Care at Home:

Experiences of people who use services

Healthwatch Isle of Wight Report

January 2017

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1. Acknowledgements

Healthwatch Isle of Wight would like to thank all those who contributed to this piece of work, in particular the following:

- All members of the public who shared information on their experiences of care at home through the Healthwatch survey
- Local organisations that helped by distributing questionnaires to people who use care at home services
- Healthwatch Dorset for sharing ideas on questionnaire design and general approach following a similar piece of work in their area

Healthwatch Isle of Wight looks forward to continuing dialogue with relevant local partners on achieving progress on the recommendations contained in this report.

2. Summary

Care at home became part of Healthwatch Isle of Wight's workplan for 2016-17 after a review of feedback and a period of public engagement.

A questionnaire was compiled, covering topics identified from national reports, and through analysis of the public's feedback to Healthwatch Isle of Wight. 180 people responded - predominantly users of care at home; most others who took part were family members of care recipients.

The majority of participants rated care highly, with many positive comments about the attitudes of care staff, organisational support from care agencies, and help from individual members of the Isle of Wight Council's social care team.

The process of arranging care was most often assisted by a social worker. Whilst many rated this positively, others encountered difficulties, especially people obliged to fund their own care. In this situation, several participants described support being withdrawn as soon as the financial assessment had been concluded.

Alongside positive experience of care staff, some participants mentioned poor communication skills and a lack of awareness of dementia. Some care staff were said to have not offered encouragement if a person initially declined a care task. Competence also varied in food preparation.

There were a number of comments on erratically-timed care visits, and frequent changes of care staff. Some participants said they had been kept well-informed about which care staff would be visiting, others less so.

Experience varied of communication with care agencies and the ease of resolving any problems. A lack of promptness was reported when support needs changed and re-assessment was required by social care teams.

Several recommendations are made at the end of this report, based on the findings of the questionnaire survey.

3. Background

Healthwatch Isle of Wight is the “consumer champion” for local health and social care services. It was formed in 2013, following legislation to bring in a Healthwatch organisation in every local authority area of England. Feedback is received from local residents on a range of services, and discussed regularly with local commissioners and providers. Each year a small number of topics are chosen for more detailed examination.

Care at home was identified as one of Healthwatch Isle of Wight’s priority topics for 2016-17 after a review of recent Healthwatch feedback, and a period of public engagement.

Care at home, also known as “domiciliary care” has grown steadily since the beginning of the welfare state in the 1940s. From the 1950s there was growing agreement that older people should have the option of being supported in their own homes as long as possible[1], before residential care or a long-stay hospital was considered. Responsibility for care at home lay with local authority social services departments, and was provided free of charge to people needing a certain level of support, whose financial assets fell below an identified sum.

Following the adoption of the NHS and Community Care Act[2] in 1990, Care at home grew further in prominence, with private care agencies being involved increasingly in provision. Local authorities began to concentrate more on assessing individuals’ needs, supporting them to find appropriate provision, and monitoring quality.

An important feature of care at home is the way that paid care workers often deliver some parts of the care, whilst unpaid carers provide other parts of it. Unpaid carers are predominantly family members of the person receiving care. Sometimes paid workers provide care on a respite basis, where an unpaid carer is the regular provider of care.

On the Isle of Wight, residential care continued to play a dominant role into the mid 2000s, when it had declined in many mainland areas. Journal articles from the time[3] describe the process the local authority followed, identifying costs to individuals of care at home as a deterrent in this geographic area, with a high percentage of people liable for funding their own care. In 2007 the Isle of Wight Council responded by introducing free homecare for people aged 80 or over who were assessed as having “critical” or “substantial” needs. With the local authority’s own Wightcare service as the main provider, numbers of people using homecare rose substantially and numbers in residential care fell. In 2010 financial assessments resumed for the over 80’s, and Wightcare’s homecare service ceased, though its community alarm service continued.

In the last five years, a number of reports have appeared at a national level, scrutinising the quality of care at home. They were issued by the Equality and Human Rights Commission[4,5] and the Care Quality Commission[6] amongst others. Whilst excellent care was received by some, the poor experience of others displayed identifiable patterns.

Typically, these national reports included descriptions of food being provided irregularly, inappropriately or without being accessible. There were concerns about awareness levels of people’s dietary and communication needs. Poor knowledge of dementia was also highlighted.

Attention to personal care was at times insufficient, often with too little time allocated to complete it. Approaches to individuals’ needs could be inflexible, whilst visits might be inconsistently-timed, with frequent changes of staff. People’s involvement in decisions about their care, and the maintenance of privacy and dignity were found to be patchy[4,5].

In many instances, the demeanour of care staff prompted greatest dissatisfaction, or a build-up of “low-level” incidents where a person’s preferences were disregarded. Lack of respect for the fabric of the home also raised concerns. Paths for giving feedback were not always clearcut.

Addressing features of the care at home system that raised concerns, the Burstow Report (2011)[7] made a number of recommendations. Amongst these were a more formalised career path for care workers, as well as better oversight of commissioning arrangements by local authorities and health and well-being boards[6].

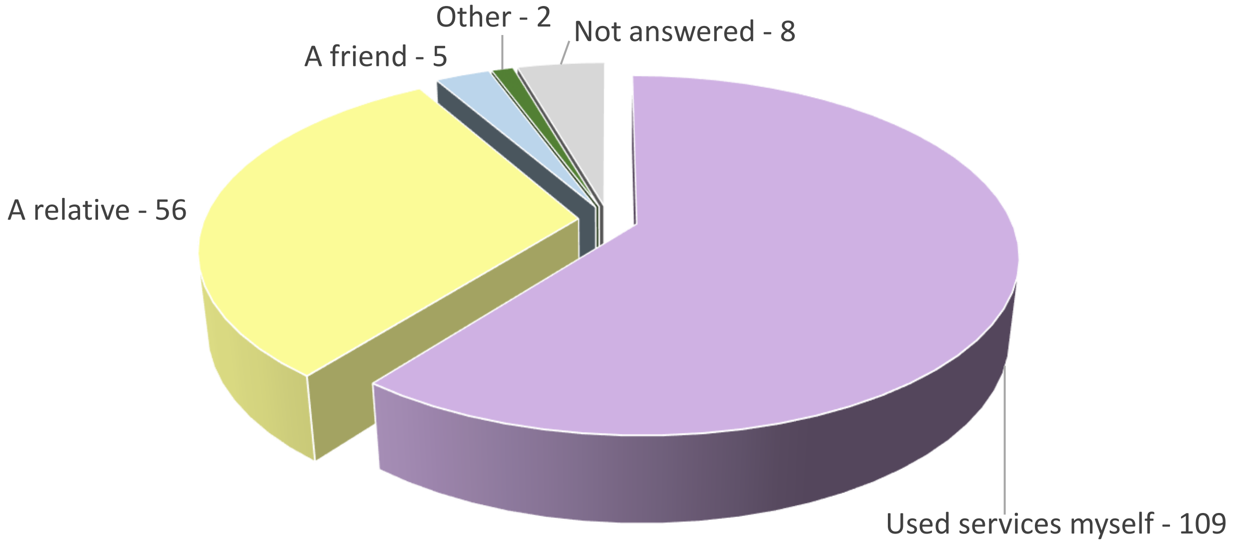
4. What Healthwatch did

Feedback received by Healthwatch Isle of Wight between 2013 and 2016 was analysed, and themes listed. A short report on that feedback is available alongside this one[8].

A questionnaire was devised, to find out more about the experiences of people using care at home services on the Isle of Wight. The themes identified from Healthwatch feedback and the reports mentioned in Section 3, were used to structure the questionnaire, with additional space for other comments. The text of the questionnaire may be seen in Appendix I (pages 41-53).

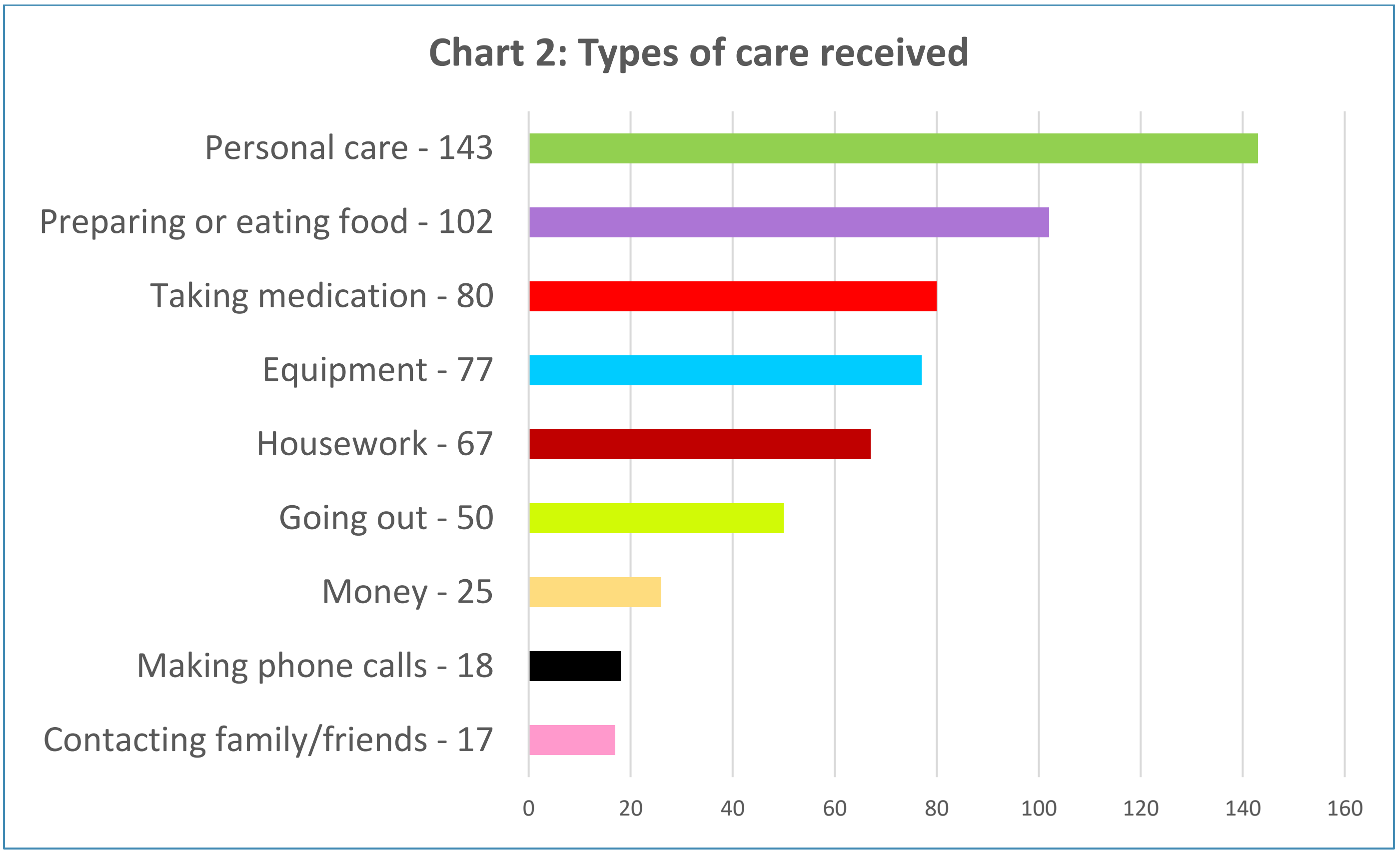
The survey was conducted between 23rd June and 29th July, 2016. 976 copies of the questionnaire were distributed, via a number of local organisations including the Isle of Wight Council, but not by the care at home provider agencies. 180 responses were received: 168 in hard copy form, and 12 electronically. A majority of questionnaires were completed by people receiving care at home, with most of the other responses being from relatives.

Chart 1: Experience of service by those responding



Further information on the age, gender and geographic distribution of people referred to in the survey may be found in Appendices E - H (pages 39 & 40).

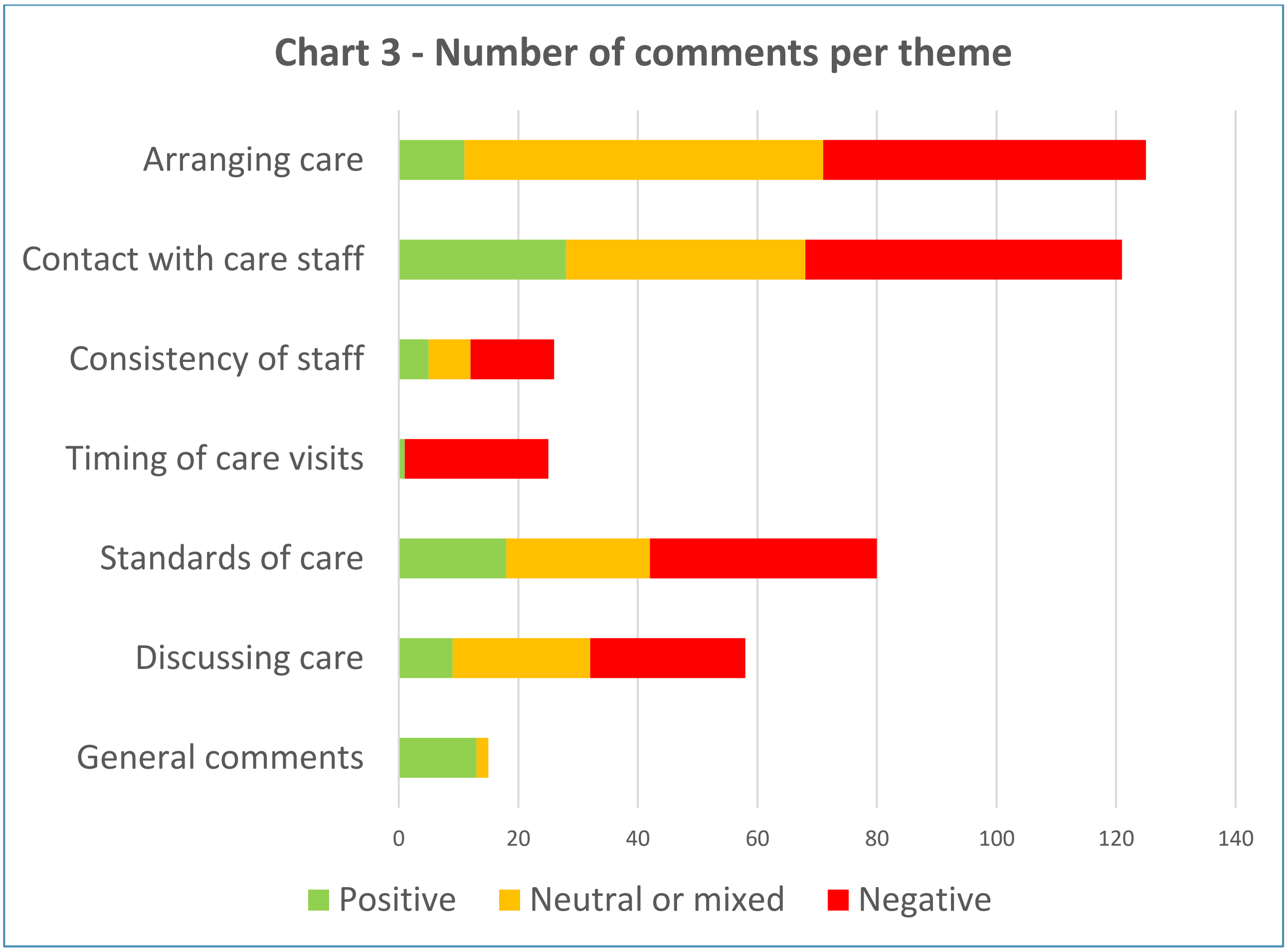
Chart 2 summarises the types of care received by people whose experiences were being referred to in the responses.



The questionnaire included six sections where people were invited to rate the quality of various aspects of their care, as well as the processes for arranging and discussing that care. In each section there was room for further comments, with a larger space at the end of the questionnaire for more general comments.

The survey comments were analysed using qualitative analysis software. Themes which were identified as a result are outlined in the following section of this report.

5. What Healthwatch found



This section of the report outlines feedback contained in the survey responses. It is structured around themes identified from participants' comments, which are presented in the same order as the chart above. Further charts follow, giving detail about the comments on each theme.

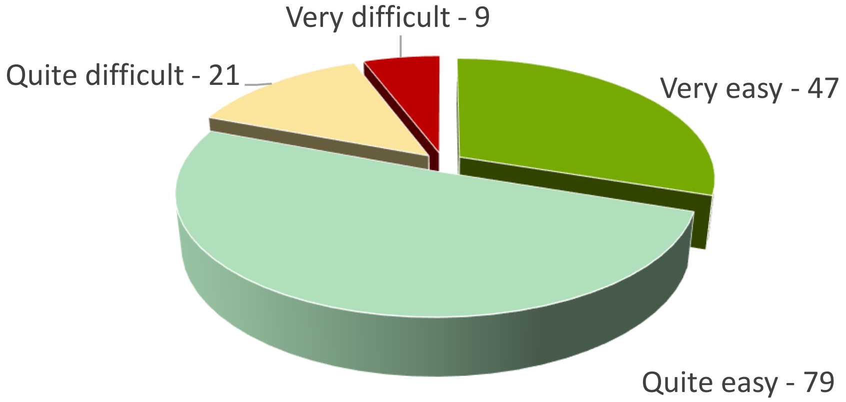
As Chart 3 (above) summarises comments on people's experiences, it should be considered alongside the charts on following pages, showing participants' ratings for their experience of various aspects of care.

The findings of this survey are presented as a snapshot of experiences of those who participated. It is hoped this will provide pointers to where good practice may be consolidated, and where improvements should be considered. It is not intended to be a systematic evaluation of services.

A - Arranging care

The survey's opening question asked how easy it had been to arrange care, when the need had first arisen.

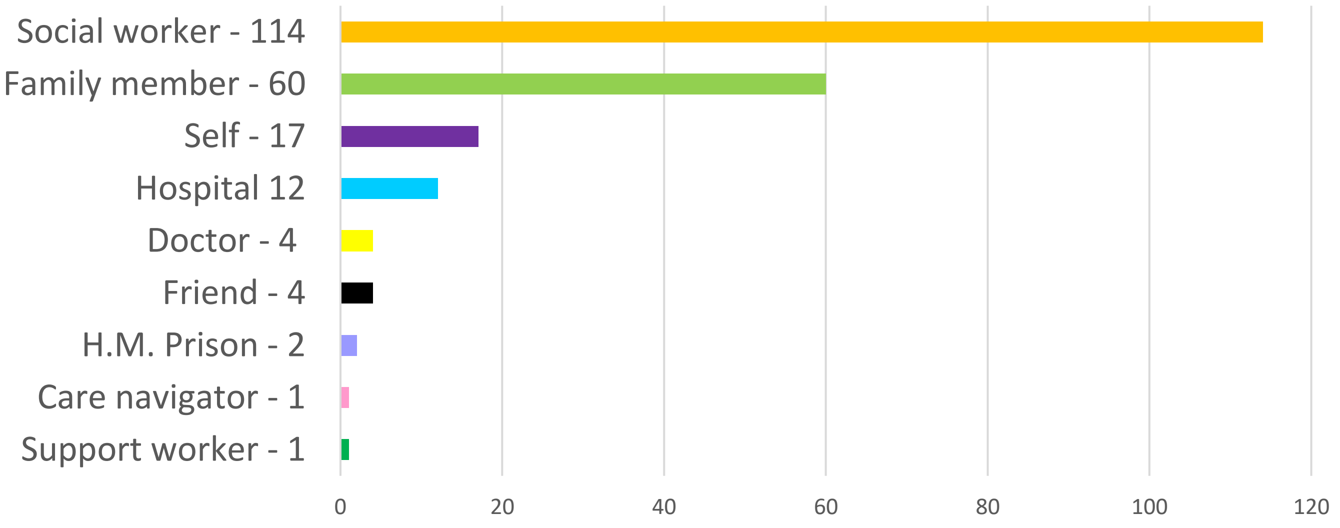
Chart 4: Arranging care (156 answered)



Overall, 30% of participants rated their experience (47) as "very easy" with 51% rating it as "quite easy" (79). 19% of people (30) felt they had a "quite difficult" or "very difficult" experience.

In response to a question about who had helped arrange care the largest number (114) mentioned a social worker, followed by 60 who said a family member had helped.

Chart 5: Help with arranging care (173 answered)



The greatest number of people whose experiences were described in the survey, paid a proportion of the fees for care, with the remaining cost met by the Isle of Wight Council. The next largest group of people had care funded entirely by the local authority, with a smaller group of participants funding the whole cost of their own care. Appendix B (page 38) shows the numbers of people funded in these different ways.

People funding their own care less often gave a positive rating to “ease of arranging care” than people fully-funded by the Isle of Wight Council. Those with jointly-funded care were somewhere between.

Chart 6: Council-funded - arranging care (36 answered)

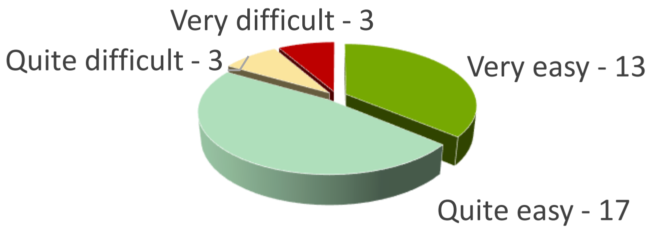


Chart 7: Mixed funding - arranging care (77 answered)

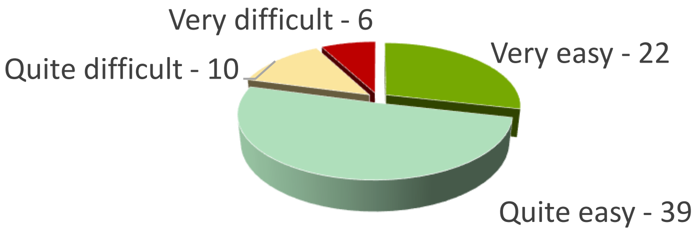
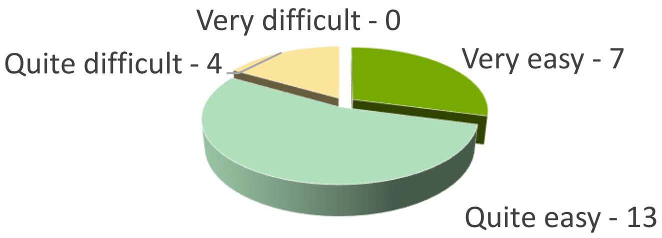


Chart 8: Self-funded - arranging care (24 answered)



The difference in these levels may be connected to a view expressed by some participants, that self-funding people had less access to help arranging care than those whose care was partly or fully funded by the Isle of Wight Council.

"I may be pretty physically disabled, but I'm still mentally effective. Just as well, because once the council officer determined I'd have to self-fund he was out of the door so fast, citing a high caseload… I had to find a good care provider…. and negotiate my own care package…"

With a majority of people receiving ***assistance from a social worker*,** this was a key part of their experience. Whilst positive comments were in all instances about the qualities of individual staff, the more negative experiences tended to stem from organisational issues. These ranged from a lack of clarity about which worker to speak with, to a perceived tone of suspicion around care recipients and families.

" I found this [process] to be very negative and frustrating, with the emphasis seeming to be about what Social Services could avoid providing, rather than what it would provide, based purely on cost [rather] than need…."

One participant spoke of feeling a need to convince social workers that the family was not trying to get "something for nothing" before a positive rapport could be achieved.

Information, largely given by letter, was felt by a number of participants to be unclear, not least in relation to funding issues. Others had found difficulty in contacting social workers, or a lack of reliability in their attendance of meetings. Several participants described the importance of family input and the need for persistence in attempts to contact social services and to make contact with the relevant person.

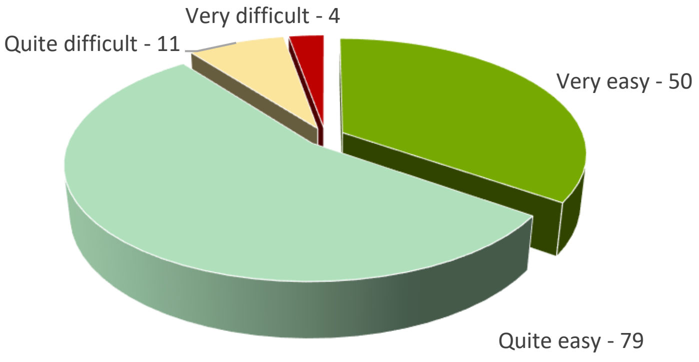
The process of arranging care ***after a stay in hospital*** did not receive any positive comments. Participants spoke of delays to discharge due to length of time taken to arrange or fund care. A lack of support following discharge and feelings of being "left to get on with it" were spoken of by people receiving care and were also described by unpaid family carers.

Not everyone had a good ***level of choice*** between care providers. One participant said only one agency could offer suitable care when they were first in need of help. Another mentioned an agency being recommended by staff at a care home, whilst staying there staying there short-term. One person commented on reluctance of some agencies to provide personal care, with agencies that do provide it having a high "turnover" of staff.

Two participants described going through an unsatisfactory ***experience with an initial provider*** before changing to one they felt gave a better service.

Payment issues were asked about specifically in the survey, with 35% of people (50) rating the experience of arranging payment as "very easy" and 55% (79) rating it is as "quite easy" 10% of people (15) rated their experience as "quite difficult" or "very difficult".

Chart 9: Arranging payment (144 answered)



A difference in experience is noticeable between participants funded in contrasting ways. Those who were self-funding more often found arranging payment "very easy" and less often "very difficult" than those funded by the Isle of Wight Council, with those funded jointly falling somewhere between. This accords with comments from some self-funders about the process for them being straightforward, and remarks from some eligible for Council funding about unclear information (sometimes never satisfactorily clarified), and cumbersome processes.

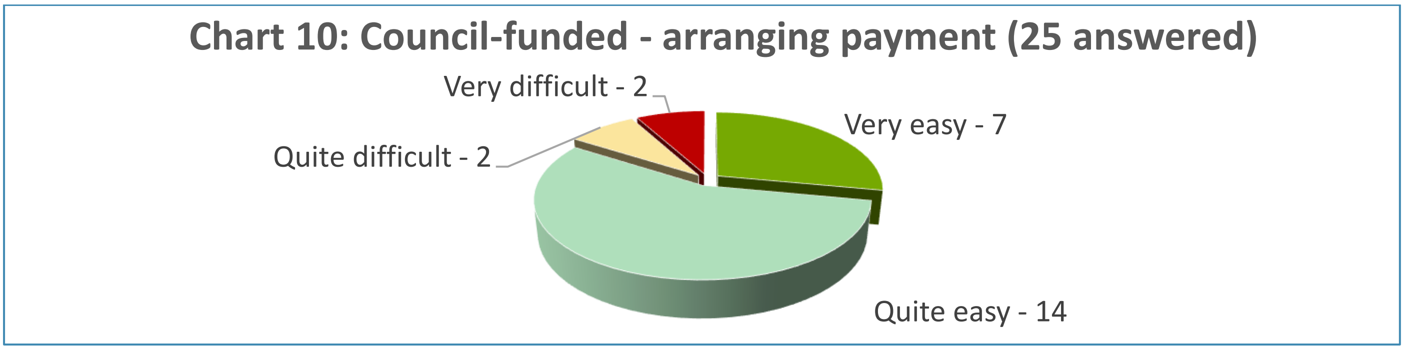


Chart 10: Council-funded - arranging payment (25 answered)

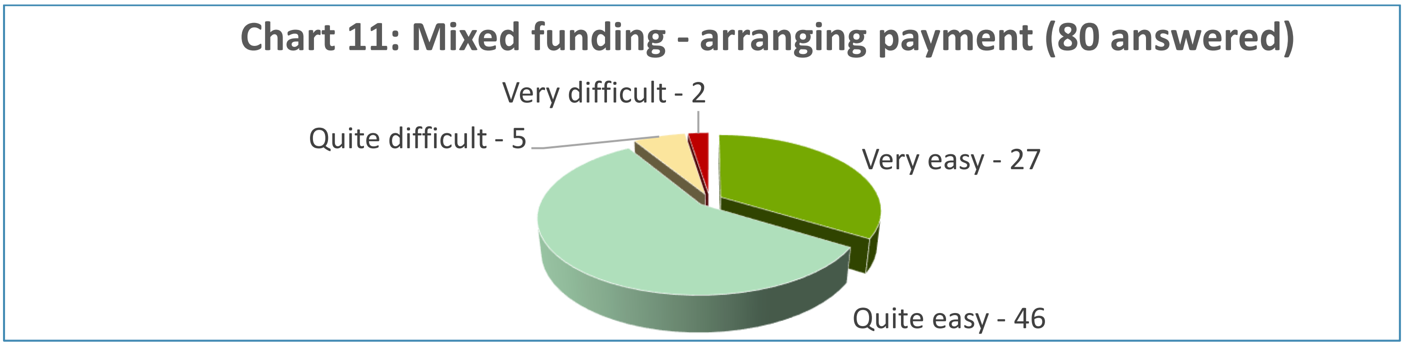


Chart 11: Mixed funding - arranging payment (80 answered)

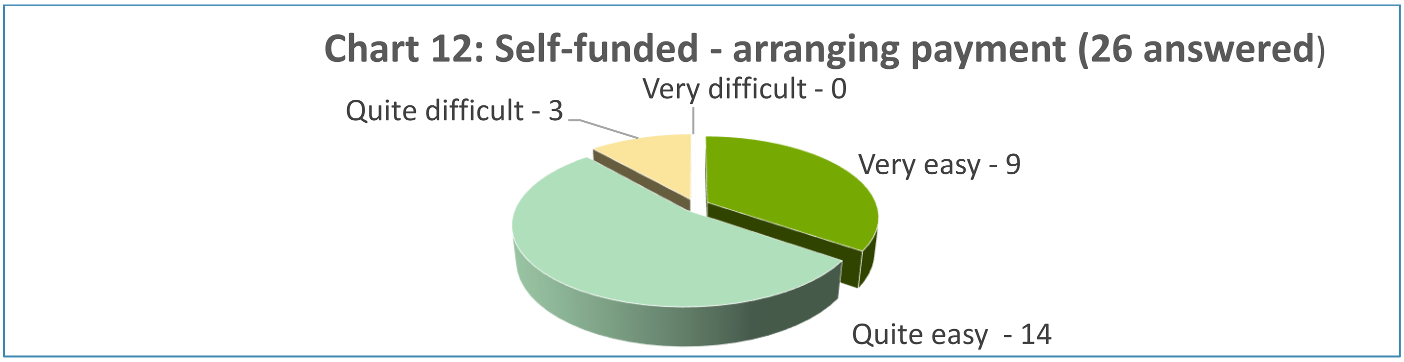


Chart 12: Self-funded - arranging payment (26 answered)

The Isle of Wight Council website was found to be rather difficult to navigate. There was inconsistency between funding information directed to all users, and that directed specifically at people funding their own care. These two examples were found on the website concurrently:

Extract from “Charging for adult social care services” (I.W. Council)

“Anyone can choose not to complete a financial assessment but they will be required to sign a part of the form that says they agree to pay the actual cost of the service they receive”

Extract from “Self-funder factsheet” (I.W. Council)

“If you have a total capital of £23,250 or above, you will be deemed a ‘self-funder’. If you have refused to disclose your financial circumstances you will also be required to pay the full cost of the services provided to you due to non-disclosure.

The following chart identifies topics within the overall theme of arranging care. Some comments refer to more than one topic, so the totals from all columns exceed the overall number of comments.

Chart 13: Detail of comment on Arranging care

Topic	*Positive*	*Neutral/mixed*	*Negative*
Advice on provider	-	2	-
Advocacy input	-	1	-
Choice of provider	-	2	1
Family input	-	7	-
Hospital discharge	-	7	6
Information provision	-	-	6
Initial provider experience	-	-	2
Occupational therapy input	1	-	-
Payment	2	10	7
Self-funding issues	1	1	4
Social work input	7	10	21
Swiftness of arranging	-	1	-
General comments	2	3	1

B – Contact with care staff

The quality of contact with care staff was a major theme of feedback to Healthwatch Isle of Wight, and in the national reports mentioned on page 7. The questionnaire therefore included questions on the extent to which recipients of care felt they had been treated with dignity, how they had been addressed, and whether their preferences and beliefs were respected. There was also space for participants to add additional comments and identify topics of their own choosing.

The majority of general comments about the ***approach of care staff*** were positive, with a few neutral remarks giving factual information about how tasks were approached. Comments about reliability referred more often to organisational issues than individual staff. Remarks about a lack of empathy or using critical language tended to relate to staff who no longer offered support, or who step in short-term for regular care staff.

Many comments about the attitudes of staff were positive, words such as “kind”, “polite” and “supportive” being typical. However, one comment was received about staff with a “laid-back, that-will-do attitude”, with another relating to a few staff being “bossy and controlling”. Whilst there were some references to care workers not reading the care plan, staff were also praised for going beyond what had been asked of them.

Two comments were made on the appearance of care staff; one complimentary, the other questioning the appropriateness of uniforms resembling those of nurses.

When asked whether staff called people receiving care by their ***preferred name,*** 98% (174) said this happened “every time” or “generally” with more than three quarters (136) saying this always occurred. There was a single comment about a care worker’s use of the title “Mrs” followed by the person’s first name.

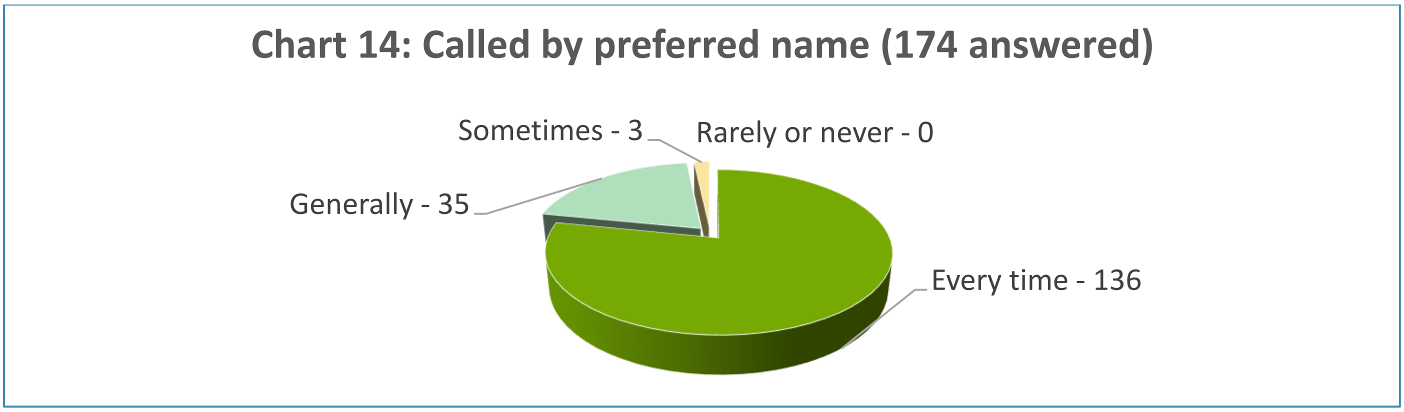


Chart 14: Called by preferred name (174 answered)

When it came to ***communication***, just over half of participants (90) stated they and the care staff could always understand each other, with a further 41% (72) stating this was generally the case.

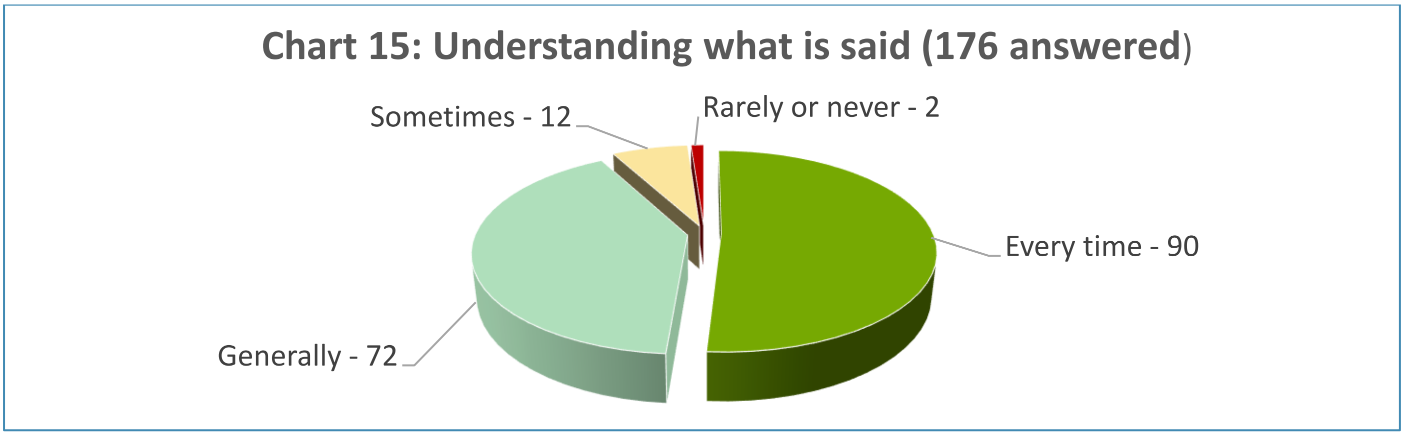


Chart 15: Understanding what is said (176 answered)

Most of the comments about communication related to the way this happened, rather than to the level of understanding. Four comments referred to care staff "talking across" the person receiving care, rather than including them.

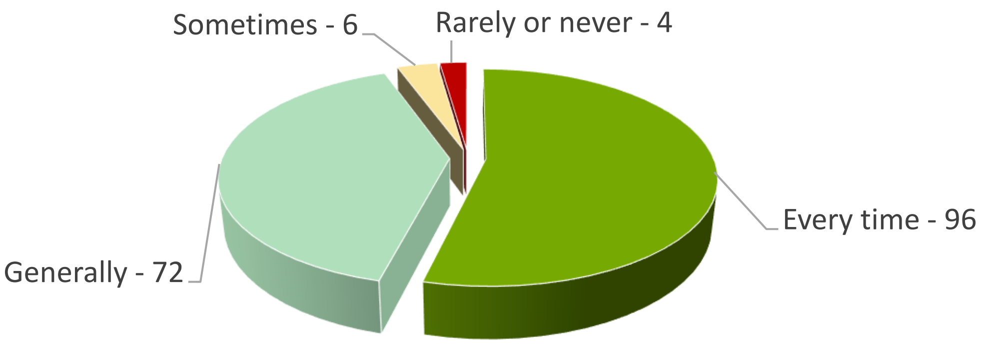
> *"It's more of a social meeting for the pairs of carers we have than them speaking to [my relative], they don't all involve her in conversations. My [relative] doesn't want to listen to them moaning about themselves or the care agency"*

Specific comments were made about communication which had not been appropriate for the person concerned, for example being given a long list of food options verbally and then asked for a decision, rather than being shown the various choices available. Other comments were made about people being given insufficient time to respond to questions.

> *"[relative] cannot speak well due to condition and carers rush her for an answer, or suggest and still rush her for an answer"*

The survey included a question about the extent to which care had been given in a way which suited the person's ***preferences and beliefs***. A little over a half (96) of people said this always took place, with a further 40% saying this was generally the case. Comments included mention of a preference not to have younger care workers, and preferring a worker of the same gender to assist with personal care tasks.

Chart 16: Preferences & beliefs noted (178 answered)



Five of the survey comments referred to negative experiences of ***cleanliness and tidiness*** being maintained. One remark described an otherwise "very good" care worker who had repeatedly left a household item in a position where it could not dry out, thus becoming mildew-stained and having to be discarded. Other comments described a person left with a drink spilt on a wheelchair, with the home left in a mess. There were descriptions of a relative routinely clearing up after a care worker following visits, or soiled items left un-bagged due to shortness of time.

Comments on ***not wanting care*** were made by a family member whose relative was unhappy with the idea of receiving care, and chose not to accept support. On a related issue there were a number of comments from family members about ***encouragement to receive care***. Typically, this refers to situations where care workers have neither persisted nor tried other approaches, when a person initially declines help with a task. Family members gave several descriptions of themselves having persevered and found ways such a person would accept care. Consequently, in such situations it has fallen to ***family members*** to step in to provide care, leading to additional concerns for relatives.

> *"My [relative] has a very small appetite and needs quite a lot of persuasion to eat. As her [relative] I am able to do this, but the carer is not allowed to enforce eating, so it concerns me that my [relative] is not necessarily eating unless I do her lunch myself…"*

Comments about ***capabilities of care staff*** often centred on variable skills in food preparation. One comment about food referred to communicating with people who have dementia – giving the example of an assumption that someone saying they have "already eaten" is referring to the immediate past.

In total there were eight comments about ***awareness of dementia***. There was felt to be an absence of knowledge of specific strategies to help, and that a "one-day training" was not sufficient. One participant mentioned encounters with a succession of care workers, none of whom had sufficient skills to support someone with dementia, and each of whom lost the trust of their relative.

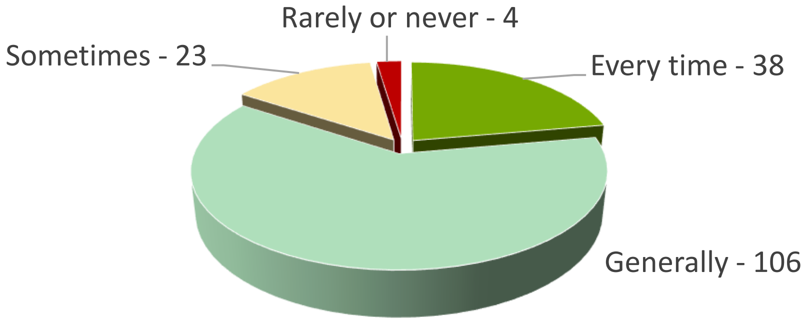
Chart 17: Detail of comments on Contact with care staff

Topic	*Positive*	*Neutral/mixed*	*Negative*
Approach of care staff	18	5	13
Capabilities of staff	-	1	6
Communication issues	-	-	7
Dementia awareness	-	-	8
Dress/appearance of staff	1	-	1
Not wanting care	-	5	-
Empathy levels	-	-	1
Encouragement to receive care	-	-	4
Family input	-	26	-
Going further than asked	1	-	-
Referring to care plan	-	-	1
Reliability	-	-	4
Following preferences	-	1	1
Supporting independence	3	2	1
Use of preferred name	-	-	1
Younger care staff	-	-	2

C – Consistency of care staff

There was a specific question in the survey about how often care visits were carried out by a familiar member of staff. Although a majority of participants stated this occurred “every time” (38 - 22%) or “generally” (106 - 62%) the percentage of positive responses was lower than any other question about care visits. Several participants whose experience had been otherwise positive, identified this as an area of concern.

Chart 18: Familiar staff visiting (171 answered)



Those who commented positively, mentioned having one or two care staff on a regular basis, with holiday cover adequately planned, and well prepared for. Some participants, however, mentioned problems arising when relief cover was in place, including at weekends.

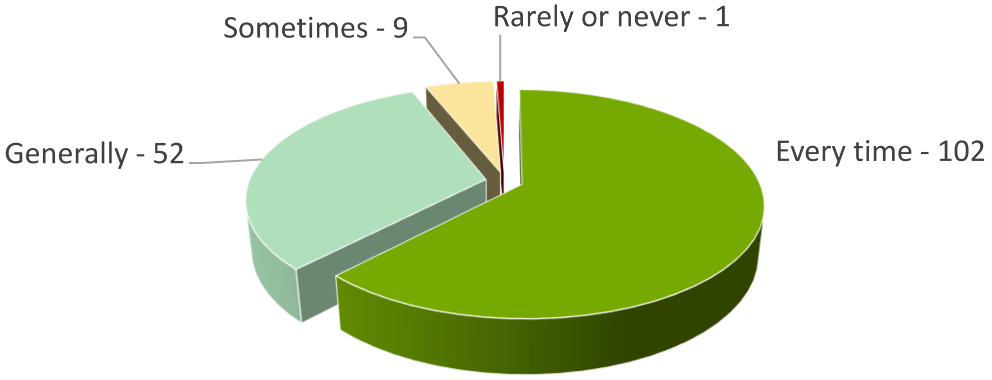
Those who gave detail of negative experiences, mentioned the effect of lack of consistency, especially for people with dementia.

> *"During the course of the week, my [relative] can have as many as six or seven carers and on some occasions visits are unallocated, so she does not know who is coming until they turn up. My [relative] has three visits per day, and is [in her nineties] so many different carers does not lead to consistency and adds to confusion."*

Whilst some participants had been kept informed of any changes in care staff, others had been worried by lack of information. One participant mentioned the increased time taken when visited by a care worker unfamiliar with her needs, as more explanation had been required.

When asked whether ***new staff introduced themselves***, 94% (154) said that this happened "every time" or "generally" with over half (102) saying it always took place. One participant mentioned new care staff only mentioning the name of the agency. Several comments referred positively to new staff accompanying a known worker on the first visit as an introduction.

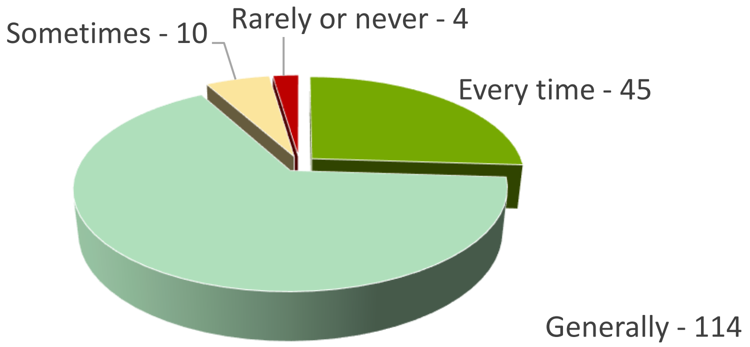
Chart 19: New staff introduced themselves (164 answered)



D – Timing of care visits

Whilst the bulk of participants rated themselves as having always or generally experienced care visits at a predictable time (159 – 92%), the number who said this had happened “every time” was barely over a quarter (26%). Several participants with an otherwise positive experience singled this out as a particular concern. Of the 25 comments made on this topic, all except one described negative experiences.

Chart 20: Predictable visit times (173 answered)

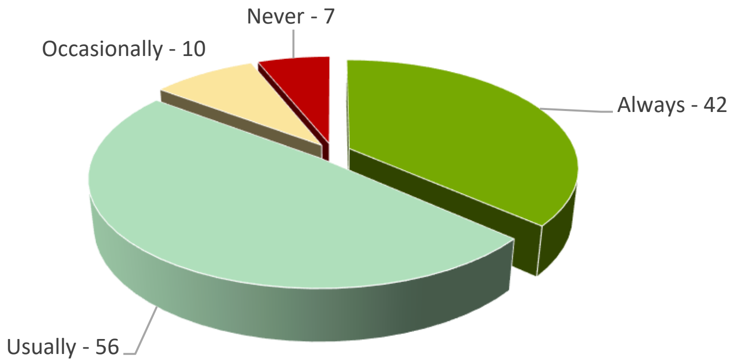


Broadly speaking, the comments related either to visits made at unsuitable times, or visits that were shorter than the allocated time.

> *“Sometimes you question the logic of getting someone dressed and breakfast at 11.30 a.m. and then providing lunch at 12.15 p.m.!”*

Whilst most of those who answered a question about food being provided at suitable times rated this positively, the level of satisfaction was lower than with other aspects of food preparation and eating (see pages 24-5).

Chart 21: Food provided at suitable times (115 anwered)



Comments about the schedule of visits referred to an unpredictability of timings (one participant quoted variation between breakfast visits as anything between 8.30 a.m. and 10.45 a.m.), the unsuitability of timings (one comment mentioned a care agency unable to arrange a washing and dressing visit before 10.00 a.m.) or to inappropriate time intervals between visits (one comment mentioned a 2½ hour space between the first two meals of the day, and then an 8 hour gap before the final meal)

Some participants felt that little account was taken of the timing of any outside activities the person might wish to do. Unpaid family carers were described as stepping in to provide care tasks that would otherwise only be provided at times which clashed with such activities.

The comments about late or shortened care visits pinpointed concerns not only about inadequate time for care, but also over a service being paid for but not fully delivered. It was mentioned by one participant that care agencies were obliged to inform clients of lateness only beyond 30 minutes, whilst others spoke of regularly receiving care visits much shorter than the agreed times. One participant expressed the view that agencies “work the time around themselves and not the clients”.

“The only problem that is continually occurring is that carers are not given enough time to get between clients, which means they are often late, or leave before the hour which I pay for is up. In one instance I only received 30 minutes of care, but paid for the hour.”

E – Standards of care

Appreciative comments on the standard of care mentioned the benefits of a good service, allowing people with severe difficulties to remain in their own homes with support. Also commented on were positive effects on unpaid family carers, for example enabling continuation in employment.

“Most of the carers are brilliant, I am looked after very well. Although disabled, I have no pressure sores or issues of mis-care”

Comments on negative experiences were sometimes about general ***quality issues***, referring to a “slapdash” approach, or to care workers being “rough” in their handling of the person receiving care.

Adequacy of care refers to situations where the completion or omission of a task has an impact on quality of life, for example hearing aid batteries not being checked, or food being left too long in a refrigerator and becoming mouldy.

Comments on ***impacts on health*** included a suggestion that care staff may be obliged to work when ill, thereby raising fears of infection. One participant mentioned differing views between professionals about the levels of support required. The response referred to care workers not assisting with cooking food, only dishing it up. Advice from the doctor had been that the person was “not allowed” to do cooking.

There were a variety of comments on ***flexibility*** of approach. On a positive note, one person mentioned being able to tell staff what help was required on any given day. Others, however, felt that fluctuating levels of need from day to day could not be accommodated, within one unvarying timeslot. This meant that on days when less help was needed, staff had little to do, as only tasks on a pre-agreed list could be carried out, whereas on days when more help was required, a choice had to be made about which tasks would have be omitted.

Some participants mentioned care workers’ variable skill levels in ***food preparation***, sometimes with unappetising results. One comment referred to a microwaved meal “literally up-sided” onto a plate. Another comment mentioned a drink being placed out of reach of the care recipient. Other participants questioned the nutrition levels of their food, and standard of hygiene of particular care workers.

> *“Carer does not wait until the meal is eaten. Undresses [relative] whilst preparing the meal….. there could have been one or two times a week when food is not adequate or at a reasonable time”*

Chart 22: Given a choice of food & drink (110 answered)

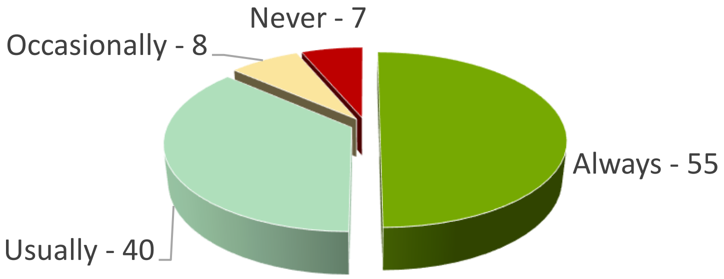


Chart 23: Food appropriate for person (114 answered)

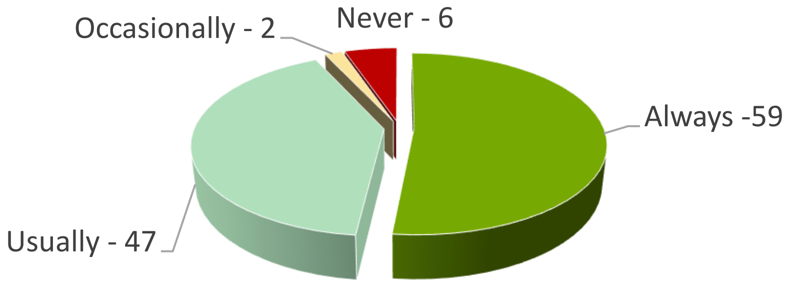
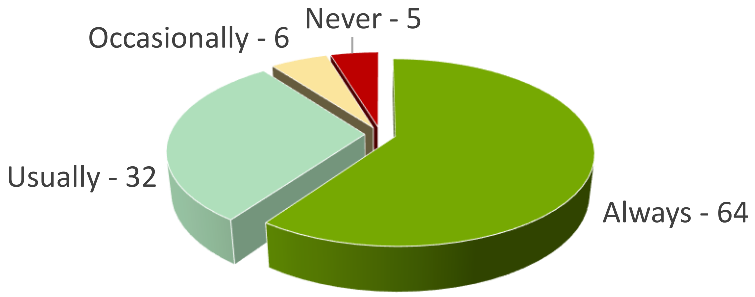
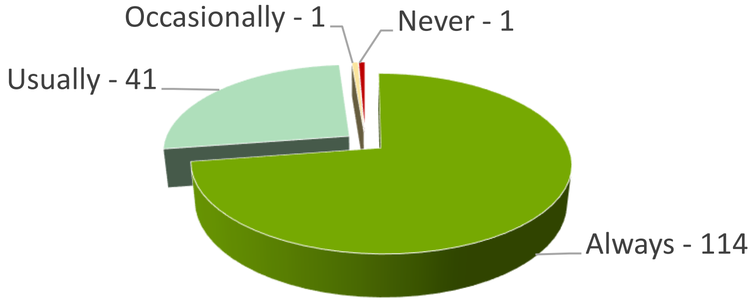


Chart 24: Dietary needs noted (107 answered)



Comments on personal care were mostly positive. In the structured questions, 72% of people (114) said they always were given enough privacy, a further 26% (41) saying this was usually the case. This is an area that had raised concerns in previous national reports (see page 7).

Chart 25: Enough privacy (157 answered)



93% (146) of participants said that care was provided appropriately “always” or “usually”. A lower percentage (87% - 134) of those responding felt tasks were “always” or “usually” explained beforehand.

Chart 26: Appropriate for person (158 answered)

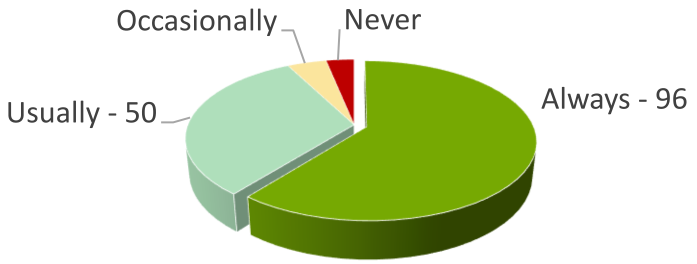
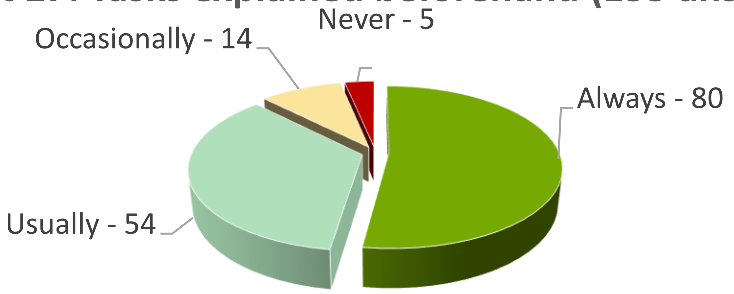
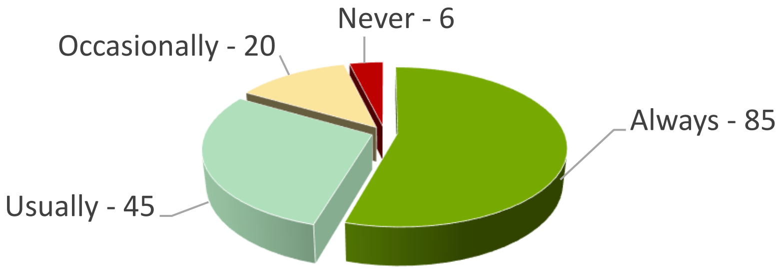


Chart 27: Tasks explained beforehand (153 answered)



There was a specific question about people being supported to be independent in tasks they could undertake themselves - national reports having highlighted this could be overlooked. In the survey 83% (130) answered that this had “always” or “usually” happened. Most of the positive comments on personal care, referred to this aspect.

Chart 28: Enough independence (146 answered)

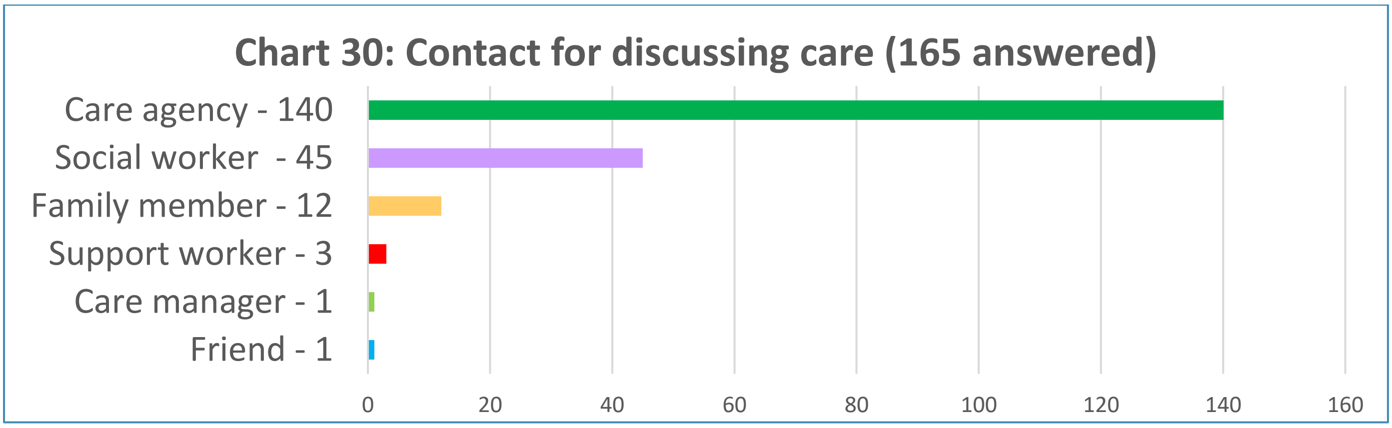


> *“My girls always support me in a helpful, kind and supportive way. They always do allow me to try, as much as I can do and do tasks and jobs to top my ability”*

Chart 29: Detail of comment on Standards of care

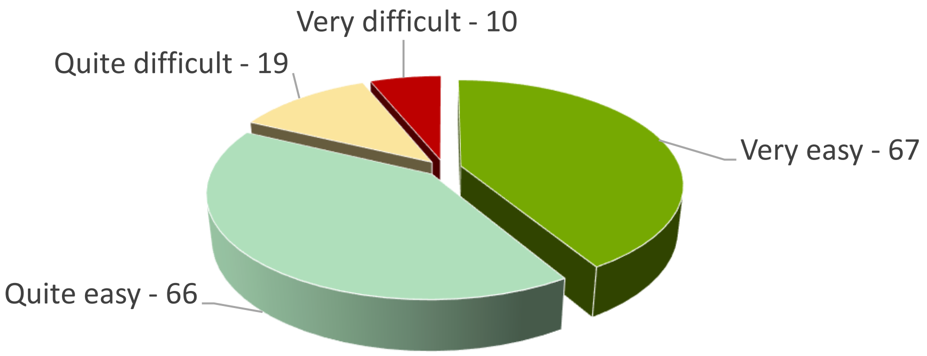
Topic	*Positive*	*Neutral/mixed*	*Negative*
Accessibility of food/drink	-	-	1
Adequacy of care	-	-	7
Choice of food/drink	-	1	1
Equipment issues	-	-	1
Flexibility	1	-	2
Food hygiene	-	-	2
Food made appetising	-	-	4
Food preparation	-	-	3
Impacts on health	-	-	4
Nutrition levels	-	-	1
Personal care support	-	-	3

F – Discussing care



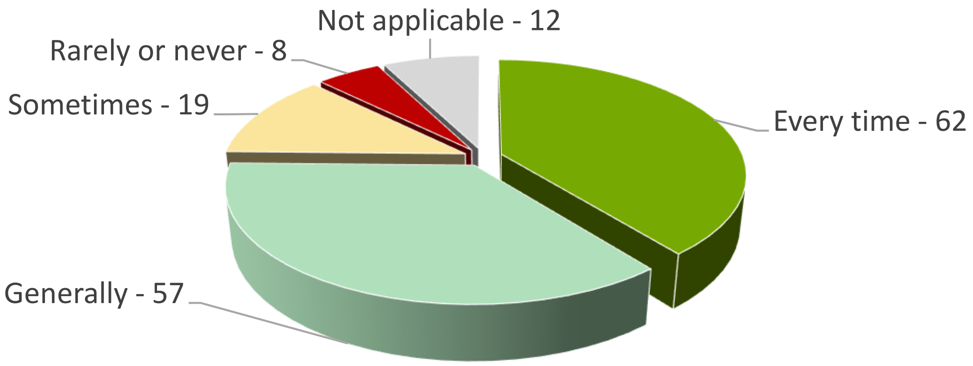
The final section of the survey looked at discussing how care is going. The greatest number of people indicated they would contact the care agency to discuss care, with a smaller number saying they would contact a social worker (see chart above). The layout of this question enabled participants to opt for more than one answer if applicable.

Chart 31: Contacting someone to talk (162 answered)



A question asking how easy it was to contact someone to talk, 82% of participants (133) rated this as “very easy” or “quite easy”

Chart 32: Problems being sorted out (158 answered)



Participants were then asked how often any problems were resolved once they had been highlighted. Overall, 81% (119) of those to whom this was applicable, felt that these were resolved “every time” or “generally”. More people who were council-funded (88% - 20) stated that problems were resolved “every time” or “generally” than self-funded people (80% - 18) – those with a mix of funding fell somewhere between (80% again, but with a larger proportion reporting that this happened “every time” – 41% compared with 30%).

“Sometimes I feel I am invisible. I feel that if I make a request it’s noted and ignored. If I criticise something I feel to be made guilty”

Chart 33: Council-funded - problems sorted out (37 answered)

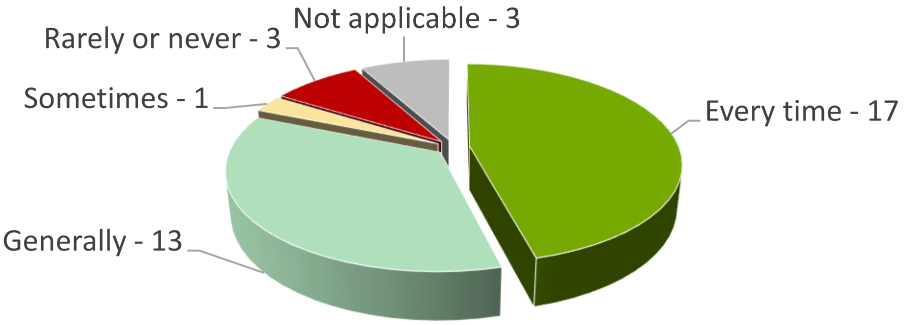


Chart 34: Mixed funding - problems sorted out (78 answered)

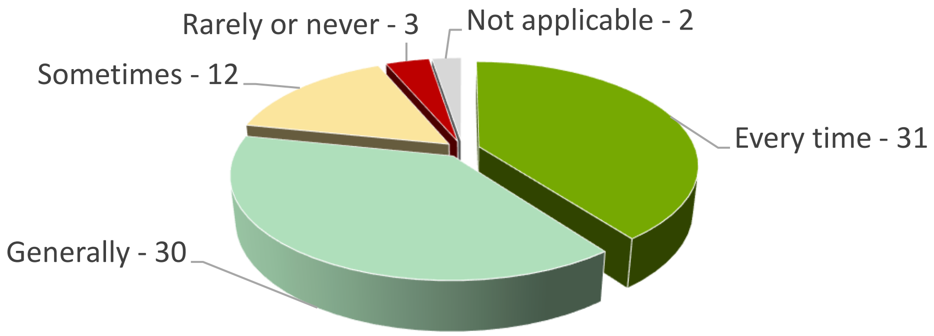
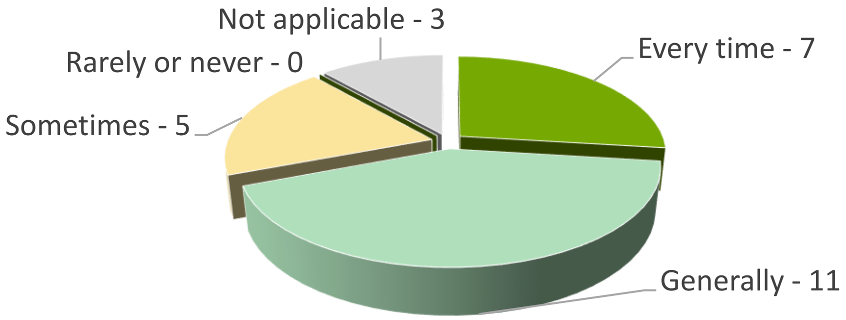


Chart 35: Self-funded - problems sorted out (25 answered)



Many comments stressed the value of building rapport with care agencies or with social services. Some participants described how much energy they had put into developing relationships with care agencies. On the other hand, one person spoke positively of a care agency whose “quality officers” visit care recipients to ask how satisfied they are with their care.

There was one description of feedback being passed on to the agency by care staff themselves, which does not appear to be good practice. Another comment referred to a “yearly survey” undertaken by a supervisor when the care worker was also present – unlikely to encourage candour from the care recipient.

Varying comments were received about the process of contacting the care agencies. Some participants spoke of office staff being friendly and helpful, though with varied levels of action taken to address any concerns. Others spoke in less positive terms, one comment referring to “defensive and rude” office staff.

> *“If there is a problem regarding the agency, a call to the office generally resolves the problem. However, if it means….. extra calls each day, social services have to be involved. Unfortunately dealings with social services are prolonged, and you do not have a name to contact”*

There were differing experiences of the time taken for agencies and social services to respond to queries. Generally, there was a greater number of comments on difficulties in contacting social services. This raised several concerns, not least where an amended schedule of care was required due to changing needs. Several participants had encountered problems in contacting social care professionals, and without a named worker had found the process cumbersome. In many cases, families or advocates had stepped in to help with making contact.

Sometimes establishing appropriate care arrangements had been hampered by a difference of view between different organisations on a person’s needs. One participant mentioned a doctor having advised to avoid a particular task for health reasons, but was regarded by social services as not requiring assistance with this. Another spoke more generally about communication between services as “causing unnecessary difficulties”.

Chart 36: Detail of comment on Discussing care

Topic	*Positive*	*Neutral/mixed*	*Negative*
Advocacy input	-	1	-
Care agency input	8	2	7
Family input	-	3	-
Interagency issues	-	-	2
Liaison via care staff	-	1	-
Social work input	2	-	12

G – General comments

It is important to put in context the varied experiences mentioned in the preceding pages, by saying that most answers to structured survey questions were positive. Similarly, nearly all the general comments about the care being received were contented and appreciative.

Some participants gave praise to particular care at home agencies, and others expressed non-specific positive feedback about services received.

“This is such an essential and valuable service. Putting aside the odd hiccup we all, as a family, would like to register our gratitude, and wish the service well for the future.”

A number of comments gave detail as to why receiving care at home had been of benefit to them. The importance of staying at home and having a choice other than residential care were at the heart of these responses.

"I love having care at home. I would hate to be in a care home. The support I receive keeps me at home, clean, fed and medication given at the right time…. Thank you for my care!”

6. Conclusions

As mentioned in Section 5, the survey was conducted as a snapshot of the experiences of people taking part – it was not intended as a systematic evaluation of services. However, it is felt that taking note of these experiences is itself a valuable exercise, and provides pointers to future action.

It is noticeable that a number of themes identified in previous national enquiries and reviews on care at home, [4,5,6] also emerge from this report.

There were contrasting experiences of ***arranging care***, with a greater proportion of self-funding people struggling with this than of those who received financial help from the Isle of Wight Council. Arranging payment, however, was more often straightforward for self-funders, compared with those navigating the local authority funding processes. Information in this area was felt to be unclear, both in letter and website formats.

Contact with care staff was mostly experienced in a positive light, but there were particular issues with regard to communication. This ranged from a feeling of being rushed, or choices not being presented in a way that could be taken on board, to a major lack of awareness of the needs of people with dementia. Several unpaid carers mentioned care staff who did not persist in encouraging people to eat, or receive important personal care, if an individual initially voiced reluctance.

Comments on ***consistency of care staff*** highlighted problems at weekends, or when regular care staff were on leave. Lack of consistency had a particular impact on people with dementia, where the need may be greater for time to build a rapport with care staff, and the vulnerability to distress at repeated change is likely to be more pronounced.

Timings of care visits stood out as a particular concern, including for a number of people who were otherwise satisfied. Impact was felt most keenly when times of meals became irregular, when timing of personal care led to a disrupted routine, or unpredictability of visits meant that involvement in community activities had to be curtailed. The length of visits was also an issue, with concern expressed that less care was sometimes being received than had been paid for.

Comments on ***standards of care*** were mainly positive, though some care staff were felt to lack skills in preparing and serving food. When receiving personal care, levels of privacy were amongst the aspects rated most positively. Some participants felt that more flexibility would be valuable, to allow for fluctuations from day to day in their need for support.

With regard to ***discussing care***, people funding their own care more often gave a negative rating to their experience of resolving problems than those with council-funded care. Disparate quality processes were described between care agencies, with more praise for some than others. Differences of view of a person’s support needs were reported between health professionals and social care teams, as well as delays in arranging re-assessments when levels of need had changed.

7. Recommendations

A – Greater access is needed to ***sources of support to arrange and review care***, for individuals deemed responsible for their own funding. A clear protocol needs to be adopted by the Isle of Wight Council to ensure there is ready access to such support, without undue cost to individuals. Robust monitoring will be needed to assess effectiveness.

B – An urgent review should take place of ***information, correspondence and communication*** between people arranging or using care at home and the Isle of Wight Council's social care department. This review should be based on service user involvement to identify problems and propose solutions. Any required changes should be made promptly to ensure consistent standards of clarity, timeliness and respectful tone.

C – ***Training requirements*** for care staff should be systematically identified by commissioners with regard to matters highlighted in this report. Training on communication and supporting people with dementia should be prioritised. Training should be arranged where applicable to ensure a consistent standard of preparing and presenting food. A clear agreement should also be developed, in parallel with suitable training, to clarify expectations on care staff supporting people who show initial reluctance to receive nutrition or personal care.

D – Mechanisms need to be further developed to allow for ***quality standards*** of providers to be rated by recipients of care. There should be a medium through which this can inform purchasing decisions, both on the part of the Isle of Wight Council, and people who fund their own care. Categories within a quality mechanism of this kind should include:

- Consistency of visits by familiar care staff, and being kept informed of unavoidable changes

- Adherence to agreed time and length of visits, whilst allowing for flexibility in content of tasks if needs or choices fluctuate

- Level of satisfaction with preparation of food, appetising presentation and appropriateness to individuals' dietary needs

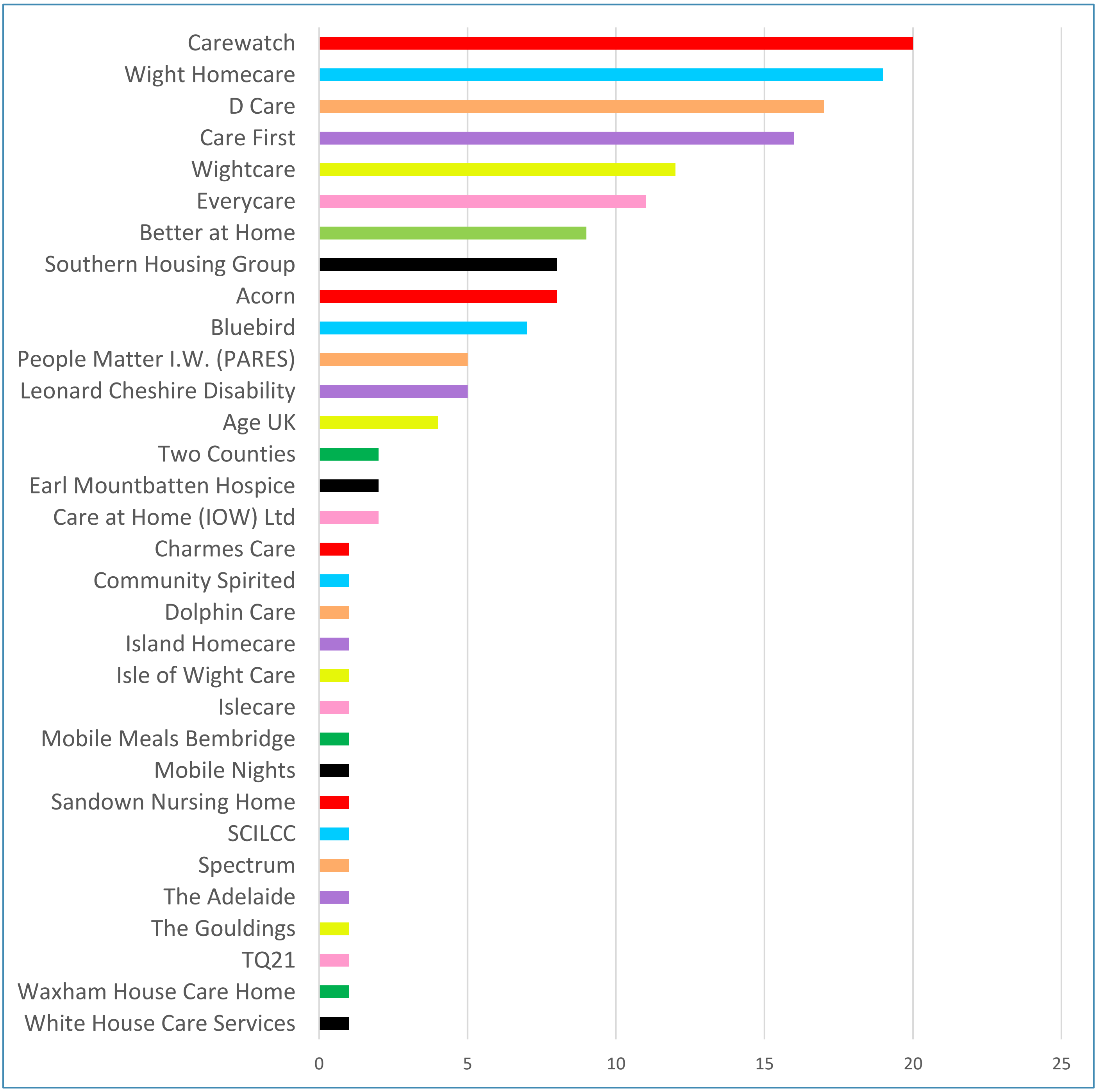
- The presence of robust and effective processes for reviewing care, and resolving any problematic issues which may arise

8. References

1. *“Securing Good Care for Older People: Taking a long-term view”,* Derek Wanless: Kings Fund, 2006
2. *“National Health Service and Community Care Act”,* H.M. Government: The Stationery Office Ltd, 1990
3. *“Free Home Care on the Isle of Wight”,* Natalie Valios: Community Care, 2008
4. *“Close to Home: An Inquiry into older people and human rights in home care”,* Equality & Human Rights Commission, 2011
5. *“Older People’s Experiences of Home Care in England”,* Wendy Sykes & Carola Groom: Equality & Human Rights Commission, 2011
6. *“Not Just a Number: Home Care Inspection Programme, National Overview”,* Care Quality Commission, 2013
7. *“Key to Care: Report of the Burstow Commission”,* Ingrid Koehler, The Local Democracy Think Tank, 2014
8. *“Care at Home Services on the Isle of Wight”,* Healthwatch Isle of Wight, 2016

9. Appendices

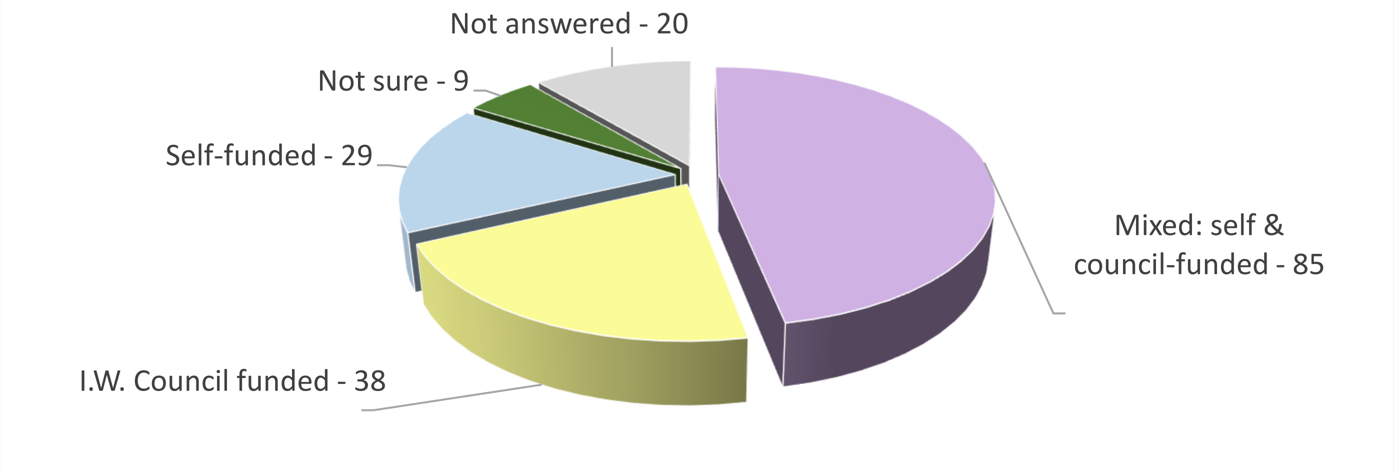
Appendix A – Number of participants naming each care at home agency



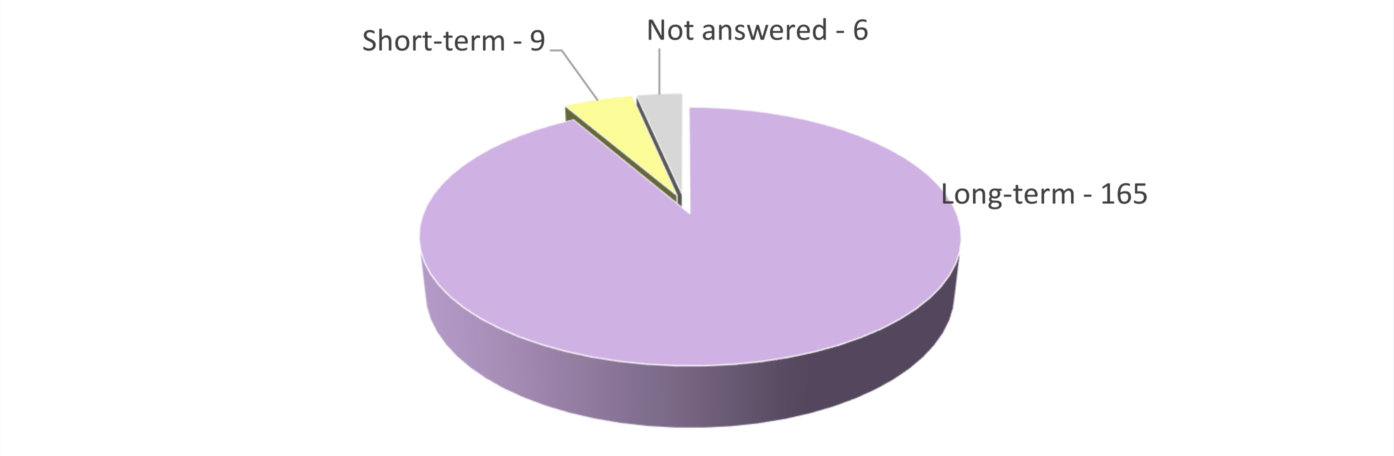
NOTE 1: Agencies are recorded as named by participants. It is acknowledged that some names do not correspond with known providers of care at home.

NOTE 2: Comments made in the survey have not been linked with specific providers in this report, but are being shared with the individual agencies.

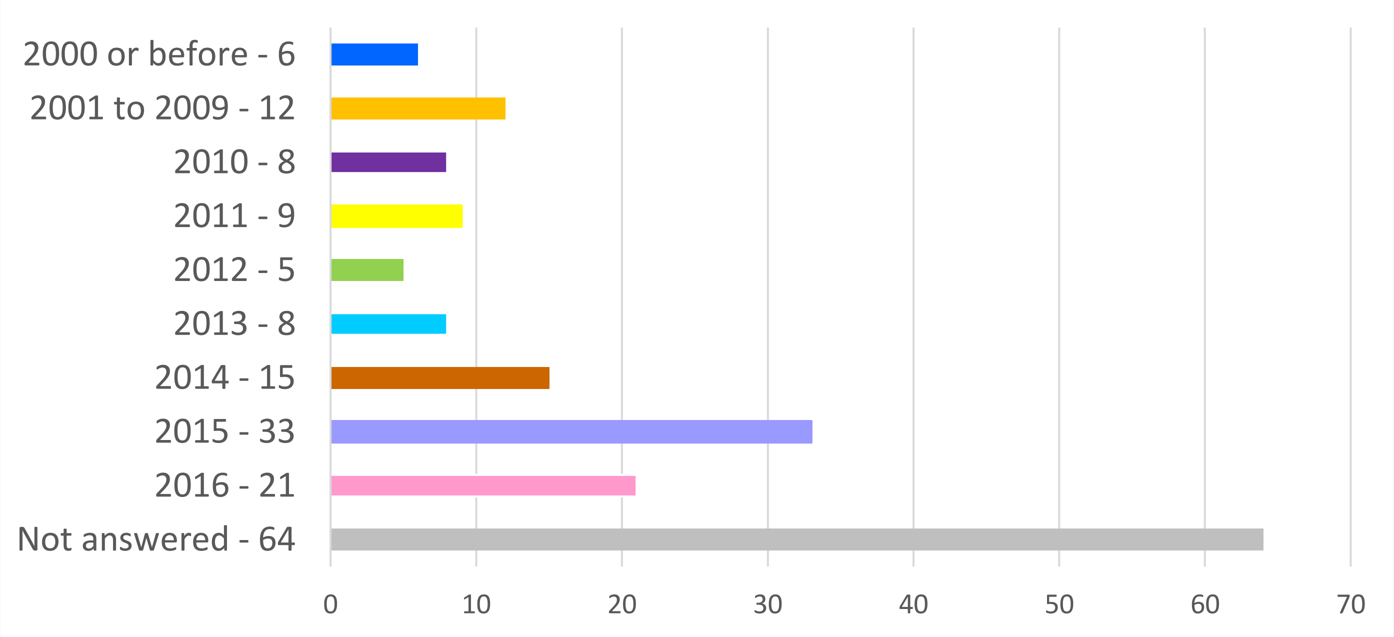
Appendix B – How care is funded



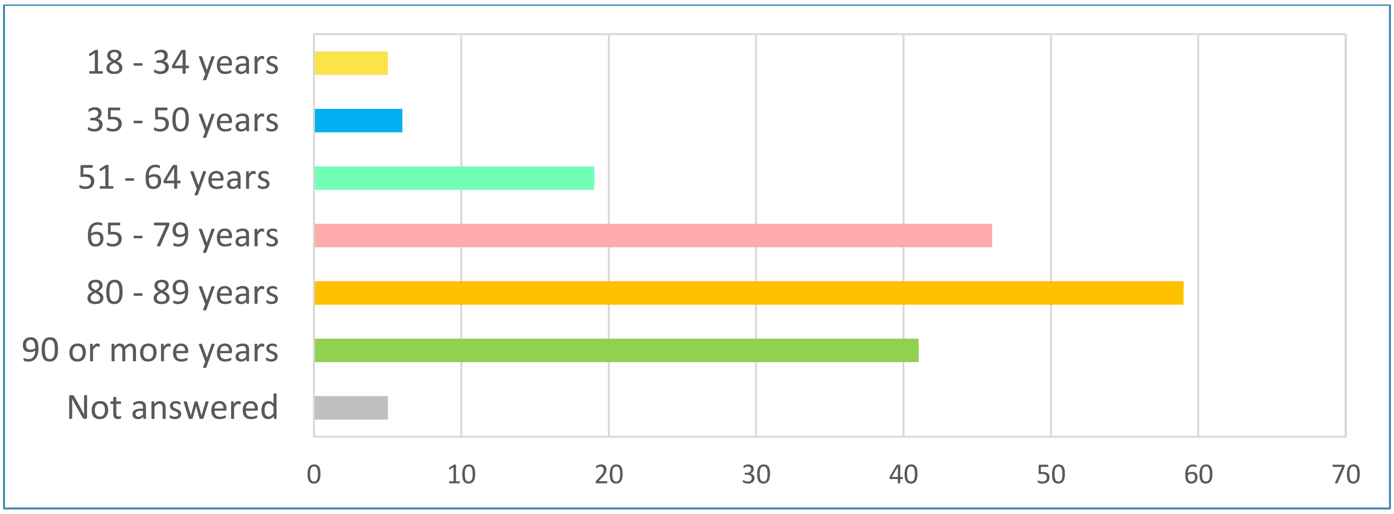
Appendix C – Long-term or short-term care (less than three months)



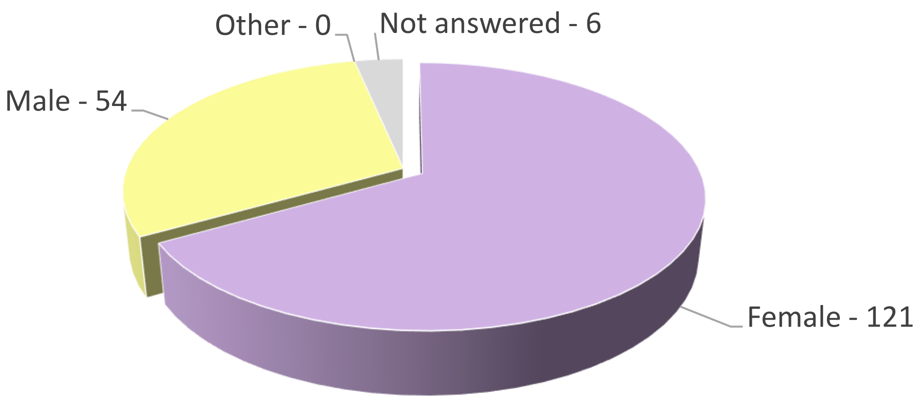
Appendix D – Year in which care was first arranged



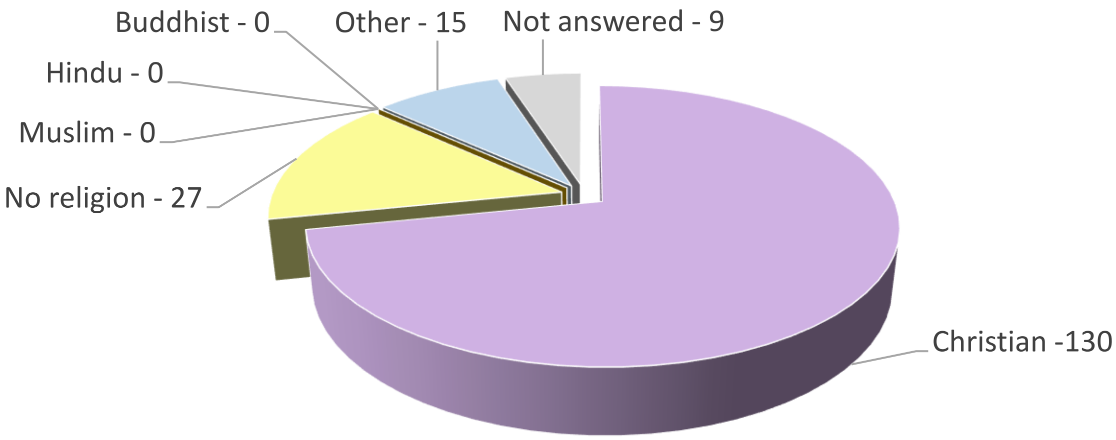
Appendix E – Age-groups of those referred to in the survey answers



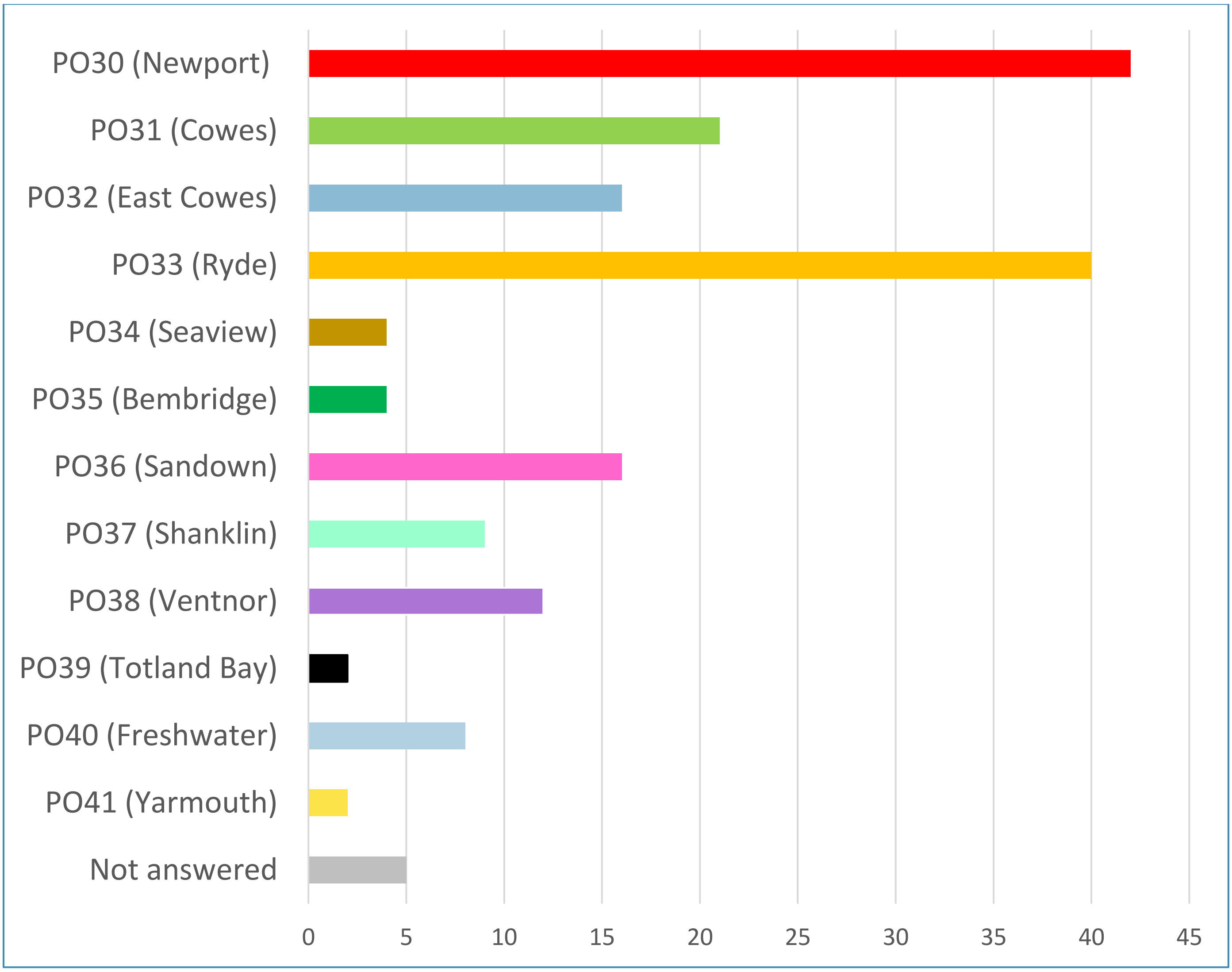
Appendix F – Gender of those referred to in the survey answers



Appendix G – Religion of those referred to in the survey answers



Appendix H – Postcode areas of those referred to in the survey answers



Appendix I – Text of Healthwatch Isle of Wight's Care at Home questionnaire

SURVEY – Care at Home

Healthwatch Isle of Wight is an independent local "watchdog" and signposting service. It works with decision-makers and service providers to help improve health and social care services on the Island.

"Care at Home" is a theme Healthwatch Isle of Wight is looking at in 2016. We would like to hear about your experiences.

Please take a few minutes to fill in this questionnaire. We want an up-to-date picture, so in all questions (except section 7) please answer only about your experience **over the last two years**.

Please read the information sheet about the survey before starting. ***If you have not received this, or have any further questions, please contact Healthwatch Isle of Wight on 01983 608608 or visit our website***

Also, please use the above contact details if you need this form in another format or version, or would like help completing it.

The questionnaire should take no longer than 15-20 minutes to fill in. The closing date is **29th July 2016**

Thank You!

1 – Overall

How have you had experience of care at home services? *(please tick one)*

Used homecare myself	A relative used services	A friend used services	Other
☐	☐	☐	☐

Was your experience of care at home short term (up to three months) or longer term? *(please tick one)*

Short-term	Long-term
☐	☐

If your experience was through a relative or friend using services, would you describe yourself as an *UNPAID CARER* for that person? (*please tick one*)

Yes	No
☐	☐

NOTE: In the questions that follow, the questions are addressed to the person who has received care (i.e. using the word “you”). If your answers are about care received by someone else, we will know this from information given on this page.

2 – Types of care received

Which of the following have you been helped with by care workers?
(please tick as many as apply)

Preparing and eating food ☐

Personal care (e.g. getting up, dressing, having a bath) ☐

Going out (e.g. shopping or appointments) ☐

Equipment (e.g. an emergency alarm) ☐

Medicine or tablets ☐

General housework ☐

Money & bills ☐

Keeping in touch with family or friends ☐

Phone calls or letters ☐

Something else *(please describe)*…………………………………………………………………

If you wish, please name the agency or company who has provided care at home for you (if more than one, please include as many as you have used)

3 – Preparing and eating food

(Please go to the next page if this does not apply to you)

Has help with food and drink been provided at ***suitable times***?

Always	Usually	Occasionally	Never
☐	☐	☐	☐

Has a ***choice*** been given about what you ate or drank?

Always	Usually	Occasionally	Never
☐	☐	☐	☐

* *

Has the help with food and drink been ***appropriate*** for you?

Always	Usually	Occasionally	Never
☐	☐	☐	☐

Have your individual ***dietary needs*** taken notice of?

Always	Usually	Occasionally	Never
☐	☐	☐	☐

*Please add any **further comments** below about help with food and drink:*

4 – Personal care (e.g. getting up, dressing, having a bath)

(Please go to the next page if this does not apply to you)

Has personal care been provided in an ***appropriate way*** for you?

Always	Usually	Occasionally	Never
☐	☐	☐	☐

Have staff ***explained*** when starting a task, the help they were about to provide?

Always	Usually	Occasionally	Never
☐	☐	☐	☐

* *

Have you been given as much ***privacy*** with personal care as you required?

Always	Usually	Occasionally	Never
☐	☐	☐	☐

Have you been given the chance to do some personal care tasks ***independently*** if you wished?

Always	Usually	Occasionally	Never
☐	☐	☐	☐

*Please add any **further comments** below about help with personal care:*

5 – Experiences of staff

(Please answer as many or few as you wish)

Have care workers arrived at a ***predictable time*** for each visit?

Every time	*Generally*	*Sometimes*	*Rarely/Never*
☐	☐	☐	☐

How often has a ***familiar care worker*** arrived, who you had met before?

Every time	*Generally*	*Sometimes*	*Rarely/Never*
☐	☐	☐	☐

If there was a ***new care worker,*** have they introduced themselves to you?

Every time	*Generally*	*Sometimes*	*Rarely/Never*
☐	☐	☐	☐

*Please add any **further comments** below on experiences of staff:*

6 – You as an individual

(Please answer as many or few as you wish)

Have care workers called you ***by the name*** you would wish them to use?

Every time	*Generally*	*Sometimes*	*Rarely/Never*
☐	☐	☐	☐

Could you ***understand*** what care workers said, and could they understand you?

Every time	*Generally*	*Sometimes*	*Rarely/Never*
☐	☐	☐	☐

Has care been given in a way that suits your ***preferences and/or beliefs?***

Every time	*Generally*	*Sometimes*	*Rarely/Never*
☐	☐	☐	☐

*Please add any **further comments** below on being treated as an individual:*

7 – Organising care

(Please answer as many or few as you wish)

How easy or difficult was it to ***arrange*** care at home when you first needed it?

Very easy	Quite easy	Quite difficult	Very difficult
☐	☐	☐	☐

If you remember which year this was, please tell us here: ……………………………….

Which of these ***gave any help*** arranging care at home: (*tick as many as apply*)

I arranged care myself	☐	A friend	☐
A family member	☐	A social worker	☐

Other, please explain………………………………………………………………………………

How easy or difficult was it to organise ***payment*** for care at home?

Very easy	Quite easy	Quite difficult	Very difficult
☐	☐	☐	☐

*Please add any **further comments** below on setting up care at home:*

8 – Discussing how it is all going

(Please answer as many or few as you wish)

How easy or difficult is it to ***contact someone*** to talk about the care being provided?

Very easy	Quite easy	Quite difficult	Very difficult
☐	☐	☐	☐

Who do you contact if something needs to be discussed about care at home?

Care agency or company ☐ Social worker ☐

Other (please say who)……………………………………………………………………..

How often are things ***sorted out*** if a problem is raised about care at home?

Every time	*Generally*	*Sometimes*	*Rarely/Never*	*Not applicable*
☐	☐	☐	☐	☐

*Please add any **further comments** below on discussing care at home:*

9 – Any other comments about Care at Home

10 – How is your care at home paid for?

I pay for it	Paid for by Council	Mixed - self and Council	Not sure
☐	☐	☐	☐

11 - About the person receiving care at home

Tick the box to let us know the first part of your/their postcode:

	Please tick one:
PO30 (Newport)	☐
PO31 (Cowes)	☐
PO32 (East Cowes)	☐
PO33 (Ryde)	☐
PO34 (Seaview)	☐
PO35 (Bembridge)	☐
PO36 (Sandown)	☐
PO37 (Shanklin)	☐
PO38 (Ventnor)	☐
PO39 (Totland Bay)	☐
PO40 (Freshwater)	☐
PO41 (Yarmouth)	☐

Are you/they? **Male** ☐ **Female** ☐ **Other** ☐

Age Group:
18 – 34 ☐
35 - 50 ☐
51 - 64 ☐
65 - 79 ☐
80 – 89 ☐
90 or over ☐

Religion:
No religion ☐ **Hindu** ☐
Christian ☐ **Muslim** ☐
Buddhist ☐ **Other** ☐

- ***FURTHER CONTACT***

Healthwatch Isle of Wight is giving people a choice about whether or not to give details of their name and address. It is completely optional – answers will be recorded in exactly the same way whether or not we know the person's name.

However, if you would like to know more about this survey, or keep in touch about the results, please fill in the contact form below. It will be detached from the rest of the questionnaire when received, so your name will not be linked to the answers you gave.

Name: …………………………………………………………….

Address: …………………………………………………………….

…………………………………………………………………..

……………………………………………… **Postcode:** …………………………..

Telephone number: …………………………………………………………

If you would like to discuss more about the survey tick here: ☐

To be sent news of the survey when complete, tick here: ☐

To receive regular updates about Healthwatch I.W. tick here: ☐

(*Tick as many or as few as you wish)

NAMES WILL BE STORED ON A SECURE DATABASE,
AND WILL NOT SHARED WITH ANY OTHER ORGANISATION

This is an anonymous survey – names of the people taking part will not be recorded next to the answers.

Comments will be recorded on a secure data system and may be quoted in reports to service providers.

PLEASE RETURN TO THE FOLLOWING ADDRESS

by Friday 29th July 2016:

Healthwatch Isle of Wight
FREEPOST RTGR-BKRU-KUEL
Riverside Centre
The Quay
Newport, Isle of Wight
PO30 2QR

Thank you for filling in this questionnaire!