

Can you hear me?

**Amplifying the voice of people receiving
care at home**



June 2019



Background and Rationale

Healthwatch Surrey has adopted 'care at home' as one of our 3-year strategic priorities. The need for high-quality home-based personal care services is increasing. The over 65 age group in Surrey is projected to grow by 17% between 2016 - 2026: three times as fast as the population as a whole. At the same time the system is working to enable people to live independently for longer: living independently is one of the Surrey Health and Wellbeing Board's strategic priorities and a key target outcome in the 10 year plan.

Surrey County Council already funds over 4,000 people's care and they estimate there are a further 12,000 people who are self-funding their care.

Through our ongoing listening programme we have heard stories from care at home users receiving excellent person-centred care, but we have also heard stories of users who are not receiving good care, and of users unwilling or afraid to complain about the quality of their care.

The principle that care should be person-centred lies at the heart of the health and social care agenda - it is one of the fundamental standards regulated under the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014. Person-centred care can only be delivered if providers, commissioners and regulators are willing and able to listen to people using the service: to hear their needs and preferences clearly, and to work in partnership with them to deliver care that responds to those needs.

Commissioners and providers need to do more than listen passively to people: the system has a duty to enable people to speak out by providing information and processes that make it easy for people to use their voice effectively.

Healthwatch Surrey exists to give the people of Surrey a voice to improve, shape and get the best from health and social services. We believe service users have a right to person-centred care, and to be listened to without fear of reprisal. We have prioritised domiciliary care users as they may be particularly reluctant to raise concerns with their service providers, are a group who Healthwatch Surrey find hard to reach through our usual engagement activities.

We therefore initiated this project to answer the question "Do care at home users have a voice?".



All photographs in this report are of people we interviewed and are reproduced here with their permission

What we did

In this research we have set out to answer two questions:

- ▶ Do the systems in place give care users a voice?
- ▶ Do users feel safe to express themselves, and do they feel listened to?

To achieve this we have spoken to people receiving care at home and to care providers:

- ▶ **Care users:** do they feel enabled, comfortable, safe and supported in expressing their needs and wishes? Are their providers responsive to their wishes?
- ▶ **Care workers:** what is their understanding and interpretation of person-centred care, and do they feel enabled to listen to their clients?
- ▶ **Care agency registered managers or care team coordinators:** what are the processes and experiences of providers when it comes to listening and the delivery of person-centred care?

In total we carried out 42 individual depth interviews:

- ▶ **16 face to face interviews** with care users in their own homes, each lasting 45 minutes - 1 hour. Most were frail elderly people receiving a number of short daily visits from care workers but we also spoke to people receiving personal support for their daily living needs. Where it was not possible to interview the person receiving the care we spoke to the loved one who took responsibility for management of their care.
- ▶ **14 telephone interviews** with care workers, each lasting 30-45 minutes
- ▶ **12 telephone interviews** with care agency managers or coordinators, each lasting 30-45 minutes

Our approach was qualitative: the sample sizes are modest and our interviewees were mostly recruited by word of mouth rather than random selection. However, our research gave people a unique opportunity to talk to an independent organisation in depth and in their own words about their own lived experiences.

We also

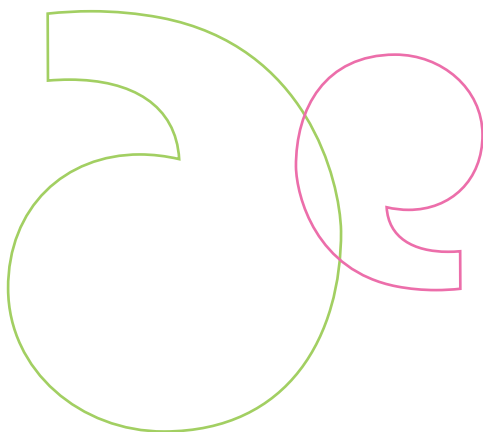
- ▶ **Reviewed commissioner priorities:** what does Surrey County Council require its providers to deliver, and how is that measured?
- ▶ **Reviewed regulatory requirements:** what does Care Quality Commission expect of providers?
- ▶ **Reviewed influencer and advisor materials:** what messages are organisations such as National Institute for Clinical Excellence, charities, Social Care Institute for Excellence disseminating about person-centred care and the value of listening?



Executive Summary

Key findings

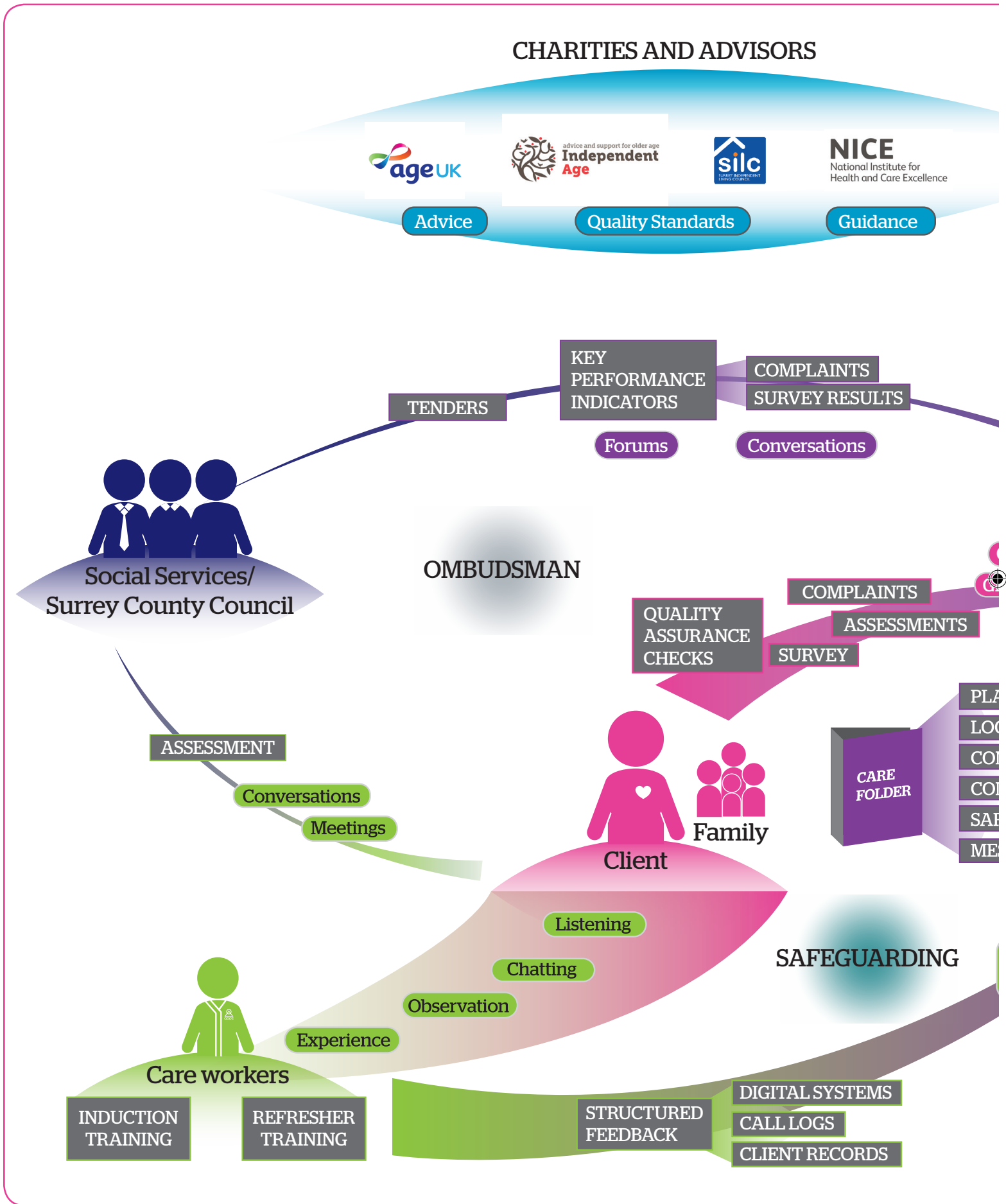
- ✓ Most care users we interviewed do feel listened to:
 - there is a well developed listening landscape providing care users with multiple formal and informal, direct and indirect routes to express their needs and preferences.
 - experience of expressing their needs has resulted in improvements to their care: most of the care users we spoke to have tested the listening system by making requests and the system has responded positively.
- ✓ Care workers provide a powerful conduit for the system to understand what users want and need: intimate, frequent, repeated contact with care users means they are uniquely well placed to understand what their clients want and need, and can feed this information back to their agency managers. Some agencies take full advantage of their care workers' insight into their clients.
- ✓ Agency staff are well motivated to listen to care users and respond to their needs: the emotional desire to do a good job is partnered with a business need to deliver good service and a requirement to conform with regulations.
- ✓ Surrey County Council require their commissioned care agencies to report regularly on measures intended to reflect whether agencies are listening effectively to people using their services.
- ✗ There are some vulnerable care users who are less willing or able to express their needs:
 - People who are not able to engage with the system and do not have an emotionally engaged advocate (parent, child, spouse) to engage on their behalf.
 - Clients who have reason to be scared of losing their care (special needs, scarce resources).
- ✗ Care workers do not always feel it is their responsibility to feed informal information back to their agency about the care their users receive. Few would consider raising a safeguarding alert without going through their agency management, or even know how to do this.
- ✗ Some agencies' systems for capturing verbal client and care worker feedback are very informal, and can be vulnerable to error and oversight.
- ✗ Some agencies do not include care worker feedback or insight when reassessing or reviewing care plans for their clients.
- ✗ Some care folders do not contain an accessible complaints procedure; some contain no information on safeguarding for either care user or care worker; some contain out of date information.
- ✗ While Surrey County Council does include Engagement measures in its care agency Key Performance Indicators these do not explicitly cover quality of listening. The data generated in these KPIs around Complaints is subjective and may not be comparable across agencies.

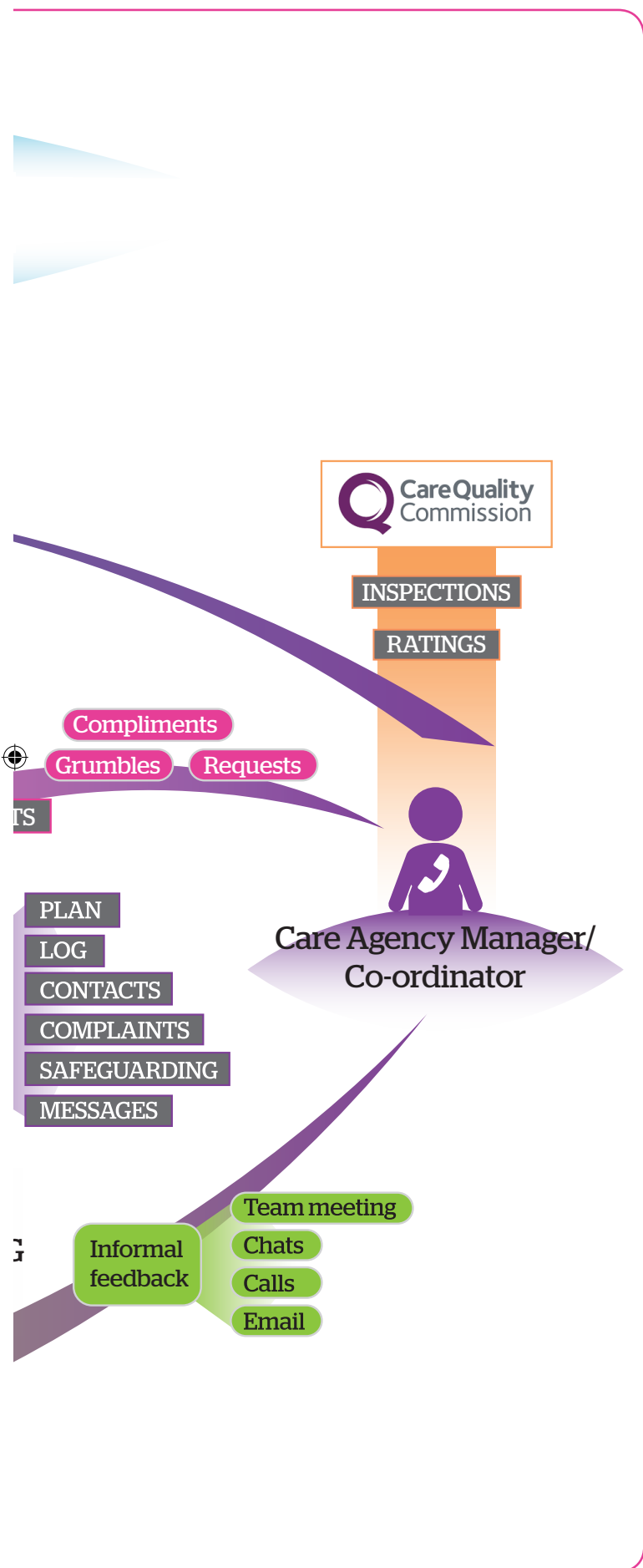


Recommendations



What we learned





There is a well developed listening landscape for care at home service users. The landscape encompasses

- People:** families, care workers, care agency coordinators and managers, social workers and care commissioners all listen to people who receive care at home. Whether they have an emotional connection to service users (family, friends) or are part of the service landscape (care workers, care agency staff, social services staff, safeguarding staff) all are well set up and well motivated to listen and respond.
- The relationships between these people:** as well as listening directly to care users these people also interact with each other, sharing what they have heard across the system to ensure the care user's voice is heard by the people who matter. For example care workers feed back to care agencies, social services tender person-centred care packages to care agencies and so forth.
- Systems and tools:** the care user's voice is enabled by systems and tools that record needs and enable good communication. For example, the care plan is a record of the tasks and style of care the provider has agreed to deliver to the care user; the care folder contains contact information to ensure all parties can communicate effectively; quality assurance checks give people the opportunity to discuss the quality of their care with care providers.
- The regulators and influencers:** while these do not necessarily listen to individuals using care at home services they do establish norms and expectations around listening.

Every service user's listening landscape is unique: regulators and commissioners work to drive consistency but needs, personalities, relationships and approaches vary across users, workers, agency staff and agencies.

While the system works very well for most users most of the time our research identified opportunities to strengthen and enhance listening to ensure all users receive the care they want and need.



The People - Care users, care workers and care agency staff



- Clients who are scared of losing their care - either because they have experienced cuts in their packages over the years, or because they know the service they need is in short supply (specialist, challenging, rural areas)

"I am frightened to complain. If we complain and lose our current carers...[last time] the council put our care package out to tender they got nobody applying for it, nobody at all..."

Care user

Care users

Most of the care users we spoke to were very happy with the care they receive, and feeling listened to was a crucial element in this satisfaction. The initial care assessments (Social services and/or care agency) focus on people's needs and preferences, sending out a clear message to new care users that their care plan is driven by their own needs and preferences. Small but important requests such as single-sex care teams, exclusion of a particular carer, time changes or specific tasks to be undertaken or skipped confirm to users that their voice matters. We also heard stories where care users had effected substantial changes in their care (rewritten care plan, changes of agency, switch to direct payment) by speaking out and having the system listen and respond to their needs.

However, there are two groups of people who struggle to express their needs:

- People who are not able to engage with the system and do not have an emotionally engaged advocate (parent, child, spouse) to engage on their behalf. These include clients who are neuro diverse (for example living with autism), have learning difficulties, dementia or mental health problems.

"...when I get scared I lash out and shout at people and they don't like that so they don't want to be my carer any more and now there is nobody to take me to football"

Person with learning difficulties

Francesca's Story



... they [old agency] didn't listen to you and if you made a complaint woe betide you, you know, just things got worse... When I felt things weren't going well I spoke to the management and they didn't listen either so I phoned them and gave them three months to get their act together because they weren't pulling their weight

Then I thought, right, I got so fed up they were making me ill so I rang social services and said can I have someone come out and visit me because I am not happy with what I am getting...

So social services said right they made an appointment to come out and visit me...the lady came and we didn't hit it off... but she went off and she asked if I wanted [current agency] who I knew already and I said yes please and we've all lived happy ever after!

* name changed to protect identity





Care workers

Care workers are by far the most important listeners in the system. Care workers spend substantial amounts of time with their regular clients and often build strong relationships.

Most of the care workers we spoke to were caring, committed advocates for their clients. Job satisfaction comes from making their clients' lives better.

"I'm not afraid to speak my piece, I've been at this game for years, not everyone would do that".

Care workers

However, not all care workers felt that proactively feeding back what they'd heard to their agency was a responsibility: it was just something a good carer would do.

"[telling the agency the client needs different care] I think that's not my job really, that's the office's job"

Care workers

While all the workers we spoke to were alert to safeguarding and to different categories of abuse, their first step would be to take this to their manager rather than raise a safeguarding concern themselves. Some felt they had no responsibility for making decisions about safeguarding referrals, and were unclear about how to raise an alert.

Care Worker Training

Care workers are aware of 'person centred care' **"you hear it everywhere, it's the current buzz word"** and vaguely recall person centred care as part of their induction training. However, few had received any update training in person centred care.

"it's more about manual handling and food hygiene, keeping your certificates up to date"

Care worker

Care agency management (registered managers and coordinators)

A key element of excellent care is responsiveness and a patient-centred approach, and the agency staff we spoke to spontaneously expressed these values. The registered managers and care coordinators we spoke to were highly motivated to deliver excellent care

- Because agencies depend on self-funded clients who have a free choice of supplier
- Because theirs is a regulated industry and the CQC rating can make or break an agency
- Because they genuinely want to make a difference and do a good job

"I left corporate life because I wanted to do something that actually made a difference to people"
"I still keep my hand in doing care visits, I love it"

Care agency managers

However, agency staff are struggling with the realities of delivering care - funding for care packages, increasingly challenging clients, family expectations vs client requests, the recruitment crisis - and admitted that clients did not always get their wishes met.

We also heard reports from care users and care workers that they had experienced agency staff (current or previous agencies) who did not listen to their clients or their workers:

"they don't care, they listen but they don't do anything about it"

Care user

"they don't know the clients at all, they have no idea".

Care workers

This was often a trigger to switch agencies for users and workers alike.



Passing the message on - communication, systems and tools

Communication between care users and care workers

Key to a successful user/worker relationship is communication. Mismatched communication was often cited as a reason for a user asking for a worker not to be sent again (doesn't listen, doesn't respond, talks too little/too much, can't understand her). Most of the care users said they communicated well with their current care workers: many had in the past requested a care worker not be sent again because of communication difficulties.

"I do feel listened to now, [my husband's] carers are good at listening, it's a relief"

Care user

Care workers know from direct questioning, from experience and from observation exactly what makes their clients happy, safe and well cared for.

"It's just natural, 'how are you today' and 'what shall we do today', it's what the job is"

Care worker

"it's the most important thing, it's what we're here for. If we weren't listening we'd be out of a job"

Care worker

The time workers spend with users means there is a huge quantity of communication and time for reflection, leading to more honest conversations and multiple opportunities to broach issues.

"I know [clients] will tell their care workers things they will never tell me"

Agency manager

However, for our few unhappy care users, not feeling listened to by carers was a key source of dissatisfaction.

"Some mornings I just don't want to get out of bed but the carers make me, it's all done to suit them"

Care user

Communication between care users and care agencies

Initial Assessment, reassessments and quality assurance checks

Care users reported thorough assessments by their care agency, focussed on their preferences and needs. Initial assessments set the tone for the relationship between user and agency, clearly establishing person-centred care as the cornerstone of the care plan.

"We had another assessment the other day, it was very efficient and professional, the [assessor] really listened and understood, I was very happy"

Care user

However, the only face-to-face contact agency staff have with care users may be reassessments or quality assurance checks, and these can be very infrequent - several care users reported not having met agency staff since their initial assessment.

Compliments

These are highly valued by the agency and staff, used as an important staff morale and management tool, and an important marketing tool.

"All the compliments go into a lottery and at the end of the month two get drawn out and those care workers get a voucher"

Care manager

While compliments are valued, they tend not to be actionable. Most compliments are very general, thanking staff and agency when a contract ends or specifically relating to a carer who has gone above and beyond. It is hard for agencies to use compliments strategically to inform practice improvements.

Informal requests and grumbles

Most direct communication between agency and user is in the form of a phone call with a request for a time change or a minor grumble. Most users feel very comfortable making requests and we heard very few cases of these being forgotten or ignored. Some users will call in their own grumbles, some will delegate this to a willing family member.



Our interviews with agency staff indicate these informal contacts are taken seriously and given immediate attention, but agencies differ in how and where they are recorded. Some agencies have double systems, with requests being recorded independently as well as logged on client records, others only log on client records.

“We don’t make a point of recording them other than on the client’s records”

Care manager

“They all get recorded on a separate care tag that goes into a file and the managers pick them up regularly during the day to deal with them”

Care manager

Many of these informal contacts are verbal so the potential for error or oversight is considerable. We heard that many service users ensured verbal requests were backed up with emails or text messages. However, these also need to be added manually to the agency system by office staff so the potential for error remains.

Agency Surveys

None of our care users spontaneously mentioned their annual agency customer survey.

From the agency perspective survey results are useful for CQC inspections, and some are clearly designed specifically for that purpose. They may also be used for marketing or for staff morale. However, they are too infrequent to be actionable (once or twice per year); response rates are unreliable; being quantitative and using closed-ended questionnaires they rarely elicit anything surprising or fresh; and some agencies struggle to administer them or analyse the results. Impartiality cannot be guaranteed - it is possible that care workers may help clients complete the surveys.

Complaints

The people we spoke to do not want to complain: care provision is an intimate relationship and making a complaint will be unpleasant and sour the relationship. Among our sample very few had made complaints.

“I hated doing it [complaining] but I had to. It took me quite a while to gather myself up and do it, a couple of months”

Care user

When asked to imagine complaining, most users would try to delegate this to a family member. Their first step would simply be to communicate to the agency that they were making a complaint - checking for a policy first did not cross their minds. One issue is the definition and recognition of a complaint:

Care user: Yes I did make a complaint once. I emailed them to complain that..

Interviewer: What did you say in the email that told them it was a formal complaint?

Care user: ...well I said I was unhappy with...

Interviewer: Would the person at the agency reading it definitely know it was a formal complaint rather than a grumble or a request?

Care user: ...oh, well, actually...I’m not sure. Maybe not, now you say it”

Care user

“If someone has a problem we discuss it with them and ask them if it’s a formal complaint and if so to put it in writing”

Care manager





Similarly, agencies avoid allowing situations to escalate to a complaint. Several staff we spoke to had handled complaints, but these were rare events. Some agency staff were experienced in handling complaints and sanguine about them:

“At my last agency it was part of my job to deal with all the complaints, I found it really interesting to be honest, you investigate and then if it’s upheld you sort it out”

Care manager

Others found complaints more of a challenge:

“It can be very difficult sometimes. A lot are not upheld, but it can be complex dealing with families”

Care manager

Communication between care workers and care agencies

The agency staff we spoke to all said they value care worker feedback, recognising that care workers are the people who hear and see what care users need.

Communications between workers and agency staff split into two types,

- Regular standardised reporting: call logs, team meetings, scheduled client update chats about the care user, handovers to new carers
- Proactive information from care workers to the agency: emails, phone calls, chats in the office

Different agencies have different policies and approaches to management of care worker feedback, and it is clear that some agency staff are better at this than others. We heard from one care worker whose agency routinely scheduled a meeting with the care team before a client reassessment and included them in the care planning process, but another care worker who was careful to follow up proactive feedback with an email and even photographic evidence to be sure the agency acted on her information.

“One day when [the carer] was here the agency came for a meeting, and I was shocked, they didn’t even say good morning to her, they just stepped over her - literally, she was kneeling doing something - to get into the room”

Care user

Other tools and systems designed to enable communication between users, workers and agencies

Digital Care Management Systems

A handful of our sample had experience of digital care management systems. Views were positive: they offer security and certainty to all parties. Workers know their records and feedback are received by the agency, and have crucial information and decision-making at their fingertips.

“It’s great, it’s all there, you can’t skimp on the calls”

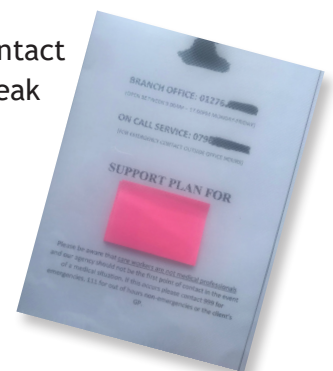
Care worker

The care users were impressed by their modernity and efficiency. The only slight regret was from a care agency: the accessibility and detail of the care log can lead to over scrutiny from relatives.

The Hard Copy Care Folder

The care folder enables the user voice to be heard by:

- providing care users with contact details so they can easily speak to the right people
- providing information that explains to people what they can expect and how to engage with the system so they can speak out with confidence
- recording a log of care, which contains information about changing needs and can trigger conversations between care users and providers





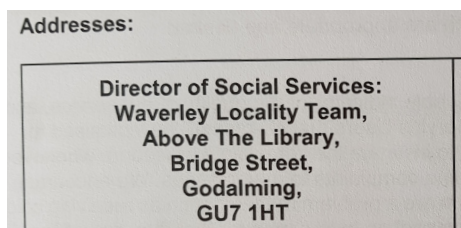
All the care folders we looked at contained:

- Contact information for the agency: often large type on the front of the folder
- Contact information (next of kin, GP) and medical information about the client
- The care plan
- A handwritten care log
- Various long form policies and terms & conditions of business

While all folders contained a **complaints policy** many of these were jargonistic policies written from the agency’s point of view, and not accessible procedures designed to enable the user to communicate with the agency. Where there were simplified procedures these were often in small print, not easily accessible for care users with problems with their sight or fine motor skills.

Few folders contained any information on **safeguarding**, either for users, families or workers.

Some of the folders contained information that was very out of date.



Care users mostly see the care folder as ‘belonging’ to the agency, containing little of interest or value to them.

“All that stuff’s there to cover their backsides”
Care user

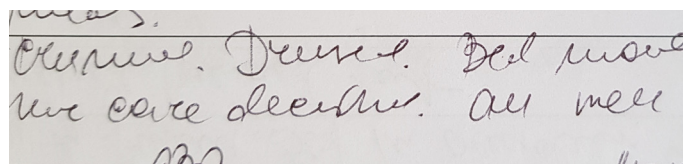
They know the **care plan** is there and roughly what it covers but these are written by the care agency for their own use and can be viewed as impersonal and jargonistic.

“There’s pages of this stuff. In all honesty a straightforward to-do list would be much more useful to everyone”
Care user

The most valuable part of the care folder is often the **contact details for the agency**. Many agencies

have an excellent easy-read contact sheet on the outside of the folder, meaning users never have to open the folder itself.

The **care log** is interesting in the early days and remains of interest to family readers. However, we were shown examples of handwritten care logs where the handwriting was illegible or the records scanty.



“I wish they’d write a bit more about how he was in himself, how he was feeling”
Care user

Care users mostly did not know if there was a **complaints policy** or procedure in their folder but assumed there was.

“[rifling through the folder] I’m sure there must be something in here somewhere”
Care user

They did not know if there was information on **safeguarding** and hadn’t considered whether this was something they should be aware of.

Care workers told us the **care log** is the most valuable element in the folder - it gives easily accessible information on the tasks to be completed and on the client’s current status.

Whether a care worker ever reads a client **care plan** depends on time available: some agencies schedule time for workers to be briefed on clients before they start going to them; others simply send the worker along. In a short visit there is no time to read the care plan unless there is no other way for the worker to understand the tasks that need to be completed.

“They assess the clients before the job starts...then I come in and live the experience. Many times I find the facts are not the same as the care plan”
Care worker



Agencies we spoke to told us they audit **care logs** regularly (monthly); they are a valuable record of compliance and an insight into the user's health and wellbeing.

Communication with Surrey County Council

Care users

While funded care users had had an assessment with Social Services at the start of their service only the most vulnerable service users had an ongoing relationship with social services. Experiences were highly individualised - some wonderful, some not - but all had struggled with changes in social worker or with losing a named social worker and having to work through the duty team system. Those relying on social services were not confident in getting the support or advocacy they felt they needed.

Care agencies

In the context of listening to the voice of care users, agencies and SCC communicate about individual care users through the tender system and informal conversations (outside the scope of this project); they communicate overall quality

of listening through Surrey County Council Key Performance Indicators.

- Number of complaints, and how many of these were upheld
- Frequency of client survey, and number of respondents
- Response rate, and % satisfied or very satisfied with the home care received
- SCC also ask Agencies for a copy of the customer satisfaction questionnaire.

SCC tell us there is about 80% compliance with this KPI.

Both the SCC business team and agency staff recognise problems with Complaints as a KPI. There is no clear definition of a complaint for care users or for care agencies: as a result, the number of complaints reported to SCC as part of the KPIs is somewhat subjective.

The survey data measures overall satisfaction but agency questionnaires are not consistent in how this is measured and there is no specific KPI around person centred care or being listened to.





Summary and key conclusions

Most people receiving care in their own homes do have a voice most of the time. At every level of the care system - advisory, regulatory, commissioner, provider, worker - the concept of person-centred care is baked in, and for the people we spoke to the system is generally delivering care that reflects people's individual needs and preferences. We heard many stories of issues that had been resolved immediately when the care user had spoken out.

However, our research has identified opportunities to reduce vulnerabilities in the system.

The system works well for those able to negotiate it (or with someone loving to negotiate for them). **But those who lack an effective voice of their own - such as those living alone with dementia and without close family - are in danger of not being heard.** In addition people who know their care provision is fragile can be unwilling to

complain for losing the care they do have. Both these groups need additional support and advocacy to ensure their voice can be heard.

Care workers are not always confident of the value of their insight or empowered to use that insight on behalf of their clients. Not all agencies have robust systems for soliciting and recording care worker feedback or including them in care reviews. But care workers are the eyes and ears of the care system with unparalleled insight into their clients' needs: the system needs to ensure this insight is used to benefit care users.

Tools and processes intended to enable people to make their voice heard - such as care folders and recording systems within agencies - are not always robust. Commissioners and providers need to ensure these tools are fit to support the people they serve.

Thank You

We would like to thank all the care users and their families, care workers and care agency staff who shared their experience with Healthwatch Surrey. Your time, openness and courage has informed future improvements to services that will benefit all.

We would also like to thank Surrey County Council staff who encouraged us to undertake this research and provided us with information into their practices and systems.





Recruitment, photos and verbatim comments

The care agency staff, care workers and care users we spoke to were all recruited directly by us through word of mouth and social media: ie we were not given the names of clients by care agencies, or names of care workers by clients. Care workers were gifted a £20 thank-you for their time and care users received a gift of £30.

All interviewees were promised anonymity: hence verbatims do not give any identifiable details and personal or identifiable information in the photos has been blanked out. We have permission from the interviewees to include their photographs in this report.

About Healthwatch Surrey

Healthwatch Surrey is an independent local champion that gives the people of Surrey a voice to improve, shape and get the best from health and social care services.

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