for SCC to co-produce and financially contribute to an important piece of research. We welcome this comprehensive report that has obtained views from over 500 customers and/or their families.

SCC contracts with over 80 home care providers that delivered almost 2 million care hours to 5,585 customers in 2016/17. We are very pleased that for almost 80% of the respondents they are satisfied with the quality of the care they receive. A much smaller number of people, 50, have then provided a more detailed response that has resulted in a number of recommendations.

SCC will take time to carefully consider and provide a detailed response to the recommendations including how they will be used to inform our plans for the future. For information, we have agreed with our providers and key stakeholders a set of Home Care Principles that we are striving to achieve; listed below:

1. Reliable Provision of safe care is the overriding priority.
2. To ensure guaranteed good quality and reliable care for customers at all times and across all areas.
3. Solutions that work for and across the whole care system and support Supporting Lives Connecting Communities and the Care Act.

4. Affordable and sustainable outcome-focused care and support in the long term with a focus on reducing demand through an enabling approach
5. Solutions that are flexible and can accommodate more complex customer needs that allow them to remain independent for as long as possible

I would like to share my heartfelt thanks to everyone who participated in the survey and Healthwatch Suffolk for completing this valuable research.



“Suffolk County Council will take time to carefully consider and provide a detailed response to the recommendations including how they will be used to inform our plans for the future.”

Mike Hennessey



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INTRODUCTION

About us...

Health and social care works best when people are involved in decisions about their treatment and care. Healthwatch Suffolk was established by the Health and Social Care Act 2012 to be the “consumer champion” for health and social care services in Suffolk. Its’ aim is to ensure that the people of Suffolk are at the heart of care.

It is an independent organisation that exists to find out what local people think about their health and social care services. It has statutory powers that enable it to use those experiences to influence, shape and improve the services now and for the future.

Healthwatch Suffolk also provides an information and signposting service to help people navigate the health and social care system and understand what to do when things go wrong in services.

What is Home Care?

Home care is defined as care provided in a person’s home. It is also sometimes called domiciliary care.

Suffolk County Council (SCC) has a statutory responsibility for the management and delivery of home care. However, Suffolk has a number of private care providers managing and delivering care independently of the council. Providers that are part of SCC’s Support

to Live at Home (STLH) service, other spot Council funded care and private providers have been included in this research.

Home care or supported living can include help with things like getting out of bed, washing, dressing, getting to work, cooking meals, eating, seeing friends, caring for families and being part of the community.

This service might also include emotional support at a time of difficulty and stress and helping people who are caring for an adult family member or friend. An adult may receive home care if they need support to live as well as coping with any illness or disabilities they may have.

The provision of home care aims to help bring about continued independence in people’s own homes, prevent admissions to other care services such as residential care homes and hospitals, and to facilitate engagement with the community where possible.

The rationale for this research...

The future of adult social care and the ability to deliver home care to acceptable standards is high on the political agenda due to rising demand and decreasing financial support¹.

These issues are confirmed in the House of Commons Library Briefing Paper Number CBP-7903 ‘Adult Social

¹The end of formal adult Social Care - a Provocation International Longevity Centre December 2015 www.ilcuk.org.uk

²Briefing paper Number CBP07903; Adult Social Care Funding (England); 19 April 2018 pp 8-13 <https://researchbriefings.parliament.uk/ResearchBriefing/Summary/>



“

To make it worse, I'm a
barcode now. I've become a barcode
and I get scanned in the mornings..

Home care service user

”



“Spending time in the community visiting users of these services, as well as working with carers, local Healthwatch are uniquely placed to gather and share intelligence about people’s experiences and ensure concerns are addressed.”



Care Funding (England)², which will be considered by the Housing, Communities and Local Government Committee and Health and Social Care Committee. They will question representatives from charities and policy experts as part of the inquiry into the long-term funding of adult social care.

On a national level, Healthwatch England identified home care as one of its top priorities for 2017. This followed analysis from across the local Healthwatch network that indicated one in five Local Healthwatch consider domiciliary care a local priority. That is double the number recorded within the previous year.

The increasing numbers of Local Healthwatch carrying out research into the delivery of home care reflects national concern about the service user experience. The comments and recommendations within their reports indicate that the issues faced by people in Suffolk should not be considered in

isolation. They are also experienced by those living in other parts of the country and as such, should be considered of national relevance.

A number of recommendations are repeated across the literature and this includes that consistency of care is an essential component of positive patient experience. Service users feel comfortable when they know and are able to develop a friendly relationship with their carer.

A second repeated recommendation is ensuring that carers have sufficient time and capacity to complete tasks on the care plan without being rushed. Local Healthwatch in Barnet³ and Redcar and Cleveland⁴ draw attention to evidence that service users sympathise with carers about issues such as travel times and poor conditions of employment.

A further common recommendation is that care agencies should try to

³ “Homecare in Barnet - A report on service user experience” - Healthwatch Barnet (2016) http://www.healthwatchbarnet.co.uk/sites/default/files/homecare_report_dec_2016.pdf

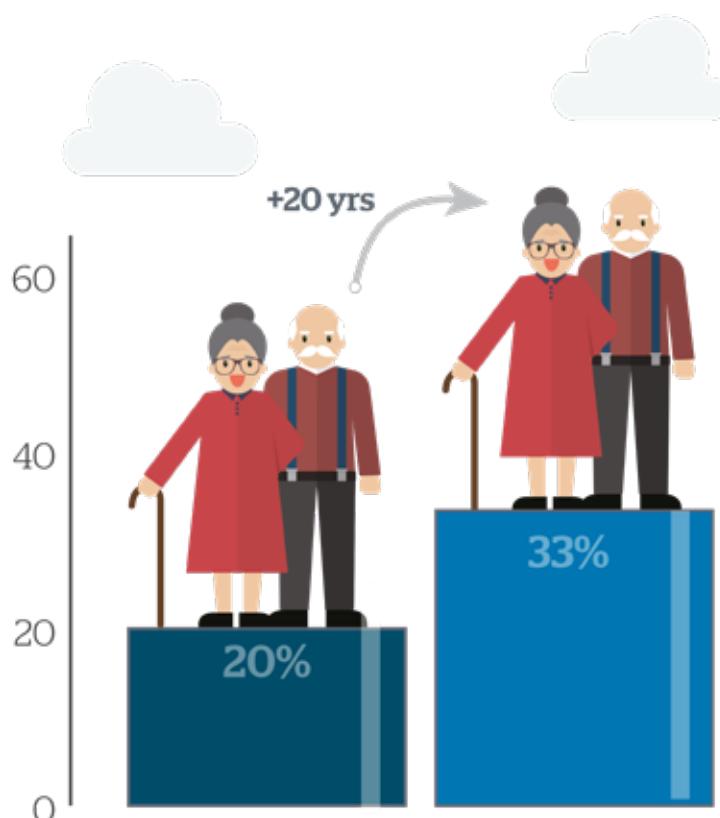
⁴ Healthwatch Redcar and Cleveland (2017) Investigating Domiciliary Care Service Provision in Redcar and Cleveland http://www.healthwatchredcarandcleveland.co.uk/sites/default/files/hw_domcarereport_final.pdf

⁵ Healthwatch East Riding of Yorkshire (2016) Home Care Services Report http://www.healthwatcheastridingofyorkshire.co.uk/sites/default/files/home_care_report_final_high_res_0.pdf

⁶ Healthwatch Halton (2016) Home Care - Who Cares? <https://www.healthwatchhalton.co.uk/wp-content/uploads/2014/06/Who-Cares-Report-web-small.pdf>

⁷ Healthwatch Warrington (2016) Opening the Door: Exploring the Quality & Safety of Care Delivered at Home <https://www.healthwatchwarrington.co.uk/wp-content/uploads/2015/07/Dom-Care-Project-Report-Final-Version.pdf>

⁸ Healthwatch Islington (2016) Homecare: Stories from Service Users https://healthwatchislington.co.uk/sites/default/files/home_care_2016.pdf



It is estimated that 1 in 3 Suffolk residents will be aged 65 or over in 20 years time, compared to 1 in 5 now. Social care will become an increasingly important factor in helping people to remain independent.

make sure service users are informed if their carer is going to be late or if a different carer has been allocated. Local Healthwatch in East Yorkshire⁵, Barnet³, Redcar and Cleveland⁴, Halton⁶, Warrington⁷ and Islington⁸ stressed that punctuality is important.

Other recommendations have sought to improve communication between the service user and the care providers office and encourage prompt problem solving to reduce the impact on the service user or their family.

Having identified this national priority, Healthwatch England produced a report called 'Home Care: What people told

Healthwatch about their experiences⁹. It brought together reports compiled by 52 Local Healthwatch and included the views of 3,415 home care users, their families and front-line staff.

Locally, after the implementation of Suffolk County Councils "Support to Live at Home" strategy in 2015, Healthwatch Suffolk received intelligence from stakeholders and the public that prompted it to seek further insight from service users as to their experience of home care services.

Historically, this has proven a challenge due to the nature of these services. Healthwatch Suffolk has therefore

⁹https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/20171002-home_care_-_what_people_told_local_healthwatch.pdf

identified “social care” as a strategic priority until it has discovered more about the experiences of these vulnerable and often isolated service users.

Another reason for prioritising social care is the fact that Suffolk has a higher percentage of adults over the age of 65, when compared with other parts of the country¹⁰. These numbers continue to grow and, in 20 years’ time, it is estimated that one in three Suffolk residents will be over the age of 65. Nearly 60,000 people will be 85 or over, nearly three times the current number¹¹.

As numbers of people in this age group increase the finance available from local government to support social care is decreasing¹². Thus, it is imperative that home care services in Suffolk are able to cope with increasing numbers of people who are more likely to need social care. Suffolk has an additional challenge as it has large rural areas where costs of care delivery are higher¹³ and deprivation often hidden.

With all of the above considered, this research has been designed to explore what is successful about the delivery of home care and what issues need addressing from the perspective of the service user and their families.

The recommendations of this report seek to highlight opportunities for bringing

about a wide range of changes that could collectively add to the current quality of home care provision in Suffolk.

Discussions also took place with Suffolk County Council (SCC), the Care Quality Commission (CQC), and NHS West Suffolk and Ipswich and East Suffolk Clinical Commissioning Groups (CCGs) to agree the research proposal.

During this process it became clear that, in addition to drawing attention to the strengths and weaknesses in the delivery of care in the home, this research could inform the re-procurement process of Suffolk County Councils Support to Live at Home (STLH) services planned for 2019.

¹⁰Public Health England. Suffolk Health Profile (2017).

¹¹ <https://www.suffolk.gov.uk/assets/council-and-democracy/our-aims-and-transformation-programmes/Suffolk-County-Council-Priorities.pdf>

¹²The Impact of Funding Reductions on Local Authorities: The National Audit Office: The comptroller and Auditor General: 19 November 2014; p9 <https://www.nao.org.uk/report/the-impact-funding-reductions-local-authorities>

¹³The personalisation of adult social care in rural areas; Tackling rural disadvantage; Commission for Rural Communities; August 2008; p7 An overview of the Domiciliary Care Market in the United Kingdom, United Kingdom Home Care Association (UKHCA) May 2016

METHODOLOGY

The project was designed in two phases and started in November 2017. Healthwatch Suffolk recognises that conducting such a survey during a winter period, and in particular a winter that had a distinct impact on rural health and care systems nationally, could be reflected in some of the survey and interview responses.

Phase one consisted of a short scoping survey (see appendix 1). It sought to identify who received care in the household, who the care provider was and how the respondent rated their care across a scale of 'excellent', 'good', 'average', 'poor' or 'very poor'. The respondent was also asked to share their experiences of the home care they received.

Those receiving letters and surveys were also asked if they would take part in an interview to explore their experience in more detail.

Originally it was intended to include carers and care providers in the research. A request for participants was made but only nine professionals responded. This meant there was insufficient evidence on which to base any credible results. For this reason, they have not been included within the analysis.

For similar reasons, it has not been possible to interview any individuals from diverse communities. It was simply not possible to identify any Black and Minority Ethnic (BME) service users from the sample of participants that returned a scoping survey.

Scoping survey distribution

Suffolk County Council (SCC) allowed Healthwatch Suffolk to access users of Council funded care. From these, SCC sent a randomly selected sample of 2,164 service users (nine of every ten who receive council funded care) a copy of the scoping survey and a letter asking for their participation.

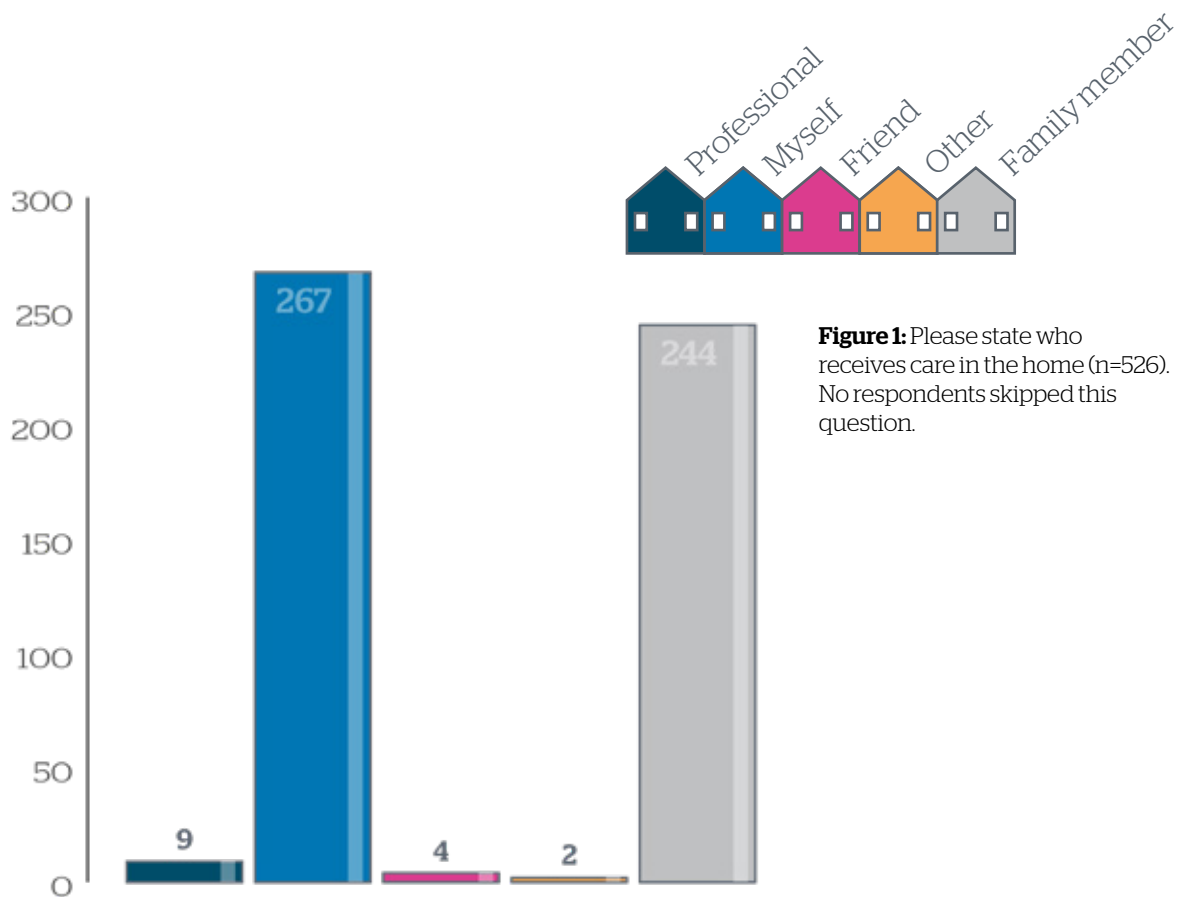
390 of these were sent to the advocate of the service user, where the service user might not be able to take part themselves but their carer might. A further 99 letters were prepared in an easy read format with an easy read survey attached. Front-line Social Work teams reviewed the list of service users being contacted to ensure that letters only went to people identified for one of the three letters.

The Healthwatch Suffolk Community Development Team disseminated surveys at community events and meetings where appropriate. Surveys were also distributed by some voluntary sector services in Suffolk.

The opportunity to take part in this phase of the project was also promoted within some parish magazines and local media including the East Anglian Daily Times. Such promotion was the only method through which it was possible to reach private home care customers not on the SCC service user list.

Response rate

Between October 2017 and 31 December 2017, a total of 526 responses were recorded.



All 526 responses received were entered on to Survey Monkey (www.surveymonkey.com), of which 267 were from service users themselves, four were friends, 244 were family members and nine responses were received from professionals who are not included in the analysis due to the low response rate.

This means the analysis was based on 517 responses. The large number of responses received and the random sampling strategy for the majority of the survey responses makes the results of this research project highly robust.

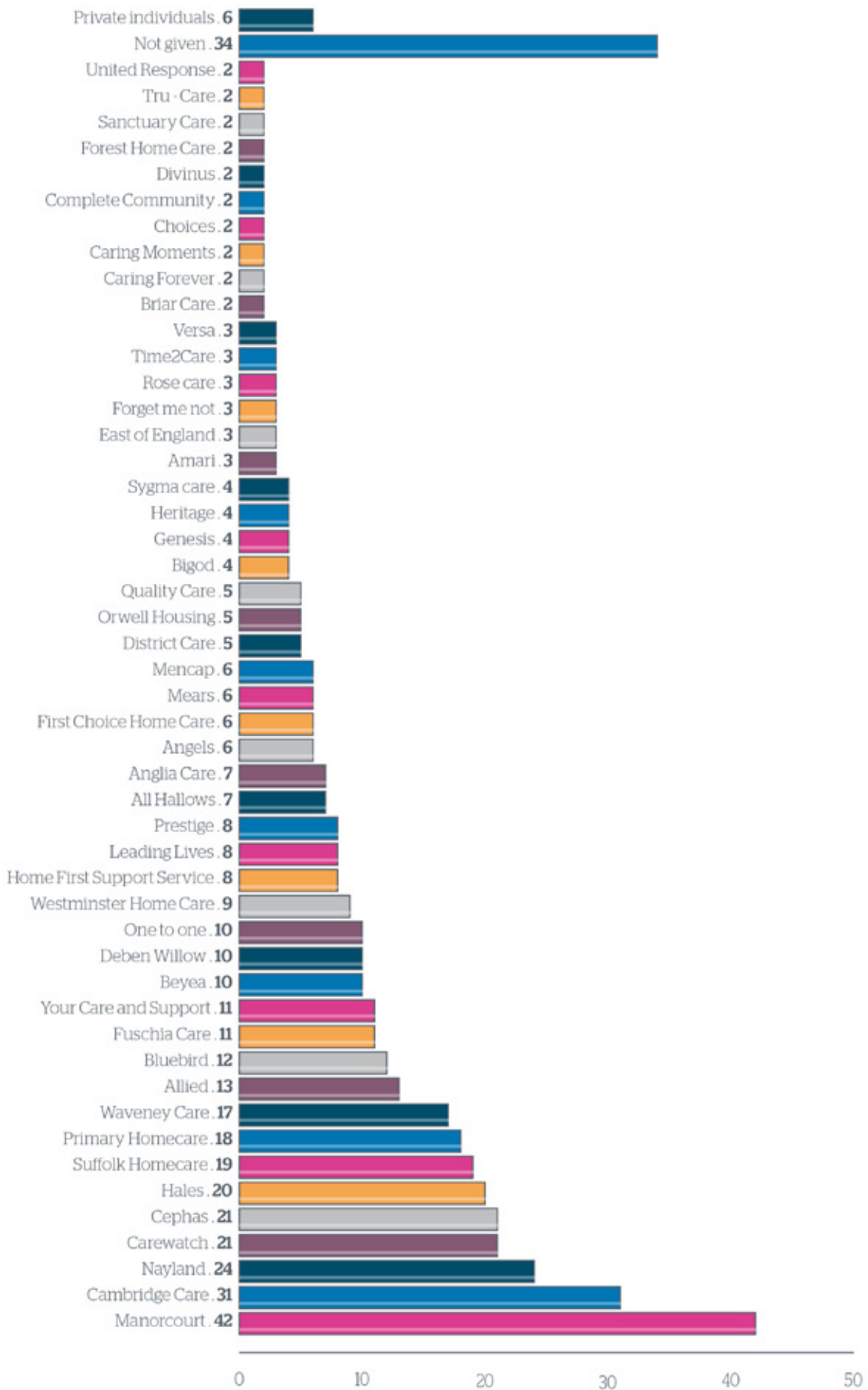
Following a literature review it is possible to state that this response rate also makes this project one of the largest of its kind across the local Healthwatch network in England. This could not have been achieved without the support of Suffolk County Council in disseminating the

survey and enabling access to service users.

The results of this analysis captured the experience of people receiving home care from 76 different care providers in Suffolk. Not every service user who received the scoping survey completed it. Therefore, there are Suffolk care providers who are not represented in the report.

Figure 2 gives details of the largest providers where more than two surveys were returned. Appendix 2 shows a full list of providers about whom surveys were received

Figure 2: Number of responses attributed to specific providers of home care in Suffolk.



Phase 2 started in December 2017 and consisted of fifty interviews, which often included both a service user and a close family member, often their family carer, at the same time. The interviews were carried out across Suffolk.

HWS interviewed 39 service users and 33 family members in these 50 interviews, meaning that 72 service users and family members voices have been included within the interview data.

This gives a valid perspective on their feelings and the impact care in the home has on their daily lives. 42 of these were individual face-to-face interviews in people's homes and eight one-to-one telephone interviews.

All interviews were conducted with the participants consent. The interviews were recorded and then confidentially transcribed by TranscribeMe. Following this the results of the interviews were analysed using NVivo. All recordings and transcripts have since been destroyed to protect the identity of participants.

The interview questionnaire (Appendix 3) was designed to build upon the information collected in the scoping survey. It covered all aspects of what is considered good care.

Interviewees were asked about the organisation, assessment, management and delivery of the care plan, ease of communication with the care provider and the resolution of any queries and problems as they arose. They were also asked whether they felt involved in designing their care plan and if they felt empowered to request change if their needs changed. Their experience of the actual care they received from carers was also explored.

Topics such as timeliness, training,



helpfulness, sociability, being treated with dignity and respect and efficiency were all discussed. Examples of care received that were above and below the expectations of the individual were also explored.

The interviews followed a semi-structured and conversational approach to make them more adaptable to the needs of the service user. Although this approach was useful in communicating with service users, the questions asked were not standardised, which made the interview transcripts more difficult to analyse numerically. However, the primary goal of the interviews was to inform and enhance the available information from the scoping survey with richer insight into service user's experiences.

It was considered essential that service users from both rural and urban areas of Suffolk should be represented in the interviews, as rurality and location are believed to be factors that could influence experience of care. Service users from larger towns such as Ipswich, Lowestoft, Felixstowe and Bury St Edmunds were interviewed as well as those in small towns and villages to ensure that the research was reflective of the needs

of users in different communities. All interviews were dependent on a willingness to participate and the availability of those receiving care.

To avoid bias care was taken to include a wide range of care providers. Four interviews were also carried out with respondents from providers specialising in customers with learning disabilities, to ensure that these providers and their clients were also represented.

The responses from the family members of these service users indicated that many of their experiences were identical to those of other interviewees.

It must be noted that the quantities of feedback reported are not sufficient to claim that the opinions expressed are representative of the entire Suffolk population. It should be considered however that the feedback provided is nonetheless important and is likely to be a fair reflection of patient experience. All participants, including those who

feature in the report as case studies, gave informed consent. Procedures to protect participants' information were followed. Those who agreed to be case studies also gave informed consent to photographs being included in the final report.

This report provides statistical and written evidence from the scoping survey and evidence gained from the views expressed by those service users participating in the individual interviews. It also includes case studies showing the individual experience of people and their families in different circumstances from across the county.

Care providers have not been identified by name. Themes are discussed in general terms to protect care providers and participants from sensitive information being made public.



They are very reliable and professional. The new ones are always taught well to do their job.

Home care service user



In order to test the results against an accepted standard of what a service user should expect from good care in the home the responses to the survey and interviews have been analysed thematically.

The themes used are those identified within the article compiled on the Healthwatch England website entitled 'What You Should Expect from Home Care Services'¹⁴.

It has been based on the guidelines developed by the National Institute for Health and Care Excellence (NICE)¹⁵ to advise older service users of the major elements by which to measure the standard of care they should expect from a provider of care in the home.

The key areas are highlighted are as follows:

1. Have care workers who are able to meet your needs...

Care workers should have the right skills needed to support people, for example if they have dementia or are deaf or blind. They should also respect the individuals cultural and religious values and make sure that their needs are met.

2. Feel comfortable with your care workers...

People should expect to see the same care workers regularly, so they can get to know them and be familiar with their needs. This includes how the individual likes to communicate and their likes and dislikes.

3. Be made aware of changes in advance...

If, for any reason, the regular care worker is unable to visit an individual, the person should be told in advance that a different care worker is coming.

4. Be given a care diary that's regularly updated...

Home care workers, and others who help a person at home such as physiotherapists or community nurses, should update the care diary each time they visit.

5. Be given a home care plan that meets your needs...

The individual should be given a plan that describes the care the agency will be providing that is focused on what is important to the person and includes any specific health problems or disabilities they may have.

To make sure that the plan is meeting the persons needs, there should be a review within the first six weeks of the first care visit. After that, the plan should be reviewed at least once a year.

¹⁴<https://www.healthwatch.co.uk/news/what-should-you-expect-home-care-services>

¹⁵<https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/better-home-care-for-older-people>



FINDINGS

The scoping survey asked for a satisfaction rating for the care which the respondent receives.

Figure 3 indicates that the overall satisfaction level for the 517 participants in the survey is high with 375 stating that their care is either 'excellent' or 'good'. Very few identified their care as 'poor' or 'very poor'.

This result reflects findings from a number of other local Healthwatch across the country who also found that satisfaction ratings were high. However, respondents who gave an 'excellent', 'good' or 'average' satisfaction rating still reported problems with their care in the open-ended survey comment section.

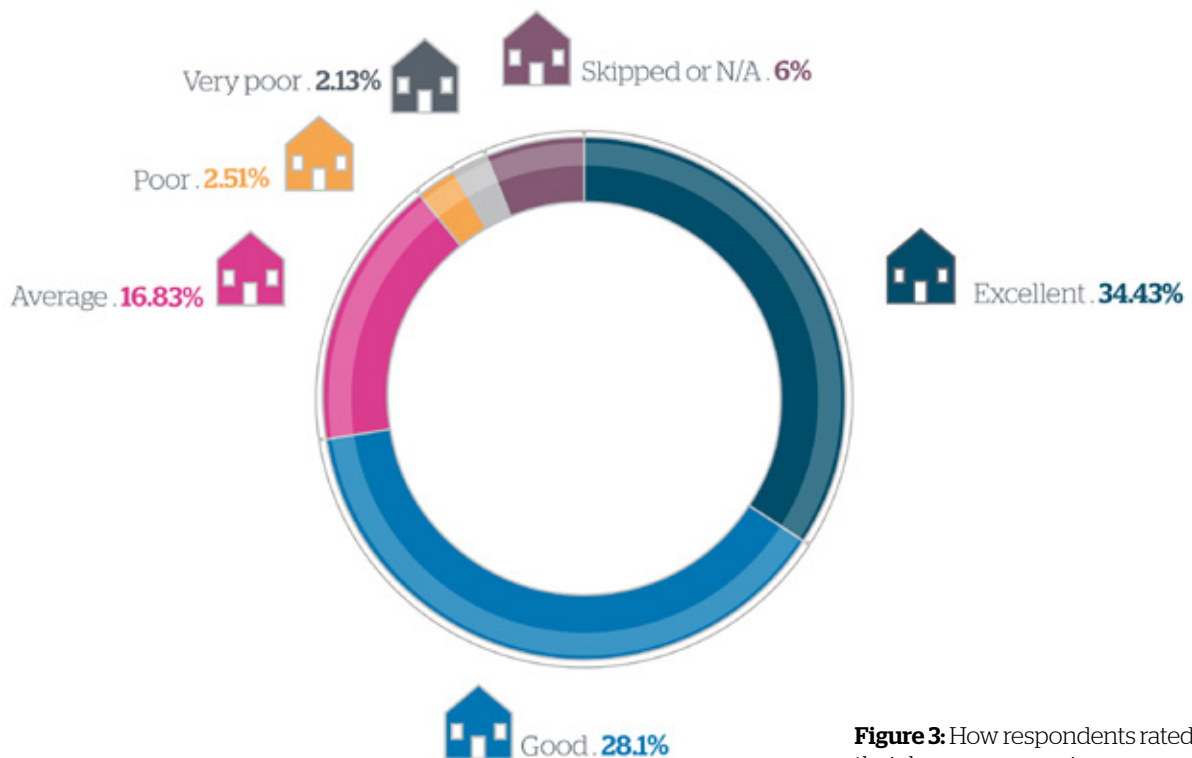


Figure 3: How respondents rated their home care service.

Several dominant topics were identified about the delivery and management of home care from the perspective of service users.

For the purposes of this analysis, these topics have been attributed sub-themes, or labels, which have then been grouped into overarching themes. Survey and interview responses were often attributed to more than one sub-theme if

the comment addressed several different topics. For instance, one comment could concern both lateness and consistency.

These themes have been developed from the Healthwatch England guidance on what people should expect from a home care service.

Two major additional themes were identified. These are “Timekeeping” and “Communication”. Two minor themes were also identified and these were “Comments about SCC involvement in home care” and “Changing care provider”.

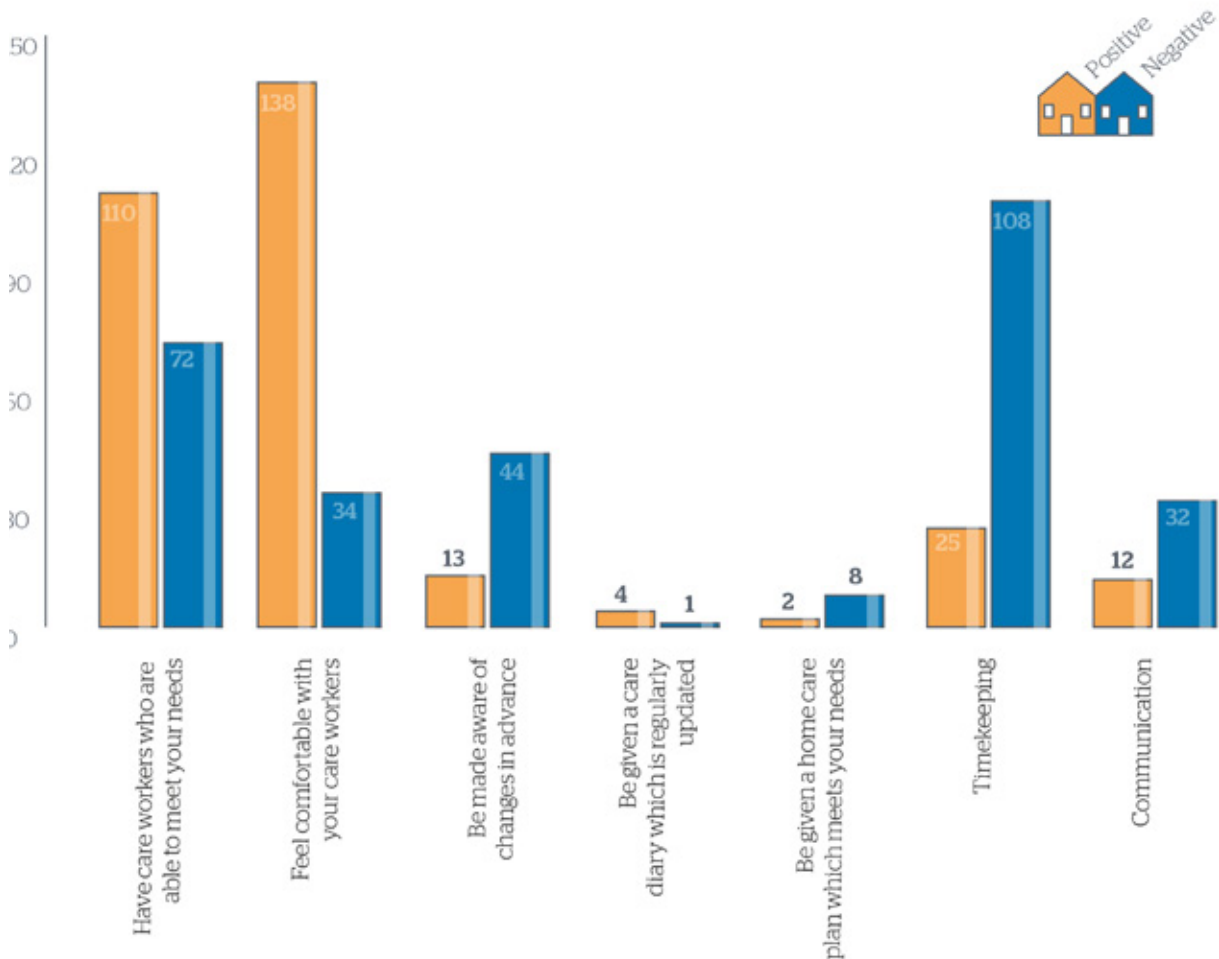
These minor themes are briefly discussed at the end of the results section after the main seven themes have been presented.

An assessment of the sentiment of the responses was made. This meant that the number of positive or negative responses within each theme or sub-theme can be identified. Figure 4 below shows the number of positive and negative survey responses categorised within each of the seven main themes.

The most common sub-themes in the survey by satisfaction ratings:

Figure 4 shows the most common sub-themes found in the survey regardless of how respondents rated their care. For instance, 46 of the 517 survey respondents commented that their carers were often late. These figures do not include the responses from the interviews, which have been analysed separately.

Figure 4: References recorded within each of the seven main themes and their sentiment.



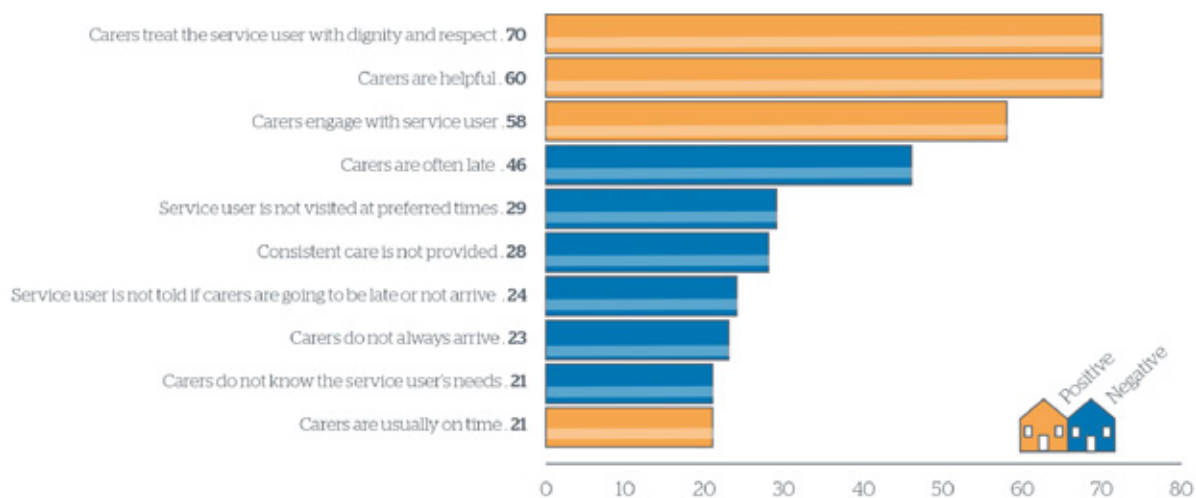


Figure 5: Most common positive and negative sub-themes.

As shown in figure 5, the top three sub-themes found in the survey comments were all related to the recipients' positive perception of their carers.

Analysis of these indicated that positive comments were most often associated with the carers themselves. Negative comments were most often associated with timekeeping and management issues.

Out of the 517 survey responses, the three most common sub-themes all related to how people are treated positively by their carers:

1. Carers treat the clients with dignity and respect (70)
2. Carers are helpful (60)
3. Carers engage with the service user (58)

The next six most common sub-themes in the survey were all negative, apart from references to carers being on time, and all relate to how care is managed:

4. Carers are often late (46)
5. Service user is not visited at preferred times (29)
6. Consistent carers are not provided (28)
7. Service user is not told if the carers are going to be late or not arrive (24)
8. Carers do not always arrive (23)
9. Carers do not know the service user's needs (21)
10. Carers are usually on time (21)



Of particular concern is that 23 of the 517 respondents to the survey made reference to carers not arriving to provide care at all.

For the 178 survey respondents who said their care was “excellent”, all of the most common sub-themes were positive and included:

- Treating the service user with dignity and respect (40)
- Engaging with service user (36)
- Being helpful (35)
- Being on time (15)
- Knowing the service user’s needs (13)

197 survey respondents who said their care was “good” overall, also made references to being treated well by their carers. This included that carers were helpful (23), engaging (17) and treated them with dignity and respect (22). However, these respondents also made reference to some negative issues including lateness (18), not having preferred visit times (13) and not having consistent care (12),

Of the 111 survey respondents who rated their care as ‘average’, ‘poor’ or ‘very poor’, most of the comments made were negative in sentiment. The most common comment was about lateness.

Respondents who rate their care as “average” also highlighted other issues of concern including non-arrival, not having preferred visit timings and not being told if the carers are going to be late or not arrive.

Only a small minority of the 517 respondents gave ‘poor’ (13) or ‘very poor’ (11) ratings.



When a new carer comes, I have to tell them what to do. It wears me out. And I hate it because I don't like asking people.

Home care service user



Liz's care...



My Canine Partner, Tenby, has changed my life and given me independence and happiness. Having him has reduced my need for carers from four times a day to two.



Liz has a stomach condition that means she can only eat or drink very small amounts by mouth. The rest of her nutrition is given intravenously. She was 'a very able and active person' until about 12 years ago after going into hospital with what was thought at the time to be food poisoning. She lives with her husband, Roy, and her support dog, Tenby.

Tenby is provided for Liz by Canine Partners and is crucial to her confidence and wellbeing. He is trained to help in practical ways as well as being a constant companion. He can retrieve things, including milk from the fridge, and take objects from Liz to Roy. He even knows the difference between the Television remote controls.

Tenby helps Liz get dressed and undressed. He also helps her into bed by lifting her legs up onto the mattress and pulling the covers over her. Tenby can do so many tasks that it reduces the need for Liz to have carers from four times a day to two times a day. Tenby is key to her independence.

Liz has received carers everyday for the last four years, and has been with her current provider for around a year. She has care in the morning and also the evening. She is also visited by a nurse twice a week.



***They're brilliant...** they can't do enough to be **gentle** with me, to do things really kindly... **you hear us laughing up there** -- and we have a lovely time... And I think that makes a difference... Especially for someone my age.*



Liz thinks her regular carers are brilliant but she finds it difficult when they cannot be there. Replacement carers do not always know how to care for her and appear unfamiliar with her care needs.

As well as knowing her needs, Liz's husband, Roy, told us that he thought there were two things most important to good care. Communication and consistency. He said it was important for

“

I've got two carers, they come in the majority of the time. But also, on the days when it's their day off... **[y]ou don't know who's coming in...** I've asked [the office] to stick to the two carers that I get on really well with and they're really good with my lines and stuff because negotiating the lines... is quite a nightmare for them. But they know exactly where they are so it's never a problem. We find when **new carers come in, it's quite difficult... [b]ecause they're quite frightened of it.**



”

them to have consistent carers in order to be able to build a relationship with them. Roy also said communication could be improved through use of a rota. The agency does not currently provide a rota. As such Liz and Roy do not know which carers will arrive and when.

Liz has a stomach condition that means she needs care twice a day. Her husband Roy, and their support dog Tenby, have been an important support.



What did people tell us about their home care?

This section presents the results of both the surveys and the interviews.

The results are presented thematically, starting with the five themes developed from Healthwatch England and National Institute of Clinical Excellence (NICE) guidance on what people should expect from a good home care service. This includes the following key themes:

- Having care workers who are able to meet your needs
- Feeling comfortable with your care workers
- Being made aware of changes in advance
- Being given a care diary that is regularly updated
- Being given a home care plan that meets your needs

These are followed by two additional themes that emerged from the research: These are:

- Timekeeping
- Communication

Finally, two other smaller themes in the research that are still crucial to good home care, but had fewer references than others, are detailed:

- Matters related to Suffolk County Council
- The view of service users on the process of changing provider

Each of these themes is comprised of several sub-themes that are explored in order of the number of comments made about them in the scoping survey.

The majority of 517 service users in the survey (212) highlighted the positive feelings they had about their carers, for example:

“

“Most carers very good, all adequate”

“I’m very satisfied with the care I receive.”

“...Nothing is too great a problem. Sister has been a lot more cheerful and positive since this team started.”

”

These comments could also often be made alongside negative sub-themes. For example:

“

“Carers are extremely good but they are exhausted by the volume of work they are expected to do. I have no patience left for the office staff. Excellent carers/poor office.”

”

The rest of the results section gives much greater detail about the specific sub-themes arising out of the research.

Theme 1: Have care workers who are able to meet your needs

'Having care workers who are able to meet your needs' was interpreted as including carers being helpful, properly trained, knowing the needs of the person they are caring for and carrying out tasks to a high standard.

Of these aspects of care, helpfulness was the most important. 'Having care workers who are able to meet your needs' was the theme that received the largest number of comments in the survey overall. Out of 517 respondents, 110 positive and 72 negative comments were made.

The largest number of negative survey responses in this category, was related to

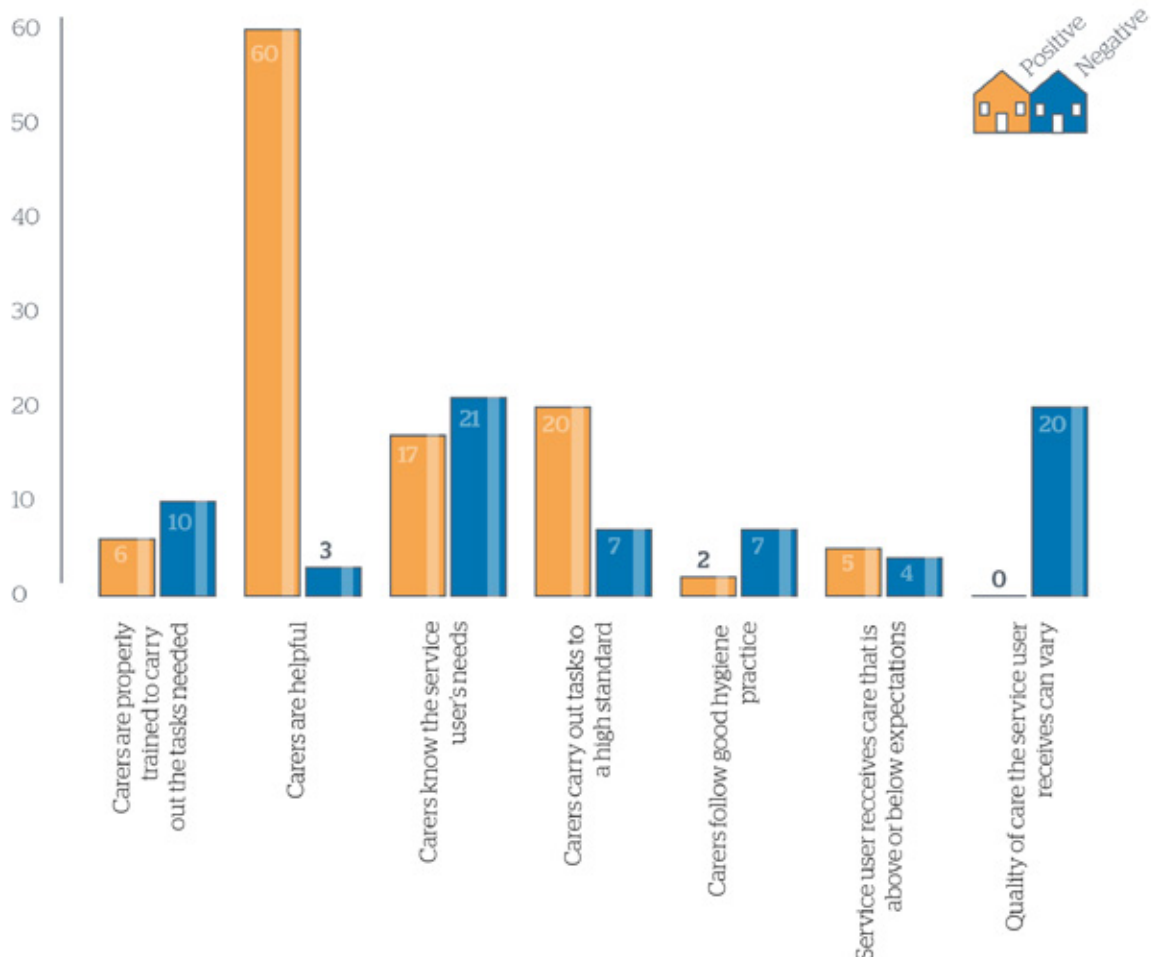
having workers who did not know their needs, including lack of knowledge of the care plan. This was often related to not having consistent care.

No respondents to the scoping survey or interviewees commented on whether their cultural or religious values had been met. This may have been because there were no identifiable replies from minority ethnic or religious groups.

Sub-theme 1a: Carers are helpful

The results of the scoping survey show that carers being helpful and asking if they can do anything else before leaving is very important to the service user, with 60 positive comments and only 3 negative out of the 517 responses.

Figure 6: The number of comments attributed to sub-themes within theme one (Have care workers who are able to meet your needs).



They know our needs...

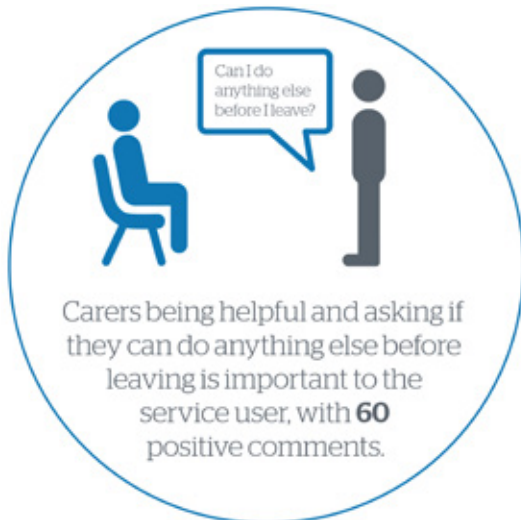
“



“Regular carers at regular times, hence they build a good relationship and understand my father’s needs. Being regular carers they also notice any changes or potential problems.”

**A relative of a home care
service user**

”



This clearly indicates that many carers in Suffolk act in a compassionate and helpful manner. The interviews confirm that helpfulness is extremely important to, and valued by, the service user.

Examples of such comments from the open-ended survey responses include:



"My support staff are very helpful. they help me with all aspects of my life, mail, personal prompts, social, prompts to do laundry, cleaning, check the food is in date etc medication checks"

"The regular carers... are excellent carers. They are kind, friendly and efficient. They always chat to my mum in a friendly way whilst helping her and ask if there is anything else they can do to help her before they leave"

"...friendly & helpful... carers mostly. Will offer to do extra duties like washing and some cleaning. A professional caring service, who appear to value and respond well to client's needs"



In the 50 interviews, there were 33 specific positive comments about the helpfulness of their carers and about their carers asking if they can do anything else to help.

Comments include:



"They say, 'Is there anything else that we could do while we're here?' And sometimes I'll say, 'Yes, could you make me another cup of coffee, please?' Or just little things like that really. If not, I'd say, 'I see you've got five minutes left or ten minutes left, would you mind just having a chat with me?'"

'She'll do anything really won't she? Yes, always. She puts your makeup on and she'd do odd bits of cleaning. She'll put the washing in. She'll iron too... It's handy having a girl. Because I used to find with that carer when I had him we'd go all the way down to town, and we didn't speak because he couldn't speak the language. I found that really infuriating'

"They always say, 'Anything else you want? What can we do?' In the evenings they prepare the breakfast for the next day, they put that all in the fridge. So I know what I'm eating for breakfast the next day because it's all so organised and it makes their life easier. And they come in and I shower and she'll do my hair. Get me dressed so that I'm ready for the day.'



With the above in mind, three survey comments and four of the 50 interview respondents made a reference to carers

being unhelpful or not asking if there is anything else they can do to help.

Where dissatisfaction is shown it normally relates to carers not listening to or knowing the service user's needs, not carrying out the tasks in the care plan or not doing the tasks that the service user requests.

Survey respondents who made negative references about their carers helpfulness said:

“

“Some carers are good, whilst others seem to not really care or listen to specific instructions to help.”

“No longer have them due to problems. 3 out of 5 days did not turn up on time. Staff were often bossy, critical and reluctant to help.”

“Personal care was not provided as requested with the excuse that offer was declined. The timing and length of visits were not helpful - too late on first visit usually after 9.00am and visits rarely lasted the full 30 minutes paid for. Seemed to have no experience of dealing with people with dementia. Did not help with feeding client. They were always friendly in arrival.”

”

Examples of comments from interviewees include:

“

“Well, they didn't listen with this [carer] then. Because I said to them,

“Don't you ever send him to this house again.” But he's still there. When he came last time, he said to me “are you trying to lose me my job?” And so I said, “Not if you do it properly.” So we didn't have any more of that conversation.’

‘When the lady came, it was in the evening. And when I first had the carers, I had morning and night time. But the night time they used to come about six o' clock to put me to bed, so that wasn't very good. And one night, this one person who is particularly bad about helping came. But I was upstairs in the bathroom. And she came in, and she just shouted up the stairs. And she went off. She didn't even see me.’

”

Sub-theme 1b: Carers know the service user's needs

‘Carers knowing what your needs are’ has been interpreted as carers knowing the contents of the care plan and knowing the service users likes and dislikes.

Figure 7 shows that 17 of the 517 respondents to the survey write about carers knowing their needs and 21 said that they did not, making this the second largest sub-theme within the overall theme of ‘having care workers who are able to meet your needs’.

Out of the 50 interviews, there were 31 comments about carers knowing their needs and 19 in which participants told HWS that carers did not know the care plan or the service users likes and dislikes. Interviewees were, therefore, more positive than the survey respondents about the carers knowing their needs.

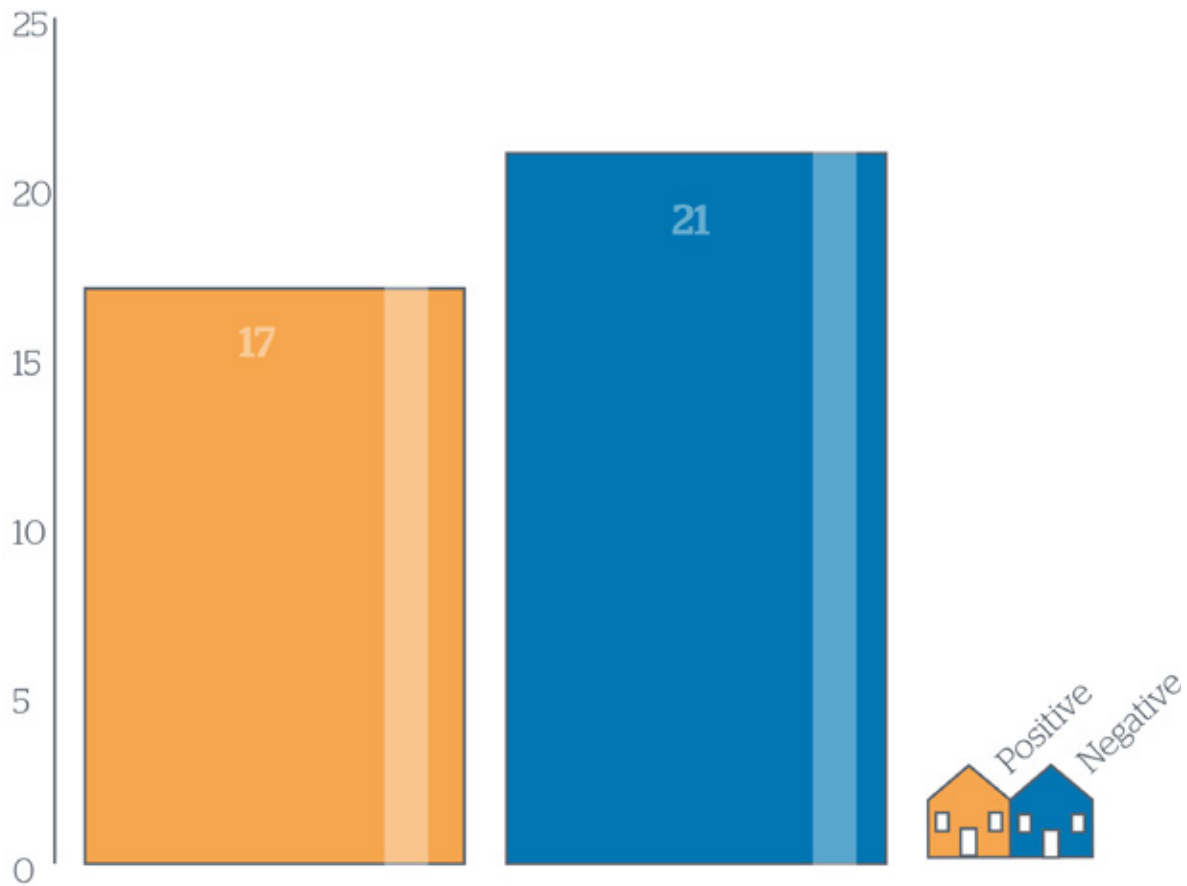


Figure 7: The number of comments within survey responses that made a reference to carers knowing the service users needs and the sentiment of the comments.

Within both the survey and the interview comments there are several service users who feel that their main carer(s) know their needs but that replacement carers have little knowledge of the care plan or are not informed enough about their likes or dislikes.

In the 50 interviews, 12 comments were made about the lack of knowledge of their care plan and needs when carers do not know the service user.

Examples of where survey respondents have made a reference to carers having good knowledge their needs include:



“The care is excellent. they all try and accommodate my needs, either at the office or the carers that come in to me.”

“Regular carers at regular times, hence they build a good relationship and understand my father’s needs. Being regular carers they also notice any changes or potential problems”

“... The staff are very good. Always polite and respectful. They listen to me and carry out the tasks in a way that I like.”



These views are confirmed by the interviewees:

““

“They are really, really good. They have all been really good. The two sort of regulars as it were, have been coming since last January and it’s been the same two. So we all know each other really, really well now and they might sort of say to me. “[My relative] not really been herself yesterday and I wonder if she’s got an infection,” or what have you. Whenever they’re on holiday or have their days off, the cover carers have also been the same ones. So they’re all people that mum knows so she sort of feels quite happy with them, quite secure with them. They’re not strangers as it were.”

“But the carer normally comes about 5:00 and that, and she’ll just heat one of them (a meal) in the microwave. She’ll get me two bottles of water at night, for the night-time, because I tend to drink it in the night. Drink one while soaps are on, and then I drink one through the night and that. And then she’ll get me a jelly and a custard, which I buy. And then I’ll have one of them. And then she’ll make sure I’ve got everything I need before she goes. She’s fantastic.”

””

Where the carer does not know their needs, the service user may have to explain what is needed which can be tiring. Some respondents told HWS that carers not knowing their needs could have a detrimental impact on their physical wellbeing.

In the survey, the following comments were made:

““

“No consistency of care as too many changes of staff on a daily basis, despite being with this company for 4 years. Carers do not have enough time to do a proper job, such as full body wash. [The client] is in constant pain if handled incorrectly by carers, despite being shown or told on several occasions.”

“No care at all. Changes to time to suit agency. Not being advised. Carers untrained. Sent in some carers that have NEVER been in. sent in some times only, 1 carer, He suffers with dementia so timing and same faces is important. However that falls on deaf ears with office.”

“All carers are friendly and helpful. I think they should have more training on information on the clients condition. My partner has to explain every time a new person comes in and it leaves him exhausted.”

””

Examples of comments from the interviews:

““

“I mean, he can certainly tell you what he wants, what he doesn’t want. So that obviously is quite helpful. You could hear him say, “Right, you do this next. And you do that next.” And so he talks them through it. But they wouldn’t have



Comments indicate that ensuring carers can develop an ongoing relationship with a service user is key to them understanding and meeting people's needs.

time to read through the care plan when every time they come in if they're new people because obviously, they only get the set amount of time."

"So something like that. But it's much more difficult. Something as straightforward as vacuuming the floors. It doesn't require any interaction. You don't need to explain anything so when it comes to asking for something more personal, even though it's in the care plan, it's much more difficult if you don't have a full relationship with that person. It's much easier if you know them quite well if you're used to talking to them. It just varies a bit because they're all different personalities and-- because they are different personalities, so when you don't know them then it does feel awkward. They all seem nice and it's nice to talk to different people, but it

takes a lot of energy. And especially as I don't get out much. There's more sort of social anxiety sort of like I'm less used to new people. It takes a lot of energy and it sort of exhausts me so it would be better to have one person."

"The biggest thing, I think, is, in fact, the continual change of carers, and I suspect that's the structure because in a period of, what, six years, we must have gone through 20, 25, 30. If you look at changes in providers, first one, then another, then another. And that must be a concern because all those changes bring different standards, and different situations, and different awarenesses, and different apprehensions by the customer, and so on. It's not an easy one, that one."

Examples of difficulties with replacement carers not knowing the service user's needs from the interviews:

“

“We find when new carers come in, it's quite difficult to find their way with the equipment. Because they're quite frightened of it. It is the odd carer, we've found that the consistent ones are very, very good. The odd carer you do notice that some are better than others, don't you?”

“The ones that are filling in now, when they first started, about six weeks ago, they just didn't have a clue. They had a job finding us, to begin with, and then after that, they'd obviously had quite a few complaints from other clients. They now have them shadowing the regular carers. But they should have done that before not do it afterwards.”

”

Sub-theme 1c: Carers carry out tasks to a high standard

Carrying out tasks to a high standard requires the carer to carry out tasks willingly but also that they try to meet the standards expected by the service user and carry tasks out to their satisfaction.

Twenty of the 517 respondents to the survey made comments that stated they feel tasks are carried out to a high standard with several examples of the very best care. Seven survey respondents were dissatisfied with how tasks were carried out.

The 50 interviews reflected a greater



dissatisfaction with the standard of care they receive with 15 negative compared to 13 positive comments.

As can be seen in the interview quotes there are various reasons given for care not meeting the standards required of the service user.

Examples of comments from the scoping survey where respondents have made reference to high standards:

“

“Carers are very helpful, plus the personal care is of a very high standard. Polite and friendly, plus a very good neat and tidy appearance.”

“There are no negative aspects. Care is excellent... [the carer] looks after all needs, bathing, teeth cleaning, medication, doctors and hospital appointments. Keeps home immaculate, cooks and washes clothes and much more.”

”

The positive interview comments where carers met high standards include:

““

“...we really couldn't ask for anybody better. The other thing is she makes sure I've got clean clothes on because otherwise I'd put the same on that I had yesterday because I never remember what I've worn from one moment to the next. She's thinking about things and always looking to do what is necessary.. Well, she's kind of part of the family now isn't she?”

“My carer is an excellent carer. She sees things that need doing. You don't always have to ask her. She doesn't overdo things but she does everything gently, nicely. She washes you. She'll wash my hair sometimes.”

“It doesn't take that long to have a shower, but she stays to make sure I don't wobble or fall down the stairs. And she actually physically helps me to shower as well. At my age, it's lovely to have your back scrubbed.”

””

Reasons given for dissatisfaction with carers who did not carry out tasks to a high standard included the carer not being fully aware of the contents of the care plan and of the service user's needs and being in too much of a rush.

Some examples of negative survey comments within this sub-theme include:

““

“Some are really kind and good but a lot are uncaring and untidy and

terrible at cooking, sometimes rude and forget to make bed, empty bins and clean my feet. Nearly always late.”

“Cups not washed up properly. Bed not made very neatly. Very slapdash. Very quick.”

“Some are very good, others are poor. Washing is variable and inconsistent.”

””

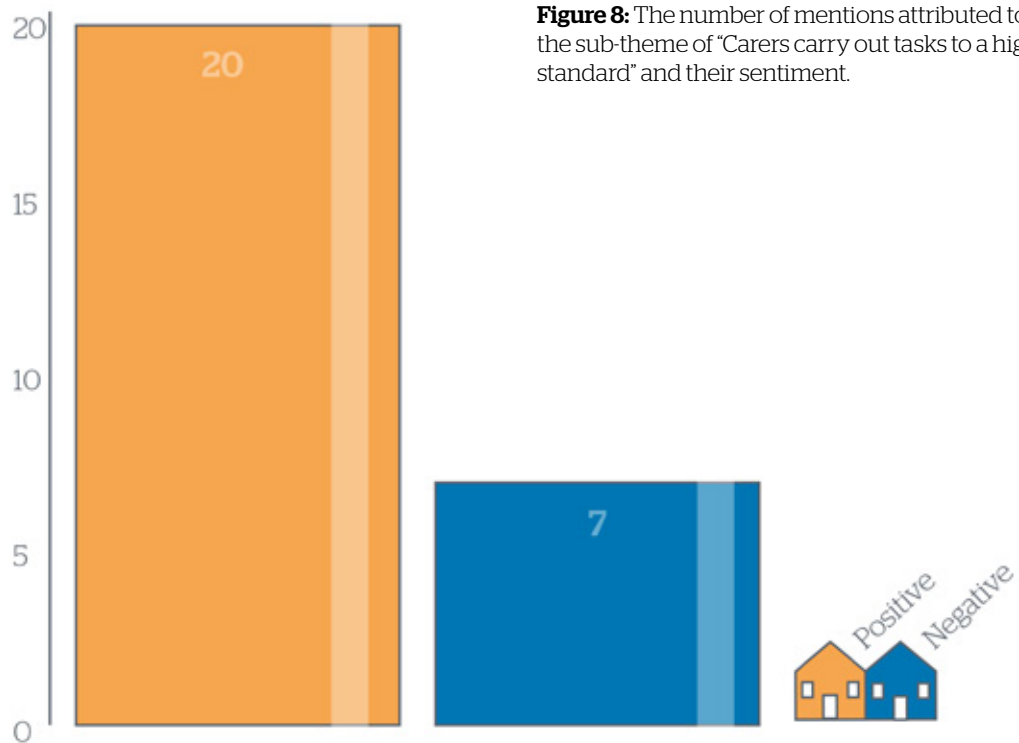
Some interviewees reported that they found it stressful that they had to explain their needs each time. Examples of the negative comments made in 13 of the 50 interviews about their carers standards include:

““

“Often, if there's a fresh carer start, not necessarily new to the job, but perhaps from some other part of their organisation, because they seem to get short of people quite frequently, and somebody comes in from somewhere else to help, and they never look. They don't have any idea when they come in of my relatives problems, and I've never seen them look in the book, either. They know because I tell them.”

“This is what I found. So exhausting. When a new carer comes, I have to tell them what to do. It wears me out. And I hate it because I don't like asking people. I'm very independent. It's a real pain to me to have to ask for anybody to do anything for me.”

””



“

“As soon, as they’ve fed me they’re back out of the door and just in one perpetual rush all the time. You can’t do this for the blind. They haven’t read my records, my medical records to see what I’m registered as, and they treat me as if I was a... moron..”

A home care service user



Several interviewees perceived that tasks not being completed to a high standard might be because of time constraints on the carers who have to travel to the next appointment.

“

‘The carers are quite good on the whole. They’re quite good. They’re often under quite a lot of pressure. I mean my relative is supposed to have half an hour at least in the morning and quarter of an hour in the evening or sometimes in the morning, it extends for about 15 minutes. She has to be dressed, washed in that time, and sometimes have a shower. It’s all too quick. I think they’re so pressurized with the calls they’ve got to make and that. But really, that isn’t our problem, is it?’

‘[Staying the half hour.] It’s not an issue as such. It’s when they start rushing in and rushing out because they’ve got other calls or, “Oh, I’ve got to do this. I’ve come in early because I’ve got to do that.” That sort of thing. That’s when it’s an issue. If they come in and do it and they’re finished 10 minutes and they go, “Do you mind if I go now?” that’s not an issue, but it’s when they come running in.’

”

Sub-theme 1d: Quality of care the service user receives can vary

Twenty of the 517 respondents to the survey made comments that were themed as ‘care variable’. These were comments which stated that the respondent received care that they described as either good or poor, depending on the person attending.



Examples of variable care in the survey responses include:

“

‘Most carers very good, all adequate’

‘Some carers are better than others’

”

Because of the semi-structured nature of the interviews, it was more difficult to categorise comments as ‘variable care’, as multiple opinions could be expressed about different aspects of care in the same interview. However, in 14 of the 50 interviews, specific comments were made where care could be described as variable including:

“

‘They vary from person to person. Some of them you only see once and then you never ever see them again. And the next carer they all know she left. She hated it. She didn’t like it. And again, if they’ve never tried it before people come into

it with certain expectations and it's not what they thought. Or it's horrible. Or they can't cope with it. So, I understand that the turnover is quite good. It's a bit of pot luck really. You get some really good carers. Like I said, during the time my [relative] has been there, I suppose she's had five or six what I would call quite good carers. She's had one or two what I'd call flight-in-the-night ones. You see them and then they're never seen again. And several of them- and again, that's I presume because the amount of rounds they've got to do. They're under pressure. Like I said, they're in and out like a shock. I complained several times. I am paying for half an hour and get five minutes.'

"...the ones that are good, they just work far too hard, and they get physically exhausted because it's a demanding job. It's a difficult job that they do. And they're all lovely, the carers that come. They do a good job. Most of them. I wouldn't say all, but most of them. And they're very good with my husband, but it's just on the odd occasion when the whole system just falls down. And I think that, well, from a client's point of view, the care should be consistent all the way through."

"Other people were actually brilliant and fantastic. But it was the initial issues, I think, things like the lack of time and the lack of listening to what work was needed, the two people in the morning, the double up. And the lack of time just to keep him moving. Well, it ended up with not enough care because of only one person being there they couldn't cope."

Sub-theme 1e: Carers are properly trained to carry out the tasks needed

There are some examples where respondents perceived that their carers may not be adequately trained to carry out their tasks.

In the 517 survey responses, six people commented positively about their carers training and ten made negative comments.

In the 50 interviews seven service users commented that they were happy with the training that their carers appeared to have received. However, in 20 of the 50 interviews comments were made that their carers seemed not to have been trained properly in the operation of medical equipment, manual handling and daily living aids.

This is of real concern as a lack of proper training to use equipment or complete tasks adequately can lead to care well below expectations.

Survey respondents made both positive and negative comments about their view of the training that the carers receive:

“

"They are very reliable and professional. The new ones are always taught well to do their job"

"...carers are always excellently trained and carefully matched to clients"

"Poorly trained staff. Very young, in and out, no attention to care"

"All carers are friendly and helpful."

”

I think they should have more training on information on the client's condition. My partner has to explain every time a new person comes in and it leaves him exhausted."

Quotes from the interviews present a more complex and concerning picture:

"....And I'm expected to sit up, which is very hard, but they haven't read my medical records so they don't really know how to deal with me. I wish they could be properly trained, these people because I'm a serious medical condition after all that's happened to me. And they're not complying with this at all."

"We've had things where she had a urine bag at one stage, and they were aware of that, and they were sending people who hadn't got any knowledge of how to change it or anything. They tend to be --- they're not consistent is the word I was looking for. They'll be good for a little while. Then they'll be terrible for a little while. Then they'll be average for a little while."

"And I think it would help, and I think letting your carers know what they're actually looking into-- because they come here, the ones that don't know, and they don't know what they're doing. Because they say to us, "What should we do? We don't know, you got to tell us." So, if I was someone with Alzheimer's,

dementia, I couldn't tell them. And I could tell them that I'm going to take all those pills, and they'd be none the wiser."

"... because (the shower sling) was a special order, it was nearly three months before he had a shower. Then, the two ladies that came to do him were so nervous, they really didn't know what to do. It looked like a child's paddling pool out there. I thought, "Oh, my god--" And they were very, very unhappy. I could tell they were. So, I phoned their boss and said, "This isn't good enough. It's not your fault. You're sending ladies out that [aren't properly trained]."

Some respondents told HWS that good training gives confidence to the service user and their family and helps to build a relationship of trust:

"And I think if you're lucky, like at the moment we're in a bit of a rich vein of people who are carers who visit my mom that actually do seem to know what they're doing."

"But I've asked her to stick to the two carers that I get on really well with and they're really good with my lines and stuff because negotiating the lines and stuff is quite a nightmare for them. But they know exactly where they are so it's never a problem. We find when new carers come in, it's quite difficult to find their way with it. Because they're quite frightened of it."

Sub-theme 1f: Carers follow good hygiene practice

Hygiene is of importance to service users. Not wearing gloves, and/or masks when appropriate, washing hands and using service user's facilities without tidying up properly can be a problem.

There are a smaller number of comments about hygiene in the surveys. Two people out of the 517 survey respondents make positive references to hygiene and seven negative. Despite this, the comments show that hygiene is clearly important to service users, especially if the carers hygiene practice is lacking in any way.

The interviews confirm this view and there are five comments out of the 50 interviews about problems with hygiene such as not wearing masks or aprons, not washing hands, attending when suffering from the norovirus, and ignoring good hygiene practice in the kitchen.

Comments in the surveys often related to wearing masks or feeling that ill carers were a potential health risk to vulnerable service users:



“When carers have coughs, colds or sickness I want them to wear masks.. I am ill and cannot afford to be coughed or sneezed over. I would end up in hospital again”

“Young carers no idea of kitchen cleanliness.. Unwell carers appear danger to frail clients.”

“Always wear uniforms, use aprons, gloves, shoe covers and mask if they have colds.”



Participants in the interviews said:



“It was just her hygiene in general. But also a big side-effect is [my relatives] immune system isn't very good at all. So we have to be careful - that particular carer came with a cold. I raised a subject of putting a mask on, which we don't normally necessarily need a mask, and I got the answer, “Well, I'm not wearing them because they're uncomfortable.” So I then said, “Well, are you provided with them?” “Oh yes, I brought them with me but I don't like wearing them.” At that point, we asked her not to come again, for the company not to send her again.”

“Well, they don't wash up or they wash up in cold water. They've washed up with a nail brush, I found one of them one day. Some of them don't put the rubbish out and they're

supposed to because it's not very easy for me to do. In the bins. They don't put things away, they leave them all round the kitchen. Sometimes my microwave can look as if it had a bomb hit it. You know inside it's disgusting.”

“

“... he was using my toilet every day... He was going in there and coming out very quickly and I thought, “Is he washing his hands?” so I checked, but no and he then washes me. And then, went to the kitchen with no gloves on to prepare my breakfast

**A home care
service user**



Sub-theme 1g: Service user receives care that is above or below expectations:

There are several examples which show that some carers are exceptional and carry out their role with sensitivity and real concern and interest in the people for whom they are providing care. There are also some examples where care falls below the service user's expectations.

There were relatively few such comments in the survey, with five of the 517 survey respondents giving examples of carers doing things above expected standards and four comments about situations below them:



'Very kind ladies who helped... a lot and were prepared to go the extra inch to help me with domestic chores'

'On a couple of occasions, the carer went above & beyond her call of duty to ensure the safety of my dad'

'All of the carers are kind, however I see my mother very frequently and she can be unwashed, in dirty clothes and generally unkept, even though carers attended to her 5 times each day and should be assisting her with these areas! I don't think this is acceptable'



'And they know when it's someone's birthday and they'll remember if you've said there's an event like this presentation thing with the dog a couple of weeks ago. As soon as they come in they're like, "Oh, how did you get on with the dog?" and, "Did it all go?" and I think that's different when someone remembers, or, "Oh, happy birthday." It's only a little thing but it makes such a difference.'



'Sometimes Mum has had to wait up to 3 hours for her visit (after her designated visit time) which means she has been in her bed for 15 hours, wet as she is incontinent, and still awaiting her medication'



There were 17 examples within the 50 interviews of service users describing care which they felt went above expectation of their carers:



'I was thinking about the care and how she helped with the prescription. Because every month we have our new prescription and the carer will pick it up. But that time it was not only our prescription but also something that we had from the doctor for having been to an appointment. And the doctor hadn't signed the prescription. So, she went to pick it up and first the drug wasn't at the chemist, so she went back later to do that. And then they said they couldn't give it to her because it didn't have a signature. She went down to the doctor's and gave it in and went back the next day and the doctor hadn't been in so she couldn't-- and went back the next day. And we were only having a

carer in once a week for two hours, but she spent three different days trying to sort it out for us. It was excellent.'

'And we've got one who goes way beyond. On one of her days off she came and sat with my mum and did little bits and pieces and helps her out. Which is way beyond what she's doing, and she's obviously not getting paid for that. But she's just a very nice

lady who's sort of got a bit of a bond with my mum there. And I asked if she could regularly be one of the regular carers. And she does see my mum-- and there's some nice little touches. Like she bought some chips from the chip shop and shared them with my mum the other night. Which was quite a good touch, beyond what you would expect from a carer.'



“

“On a Saturday, she does a fish and chip run for several of us.. And she'll sometimes take me to the factory shop so I can have a look. One day the lady didn't turn up to walk the dog. “I'll do my rounds and I'll come back. I'll walk the dog.” She is absolutely wonderful.”

A relative of a home care service user

”



Respondents to the survey and interviews highlighted a number of experiences where it was clear their carer had gone “the extra mile” and this had a highly positive influence on their view of the person.

There were also fifteen instances in the 50 interviews where service users believe that care is below expectation. Most of these comments are included in other relevant sections of the report but three examples are:

“

“The other three, one of them is supposed to start at ... 8:30, he told me that because [his daughter is ill], there might be occasion[s] when he's a little bit late in. Which is fine. I understand that. He never once came on time. What he would do, he would come and he'd write in the diary that he arrived at 8:36. He would sit on the wall at the front there and he'd be there for about 10 minutes, then he would knock on the door and ask if he could have the key to the garage to put his bike in the garage. Which I was fine with him leaving his push bike in the garage. And then he would come in and he would go straight through to [the] bathroom and shut the door, even though I was already washing and dressing [my relative] by then because by this time it's 8.50.”

If you rang up or you told them about something, and if they were not very happy about it, they'd take all your known carers away and you'd find you'd have different people in, for two or three weeks. I'm not the only one that's said that. I know other people have found that, too... it can happen anytime. You might find that you've got carers that you'd never, ever seen before, for two or three weeks. And then, your own carers will come back one at a time, perhaps two this week, three next

week. You might never see someone again. I think it's to get own back on you for saying something.’

”

Janet's story...



It gives me time to lead my own life. To take the dogs for a walk or walk my grandson to school. A little normality in a day that can be exhausting. I know my husband is cared for.



Janet is the main carer for her husband who suffered brain damage following a fall in 2011. He has since been mostly bed ridden and in need of 24 hour care.

Up until last year the care they received was excellent but unfortunately, due to staff changes in both carers and managers, the care has been disrupted. It is now causing Janet some concern.

Janet has received invoices from her care provider, which is unusual and is becoming increasingly concerned because some of them are very old.

She is also confused about the different methods available to her for managing the payments she receives for her husband's care. She is also confused about

the different methods available to her for managing the payments she receives for her husband's care.

In addition to managing payments, her husband's carer has also changed. He had the same carer for six years and they were happy that the carer understood his needs.



*She **understands my needs**, and she uses her initiative and she helps support both of us really. She's never late. She acts like a PA for me as well. She will sort out things that have to happen, like my husband having his haircut. She makes sure it is all arranged... I can walk out of my house and **I just feel that everything is under control**. I feel happy that she is there.*



Unfortunately, due to changes in management, the time they have with this carer has been reduced. Janet feels they must now start again to



Having carers she could trust means Janet could find time to walk Oscar, which is important for her wellbeing.



Janet is the main carer for her husband who suffered brain damage after a fall in 2011. He needs 24 hour care.

build a relationship of trust with other carers, which is hard. She is also worried about whether the company has the capacity to provide properly trained carers.

Her husband can be demanding because of his brain damage. Having carers he likes and that they can trust is core to their experience being positive but Janet feels the changes to staff are undermining this and causing them stress.

Janet is positive about the carers. If her husband is asleep, they are willing to help with other household tasks. If he is awake, the carers will sit and engage with him.

The carers are understanding of how the changes in staff cover are affecting the couple. They do everything they can to 'keep the package going' by talking to

each other and ensuring that cover is available.

“I can’t fault the individual carers that come out ... but they are struggling.”

Janet is worried about the future of her husband's care and also about the respite she receives because of issues with funding. She is hoping that things will improve as the care and the office used to be so good.

She cannot fault her carers and considers the care agencies office and council systems to be the cause of her stress and uncertainty.

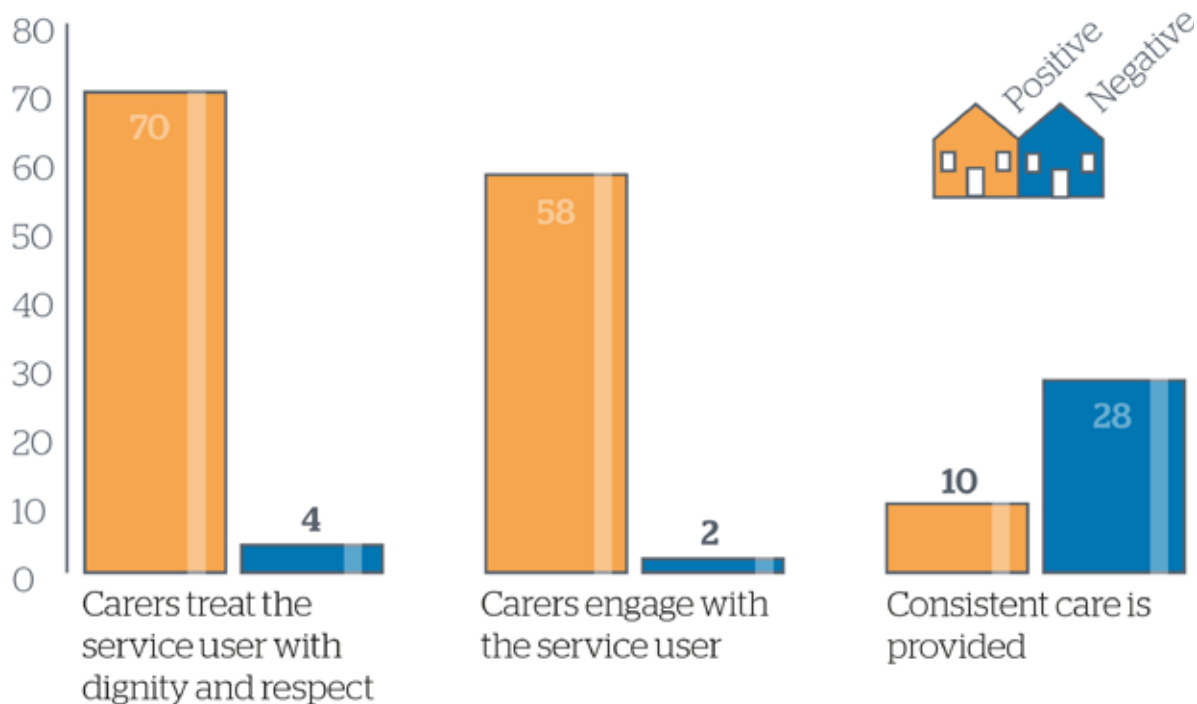


Figure 9: The number of mentions attributed to sub-themes within theme two (“Feel comfortable with your carers”).

Theme 2: Feel comfortable with your carers

‘Feeling comfortable with their carers’ had the second largest number of comments attributed to it in the survey with 177 of 517 comments overall.

138 of these comments were positive. In the survey overall and within this theme, being treated with dignity and respect had the highest number of positive comments (70).

These are positive factors that emerge

from respondents having an established relationship with the carers who come into their home. However, there were 28 negative comments about not receiving consistent carers.

The interviews confirm that being comfortable with carers is very important to service users. In 34 out of the 50 interviews, interviewees said that their carers treated them with dignity and respect, and only 5 made negative comments.

Twenty-six also stressed the importance of engaging with their carer and the



“I think that being comfortable with the person, it’s about-- it’s a personal thing, isn’t it? And you’re allowing somebody into your own personal house, your own space, to do a personal thing. And I think it’s important to have that rapport, whereas, if it continually changes, it’s like, a stranger suddenly come to do a personal thing.”



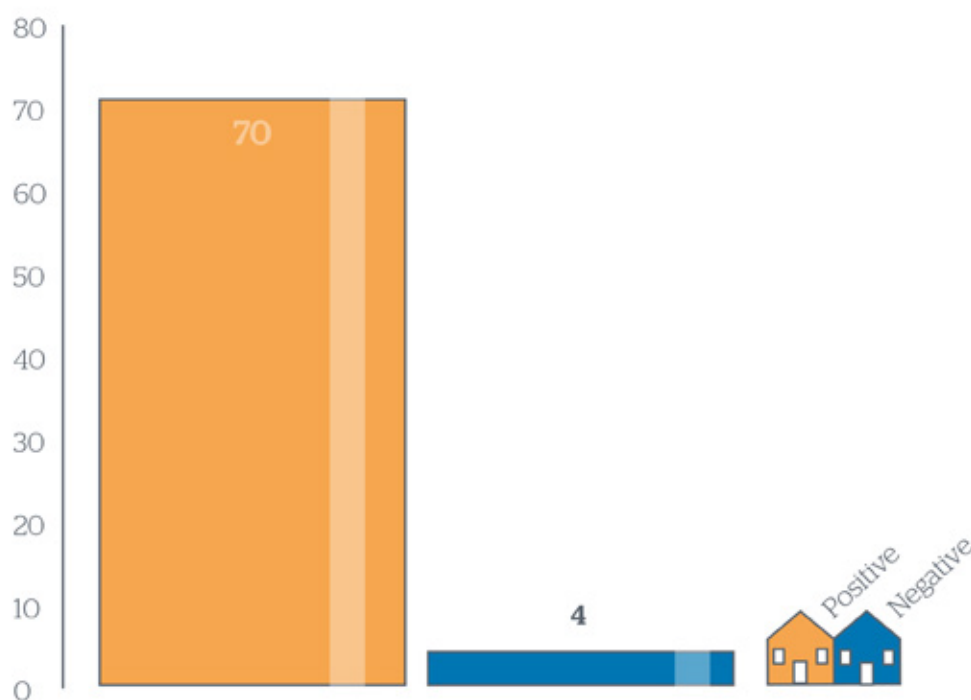


Figure 10: The number of mentions attributed to the sub-theme of “Carers treat the service user with dignity and respect” and their sentiment.

benefits talking to them gave them and how it helps improve their lives. Similarly, twenty one interviews of the 50 confirmed that they had consistency of care and described in the interviews how important establishing a relationship depends on getting to know their carer and the carer knowing them.

Eighteen said that they did not have consistency of care and negative comments often expressed sympathy with carers and included reference to lack of consistency due to agencies not having enough staff.

Sub-theme 2a: Carers treat the service user with dignity and respect

One of the interviewees explains the benefit of being treated with dignity and respect and chatting, laughing and being sociable with the carers very well;

“

“The carers are very good. The main carers. They’re brilliant. They do everything and more. And they can’t do enough to be gentle with me, to do things really kindly. I have a laugh with them, you hear us laughing up there and we have a lovely time where we do it. And I think that makes a difference.”

”

The dignity and respect sub-theme was defined as treating the service user in the manner which they which they would expect from good care. This includes being polite, kind and caring as well as providing personal care in a considerate way.

Seventy of the 517 respondents to the survey told HWS that they were treated

with dignity and respect by their carers. Only four survey respondents expressed negative feelings, making this one of the largest and most positive categories of comments in the survey data. This is a very positive result and suggests that in terms of treating service users with dignity and respect, there is a lot of good practice by carers.

The positive comments from survey respondents within this sub-theme include direct references to being treated with dignity or respect (9):

“

“I too receive care. The [carers] are all friendly and do their job professionally and keeping the customers dignity in mind. I would highly recommend them to anyone.”

”

Other types of survey comment included in this sub-theme include references to politeness (16), kindness (25) and a caring attitude (18). HWS researchers felt that these were important elements of being treated with dignity and respect:

“

“People are nice and polite, they care and support me when I need that.”

“Caring and compassionate, well managed and flexible.”

“Everyone has been kind and considerate and have been helpful.”

”

The numbers associated with each of these categories within dignity and respect sometimes overlap, as can be seen from this comment:

“

“The carers appear very kind & caring. They treat my father with dignity and respect. They encourage him to be as independent as his condition allows... They are friendly and professional.”

”

One comment was made in the survey which did not fit neatly within any of these categories, but still appeared to fit with the general sub-theme of being treated with politeness/ dignity and respect:

“

“The two regular carers are excellent. They are very good with my husband and do not talk down to him.”

”

Thirty-four of the 50 interviews contained specific positive comments about how highly they rate their carers and the care they receive. Being treated with dignity and respect is implicit within comments about carers being polite and treating the service user with kindness and consideration.

Only four made negative comments about specific carers.



“Now he spends quite a bit of time with me. And I like him very much. I’m wonderful with him. I trust him and he’s coming in my home.”

“And then I feel very lucky because then you read of some of these horrible cases and you think, “Well you do have to trust these people.”

“They’re not just called carers, they are caring people. They really are. I’ve never seen them sort of short-tempered. I’ve never seen them flustered. Never seen them sort of stressed. They’ve always been calm, and kind, helpful, on time, reliable. What else can you say? They’ve been sort of everything that you’d like your carer to be.”

“But anyway, she said, “Right. Hang on.” She says, “I’ll ring the office.” So she rang the office. She said, “Is there anyone who can help me with [the service user] because I am a two-person carer.” They always do a double up with me. And they couldn’t send somebody for over an hour because they were all busy. So she said, “All right, don’t worry.” So she said, “Right, we’ll deal with it.” And she did deal with it. We stood up, she got me stripped off, she washed me, got me dressed back, and put me back down again. Brilliant. Absolutely brilliant. Nothings too much trouble. Beyond the call of duty with me.”

“No, nobody’s ever been particularly bad. But, as I say, at the moment the carer I’ve got is absolutely wonderful she’s worked for ... for a very long time. She knows what she’s doing.

They know they can trust her to do exactly what’s needed. And she comes with all sorts of things, not all the carers do. And she does it cheerfully and skilfully. She’s a very, very nice person. She is 100% carer. I feel that’s the sort of person where perhaps carers should be graded. And somebody who’s been doing it as long as she has, should not just be on a basic wage. They should be on a big salary each year because they are so good. But then that’s me. When I worked I was always on a salary, so. Never a very high one but, nevertheless, a salary.”



There are four negative comments out of the 517 survey responses about not being treated with dignity and respect. Where there are comments, these clearly fall below the standard expected of good care. A couple refer to carers being rude, and one refers to being handled in a disrespectful manner, causing pain.



“Lack of respect. Rudeness, shoddy care by some staff... Some staff are very good and kind. Consider the problem a management issue.”

“Some are really kind and good but a lot are uncaring and untidy and terrible at cooking, sometimes rude and forget to make bed, empty bins and clean my feet. Nearly always late.”

“[the client] in constant pain if handled incorrectly by carers, despite being shown or told on several occasions.’



Only five of the 50 interviews mention not being treated with dignity and respect:

““

“They do put the occasional new member staff in. I’ve only ever told one staff member to go because her language was so appalling.”

””

Eight interviews also talked about being treated with dignity and respect whilst receiving personal care including showering, dressing and other more intimate tasks.

““

“It’s strange, really. I mean, I can be sort of standing there naked with a stranger who I’ve never seen before and they always put you at ease... they’re very nice. As I say I feel comfortable with them all”

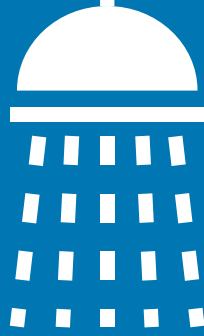
“When they come through the door now we feel as if it’s a friend coming in. Because my relative did say at the beginning, “I don’t know if I can have a young lady give me a shower and things.” And I said, “Well, you’re going to have to.” But I said, “You’re going to have to say I’m in a hospital with a nurse and that’s it.” And since then he has no problem at all with them doing it. Because you don’t feel that they’re being personal, they’re just doing their job. But they are very good. I would praise them all and recommend them to anybody.”

“We only have one carer in the morning to help him shave and

dress. And they make his bed and change a sheet, so do whatever is needed there. Help him with his clothes. And probably think things through because he will say he doesn’t need to shave. Some of them will shave him. Sometimes he will say, “I don’t want to. But they are a lot better than I could be in getting most important things done. Most of them have a very nice way with him. And he will respond to them. If I said to him he needed to shave--It wouldn’t go down very well. So, there are all sorts of things from that point of view. That’s the whole reason why I don’t do it. I have never believed for his own dignity that it’s appropriate for me to do the personal care. It’s not much else I don’t do but they do that.”

“Because the carer will shower him. She’s even got to wash his hair. And he’s very difficult. He doesn’t want any water on his hair. Well, she’s managed to do it. So, you see because she’s talking to him she built up a rapport.”

””



“

“Because the carer will shower him. She’s even got to wash his hair. And he’s very difficult. He doesn’t want any water on his hair. Well, she’s managed to do it. So, you see because she’s talking to him she built up a rapport.”

A relative of a home care service user

”

Sub-theme 2b: Consistent care is provided

Both survey respondents and interviewees say what a difference it makes to them when they have a carer or carers who attend them regularly over a longer period of time, with whom they have built a good rapport. Relationships between service users and carers are based on trust, knowledge of the needs of the person being cared for and a certainty that tasks will be carried out to the highest standard.

In the 517 surveys, not having consistent carers was highlighted as one of the sub-themes of most concern to participants. Of those who gave a good or average rating, 21 people made negative comments about the consistency of their care. This indicates that consistency of care is important to service users even if they rate their care as adequate or good.

Three respondents who gave an excellent rating also made negative comments about the consistency of their carers. Some survey respondents told HWS what was important about consistency and how this impacted on their care.

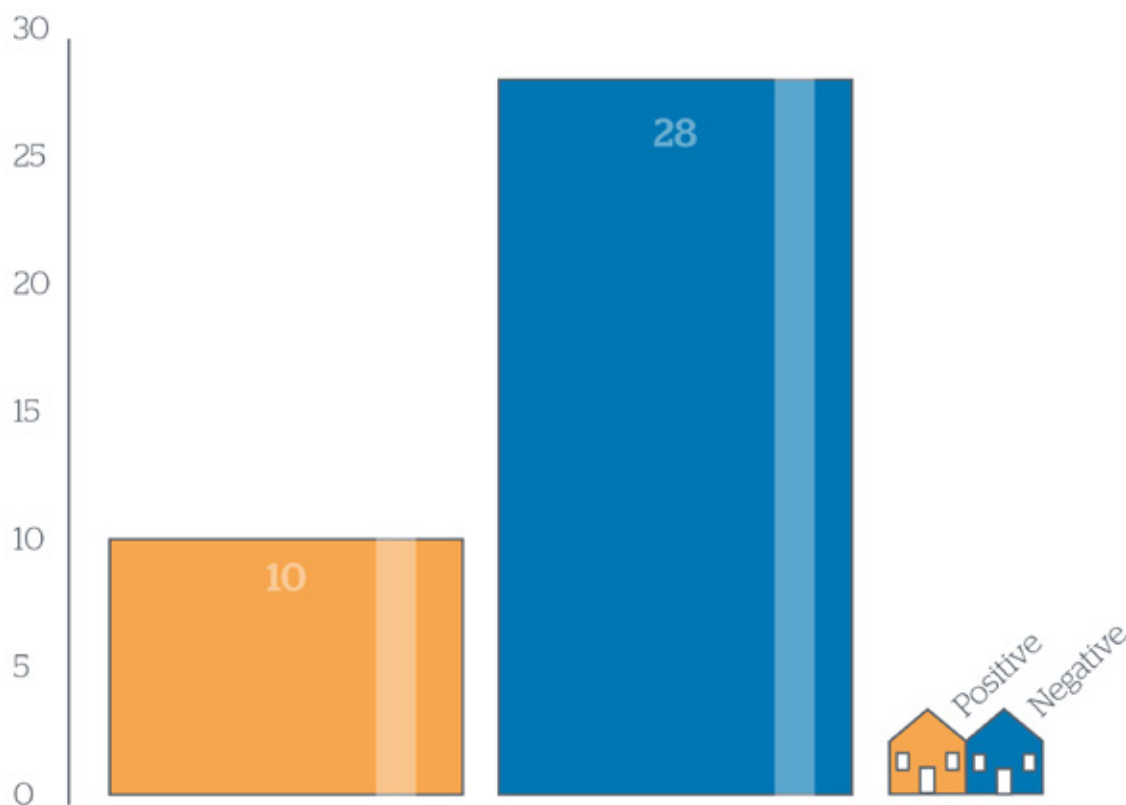


Figure 11: The number of mentions attributed to the sub-theme of “Consistent care” and their sentiment.

“

“Times had been very erratic when main carer was on holiday or away. Have recently settled into regular times now main carer back and has given mum more confidence as she likes routine and stability. Just hope this continues.”

“Regular carers... have become friends to mum.”

“Regular carers at regular times, hence they build a good relationship and understand my father's needs. Being regular carers they also notice any changes or potential problems.”

”

Twenty-one of the 50 interviews confirmed that they had consistent carers and described the benefits of this with comments such as:

“

“I think it's a couple of weeks ago as they were looking at the issue of maintaining regular rounds and consistency. To begin with, the changeover was just really anybody, but to be fair they're now, I think, settling down to that consistency and seem to have got settled and looking at that situation. The consistent ones are very, very good. It is the odd carer, you do notice that some are better than others, don't you?”

“I don't have any problems Well, they've become part of the family sort of thing. I mean you see them

all the time. I like that side of things. They're not strangers, if you know what I mean.”

“Yes. Oh, we have a lot of laughs. Researcher: Do you? Good. Because that's part of building that relationship, isn't it?”

“Well, that's been built, yes. Because you must think- like in the beginning, they was a little bit upset as well that things weren't going as they should. They knew that we were upset. So it took a little bit of time to get onto a level footing, which we've got now. And I hear them laughing in there in the bedroom.”

“Oh, yes I have [the carer] come and she's marvellous, isn't she? Yes she's good. We like her because she's always happy, always got a smile for you. And she's a regular. Usually brings the sun with her when she comes, as well.”

”

Twelve of the negative comments about consistency of care from the 517 survey responses related inconsistent care to management issues or made a reference to care agencies not having enough staff:

“

“Carers are good. Office is not. They struggle with shortage of carers. When our regular carer has days off, cover is chancy. If carer is late or unavailable they don't always let us know. They come to us under contract to Suffolk County Council

but I'm now considering ending that and engaging a different agency."

"The carers are excellent but the office staff let the carers and company down. Lack of communication and planning e.g. times and covering absence of carers (if off sick). There is no continuity of carers through the week (sometimes 7 different carers) and the times are all over the place ranging from 7 am to 10 am. I don't understand why this happened - it would be nice to have one to two carers and a regular time."

"They are not always consistent on timing. Arriving mid-morning which makes it difficult for mum to plan if she is going out. Also they do have quite a lot of staff turnover. Mum would prefer to build a relationship with the carers."

Eighteen of 50 interviews spoke about not having consistency of carers and highlighted that this would be their preferred option with comments such as:

“

"They all seem nice and it's nice to talk to different people, but it takes a lot of energy. And especially as I don't get out much. There's more sort of social anxiety and I'm less used to new people. It takes a lot of energy."

"Yes. But first we had the same young woman who came for many weeks. And that was working really well because we were able to ask her

to do different things. And because I'm quite tired and sometimes less articulate than others, it's quite difficult for me to ask, especially people I don't know, to ask to do some paperwork or other help. It's much more difficult to talk to people I don't know. And so we had the same person for a couple of months. And then, since then, it's I mean, there are familiar faces. People we have seen often, but it's different one week to the next."

"... and it's someone different all the time, coming in all different times. She goes in the office. She went in and said that it's not fair. But she'll be taken off our run. At nights she come running in at 8 o'clock. "Sorry. Sorry, I'm early, but they've taken your carer - they want me to do this run and the double run. They're not taking my needs into account, really. It makes me feel uncomfortable and I'm very upset."

"... but it's the rest of it has been quite difficult with different people coming in and, unfortunately, main carer had some time off. And so that's when I sort of saw how behind the scenes, there wasn't very much keeping it all going. Again, it feels, is there wasn't that many people for them to call on. It's been difficult getting people in. I've had various different people coming in to shadow, then I never see them again. People, they've not had all the training that they have to have had because it's manual handling, it's medication. And so they've not been able to come back until that's all happened, and then staff who had been part of the package left, and I've

not really-- even now, I haven't really quite got it sorted.'

'It can be quite exhausting sometimes trying to explain to them and explain how you need to do things in a certain way. And it can take a minute for them to really understand what you need. When they come two or three times, they know exactly what you need. And not everybody can be handled in the same way.'

Interviewees also attributed having too many different carers to management problems and not having enough carers to cover all the people needing care. Comments were made showing great sympathy with carers and their situation including:

"... and the care company had a lot of change of managerial staff over the time I've been there, and those managers varied from the sublime to the ridiculous. Some of them didn't seem to know one end of a pen from another, without being rude. As a whole, their carers—obviously they have a great churn of carers, and we have patches of good carers and we have patches of carers that like their trousers are on fire because they want to get out of the place as quick as they possibly can. I think I know that that all will be to do with the rate of pay and it's not the greatest job, blah, blah, blah. But putting that all aside, it is the managers skill with things like rostering and when visits should be."

"I would like to see more competent people in the office. For example, preparing rotas the treatment of carers-- they're forever leaving. And if they were treated properly, it wouldn't happen. And if they got more money. But I do get quite upset about the conditions. For example, one of the carers was telling me only this morning that he travelled 25 miles a day and it's going backwards and forwards, nothing planned. And I do think the office could do something about this because they don't get very much money for their motoring expenses. And they lose out."

"And you can't put the blame at their door. And if they're late, you can't do that either because they're short staffed. I don't know if other companies have this problem as well. So you can't complain if they're a bit late or-- and like now, there's a bug going around and a couple of them are off sick and that's going to cause terrible problems. So I just take all that in my stride and I'm very grateful to them and they're all very nice."

'Yes. I've had two or three come in who were obviously unwell. One lady came in she had a very bad headache and she looked terrible and she wasn't fit to be driving. I sent her home and found out from what she told me afterward, when she came back from a short sick leave, that her blood pressure had been sky high. Another one has come in with very bad asthma attacks and I thought two or three times I would have to get the paramedics out to look after her. And they just told

me, "well, there's no one to take over from us. We couldn't get any cover so we had to come out."

Sub-theme 2c: Carers engage with the service user

Both survey respondents and interviewees stated that it was extremely important to service users for carers to engage with them, including being friendly and sociable.

For those living alone, the carer may be the only person they will see during the day. Small actions such as a chat over a cup of tea, or while completing the tasks involved in the care plan, can be extremely important.

Service users also commented that carers are coming into their home and therefore being treated with consideration is important to them.

Fifty-eight of the 517 respondents to the survey commented to say that their carers engaged with them. This is one of the largest positive sub-themes in the survey overall.



"Almost always on time. Great communications. Good hard caring workers. Experienced and friendly always ask first and show decency to me."

"Nearly always on-time. Always cheerful. Look forward to them coming. Very chatty. Nice."

"I have used [my] carers for the past 5 years and I have no complaints.. I'm 96 but still got a good sense of humour, so I like to have a laugh and joke with the [carers]."

"[The carers] have been excellent, really got to know my mum. Sometimes they just do their checks and and spend rest of time talking to her which is fabulous. she is very sociable and misses company."

"There is a 'main' carer - who quickly established a really good relationship with mum (& dad) They regard her as a sort of surrogate member of the family which means they listen to her when she has to prompt them to do (or not to do) things. She (main carer) is excellent at keeping in touch with me about anything that's changed etc."

Twenty-six of the 50 interviews confirmed how important carers engaging with them can be and how it improves their experience of care.



“

“I think he’s happy. I think he likes it, and the interaction for him for somebody else is so good. It might be the only person he speaks to the whole day or for several days other than me. You see?”

“He is difficult and if [The carer] wasn’t of the right mind, she would get with justification wild, angry, and upset. But she doesn’t. She’s always level-headed. And she always talks to him and not down to him. She just talks to him and coaxes him. She’s very good at that. She’s better than I am. She’s more experienced.”

“Well, when they finish early they sit on the couch till the half an hour is up and we have a chat. They said they all like coming here.”

“I think I didn’t realise that a lot of the input I was getting was from the conversation as much as from the actual physical health care. Researcher: So in a sense, it’s the social side that you felt was helpful? And that was definitely missing with the primary care. It seems silly saying you need a carer just to cheer you up but it helped”

“Well, they came in every day for social interaction and to check out that I’ve taken my pills and everything like that, which when you’re depressed, you don’t always get around to. Fortunately, even when I was depressed, I managed to keep my sort of morning and night routines going. I just happened to sleep most of the day [laughter] as well. But it took me about 18 months to climb out of it. But I did gradually

get out and I think it was as much due to the daily interaction with somebody who’s coming, knowing somebody was coming in to see me and talking to me and basically, as I say, just good social interaction.”

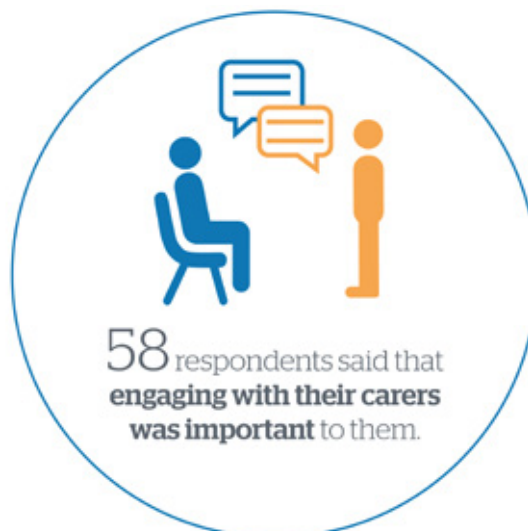
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Ten participants confirmed that their carers do not chat and engage with them in a comfortable manner. They all expressed disappointment with this.

“

“To make it worse, I’m a barcode now. I’ve become a barcode and I get scanned in the mornings it’s all done by phone so they have to go on their phone for about 10 minutes to sign in, to tick box or what they’re doing or what they’re not doing, so that’s 10 minutes out of your time.”

“It’s difficult to say because they’re in the care business, but it almost was a monetary thing. The carers I got it was clock on, do the job, clock out. End of story. There was very little



interaction but with the exception for one gentleman. But then I heard that he was leaving their service. I thought, perhaps, it's because he's actually prepared to chat to the patient. It wasn't just, right, well your bath. Well, you get dressed. There was a lot of interaction. There was a lot of chat. And when you're in that condition, you're not exactly at your brightest. You're quite low, quite depressed. And their chat helped to lift you out of the depression. And it helped."

"We've had one week on a Thursday (for his day out), a young girl come and she's only 18. But I say she's a nice kid. And she had a small car and the wheelchair wouldn't fit in. But does he want to spend two and a half hours walking the streets? Well, you couldn't could you, it was pouring rain. So he couldn't go out. So he said to her, "Go," because there's no point. He's got nothing in common with an 18-year-old. Bless her heart. What was she going to sit and talk to him for?"





Edward's care...



Edward is 80. He was an engineer and has developed complex health issues including Ataxia, Osteoporosis, Epilepsy and Coeliac Disease. He is now also developing Dementia and is suffering from mild depression. His deteriorating neurological condition affects his mobility.

He and his wife have lived in their home for over 30 years. They receive one carer in the morning, four days a week for half an hour and for three-quarters of an hour on three days a week. They describe their carers as **“very pleasant”** and **“reliable”**.

During the initial assessment of their needs, the couple felt there were too many people involved. Furthermore, despite these meetings, there were discrepancies between the care plan they received and the copy held by the

It gives my husband his dignity and some companionship. For me, it provides me with some time to myself, whilst knowing he is safe.

provider. However, they said most of the carers knew what they had to do when they arrived and, those who didn't, always read their care plan.

Edward and his wife were occasionally disappointed because, although they received a rota, they were not notified of any changes or contacted if carers were going to be late. Lateness was a problem, especially at weekends, when Edward could be waiting until 11am to be dressed.

Despite these issues, they knew all of their carers and Edward has always been satisfied with his care; even if they were seeing up to five different people in any given week.

“There was overkill in that one day I had three people in my breakfast room, sitting there having coffee ... I felt that was total duplication having given the first member of staff all the information to write up the care plans ...”



Edward has complex health issues but the efficiency and support of his carers means he can get to his weekly art class.

“

*I think **he's happy...** and the interaction for him with somebody else is good. **It might be the only person other than me he speaks to** for several days.*

”

After a call to the manager of the care agency about the problems they were having, things have got better. Carers now arrive on time and are always known to them.

Edward is now getting “**superb care**”. He is able to get to his weekly art class on time due to the carers’ efficiency. He enjoys this class enormously and produces some very good artwork. His wife can find time to meet with friends and she often dashes out while the carer is present.

“...the carers are all very cheerful, have a good attitude and do everything asked of them.”

Theme 3: Be made aware of changes in advance

The theme 'be made aware of changes in advance' is about receiving an accurate rota which is adhered to. Service users told HWS that changes being made to who will attend and timings of visits without being notified can cause distress and inconvenience.

Being made aware of changes in advance is often related to other areas such as timekeeping and communication.

Sub-theme 3a: Service user is told if the carers are going to be late or not arrive

Only five of the 517 respondents to the survey made positive comments about communicating changes, and 24 said that they were often not informed. Of these, 21 negative comments were from respondents who gave an 'excellent', 'good' or 'average' rating, suggesting that not being notified of changes also affects respondents who otherwise think the care they receive is adequate or good.

Both the survey comments and the interviews suggest that not notifying the service user if there are changes has the potential to cause inconvenience and distress.

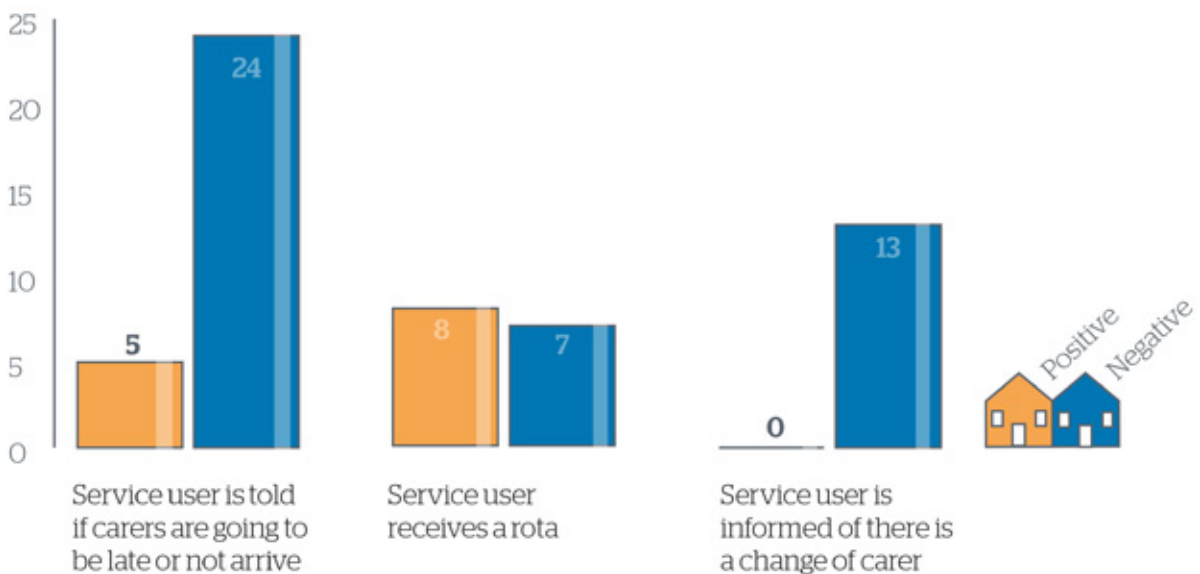
Examples of survey comments about not being notified of changes:

“They are kind and caring. If they are not able to get here on time booked they will always ring to say how long they will be.”

“Lack of communication - carers arriving late and 2nd night not at all. Not notified!”

“I have no complaints whatever about the caring staff. I find them very helpful always cheerful and a pleasure to deal with. With regards to the admin staff I find them less easy to deal with. They do not

Figure 12: The number of mentions attributed to the theme of “Be made aware of changes in advance” and their sentiment.



always seem to handle and complaints about changes to rotas, time of visits etc in an understanding way. We are often left uninformed of any such changes."

"The care is on the whole good but often alterations are made to calls, change of carer at the time and the client is not given notice of these changes."

Only three of the 50 interviews made positive remarks about being notified of change and being confident about when carers will arrive:

"...they send me an email telling me who's coming the following week, usually, Tuesday and Friday, and they put the times down. It doesn't change. If someone's poorly or something's happened, they will ring me and tell me that."

'Oh, they never not arrive. If they are late, they ring up and say, "We're going to be late."

Eighteen interviews also talked about the negative impact of not being notified of changes to times, including cases of non-arrival. The interviews give examples of this reasons such as no-one being available, car breakdown or shortage of staff through illness or inability to recruit and retain staff are often not the carers fault but that of management.

“

"... then they're short of people. I understand all of that. But there's no recovery, there's no-- if they're not going to send somebody at 10 why don't they phone me up and say, "Can you have a word with your relative? This is what's happened." But that's not what happened. They'll just let you down. And that's real-- that's the customer care gone out of the window. If I hadn't rung my relative would've just not had anything until four in the day. Because nobody would've come. And they didn't even know that no one had been. They said, "What do you mean no one has been?" I said, "Well, nobody's been. No carers." And they went, "Well, we sent someone." And I said, "Well, perhaps they've been kidnapped. I don't know but they didn't turn up at the house." And then they said, "She came back the next day with her car broke down and then she forgot the road to it. And she was new." A whole reel of excuses. But you can do that-- the trouble they've got is the whole crying wolf business. If you keep doing it time and time again, even when they're telling the truth you think they're telling lies."

”

The interviews suggest that some service users attribute these problems to management rather than carers themselves:

“

“The carers are excellent but the office staff let the carers and company down. Lack of communication and planning eg times and covering absence of carers (If off sick). There is no continuity of carers through the week (sometimes 7 different carers) and the times are all over the place ranging from 7 am to 10 am. I don't understand why this happened – it would be nice to have one to two carers and a regular time.”

“I mean, I sit here waiting for a carer and the carer doesn't arrive. So after half an hour or so I ring up and I say, “What's happened? Where's my care? Oh, he's had to do such and such. But we'll get there as soon as we can'. But they should have notified us I can't see why they can't phone me and just say, “your carer, is going to be half an hour late.” And, of course, because, unfortunately, my husband is a worrier. And when things don't happen like they should he starts to worry. And particularly, I mean, I have laughingly said—if the weather's bad we then wonder—we had one young lady, she came on a motorbike. Well, sometimes if she'd been late we'd have said, “Oh, dear. Has she had an accident?”. Because we feel so close to the carers that we do worry.”

“No, I find this is a problem. They don't ring you. This lady was coming—there's nothing wrong with the lady because she had been here

once before. But I just feel if they know someone strange is going to come, they could just tell my wife, simple text, if I'm not here, there's not a stranger walking in here in the dark, or do you know what I mean? But they don't. They don't give her notice. How long does it take? Not long, does it? And the first time this lady came, she came at Christmas time, and she got here at 10:30 because they've got all these visits. And we took her from here to her next visit, because she didn't know where it was. She said, “I don't know how to find it.” And I said, “Well, I know where it is. I'll take you.” And she followed me, and I just drove my vehicle.”

”

The variety of positive comments made in interviews about carer(s) makes assessing the number of specific references difficult but there are 28 specific positive comments showing understanding and sympathy towards carers:

“

“The care my husband receives from the carer is of a very high quality and they have a good rapport. The carer always lets me know if a problem has occurred to delay their arrival. The carer rarely arrives at the scheduled time but I believe that this is NOT the carers fault. Our rural location may be an issue with regards to travel time. So, this is quite acceptable.”

“Researcher: And do they come on time? Yes I think there was one time

“

when someone was quite late and it was very much an exceptional circumstance. No. They weren't late. They were early. And it was when someone had gone off sick. And there was one other time. And the carer phoned us, directly, to make sure that the new time would be all right. Which was absolutely fine.”

”

“



“I sit here waiting for a carer and the carer doesn't arrive. So after half an hour or so I ring up... 'Oh, he's had to do such and such. But we'll get there as soon as we can'. But they should have notified us. I can't see why they can't phone me and just say, 'your carer, is going to be half an hour late.'”

A relative of a home care service user



Sub-theme 3b: Service user receives a rota

The number of respondents to the survey referring directly to receiving a rota was small (eight positive and seven negative references out of 517 responses). However, as can be seen from the survey quotes below, it can be both helpful and a comfort to the service user to know who is coming and at what time:

“

“...always notified by post who will visit.”

“...the company provide a rota of carers each week.”

“Staff are all good, I'm pleased that I have a 'rota' given to me so I am well informed of who and when they are coming”

“For some individuals, it was variable whether they were given a rota or not.”

“They are always short staffed. That is the reason given for being late or not having the person named on the weekly list that we are sometimes given.”

”

Twenty-three of the 50 interviews told HWS that they received a rota:

“

‘On a Thursday, we get something in the post telling us who's coming on the Tuesday following. So, there's

plenty of time.’

‘Yes, they send a rota every week in to us and there are the times and the girls and to say mostly they are the same girls. It sometimes changes on the weekend when perhaps one has got a weekend off which obviously, I think, they do every other weekend they have off. So then there's two others. But it's still keeping in the same 4 or 5 I think. No more than that. They're all lovely. Can't fault them at all, they are wonderful.’

‘Well, they stopped doing them and this was sometime back and I rang them up and I said, “Why are we not getting rotas?” “Well, we don't think you need them.” I said, “Well, if you don't mind, I think we need them.” Because you can sit and wait. You don't know who's coming. You don't know what time they're coming. If you got a rota, even though they might not come at that time, it gives you some idea. And if they are late, later than what it says on here, you can ring out and find out why. So, they did start giving us those, then they stopped again. And I rang again and I said, “I insist on having rotas.” They then started again fairly quickly.’

”

Not receiving a rota can impact negatively on the service user's experience of care as they have no idea who will be arriving or when. For example, quotes from survey said:

“

“Since moving [care providers] things aren’t so smooth like they used to be with no time table to say who and when the carers arrive.”

“We no longer receive notification of the time they are coming and the name of the person who will be visiting.”

“The carers themselves are great at what they do but the company is not so good. Have experienced missed visits and now do not get a weekly schedule from them.”

”

Nine of the 50 interviews stated that they did not receive a rota:

“

“Well, they (the carers) get a rota. But we don’t get a copy of that rota. They all get a copy once a week or something of the times and the clients and that kind of thing. But we don’t get anything like that. They get the times and they know where they’re coming to, but we don’t but know who’s coming to us, kind of thing.”

“No. No. She just said this morning, “I’ll see you Monday then. Bye-bye.”

“We did get a rota at first. The first few weeks, a rota came through the post. Then that stopped. I did eventually ask why because of the times because the rota had their projected times. Not that they could stick to

those times always because they’re dealing with a daily quota of people. And if they have problems, they can get behind. I mean, that’s well understood.”

”

Having “unallocated” carers on the rota came up three times in the interviews and has been included in this sub-theme. Where no allocation has been made at all, service users have no idea who is coming and reported that this could cause stress.

“

“The office is a waste of space. It’s like tonight - the regular carer that comes in, she’s off tonight and tomorrow night and Sunday night. So we don’t know who’s going to come in. We don’t know what time. Cause it’s unallocated on the rota. So that could be anybody coming in. No one’s bothered phoning to say, “Johnny’s coming in tonight and he’ll be there at nine o’clock”, or they could turn up anytime from half passed seven to 10 o’clock and we don’t know who. That is not right, it happens often. I get very stressed over it sometimes. I’m not good with change am I.”

“Right. This is the rota. Now that is all wrong because he, who came Monday and Tuesday, was here at 8 o’clock. And she was here until 8.30. I always get that wrong. She was here at the right time. And [another carer] was this morning. And now they’ve got nobody coming- I don’t know who’s coming Saturday and Sunday.”

"The rota had already changed between- and you know as soon as it has that word unallocated and you phone up and say, "Has it been allocated yet?" And they'll go, "Oh, just let me have a look. Oh, no. It hasn't. Do you need us to tell you?" "Yes, please." And then they ring back and they say, "Oh, I'm really sorry. We can't cover." But if you don't challenge the unallocated call, you'll never know."

Sub-theme 3c: Service user is informed if there is a change of carer

This sub-theme was used to refer to a different staff member than the one stated on the rota arriving to provide care. Not being informed of changes to the rota, different carers arriving other than those on the rota, or unknown carers coming, can cause uncertainty for service users. Some told HWS that they find change difficult to deal with.

None of the 517 survey respondents made comments to indicate that they were informed of such changes and 13 made negative comments that they were not informed of changes to the staff member attending.

Examples of not being informed of changes of the carer attending from the scoping survey responses include:

“

"They are always short staffed. That is the reason given for being late or not having the person named on the

weekly list that we are sometimes given."

"I am very satisfied with the care given to me on a personal basis. The carers are friendly, efficient and very willing. With regards to the admin staff, they rarely notify me of changes of staff or times of service. Any complaints on these matters seem to be ignored. Promises made but not kept."

"Carers excellent if familiar and on time. Weekends are erratic no information given - strangers come. They don't wear gloves or aprons. The timings are always erratic too and this can very upsetting and unnerving."



Thirteen out of 50 interviews mentioned not being informed of changes of the carer attending. Comments included:

““

“Lately, it's been changing quite a bit. But [the manager] is going to see if she can keep it so that it stays sort of fairly the same for me because I don't like too much change.”

“Well, I mean, we're completely satisfied with the regular ones, it's just the fill in ones. We don't really know who's going to come whether they're going to be the regular ones or not... We get a rota but not all the time. We get a rota and you'll see there that, that's the fill in carers there. So these aren't (the regular ones) they have one day off and that's the fill in carers.”

“Of all the care places, it's normally the office staff. It's a lack of communication. If they could only get that right, and they knew the individual people, they knew [my relative] didn't want to be with his pyjamas at 7 o'clock at night. Well, he wants someone he knows. They should phone up and say, because even if it's an older person, they don't just want anybody walking in their door. But they don't communicate at all.”

“They don't turn up. And we do try at the time to telephone them. Then often you just don't get a reply from anybody. There's often not anybody in the office, and it's supposed to go to somebody who is on call, but it doesn't do that, unfortunately. And recently I've been trying to send

emails to this manager that's on call. And it has got a bit better but I don't think it's still right.”

””

Gill's care...



The most important thing to me is the day care they receive because they are stimulated. They do two different activities each day like sailing and swimming. They can do so many different things that stimulate them at the day centre.



Gill is a widow caring for two sons with learning difficulties and a brother of 76, also with learning difficulties, who has a flat within a supported living complex.

Her brother lived at home with his parents until they died, when Paula took over his care. He lived in a bungalow at the bottom of her garden. After the death of her husband, she found looking after all three of them too difficult and so she arranged for her brother to move into supported living.

Gill is still the main carer for her two sons, both of whom live at home and receive day care.

She feels that one of the providers is not satisfactory because they are not stimulating her son as much as she feels he needs. She is hoping to transfer him to the day centre that her other son attends and where they do something different every day. He loves it.

The family are still grieving for her husband and she is finding the situation difficult. She says **"I have got to get**

through it for the boys". She is grateful for her good neighbours and the care her family receive.

She did try respite but her son was distressed because he thought she might also disappear. She therefore needed to cancel it. However, she is considering contacting Suffolk Family Carers to see how they can help.

Gill does manage to find some time for herself during the day and her little dog is great company.

Her brother is happy with his new living arrangements and Paula feels they are **"really kind, caring people"**. When asked after a week whether he wanted to go back to the bungalow he said no. She visits him every week and checks that everything is going well.

His carers visit his flat to make his breakfast and his tea. Although they check on him just before he goes to bed he doesn't have to go at any particular time.

“

They support him with a shower and help with the clothes he is going to wear. He has lunch in the canteen with everyone else. They just look after him generally.

”

Gill has always felt included in discussions about his care and everything is written down in a book. Although obviously being a carer for three adults is difficult, she is an active and sociable person who cares deeply for her family.



Gill feels that the stimulating activities provided by the day care centre her son attends (e.g. sailing and bowling) are important to the wellbeing of the family.

G



Theme 4: Be given a care diary that is regularly updated

Having a care diary was not a significant issue in the scoping surveys and is only referred to by 5 of the 517 respondents.

Three respondents told HWS that they are provided with a care diary, two of them reported that the care diary is filled in and one that it has been filled in with inconsequential information and is not detailed enough.

It was asked in all 50 interviews whether participants had a care diary. In twenty-six interviews, interviewees confirmed that they had a care diary that was filled in accurately and checked regularly.

Examples of survey responses referring to care diaries include:

“

“Carer comes most days at between 5.45pm & 6.35pm and stays for 15 minutes and writes a note to say how I am and what I am having for tea.”

“I do not think comments written in the care plan book daily are detailed enough and often about inconsequential things.”

”

Examples of positive references to the care diary in the interviews:

“

“Oh yes, they have to sign everything. Oh, it's all filled in, it's all

filled in. For me, yes. Yes, it's filled in exactly as what they say.”

“Yes, they always sign it. They don't always remember to get one of us to sign it, but I can justify that if I feel somebody else is checking. I don't read what they write every day because I'm sure my husband would point out if something hadn't happened or wasn't right. But no, as I say, I think the carers themselves are probably better than the management that they're under.”

“No, but they write down what they've done with [my relative]. If they've washed his hair, given him a shave, whatever they do with him it's all in. And all my medicines are logged in there, so they-- to say they give me my medicines is a bit of a joke. They give me a cup which is filled with the tablets, and there's quite a lot of them. About 15 or 16 a day I take, but it's all recorded there as to what I have.”

”

Four of the 50 interviews described issues with care diaries. Although they received a care diary, they felt that sometimes the diary was not completed properly and not checked by the office.

Two interviews mentioned that the information entered was not always completely accurate. This is especially a problem if times of arrival and length of visit and tasks performed were inaccurate as respondents or the council may have to pay for care which may not be received.

“

“About their stuff that they write down. And their times, I mean, [My relative] paid for five and a half hours a week and she's lucky if she gets three. Anyway, I phoned the council and they said, “Well, maybe it's because your Mum don't need that much time.” I said, “But she's still paying you, Suffolk County Council, nearly £350 a month for you to deliver a service.” Now I know it's not an easy job, I understand that. This is not a gripe at any particular person, but they're putting down on their sheet— [My relative] made a note of the time they come. Like she said this morning, they were only here, what about 15 minutes?”

“They don't say what they do. It's not filled in every day it looks like. I had a joke with them and said, “Why don't you just get a little stamp and just put the same. They probably get fed up with writing the same thing down every day”

“So that they're all-- there's no need to have it on there (the care diary) because they put on their phones what they're supposed to be doing. So, they changed like that.

Researcher: So, would it make you feel better if you had something in that folder so that you could show people?

Well, it hasn't affected me much, to be honest, because I just tell them what they've got to do and they do it mostly.”

”

“

‘Diary? They never collect these pages. They write what they've done and then they sign it. And that's where it stays.’

”

One interviewee reported that their care diary was not collected and checked:

Theme 5: Be given a home care plan that meets your needs

Only 10 out of 517 responses to the scoping survey included comments about care plans. Interviewees were asked specific questions about care plans and planning. The comments are detailed in the relevant sub-themes below.

45 of the 50 interviews confirmed that the service user had a written care plan. Four did not explicitly refer to having a care plan and one was uncertain. In eight interviews, participants did not know what the care plan or other documentation was. HWS researchers often found it difficult to identify the care plan within the documentation in the care folder.

Sub-theme 5a: Service user has a care plan which meets their needs

This refers to service users who either have care plans that do not meet all their needs or have inaccurate care plans which do not include all the agreed tasks.

Seven of the 517 survey respondents made comments which suggested that they had additional needs to what was already included in their care plan. Examples of unmet needs in the comments from the survey include help with domestic tasks, needing a night call out service and needing specialist dementia care:



“As I understand caring for the elderly can be hard, I do not feel that some of the carers have chosen this as a vocation. Many of the carers are in and out of my mother’s

within 10 minutes. I work but visit both my father and my mother daily attending to many of their needs, meals, bathing, cleaning, and washing, I would appreciate if they could make a meal etc. a few times.”

“They do a good job but I don’t know how far they are allowed to go, I need more help really for example, looking at the morning, my children do it but it seems so undone. But the cost of cleaning & gardening is so high.”

“Night call service totally absent... GP has stated night call out needed.”

“...they won’t take me shopping when they are supposed to take me. They won’t come to appointments with you when you ask them to come with you. If they take you anywhere in their cars you have to pay for their miles and if they come away on holiday with you, you have to pay for them as well.”

“We need dementia care. This was very lacking as staff unable to persuade mother to take meds or allow them to help her in any way.. The carers appeared caring but unable to deal with someone who is difficult... I was never told when they were unable to give her the meds. I would read about it later in her records. They have just recently cancelled their visits as they no longer visit our area.”



Fifteen of the 50 interviews told HWS that their care plan met their needs:

““

“And the head one she first came out and she did the care plan. And she’s been brilliant for anything. If I had been somewhere and I don’t need anybody I phone through and she’s like why and where and what’s going to happen and how does it affect things. She’s very good at it.”

“At the moment, I get an hour in the morning, half an hour for tea and half an hour for bed and except on a Thursday, I get one week it’s two hours two go shopping and then the next week it’s five hours and the five hours is to go down to the town to pay my bills, to get any sort of birthday cards, presents, etc, have a coffee, then go and visit my wife’s grave and then we go shopping and then come home. And then I also get a two-hour cleaning visit.”

””

Twelve of 50 interviews spoke about the care plan not meeting their needs:

““

“She was the relief. And she said, “I’m sorry to tell you this, but I don’t think he does.” And I said, “Well, he should be getting one to one.” She said, “I don’t think he does.” So I rang the manager up there at the time. And he said, “Well, no. he doesn’t get one to one.” And I said, “Well, he did get one to one, so why is it stopped?” And he said, “Well, I don’t know. He doesn’t get one to one.” So I rang social services, and I explained

what was happening, and they said, “Well, he should be getting one to one because we’re paying for it.” So they rang the manager. He then rang me back and said he needs to eat humble pie. He’s very sorry, but he didn’t realise that my relative was one to one, and therefore he’s going to put one to one back in place immediately, but it is going to take time to get someone used to working with my relative because the person that he was having can’t work with him anymore.”

“One of his complaints was that the care plan was not itemised enough, which is the fault of the coordinator, not the carers. He said if two strangers come into this bungalow to care for my relative, and they look in there, they’re not going to know what to do.”

””

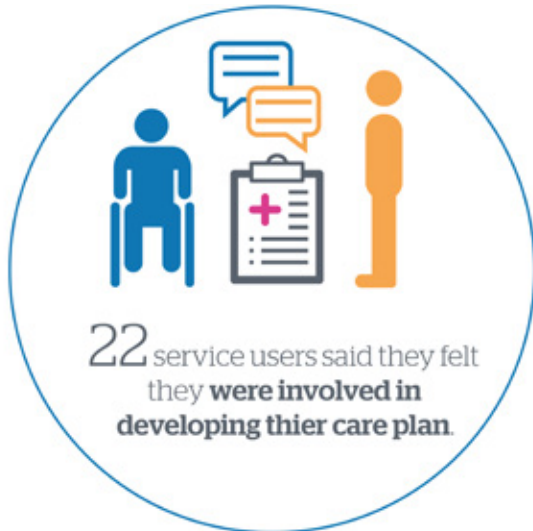
Sub-theme 5b: Service user felt involved in developing the care plan

There was only one survey comment out of 517 about service users being involved in developing the care plan:

““

“We are pleased with the care received to date, carers are respectful and arrive on time, all care plans have been discussed and the company have listened and worked well to put in place the care needed working with the occupational therapist to get it right for my partner.”

””



However, how involved the service user felt in developing the care plan was part of the interview conversation. Twenty-two of the 50 service users interviewed made specific reference to feeling they were involved in developing their care plan and made comments such as:

“

“Yes. They asked what we wanted, what sort of care we wanted, and did we want them to do the pills, but I said I always do the pills. So, yes.”

“Yes. And it's not long since they did the update to all the paperwork. Yes, and circumstances change. Last year, when I came out of hospital, things were different. I needed more help when I was poorly, and they found me away with the fairies.”

“The lady that runs the care company came and sat with us, and she must have been here a couple of hours at least. She was very thorough, went through everything to find out all about you, didn't she? And then she asked me what I could do and couldn't do, or would need help with, to find out

what we needed. I felt she was very thorough.”

“Were you involved when they drew up the care plan? Did they consult with you? Yes. It was as we wanted it, from the moment you got out of bed what happened, it happened as my wife wanted it to happen.”

”

Six interviews talked about not feeling involved in the process, and made comments such as:

“

“I would say they more or less told me what was going to happen. I wasn't that worried about it. I might have been a bit more worried if they said I wasn't going to get any help.”

“Researcher: So, if you don't have a care plan, when you first talked to the care agency, did you agree with them what sort of things you'd like them to do? No, I don't really, I don't remember doing that. No.”

“When you were organizing this, then, when you were discussing your plan did you feel involved. Oh, they're all clever in doing that, you get people come and go, “We'll do that for you. That's fine. Yes, we can do them times. We can do this for you.” Always, Brilliant, yeah, that's fine. Lip service is very, very good.”

”

Sub-theme 5c: Service user feels able to make changes to the care plan

In four of the 50 interviews, participants reported not feeling they had total control over their care. This can be related to difficulties in communication with the office, failure to review care plans regularly or care plans changed without consultation. No survey respondents mentioned making changes to the care plan.

Examples of comments by interviewees about being able to make changes to the care plan:

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*“Researcher: So if you want to make changes, do you feel that you can? Do you feel empowered to be able to go and say, ‘Look, this isn’t working, can we change things?’
I think so. I think in terms of complaint, we know how to do that. I think if we felt that there were changes required on her plan, presumably we’d then contact her again. And she was so excellent that I don’t see any worry there.”*

“Researcher: Speaking of the office, you put here that there’s an unpleasant coordinator who you couldn’t talk to as well. She’s just very unpleasant and she explains something that might happen or you might not be here or something and she gets quite abrupt with you and says, ‘Well, I can’t change your time.’ And that’s it. And I understand now what she’s doing and my care plan has been changed and I wasn’t even asked if that was acceptable or would I mind.”

*Researcher: So in that sense do you think that you can make decisions about your home care
Not really. Not unless you cancel the call completely.”*

“Yes, at the beginning but then you see my relative was still here then. So, I needed a bit more help doing things. And now I’m on my own and I can do things when I want to do them. Things don’t need to be quite the same and it’s still all in my care plan. And the last time my care plan was supposed to be sorted out, they were supposed to come over to see if it still works, they didn’t even bother to come out. They didn’t even ring me up and talk about it. They just redid it and sent it out. The year before and the year before that.”

“Researcher: When you’re organising things, reorganising things, do you feel you are included properly, that they discuss it with you and listen to you?

They used to be better at that. I mean, it used to be that we would have meetings and come around. But I think the last team leader, I didn’t even meet, so she didn’t have time. She didn’t come out. And I do phone up. I do email. So I’ve honestly been doing that quite a bit recently because there’s been queries. So, yes. I do feel that I’ve got recourse to them. But it’s just it’s not always happening.”

“And then there was some issue, because that wasn’t on the care plan. It was written on our care plan, but it wasn’t on theirs. And we were promised, but I thought it might all

be reprinted and we would get the up-to-date copy. It doesn't matter to me. It's written there and the most carers know when they arrive, but those who don't always do read the care plan."

Sub-theme 5d: Service user knows what is in care plan

There were no comments in the 517 survey responses about care plans other than one respondent who commented they did not know what they should receive as part of their care. In eight of 50 interviews, participants told HWS that they were not sure what is in the care plan, do not understand what they are paying for, or are not sure what the documents they have are.

The one survey comment which referred to not knowing what was in their care plan stated:

“

"I wasn't really sure what tasks they were meant to be helping with, I left it to them."

”

Comments from the interviews gave examples of service users not knowing what is in the care plan in more detail:

“

"I don't know how many months they do it at a time or anything.

I don't like to look too closely because I'll see it's people's personal information.

Researcher: But it's about you. It's your folder, and you are perfectly entitled to read it as and when you want to.

I didn't know that. I didn't know there was something about me.

Researcher: You probably thought it was theirs. It's yours. It's a record of your care.

Yes, I thought it was theirs. I never knew that it was mine."

'Researcher: Has anybody ever come back to you to talk about your care plan and any changes that you might wish to make?

They came when they cut me down. They cut me down to just lunchtime.

Researcher: Did the price you pay go down, too?

No.

Researcher: So you paid the same for three visits a day as you pay now for one visit a day?

Well, to start with, you don't have to pay, you see. So I didn't have to pay, but yes, I think it is the same. I think they may well pay some of it. I don't know. Because I don't know what it costs. I pay £54 a week, but whether that covers a half an hour, but as I said, I don't know the cost.'

”



Karen's care...



The most important thing is that I have not got to worry. Whatever happens, I know there will be someone to get me up in the morning whereas, if my partner is ill, we have to worry about finding someone else to come in to support me during the day.



Karen lives with her partner in a house designed for living with a disability. She has MS but is determined to live as independently as possible. She works tirelessly to ensure that her physical and mental mobility remain as good as she can possibly achieve. Through working with Suffolk County Council, she believes she has achieved this.



...one of my things that I first said to them was I wanted to feel like I was running my home. I wanted to decide, I can't always do it. I can't do the dinner, but I can plan them out... I can have everything in place, and there's a meal on the table at 6 o'clock. I might not have done it, but I've organised it all. And that was important to me.



Karen receives a personal budget from Suffolk County Council which she controls. It means she can arrange the care she needs herself.

She has had care since retiring from work on medical grounds seven to eight years ago. Her present carer has been with her for over three years. Her care plan has been increased gradually and she now has carers twice a day as well as other support during the day.

“They get me up at 07.30 - 08.00, and then I have somebody come in at 9:30am till 3:00pm. And then my partner comes home and that time varies. I can't set the times, but they've (the carers) got specific hours.”

The evening carers prepare her for bed around 9pm and prepare breakfast before they leave. Both she and her partner trust and rely on the carers and he often contacts the carers, or they him, to clarify what has happened at, for example, a doctors appointment because Karen is apt to forget.

She has always found Suffolk County Council responsive.



Remaining as independent as possible is hugely important to Karen, who has MS. She feels in control of her life and her household because her care is arranged to account for her needs and wishes.

“I have to say, they’ve always listened. They’d go into my lifestyle, and one of the things in the early days was, “You need to get out. You’ve got to have somebody to get you out for your well-being, even if it’s only for a cup of coffee. What do you like to do?”

Karen feels the first provider she had was ‘not fit for purpose’ and she then transferred to her present provider who is local. Her life is busy and remaining involved is enormously important to her.

“Oh yes. Oh yes, I’ve got loads to be doing. I’m always active. The telly never goes on until 5 o’clock at night. And we’re always doing, aren’t we? We’ve always got some little project that I want to attack.”

So, with the support of her partner, her carers and her friends Karen maintains an active and interesting life style despite her limited physical mobility. She is highly motivated, organized and determined to live life to the full.

“

‘... And that’s what I’m grateful for. Having that personal allowance and working closely with Suffolk County Council, I can run the house with the people that I get on with. They’re not people that are being told, “Just go in and sort her out.” Because you might not get on with those sorts of people.. so there’s that trust’.

”

Her carers always know what Karen wants to do and they can make it happen even if she can’t and as she says **“there is a real rapport between us’.**

Theme 6: Timekeeping

Timekeeping as a theme was of significant concern to the service user. 133 of 517 respondents made reference to timekeeping in the survey, with 108 negative and 25 positive comments.

Timekeeping was also highlighted as an important theme by interviewees, with 30 of the 50 interviews containing references to not having their preferred times, carers arriving late, and not staying for the agreed time. Problems related to timekeeping were often considered by the service users to be a management issue rather than failure on the part of the carer.

In twenty-four interviews, participants stated that problems related to timekeeping are, in their perception, related to issues of management and administration in the care provider office. This is not discussed as a separate sub-theme, however, examples of these are given throughout the quotations below.

Sub-theme 6a) Carers are usually on time

Although 21 of the 517 survey respondents said that their carers are usually on time, punctuality was the most commonly reported negative sub-theme in the survey with 46 people commenting that carers are often late, making this the most common negative comment overall.

Just under half the negative comments about timekeeping came from respondents who gave a good or excellent satisfaction rating, highlighting that timekeeping can be poor even for respondents who rate the care they receive highly.

Thirty of the 50 interviews made negative references to timekeeping and only eight interviews confirmed that carers are usually on time.

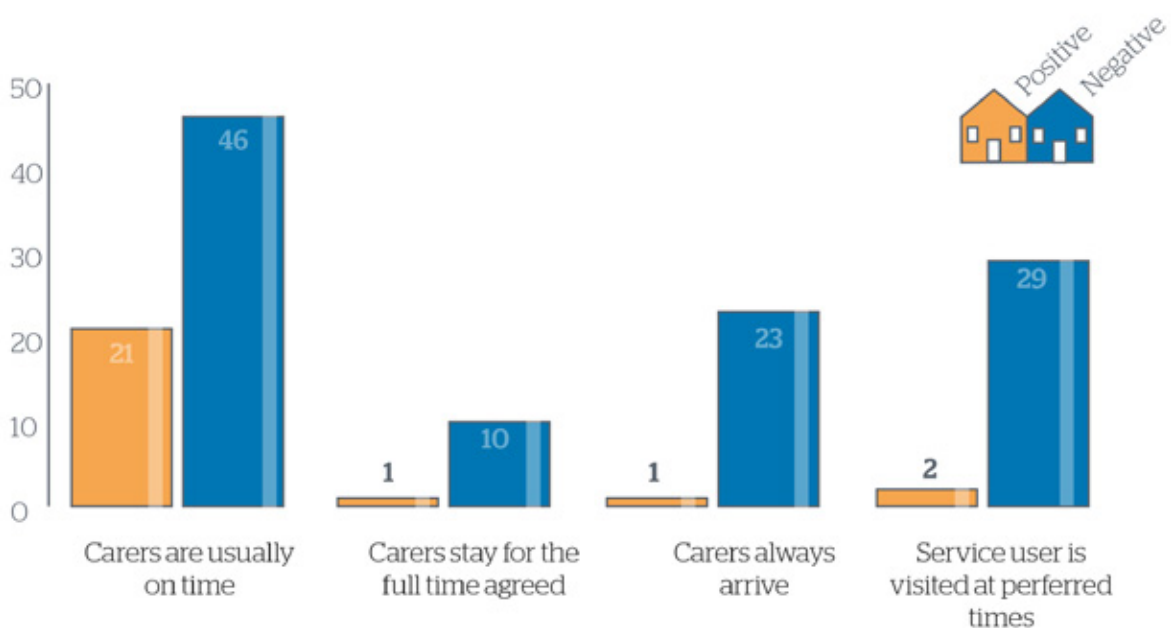
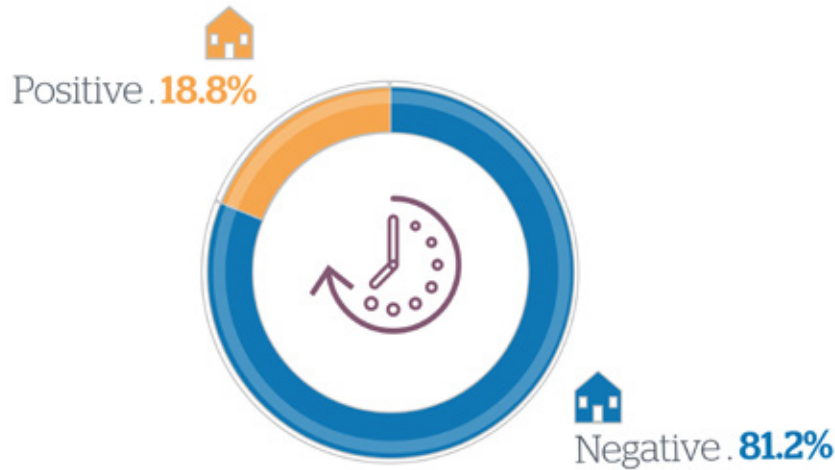


Figure 13: The number of mentions attributed to the theme of "Timekeeping" and their sentiment.



81% of survey respondents that mentioned **timekeeping** were negative about it.

Examples of positive and negative comments about timekeeping from the surveys include:



"Almost always on time."

"The carers are always on time & neat and tidy, they always put on aprons and gloves."

"Excellent, friendly, punctual, caring."

"Nearly always late."

"The care provided is normally very good although the carers arrive quite late sometimes. But not their fault, as they can be help up in their previous calls, or held up by traffic."

"Overall, I feel I receive good care, however sometimes my time of visit is wrong and this does upset."



Examples of positive comments about punctuality from the interviews:



"...they're always on time."

"Yes, it was because I've actually been looking at when they arrive. I think it was in August. It was the middle of August. So, since then, it has now settled down, and it's absolutely fine. So, I would say, well, now, yes. They've cooperated with me. They've cooperated with the person who wants to come in to me. And that's not favouritism. That's because it fits in with the both of us because she doesn't live very far from me, and it means that she can do me, and go home for her break, and then carry on with her lunches."

"I have one visit a day, every day. And two on Tuesdays and Thursdays to have a bath. [They come] at 7 o'clock in the morning and my bath now is 5

o'clock on Tuesdays and Thursdays. Researcher: Do they arrive on time? Yes, because the carer I have is extremely good."

Examples from the interviews of poor timekeeping, carers being late and in too much of a hurry:

“

"...they just come when they do."

"The only thing that sometimes annoys me is that they have certain times that they'll say-well 8.30 or somebody will come at 8.30 and in the end, they don't come until 9am or something like that. That kind of thing annoys and I like them to keep to their times it's nothing serious because they all are pretty good. Well, it's not half the job, but a bit of the job too is to provide a bit of company as well, to come and talk to you too which is what they do and which I quite like because I like to see people now and again and have a bit of company now and again. So I would just say that, well, I think to be excellent is pretty high rate. Excellent."

"My relative was getting really distressed because she hadn't had anything to eat for hours on end. And obviously, she wouldn't go to sleep then because she goes to sleep most often as soon as they leave at 8:00. And the window we had was been 6:00 and 8:00, but like I said, 10:00 is not very near either of those, is it?"

"When they were coming for breakfast so late that one of them left and she's hardly got outside and the person for dinnertime my relative was like, "I can't eat my dinner. I've only just had my breakfast," which makes a mockery, one, of our agreement and of common sense. I mean, you just wouldn't do that, would you? Basically, the person came late for breakfast and the lunchtime person came really early."

"Researcher: But while you were waiting all that time, did anybody ring you to say they were going to be late?"

I was warned the night before, the carer that came the night before, she said, "They might be a bit late tomorrow." So I wasn't expecting them before 9:30 or something like that, 9:45. But when it got to 10:30 I was really getting cross. It was 10:40 when they actually came to the door. There wasn't snow on the ground or anything like that. It was purely problems within their own organisation. I can't tell you exactly what because you get different stories. They're always full of apologies. But they also point out that they got lots of people to do and all the rest of it, you know. And I understand that. But I would like to be within, say, an hour time slot so that you know where you are, but it doesn't I suppose on the whole, it is perhaps between 8:30 and 9:30, but it does quite frequently go late. And the same in the evenings."

"In the evenings, they never come before 7:30 but occasionally they come at 7:30. And then from then on, it can get round to - it was 9:30,

9.35 the other evening. Once again, it's quite a large time slot. Doesn't matter so much in the evening because we're sitting here watching television but always very ready to go bed anyway. She gets very tired. So from 7.30 onwards, she's waiting for them to come. If it stretches out to after 8.30, well she goes to sleep by then."

One service user told HWS about the positive impact good timekeeping by her carers had:

“

"Because I'm okay and it's just for my shower. I don't want somebody turning up at 11 o'clock, in a frantic hurry to get onto the next person to do her lunch, when I've been sitting around since 8:30 in the morning waiting to have my shower. And now we've got that sorted out, and I've got one person who comes regularly. She comes about half-past 9:00 to 10 o'clock in the morning which is a perfect time because I've come downstairs in my bathrobe, I've had my breakfast, I've had my pills, and I'm ready to have my shower. So once we got all that sorted out, it was fine because she likes coming to me as well. So basically, it works very well. And I think that's one of the things which is important to those of us who aren't demented, or just need physical care, to be able to rely on the person who's coming in."

In ten interviews out of 50, interviewees stated that not being notified if the carer is going to be late can cause them inconvenience and stress.

“

"It's just it never changes. It never changes. And the lady that came we told her all about it and she said it's really not on, because they should be phoning us. It's not up to us to find them to find out who's coming in. It's up to them to find us to tell us who's coming in. But they don't. Ever. Even if, say, a carer goes off sick first thing in the morning, they wouldn't phone up to say to [my relative], "Oh, by the way, we're going to be a half hour late," or something like that. They wouldn't let you know."

"And then they're short of people. I understand all of that. But there's no recovery, there's no-- if they're not going to send somebody at 10 why don't phone me up and say, "Can you have a word with your mum? This is what's happened." But there's not a what happened. They'll just let you down. And that's real-- that's the customer care gone out of the window. If I hadn't rung one night my mum would've just not had anything until four in the day. Because nobody would've come. And they didn't even know that no one had been. They said, "What do you mean no one has been?" I said, "Well, nobody's been. No carers." And they went, "Well, we sent someone." And I said, "Well, perhaps they've been kidnapped. I don't know but they didn't turn up at the house."

In twenty interviews, service users and family members also told us that they sympathised with their carers. They attributed problems with timekeeping to poor management, the carers busy schedule, the long travel distances between appointments, and unexpected events such as illness or traffic conditions delaying them:

Examples of comments from the interviews are:

“

“It’s not their fault if they’re late sometimes because they never know what they’re going into. And I understand all that. And we’re very happy with them. Precisely. I don’t think they’re paid to the value of their roles. Most definitely not. No, do they get paid some allowance for their petrol? They don’t get paid for the wear and tear on the car. And they do miles.”

“I mean, there are occasions, obviously, when [the carer] has gone into somebody’s house and they found them collapsed on the floor, or they can’t rouse them from their sleep. Then they call 111. And they have to stay with them until the ambulance arrives, but fair enough. That will put you behind, and everybody understands that. But again, if they’re just communicating, and just told us, that will be fine. But the carers are not allowed to have our telephone number. And I can’t get my head around this because I think, “They’ve got a key to get in my house, but they’re not allowed to have my telephone number.” You see? If they had the number and they were delayed for any reason-- could be an accident on the road

and they’re held up in traffic, then you’ve got to dial and say, “I’m really sorry I’m caught up in this traffic.” Or, “I’ve got to wait for an ambulance.” Then you’d understand. And you could carry on what whatever’s got to be done.”

“I would say eight months to a year now. Considering I will have been since 2013. It has got better but again, the care agency and the office staff do not appreciate some of the carers and I don’t think society does. Just like waitresses. No. I don’t think people look at it as a career. It’s like, “Oh, you’re just a carer.” Well, to me, carers should be shown a bit more respect because they-- in hospital, the auxiliary nurses can only take your temperature and your pulse or whatever. Yeah. In the community, these carers can administer medication and they have to do all these personal things, etc. There’s a lot more to it, and I don’t think the care agency really respects the staff enough, you know?”

“And I realise that all care agencies are up against it. And it’s difficult for them to survive. I think a lot of the carers that I’ve had have been-- I still have one main carer who is absolutely excellent. She was originally with ..., so she’s gone through lots of changes and lots of the people have been changed. She’s been taken over and her contract’s changed. She was on one contract and then suddenly she’s on a different contract. She was on one hourly rate. That’s suddenly removed. So there’s been lots of things, I think, happening to the carers.”

”

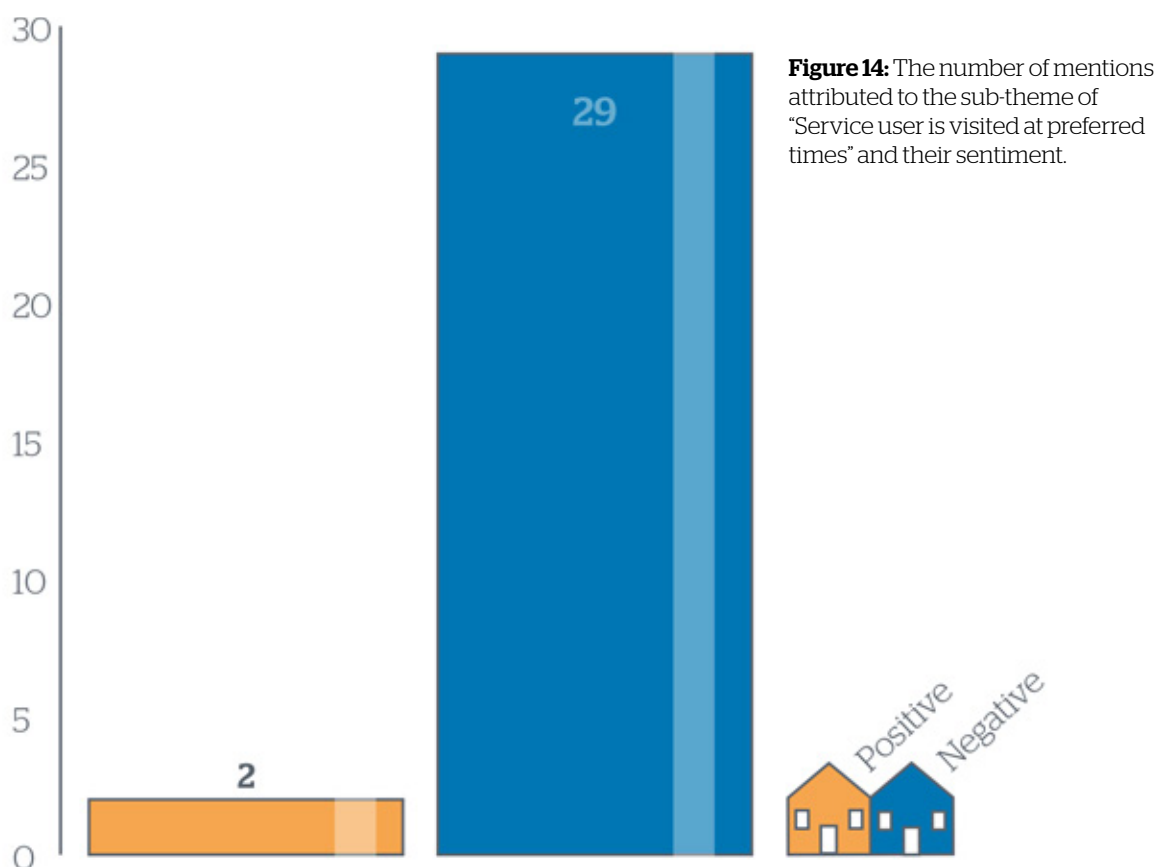


Figure 14: The number of mentions attributed to the sub-theme of “Service user is visited at preferred times” and their sentiment.

Sub-theme 6b: Service user is visited at preferred times

Twenty-nine survey respondents out of 517 made comments stating that their preferred timings are also often ignored and only two stated that carers arrived at the preferred time.

A majority of these negative responses (24) were made by service users who gave a ‘good’ or ‘average’ rating to their care. Comments stating that the service user is not visited at preferred timings was also the second most important negative sub-theme in the survey overall.

In 23 of the 50 interviews, interviewees stated that carers did not arrive at their preferred times. Criticisms included carers arriving very late to help service users get ready for the day, very early to put them to bed; often meals had

to be taken at inconvenient times and appointments missed.

Comments from interviewees showed that there is some understanding from service users that they cannot always have their preferred timings due to pressures on the carers. Not having preferred times can lead to situations that fall below the standards expected of good care.

Service users who responded to the scoping survey said:



“Do not have preferred timings: Timings of visits not always appropriate. IE. Arriving at 3pm to prepare my mother’s tea, arriving early for bedtime, sometimes

around 8pm making for a very long night.”

“We have to accept early morning or late morning visits occasionally but not ideal.”

Examples of comments from interviewees about lateness and inconvenient times:

“

“That did start to be a little bit late, particularly at weekends when my husband would be hanging around in a dressing gown. And when they run late, because weekends are always slightly difficult for me. And he can't get going with his day when they aren't here till 11:00, you see 8:00 start on one, and 11:00 on another. And I know everybody's needs are much the same. The same time. And I don't push to say, “Well, we-” because my husband, doesn't really want very early-- many older people, they don't want very early. We'll do exceptions because we are not going to make waves.”

Examples of interview comments about arriving too early to help put to bed and arriving late in the morning:

“

“And he doesn't like it because when he was first having these carers four times a day. He was being put to bed some nights at 7:30, and getting

up at 10:30 the next morning and that's too long in bed. If we did have to complain about that. It's now got later. And some nights now it can be 9:30, or 9:00 o'clock--I just had one early this week, and that was last night. And that was 8:30 Yes. That was a bit early, but they are short staffed at the moment. So we have to give and take.”

“I mean, sometimes they're here by 7:00 to put him to bed. Well, we have our evening meal at 6:00, so by the time we've washed up and cleared away and just going to go and sit in the living room, they turn up to put him to bed. That is unfortunate. And they say, “Oh, well, we can't do anything about that. That was the times that were down.” And it's not the carer. The carers, on the whole, are very, very good. It is the management team. They just cannot get their act together. They cover a very large area and they expect the carers to go from-- well, you probably don't know the area-- do you know the area at all?”

“They come whenever they can fit me in. Anytime from 7:15, which is what they started coming at. What a ... ridiculous time to come and get me up, isn't it? When all I do is sit here all day because I can't walk now and can't see where I'm going either. So, what a damn ridiculous, that organisation.”

In nine of the 50 interviews, participants suggested that problems relating to not having their preferred visit time or carers arriving late were the responsibility of management and poor administration

practices. Service users voice the view that care providers often did not give their carers enough time to complete their tasks and then travel to the next appointment on time.

Poor recruitment and retention of carers was thought to lead to heavy schedules, and long hours. However, the sympathy that the service user expresses for the carer reflects the very positive view they have of their carers and the sometimes difficult circumstances under which they work.

Examples from the interviews about care providers not giving carers enough travelling time include:

“

“I mean you have to agree to it within a half an hour. I think it’s all carers being like that. Because they’ve got to get around. See the problem they have is because there’s no time in between calls. One call finishes at 10 o’clock in the morning, and they’re supposed to be at the next call at the same time, at 10 o’clock.”

“There is a lady from-- the carer who does me in the morning, she goes from here, she has two corners to go around, around a big loop, and she’s at the next one. And she said to me, “Look. They’ve given me one minute.” I said, “No.” And she said, “They’ve given me one minute. When I get out of your door, to get into my car, drive around, get out, then get to the next one.” She said, “Now, if that car is held up again, or got a bit icy, I’ve now got to defrost it. I’ll never make it.” I said, “That’s

ridiculous.”

“The carers are given unrealistic times between visits, and unrealistic bedtime calls and times.”

”



*...she has two corners to go around, around a big loop, and she's at the next one. And she said...
"They've given me one minute. When I get out of your door, to get into my car, drive around, get out, then get to the next one."*

**A home care
service user**



Sub-theme 6c: Carers always arrive

23 of 517 survey respondents said that their carers do not always arrive. In some cases this was of real concern as service users had been left for long periods of time without care.

Some service users told HWS about instances where the carers had not arrived, and there is no response from the office, leading to service users being left overnight with no care at all. Some individuals said that they had been left alone through the day which may mean that they do not have adequate nutrition or personal care. Often, family members were required to substitute for the care provider.

Examples of quotes from the survey about non-arrival:



"Visits were twice a day, on a particular day care was not arranged by them [the agency] so there was no visit. [Relative] fell in the morning and was found by myself in the early evening. She had had nothing to eat or drink all day and had been incontinent as she could not wait any longer."



Respondents to the survey commented about carers not turning up:



"I had some good ones [carers] and they were good in their work then I had some never turn up."

"Occasionally no carer has turned up, this is particularly of a concern on the first and last visits (out the four a day) when it involves getting up and putting to bed which cannot be done independently. This had resulted in emergency cord having to be pulled."

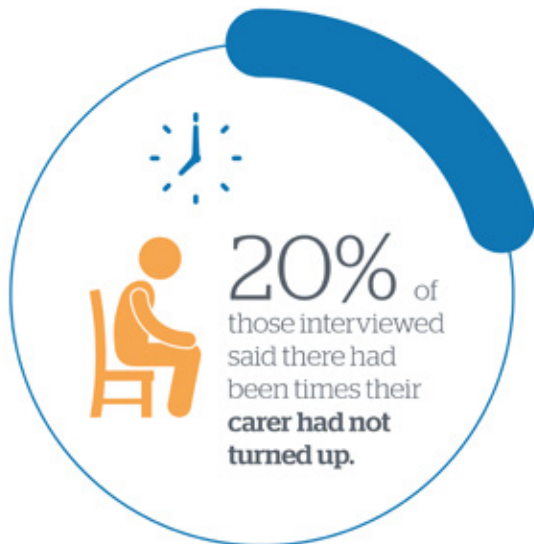


In ten out of 50 interviews, interviewees told HWS that there were occasions when no carer had arrived. Three made positive references to carers always arriving.



"Well... we had one, two, three, four, five, six missed calls. And two of those have been no care at all during the day. They don't turn up. And we do try at the time to telephone them. Then often you just don't get a reply from anybody. There's often not anybody in the office, and it's supposed to go to somebody who is on call, but it doesn't do that, unfortunately. And recently I've been trying to send emails to this manager that's on call. And it has got a bit better but I don't think it's still right."

"Again, I think it's just a bit hit and miss. I mean, if it's a serious sort of thing then I think, yes, it would. But if it's just another sort of query or something or someone- I mean, they have, they missed me one night, putting me to bed. And it meant I had to sit up until my son come home because I couldn't get through on the phone, no one would pick up. And my son come home"



and like this, "What are you still doing up?" I said, "Well, the carer did not turn up. I can't get through on the phone, no one's picking up." "Oh." So he put me to bed, went up there the next morning, was like, "Yeah. We had some trouble with the phone." "Why didn't you turn up?" "Well, I don't know. But I can look into that." But, I mean, they shouldn't be missing people. Again, I'm lucky. One, I can get over like using the toilet, and two I have my son here. But if I was elderly and I needed the toilet, I'm going to wet myself or foul myself or anything. It's just poor really."

"This last week actually. They've been pretty good for awhile because they've been using agency staff. And we had one that was excellent, but they've now got rid of their agency staff. And when it comes to holiday times and weekends, they've taken on lots of part-time staff that only want to work school hours. And consequently, we can't get anybody-- because we don't live in town. We live outside the town and they can't get anybody to do the evenings. And

sometimes the mornings, but mainly the evenings. So this last week, we've had three, four-- four times they've phoned up and said that they can't find anybody, so I've just said, "Well, I'll do it." I mean, what else can I say, really. It was lucky this week I was around."

"Researcher: And what time are they supposed to come in?"

Well, any time after 12:00 or just before 12:00. (they don't) always arrive on time. Not really. As long as they're not too late. But on one occasion, they didn't come at all. What did you do? Well, I'd had my cleaner in in the morning, and she had made me a sandwich for tea. So, I ate the sandwich, and then I made another one for tea. And so you had sandwiches that day, you didn't have a hot meal. So, I had sandwiches that day."

Sub-theme 6d: Carers stay for the full time agreed

Ten out of 517 survey respondents and 13 out of 50 interviews stated that the carers did not stay the time agreed in their care plan. In some instances, this is not considered a problem if the carers have carried out all the tasks detailed on the care plan. However, some respondents felt that in leaving early they were missing out on valuable time which could be used to engage with their carers.

There was one positive survey comment in the survey about carers staying for the full time agreed:

““

“...My carer is on time and will let me know what time she will be in the next day or as near as, she is friendly and willing to help wherever, she is also smart in uniform, and stays her full time.”

””

In six interviews out of 50, participants told HWS that they often understand that the carer may want to leave early to get to the next service user and if they have completed all their tasks this is not a problem:

““

“They’ll stay as long as they need - it takes about 10 minutes... They’ll sit and chat for a time. But I say “If you want to go, go.” because I know they’ve got to get to the next call.”

“I’m lucky I’m in the position where I

can say, “No, thank you. I’ll do that for him. You get off now.”

“Yes. It does vary a little bit but they’re not much under that and they don’t often go over that. There are occasions if everything goes well, they can go before their due period. It might matter if it was a person on their own, they might like that social company for that period of time. In our case, it doesn’t really matter. As long as they do their job as professionally as they should do, so instead of that half hour, and now if it’s say 22 minutes or 25 minutes or 20 minutes, it doesn’t really matter because mother’s got the rest of us around her.”

””

Thirteen interviews of 50 mentioned that carers did not stay for the full agreed time. The comments in the interviews indicate that they may be OK with this so long as they do not need any further support, but they sometimes do feel deprived of care when tasks are hurried and not carried out to a high enough standard:

““

“... It affects the routine. We have a routine. My relative has his breakfast, I give him his pills, then I can go shopping because I have to lock him in. I have to leave him for 20 minutes so I can do my shopping unless my neighbour’s in and he’ll sit with him. But if they don’t come here until 9 o’clock and then they decide to be gone by 9:15, everything is out. All the pills and everything is out. I mean, we did have good relations

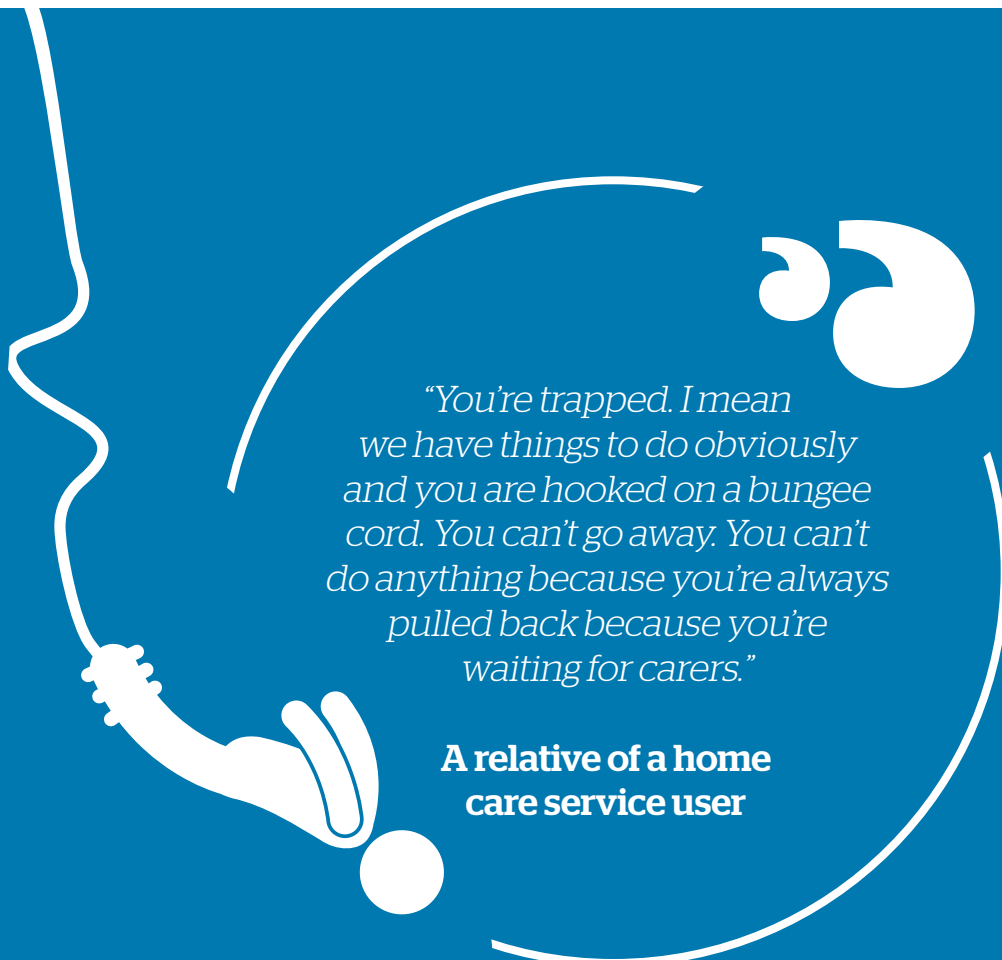
but everything's changed at this care provider."

"They've never got any time to prepare a proper breakfast. Just a bowl of porridge, a cup of tea, and then quick as can be, they're out of the door. And if they're done 22 minutes, and they rush out of the door. Whether they've been given too much work, so they've to get on to the next client, I just don't know. Nothing is disclosed to me at all. Every time they leave after 20, 22 minutes."

"Tomorrow morning, they will stay for the full half hour because I'll have a shower, all right. But otherwise,

very seldom, no they don't. But it's not their fault..."

"I understood that it would be about 45 minutes, but they're basically here never more than half an hour. And sometimes less than that."



Examples of negative comments about carers staying as long as agreed from the survey responses include:

“

“I tend to get lonely at times and more time given to care would be better some stay longer, some stay shorter periods of time, they generally are helpful with various jobs about the house, washing, shopping, collecting mail and washing dishes. They always seem to be in a hurry! About everything. More time please.”

“Paying for 45 mins rarely receive 30 mins!”

“They do not always turn up and do not stay for the amount of time they’re supposed to.”

“One day the carer came at 9.20am and went at 10am. I don’t think this is fair when I pay £9 per visit.”

”

Examples of comments from the interviews which mention carers not staying for the full time agreed include:

“

“It’s not the carers as such, the carers are working a system they’re given, you see what I mean? The carers they’re very good. Unfortunately, because it is a system that is running, they’ve got to make profit. We’ve put it in a nutshell. They’ve got to make a profit, so they’ve got to

do as least running about as they can. Sometimes like [one carer] in particular - he’s always in a hurry. Because he’s going to go from here, to here, to here, to here. And if he goes in 10 minutes taken off you, 10 minutes taken off him, and 10 minutes off him-- but what do you do? You know what he does - we both know if he’s about to go to the door, and she says, “Oh, can you just,” he would come around and do that. So what do you do? You know, we could kick up and end up with somebody who was terrible.”

”



Theme 7: Communication

Thirty-two of the 517 respondents to the scoping survey made negative comments about communication with care provider office staff. By contrast, there were only 12 positive comments.

Although the survey responses contained more negative comments about communication than positive, the interviews were balanced in sentiment.

Twenty-three interviews out of 50 make negative comments about communication and problem solving between the service user and the care provider. Twenty-four interviews, however, made positive comments within this theme.

This suggests that despite the high proportion of negative comments made in the survey, some care providers do resolve issues to the satisfaction of the service user.

Sub-theme 7a: Care provider resolves complaints and problems

Twenty-three of the 517 survey respondents said that their provider does not respond to their complaints and problems in a satisfactory way. 10 made positive comments about this. Where there is good practice, issues are resolved quickly and to the satisfaction of the service user.

Examples positive from the survey responses include:



“Office support and communication is very good. Very good at providing options/solutions.”

“We have one or two issues with carers that have always been listened to by [the provider] and have been sorted out.”

“The carers are kind and supportive of the office happily help solve any problems, such as needing to change a care time if necessary.”

“I am pleased by the way the new manager has turned this place around as he has the welfare of clients foremost. I hope he stays for a very long time. I do feel I can

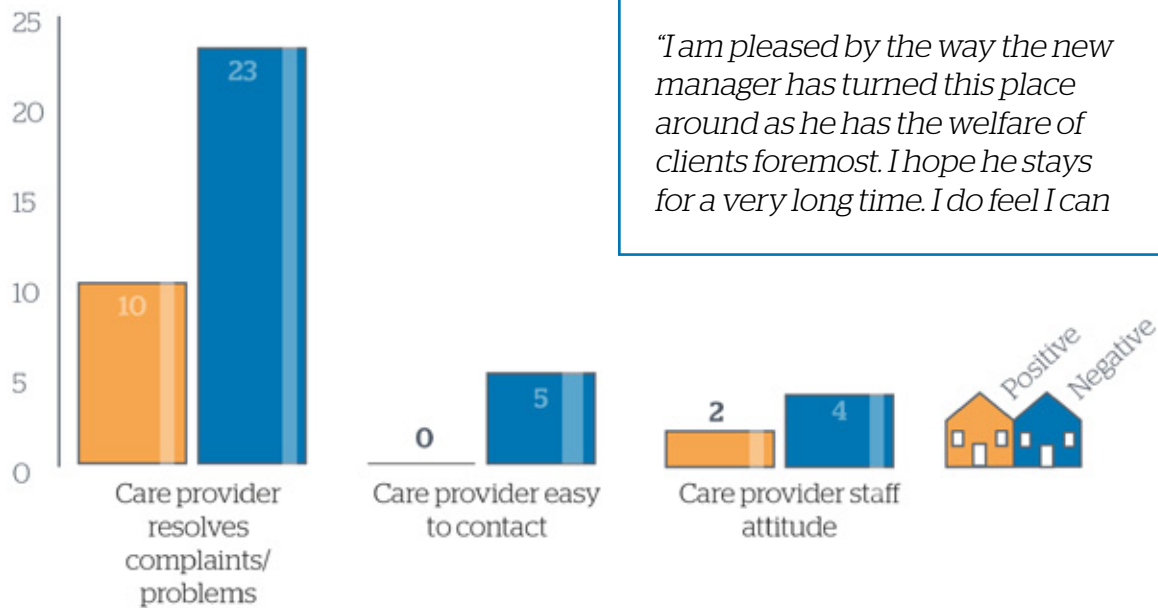


Figure 15: The number of mentions attributed to the theme of “Communication” and their sentiment.

approach him and any problems seem to get attended to quite quickly.”

Twenty-three of 50 interviews made positive references to care providers response to complaints and problems. Examples of these comments include:

“

“Any complaints or if you want them to come to see you, you ring them, or my grand-daughter rings them and they sort it out. And they sort it out quickly.”

“... one of the last things she said is, “If you have any worries, or any queries, or anything at all, do pick up the phone.” And I have felt that we are able to do that. I feel we just instantly sort of gelled with the lady, and I felt yes, I would ring her, and I would tell her things. Because I feel that it's only fair to her, to know if we had something- rather than let it niggle away and worry us, we would speak to her and explain, and she would address it and sort it.”

“...They came out to see me. “What's the problem?” and you tell them and it solves it.”

“Oh, yes. We have contact with them. Well, he's a supervisor. He rings us up if there's a problem or he'll come down and visit. If he's passing, he'll pop in and say, “How are things going?”



Negative comments from the survey include:

“

“Getting hold of [the care agency] on call is very, very difficult and you are never informed when a carer is not coming. Complaints ignored by office.”

“...Making cup of tea instead of personal care that is required - not coming at the time slot allocated... I have discussed concerns with agency, still no change.”

“The office personnel are dreadful. Don't listen when you phone and regularly making mistakes.”

Twenty-three of the 50 interviews also made negative comments about provider's responses to complaints and problems. Examples of negative comments about query resolution from the interviews:



“You get the feeling that they just agree with you for agreeing sake. See, when I phoned up at 10:20 the morning visit should have been at 8:30, the office could have said, well, yes, they, sorry about that, really, but there was an emergency further down the line. Well, instead of that, it was some excuses like what we did in the time that we thought we’re allowed. We’re allowed, I think she said, two hours, right? Flexibility. Well, to use that as an excuse, we did it in our flexibility time. It’s unnecessary. I said, “Yes, I’m sorry about it.” And perhaps on reflection, possibly we could have given you a ring.’

“No, I feel I’m just talking to somebody in the office because that’s basically, during office hours, who you get is the person in the office who’s always apologetic and says they’ll pass it on, sort of thing, and make sure it’s attended to and all that sort of thing. But you don’t feel that you’re talking to anybody of particular repute...”

“They’re always full of apologies. But they also point out that they got lots of people to do and all the rest of it, you know. And I understand that. But I would like to be within, say, an hour time slot so that you know where you are, but it doesn’t-- I suppose on the whole, it is perhaps between 8:30 and 9:30, but it does quite frequently go late. And the same in the evenings.’

“I’m afraid now. I very rarely ring up. It’s only if I need something changed or I want to cancel something, I ring

them up. Because otherwise, it’s not worth it.”

“...there is some fantastic carers out there and I mean really people who love the job and love the clients. But like in any job, you’ve got people who just do the job for the money and don’t really care too much. Don’t go the extra mile shall we say. But there’s other times when people, they phone up and-- I don’t want to say lie, it’s not a nice thing to say but when they say things like, “Your carer’s gone off sick,” or, “Your carer’s gone off this, that and the other so your care is going to be late and we’re trying to cover it,” and all this. Okay, and the next time you see that carer, “Oh, you feeling better?” They go, “Feel better? I ain’t been sick. What you on about?”: “Well, they phoned up and said you couldn’t come in.” That annoyed me. So that was a lot of the time.”



Sub-theme 7b: Care provider easy to contact

Comments attributed to the sub-theme of ease of contact with the office relate to service users being able to speak to someone at the office when they needed to. This might not occur for a number of reasons, for example, a lack of information such as phone numbers to contact or unavailability of office staff.

There were 15 comments from the 50 interviews about whether the office of the care provider was easy to contact. In eight interviews, interviewees told HWS that their care provider is easy to contact, and in seven, participants said that they were not.

There were five negative comments in the 517 survey responses about contacting the care provider office. Examples of survey responses include:

“

“Getting hold of [the office] is very, very difficult and you are never informed when a carer is not coming. Complaints ignored by office.”

“You can never get hold of anyone on their ‘emergency out of hours’ number. If you do they never pass on messages. Sometimes they can be sarcastic and the office a lot of the time never passes messages on and is very unhelpful. The communication is poor.”

”

Examples of interviewees who had difficulties in communicating with the office:

“

“Researcher: And so what’s the communication with the office been like?

There’s none. There isn’t any. A lot of them have kind of like a half-hour window that they’re supposed to let you know. Yes. But I mean, that was just a figure of speech. Even if they have two hours left, they wouldn’t (ring).”

“No, they don’t do it at all. No no-one arrives and I ring and I ask ‘Have I got a sitting today?’ But [they know?] sitting time’s 2.00. ‘Oh, we can’t get anybody.’ ‘But why couldn’t you

have told me then?’”

“...Its the attitude of the office. It used to be very, very good. Up until about two years ago, it was brilliant. You could ring them up and if you had got a problem or anything and they would be very happy to help you. Now, they just don’t answer your call and that’s it. And you might get put off when I asked about my time in the morning. I was just told, ‘Oh, we’ll look into it.’”

“Well, you wonder whether they’re going to come or whether they’ve forgotten you. I think if it gets to about 1.40 then I did try to ring up but there was no one there. Sometimes, when you ring up to complain about something, there’s nobody there because they’re so short of staff. No one answered the phone at all.”

“When you get hold of the office. You can’t always get hold of the office. Researcher: So, do they have a voicemail, or what happens when you can’t get hold of them? Well, you’re supposed to ring the other office if you can’t. And then, you can’t always get hold of them.”

”

However, the interviews showed that some care agencies responded well to problems, queries and were easy to contact:

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“I know the woman who’s mainly on the office and she’s excellent. So, when we’ve had to change a day or something like that it’s been very easy to get in contact and get that

“

sorted. But it has been explained to us the process if we have a complaint and which number to ring. It's all in the folder. Very straightforward.”

“One thing they do do now is if you ring at 11 o'clock at night, they do answer the phone... I've phoned and in fact, a couple of times the person I've phoned has said, “We haven't got anybody, I'll come,” and they've got in the car and come themselves.”

Sub-theme 7c: Care provider staff attitude

Both the interviews and the survey comments highlight that the attitude of office staff is an important aspect of determining service user's perceptions of their care provider. This includes being polite and providing good service when speaking to service users.

This was a smaller sub-theme in the research, with only two positive and four negative comments made in the surveys out of 517 responses. In the 50 interviews, there were four positive comments and seven who told HWS that office staff could sometimes be impolite.

Examples of comments from the survey:

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“The office staff are very friendly and helpful.”

“All of the carers and office staff are polite, caring and provide excellent care.”

“... communication between members of staff isn't always good and find that senior staff [can be]... aggressive and rude when trying to sort a problem out with myself and my family members, not very helpful.”

“Unpleasant...!! not nice to talk too.”

Comments about care provider staff attitudes from the interviews:

“

“Not particularly good. I even had the response one time when I complained about the times and the person on the other end said, “Well, you could always look for another provider.” I thought, “Well, that's nice... I don't want another provider. I'm quite happy with the carers. I just want the times sorted out:”

“..you wouldn't get anywhere if you had a problem. Lately, it's not even worth hanging up if you think it's that bad... There's two that coordinate. One is brilliant and the other one is terrible. If your calls at night, late, one will ring you up and tell you and the other one won't bother.”

“Well, no. I don't. Because when I rang up about the cups, she said, “We're not a-” what did she say? I can't remember now but it was as much to say, “What do you expect?” You know. She was very off putting, so I didn't ever complain again.”

Additional theme one: Suffolk County Council

Negative comments about Suffolk County Council arose from problems relating to incorrect and late invoicing, funding for care and being charged for home care that has not been received according to the agreed care plan.

Other sub-themes include the involvement of social services in the management, provision and operation of care in the home.

Sub-theme A1: Problems with invoicing or funding

The main topics of concern for service users in relation to Suffolk County Council were incorrect invoicing or unavailability of funding for care.

Twelve survey respondents out of 517 made negative comments about SCC, eight of which related to incorrect invoicing or unavailable funding for care. Eleven of the 50 interviews mentioned that invoices were often incorrect, with service users or family members stating they or SCC may have been charged for care they had not received.

Examples of survey comments describing problems with invoicing or funding of care include:



"My main problem is SCC who invoice for my mother in laws care. The invoices are NEVER correct and they always overcharge. I am presently in dispute with them. I would like to discuss this with you."

"Only problem I have is with Suffolk

Council. If I cancel a day [the care agency] put time sheets in but council do not read them and just take standard payment."

"When [the care provider] first visited us, we were assured that we would not have to pay anything for the weekly help for my daughter... from a member of their staff. No mention was made of the fact that they would be passing bills on to Suffolk County Council. The young lady who came to look after my daughter... was very good but we feel we should have been told that we WOULD be billed."



Four of these survey comments about SCC relate to funding or the availability of care. These topics were not found in the interviews. Examples of comments about funding and availability of care:



"Initially told I couldn't have a carer, so sister had to come in [to my home] for several months. Then Suffolk Independent Living made council change mind. I was then on an 'urgent' list for several weeks, until I rang round care agencies myself and found someone taking on new packages. When I rang the council and asked for details of direct funding, my social worker then ran through care agencies and organised for [one] to start the following week. They are wonderful."

"Re Suffolk etc, When I have tried to discuss payment issues they rarely answer my questions."

"We tried getting personal payments but stopped as we were told that nearly all would have to be paid back! Could not afford to do that as we are on benefits."

"More hours were requested and recommended by his Social Worker, then refused by her manager. Any further hours would have required funding by social services."



Examples of remarks about payments and invoicing made in 11 out of the 50 interviews:



"Well, we've had social services involved. When we had all this about 18 months ago and I've been in touch with the council all the time. Every time you phone you get somebody different. So their name changes and you have to explain again and then in the end-basically, we gave up on this. I pay out all that money. I don't mind paying it if I get the time they say I should do."

"She was the relief. And she said, 'I'm sorry to tell you this, but I don't think he does [get one-to-one].' And I said, 'Well, he should be getting one-to-one.' She said, 'I don't think he does.' So I rang the manager up there at the time, or team leader. And he said, 'Well, no he doesn't get one to one.' And I said, 'Well, he did get one to one, so why is it stopped?' And he said, 'Well, I don't know. He doesn't get one to one.' So I rang social services, and I explained

what was happening, and they said, 'Well, he should be getting one-to-one because we're paying for it.' So they rang the manager. He then rang me back and said he needs to eat humble pie. He's very sorry, but he didn't realize that my relative was one-to-one, and therefore he's going to put one-to-one back in place immediately, but it is going to take time to get someone used to working with my relative. So they're finally agreed, we have to have the one-to-one back."

"[I think] some of the charging mechanism hasn't been exactly right. All I can tell is how it's affected me, really because there's different types, aren't there? I'm not doing it yet, but I've said because all those hours that I've lost, and there have been several when they've not been able to cover, I lose completely. They're not banked, which I've got to say did happen at one point, that hours would be banked but then they'd been told by the county that you can't bank hours. They have to just invoice exactly what they do, not for what they haven't done. In all honesty, I can't believe that's happened, really, and I think that's why it's [the county] to be looking at that."

"We've had, one, two, three, four, five, six, seven incorrect invoices. Out of the first eight, seven were incorrect... So the only reason one was correct was as I said because I had a telephone conversation with a member of their staff and they obviously managed to pass the message on and sort it out... But every time, every other invoice was incorrect. Finally, I had an email

from them saying that their senior finance officer would speak to me... And I then had a call from him and I went through everything with him and since then things have now seemed to get sorted. I think the last two invoices I've had have been correct.'

Three interviews told HWS that there were instances of invoices being late:

"I know what I'm getting billed for. I mean, I know they were very behind with their bills. Somebody said, "Well, be careful." You get a big bill, fortunately, I can manage financially. I try and cope with that sort of thing."

"And that was another complaint with County Council because today, they will have taken this month but that's paying for November. They're two months behind. Now my attitude is if he was to die they would tell me I owe two months care and I would say, "No" because his pension stopped. And it's their fault because they never got up to date. I find that's very bad management when councils are crying out for money. That their accounts are two months behind."

Two interviews mentioned that service users did not know what they were paying for.

"No. I think one of the things I'm really not quite sure is what I am paying for. I had an assessment, a financial one from Suffolk County Council. We went through the paperwork as to my understanding. Then I had a phone call to say, "Okay. This is what it's going to cost you." But I have no idea what my costs are. I've been billed, but what my proportion is, I don't know what I have been covered for."

"They came when they cut my visits down. They cut me down to just lunchtime.

Researcher: Did the price you pay go down, too?

No. Well, to start with, you don't have to pay, you see. So I didn't have to pay, but yes, I think I am paying the same."

One interviewee had problems with financial payments to the county council and commented:

"I asked them on many occasions probably over a space of nine months if not nearly a year to correct her account because I'm responsible for her account and they didn't. Fortunately, they stopped taking the direct debit. So I let that drift for three or four months until I was on the right side of it and then I sent them a balancing cheque for what I owed them. They rang up and said, "Oh, we understand." They wouldn't acknowledge the letter, which

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“But I’ve just received an invoice, or two invoices, that are three years old, two years and three years old. And I can’t even remember what they’re for...”

A home care service user



they've never done to date. But they did cash the cheque, so in my opinion, they acknowledged what I did. And then, they started the direct debit again. And the account details did not change, so you tell me what goes on. But from that point of view, if it had been my relative having to look after her own account-- so I've been worrying for her."

Sub-theme A2: Social Services

Opinions about social workers were not specifically sought in the research. However, social services was referred to in both the surveys and the interviews.

There were six positive comments and eight negative comments in the 50 interviews carried out. Three negative comments were made about social services within the 517 survey responses.

In the interviews, social workers were often positively regarded, helping and supporting many of the service users and their families on an ongoing basis. There were positive comments about social workers' support with the assessment process and how they continued to sort out problems and ensure that the home care is satisfactory.

Examples of positive comments about social workers from the interviews include:

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"So we contacted Social Services, and the lady came round. She came round, and she was excellent. Really helpful. Because we didn't really

know what we were asking for. We didn't know what was available. We imagined that we would only get care for things like washing, and getting dressed in the morning, and things, which if I'm not able to do that, I'd rather not do it. I'd rather not get dressed than have people come in and fuss. It would be more tiring than just living in my pyjamas. And so we didn't know we could get help with other things. We get help with housework, so once a week someone comes in and remakes the bed and sorts out washing and cleans the bathroom and helps even clear up if he's done."

"If you have a social worker behind you it makes a big difference.. We know that she'll take matters up for you. If you say, "Well, this issue." She'll be like, "Right. Right. I'll deal with that." Or, "Perhaps we ought to suggest this." Or maybe, "We could do that." And so I think she's very proactive about things. Well, she seems to have a genuine interest in whatever. But certainly trying to think back things are easier if you've got a social worker, I think. I mean I think sometimes social workers get a bad press, don't they?"

"Well, the good thing with that is I can use the facility by Suffolk County Council of their care services to act as the real arbiter of what should or should not be provided. And on that basis, they were very supportive in that. So I've got no problem with that one. I still think the validity of having Suffolk as a backbone towards the care companies has some merit as I've just described. And I haven't got a diploma in it, it's just we've got to

work together to make it certain.”

Examples of negative comments about social workers from the surveys:

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“...[P]oor assessment of needs by social worker has put the agency in a difficult position when providing care.”

“... [W]e have not had any help as to respite care from the social services, having tried several times. We need this help as we have had to make our own arrangements.”

“... Suffolk Social Services think of how they can avoid helping my Mum rather than ways of helping her... when we said Mum was moving to Suffolk, they came up with reasons that we wouldn't get a carer... Suffolk Social Services were looking to do the minimum possible rather than looking at the whole picture.”

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Examples of negative comments from the interviews include:

“

“Never seen them. They don't come and see me... They don't speak to me on the phone, no. I have no connection whatsoever with them. First of all, we had a lady that was absolutely useless. Then we got a nice man and we phoned up and we hadn't even got a social worker.

We just hadn't got one, had we? So they got who was our social worker, but he's really overloaded with work. He says he's looked beds, but there's nothing.”

“They measured her a chair with this customized seat which was lovely but they made it too low. So it's sitting there. It's been sitting there all this time and nobody's done anything about it. Social services and the OT aren't completing their job properly really at the moment. On the other hand, at times, they are very good, but this time they really are dragging their heels.”

“I mean, they go through such detail with so many other things. I've struggled with the enablement package. And I know everybody's got to be careful where money goes and they're not going to waste it. But I heard rumours that I was entitled to something for six weeks. I mean, this was the learning curve for me. And I really struggled to find out what I was entitled to.”

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Additional theme two :Changing care provider

Only a small number of the 517 survey respondents referred to the experience of changing provider. Five survey respondents made positive comments and three negative. However, 31 of the 50 interviews discussed changing providers.

The most common reasons for changing care provider were that either a care company ceased to provide home care or, alternatively, the service user was dissatisfied with the home care they were receiving and chose to change.

Five survey respondents commented that their new provider was an improvement over a previous provider. Examples include:



"We found having a variety of carers unsettling for my husband. This was provided by a former care company. [The new care company] are providing us with the same carer each day (apart from the day off)."

"Previous agencies to this one lacked training in various areas. This... needs to be addressed... as yourself as safety has been compromised and will continue to be so."

"Have had very bad experiences in the past with other agencies. [The new provider is] consistently good and has provided a stable package of care for some years. Carers are always excellently trained and carefully matched to clients. [They] endeavour to create a good working relationship between clients, carers

and management staff. Issues are dealt with quickly and they provide a good service all round."



Two survey respondents told HWS that their current provider was not as good as a previous one:



"The normal... carers are great and I always like to have a normal selection of carers who cover my care. Since moving to [a new care agency] things aren't so smooth like they use to be with no time table to say who and when the carers arrive.' [My previous provider's carers] were all caring, considerate and interested in getting me well as soon as possible. The [new provider's] carers do not have the same support. The excellent rating refers to [my previous provider]."



One survey respondent referred to difficulties in arranging care:



"Provided with a list of private providers [but] basically nothing to do with them. Never phoned me back. Very difficult to arrange the care, didn't get any care. Doctors were very good but hands tied. Left on own with no support as no agency available. [One care agency]

previously provided care but then stopped as difficulties ensued.”

Interviewees who chose to change providers made statements such as:

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“I liked [the other company] to start with, but then things started to go pear-shaped. They’d forget to come and they’d come when they thought they would and leave me in the morning standing there waiting and waiting and waiting. A half-past seven call would be quarter to nine, and I wasn’t happy with it. So my relative researched and found me this company. They are good. They’re very kind and I’m very pleased.”

When the care provider is changed because a company is no longer offering home care, as the following statement makes clear, it can cause anxiety and uncertainty for service users who should be kept informed about what is happening:

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“[Change] can be a bit disconcerting and whatever, because all of a sudden the company’s changing. Well, hang on. We didn’t choose to change companies. But is this person suddenly going to go? Are we

keeping the same person? And I can appreciate you couldn’t probably tell everybody everything, but I think we got the initial thing, and then it was like, “Oh, yes. Everything’s okay. Don’t worry.” Sort of thing. And okay. To be fair, it did settle down. It’s settling down. But I think a little bit more assurance to people, especially some people that aren’t quite extroverts. It wouldn’t worry me to pick up the phone and say, “I want to discuss this with you.” Or whatever. But I’m sure there may be other people that aren’t practiced at talking about it, that may just sit and worry about it, possibly, I don’t know, could sit all day worried about it.”

“It was abysmal. When they first took over, it was a nightmare. My son tried to get me somewhere else. There just aren’t any places to go. I moved myself from them. Fortunately, I went to another company who were brilliant.”

“With the changes coming, we just went along with the process. We didn’t choose the carer, we just said oh, we’ll go along with whatever carer you say we’re in- whichever area we’re in. So we didn’t actually choose. We didn’t want to change but we kind of understood why they were doing it and went along with it.”

In 17 of the 50 interviews, respondents told HWS that they had no choice of provider. The two reasons quoted are that the care provider ceased to provide home care or on leaving hospital the service user was allocated a care provider through the hospital and social services. Comments included:

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“Well, it was it was done at the hospital. I don't know how they link into each other, the social services and the sort of the hospital team of social workers. I assume they're all part of the county council. But yes... it was chosen for us. I didn't choose them.”

“Yes. What happened was when my wife passed away, obviously, we were at the hospital, and one of the nurses come up - I think it was the nurse - and said, “she was obviously your main carer--” well, see, my daughter was home at the time and could look after me for another week or so, so they got everything in place. So everything was done through the hospital, then the social services, so I didn't have a choice or anything. It was just whoever could take me on.”

“...the social worker said she couldn't find any other company with any vacancies.”

“When we first moved here in December 2014, it was one company just for a few weeks, and then they changed over to the other. They just said, “Oh, you're going to have [them] now.”

“It just happened within a week. It was so strange. On the day [this company] took over the lady still came in for one to one. One to one had no idea that they'd been changed. And I never did find out why they were changed. I did try, but I've never been able to find out why. Because they were very very good.”

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Four interviews indicated that they had been able to choose a care provider:

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“It was a choice-- I can't remember the name of the first company that they offered us, but the timings weren't at all suitable. So the first one that was offered to us, I actually did say, “No. I think we'll wait to see if we can find a company with some better times.” And then the social worker rang a few weeks after that-- a couple of weeks or so after that to say that she'd found-- there was another care company. I think they put the care package out for [tender?].”

“And I decided, or we decided-- because [my relative was happy and wanted to keep the carer] And we wanted to keep how we were working if we could so we opted to stay with the company.”

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CONCLUSION

This Healthwatch Suffolk [HWS] research has accessed the views of a large and robust sample of service users about the care they receive in their home. With the crucial support of Suffolk County Council, HWS received survey responses from over 500 service users.

From this initial contact the in-depth interviews carried out with a sample of 50 of the survey respondents have provided a more detailed insight into the strengths and weaknesses of home care in Suffolk.

From the scoping survey and interview analysis, key themes emerged which were grouped according to the guidance on what good care in the home should look like developed by the National Institute for Clinical Excellence [NICE], as reported on by Healthwatch England.

Of the five criteria in this guidance, the themes of most importance to service users were 'having care workers who can meet your needs' and 'feeling comfortable with your care workers'. Themes such as 'having a care plan which is regularly updated' and 'having a care diary' were mentioned less by service users in the surveys but featured more prominently in the interviews.

Two major additional themes emerged during the analysis of the results of the research.

These were:

1. 'Timekeeping', including late arrival, leaving early and not having preferred visit times and;
2. 'Communication', including sub-themes related to contacting the care agency and how queries and complaints were handled.

Two smaller additional themes emerged. Although mentioned by fewer respondents, these were found to impact on service user experience:

1. References to Suffolk County Council's involvement in service user's care and;
2. Changing care provider

The evidence from both the surveys and the interviews shows that service users are extremely positive about their carers. Satisfaction ratings in the surveys are very high, with the majority of respondents reporting a 'good' or 'excellent' rating.

In the survey responses, the first two themes, 'having care workers who are able to meet your needs', and 'feeling comfortable with your care workers' received by far the majority of the positive comments in the survey overall (over 250). These results were reflected in the analysis of the individual interviews, where interviewees confirmed the importance of these aspects of their care.

When service users raised problems with their home care, these were often related to issues of management and

communication, rather than the carers themselves. For example, timekeeping, was related by some service users in the interviews to travel distances or not having enough staff to cover all the service users adequately. Similarly, two other themes which received more negative than positive comments, 'being made aware of changes in advance' and 'communication', both refer to areas which are primarily a care provider office responsibility.

The recommendations from this report are intended to inform care providers and Suffolk County Council in order to enable them to build upon current strengths, such as the consistently good quality interaction between service users, family members and their carers, and also to address current weaknesses in home care in Suffolk, from the perspective of the service user.

The breadth and depth of feeling and observations expressed by service users and their family members, varies from one recommendation to another.

The intentions of the 15 recommendations lie in the premise that an ambition to address them, collectively, would lead to a more rounded, more consistent and more efficient local service, and improved outcomes for the service user.

RECOMMENDATIONS

Knowing the service user's needs

1. Replacement carers should have access to a record of relevant service user needs, likes and dislikes and take note before caring for the individual.

A number of service users stated that their main carers were aware of their needs, likes and dislikes. This does not apply to replacement carers who, as HWS research shows, are not always fully informed of the care plan and the preferences of the service user.

Being treated with dignity and respect

2. Providers should ensure that carers are aware of what it means to be treated with dignity and respect.

The majority of service users were happy with the way that they are treated by their carers. Carers should always be made aware of what it means to be treated with dignity and respect. Being treated politely, with consideration and sensitivity was reported to be of most importance to the service user in the HWS survey.

Helpfulness and time to care

3. Care providers need to ensure that carers are given time to meet service user's needs and to carry out the tasks required.

Service users told HWS that most carers carry out the duties on the care plan willingly and to a high standard. They also reported that their carers were very helpful and ensured that the service user did not need anything else before they left. Although this is evidence of good practice, carers having to leave earlier than agreed on the care plan to get to the next appointment on time can impact on the service user's view of the care they are receiving.

Engaging with the service user

4. Care providers should always aim to make carers aware of the importance of talking and listening to the service user. Carers need to recognize that they are in the service user's home and treat them with kindness and consideration, taking into account their spiritual, social and cultural needs.

One of the most important issues raised was how carers engaged, talked with and listened to service users. This is essential to building a relationship of trust and confidence between the carer and the service user.

Consistent carers provided

5. Care agencies should aim to guarantee that their staff/ service user ratio is sufficient to ensure that a service user can rely on a specific carer or group of carers on a regular basis.

One of the issues raised by service users was having too many carers attending them. Where this occurs, HWS research shows that this can be disruptive and upsetting to the service user and prevents developing relationships of trust and confidence.

Carers travel distances

5. Care agencies should ensure that the travel distances between appointments are realistic.

Service users drew attention to the distances of travel that carers had to make between appointments, which was often perceived to be a cause of lateness or of leaving early.

Notifying the service user of changes

6. Service users should have ready access to an accurate rota. If any changes occur to the carer attending, or the time of arrival, the service user should be notified at the earliest opportunity.

Service users were often not informed of changes to timing of visits and rotas. Waiting without knowing when your carer is going to arrive, or who it will be, can bring uncertainty and stress.

Training

7. Suffolk County Council and care providers should aim to ensure that training for carers meets statutory and regulatory requirements and be consistent across providers. The training should be aimed at meeting the needs of service users and comply with manual handling and health and safety requirements. Carers should also receive appropriate training in food preparation, hygiene and infection control.

Several examples were quoted of the consequences to the service user of carers not being able to use hoists, shower slings and other equipment or daily living aids effectively, from which pain and discomfort may result. Some service users also told HWS that food preparation was often not carried out to a high standard.

Preferred times

8. Care providers should, where possible, offer service users their preferred timings and when this is not possible, notify them at the earliest opportunity.

Many service users talked about not receiving visits at their preferred times. Although there is some understanding that this is not always feasible, it can cause inconvenience and distress if timings are inappropriate.

Care plan, care diary and personal information

9. Personal care plans should be co-produced with the service user, and reviewed every six months. Care plans need to be printed in an accessible manner and stored in a clearly marked folder. The folder should also contain a copy of the care diary and this should be correctly completed.

During the interviews the HWS interviewers often found it difficult to identify the service user's care plan, care diary and likes and dislikes within the care folder. The implications of this are that service users and carers may not be well informed about the details of their care.

Carers not arriving at all

- 10.** The care provider should aim to inform the service user, at the earliest opportunity, if a problem with keeping to an appointment arises, and replacement carers are sent.

Service users told HWS that the consequences of carers not arriving can be very serious, with some service users being left for many hours without any care at all.

Contacting the care agency

- 11.** Service users would benefit from having contact numbers and names, which should be displayed prominently in the care folder. A commitment to answering calls should be made by the provider for the hours that the contract specifies.

Service users told HWS that there were occasions when they tried to contact the agency and nobody answered their call. This can lead to problems and concerns not being addressed promptly causing stress and uncertainty for the service users.

Changing providers

- 12.** Where possible service users should be given choice of provider and if change has to be imposed for any reason the service user should be kept informed and reassured during the process.

How service users felt about any change in their care provider varied depending on whether they had any control over the change. If change is imposed on the service user, rather than chosen by themselves, anxiety can be caused by a lack of information and concerns about carers changing. Following discharge from hospital the research indicates that choice is often limited and depends upon which care provider can meet the needs of the care plan.

Caring as a career

- 13.** These issues could be addressed by implementing a proper career pathway for carers with improved training and recognised qualifications which could raise the public perception of caring as a career.

Interviewees often expressed sympathy for their carers. They believed their carers were held in low esteem by society, received low pay, worked long hours and did not get the respect they deserved for the excellent service they provided. Service users told us that they thought that this led to issues of low retention and had implications on the care provider's ability to provide consistent carers.

Suffolk County Council invoicing

- 14.** The processes and procedures of Suffolk County Council home care service invoicing could be improved to prevent inaccuracies and lateness.

Several survey respondents and interviewees told HWS that invoicing between the service user, care provider and Suffolk County Council could be late or inaccurate. This can have a negative financial impact on service users, care providers and the local authority and can cause distress and confusion for service users.

REFERENCES

- International Longevity Centre. (2015). The End of Formal Adult Social Care - A Provocation. pp. 4 -12. Available from: http://www.ilcuk.org.uk/images/uploads/publication-pdfs/The_end_of_formal_social_care_1.pdf
- Cromarty, H. (2018). Adult Social Care Funding. Briefing paper Number CBP07903. 19 April 2018. pp. 8 -13. Available from: <http://researchbriefings.files.parliament.uk/documents/CBP-7903/CBP-7903.pdf>
- Healthwatch England (2017). Home Care: What People Told Healthwatch About Their Experiences. pp.1 -17. Available from: https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/20171002-_home_care_-_what_people_told_local_healthwatch.pdf
- Public Health England. (2017). Suffolk County Health Profile: Adult Social Care. Available from: <https://fingertips.phe.org.uk/profile/adultsocialcare/data#page/4/gid/1000105/pat/6/par/nn-1-E10000029/ati/102/are/E10000029/iid/1174/age/20/sex/4/nn/nn-1-E10000029>
- Suffolk County Council (2017). Our Priorities 2017 - 21. pp. 20 - 21. Available from: <https://www.suffolk.gov.uk/assets/council-and-democracy/our-aims-and-transformation-programmes/Suffolk-County-Council-Priorities.pdf>
- The National Audit Office (2014). The Impact of Funding Reductions on Local Authorities. p.9. Available from: <https://www.nao.org.uk/wp-content/uploads/2014/11/Impact-of-funding-reductions-on-local-authorities.pdf>
- Commission for Rural Communities. (2008). The Personalisation of Adult Social Care in Rural Areas: Tackling Rural Disadvantage. p.7. Available from: <http://webarchive.nationalarchives.gov.uk/20110215135124/http://ruralcommunities.gov.uk/files/CRC%2078%20Adult%20Social%20Care.pdf>
- Healthwatch England. (2017). What Should You Expect from A Good Home Care Service? Available from: <https://healthwatch.co.uk/news/what-should-you-expect-home-care-services>
- National Institute for Health and Care Excellence [NICE]. (2018). Better Home Care for Older People. Available from: <https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/better-home-care-for-older-people>
- Healthwatch Leeds. (2016). Care at Home. Available from: http://www.healthwatchleeds.co.uk/sites/default/files/uploads/Follow_up_Home_Care_report.pdf
- Healthwatch East Riding of Yorkshire. (2016). Home Care Services Report. Available from: http://www.healthwatcheastridingofyorkshire.co.uk/sites/default/files/home_care_report_final_high_res_Opdf

Healthwatch Redcar and Cleveland. (2017). Investigating Domiciliary Care Service Provision in Redcar and Cleveland. Available from: http://www.healthwatchredcarandcleveland.co.uk/sites/default/files/hw_domcarereport_final.pdf

Healthwatch Halton. (2016). Home Care – Who Cares? Available from: <https://www.healthwatchhalton.co.uk/wp-content/uploads/2014/06/Who-Cares-Report-web-small.pdf>

Healthwatch Hampshire. (2017). Care at Home: Domiciliary Care Services from the Patient's Point of View. Available from: http://www.healthwatchhampshire.co.uk/sites/default/files/care_at_home_report_final_22.06.17-min.pdf

Healthwatch Warrington. (2016). Opening the Door: Exploring the Quality & Safety of Care Delivered at Home. Available from: <https://www.healthwatchwarrington.co.uk/wp-content/uploads/2015/07/Dom-Care-Project-Report-Final-Version.pdf>

Healthwatch Dorset. (n/d). Where the Heart Is: An Investigation into Home Care Services. Available from: https://www.healthwatchdorset.co.uk/sites/default/files/home_care_summary_report_a44.pdf

Healthwatch Barnet. (2016). Homecare in Barnet – A Report on Service User Experience. Available from: http://www.healthwatchbarnet.co.uk/sites/default/files/homecare_report_dec_2016.pdf

Healthwatch Islington. (2016). Homecare: Stories from Service Users. Available from: https://healthwatchislington.co.uk/sites/default/files/home_care_2016.pdf

Healthwatch Bexley. (2015). Care for Me at Home. Available from: http://www.healthwatchbexley.co.uk/sites/default/files/care_for_me_at_home_full_report.pdf

Bibliography

United Kingdom Home Care Association [UKHCA]. (2015). An Overview of the Domiciliary Care Market in the United Kingdom. Available from: <https://www.ukhca.co.uk/pdfs/DomiciliaryCareMarketOverview2015.pdf>

Age UK. (2017) How to Find the Help You Need at Home. Available from: <https://www.ageuk.org.uk/information-advice/care/find-care-support/how-to-find-help-at-home/>

Humphries, R et al. (2016). Social care of older people: home truths. King's Fund and Nuffield Trust. Available from: <https://www.nuffieldtrust.org.uk/files/2017-01/social-care-older-people-web-final.pdf>

Suffolk County Council (2018). Help to Live Independently. Available from: <https://www.suffolk.gov.uk/adult-social-care-and-health/help-at-home-care-home-information-and-mental-health/help-to-live-independently/>

National Audit Office. (2014). Adult social care in England: Overview. Available from: <https://www.nao.org.uk/report/adult-social-care-england-overview-2/>

Dilnot, A. (2011). Fairer Care Funding Report. The Commission on Funding of Care and Support. Available from: http://www.ilis.co.uk/uploaded_files/dilnott_report_the_future_of_funding_social_care_july_2011.pdf

Local Government Association [LGA]. (2016). Don't Be Left in the Dark: Adult Social Care. Available from: <https://www.healthwatchgloucestershire.co.uk/wp-content/uploads/2017/05/About-Adult-Social-Care.pdf>

Bolton, J. and Townson, J. (2018). Messages on The Future of Domiciliary Care Services. Kings Fund. Available from: <http://ipc.brookes.ac.uk/publications/pdf/The%20Future%20of%20Domiciliary%20Care%20%286%20April%29%20-%20Final%20version%2020180410.pdf>

Healthwatch Knowsley (2017). Domiciliary Care Survey. Available from: <https://www.healthwatchknowsley.co.uk/wp-content/uploads/2017/09/Dom-Care-Report-16-17-Final.pdf>

APPENDIX 1 - Scoping survey

APPENDIX 1



What are your experiences of home care services in Suffolk?

At Healthwatch Suffolk we are here to listen to your experiences of health and social care services in Suffolk, so that we can use your views to make services better. We work independently from the services that commission home care services. With your support, we can improve services for all.

What is domiciliary care?

Domiciliary care is care provided in a person's home, sometimes it is called home care or 'support to live at home'. Home care can include help with things like helping people getting out of bed, washing, dressing, getting to work, cooking meals, eating, seeing friends, caring for families and being part of the community.

Home care might also include emotional support at a time of difficulty and stress, helping people who are caring for an adult family member or friend.

Who might receive it and how is it paid for?

An adult may receive home care if they need support to live as well as possible with any illness or disability they may have.

Home care may be paid for by means tested support from Suffolk County Council (SCC). Care may be paid for through a person's personal budget or a person receiving care may fund their care themselves. Some people may choose the option of having a SCC managed service. Their care will be provided by one of SCC's contracted providers of home care, called 'Support to Live at Home Providers'.

Please turn over and share your experience of receiving home care in Suffolk, by answering this short survey.

If you would like to withdraw, or if you have any more questions about this project then you can call Healthwatch Suffolk on 01449 703949.

Thank you for taking the time to share your views with us.



For full terms and conditions please visit www.healthwatchesuffolk.co.uk or alternatively call 01449 703949.

APPENDIX 1

Please share your experiences of using home care services in Suffolk

1. Please state who receives care in their home.

Myself Family member (Please state their relation to you) _____
 Friend Other _____

2. Please state who provides the home care. *If you know the name of the care agency who provides the care, please record it below.*

3. Please tell us how you would rate the care that you/they are receiving.

Excellent Good Average Poor Very Poor

4. Please share some details about your/the experience of home care in the box below. We are interested in all aspects of home care (positive and negative).

5. Can our researcher contact you to discuss your experience in some more detail?

Yes No If yes, please share your details below:

Full Name: _____ Telephone Number: _____

Email address: _____

Locality: *e.g. The area that the person lives in who receives the home care*

Important Information: This is your opportunity to influence your health and social care services. Your feedback (whether anonymous or not), will be featured on www.healthwatchesuffolk.co.uk and used to make recommendations for change.

For full terms and conditions please visit www.healthwatchesuffolk.co.uk or
 alternatively call 01449 703949.

APPENDIX 2 - List of providers and responses

Provide	Percent of total	Responses
Manorcourt	8.68%	42
Cambridge Care	6.40%	31
Nayland	4.96%	24
Carewatch	4.34%	21
Cephas	4.34%	21
Hales	4.13%	20
Suffolk Homecare	3.93%	19
Primary Homecare	3.72%	18
Waveney Care	3.51%	17
Allied	2.69%	13
Bluebird	2.48%	12
Fuschia Care	2.27%	11
Your Care and Support	2.27%	11
Beyea	2.07%	10
Deben Willow	2.07%	10
One to one	2.07%	10
Westminster Home Care	1.86%	9
Home First Support Service	1.65%	8
Leading Lives	1.65%	8
Prestige	1.65%	8
All Hallows	1.45%	7
Anglia Care	1.45%	7
Angels	1.24%	6
First Choice Home Care	1.24%	6
Mears	1.24%	6
Mencap	1.24%	6
District Care	1.03%	5
Orwell Housing	1.03%	5
Quality Care	1.03%	5
Bigod	0.83%	4
Genesis	0.83%	4
Heritage	0.83%	4
Sygma care	0.83%	4
Amari	0.62%	3

East of England	0.62%	3
Forget me not	0.62%	3
Rose care	0.62%	3
Time2Care	0.62%	3
Versa	0.62%	3
Briar Care	0.41%	2
Caring Forever	0.41%	2
Caring Moments	0.41%	2
Choices	0.41%	2
Complete Community	0.41%	2
Divinus	0.41%	2
Forest Home Care	0.41%	2
Sanctuary Care	0.41%	2
Tru-Care	0.41%	2
United Response	0.41%	2
A Class	0.21%	1
Addocare Scole	0.21%	1
Ann Mason	0.21%	1
Christian Care	0.21%	1
Christies Care	0.21%	1
Dimensions	0.21%	1
Donna Cooper Services	0.21%	1
Elimay Homecare	0.21%	1
First Prime	0.21%	1
Frantec Ltd	0.21%	1
Hawes	0.21%	1
Headway	0.21%	1
Helping Hands	0.21%	1
Home Instead	0.21%	1
HomeAssist	0.21%	1
Housing and Care 21	0.21%	1
Insignia	0.21%	1
Invent	0.21%	1
Locums 4 Care	0.21%	1
Mavam	0.21%	1
My Care	0.21%	1
North Bay	0.21%	1
Orders of St John	0.21%	1
Papworth Trust	0.21%	1
PSN	0.21%	1
S & M	0.21%	1

St Elizabeth Care Agency	0.21%	1
Not given	70.2%	34
Private individuals	1.24%	6

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APPENDIX 3 - Interview schedule

APPENDIX 3

Home Care Research Interview Guide

Introduce: Both interviewers

Explain HWS, research rationale

What HWS can/can't do within the remit of this project

- Explain SCC's role in this project
- Safeguarding – Interviewers obligation to report
- Confidentiality/Anonymity The interview will be recorded you have a right to withdraw at any time and up to a week prior to transcribing the interview. The recording will be destroyed following transcription of the recording. Your comments will be anonymized if included in the report and your details will not be passed on unless we fear for your safety.
- Explain right to withdraw - I am the lead researcher, we can stop at any time and you do not have to continue if you don't feel comfortable. We can take a break if we have any interruptions e.g. somebody knocks at the door or the phone rings, that is no problem.
- Confirm expected length of interview and refer to the time that the interviewers have to leave.
- **[Consent Form] – Written Expressed Consent**

[Begin interview] – **TED QUESTIONS - TELL ME, EXPLAIN TO ME, DESCRIBE TO BE**

- Demographics – Age, Overall health, Visitors, Level of social support, Interaction with other services
- Confirm responses from scoping survey on Phase 1 (Who receives the care, who provides the care, satisfaction rating, experiences of home care)
- Explore details about the care package (Regularity of visits, length of visits, how many carer(s) attend, how long they have received this care)
- Previous history of home care provision e.g. historically was it provided by a different DCA? What was the reason for changing the provider? Were they given a choice?
- Explore instances where care may not be up to standard or where care may have exceeded the interviewee's expectations of home care

[Comfort Break offered]

**Prompts will not be read verbatim. Mindful of the client group open-ended TED questions will be used and exact wording will be tailored to ensure that it is appropriate for the needs of the interviewee.*

APPENDIX 3

- Do they feel empowered to make decisions about their home care?
- Does the interviewee feel involved in the process? E.g. were they involved in the care assessment/development of the care plan.
- Has the respondent experienced any challenges/issues with the DCA? E.g. timeliness of staff/ different staff attending/unexpected absences/acts performed that are not included in the care plan
- Has there ever been an instance where one of the staff did something that the interviewee had not asked for/were not comfortable with?
- Does the interviewee feel that complaints/concerns are taken seriously by the carer(s)/DCA?
- Invite any other details that they would like to share regarding home care
- [Paraphrase and Summarise Findings]
- [Signpost if appropriate] [Discuss concerns if appropriate]
- If appropriate ask if they would mind being a case study with photo
- [Thanks and close]

**Prompts will not be read verbatim. Mindful of the client group open-ended TED questions will be used and exact wording will be tailored to ensure that it is appropriate for the needs of the interviewee.*

This report will be publicly available on the Healthwatch Suffolk website. It will also be made available to Suffolk County Council, which is responsible for the commissioning of home care services in Suffolk.

We confirm that we are using the Healthwatch Trademark (which covers the logo and Healthwatch brand) when undertaking work on our statutory activities as covered by the licence agreement.

If you require this report in an alternative format please contact us on 01449 703949 or by email to info@healthwatchsuffolk.co.uk

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