
Lifetime Care and Support Authority

2010 Participant Satisfaction Survey Report

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Date: 3 February 2011
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Executive Summary

Overall Satisfaction with the Scheme and Services Remains High

A vast majority (83%) is satisfied to some extent with how the Scheme meets needs, and this is unchanged from 2009 (84%). This level meets and exceeds the standard benchmark of 75% for customer and staff satisfaction surveys. Further, for each of eleven services (including case management, attendant care, and physiotherapy) at least 80% reported they were satisfied to some extent. This is similar to the 2009 results in which the corresponding figure is 75%.

The 2010 findings build on the 2009 research which identified a strong feeling of gratitude and good will among participants and their families towards the Authority even in cases where there were issues still to be resolved, for example, with service providers.

This goodwill is reflected also in the strong survey response rate (74.5%) and the very low overall refusal rate (4%).

Improvements to the Authority

Overall the data on interactions with the Authority and possible improvements are consistent with those of 2009. This is likely to be because the suggested improvements relate to systems and practices. The time course for any changes to systems and practices that have resulted from the 2009 survey is likely to extend beyond the 2010 survey period.

Over one third (39%) feel that no improvements to the Authority are necessary, while 59% specified improvements. Improvements come from asking all respondents for their suggestions as well from understanding reasons why respondents experience problems with the Authority (20%). Improvements fall into two main groups: (1) Decreasing delays with approvals and access to services; (2) Increasing or improving communication.

(1) Decreasing Delays with Approvals and Access to Services

Unprompted, 17% of all respondents suggest that approvals and access to services speed up. Later in the questionnaire respondents were given a prompted question: 42% agreed to some extent that 'there are now long delays waiting for services to be approved by Lifetime Care and Support'. Given the requirement for LTCS to respond to requests within 10 days of receiving them, it may be that delays from service providers are misattributed to the Authority. Nonetheless it is a significant issue.

(2) Increasing or Improving Communication/Contact

Approximately a quarter (24%) suggest improving or increasing communication or contact. While the case manager is usually the main contact, some people still want or expect personal contact with the Authority through their coordinator especially when there are problems with services (including problems with their case manager).

As found in the 2009 research, a phone call every 2 to 3 months to 'check-in' would be sufficient and may help to clarify the Authority's role and approvals processes.

Initial Contact

The NPI (Initial Nominated Person) was asked about the initial contact with the Authority through the coordinator. Of the 84% of NPIs that remembered the initial contact, almost all (96%) are satisfied to some extent. This is well above a 75% benchmark.

Almost three-quarters (73%) report that there are no improvements necessary. However, building on the results from the 2009 research where NPIs reported that the trauma at the time interfered with retaining information given in the meetings, it seems sensible to suggest that information is repeated, perhaps in a hard copy format, at around 3 months after the initial contact, when the shock of the situation has subsided somewhat.

Written Communication

Respondents were asked to indicate their most preferred method to receive information from the Authority. As for 2009, the top three are brochures mailed (41%), verbally via the case manager (31%), and brochures emailed (23%). No respondent chose the LTCS website as their most preferred method of communication.

Resolution of Problems with the Authority

A large majority (80%) reported there had been no problems with the Authority *in the last 3 months* while one fifth (20%) reported there had been problems such as delays. This latter figure is relatively low. However to the extent those delays with approvals are misattributed to the Authority, this estimate may be inflated.

Over half (54%) of those who had had problems with the Authority do not expect the problem will be sorted out. As mentioned above, this is likely to be because the issues are more to do with systems and practices rather than the resolution of a one-off problem.

Contacts and Role Delineation

Nearly all (93%) have or have had a case manager. A majority (84%) report they have a coordinator, although 80% recognised their coordinator's name.

However, 79% of the 2010 population who are *new* to the Scheme (and were not part of the 2009 survey) were aware that they have a coordinator and while still a large majority, this figure is significantly lower than the 2009 figure of 85%.

Those with both a case manager and a coordinator were asked which of these people they would contact for each of eight scenarios. The case manager role is pivotal as over two-thirds (67%) said they would contact their case manager if they had problems with a service provider. Case managers are also the preferred contact for providing information on the types of services funded by the Authority (52%),

for making a complaint about a service provider (78%) or helping to organise medical appointments (84%).

There is no scenario for which Coordinators are more likely than case managers to be the contact.

Improvements to Case Manager Role

Nearly three-quarters (73%) feel no improvements are necessary. This is in accordance with the 88% satisfaction rating found for case management/ case managers.

However, more contact or communication was suggested by approximately one in eight respondents (13%).

Improvements to Coordinator Role

Approximately half (48%) felt no improvements are necessary, and only one in twenty (6%) felt they could not suggest any improvements as they had little contact with their coordinator, if any. The main suggestion for improvement is more or regular contact (29%), which overlaps with the communication improvements to the Authority itself. 'Other' improvements are to give more information on guidelines and appropriate services.

It is worth noting here that nearly two-thirds (64%) agree to some extent that the coordinator treats the participant as an individual. A further fifth (20%) either 'Don't know' (13%) or are undecided (7%) and this is most likely due to a lack of contact.

Resolving Problems with Services

Just over a quarter (28%) reported there had been problems with services in the last 3 months, and 71% reported there had been no problems. Reported problems included issues with attendant care, delays with approval or access to services, equipment supply or performance problems and inadequate case management. Of those who reported problems in the last 3 months, approximately two in five reported that some or all problems had been sorted out. A further third expect their problems will be sorted out, but just over a quarter (27%) do not expect the problems will be sorted out.

Attendant Care

Just over one third (36%) had received attendant care services in the last 3 months. The vast majority of these agreed that their carer(s) usually arrive on time (93%) and again a large majority agreed they are available when they need them (90%).

However half (53%) of the 56 participants receiving attendant care in the last 3 months had had a problem at some stage with their carer or carers. The top three issues were that (1) carers were not sufficiently skilled or trained, (2) that they do not follow instructions and (3) they do not turn up or are unreliable. A large majority (87%) reported that the problem(s) had been dealt with either 'completely' or 'somewhat' to their satisfaction. It is interesting that 90% of those reporting attendant care was received in the last 3 months said that they were satisfied to some extent with the service, even though

53% had had a problem at some point. It is most likely that those who had had a problem express overall satisfaction with attendant care because the problem was resolved to some extent.

Knowledge of Services

Respondents were read a list of eleven services and items and asked which of these they believe the Authority might pay for, for its clients. Overall respondents have a good understanding. For example, while 90% said the Authority might pay for clinical psychology or psychiatry, only 14% thought it might pay for home insurance. Income is the item with the highest proportion reporting 'Don't Know' (17%).

However, 38% agree to some extent that 'I need more information from the Lifetime Care and Support Authority'.

Goals and Community Engagement

Approximately half (53%) believe the participant has goals set in a plan. This is a significant decrease from the 2009 figure of 71%. However, 61% of the 2010 population who are new to the Scheme (and were not part of the 2009 survey) reported having goals. This suggests that much of the overall decrease from 2009 to 2010 is due to a lack of goals for those who have been in the Scheme longer.

Approximately half (53%) reported participants had help setting their goals and nearly a third (30%) reported that they had set their goals themselves. For participants who had had help setting their goals (n=44), their level of involvement was rated as 'the right amount' in nearly all cases (97%), while 3% felt they should have had 'more involvement'. For participants who reported they had set their goals themselves their level of involvement was always rated as 'the right amount'.

Participants' community engagement was measured via four statements.

- A large majority (84%) agrees to some extent that "Considering my stage of rehabilitation, I am happy with how much I get out into the community."
- Over a third (37%) agrees to some extent that they are "progressing too slowly with their goals".
- Three-quarters (76%) agree to some extent that they "feel part of a community" and this is a significantly greater than the corresponding figure for 2009 (64%).
- Just under three-quarters (73%) agree to some extent that they "have enough time with friends" and this is significantly greater than the corresponding figure for 2009 (60%).

Conclusion

Satisfaction levels for the Scheme and services consistently exceed benchmark levels. Generally, problems with services seem to be resolved to the extent that they leave at least an 80% satisfaction rate for each of the eleven services tested.

Some delays with service delivery may be misattributed to the Authority due to a lack of knowledge of the Authority's processes.

However, for the cases where there are particular problems with service providers or the Authority, the effects on the participants and their families are magnified by the nature of the injuries and traumatic circumstances. As a result, the consequences often elicit intense emotional responses in the participant and their families.

Summary Table

Key Measure	2010	2009	Comparison
Overall Satisfaction with Scheme	83%	84%	Stable
Minimum Net Satisfaction Rating for a Service	80%	75%	Stable
Problems with service providers in the last 3 months	28%	27%	Stable
- Some or all problems sorted out	39%	40%	Stable
Problems with the Authority in the last 3 months	20%	21%	Stable
- Some or all problems sorted out	19%	17%	Stable
Unprompted Awareness of Coordinators	84%	85%	Stable
Net Satisfaction with Initial LTCS Contact	96%	92%	Stable
Per cent with CLP Goals	53%	71%	Decrease
Per cent Agree <i>'The Lifetime Care and Support Coordinator treats me/ participant as an individual'</i>	68%	64%	Stable
Per cent Agree <i>'I need more information from the Lifetime Care and Support Authority'</i>	38%	42%	Stable
Per cent Agree <i>'There are now long delays waiting for services to be approved by Lifetime Care and Support'</i>	42%	44%	Stable
Per cent Agree <i>'I feel part of a community'</i>	76%	64%	Increase
Per cent Agree <i>'I feel I have enough time with friends'</i>	73%	60%	Increase
Per cent Agree <i>'I feel I'm progressing too slowly with my goals (in my Community Living Plan)'</i>	37%	29%	Stable
Per cent Agree <i>'Considering my stage of rehabilitation, I am happy with how much I get out into the community'</i>	84%	80%	Stable
Had a problem with attendant care	53%	50%	Stable
Most Preferred Communication Method is Brochure emailed or mailed	64%	71%	Stable

Recommendations

There are two groups of recommendations: (A) recommendations for the Authority and Scheme (B) recommendations for the survey process and analysis.

(A) Recommendations For The Authority And Scheme

Recommendation 1: Establish A Secondary Contact For All Participants For The Purpose Of Maintaining Contact Details. It is proposed that this secondary contact is simply used to source contact details rather than receive information or assist in organising treatments, rehabilitation or care. This would be particularly helpful where direct communication between the main contact and the Authority is infrequent and ensures contact details for the participant do not become out-dated. This will also assist the longitudinal survey process maximise re-contact and response rates.

Recommendation 2: Improve Communication Between The Coordinator And Participant / Nominated Person

- (a) **Coordinators make phone contact with the participant or nominated person every 2 to 3 months to 'check in' and face-to-face contact every 6 months where reasonable and appropriate.** There are several reasons for this (e.g. it will make the participant feel that they are treated as an individual, will promote 'trouble-shooting', will help to make people feel comfortable contacting their coordinator when they need to, assist the coordinator to understand the participant's level of community engagement. Contacts at regular intervals could be a task created in Navigator.
- (b) **Coordinators / the Authority repeat written information given at the initial contact at 3 months post discharge** when the shock of the situation has subsided sufficiently that information can be processed by the nominated person. This should be irrespective of whether the participant is subsequently the main contact for the Authority.
- (c) **Provide the coordinator's contact details as a fridge magnet/ SMS.** This is more likely to be kept than a business card. This could be given again as part of the repeated information package mentioned above.
- (d) **Provide a one-page brochure** (perhaps laminated) that communicates who should be contacted for different queries or problems.

Recommendation 3: Consider Communication And Education For Participants And Their Families On The Request And Approval Process. The survey results suggest there is a common misperception regarding both how requests are assessed and the Authority's role in the delays experienced with access to services and equipment. It may be helpful to indicate on the Certificate setting out approved services the date of receipt of the request. In this way the recipient will be able to identify the time taken by the Authority to process the request and separate that from the time taken to receive the request.

Recommendation 4: Reduce Delays In The Reimbursements Process.

Recommendation 5: Improve Regional And Remote Service Provision. While participants from all areas of NSW are supported by the Scheme, there are geographic areas for which knowledge of service providers is patchy or appropriate expertise is unavailable. Case managers sometimes request services for which there are no service providers within 100km of the participant. Currently, finding a service provider may then be left to the participant or their nominated person. The Authority should identify the existing service providers with appropriate expertise in regional and remote areas and consider strategies to increase service provider expertise in brain and spinal cord injury in regional and remote areas.

(B) Recommendations For The Satisfaction Survey

Recommendation 6: Reduce The Average Survey Duration To A Maximum Of 25 Minutes. It is appropriate to review the survey instruments at a time closer to the next survey so that the process is informed by any changes in the Authority's practice or policy. At this review it will be helpful to categorise the questions as 'core' (repeated as part of the longitudinal program so that changes can be identified across time) and part of 'modules' (questions that may be included only for 1 or 2 surveys or only every 2 or 3 years).

Recommendation 7: Retain The Dual Interview Procedure and Small Telephone Interviewing Team

The dual interview option allows both the participant and their nominated person to make evaluations, comments and suggestions, where the participant is not the main contact, and so optimises the feedback and input from participants. For the proportion of the sample for which there are dual data, priority may be given to the NPs data when assessing KPI's . However even for these data items, assessment of participants' data allows for the exploration of the range of responses to a particular issue, capturing as many suggested improvements as possible and locating the participant as fundamental to the survey.

Given the traumatised population, and the greater need for flexibility in the survey process to accommodate varying levels of functioning, it is recommended that a small team of expert interviewers undertake interviewing, as was the case for the 2009 survey. While a telephone methodology is employed, the interview is effectively a structured in-depth interview which requires different skills than a standard market research CATI interview.

Background and Objectives

Introduction

The Lifetime Care and Support Authority (the Authority) required a survey to measure satisfaction with the Lifetime Care and Support Scheme (the Scheme) to enable assessment of the Scheme's performance for quality improvement purposes. This document sets out the objectives, methodology, results and recommendations of the 2010 Participant Satisfaction Survey.

The 2010 Participant Satisfaction Survey is the second survey in a longitudinal research program. In 2009 the survey methodology and instruments and analyses were developed to take account of the variety of functioning associated with participants' injury-related needs. The variety of functioning relates to participants' possible fatigue, anterograde memory issues, the level of insight into difficulties, comprehension, motivational issues and interpersonal skills. The flexible approach developed in 2009 was employed in the present survey to maximise the involvement of participants themselves.

The Scheme began for children injured in motor accidents from 1 October 2006 and began for adults from 1 October 2007. For the purpose of the survey children are defined as less than 16 years of age and adults are defined as 16 years and over. People who are eligible for the Scheme have a spinal cord injury, moderate to severe brain injury, multiple amputations, severe burns, or are legally blind as a result of the motor accident.

The Authority indicated that participants and/ or their nominated persons were eligible to be involved in the satisfaction research if the participant had been supported by the Scheme for a minimum of 6 months. There are two advantages to the 6 month minimum.

- a) 6 months is a sufficiently long time to have participated in order to reflect and provide feedback;
- b) At least some confusion associated with traumatic brain injury (TBI) will have settled in the 6 months post-injury making it more likely that the participant will be able to respond to the survey directly.

A qualitative stage was not required for 2010 as this survey followed on from the 2009 developmental research and since there had been no policy or program changes that necessitated changes to the survey instruments. The present document summarises the main findings from the 2010 research. The 2009 developmental research has previously been reported in three documents: *Participant Satisfaction Survey - Summary of In-depth Interviews* (1 September, 2009) and *Participant Satisfaction Survey - Summary of Cognitive Testing Results* (30 September, 2009) and *Participant Satisfaction Survey Report* (2 February, 2010).

Background and Objectives

Research Objectives

The overall objective is to deliver feedback from participants and/ or their nominated persons to allow the Authority to evaluate the Scheme's performance for quality improvement purposes. As for the 2009 survey, the present research addresses research issues reflecting the three key themes identified by the Authority.

One: Treat me as an individual

1. The overall satisfaction with how the Scheme meets participants' needs.
2. Participants' involvement in the development of, and awareness of, their last Community Living Plan (CLP).
3. The awareness of Coordinators and the degree to which Coordinators are perceived to treat Participants as individuals.

Two: Resolve my issues

4. Satisfaction with services received in the last 3 months.
5. The identification and resolution of any problems with Authority-funded services, including attendant care.
6. The identification and resolution of any problems with the Authority itself.
7. The understanding of what services the Authority does and does not pay for.
8. The knowledge and perceptions of the LTCS Coordinator and Case Manager roles.
9. Possible improvements to Authority-funded services, the Coordinator role and Case Manager roles.

Three: Keep me up-to-date

10. The usefulness and clarity of communications from the Authority.
11. The preferred means of communication from the Authority.

Further objectives include the following:

12. Understanding participants' level of community participation/ engagement.
13. Maximise the validity of data i.e. making sure that each questions is understood as intended and that the response codes are meaningful to the target population.
14. Maximise the response rate, and so minimize non-response bias, while being sensitive to the needs of participants and their nominated persons.
15. Maximise the direct participation of the Scheme participants themselves where possible
16. Minimise the impact of the research on the welfare of the respondents.
17. Cast the approach to surveying this population in terms of the International Classification of Functioning, Disability and Health model.

Quantitative Methodology

Target Population and Response Sets

The target population is defined as participants who:

- have been in the scheme for 6 months or longer,
- are no longer hospitalized,
- are not in custody or incarcerated, and
- are residing in either Australia or New Zealand.

One participant opted-out of the survey.

There are two groups of data items for this target population. Broadly, one set of data items covers communication with the Authority and service providers and management and access to services, and another set of data items relates to receiving services and progressing with goals.

Main Contact Response Set = Participants or their NPs: For the majority of data items which relate to the performance of the Authority, Scheme and service providers (e.g. evaluation of communication) the target respondent is those individuals who deal with the Authority and associated service providers. People in this population will be either the participant or their nominated person.

Participant-Only Response Set = Participants: Other data items are those only the participant can address (e.g. rating the extent to which they feel part of a community). For these items the target respondents are always the participants.

Telephone Methodology

The telephone methodology was retained for the following benefits:

- ✓ The best data quality and population coverage for cost while also offering
- ✓ Flexibility in the interviewing process in order to meet participants' needs (e.g. suspensions due to fatigue);
- ✓ The Telephone Interpreter Service NSW (TIS) is available to cater to languages other than English on a case by case basis and was used at recruitment and interviewing as required;
- ✓ The interviewer can build rapport with the respondent while allowing the respondent to maintain anonymity.

Up to 8 calls were made in an attempt to make initial contact for each respondent. These calls were made across different times of the day and across different days of the week to maximise contact rates. If no contact was made this was classified as 'no contact'. Where more than one phone number was available for a respondent, each phone number was tried up to 8 times. Where contact was made an interview was either completed, an appointment made or a call-back was scheduled. If an appointment was made more than 3 days hence then a reminder call was made the day before. Up to 6 call-backs were made to complete an interview once contact was made with a participant and / or their NP. When a language requirement was known from the outset, TIS was used for each call attempt. If a language requirement was not known at the outset but became apparent at the initial contact then TIS was used.

Timeline

The Authority made initial contact with participants and any nominated persons by a primary approach letter. The letters and information sheets were sent on 10 September, 2010, prior to any research. The letter allowed for participants or their NPs to opt out of the research program. One participant opted out. Contact details were then passed to the researchers.

These documents are given in Appendix A.

The survey field time was 23 October to 10 December 2010. The initial schedule had the field work finishing by 23 November. However an extension was agreed to allow (i) a face-to-face interview with a nominated person who was unable to easily communicate by phone (the interviewer travelled to the respondent) (ii) follow-up with other participants who had been unavailable in the early part of the survey period.

Survey Instrument Development

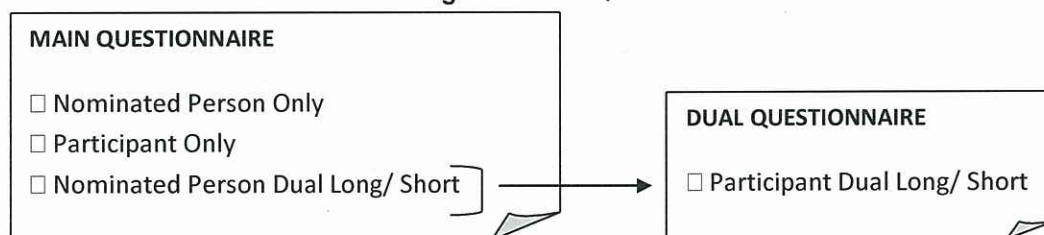
In 2009 the development of the survey instruments was informed by two qualitative research phases and involved close consultation with the Authority and input from a consultant neuropsychologist.

The survey instruments were virtually unchanged from 2009. The questionnaires were designed to have both core questions (to accommodate the need to compare across surveys) and modules (that can change across survey years to reflect any changes in research objectives). There were no changes to modules given that the research objectives remained unchanged: the Scheme is still relatively new so the initial cohort of participants have and systems have not changed sufficiently to warrant different data items .

The single change for 2010 was to modify a question regarding problems with attendant care to allow those previously surveyed to reflect on the last 12 months only (i.e. 2009/10 rather than previous periods for which they had already been surveyed).

Two questionnaires are the main questionnaire and dual questionnaire (Figure 1).

Figure 1: Two Questionnaires



The two questionnaires and recruitment script are given in Appendix B. The dual questionnaire was a sub-set of questions from the main questionnaire.

The topics for each questionnaire type are summarised in Figure 2 below.

Figure 2: The Main and Dual Questionnaire Topics

Section	Topic	Questionnaire	
		MAIN	DUAL
Section A	Overall Satisfaction	✓	✓
Section B	Services (incl. Initial LTCS contact)	✓	Partial
Section C	Contacts: Case Manager and Coordinator Roles	✓	✗
Section D	Community Living Plan Goals	✓	Partial
Section E	Perceptions & Expectations	Partial	Partial
Section F	Attendant Care	✓	✓
Section G	Communication	✓	Long only
Section H	Open-ended Comment	✓	✓

There were three ways of completing interviews and in each case a main questionnaire was administered.

- i. A 'Participant Only' format was where the participant was the main contact themselves and so completed the main survey.
- ii. A 'Nominated Person Only' format was where a nominated person was the main contact and completed the main survey on behalf of the participant where the participant was unable.
- iii. A 'Dual Long' or 'Dual Short' format involved the nominated person completing the main survey and the participant completing a dual questionnaire. In the dual format the nominated person always completed their interview first so that some factual information was available from their interview to tailor the participant's interview. This allowed the participant's interview to be shorter. Usually a dual short interview was conducted unless at recruitment the NP indicated that the participant also dealt with the Authority and service providers and that it was appropriate to interview the participant.

The recruitment script guided the selection of the appropriate interview format and respondent(s).

There are two sets of questions to note:

1. There were four statements regarding community engagement that were only asked of participants (questions E1d to E1g). There was one question in Section D (D2) that was asked only of participants. For those interviews where a nominated person only was interviewed these data are not available. Data were obtained from 101 participants.

2. For new participants only, a few questions were asked of the nominated person (Nominated person initial or NPI) who helped the participant at the time of injury. These questions were on the main survey (questions C6a to C6d) but these questions did not need to be answered prior to a participant's dual interview as they had no bearing on that interview's content. The NP and NPI were often the same person.

Recruitment and Questionnaire Administration

A small team of four expert interviewers who had conducted the 2009 survey also conducted the recruitment and interviewing for the 2010 survey. Two of these were the researchers on the project (one of whom is the project director).

Each interviewer was allocated sample so that a household was only ever contacted by one person.

Recruitment

A recruitment script was structured to determine who was the most appropriate person or persons to interview. Wherever possible the participant themselves was involved and in 72% of cases the participant was interviewed either alone (Participant only) or as part of a dual interview format (Dual Long/ Short).

The recruitment script logic first determined who mainly dealt with the Authority and service providers: this would either be the participant (P) themselves or a nominated person (NP). If the Participant was the main contact then a screening question was given to determine the extent of their awareness. If they indicated that they knew 'a little' or 'a lot' then they selected which of the three interview formats suited their needs. If the NP was the main contact then they were asked about the appropriateness of involving the Participant in a telephone interview. If appropriate then a dual interview was completed. If inappropriate then an NP only interview was completed. For the paediatric group (the Under 16 year's group) the respondent was always the nominated person. For participants who were 16-17 years at the time of interviewing, parental consent was sought prior to interviews.

Survey Administration

- The survey administration allowed for suspensions. In practice there were no suspensions in 2010..
- Comprehension of survey questions appeared good. There were no terminations due to an inability to understand the questions or response codes. For one participant a satisfaction scale was revised to be binary – satisfied/ dissatisfied.
- Disinhibition. There was one instance where a participant was quite disinhibited. However they were able to complete a dual short interview.
- Distress. There were several instances where respondents were distressed. The interviewer voiced appropriate concern and always gave the respondent the option of suspending or terminating the interview. No respondents terminated due to distress as they wished to express their concerns and/ or experiences. Three notifications of potential crisis situations were made to the Authority with the respondents' consents.

- **Duration.** The average durations for main and dual questionnaires were 26 minutes and 12 minutes respectively. As in 2009, several nominated persons needed to communicate their experiences in narrative form prior to settling to a survey format of discrete questions. Given the sensitive topic and traumatised population, the interviewer listened and voiced appropriate concern rather than rushing the respondent. The longest main survey was 80 minutes. The longest dual survey was 59 minutes.
- **TIS.** Ten contacts required interpreters spanning six different languages. Five of these contacts went on to complete an interview.

Sample Design and Weights

The target population for the longitudinal program has the same definition as that for the 2009 research except that those participants who were excluded for 2009 due to prior involvement in research are included from 2010.

The 2009 research found widespread goodwill towards the Authority and Scheme which contributed to the low refusal rate and high response rate. For this population an annual survey of every participant and/ or their NP would not produce unwanted burden. However, the quantitative interview process is more like an in-depth interview than a simple market research telephone interview and the sample size is therefore managed to feasibly retain this necessary methodology with a specialised interview team in a reasonable 5 to 10 week fieldwork timeframe.

Sample Rules

Sampling rules can be expressed from two points of view - either from the perspective of a given participant or from the point of view of a survey in a given year. The rules below give firstly the participants' perspective and then the survey year perspective.

SAMPLING RULES - Participants' perspective

- No participant will be surveyed in their first 6 months in the scheme.
- Half of the participants who have been in the scheme for more than 18 months and up to 60 months will be sampled only ONCE in that 3.5 year period and the other half will be sampled TWICE in that period, in order to preserve sample balance.
- Participants who have been in the scheme for more than 60 months will be sampled ONCE every 5 years.

SAMPLING RULES - Survey year perspective

- In each year a survey of participants will be conducted in October and November.
- Participants who have been in the scheme from between 0 and 6 months on September 30 of the survey year will NOT be surveyed in that year.
- Participants who have been in the scheme from more than 6 and up to 18 months on September 30 of the survey year will ALL be surveyed in that year (a census).

- 1 in 3 of participants who have been in the scheme for more than 18 months and up to 60 months on September 30 of the survey year will be surveyed in that year.
- 1 in 5 of participants who have been in the scheme for more than 60 months on September 30 of the survey year will be surveyed in that year.

For 2010 the resulting selected sample is given in figure 3 below.

Figure 3 Selected Sample

		BI	SCI & Other	Total	
New	Population	100	26	126	→ Census of New Participants
	Selected	100	26	126	
	Achieved	79	20	99	
Repeat	Population	144	48	192	→ Sample of Repeat Participants
	Selected	46	16	62	
	Achieved	28	13	41	
Total	Population	244	74	318	
	Selected	146	42	188	
	Achieved	107	33	140	

Achieved Sample and Weighting

Figure 4 summarises the target population, unweighted sample and weighted sample by the key variables of age, sex, injury type and area. Weights were applied with respect to age, gender, area category, Injury type, and repeat status (new, repeat).

Figure 4 Sample and Main Target Population by Key Variables

Variable Name	Variable Level	Unweighted Sample	Weighted Sample	Target Population
Age: Females	Female under 16	5	11	12
	Female 16-25	9	24	27
	Female 26-45	15	21	24
	Female over 45	16	40	33
	Total Females	45	96	96
Age: Males	Male under 16	5	14	20
	Male 16-25	29	78	72
	Male 26-45	32	82	73
	Male over 45	29	48	57
	Total Males	95	222	222
Grand Total	140	318	318	
Injury Type	Brain Injury	107	244	244
	Spinal Chord Injury & Other	33	74	74
	Total	140	318	318
Area	Sydney Metropolitan	58	140	140
	Rest of NSW and Other	82	178	178
	Total	140	318	318

Note that values for the weighted sample are not always equal to the population values at the cell level for age by sex. For example there were 16 females over 45 years in the sample (in aggregate across Injury type, area and repeat status) and these were weighted up to 40 rather than the 33 in the population. The reason for this is that empty cells in the sample for which there were cases in the population were collapsed with similar sample cells for weighting purposes. The effect of this is to impute the value of an achieved cell for an empty cell that has the same characteristics for most but not all variables. For example, the population has 7 females in with a SCI that reside in the Rest of NSW and have repeat status and are over 16 years across three ages categories: one 16-25 years, three 25-45 years and three over 45 years. However the sample yielded only one respondent in one of these age categories for this type of respondent (SCI & Other, Rest of NSW, Repeat). Therefore the responses of this respondent were weighted up to represent the total of seven in the population. This was done by collapsing across the age categories.

Further collapses were investigated to minimise cell level discrepancies between the weight sample and target population values. However given the sample available and the heterogeneous nature of the population trying to improve one set of weights disrupted others. Figure 4 above indicates the best

weighting solution for the 2010 data.¹

¹ RIM weighting was not possible due to the number of empty cells in the population.

Survey Outcomes and Achieved Sample

Unique IDs: The selected sample of 188 is made up of those individuals who deal with the Authority and associated service providers for eligible participants. We will refer to each of these 188 as a unique ID given that there may be more than one respondent (e.g. from a dual interview).

One participant opted out of the survey.

Figure 5 summarises the call outcomes for the 188 cases in the selected sample.

Figure 5: Call Outcomes

Outcome	Count
Interview	140
Refusals	7
Unavailable during interview period	16
No contact	8
No valid telephone number could be sourced	11
No one suitable to interview	5
Opt-out	1
Total	188

There were only 7 refusals. The main reason given for refusal was disinterest. Together with the 1 opt-out this is a 4% refusal rate, which is extremely low. This unchanged from the 2009 survey.

Sixteen participants were unavailable during the survey period. This included participants with whom appointments were made up to four times but could not be kept by respondents for varying reasons.

For five participants there was no one suitable to interview. An example was where the participant was unable to be interviewed themselves, and their nominated person was away on holidays.

Interviews were achieved with 140 participants and/ or their nominated persons.

Two of the participant-only interviews were 'quick' interviews. An example was where the participant was very keen to do the survey but was moderately distressed (for reasons unconnected to the survey) and so completed a 5 minute quick version of the main questionnaire.

Total Respondents: For a given ID there can be more than one respondent. In total there are 163 respondents or unit records covering the 140 unique IDs. Figure 6 summarises unit records by respondent type and questionnaire against unique IDs.

Figure 6: Summary of Respondents and Unique IDs

Interview Type	Questionnaire	Respondent Type	Respondent Count	Unique ID Count
NP Only	Main	NP	39	39
P Only	Main	P	78	78
Dual (Long)	Main	NP	5	5
	Dual	P	5	
Dual (Short)	Main	NP	18	18
	Dual	P	18	
Total			163	140

In 101 of the 130 non-paediatric unique IDs the participant was interviewed either alone or as part of a dual interview format.

- This equates to a 78% participation rate in interviews for participants.

It is worth noting that sometimes the NP was not the NPI (the person who helped the participant at the time of the injury). In these cases the NPI was contacted where appropriate. In some cases the Participant or NP refused on behalf of the NPI (e.g. due to ill-health, relationship breakdown). If the NPI are included in a count of respondents the total is greater than 163.

Response Rates

- A 74.5% response rate was achieved in the quantitative survey. This is a very strong response rate as for the 2009 survey (78%).

The response rate is given by the number of achieved interviews (140) divided by the number of possible interviews (188).

Main Survey Results: Introduction

Given the two target populations and the interview structures there are two types of data presentation in this report.

- (1) Main Questionnaire data for the Main Target Population (n=140) are the main data presented in this report.
- (2) Participants' data for D1, E1(d) to E1(g) are presented (n=101).

The main questionnaire data are examined by key variables of age, sex, area and injury type where appropriate. The four age categories are: under 16 years, 16 to 25 years, 26 to 45 years, over 45 years. The two area categories are: Sydney and Other, where interstate and NZ were included in the Other category. The two injury type categories are BI and SCI & Other. Injury Severity was also investigated with respect to key variables. The two categories are More Severe and Less Severe. More severe: CANS 5, 6 & 7 for TBI and C1-C8 for SCI. Less severe: CANS 1-4 for TBI and all others for SCI.

Also, as 2010 is the second year in a longitudinal research program the data will be compared with that for 2009 for key variables in order to track the performance of the Scheme.

Comparisons will be:

- 2009 population estimates with 2010 population estimates.
- 2009 participants (all) with 2010 'new' participants to understand how Scheme entry experiences may change across time.

The presentation of results removes details that could possibly identify the participant. For example if a respondent mentions their coordinator's name then 'coordinator' is used instead. Similarly if a NP refers to a participant by name then 'participant' is used instead in any verbatim responses in the report and data file.

Rounded figures are presented. Therefore totals may not add exactly to 100% for single-response items.

Two-tailed t-tests for independent samples with $\alpha=0.05$ are used to test differences between proportions for sub-group comparisons, using a finite population correction factor. Only significant results (i.e. where $p<0.05$) are reported.

The main questionnaire was answered by either the Participant or NP and so had alternative wordings to suit the respondent. When presenting these data the term 'main respondent' will be used. Consequently the participant may be both the respondent and subject in a statement (e.g. "The main *respondent* was then asked to rate their satisfaction or dissatisfaction with each service the participant received" – the participant and respondent may be the same person for a given case).

Verbatim responses are included as part of this report. In part this is to make coded data meaningful, but also to:

- (a) convey the varied and specific nature of issues that are summarised by grouped data presentation;
- (b) explore the range of responses to open-ended, unprompted questions;
- (b) communicate the emotional intensity of responses in this survey.

Main Survey Results: Overall Satisfaction (Section A)

SATISFACTION WITH THE SCHEME

At the beginning of the survey respondents were asked to indicate their overall level of satisfaction or dissatisfaction with how the Lifetime Care and Support Scheme meets participant needs. A rating scale was used where 1= Extremely Dissatisfied and 7=Extremely Satisfied. A mid-point of 'Neither satisfied nor dissatisfied' was not read out.²

The level of overall satisfaction is high at 83%.

- 83% is Satisfied (32%), Very Satisfied (23%) or Extremely Satisfied (28%) with how the Scheme meets needs (see Figure 7 'Total' below).
- Only 13% is Dissatisfied (5%), Very Dissatisfied (4%) or Extremely Dissatisfied (5%) with how the Scheme meets needs.

Only 3% is 'Neither Satisfied nor Dissatisfied', and only 1% said Don't Know.

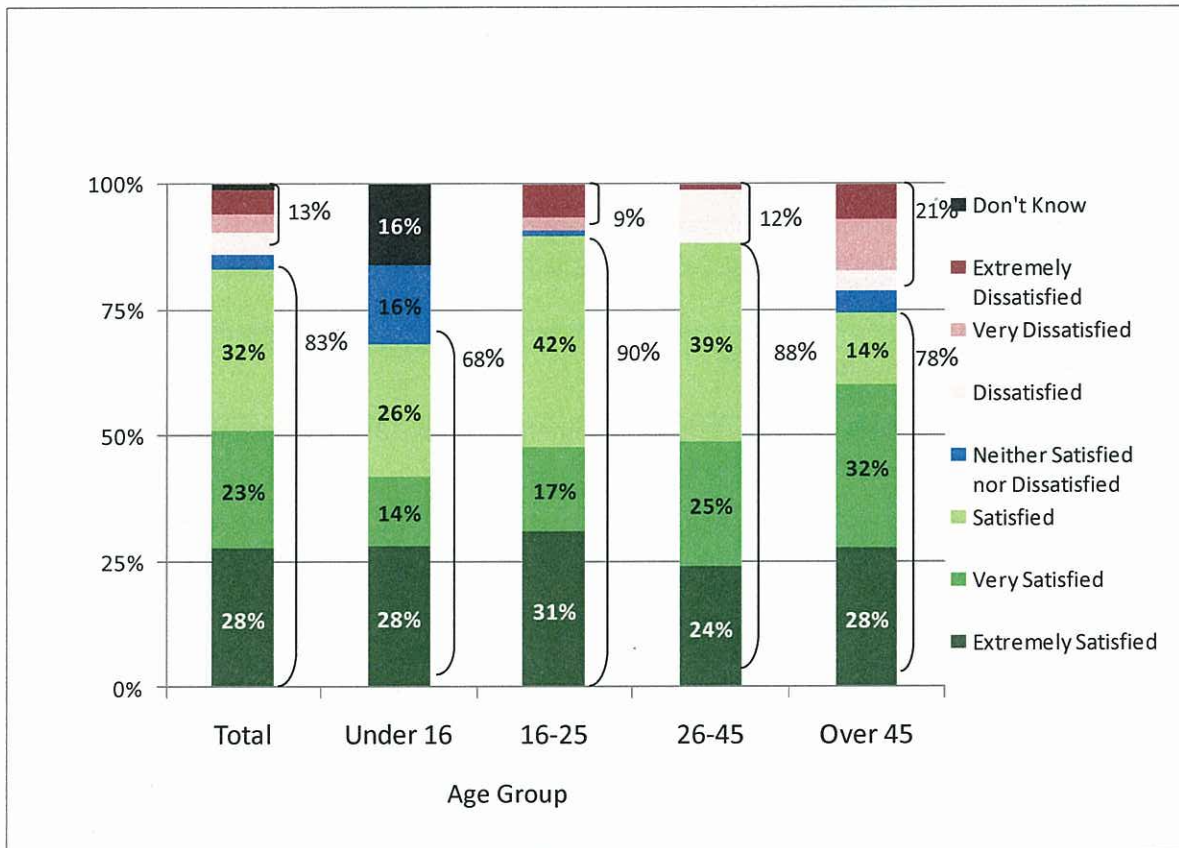
Seventy-five per cent is a standard benchmark for customer or staff satisfaction surveys and the 83% overall satisfaction substantially exceeds this.

Age The participant's age affects satisfaction with how the Scheme meets needs. Figure 7 shows that the Under 16 years age group shows a lower net satisfaction (Extremely Satisfied, Very Satisfied, and Satisfied responses aggregated) than did the other age groups (68% for the under 16 year group, 90% for the 16-25% group, 88% for the 26 to 45 year group and 78% for the over 45 year group.

Net satisfaction and net dissatisfaction are robust with respect to Injury type, Area, Sex and Injury Severity variables.

² The scale was used in a two-step manner to be manageable for participants (see the Main Questionnaire in Appendix B). The 2009 qualitative research found such gratitude and satisfaction with the Scheme that it was appropriate to 'stretch' the scale to allow finer discriminations. The inclusion of 'extremely satisfied' and 'extremely dissatisfied' in the scale is to provide a more sensitive measure of satisfaction to better detect any differences between sub-groups (and changes across time when the survey is repeated), where they exist.

Figure 7: Overall Satisfaction (A1)



Q A1: I'd like you to think about the Lifetime Care and Support Scheme. The Scheme covers treatment, rehabilitation and care needs. Are you satisfied or dissatisfied with how the Lifetime Care and Support Scheme meets [your /participant's name's] needs?

IF SATISFIED: And are you satisfied, very satisfied or extremely satisfied?

IF DISSATISFIED: And are you dissatisfied, very dissatisfied or extremely dissatisfied?

Total Base=140

Under 16=10

16-25=38

26-45=47

Over 45=45

2009-2010 Comparison

Overall satisfaction with the Scheme does not vary from 2009 to 2010.

Figure 8: Overall Satisfaction By Survey Year (A1)

Overall Satisfaction with the Scheme (A1)	2010 Base=140	2009 Base=112	Comparison
	83%	84%	Stable

REASONS FOR DISSATISFACTION WITH THE SCHEME

Only 13% is either Dissatisfied (5%), Very Dissatisfied (4%) or Extremely Dissatisfied (5%) with how the Scheme meets needs. Those who indicated they were dissatisfied to some extent were asked why (A2). Figure 9 gives the results as a per cent of those dissatisfied to some extent and also as a per cent of all main respondents.

Figure 9: Reasons For Dissatisfaction With How the Scheme Meets Needs (A2)

Reason For Dissatisfaction	Per cent of Dissatisfied & Neither n=21	Per Cent of All Main Respondents n=140
Delays/ Difficulty with approval process	56%	8%
Needs not met/ Service providers inadequate	83%	13%
Issue with Coordinator	20%	3%

Q A2: And why are you dissatisfied?

Bases given in figure

- 'Needs not met/ Service providers inadequate ' is the top reason for dissatisfaction with the Scheme (83% of those dissatisfied to some extent or 13% of all main respondents).

An example of a comment in this category is:

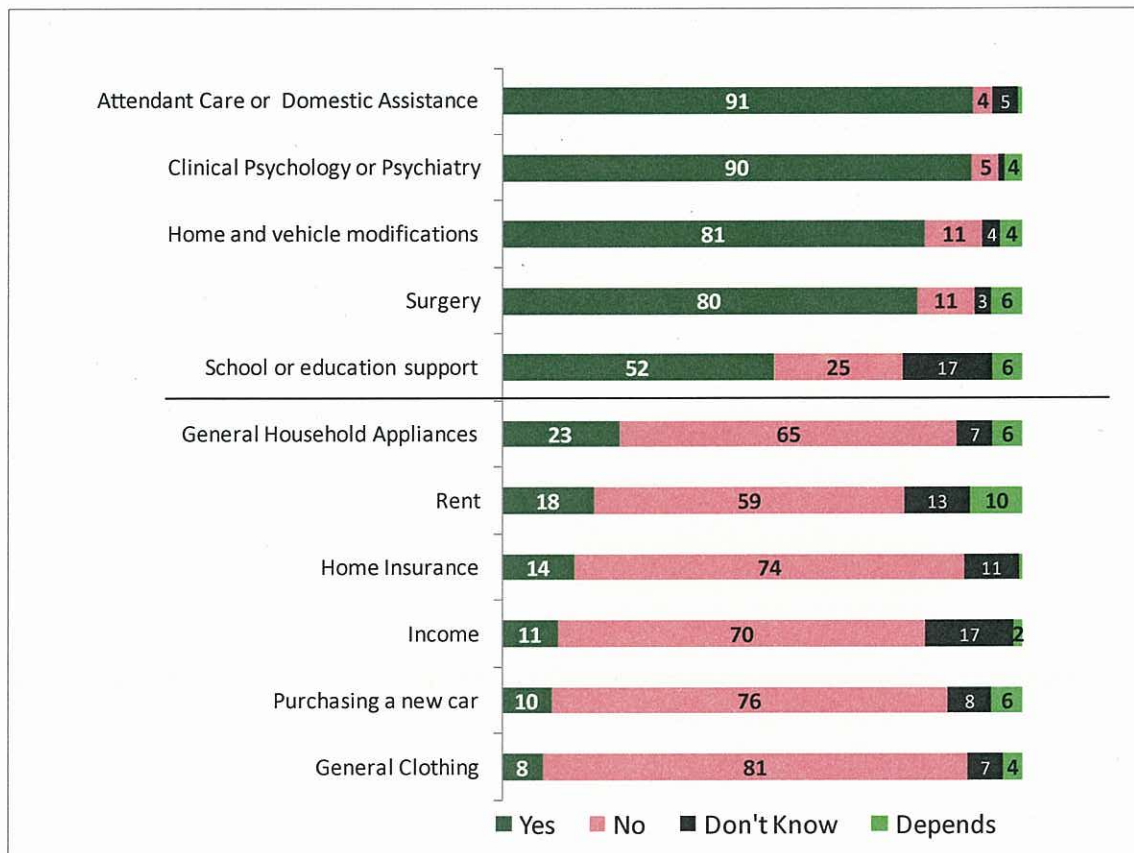
'The Scheme pays for a lot but there's minimal improvement and [participant] is still not back to work. The case manager is poor- too few appointments and too few apart.' (Sydney, NP)

Main Survey Results: Services (Section B)

RESPONDENTS' UNDERSTANDING OF WHAT SERVICES THE AUTHORITY MIGHT PAY FOR

Main respondents were read a list of eleven services and items and asked which of these they believe the Authority might pay for for its clients. Figure 10 shows the results split the eleven into two distinct groups suggesting that overall these respondents have a good understanding of what the Authority will and will not pay for. 'School or education support', 'Income' and 'rent' are the items with the highest proportion reporting 'Don't Know' (17%, 17%, and 13% respectively).

Figure 10 Services the Authority Might Pay For (B1)



Q B1: Which of the following services do you believe the Lifetime Care and Support Authority might pay for, for its clients? Please answer yes or no to each.

Total Base=136 to 137

There are sub-group differences for some items.

- All respondents in the Under 16 year's category indicated that the Authority pays for School or Education Support. For other age groups the proportion that either does not know or does not believe the Authority pays for School or Education Support is at least one third: 16-25 years=33%, 26-45 years=40% and over 45 years=54%.

- All those in the SCI and Other group (100%) believed the Authority might pay for Home and Vehicle Modifications, compared with 73% of those in the BI group.

SERVICES RECEIVED IN THE LAST 3 MONTHS

Main respondents were read a list of services and indicated which of these the participant had received in the last *three months* (B2a and B3a). Not all respondents were asked about driving lessons: 17% were excluded from this item due to the participant’s age (under 17) or initial injury severity (if initial CANS score = 6 or greater; if SCI is C1, 2, 3, 4, or 5). Figure 11 summarises the results.

Figure 11 Services Received in the Last 3 months (B2a and B3a)



Q B2a: Now I’m going to read another list of services. I’d like you to think back over the last 3 months. Please tell me which services [you have had / (participants name) has had] that were paid for by the Lifetime Care and Support Authority.

Total Base=137 for all except item (j) Driving lessons base =256.

The top three services received by a majority of participants in the last 3 month period were:

1. Case manager (90%)
2. Physiotherapy (69%)
3. Occupational Therapy (60%)

The bottom three services received by a minority of participants in the last 3 month period were:

1. Home or vehicle modifications (15%)
2. Driving lessons (14%)
3. Vocational or education assistance (13%)

Nearly two in five (39% participants had received attendant care in the last 3 months.

SATISFACTION WITH SERVICES RECEIVED IN THE LAST 3 MONTHS

The main respondent was then asked to rate their satisfaction or dissatisfaction with each service received (B2b and B3b). Figure 11 shows that for each service at least 80% reported they were Satisfied, Very Satisfied or Extremely Satisfied.

Figure 12 Satisfaction With Services (B3a)

Service	TOTAL SATISFIED	Extremely Satisfied	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied	Extremely Dissatisfied	TOTAL DISSATISFIED	Don't Know
h. Driving lessons (Base=20)	100	38	45	16	0	0	0	0	0
a. Equipment (Base=100)	94	20	40	34	4	0	1	5	1
e. Physiotherapy (Base=100)	93	26	33	34	1	2	4	7	0
g. Cab charges & other travel (Base=72)	90	26	29	36	8	0	2	10	0
d. Vocational/education assistance (Base=22)	90	27	42	21	0	10	0	10	0
f. Attendant care (Base=57)	90	20	43	27	2	1	8	10	0
i. Exercise program/ gym membership (Base=65)	89	24	42	24	10	0	0	10	1
k. Clinical psychology/ Psychiatry (Base=74)	89	20	35	34	11	0	0	11	0
c. Occupational therapy (Base=79)	89	27	38	24	6	5	0	11	0
b. Case manager or management (Base=126)	88	34	30	24	4	6	0	10	2
j. Home or Vehicle Modifications (Base=27)	80	12	27	40	11	2	7	20	0

Q B3a: Thinking firstly about [FIRST MENTION AT B2a] are you satisfied or dissatisfied with it/ them?

IF SATISFIED: And are you satisfied, very satisfied or extremely satisfied?

IF DISSATISFIED: And are you dissatisfied, very dissatisfied or extremely dissatisfied?

Bases given in figure for each service.

Injury severity was investigated with respect to satisfaction ratings for eight of the eleven services.^{3,4} Those in the More Severe group had a higher level of net satisfaction than did those in the Less Severe group for five of the eight services tested (Figure 13).

Figure 13 Total Satisfaction With Services by Injury Severity (B3a)

Services for which 'More Severe' group have significantly greater total satisfaction than do 'Less Severe' group	Less Severe Total Satisfied: Per cent	More Severe Total Satisfied: Per cent
Case manager or management (Base=105)	57%	81%
Equipment (Base=48)	47%	80%
Exercise program/ gym membership (Base=57)	51%	87%
Clinical psychology/ Psychiatry (Base=63)	47%	71%
Cab charges & other travel (Base=61)	85%	99%

Q B3a: Thinking firstly about [FIRST MENTION AT B2a] are you satisfied or dissatisfied with it/ them?

IF SATISFIED: And are you satisfied, very satisfied or extremely satisfied?

IF DISSATISFIED: And are you dissatisfied, very dissatisfied or extremely dissatisfied?

Bases given in figure for each service.

Eight main respondents reported at least one other service received in addition to those listed in B2a. For all but one service the rating was Satisfied, Very Satisfied or Extremely Satisfied. These additional services included dental, dietician, eye specialist, rheumatologist, medications, and lawn mowing.

2009-2010 Comparison

The minimum net satisfaction with any service does not vary from 2009 to 2010.

Figure 14: Net Satisfaction Score Minimum By Survey Year (B3a)

Minimum Total Satisfaction	2010 Base=140	2009 Base=112	Comparison
	80%	75%	Stable

³ It is worth noting that injury severity did not effect overall satisfaction ratings (A1).

⁴ For three of the services (driving lessons, home and vehicle modifications, vocational/ educational assistance) there were too few qualifying respondents in the more severe category.

PROBLEMS WITH SERVICES RECEIVED IN THE LAST 3 MONTHS

Main respondents were asked if there had been any problems with Authority-funded services in the last 3 months (B4a).

- **71% reported there had been no problems with Authority-funded services** in the last 3 months, 28% reported there had been problems, and 1% said ‘Don’t Know’ (see Figure 15).

This overall result shows no change from 2009 data. However, unlike 2009 data this proportion does not vary by area.

Age Those in the groups spanning 45 years or under are *less* likely than those in the Over 45 years group to report recent problems with services (see Figure 12). This contrasts with the 2009 results where the Under 16 year’s group was most likely to report that they had recent problems with services.

Figure 15: Problems With Services By Age (B4a)

Problem with Services?	Total Base=140	Under 16 Years Base=10	16-25 Years Base=38	26-45 Years Base=47	Over 45 Years Base=45
Yes	28%	16%	27%	24%	39%
No	71%	84%	73%	76%	59%
Don’t Know	3%	0%	1%	0%	2%
<i>Total</i>	<i>100%</i>	<i>100%</i>	<i>100%</i>	<i>100%</i>	<i>100%</i>

Q B4a: In the last 3 months [have you had / has (participant’s name) had] any problems with any services that were paid for by the Lifetime Care and Support Authority?

Bases given in figure.

Injury Type While a higher proportion of those in the SCI & Other group reported problems with services in the last 3 months (38%) compared to the BI group (25%), this difference did not reach significance (p=0.07) (Figure 16).

Figure 16: Problems With Services By Injury Type(B4a)

Problem with Services?	Total Base=140	BI Per cent Base=107	SCI & Other Per cent Base=33
Yes	28%	25%	38%
No	71%	74%	59%
Don’t Know	1%	1%	3%
<i>Total</i>	<i>100%</i>	<i>100%</i>	<i>100%</i>

Q B4a: In the last 3 months [have you had / has (participant’s name) had] any problems with any services that were paid for by the Lifetime Care and Support Authority?

Bases given in figure

Injury Severity A greater proportion of those in the Less Severe group reported problems with services in the last 3 months (38%) than did those in the More Severe group (25%) (Figure 17).

Figure 17: Problems With Services By Injury Severity (B4a)

Problem with Services?	Total	Less Severe Per cent <i>Base=79</i>	More Severe Per cent <i>Base=40</i>
Yes	28%	33%	18%
No	71%	66%	81%
Don't Know	1%	0%	2%%
Total	100%	100%	100

Q B4a: In the last 3 months [have you had / has (participant's name) had] any problems with any services that were paid for by the Lifetime Care and Support Authority?

Bases given in figure

2009-2010 Comparison

The proportion that reports problems with services in the last 3 months does not vary from 2009 to 2010.

Figure 18: Problems with Services By Survey Year (B4a)

Problem with Services? Per cent 'Yes'	2010 <i>Base=140</i>	2009 <i>Base=112</i>	Comparison
	28%	27%	Stable

Respondents were then asked what problems they had had (B4b). There was a wide range of very specific problems reported, although there are four categories that emerged (see Figure 19).

Figure 19: Problems With Services (B4b)

Problem Type	Per Cent Of Those Who Experienced Problems <i>Base=41</i>	Per Cent Of All Main Respondents <i>Base=140</i>
Problems with Attendant Care/ Domestic Assistance	27%	7%
Delays with approval for/ access to services	35%	8%
Equipment supply/ performance problems	19%	9%
Inadequate Case Manager/ Management	22%	5%
Other	47%	16%

Q B4b: What problems were they?

Bases given in figure

- Delays with approval for or access to services (35%) and problems with attendant care or domestic assistance (27%) are the two biggest categories, as they were in 2009.

Problems with attendant care will be discussed in the *Main Results: Attendant Care (Section F)*.

While the resolution of delays with services is more relevant perhaps to issues with the Authority (B7), **delays with approval or access to services** came up in response to this question on problems with services.

Equipment supply/ performance problems are related to delays, as in the case of a child who grows out of the wheel chair by the time it has been delivered.

Examples of comments on **inadequate case management** are:

The Case manager is very poor – there’s miscommunication [between CM and participant and partner]. There are delays in approvals, infrequent services. Services are mismanaged. (Sydney, NP)

Problems in the **Other** category include:

I had to change physio as the first physio became less interested in helping me, and made sessions shorter. (P, Rest of NSW & Other).

Current OT is slack and lazy. He is new. The initial one was terrific. (P, Rest of NSW & Other).

Those main respondents who experienced problems with Authority-funded services in the last 3 months were asked whether the problem(s) was sorted out (B4c).

- Only 27% reported all problems were sorted out (Figure 20). Just over a quarter (27%) does not expect the problems will be sorted out and 1% don't know.

Figure 20: Resolution of Problems With Service Providers (B4c)

Resolution of Problem	Per cent
Yes - All problems were sorted out	27%
Yes - Some problems were sorted out	11%
No - Problems not sorted out but expect they will be	33%
No – Problems not sorted out and don't expect they will be	27%
Don't know	1%
Total	100

Q B4c: Was/ were the problem(s) sorted out?

PROBE FOR 'SOME OR ALL' OF PROBLEMS SORTED OUT, PROBE FOR WHETHER THEY EXPECT UNRESOLVED PROBLEMS TO BE SORTED OUT.

Base=41

Seven per cent (11%) reported some problems were sorted out, and a further third (33%) expect their problems will be sorted out.

2009-2010 Comparison

The proportion that report resolution of some or all problems with services in the last 3 months does not vary from 2009 to 2010.

Figure 21: Net Satisfaction Score Minimum By Survey Year (B4c)

	2010 Base=41	2009 Base=30	Comparison
Some or All Problems Resolved	38%	40%	Stable

Those respondents who experienced problems then rated their satisfaction or dissatisfaction with how problems were resolved (B4d).

- Just under one third (31%) were satisfied to some extent with how the problem(s) was resolved, and a majority (60%) were dissatisfied to some extent (see Figure 22).

Figure 22: Satisfaction With Resolution of Problems (B4d)

Resolution of Problem	TOTAL SATISFIED	Extremely Satisfied	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied	Extremely Dissatisfied	TOTAL DISSATISFIED	Don't Know
	31%	0%	7%	24%	28%	13%	19%	60%	9%

Q B4d: Overall, are you satisfied or dissatisfied with how the [problems were / problem was] sorted out?

IF SATISFIED: And are you satisfied, very satisfied or extremely satisfied?

IF DISSATISFIED: And are you dissatisfied, very dissatisfied or extremely dissatisfied?

Base=29

The main reason for dissatisfaction is that they were **still waiting for a resolution** (75% or 15 of the 20 respondents) (B4e).

Other reasons include:

Not being told before or afterwards what is happening. No calls, no documents, just [services] taken away. No explanation. Very dissatisfied. (P, Rest of NSW & Other)

Strongly disbelieve that correct treatment has occurred. No neurologist brought in from outset. Brain injury coupled with existing illness nearly killed her. (NP, Sydney)

All main respondents were asked who they would contact *if* they had any problems with a service (B5).

- Just over two-thirds (67%) indicated they would contact their case manager, but a further 8% indicated they would contact their case manager in addition to an alternative (5% case manager or coordinator, 3% case manager or other) (Figure 23).
- Sixteen per cent (20%) would contact their LTCS coordinator only.

'Other' contacts were the service provider themselves or 'my doctor'. Only 1% 'don't know' who they would contact.

Figure 23: Who Would You Contact If You Had Any Problems With A Service Provider? (B5)

Contact	Per cent
Case Manager	67%
Coordinator	20%
Case Manager or Coordinator	5%
Case Manager or other	3%
Other	5%
Don't Know	1%
<i>Total</i>	<i>100</i>

Q B5: Who would you contact if you had any problems with a service you received? PROBE: Do you know what their position title is?

Base=137

All main respondents were asked how any of the services (apart from attendant care) could be improved to better meet needs (B6).

- Just over half (53%) reported no improvements were necessary or that they could not think of any improvements, while 12% 'Don't Know' (see Figure 24).

Figure 24: Improvements To Services Apart From Attendant Care (B6)

Improvements to Services	Per cent
No improvements necessary/ suggested	53%
Resolution of specific issue	26%
Speed up approvals/ reduce delays	11%
Improving/ increasing communication/ contact	8%
Other	17%
Don't know	2%

Q B6 [Apart from attendant care], how could any of the services be improved to better meet [your needs/ (participant's name) needs]?

Base=136

Twenty-six per cent (26%) had a very specific issue to resolve (e.g. 'Should have been a warning that I was about to exceed my script allowance - my script was frozen.'). Fourteen per cent (11%) cited 'Speed

up approvals/ reduce delays' as an area for improvement and 8% suggested improving or increasing communication or contact.

Examples of **improving or increasing communication or contact** are the following:

'More internal liaison with the LTCS - one says one thing and someone else seems to be contradicting it.'

Don't know if delays are at least in part caused by CM. She does not respond in a timely way - doesn't want to put things in writing.

Examples of **Other** improvements are:

'Just the vocational guidance could be better. Having a better understanding of what the jobs require and supporting the client in a trial period perhaps'

'Service Providers need to be more educated in the ways that LTCS plans things and needs to be approached'

'Don't know what other services P is entitled to.'

PROBLEMS WITH THE AUTHORITY IN THE LAST 3 MONTHS

Respondents were asked if there had been any problems with the Authority in the last 3 months (B7a).

- **80% reported there had been no problems with the Authority in the last 3 months**, while 20% reported there had been such problems.

Sex Those in the Female group (30%) were more likely to have had a problem with the Authority in the last 3 months than were those in the Male group (15%). This is the reverse of the pattern seen in 2009 (Males: 24%, Females: 15%).

2009-2010 Comparison

The proportion that reports problems with the Authority in the last 3 months does not vary from 2009 to 2010.

Figure 25: Problems with the Authority by Survey Years (B7a)

Problem with the Authority? Per cent 'Yes'	2010 Base=140	2009 Base=112	Comparison
	20%	21%	Stable

Respondents were then asked what problems they had had (B7b).

- Almost a quarter (24%) of those who had experienced problems with the Authority cited 'Delays/ Time taken for approvals', and another quarter (24%) cited issues with 'Reimbursements/ Payments'. Nearly one in five (18%) cited insufficient services (see Figure 26).

Figure 26: Problems With The Authority (B7b)

Problem Type	Per Cent Of Those Who Experienced Problems <i>Base=34</i>	Per Cent Of All Main Respondents <i>Base=140</i>
Delays	24%	5%
Reimbursement/ Payments	24%	5%
Insufficient Services	18%	4%
Coordinator Issues	12%	2%
CM issues	10%	2%
Other	13%	2%

Q B7b What problems did you have?
Base=136

Other responses included the following:

'The lack of compassion - treat us like we are trying to rip off the system. LTCS have made it difficult at every point.'

Those respondents who experienced problems with the Authority in the last 3 months were asked whether the problem(s) was sorted out (B7c).

- Over half (54%) do not expect the problems will be sorted out and 8% 'Don't know' (see Figure 27).

Only 17% reported all problems were sorted out and a further 25% do expect their problems will be resolved.

Figure 27: Resolution of Problems with Authority (B7c)

Resolution	Per cent
Yes - All problems were sorted out	17%
Yes - Some problems were sorted out	2%
No - Problems not sorted out but expect they will be	25%
No - Problems not sorted out and don't expect they will be	54%
Don't know	1%
Total	100%

Q B7c Were the problems sorted out / Was the problem sorted out?
PROBE FOR 'SOME OR ALL' OF PROBLEMS SORTED OUT, PROBE FOR WHETHER THEY EXPECT UNRESOLVED PROBLEMS TO BE SORTED OUT.
Base=34

2009-2010 Comparison

The proportion that report resolution of some or all problems with the Authority in the last 3 months does not vary from 2009 to 2010.

Figure 28: Resolution of Problems with the Authority by Survey Years (B7c)

	2010 Base=34	2009 Base=24	Comparison
Some or All Problems Resolved	19%	17%	Stable

These respondents rated their satisfaction with how problems were resolved. One in five (19%) are satisfied to some extent with how the problem(s) was resolved, but almost three-quarters (72%) are dissatisfied to some extent (see Figure 29).

Figure 29: Satisfaction With Resolution Of Problems With The Authority (B7d)

Resolution	TOTAL SATISFIED	Extremely Satisfied	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied	Extremely Dissatisfied	TOTAL DISSATISFIED	Don't Know
	19%	0%	3%	16%	37%	7%	28%	72%	9%

Q B7d Overall, are you satisfied or dissatisfied with how the problem(s) was/ were sorted out?
 IF SATISFIED: And are you satisfied, very satisfied or extremely satisfied?
 IF DISSATISFIED: And are you dissatisfied, very dissatisfied or extremely dissatisfied?
 Base=34

Fourteen (14) of the 23 dissatisfied respondents were still waiting for the problem to be sorted. The remaining respondents cited a range of other reasons for dissatisfaction including:

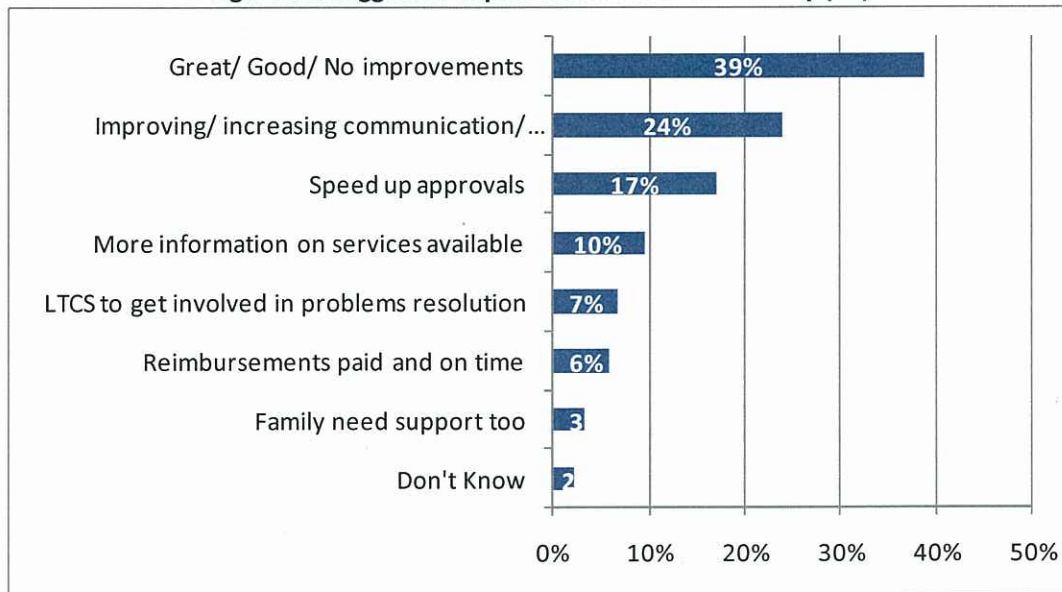
- *'Large reimbursements create a huge stress level, especially as I am on the pension and my bank account gets very low if reimbursements don't happen on time.'*
- *'They want to get me off the books as soon as possible I think. They are becoming more difficult, especially about small things.'*

IMPROVEMENTS TO THE AUTHORITY

Respondents were asked how they thought the Authority could improve (B8). Given the high level of gratitude for the Scheme and services, they were reassured that even small improvements are worth knowing.

- Over one third (39%) of respondents feel that no improvements are necessary, and 2% do not know,
- 59% specified improvements (see Figure 30).

Figure 30: Suggested Improvements to the Authority (B8)



Q B8 And how could Lifetime Care and Support improve? Even small improvements are worth knowing.
[PROBE: And is there anything else?]
Base=137

The top three suggestions for improvement are:

- Improving or increasing communication/ contact (24%).
- Speeding up approvals (17%)
- More information on services available (10%)

The top two suggestions were investigated for sub-group differences. The only difference is that a greater proportion of those in the Female group (29%) than Male group (12%) suggested speeding up approvals.

Main Survey Results: Contacts (Section C)

AWARENESS OF COORDINATORS

Respondents were asked if they had a LTCS Coordinator (C1).

- The vast majority (84%) reported that they had a coordinator (see Figure 31).

Figure 31 Awareness of Coordinators (C1)

		C1: Do you have a Coordinator?			
		Yes	No	DK	Total
		84%	9%	6%	100%
Recognition of Coordinator's name (C2a, C3)	Yes	75%	3%	2%	80%
	No	1%	6%	3%	10%
	DK	9%	0%	0%	9%

Q C1 [Do you / Does (participant's name)] have a Lifetime Care and Support Coordinator?

Q C2a Is their name [READ OUT LTCS COORDINATOR NAME]? / C3 Do you know the name [READ OUT LTCS COORDINATOR NAME]?

C1 Base=137

A minority (16%) either did not know (6%) or reported that they did not have a coordinator (9%).

All respondents, whether or not they knew they had a coordinator, were then read out their coordinator's name and asked if they recognised it (C2a, C2b).

- Overall 80% recognised their coordinator's name.

Fifteen (15) of the 140 respondents both believed they did not have a coordinator or did not know if they did *and* also did not recognise their coordinator's name. These respondents were asked if they had ever had a coordinator. Three (3) said 'No' and twelve (12) said 'Don't know'.

Injury Type Those in the BI group were more likely to say either they did not have a coordinator or did not know if they did (19%) than were those in the SCI & Other group (5%).

Age Those in the Over 45 years age group are the least likely to say either they did not have a coordinator or did not know if they did (6%) than are those in the other age groups (Under 16 years: 26%; 16-25 years: 19%; 25-45 years:18%).

2009-2010 Comparison

The proportion that reports they have a Coordinator does not vary from 2009 to 2010.

Figure 32: Unprompted Awareness of Coordinators by Survey Years (C1)

Unprompted Awareness of Coordinators	2010 <i>Base=112</i>	2009 <i>Base=140</i>	Comparison
	84%	85%	Stable

However, 79% of new respondents in 2010 (those that were not part of the 2009 survey population) were aware that they have a Coordinator. While this is still a large majority it is significantly less than the 2009 figure.

AWARENESS OF CASE MANAGERS

Respondents were asked if they have, or have ever had, a case manager (C5).

- Nearly all (93%) reported that they have or have had a case manager.
- A large majority (80%) report having or having had *both* a case manager and a coordinator.

ROLES OF CASE MANAGERS AND COORDINATORS

The 80% that have or have had both a case manager and coordinator were then asked which of these people they would contact for each of eight scenarios (C7a to C7g). The results are shown in Figure 33.

Figure 33 Roles Of Case Managers And Coordinators (C7)

	Case Manager	Coordinator	Either	Neither	Don't Know
a. Help organise rehabilitation or medical appointments	84%	1%	5%	9%	1%
b. Organise reimbursement for expenses	56%	34%	1%	4%	4%
c. Sort out any problems you have with services	72%	18%	7%	1%	3%
d. Provide information on the <u>types</u> of services funded by Lifetime Care and Support	52%	34%	7%	4%	3%
e. Question a decision not to approve services for your treatment, rehabilitation or care.	51%	30%	9%	3%	7%
f. Make a complaint about the Lifetime Care and Support Authority	44%	40%	8%	2%	5%
g. Make a complaint about a service provider	78%	12%	6%	2%	2%

Q C7: I am now going to read out a list of tasks. For each one please tell me who you would contact: [your/ participant's name] Coordinator or [your/ participant's name] Case Manager.

IF RESPONDENT SAYS 'I've never done that/ asked for that' THEN ASK 'If you did need someone to [statement], who would you contact? C7

Base=113

Case managers are the most likely contact for four of the tasks to do with managing services and reimbursements:

1. Help organise rehabilitation or medical appointments (84%)
2. Make a complaint about a service provider (78%)
3. Sort out any problems you have with services (72%)
4. Organise reimbursement for services (56%)

There is no scenario for which coordinators are more likely than the case managers to be the contact.

The scenario in which the proportion that would contact their case manager is similar to the proportion that would contact their coordinator is 'making a complaint about the Lifetime Care and Support Authority' (44% and 40% respectively).

CASE MANAGER IMPROVEMENTS

Those with a case manager were asked 'In what ways could your case manager improve? Even small improvements are worth knowing' (C8).

- More contact/ communication was suggested by 13% of respondents (see Figure 34),
- Nearly three-quarters (73%) felt no improvements are necessary.

Figure 34 Case Manager Improvements (C8)

Item	Per Cent
Good/Great / No improvements necessary	73%
Speed up approvals/ Lessen delays	17%
More contact / communication	13%
No comment	3%
Other	10%

Q C8: In what ways could [your/ participant's name's] Case Manager improve? Even small improvements are worth knowing.

Base=131

Seventeen per cent (17%) suggest the case manager should lessen delays/ speed up approvals for services.

Area Those in the Sydney group are more likely than those in the Rest of NSW & Other group to suggest 'more contact needed/ communication' (18% and 9% respectively).

Injury Type Those in the SCI & Other group are:

- more likely than those in the BI group to indicate 'Good/ Great/ No improvements necessary' (83% and 70% respectively),
- less likely than those in the BI group to indicate 'More contact/ Communication 5% and 16% respectively)

Sex Those in the Female group are more likely than those in the Male group to suggest 'more contact needed/ communication' (22% and 10% respectively).

An example comment from the **Other** category is:

'Be more committed and not so slack, be more aware of how the process works and what is and is not covered.'

COORDINATOR IMPROVEMENTS

Those with a coordinator were asked 'In what ways could your coordinator improve? Even small improvements are worth knowing' (C9).

- The main suggestion for improvement is more or regular contact (29%).

Some suggested a phone call from the coordinator to the main contact every 2 months or so would be beneficial not only for case management but also so the Authority can make some assessment of whether service providers are doing what the Authority is funding them to do.

- Approximately one half (48%) felt no improvements are necessary, and approximately one in twenty (6%) felt they could not suggest any improvements as they had little contact with their coordinator, if any (see Figure 35).

Figure 35 Suggested Coordinator Improvements (C9)

Item	Per Cent
Good/Great / No improvements necessary	48
More/ Regular contact	29
Don't know because had no contact	6
Other	13
Don't Know	3

Q C9: In what ways could [your/ participant's name's] Lifetime Care and Support Coordinator improve? Even small improvements are worth knowing.
Base=123

Comments in the **Other** category include the following:

'To send a schedule in the mail about when services are likely to be approved or disapproved.'

'I can't comment - I only time I have met the Coordinator was initially at hospital. Need more contact with Coordinator. Coordinator has never contacted us since initially. Previous case manager directed that I was not to contact her and the case manager reiterated this several times.'

'To send a schedule in the mail about when services are likely to be approved or disapproved.'

EVALUATION OF INITIAL CONTACT WITH INITIAL NOMINATED PERSON

The NPI (Initial Nominated Person) was asked about the initial contact with the Authority through the coordinator. For nine cases the data was missing due to refusals, illness, death, or relationship breakdown. The remaining base is n=90.

NPIs were initially asked if they remembered their first contact with the Authority through the coordinator (C6a).

- The majority (84%) of NPIs remember their first contact, while 10% do not and 6% 'Don't know'.

Those that remember were asked to rate their satisfaction or dissatisfaction with that contact (C6b).

- Almost all NPIs (96%) are satisfied to some extent (Extremely Satisfied 36%; Very Satisfied 43%; 16% Satisfied) (see Figure 36).

Figure 36: Satisfaction With Initial Contact (C6b)

C6b	Satisfaction or Dissatisfaction with initial contact	TOTAL SATISFIED	Extremely Satisfied	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied	Extremely Dissatisfied	TOTAL DISSATISFIED	Don't know
		96	38	45	13	3	0	1	4	0

Q C6b: Were you satisfied or dissatisfied with that contact?

IF SATISFIED: And are you satisfied, very satisfied or extremely satisfied?

IF DISSATISFIED: And are you dissatisfied, very dissatisfied or extremely dissatisfied?.

Base=90

The reasons given by the few who were dissatisfied to some extent were the following:

'It was by letter - very impersonal.'

'LTCS left a note at the hospital and said they would come back but they never did. In the end I had to ring.'

'We didn't want [the Participant] to be in the Scheme in the first place. We wanted to get the insurance company to pay for [the Participant's] costs.'

2009-2010 Comparison

The proportion that is satisfied to some extent with the initial contact from the Authority does not vary from 2009 to 2010.

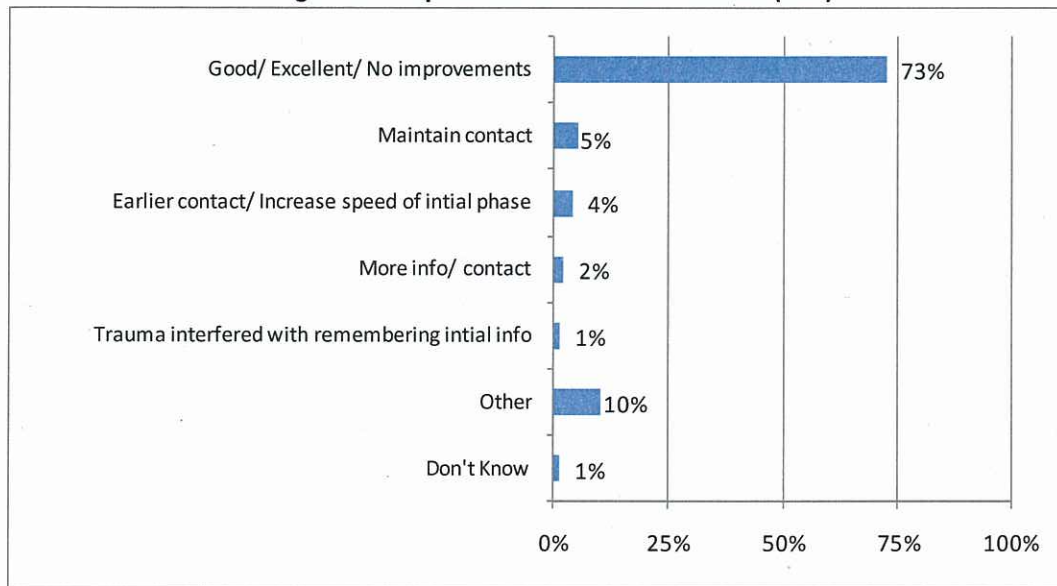
Figure 37: Initial Contact by Survey Years (C6b)

Net Satisfaction with Initial Contact	2010 Base=90	2009 Base=84	Comparison
	96%	92%	Stable

Those NPIs that remember their initial contact were asked how that contact could have been improved to better meet their own needs and the participant's needs at the time (C6d).

- Nearly three-quarters (73%) reported that there were no improvements necessary, 1% don't know (Figure 38). The remaining 26% made specific comments.

Figure 38: Improvements To Initial Contact (C6d)



Q C6d: How could this first contact have been improved to better meet your needs and [participant's name] needs (at the time)? [PROBE: And what else/ Is there anything else?].
Base=75

Five per cent (5%) suggested contact be maintained.

'Maintain contact from the initial contract - the Coordinator told us to email, but no there's no communication now - more would be appreciated.'

It may be that after the initial contact there is an expectation the coordinator will continue to initiate contact with the participant and/ or NP during treatment, rehabilitation and care rather than 'handing over' to a case manager. If this handover has been communicated in the initial contact it may not be remembered due to the trauma.

Ten per cent (10%) made other comments or suggestions, including:

'Maybe the hospital itself could be more aware of the Scheme and its availability'

'Excellent beginning, but they haven't followed up on promises.'

'Seemed complicated, the approval process. Things were not going to happen instantly. Had to go through a formal process - found that a bit overwhelming as things needed to be done straight away.'

'We were left unsure of what LTCS looks after and what work cover looks after. Still not sure, but they take care of everything.'

Main Survey Results: Community Living Plan Goals (Section D)

AWARENESS OF AND INVOLVEMENT IN SETTING CLP GOALS

Section D examined the awareness of, and the participant's level of engagement in, developing their Community Living Plan (CLP). It is noted that there is also a plan known as the Community Discharge Plan, which is developed when clients leave hospital and aims to help the client with the transition from hospital to home and the community. This may be some participant's most recent plan; however most should have had another plan developed since then. The interviewer tried to get the participant to think of their most recent plan/goals. The question wording allowed for differing terminology.

Main respondents were given the following question: "Often people in the Lifetime Care and Support Scheme have goals set as part of a plan. This plan might be known as a rehabilitation plan, a community living plan or plan for services. Do you/ does (participant's name) have any goals set in a plan?" (D1).

- **53% believe the participant has goals set in a plan**, 41% do not believe they have goals and 6% don't know (*Base=140*).

Injury Type Those in the SCI & Other group are more likely to report that the participant has goals (68%) than are those in the BI group (49%).

Sex Those in the Female group are more likely to report that the participant has goals (75%) than are those in the Male group (43%).

2009-2010 Comparison

The proportion that report that the participant has goals set in plan is significantly less in 2010 relative to 2009.

Figure 39: CLP Goals by Survey Years (D1)

	2010	2009	Comparison
Per cent with Goals	<i>Base=140</i>	<i>Base=112</i>	
	53%	71%	Decrease

However, 61% of the 2010 population who are *new* to the Scheme (and were not part of the 2009 survey population) reported having goals. This suggests that much of the overall decrease from 2009 to 2010 is due to a lack of goals for those who have been in the Scheme longer.

Participants, but not their NPs, were asked if they knew what their most recent goals are (D2). It is necessary to consider here the data from all participants, whether they completed a main questionnaire (P Only format) or a dual questionnaire (Dual Long/ Short format). There are 101 participants that responded in total. Of these:

- 93% stated they are aware of the most recent goals, 6% state they are not aware and 2% don't know (See figure 40).

Figure 40: Awareness of Most Recent Goals (D2)

Aware?	Per cent
Yes	93%
No	6%
Don't know	2%
Total	100%

Q D2: Are you aware of what your most recent goals are?
Base=58 Participants

Main respondents were asked which of three statements best describes the participant's involvement in setting goals (D3).

- Just over half (53%) reported participants had help setting their goals and just under a third (30%) reported that they had set their goals themselves (Figure 41).
- In 14% of cases the participant was not involved in setting their goals.

Figure 41: Level Of Participant Involvement In Setting Goals (D3)

Involvement Level	Per cent
All goals set by participant	30%
Participant had help setting goals	53%
Participant not involved in setting goals	14%
Don't know	4%
Total	100%

Q D3: Which of the following best describes [your/ participant's name's] involvement in setting [your / his/her] goals? READ OUT [ROTATE]

1. I set all my goals myself / He set all his goals himself/ She set all her goals herself
2. I / He/ She had help in setting my/his/her goals
3. I / He/ She was not involved in setting my/ his/ her goals
4. DON'T KNOW (DO NOT READ OUT)

Base=75

Injury Type Those in the BI group are more likely to report that the participant was *not involved* in setting the goals (19%) than are those in the SCI & Other group (4%).

Area Those in the Sydney group are more likely to report that the participant was *not involved* in setting the goals (21%) than are those in the Rest of NSW & Other group (9%).

Sex Those in the Female group are more likely to report that the participant was *not involved* in setting the goals (29%) than are those in the Male group (3%).

Main respondents were asked whether they felt the respondent should have had more involvement in setting their goals, less involvement, or whether it was the right amount of involvement (D4a, D4b). As for 2009, no respondents felt the participant should have had less involvement. If the participant had set the goals themselves (n=21) this was always rated as the right amount. For participants who had had help setting their goals (n=44), their level of involvement was rated as the right amount in 97% of cases, while 3% felt they should have had more involvement. Where the participant was not involved in setting their goals (Base=9) 70% of respondents felt the participant should have had more involvement.

The 47 participants who were themselves the person who mainly deals with the Authority and service providers, who have goals *and* who have both a case manager and coordinator, were asked who they would contact for help setting their goals, their Coordinator or their Case Manager (D5).

- 77% would ask their case manager for help setting their goals, none would ask their coordinator, 12% would ask neither, 5% would ask either and 5% do not know.

Main Survey Results: Perceptions (Section E)

Respondents were read statements and were asked to rate their agreement or disagreement with each (E1). Statements (a) to (c) relate to the Scheme itself and so were asked of main respondents who were the main contact for the Authority and service providers. Statements (d) to (g) relate to participants' feelings of social engagement and so were asked only of participants themselves who were over 16 years (i.e. no NPs were given these statements).

Statement E1(a) The LTCS Coordinator treats me as an individual: Just over two thirds (68%) of those that know they have an LTCS Coordinator either agree (39%) or strongly agree (29%) that their coordinator treats the participant as an individual (Figure 42). Just over one in ten (12%) disagree (1%) or strongly (11%) disagree with the statement. A further fifth (20%) either don't know (13%) or are undecided (7%) and this is most likely due to a lack of contact.

Figure 42: Perceptions E1 (a) to (c)

	TOTAL AGREE	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	TOTAL DISAGREE	Don't Know
a. The LTCS Coordinator treats me/ (participant's name) as an individual <i>Base=121</i>	68	29	39	7	1	11	12	13
b. I need more information from the Lifetime Care and Support Authority <i>Base=137</i>	38	18	19	2	54	6	60	0
c. There are now long delays waiting for services to be approved by Lifetime Care and Support <i>Base=136</i>	42	19	23	8	31	14	45	5

Q E1: I am now going to read out some statements that relate to the Lifetime Care and Support Scheme. For each one please tell me whether you agree, disagree, or are undecided.

IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

Bases given in figure

Statement E1(b) I need more information from the Lifetime Care and Support Authority: Thirty-eight per cent (38%) either agree (19%) or strongly agree (18%) that they need more information. Given the previously mentioned inability of some BI participants with memory problems, and NPIs in trauma, to retain information this suggests there is an opportunity to support participants and their families with ongoing provision of information regarding services and supports. This will help to ensure people know who to contact when they have particular types of queries. This information may best be given directly by the Authority rather than through case managers. It may be useful to have a secondary contact, with the participant's consent, who receives duplicate information.

Statement E1(c) There are now long delays waiting for services to be approved by Lifetime Care and Support: The Authority has indicated that there were teething problems with the approval process at the commencement of the Scheme and that improvements are ongoing. To be able to detect changes

across time (e.g. 2009 compared to 2010) the statement directs the respondent to the present rather than asking if there had ever been any delays (so that early problems do not confound measurement of perceptions for a given year). This question is the first prompted question on delays. Data on delays described earlier in the report came from open-ended/ unprompted questions.

Over two in five (42%) either agree (23%) or strongly agree (19%) that there are now long delays waiting for services to be approved by the Authority. This result repeats the finding from the unprompted questions earlier in the questionnaire. Approximately the same proportion (44%) either disagree (31%) or strongly disagree (14%) that there are now long delays.

2009-2010 Comparison

The proportion that 'Agree' or 'Strongly Agree' does not vary from 2009 to 2010 for the following statements.

Figure 43: Perceptions by Survey Years (E1)

Per Cent Total Agree	2010 Base=41	2009 Base=104	Comparison
The LTCS Coordinator treats me/ (participant's name) as an individual	68% Base=121	64% Base=104	Stable
I need more information from the Lifetime Care and Support Authority	38% Base=137	42% Base=110	Stable
There are now long delays waiting for services to be approved by Lifetime Care and Support	42% Base=136	44% Base=110	Stable

Statement E1(d) I feel part of a community: Three-quarters (76%) either agree (57%) or strongly agree (19%) that they feel part of a community (Figure 44). However approximately one fifth (19%) disagrees (14%) or strongly (5%) disagrees with the statement and 4% are undecided.

Figure 44: Participant Community Engagement E1 (d) to (g)

Statement	TOTAL AGREE	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	TOTAL DISAGREE	Don't Know
d. I feel part of a community Base=100	76	19	57	4	14	5	19	0
e. I feel I have enough time with friends Base=100	73	26	47	8	14	5	19	0
f. I feel I'm progressing too slowly with my goals (in my Community Living Plan) Base=58	37	8	30	6	39	14	53	4
g. Considering my stage of rehabilitation, I am happy with how much I get out into the community Base=100	83	34	49	4	6	8	14	0

Q E1: I am now going to read out some statements that relate to the Lifetime Care and Support Scheme. For each one please tell me whether you agree, disagree, or are undecided.

IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

Bases given in figure

Statement E1(e) I feel I have enough time with friends: Almost three-quarters (73%) either agree (47%) or strongly agree (26%) that they feel they have enough time with friends. However one fifth (19%) disagree (14%) or strongly (5%) disagree with the statement and 8% are undecided.

Statement E1(f) I feel I'm progressing too slowly with my goals (in my Community Living Plan): Approximately half (53%) either disagree (39%) or strongly disagree (14%) that they are progressing too slowly with their goals. However almost two in five (37%) either agree (30%) or strongly agree (8%) with the statement and 6% are undecided.

Statement E1(g) Considering my stage of rehabilitation, I am happy with how much I get out into the community: A large majority (83%) either agree (49%) or strongly agree (34%) that they are happy with how much they get out into the community. However almost one in seven (14%) either disagree (6%) or strongly disagree (8%) with the statement. Only 4% are undecided.

2009-2010 Comparison

The proportion of participants that report that 'I feel part of a community' is significantly greater in 2010 relative to 2009.

Figure 45: Participant Community Engagement by Survey Years (E1)

Per Cent Total Agree	2010	2009	Comparison
I feel part of a community	76% Base=100	64% Base=75	Increase
I feel I have enough time with friends	73% Base=100	60% Base=75	Increase
I feel I'm progressing too slowly with my goals (in my Community Living Plan)	37% Base=58	29% Base=52	Stable
Considering my stage of rehabilitation, I am happy with how much I get out into the community	84% Base=100	80% Base=75	Stable

Main Survey Results: Attendant Care (Section F)

Just over one third (36%) had received attendant care services in the last 3 months (B2a(f) and F1). These respondents were asked several questions to assess the services and any problem resolution.

Respondents were read statements and were asked to rate their agreement or disagreement with each (F2).

Statement F2(a) The attendant carer(s) usually gets here on time: A large majority (93%) either agree (38%) or strongly agree (55%) that their attendant carer usually arrives on time (figure 46). Only 6% either 'disagree' (4%) or 'strongly disagree' (2%). This majority is stable with respect to all key variables.

Figure 46: Attendant Care Availability and Punctuality (F2)

Statement	TOTAL AGREE	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	TOTAL DISAGREE	Don't Know
a. The attendant carer(s) usually gets here on time	93	55	38	1	4	2	6	0
b. The attendant carer(s) is available when I need them	90	31	59	2	3	5	8	0

Q F2: I am now going to read out some statements that relate to [your/ participant's name] attendant carer or carers. For each one please tell me whether you agree, disagree, or are undecided.

IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

Base=56

Statement F2(b) The attendant carer(s) is available when I need them: A large majority (90%) either agree (59%) or strongly agree (31%) that their attendant carer(s) is available when they need them. Only 8% either 'disagree' (3%) or 'strongly disagree' (5%).

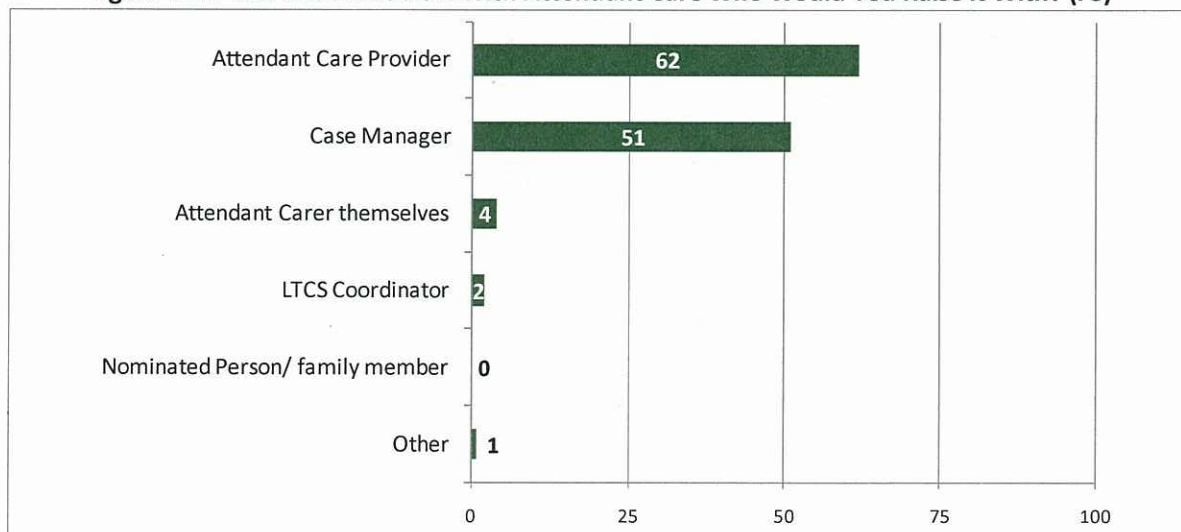
Area Those in the Sydney group are more likely to report that the 'The attendant carer(s) is available when I need them' (99%) than are those in the Rest of NSW & Other group (79%).

Main respondents who had reported attendant care was received in the last 3 months were asked who they would contact if they had a problem with attendant care (F3). They could nominate as many contacts as applied. The two most cited contacts are the:

1. Attendant care provider (62%) and the
2. Case manger (51%) (Figure 47).

Only 2% would contact their LTCS Coordinator. No one reported that they did not know who they would contact.

Figure 47: If You Had A Problem With Attendant Care Who Would You Raise It With? (F3)



Q F3 If you had a problem with [your/ the] attendant carer(s), who would you raise it with?
Base=56

All main respondents who had reported attendant care was received in the last 3 months (n=56) were asked if there had been a problem with attendant care (F4a). 'New' main respondents were asked if there had *ever* been a problem and 'repeat' main respondents were asked if there had been a problem *within the last year*.

- **Fifty three per cent (53%) of respondents had had a problem with their carer or carers and the remaining 47% had not.**

The top three problems were that carers:

1. Were not sufficiently skilled or trained (53% of those who had had a problem, Figure 48)
2. 'Don't turn up' or are 'unreliable' (35% of those who had had a problem)
3. Don't follow instructions (21% of those who had had a problem)

Responses in the 'Other' category included specific issues (e.g. 'carer was lazy', 'carer assaulted the participant').

Figure 48: Problems With Attendant Care (F4a)

Problem	Per Cent of those who had experienced a problem (n=27)	Per cent of those who reported attendant care received (n=56)
Not sufficiently skilled/ trained	41%	22%
Don't follow instructions	21%	11%
Doesn't turn up/ unreliable	35%	19%
Not caring/ warm	17%	9%
Personality clash	11%	5%
NESB carer hard for BI patient to understand	4%	3%
Other	21%	12%

Q F4a: Have you ever had a problem with [your / the] attendant carer(s)? IF YES: And what was it?
Bases given in figure

In other cases there have been inappropriate behaviours from carers. One respondent indicated that the carer had assaulted the participant. Another reported that the carer was 'on the computer all the time'. Another participant indicated that a carer was removed because of highly inappropriate and distressing behaviour.

2009-2010 Comparison

The proportion that report having had a problem with attendant care is unchanged from 2009 to 2010.

Figure 49: Attendant Care Problems by Survey Years (E1)

Per Cent Experienced Problem with Attendant Care	2010 Base=56	2009 Base=38	Comparison
	53%	50%	Stable

The 27 respondents who had experienced a problem were asked who they had raised it with (F4b). All responded that they had raised it with someone rather than no one. Most (88%) had raised it with the attendant care provider themselves and/ or their case manager (63%) (Figure 50). No respondents reported raising it with both their case manager and coordinator.

Figure 50: When You Had A Problem With Attendant Care Who Did You Raise It With? (F4b)



Q F4b: If did you raise this/ these concern(s) with?
Base=27

Those who had had a problem were asked whether it was dealt with to their satisfaction (F4c). Nearly nine in ten (87%) reported that it had been dealt with to their satisfaction either completely (62%) or somewhat (25%) (Figure 51). Just over one in eight (13%) reported it had not been satisfactorily dealt with.

Figure 51: Satisfaction with Attendant Care Problem Resolution? (F4c)

	Per Cent
Yes, completely	62%
Yes, somewhat	25%
No	13%
Total	100%

Q F4c: Was/ were your/the concern(s) dealt with to your satisfaction? [PROBE: And was that somewhat dealt with or completely dealt with?].

Base=27

It is interesting that 90% of those reporting attendant care was received in the last 3 months said that they were satisfied with the care to some extent (B3af), even though 53% had had a problem at some point (F4a). It is most likely that those who had had a problem express overall satisfaction with attendant care because the problem was resolved at least to some extent.

Respondents were asked how attendant care services can be improved to better meet needs and were reassured that even small improvements are worth knowing (F5). Thirty-eight per cent (38%) made no suggestions or reported that no improvements were necessary, while 8% 'Don't know' (Figure 52).

Figure 52: Improvements To Attendant Care (F5)

Improvements	Per cent
No improvements necessary/ suggested	38
Training/ empathy of carers	7
Cover required hours/ deliver care as agreed	5
Improve communication	17
Other	25
Don't Know	8

Q F5: How can attendant care services be improved to better meet [your/ participant's name's] needs? Even small improvements are helpful to know. [PROBE: And is there anything else?]
Base=56

Over half (54%) made suggestions. The three main suggestions were:

1. Improve training/ empathy of carers (7%).
2. Cover required hours/ deliver care as agreed (5%).
3. Improve communication (17%).

Other responses were very specific and included:

'Open communication lines, being open to feedback; carers should suggest activities – [the participant] is a child and bored.'

'Send more mature carers for older person. Mind set of a very young person (e.g. 20 yr old) too different for older person.'

'The carers are used to old people and they just sit there and watch TV. Carers don't participate actively in [the participant's] rehabilitation. We need continuity - the same people coming in instead of different people each time.'

'Allow more time at night to be alone. Carer turns up at 7pm and then I'm put to bed at 9pm. Can't meet up with mates. Can't reorganise the schedule. There's no flexibility. No freedom. Being treated inappropriately.'

Main Survey Results: Communication (Section G)

Main respondents were asked whether they remembered receiving any information sheets, letters or brochures from the Authority since Scheme entry (G1).

- A large majority (84%) of main respondents remember receiving information sheets or letters or brochures from the Authority, while 12% do not remember receiving any and 4% do not know.

Those that did remember were then given statements and asked to indicate the extent to which they agreed or disagreed with each (G2a to G2d). Generally respondents were more decisive (fewer selected 'Don't know') when responding to statements on letters. The results are summarised in Figure 53.

Figure 53: Evaluation Of Communication (G2)

Statement	TOTAL AGREE	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	TOTAL DISAGREE	Dcn't Know
The <u>letters</u> from the Lifetime Care and Support Authority are very useful	69	19	50	11	14	4	18	3
The letters from the Lifetime Care and Support Authority are hard to understand	9	2	7	5	61	15	77	9
The brochures from the Lifetime Care and Support Authority are very useful	54	7	48	5	14	3	17	24
The brochures from the Lifetime Care and Support Authority are hard to understand	11	8	48	9	7	3	56	24

Q G2 (a to d): I am now going to read out some statements. For each one please tell me whether you agree, disagree, or are undecided.

IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

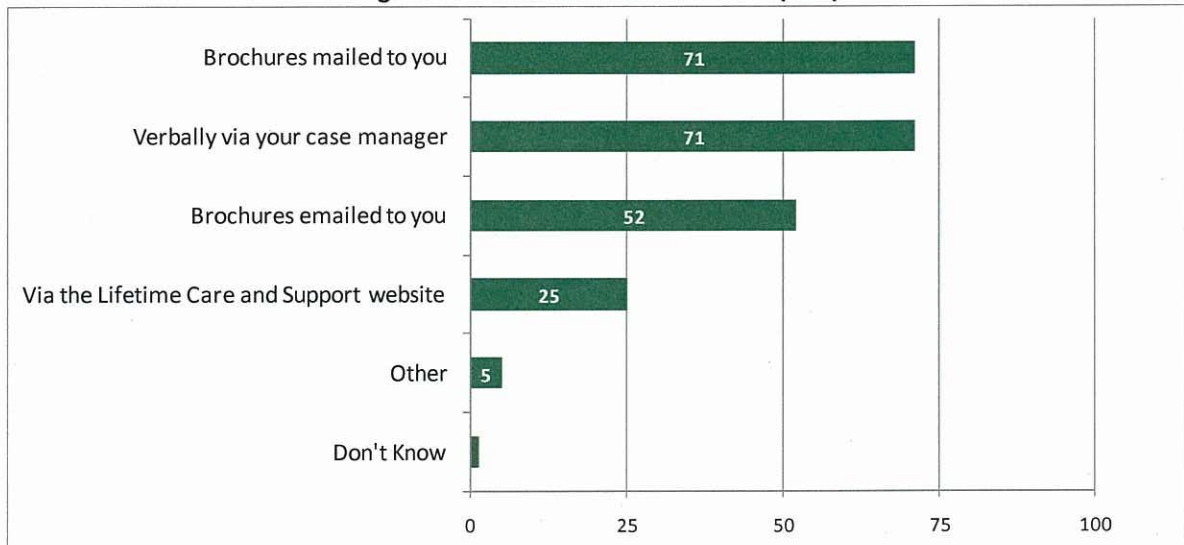
Base=111

Main respondents were asked how they would prefer to receive information from the Authority. They were read a list of communication methods and asked to say 'yes' or 'no' to each (G3a).

- The most popular methods are 'Brochures in the mail' and 'Verbally via your case manager' (71%) (Figure 54).

The second and third most popular methods are 'Brochures emailed to you' (52%) and the LTCS website (25%).

Figure 54: Communication Methods (G3a)

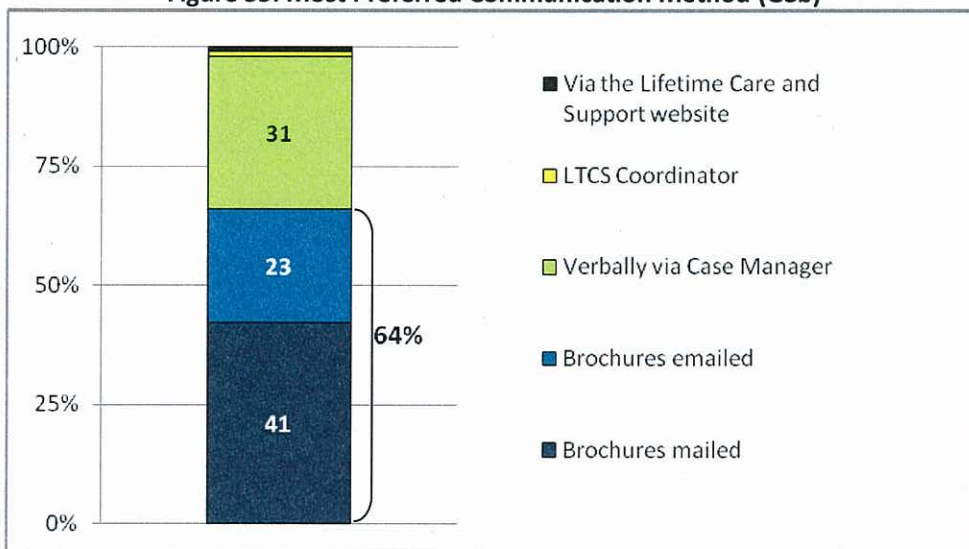


Q G3a: How would you prefer to receive information from the Lifetime Care and Support Authority? Please say yes or no to each. Base=137

They were then asked to nominate their *most preferred* method of communication (G3b). The ranking of the top three options was unchanged: brochures mailed, verbally via the case manager, and brochures emailed. No respondent chose the LTCS website as their most preferred method of communication (Figure 55).

- Almost two-thirds (64%) most prefer brochures, either by mail (41%) or email (23%).
- A further one third (31%) most prefers 'Verbally via Case Manager'.

Figure 55: Most Preferred Communication Method (G3b)



Q G3b: And which method do you most prefer?
Base=137

2009-2010 Comparison

The profile of the most preferred communication methods is unchanged from 2009 to 2010.

Figure 56: Most Preferred Communication Method by Survey Years (G3b)

Most Preferred Communication Method	2010 Base=137	2009 Base=95	Comparison
Brochures Emailed	23%	21%	Stable
Brochures Mailed	41%	49%	Stable
Brochures Total	64%	71%	Stable
Verbally via Case Manager	31%	26%	Stable

Main Survey Results: Open Comment (Section H)

A final question offered the opportunity to comment on anything related to the Scheme or services. A total of 82 unique IDs (80%) returned comments, while 20% did not. Figure 57 summarises the results.

Figure 57: Final Open Comment (H1)

Comment	Per Cent Unique IDs
Positive comment on Scheme as a whole	39
No comment	36
Suggestions/ Constructive criticisms	12
Negative comment (incl. need for help)	10
Delays with approvals or reimbursements	1
Other	2
<i>Total</i>	<i>100</i>

Q H1: We've come to the end of the interview. Is there anything else you would like to comment on about the Lifetime Care and Support Scheme, Authority, or Service Providers? [PROBE: And is there anything else?]
Base=140

Only 1% mentioned delays with approvals or reimbursement. Issues associated with delays included missing the window of opportunity for rehabilitation post-injury and that delays contributed to a sense of helplessness or loss of autonomy.

Other **negative comments** included moderate to strong distress and spanned issues such as the worry of the two year review process to strong feelings of isolation without help or hope:

Service Providers need to do what they promise. Family is tired of appearing to whinge. More communication.

Prefer to burn alive than be in LTCS. Very disappointed.

To hire qualified people. It took so long for LTCS to resolve the problem - we had to sack our original carers.

Other comments included communication and information issues.

They don't inform you well enough on what you can and can't do. Expect you to read website, but that is difficult to understand. Better communication from top to bottom. Anything you say doesn't get done.

Several respondents made suggestions and **constructive criticisms**.

In the early stages I felt like it was a huge battle - it may have been my lack of knowledge - I feel that the participant needs to be educated better. Felt like it was left up to me to ask for things.

Overall a good scheme but they need to think seriously about how they go about costings. Because they are in the city they don't understand what is going on in the country. They should be using local services instead of sending people from Sydney that cost more.

Assessment process needs to be reviewed as incorrect assessment meant services were taken away.

No problems, but what other services could [Participant] be getting? We have a language problem with written information.

Brochures are too basic - need more detail.

Approximately 2 in 5 (39%) made a **positive comment** on the Scheme and/ or services. Some examples include:

'Nothing else. Very happy with everything that has been given. Wonderful services for over 2 years.'

'I think what they are doing is fabulous - if it wasn't for them'

'Being a life member makes me feel lucky. A strong group of people are looking after me.'

'Absolute godsend to me. Amazing to have guidance at such a vulnerable time.'

Appendix A: Primary Approach Letter and Information Sheet

Primary Approach Letter

Date

Participant / Nominated Person
Address
Suburb, State, Postcode

2010 Satisfaction Survey: Have your say about the *Lifetime Care and Support Scheme*

Dear [Participant] / [Nominated Person]

We are writing to let you know about an important survey that we are conducting. The purpose of the survey is to find out how well the *Lifetime Care and Support Scheme* is meeting participant needs. It is an opportunity to give us feedback about the Scheme. The information from the survey will be used to improve our services.

A team of independent researchers will conduct the survey on behalf of the Authority. They will make contact by telephone to make an appointment for an interview at a time that suits you. All responses are anonymous and the Authority will not be told your individual responses.

You will be contacted in October or November of this year. In some cases the researcher will need to speak to the participant and a family member or contact person who can answer questions on behalf of the participant.

We welcome your participation in this important survey. The enclosed sheet provides more information.

If you have any questions about the survey, or do not wish to participate, please contact your LTCS Coordinator on 1300 738 586 by 15 October. If you would prefer to not speak with your Coordinator about the survey, please contact Gemma Lloyd at the Authority on 9394 1318.

Yours Sincerely

Suzanne Lulham
Director, Service Delivery

Information Sheet

More Information About the Survey

What is the purpose of research?

To improve the Lifetime Care and Support Scheme and better meet the needs of participants.

Who is being contacted?

Participants who have been in the Scheme for at least 6 months. In some cases their nominated person will also be contacted.

Who do we want to speak to?

If possible, we would like to speak to the participant themselves. In some cases we will also need to speak to their nominated person. If the participant is aged 16 to 18, then we will ask for parental/guardianship consent. For children under 16 the parent/guardian would be interviewed.

Who will be contacting you?

A team of independent researchers is conducting the survey. This team consists of Sandra Rickards, Neva Miller, Jenny Green and Andrew James. Some of your personal details, including your name and contact number, will be passed onto this team to help with the survey. A researcher will contact you by telephone. Your details will remain confidential and secure at all times, in accordance with the Privacy Act.

How will the survey information be used?

The information from the survey will be used to find out about:

- satisfaction levels with the Scheme,
- any areas for improvement,
- how the Scheme can better meet the needs of participants.

Do you have to do the survey?

Doing the survey is voluntary. However, the more people that do the survey the better the information on what participants need. If you do not want to do the survey, please telephone your LTCS Coordinator on 1300 738 586 by 15th October. If you would prefer to not speak with your Coordinator about the survey, please contact Gemma Lloyd at the Authority on 9394 1318. Otherwise a researcher will be in contact with you.

Whether you do the survey or not has no effect on being supported by the Scheme in any way.

Are your answers confidential?

Yes, your answers will remain completely confidential and your privacy is assured. The independent research team abides by the Privacy Act and is required by law to remove all identifying information from the survey response data before providing it to the Authority. This means all information that could identify your comments will be removed from the results before they are given to the Authority. Therefore, no responses will be linked to a participant or their nominated person. At the end of the survey identifying information will be held independently by The University of Sydney Rehabilitation Studies Unit. This department will not receive contact details and will not use the information for any other purpose.

Appendix B: Questionnaires

Main Questionnaire

**LTCS SURVEY
MAIN QUESTIONNAIRE**

TICK

Date _____ 2010
Time Start _____

- PARTICIPANT ONLY**
- NOMINATED PERSON ONLY**
- LONG/SHORT DUAL NOMINATED PERSON**

SECTION A – GENERAL SATISFACTION

IF CALLING BACK FOR AN INTERVIEW: Hello this is, I am calling about the Lifetime, Care and Support Scheme interview. May I please speak with.....? Is now still a good time for the interview?

The research group I work with is completely independent from the Lifetime Care and Support Authority. We are conducting this research for them. When we report to Lifetime Care and Support, none of your responses will be linked to your name, so please feel free to be honest and open with your answers. There are no right or wrong answers, it is your opinions and perceptions we are interested in.

A1 I'd like you to think about the Lifetime Care and Support **Scheme**. The Scheme covers treatment, rehabilitation and care needs. Are you satisfied or dissatisfied with how the Lifetime Care and Support Scheme meets [your /participant's name's] needs?

IF SATISFIED: And are you satisfied, very satisfied or extremely satisfied?
IF DISSATISFIED: And are you dissatisfied, very dissatisfied or extremely dissatisfied?

- 1. Extremely Dissatisfied – GO TO A2
- 2. Very Dissatisfied – GO TO A2
- 3. Dissatisfied – GO TO A2
- 4. Satisfied – GO TO SECTION B
- 5. Very Satisfied – GO TO SECTION B
- 6. Extremely Satisfied – GO TO SECTION B
- 7. DON'T KNOW (DO NOT READ OUT) – GO TO SECTION B

A2 And why are you dissatisfied? _____

Main Questionnaire

SECTION B – SERVICES

B1 Which of the following services do you believe the Lifetime Care and Support Authority might pay for, for its clients? Please answer yes or no to each.

ORDER	READ OUT. ROTATE ORDER.	Yes	No	Don't Know	Depends
		1	2	3	4
	a. Surgery				
	b. Rent				
	c. Attendant Care or Domestic Assistance				
	d. Home and vehicle modifications				
	e. Home Insurance				
	f. Clinical Psychology or Psychiatry				
	g. School or education support				
	h. General Clothing				
	i. Purchasing a new car				
	j. Income				
	k. General Household Appliances				

Main Questionnaire

B2a Now I'm going to read another list of services. I'd like you to think back over the last 3 months. Please tell me which services [you have had / (participants name) has had] that were paid for by the Lifetime Care and Support Authority.

READ OUT FROM GRID BELOW AND TICK APPROPRIATE NUMBER FOR B2a COLUMN, THEN COME BACK TO B2b.



IF CANS 6 OR 7, OR SCI C1,2,3,4 OR 5, OR IF 16 OR UNDER THEN DO NOT READ OUT DRIVING LESSONS.

B2b Are there any other services paid for by the Authority that [you have had / (participants name) has had] in the past 3 months? WRITE IN AT B2b OF GRID BELOW.

B3a ASK FOR EACH MENTIONED AT B2a: Thinking firstly about [FIRST MENTION AT D2a] are you satisfied or dissatisfied with it/ them?

IF SATISFIED: And are you satisfied, very satisfied or extremely satisfied?

IF DISSATISFIED: And are you dissatisfied, very dissatisfied or extremely dissatisfied?

INTERVIEWER NOTE: TICK APPORRIATE BOX IN GRID BELOW.

Now thinking about [2nd mention at D2a] are you satisfied or dissatisfied with it/ them? [Repeat for 3rd mention, 4th mention, etc] CONTINUE FOR ALL MENTIONS AT B2a AND B2b

ORDER	READ OUT. ROTATE ORDER	B2a	B3a						
			Extrem Satisfie 6	Very Satisfie 5	Satisfie 4	Dissatis 3	Very Dissatis 2	Extrem Dissatis 1	Don't Know 7
	a. Case manager or management								
	b. Equipment								
	c. Physiotherapy								
	d. Exercise program/ gym membership								
	e. Occupational therapy								
	f. Attendant care								
	g. Clinical psychology/ Psychiatry								
	h. Home or Vehicle Modifications								
	i. Vocational/education assistance								
☆	j. <u>Driving lessons</u>								
	k. Cab charges & other travel								
	WRITE IN (IF ANY)	B2b	B3b						
	a.								
	b.								
	c.								

B4a In the last 3 months [have you had / has (participant's name) had] any problems with services that were paid for by the Lifetime Care and Support Authority?

1. Yes – GO TO B4b
2. No – GO TO B5
3. Don't know – GO TO B5

B4b What problems were they?

B4c Was/ were the problem(s) sorted out?
PROBE FOR 'SOME OR ALL' OF PROBLEMS SORTED OUT, PROBE FOR WHETHER THEY EXPECT UNRESOLVED PROBLEMS TO BE SORTED OUT.---

1. Yes - All problems were sorted out
2. Yes - Some problems were sorted out
3. No - Problems not sorted out but expect they will be
4. No – Problems not sorted out and don't expect they will be
5. Don't know

B4d Overall, are you satisfied or dissatisfied with how the [problems were / problem was] sorted out?

IF SATISFIED: And are you satisfied, very satisfied or extremely satisfied?

IF DISSATISFIED: And are you dissatisfied, very dissatisfied or extremely dissatisfied?

1. Extremely Dissatisfied – GO TO B4e
2. Very Dissatisfied – GO TO B4e
3. Dissatisfied – GO TO B4e
4. Satisfied – GO TO B5
5. Very Satisfied – GO TO B5
6. Extremely Satisfied – GO TO B5
7. DON'T KNOW (DO NOT READ OUT) – GO TO B5

B4e Why were you dissatisfied?

Main Questionnaire

B5 Who would you contact if you had any problems with a service you received? PROBE: Do you know what their position title is?

1. (specify name and/ or position title) _____
2. Don't know who or what position

B6 IF AT B2a THEY HAVE NOT RECEIVED ATTENDANT CARE ASK: How could any of the services be improved to better meet [your needs/ (participant's name) needs]?

IF AT B2a THEY HAVE RECEIVED ATTENDANT CARE ASK: Apart from attendant care, how could any of the services be improved to better meet [your needs/ (participant's name) needs]?

INTERVIEWER NOTE: HAVE PAGE 3 HANDY

I am now going to read out a definition of service providers: Service providers are the people and organizations that provide the services to [you/ participant's name] such as the [LIST SERVICES ACTUALLY RECEIVED AS PER B2a AND B2b]. They are separate from the Lifetime Care and Support Authority. Lifetime Care and Support may pay for services [you/ participant's name] receive from these organizations and people.

INTERVIEWER INSTRUCTION: RESPONDENTS MAY HAVE QUESTIONS - IT IS NECESSARY WHEN TRYING TO ANSWER THESE TO KEEP TO THE STRUCTURAL DEFINITION SO THAT VALUE STATEMENTS ARE NOT MADE THAT COULD INFLUENCE THE WAY THE RESPONDENT ANSWERS SUBSEQUENT QUESTIONS. E.g. If respondent queries 'But aren't they all part of the same insurance company?' An answer would be 'No, the Lifetime Care and Support Authority is part of the NSW government. Service providers are separate organizations, and are not part of an insurance company. The Service Providers may be part of a hospital, a private company or a non-government organization. The Lifetime Care and Support Authority may pay for services [you/ participant's name] receive(s) from service providers. IT WOULD BE LEADING TO INCLUDE A STATEMENT SUCH AS 'The Lifetime Care and Support Authority may pay for the services that help [you/ participant's name] get better and back into the community'.

Main Questionnaire

B7a In the last 3 months [have you had / have you or (participant's name) had] any problems with the Lifetime Care and Support Authority itself?

1. Yes – GO TO B7b
2. No – GO TO B8
3. Don't know – GO TO B8

B7b What problems did you have?

B7c Were the problems sorted out / Was the problem sorted out?

PROBE FOR 'SOME OR ALL' OF PROBLEMS SORTED OUT, PROBE FOR WHETHER THEY EXPECT UNRESOLVED PROBLEMS TO BE SORTED OUT.---

1. Yes - All problems were sorted out
2. Yes - Some problems were sorted out
3. No - Problems not sorted out but expect they will be
4. No – Problems not sorted out and don't expect they will be
5. Don't know

B7d Overall, are you satisfied or dissatisfied with how the problem(s) was/ were sorted out?

IF SATISFIED: And are you satisfied, very satisfied or extremely satisfied?

IF DISSATISFIED: And are you dissatisfied, very dissatisfied or extremely dissatisfied?

1. Extremely Dissatisfied – GO TO B7e
2. Very Dissatisfied – GO TO B7e
3. Dissatisfied – GO TO B7e
4. Satisfied – GO TO B8
5. Very Satisfied – GO TO B8
6. Extremely Satisfied – GO TO B8
7. DON'T KNOW (DO NOT READ OUT) - GO TO B8

B7e Why are you dissatisfied?

Main Questionnaire

B8 And how could Lifetime Care and Support improve? Even small improvements are worth knowing. [PROBE: And is there anything else?]

Main Questionnaire

SECTION C – CONTACTS

C1 [Do you / Does (participant's name)] have a Lifetime Care and Support Coordinator?

1. Yes – GO TO C2a
2. No – GO TO C3
3. Don't know – GO TO C3

C2a Is their name [READ OUT LTCS COORDINATOR NAME]?

1. Yes – GO TO C5
2. No – GO TO C2b
3. Don't know – GO TO C2c

C2b What is their name? _____ - GO TO C5

C2c We have it recorded that [READ OUT LTCS COORDINATOR NAME] is [your/ participant's name's] Lifetime Care and Support Coordinator. - NOW GO TO C5

C3 Do you know the name [READ OUT LTCS COORDINATOR NAME]?

1. Yes [SAY: We have it recorded that this is [your/ participant's name's] Lifetime Care and Support Coordinator.] GO TO C5
2. No GO TO C4
3. Don't know GO TO C4

C4 [Have you / Has participant's name] ever had a Lifetime Care and Support Coordinator?

1. Yes – GO TO C5
2. No – GO TO C5
3. Don't know – GO TO C5

C5 [Do you have or have you ever had / Has (participant's name) had or has he/she ever had] a case manager? Sometimes case managers are called caseworkers.

1. Yes – IF RESPONDENT IS ALSO INITIAL NOMINATED PERSON THEN GO TO C6a, ALL OTHER RESPONDENTS GO TO FILTER BEFORE C7
2. No – GO TO GO TO FILTER BEFORE C7
3. Don't know – GO TO GO TO FILTER BEFORE C7

Main Questionnaire

TO BE ANSWERED BY INITIAL NOMINATED PERSON

IF NECESSARY USE Z5 FROM RECRUITMENT SCRIPT.

C6a Do you remember your first contact with the Lifetime Care and Support Authority through the Coordinator?

- 1. Yes – GO TO C6b
- 2. No – GO TO GO TO FILTER BEFORE C7
- 3. Don't know – GO TO GO TO FILTER BEFORE C7

C6b Were you satisfied or dissatisfied with that contact?

IF SATISFIED: And are you satisfied, very satisfied or extremely satisfied?

IF DISSATISFIED: And are you dissatisfied, very dissatisfied or extremely dissatisfied?

- 1. Extremely Dissatisfied – GO TO C6c
- 2. Very Dissatisfied – GO TO C6c
- 3. Dissatisfied – GO TO C6c
- 4. Satisfied – GO TO C6d
- 5. Very Satisfied – GO TO C6d
- 6. Extremely Satisfied – GO TO C6d
- 7. DON'T KNOW (DO NOT READ OUT) – GO TO C6d

C6c Why were you dissatisfied? _____

C6d How could this first contact have been improved to better meet your needs and [participant's name] needs (at the time)? [PROBE: And what else/ Is there anything else?]

Main Questionnaire

FILTER: INTERVIEWER TO RECORD WHICH APPLIES

1. HAS / HAD A COORDINATOR AND HAS / HAD A CASE MANAGER: GO TO C7
2. HAS / HAD A COORDINATOR ONLY: GO TO C9
3. HAS / HAD A CASE MANAGER ONLY: GO TO C8
4. NEITHER: GO TO SECTION D

C7 I am now going to read out a list of tasks. For each one please tell me who you would contact: [your/ participant's name's] Coordinator or [your/ participant's name's] Case Manager.

IF RESPONDENT SAYS 'I've never done that/ asked for that' THEN ASK 'If you did need someone to [statement], who would you contact?'

ORDER	READ OUT. ROTATE	Case Manager	Coordinator	Either	Neither	Don't Know
		1	2	3	4	5
	a. Help organise rehabilitation or medical appointments					
	b. Organise reimbursement for expenses					
	c. Sort out any problems you have with services					
	d. Provide information on the <u>types</u> of services funded by Lifetime Care and Support					
	e. Question a decision not to approve services for your treatment, rehabilitation or care.					
	f. Make a complaint about the Lifetime Care and Support Authority					
	g. Make a complaint about a service provider					

Main Questionnaire

C8 In what ways could [your/ participant's name's] Case Manager improve? Even small improvements are worth knowing.

C9 In what ways could [your/ participant's name's] Lifetime Care and Support Coordinatc improve? Even small improvements are worth knowing.

Main Questionnaire

SECTION D – COMMUNITY LIVING PLAN GOALS

INTERVIEWER NOTE: There is also a plan known as the Community Discharge Plan, which is developed when clients leave hospital and aims to help the client with the transition from hospital to home and the community. This may be some client's most recent plan, however most should have had another plan developed since then. Try to get the participant to think of their most recent plan/goals.

D1 Often people in the Lifetime Care and Support Scheme have goals set as part of a plan. This plan might be known as a rehabilitation plan, a community living plan or plan for services.

[Do you / Does participant's name] have any goals set in a plan?

1. Yes – PARTICIPANTS GO TO D2; NOMINATED PERSONS GO TO D3
2. No – GO TO E1
3. Don't know – GO TO E1

D2 Are you aware of what your *most recent* goals are?

1. Yes – GO TO D3
2. No – GO TO D3
3. Don't know – GO TO D3

D3 Which of the following best describes [your/ participant's name's] involvement in setting [your / his/her] goals?

READ OUT [ROTATE]

1. I set all my goals myself / He set all his goals himself/ She set all her goals herself GO TO D4a
2. I / He/ She had help in setting my/his/her goals GO TO D4a
3. I / He/ She was not involved in setting my/ his/ her goals GO TO D4b
4. DON'T KNOW (DO NOT READ OUT) GO TO SECTION E

D4a How do you feel about [your/ participant's name's] level of involvement in setting [your / their] goals? Do you feel [you/ he/she] should have had more involvement, less involvement, or was it the right amount of involvement?

3. More involvement GO TO FILTER BEFORE D5
2. The right amount of involvement GO TO FILTER BEFORE D5
1. Less involvement GO TO FILTER BEFORE D5

D4b How do you feel about [your/ participant's name's] level of involvement in setting [your / their] goals? Do you feel [you/ he/she] should have had more involvement, or not?

3. More involvement
2. Not

Main Questionnaire

FILTER: IF D1=CODES 2 OR 3 GO TO Section E; IF D1=CODE 1 (YES) CONTINUE
INTERVIEWER: TICK WHICH APPLIES

- RESPONDENT IS PARTICIPANT WHO HAS COORDINATOR AND CASEMANAGER GO TO D5
- RESPONDENT IS NOMINATED PERSON: GO TO SECTION E
- ALL OTHERS GO TO SECTION E.

D5 Please tell me who you would contact for help setting goals: your Coordinator or your Case Manager.

1. Coordinator
2. Case Manager
3. Either
4. Neither
5. Don't Know

Main Questionnaire

SECTION E – PERCEPTIONS AND EXPECTATIONS

E1 I am now going to read out some statements that relate to the Lifetime Care and Support Scheme. For each one please tell me whether you agree, disagree, or are undecided.

IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

1. Strongly Disagree
2. Disagree
3. Undecided
4. Agree
5. Strongly Agree
6. DON'T KNOW (DO NOT READ OUT)

FILTERS:



1. IF AT SECTION C THEY HAVE NEVER HAD A COORDINATOR (OR DON'T KNOW IF THEY HAVE) THEN LEAVE OUT STATEMENT (a) RE **Coordinator**.
2. IF D1=NO/ DK THEN LEAVE OUT STATEMENT (f) RE **Goals**.



3. IF RESPONDENT IS NOMINATED PERSON LEAVE OUT STATEMENTS (d), (e), (f), (g).

ORDER	READ OUT. ROTATE ORDER.	Strongly Agree 5	Agree 4	Undecided 3	Disagree 2	Strongly Disagree 1	Don't Know 6
★	a. <i>My/ The Lifetime Care and Support Coordinator treats me (Participant's name) as an individual</i>						
	b. I need more information from the Lifetime Care and Support Authority						
	c. There are now long delays waiting for services to be approved by Lifetime Care and Support.						
	d. I feel part of a community						
	e. I feel I have enough time with friends						
★	f. <i>I feel I'm progressing too slowly with my goals (in my Community Living Plan)</i>						
	g. Considering my stage of rehabilitation, I am happy with how much I get out into the community						

Main Questionnaire

SECTION F - ATTENDANT CARE

F1 CHECK B3a

1. Yes - Participant has received attendant care – GO TO F2
2. No - Participant has not received attendant care – GO TO SECTION G
3. Don't know if received attendant care – GO TO SECTION G

F2 I am now going to read out some statements that relate to [your/ participant's name] attendant carer or carers. For each one please tell me whether you agree, disagree, or are undecided.

a) [My/ The] Attendant carer(s) usually gets here on time?

IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

1. Strongly Disagree
2. Disagree
3. Undecided
4. Agree
5. Strongly Agree
6. DON'T KNOW (DO NOT READ OUT)

b) [My/ The] attendant carer(s) is available when [I need/ participant's name needs] them?

IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

1. Strongly Disagree
2. Disagree
3. Undecided
4. Agree
5. Strongly Agree
6. DON'T KNOW (DO NOT READ OUT)

F3 If you had a problem with [your/ the] attendant carer(s), who would you raise it with?

DO NOT READ OUT. MULTIPLE RESPONSE

1. Attendant care provider
2. Attendant carer themselves
3. Nominated person/ family member
4. Case Manager
5. LTCS Coordinator
6. Other (specify with job title if appropriate) _____
7. Don't know / Depends

Main Questionnaire

F4a Have you ever had a problem with [your / the] attendant carer(s)? IF YES: And what was it? *MULTIPLE RESPONSE*

DO NOT READ OUT

1. Yes, not sufficiently skilled/ trained – GO TO F4b
2. Yes, not caring/ warm – GO TO F4b
3. Yes, don't follow instructions – GO TO F4b
4. Yes, personality clash – GO TO F4b
5. Yes, other (specify _____) – GO TO F4b
6. No – GO TO F5
7. Don't know – GO TO F5

F4b Who did you raise this/ these concern(s) with? [*MULTIPLE RESPONSE*]

DO NOT READ OUT

1. Attendant care provider – GO TO F4c
2. Attendant carer themselves – GO TO F4c
3. Nominated person – GO TO F4c
4. Case Manager – GO TO F4c
5. LTCS Coordinator – GO TO F4c
6. Other (specify with job title if appropriate) _____ – GO TO F4c
7. Don't know – GO TO F5
8. No-one – GO TO F5

F4c Was/ were your/the concern(s) dealt with to your satisfaction? [*PROBE: And was that somewhat dealt with or completely dealt with?*].

1. Yes, completely
2. Yes, somewhat
3. No
4. Don't know

F5 How can attendant care services be improved to better meet [your/ participant's name's] needs? Even small improvements are helpful to know. [*PROBE: And is there anything else?*]

Main Questionnaire

SECTION G – COMMUNICATION

G1 Now I would like to ask you some questions about the way the Lifetime Care and Support Authority communicates important information to you. Since [you have/ participant's name has] been in the Lifetime Care and Support Scheme, do you remember receiving any information sheets, letters or brochures from the Authority?

1. Yes
2. No GO TO G3a
3. Don't know / maybe GO TO G3a

G2 I am now going to read out some statements. For each one please tell me whether you agree, disagree, or are undecided.

IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

1. Strongly Disagree
2. Disagree
3. Undecided
4. Agree
5. Strongly Agree
6. DON'T KNOW (DO NOT READ OUT)

READ OUT. ROTATE ORDER OF PAIRS.	Strongly Agree 5	Agree 4	Undecided 3	Disagree 2	Strongly Disagree 1	Don't Know 6
a. The <u>letters</u> from the Lifetime Care and Support Authority are very useful						
b. The <u>letters</u> from the Lifetime Care and Support Authority are hard to understand						
c. The <u>brochures</u> from the Lifetime Care and Support Authority are very useful						
d. The <u>brochures</u> from the Lifetime Care and Support Authority are hard to understand						

G3a How would you prefer to receive information from the Lifetime Care and Support Authority? Please say yes or no to each.

READ OUT. MULTIPLE RESPONSE – CIRCLE AS MANY AS APPLY

1. Brochures mailed to you
2. Brochures emailed to you
3. Via the Lifetime Care and Support website
4. Verbally via your case manager
5. Other (specify) _____
6. DON'T KNOW (DO NOT READ OUT)

Main Questionnaire

G3b And which method do you most prefer?
WRITE IN NUMBER FROM G3a
IF NECESSARY, READ BACK THE TYPES SELECTED IN G3a.

SECTION H – OVERALL COMMENT

H1 We've come to the end of the interview. Is there anything else you would like to comment on about the Lifetime Care and Support Scheme, Authority, or Service Providers? [PROBE: And is there anything else?]

That brings us to the end of the interview. Thank you very much for your time and help. My name again is This market research was conducted on behalf of the Lifetime Care and Support Authority. It is carried out in compliance with the Privacy Act, and the information you provided will be used for research purposes only.

SANDRA: If you would like any more information about this project or the researchers you can phone XXXX XXX XXX.

NEVA/ JENNY/ JAMES: If you would like any more information about this project or the researchers you can phone XXXX XXX XXX.

Time Finished _____

Interviewer Name (PRINT) _____
Interviewer Signature _____

Dual Participant Questionnaire

LTCS SURVEY
DUAL PARTICIPANT QUESTIONNAIRE

DUAL PARTICIPANT

Date _____ 2010
Time Start _____

LONG

SHORT

SECTION A – GENERAL SATISFACTION

IF CALLING BACK FOR AN INTERVIEW: Hello this is, I am calling about the Lifetime, Care and Support Scheme interview. May I please speak with.....? Is now still a good time for the interview?

The research group I work with is completely independent from the Lifetime Care and Support Authority. We are conducting this research for them. When we report to Lifetime Care and Support, none of your responses will be linked to your name, so please feel free to be honest and open with your answers. There are no right or wrong answers, it is your opinions and perceptions we are interested in.

A1 I'd like you to think about the Lifetime Care and Support **Scheme**. The Scheme covers treatment, rehabilitation and care needs. Are you satisfied or dissatisfied with how the Lifetime Care and Support Scheme meets your needs?

IF SATISFIED: And are you satisfied, very satisfied or extremely satisfied?
IF DISSATISFIED: And are you dissatisfied, very dissatisfied or extremely dissatisfied?

1. Extremely Dissatisfied – GO TO A2
2. Very Dissatisfied – GO TO A2
3. Dissatisfied – GO TO A2
4. Satisfied – GO TO SECTION B
5. Very Satisfied – GO TO SECTION B
6. Extremely Satisfied – GO TO SECTION B
7. DON'T KNOW (DO NOT READ OUT) – GO TO SECTION B

A2 And why are you dissatisfied? _____

Dual Participant Questionnaire

SECTION B – SERVICES

Now I would like to talk about the services that are paid for by the Lifetime Care and Support Authority. Please remember it is your perceptions we are interested in, not whether it is right or wrong.



INTERVIEWER INSTRUCTION: FILL IN B2a AND B2b FROM NOMINATED PERSON'S INTERVIEW.

B2a/b I'll read a list of services that (nominated person's name) said you have received over the last 3 months. READ OUT SERVICES FROM NOMINATED PERSON'S B2a/ B2b.

B3a ASK FOR EACH INDICATED AT B2a and B2b: Thinking firstly about [FIRST MENTION AT D2a) are you satisfied or dissatisfied with it/ them?

IF SATISFIED: And are you satisfied, very satisfied or extremely satisfied?

IF DISSATISFIED: And are you dissatisfied, very dissatisfied or extremely dissatisfied?

INTERVIEWER NOTE: TICK APPORRIATE BOX IN GRID BELOW.

ORDER	READ OUT. ROTATE ORDER	B2a	B3a						
			Extrem Satisfie 6	Very Satisfie 5	Satisfie 4	Dissatis 3	Very Dissatis 2	Extrem Dissatis 1	Don't Know 7
	a. Case manager or management								
	b. Equipment								
	c. Physiotherapy								
	d. Exercise program/ gym membership								
	e. Occupational therapy								
	f. Attendant care								
	g. Clinical psychology/ Psychiatry								
	h. Home or Vehicle Modifications								
	i. Vocational/education assistance								
	j. <u>Driving lessons</u>								
	k. Cab charges & other travel								
	WRITE IN (IF ANY)	B2b	B3b						
	a.								
	b.								
	c.								

Dual Participant Questionnaire

B5 Who would you contact if you had any problems with a service you received?

PROBE: Do you know what their position title is?

1. (specify name and/ or position title) _____
2. Don't know who or what position

B6 IF AT B2a THEY HAVE NOT RECEIVED ATTENDANT CARE ASK: How could any of the services be improved to better meet your needs?

IF AT B2a THEY HAVE RECEIVED ATTENDANT CARE ASK: Apart from attendant care, how could any of the services be improved to better meet your needs?

DUAL SHORT- GO TO SECTION D
DUAL LONG CONTINUE WITH DEFINITION & B8

INTERVIEWER NOTE: HAVE PAGE 2 HANDY

I am now going to read out a definition of service providers: Service providers are the people and organizations that provide the services to you such as the [LIST SERVICES ACTUALLY RECEIVED AS PER B2a AND B2b]. They are separate from the Lifetime Care and Support Authority. Lifetime Care and Support may pay for services you receive from these organizations and people.

INTERVIEWER INSTRUCTION: RESPONDENTS MAY HAVE QUESTIONS - IT IS NECESSARY WHEN TRYING TO ANSWER THESE TO KEEP TO THE STRUCTURAL DEFINITION SO THAT VALUE STATEMENTS ARE NOT MADE THAT COULD INFLUENCE THE WAY THE RESPONDENT ANSWERS SUBSEQUENT QUESTIONS.

E.g. If respondent queries 'But aren't they all part of the same insurance company?' An answer would be 'No, the Lifetime Care and Support Authority is part of the NSW government. Service providers are separate organizations, and are not part of an insurance company. The Service Providers may be part of a hospital, a private company or a non-government organization. The Lifetime Care and Support Authority may pay for services you receive from service providers. IT WOULD BE LEADING TO INCLUDE A STATEMENT SUCH AS 'The Lifetime Care and Support Authority may pay for the services that help you get better and back into the community'.

Dual Participant Questionnaire

B8: How could Lifetime Care and Support improve? Even small improvements are wo knowing. [PROBE: And is there anything else?]

**NO SECTION C. PLEASE
CONTINUE TO SECTION D.**

Dual Participant Questionnaire

SECTION D – COMMUNITY LIVING PLAN GOALS

INTERVIEWER NOTE: There is also a plan known as the Community Discharge Plan, which is developed when clients leave hospital and aims to help the client with the transition from hospital to home and the community. This may be some client's most recent plan, however most should have had another plan developed since then. Try to get the participant to think of their most recent plan/goals.

D1 Often people in the Lifetime Care and Support Scheme have goals set as part of a plan. This plan might be known as a rehabilitation plan, a community living plan or plan for services.

Do you have any goals set in a plan?

1. Yes – GO TO D2
2. No – GO TO E1
3. Don't know – GO TO E1

D2 Are you aware of what your *most recent* goals are?

1. Yes – GO TO D3
2. No – GO TO D3
3. Don't know – GO TO D3

D3 Which of the following best describes your involvement in setting your goals?

READ OUT [ROTATE]

1. I set all my goals myself GO TO D4a
2. I had help in setting my goals GO TO D4a
3. I was not involved in setting my goals GO TO D4b
4. DON'T KNOW (DO NOT READ OUT) GO TO SECTION E

D4a How do you feel about your level of involvement in setting your goals? Do you feel you should have had more involvement, less involvement, or was it the right amount of involvement?

3. More involvement GO TO SECTION E
2. The right amount of involvement GO TO SECTION E
1. Less involvement GO TO SECTION E

D4b How do you feel about your level of involvement in setting your goals? Do you feel you should have had more involvement, or not?

3. More involvement
2. Not

Dual Participant Questionnaire

SECTION E – PERCEPTIONS AND EXPECTATIONS

E1 I am now going to read out some statements that relate to the Lifetime Care and Support Scheme. For each one please tell me whether you agree, disagree, or are undecided.

INTERVIEWER NOTE: STATEMENTS (b) and (c) ARE FOR DUAL LONG RESPONDENTS ONLY. THERE IS NO STATEMENT (a).

IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

1. Strongly Disagree
2. Disagree
3. Undecided
4. Agree
5. Strongly Agree
6. DON'T KNOW (DO NOT READ OUT)



FILTERS:

1. IF D1=NO/ DK THEN LEAVE OUT STATEMENT (f) RE Goals.

ORDER		READ OUT. ROTATE ORDER.	Strongly Agree 5	Agree 4	Undecided 3	Disagree 2	Strongly Disagree 1	Don't Know 6
	LONG ONLY	b. I need more information from the Lifetime Care and Support Authority						
	LONG ONLY	c. There are now long delays waiting for services to be approved by Lifetime Care and Support.						
	ALL	d. I feel part of a community						
	ALL	e. I feel I have enough time with friends						
	<u>ALL</u>	<u>f. I feel I'm progressing too slowly with my goals (in my Community Living Plan)</u>						
	ALL	g. Considering my stage of rehabilitation, I am happy with how much I get out into the community						

Dual Participant Questionnaire

SECTION F - ATTENDANT CARE

F1 CHECK B3a

1. Yes - Participant has received attendant care – GO TO F2
2. No - Participant has not received attendant care – GO TO SECTION G
3. Don't know if received attendant care – GO TO SECTION G

F2 I am now going to read out some statements that relate to your attendant carer or carers. For each one please tell me whether you agree, disagree, or are undecided.

a) My Attendant carer(s) usually gets here on time?

IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

1. Strongly Disagree
2. Disagree
3. Undecided
4. Agree
5. Strongly Agree
6. DON'T KNOW (DO NOT READ OUT)

b) My attendant carer(s) is available when I need them?

IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

1. Strongly Disagree
2. Disagree
3. Undecided
4. Agree
5. Strongly Agree
6. DON'T KNOW (DO NOT READ OUT)

F3 If you had a problem with your attendant carer(s), who would you raise it with?

DO NOT READ OUT. MULTIPLE RESPONSE

1. Attendant care provider
2. Attendant carer themselves
3. Nominated person/ family member
4. Case Manager
5. LTCS Coordinator
6. Other (specify with job title if appropriate) _____
7. Don't know / Depends

Dual Participant Questionnaire

F4a Have you ever had a problem with your attendant carer(s)? IF YES: And what MULTIPLE RESPONSE

- DO NOT READ OUT
1. Yes, not sufficiently skilled/ trained – GO TO F4b
 2. Yes, not caring/ warm – GO TO F4b
 3. Yes, don't follow instructions – GO TO F4b
 4. Yes, personality clash – GO TO F4b
 5. Yes, other (specify _____) – GO TO F4b
 6. No – GO TO F5
 7. Don't know – GO TO F5

F4b Who did you raise this/ these concern(s) with? [MULTIPLE RESPONSE]

- DO NOT READ OUT
1. Attendant care provider – GO TO F4c
 2. Attendant carer themselves – GO TO F4c
 3. Nominated person – GO TO F4c
 4. Case Manager – GO TO F4c
 5. LTCS Coordinator – GO TO F4c
 6. Other (specify with job title if appropriate) _____ – GO TO F4c
 7. Don't know – GO TO F5
 8. No-one – GO TO F5

F4c Was/ were your concern(s) dealt with to your satisfaction? [PROBE: And was it somewhat dealt with or completely dealt with?].

1. Yes, completely
2. Yes, somewhat
3. No
4. Don't know

F5 How can attendant care services be improved to better meet your needs? Even improvements are helpful to know. [PROBE: And is there anything else?]

Dual Participant Questionnaire

SECTION G – COMMUNICATION

DUAL SHORT– GO TO SECTION H

DUAL LONG CONTINUE TO G1

G1 Now I would like to ask you some questions about the way the Lifetime Care and Support Authority communicates important information to you. Since [you have/ participant's name has] been in the Lifetime Care and Support Scheme, do you remember receiving any information sheets, letters or brochures from the Authority?

1. Yes
2. No GO TO G3a
3. Don't know / maybe GO TO G3a

G2 I am now going to read out some statements. For each one please tell me whether you agree, disagree, or are undecided.

IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

READ OUT. ROTATE ORDER OF PAIRS.	Strongly Agree 5	Agree 4	Undecided 3	Disagree 2	Strongly Disagree 1	Don't Know 6
a. The <u>letters</u> from the Lifetime Care and Support Authority are very useful						
b. The <u>letters</u> from the Lifetime Care and Support Authority are hard to understand						
c. The <u>brochures</u> from the Lifetime Care and Support Authority are very useful						
d. The <u>brochures</u> from the Lifetime Care and Support Authority are hard to understand						

G3a How would you prefer to receive information from the Lifetime Care and Support Authority? Please say yes or no to each.

READ OUT. MULTIPLE RESPONSE – CIRCLE AS MANY AS APPLY

1. Brochures mailed to you
2. Brochures emailed to you
3. Via the Lifetime Care and Support website
4. Verbally via your case manager
5. Other (specify) _____
6. DON'T KNOW (DO NOT READ OUT)

G3b And which method do you most prefer?

WRITE IN NUMBER FROM G3a

IF NECESSARY, READ BACK THE TYPES SELECTED IN G3a.

Dual Participant Questionnaire

SECTION H – CLOSE AND DEMOGRAPHICS

H1 We've come to the end of the interview. Is there anything else you would like to comment on about the Lifetime Care and Support Scheme, Authority, or Service Providers? [PROBE: And is there anything else?]

That brings us to the end of the interview. Thank you very much for your time and help. My name again is This market research was conducted on behalf of the Lifetime Care and Support Authority. It is carried out in compliance with the Privacy Act, and the information you provided will be used for research purposes only.

SANDRA: If you would like any more information about this project or the researchers you can phone 0408 111 106.

NEVA/ JENNY/ ANDREW: If you would like any more information about this project or the researchers you can phone 0406 198 280.

Time Finished _____

Interviewer Name (PRINT) _____
Interviewer Signature _____

Quick Participant Questionnaire

LTCS SURVEY QUICK PARTICIPANT QUESTIONNAIRE

Date _____ 2010
Time Start _____

INTRODUCTION

IF CALLING BACK FOR AN INTERVIEW: Hello this is, I am calling about the Lifetime, Care and Support Scheme interview. May I please speak with.....? Is now still a good time for the interview?

The research group I work with is completely independent from the Lifetime Care and Support Authority. We are conducting this research for them. When we report to Lifetime Care and Support, none of your responses will be linked to your name, so please feel free to be honest and open with your answers. There are no right or wrong answers, it is your opinions and perceptions we are interested in.

SECTION D – COMMUNITY LIVING PLAN GOALS

INTERVIEWER NOTE: There is also a plan known as the Community Discharge Plan, which is developed when clients leave hospital and aims to help the client with the transition from hospital to home and the community. This may be some client's most recent plan, however most should have had another plan developed since then. Try to get the participant to think of their most recent plan/goals.

D1 Often people in the Lifetime Care and Support Scheme have goals set as part of a plan. This plan might be known as a rehabilitation plan, a community living plan or plan for services.

Do you have any goals set in a plan?

1. Yes – GO TO D2
2. No – GO TO E1
3. Don't know – GO TO E1

D2 Are you aware of what your *most recent* goals are?

1. Yes – GO TO D3
2. No – GO TO D3
3. Don't know – GO TO D3

D3 Which of the following best describes your involvement in setting your goals?

READ OUT [ROTATE]

1. I set all my goals myself GO TO D4a
2. I had help in setting my goals GO TO D4a
3. I was not involved in setting my goals GO TO D4b
4. DON'T KNOW (DO NOT READ OUT) GO TO SECTION E

Quick Participant Questionnaire

D4a How do you feel about your level of involvement in setting your goals? Do you feel you should have had more involvement, less involvement, or was it the right amount of involvement?

3. More involvement
2. The right amount of involvement
1. Less involvement

D4b How do you feel about your level of involvement in setting your goals? Do you feel you should have had more involvement, or not?

3. More involvement
2. Not

SECTION E – PERCEPTIONS AND EXPECTATIONS

E1 I am now going to read out some statements that relate to the Lifetime Care and Support Scheme. For each one please tell me whether you agree, disagree, or are undecided.

THERE are NO STATEMENTS (a) to (c).


IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

1. Strongly Disagree
2. Disagree
3. Undecided
4. Agree
5. Strongly Agree
6. DON'T KNOW (DO NOT READ OUT)

FILTERS:

1. IF D1=NO/ DK THEN LEAVE OUT STATEMENT (f) RE Goals.

ORDER	READ OUT. ROTATE ORDER.	Strongly Agree 5	Agree 4	Undecided 3	Disagree 2	Strongly Disagree 1	Don't Know 6
d	I feel part of a community						
e	I feel I have enough time with friends						
 f	<i>I feel I'm progressing too slowly with my goals (in my Community Living Plan)</i>						
g	Considering my stage of rehabilitation, I am happy with how much I get out into the community						

Quick Participant Questionnaire

SECTION F - ATTENDANT CARE

F1 Do you have an attendant carer?

1. Yes - GO TO F2
2. No - GO TO SECTION G
3. Don't know if received attendant care – GO TO SECTION G

F2 I am now going to read out some statements that relate to your attendant carer or carers. For each one please tell me whether you agree, disagree, or are undecided.

a) My Attendant carer(s) usually gets here on time?

IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

1. Strongly Disagree
2. Disagree
3. Undecided
4. Agree
5. Strongly Agree
6. DON'T KNOW (DO NOT READ OUT)

b) My attendant carer(s) is available when I need them?

IF AGREE: And do you agree or strongly agree?

IF DISAGREE: And do you disagree or strongly disagree?

1. Strongly Disagree
2. Disagree
3. Undecided
4. Agree
5. Strongly Agree
6. DON'T KNOW (DO NOT READ OUT)

F3 If you had a problem with your attendant carer(s), who would you raise it with?

DO NOT READ OUT. MULTIPLE RESPONSE

1. Attendant care provider
2. Attendant carer themselves
3. Nominated person/ family member
4. Case Manager
5. LTCS Coordinator
6. Other (specify with job title if appropriate) _____
7. Don't know / Depends

Quick Participant Questionnaire

F4a Have you ever had a problem with your attendant carer(s)? IF YES: And what MULTIPLE RESPONSE

DO NOT READ OUT

- 1. Yes, not sufficiently skilled/ trained – GO TO F4b
- 2. Yes, not caring/ warm – GO TO F4b
- 3. Yes, don't follow instructions – GO TO F4b
- 4. Yes, personality clash – GO TO F4b
- 5. Yes, other (specify _____) – GO TO F4b
- 6. No – GO TO F5
- 7. Don't know – GO TO F5

F4b Who did you raise this/ these concern(s) with? [MULTIPLE RESPONSE]

DO NOT READ OUT

- 1. Attendant care provider – GO TO F4c
- 2. Attendant carer themselves – GO TO F4c
- 3. Nominated person – GO TO F4c
- 4. Case Manager – GO TO F4c
- 5. LTCS Coordinator – GO TO F4c
- 6. Other (specify with job title if appropriate) _____ – GO F4c
- 7. Don't know – GO TO F5
- 8. No-one – GO TO F5

F4c Was/ were your concern(s) dealt with to your satisfaction? [PROBE: And was it somewhat dealt with or completely dealt with?].

DO NOT READ OUT

- 1. Yes, completely
- 2. Yes, somewhat
- 3. No
- 4. Don't know

F5 How can attendant care services be improved to better meet your needs? Even small improvements are helpful to know. [PROBE: And is there anything else?]

Quick Participant Questionnaire

SECTION H – CLOSE AND DEMOGRAPHICS

H1 We've come to the end of the interview. Is there anything else you would like to comment on about the Lifetime Care and Support Scheme, Authority, or Service Providers? [PROBE: And is there anything else?]

That brings us to the end of the interview. Thank you very much for your time and help. My name again is This market research was conducted on behalf of the Lifetime Care and Support Authority. It is carried out in compliance with the Privacy Act, and the information you provided will be used for research purposes only.

SANDRA: If you would like any more information about this project or the researchers you can phone XXXX XXX XXX.

LIZ/ NEVA: If you would like any more information about this project or the researchers you can phone XXXX XXX XXX.

Time Finished

Interviewer Name (PRINT) _____

Interviewer Signature _____

Recruitment Script

NON ENGLISH SPEAKING BACKGROUND

If at INTRODUCTION, the person you need to speak to does not speak English, then try to identify the language they speak. Only record a specific language if you are fairly certain this is the language they speak.

1. Specify Language _____ **TELL PROJECT DIRECTOR IMMEDIATELY**
2. Cannot tell what language they speak. **TELL SANDRA IMMEDIATELY**

RECORD ON CALLSHEET

WRONG NUMBER

Firstly ask the person you are speaking to if they know the participant:

1. If do know participant – ask if they have a contact number for them _____
2. If do not know participant OR does not provide number – **TELL PROJECT DIRECTOR IMMEDIATELY**

RECORD ON CALLSHEET

NOTE: PARTICIPANT AND NOMINATED PERSON INTERVIEWS DO NOT HAVE TO BE ON THE SAME DAY. HOWEVER WE NEED TO INTERVIEW THE **NPC BEFORE THE PARTICIPANT**. THE NPI CAN BE INTERVIEWED AT ANY TIME.

INTRODUCTION

Good morning/afternoon/evening, my name is I am calling on behalf of the Lifetime Care and Support Authority.

S1 Could I please speak to the person who mainly deals with the Lifetime Care and Support Scheme and services associated with the Scheme, for [participant's name]?

ONCE SPEAKING TO THE NOMINATED PERSON/ PARTICIPANT, REINTRODUCE YOURSELF IF NECESSARY

I am part of an independent research organization that is conducting a survey on behalf of the Lifetime Care and Support Authority.

S2. IF NECESSARY - IS YOUR NAME [Participant's Name]?

1. YES = PARTICIPANT
2. NO = NOMINATED PERSON Can you please tell me your name and relationship to [Participant's Name]? (Specify name & relationship _____)

LETTER

L1: IF SPEAKING WITH PARTICIPANT: you should have received a letter recently telling you about a research study the Lifetime Care and Support Authority is conducting, and that we would be calling you. Do you remember seeing this letter?

IF SPEAKING WITH NOMINATED PERSON: (Participant's name) and perhaps you yourself should have received a letter recently telling you about a research study the Lifetime Care and Support Authority is conducting, and that we would be calling you. Do you remember seeing this letter?

1. Yes – GO TO "PARTICIPANT" (p3) OR 'NOMINATED PERSON' SECTION (p7)
2. No – GO TO L2

L2. Does someone else in your household recall seeing this letter?

1. Yes – GO TO "PARTICIPANT" (p3) OR 'NOMINATED PERSON' SECTION(p7)
2. No – GO TO L3

L3. IF NO LETTER RECEIVED: Would you like me to organise a replacement letter, or can I organise an interview with you now?

1. Replacement letter – GO TO L4
2. Organise interview time – GO TO "PARTICIPANT" (p3) OR 'NOMINATED PERSON' (p7)SECTION

L4. What is the best address to send the letter to?

The letter should be with you in the next couple of days and I will call you again in one week.

IF APPROPRIATE: Can I organise a time to call back?

RECORD: DATE _____ TIME: _____(put it in your diary)

THANK AND CLOSE.

RECORD ON CALLSHEET AND SEND DETAILS TO SANDRA IMMEDIATELY FOR REPLACEMENT LETTER TO BE SENT.

PARTICIPANT

We would like to conduct an interview over the phone to find out what people think about the Lifetime Care and Support Scheme and ways it could be improved to better meet the needs of clients.

S3. But first can I just check which of the following best describes you:

- 1. I know the name 'Lifetime Care and Support' but not what they do. GO TO PARTICIPANT A
- 2. I know a little about what Lifetime Care and Support do GO TO PARTICIPANT B (p5)
- 3. I know a lot about what Lifetime Care and Support do GO TO PARTICIPANT B (p5)

PARTICIPANT A

Thanks for that. I may wish to interview you for 5 to 7 minutes.

A1: Is there a family member or someone else that helps you with the Lifetime Care and Support Scheme?

- 1. Yes GO TO A3
- 2. No GO TO A2

A2. OK, may I interview you now for around 5 minutes? GO TO QUICK QUESTIONNAIRE

A3. IF NECESSARY: And who is that? (Specify _____). I would like to interview (name/ relationship) too and I'd need to interview them first. Would you prefer that (name/ relationship) does the whole interview, or that I interview both of you?

- 1. Other person does whole interview = *Main q'aire - Nominated Person Only* GO TO A4
- 2. Both = *Dual Q'aire – Short Dual* GO TO A6

A4. Could I please speak to (name/ relationship)?

IF NOT AVAILABLE, THEN ASK FOR THE PERSONS FULL NAME AND PHONE NUMBER.

Name _____ Ph _____

THANK AND CLOSE.

IF/ WHEN AVAILABLE THEN GO TO A5.

A5. Good morning/afternoon/evening, my name is I am calling on behalf of the Lifetime Care and Support Authority. I am part of an independent research organization that is conducting a survey on behalf of the Lifetime Care and Support Authority. We would like to conduct an interview over the phone to find out what people think about the Lifetime Care and Support Scheme and ways it could be improved to better meet its clients' needs. (Participant's name) has asked that you complete an interview on his/ her behalf.

I would like to speak to you for around 20 minutes. May I interview you now or make a time with you for another day?

- 1. Yes – Now GO TO SECTION Z BEFORE STARTING *Main Questionnaire: Nominated Person Only*
- 2. Yes – Appointment RECORD DATE, TIME AND NAME/S BELOW THEN GO TO SECTION Z

RECORD: DATE _____ TIME: _____ (put it in your diary)

- 3. No/refused interview (specify reason) _____

IF INTERVIEW IS 3 OR MORE DAYS AWAY: I will call you the day before the interview to confirm the time still suits. (Put in diary)

A6 I'll need to interview (name/ relationship) first, so can I make a time to call you back for : interview please? INTERVIEWER NOTE: PERHAPS MAKE APPT IN 2 DAYS TIME TO ALLOW FOR NP INTERVIEW TO BE DONE FIRST.

RECORD: DATE _____ TIME: _____(put it in your diary

IF INTERVIEW IS 3 OR MORE DAYS AWAY: I will call you the day before the interview to confirm the time still suits. (Put in diary)

A7 And Could I please speak to (name/ relationship) now?

IF NOT AVAILABLE, ASK FOR THE PERSONS NAME, PHONE NUMBER, & A GOOD TIME TO CALL.

Name _____ Ph _____

THANK AND CLOSE.

IF/ WHEN AVAILABLE THEN GO TO A8.

A8. Good morning/afternoon/evening, my name is I am calling on behalf of the Lifetime Care and Support Authority. I am part of an independent research organization that is conducting a survey on behalf of the Lifetime Care and Support Authority. We would like to conduct an interview over the phone to find out what people think about the Lifetime Care and Support Scheme and ways it could be improved to better meet its clients' needs. (Participant's name) has agreed to complete an interview, but I would like to interview you for around 20 minutes.

May I interview you now or make a time with you for another day?

1. Yes – Now GO TO SECTION Z BEFORE STARTING *Main Questionnaire: Dual Nominated Person*
2. Yes – Appointment RECORD DATE, TIME AND NAME/S BELOW THEN GO TO SECTION Z

RECORD: DATE _____ TIME: _____(put it in your diary)

Name of nominated person being interviewed? _____

3. No/refused interview (specify reason) _____
IF NOMINATED PERSON REFUSES INTERVIEW THEN CALL PARTICIPANT AT AGREED TIME AND DO THE QUICK QUESTIONNAIRE.

PARTICIPANT B

B1 Thanks for that. We would like to conduct an interview over the phone to find out what you think about the Lifetime Care and Support Scheme and ways it could be improved to better meet the needs of clients. We need to speak to you for around 20 minutes. If 20 minutes is too long for you, we can do half of it on one day and the other half the next day. Or, we can conduct part of the interview with you and part of it with someone else: a partner or other relative who has also been dealing with the Lifetime Care and Support Scheme matters. Which option suits you?

1. Participant only interview = *Main Q'aire -Participant only interview* – GO TO B2
2. Shared = *Main Q'aire - Long/short dual nominated person PLUS Dual Participant Q'aire* – GO TO B3
3. Nominated person only interview – *Main Q'aire –Nominated Person only interview* GO TO B3
4. No/Refused – RECORD REASON FOR REFUSAL _____

B2. APPOINTMENT: May I interview you now or make a time with you for another day?

1. Yes – Now - GO TO SECTION Z BEFORE STARTING *Main Questionnaire: Participant Only*
2. Yes – Appointment - RECORD DATE, TIME AND NAME/S BELOW THEN GO TO SECTION Z

RECORD: DATE _____ TIME: _____(put it in your diary)

3. No/refused interview (specify reason) _____

IF INTERVIEW IS 3 OR MORE DAYS AWAY: I will call you the day before the interview to confirm the time still suits. (Put in diary)

B3. I'll need to interview (name/ relationship) first, so can I make a time to call you back for an interview please? INTERVIEWER NOTE: PERHAPS MAKE APPT IN 2 DAYS TIME TO ALLOW FOR NP INTERVIEW TO BE DONE FIRST.

RECORD: DATE _____ TIME: _____(put it in your diary).

IF INTERVIEW IS 3 OR MORE DAYS AWAY: I will call you the day before the interview to confirm the time still suits. (Put in diary)

B4 And Could I please speak to (name) now?

IF NOT AVAILABLE, ASK FOR THE PERSONS NAME,PHONE NUMBER & A GOOD TIME TO CALL.

Name _____ Ph _____

THANK AND CLOSE.

IF/ WHEN AVAILABLE THEN GO TO B5.

B5. Good morning/afternoon/evening, my name is I am calling on behalf of the Lifetime Care and Support Authority. I am part of an independent research organization that is conducting a survey on behalf of the Lifetime Care and Support Authority. We would like to conduct an interview over the phone to find out what people think about the Lifetime Care and Support Scheme and ways it could be improved to better meet its clients' needs. (Participant's name) has agreed to complete an interview, but I would like to interview you first for around 20 minutes.

1. Yes – Now GO TO SECTION Z BEFORE STARTING *Main Questionnaire: Dual Nominated Person*
2. Yes – Appointment RECORD DATE, TIME AND NAME/S BELOW THEN GO TO SECTION Z

RECORD: DATE _____ TIME: _____ (put it in your diary)

3. No/refused interview (specify reason) _____

IF INTERVIEW IS 3 OR MORE DAYS AWAY: I will call you the day before the interview to confirm the time still suits. (Put in diary)

Name of nominated person being interviewed? _____

IF NOMINATED PERSON REFUSES INTERVIEW THEN CALL PARTICIPANT AT AGREED TIME AND DO THE QUICK QUESTIONNAIRE

NOMINATED PERSON

NP1 We would like to conduct an interview over the phone to find out what you and [participant's name] think about the Lifetime Care and Support Scheme and ways it could be improved to better meet its clients' needs.

We would like to speak to you first for around 20 minutes and then [participant's name] for around 5 to 7 minutes. Or if you feel [participant's name] is not able to be interviewed we can just interview you. Which option is best?

1. Nominated person only interview – GO TO NP2
2. Short Dual– GO TO NP3
3. No/Refused – RECORD REASON FOR REFUSAL

NP2 May I interview you now or make a time with you for another day?

1. Yes – Now GO TO SECTION Z BEFORE STARTING *Main Questionnaire: Nominated Person Only*
2. Yes – Appointment RECORD DATE, TIME AND NAME/S BELOW THEN GO TO SECTION Z

RECORD: DATE _____ TIME: _____ (put it in your diary)

3. No/refused interview (specify reason) _____

IF INTERVIEW IS 3 OR MORE DAYS AWAY: I will call you the day before the interview to confirm the time still suits. (Put it in diary)

Name of nominated person being interviewed? _____

NP3 May I interview you now or make a time with you for another day?

1. Yes – Now GO TO SECTION Z BEFORE STARTING *Main Questionnaire: Dual Nominated Person.*

***ONCE INTERVIEW IS COMPLETE ASK TO SPEAK TO PARTICIPANT.**

2. Yes – Appointment RECORD DATE, TIME AND NAME/S BELOW THEN GO TO SECTION Z

RECORD: DATE _____ TIME: _____ (put it in your diary)

Name of nominated person being interviewed? _____

3. No/refused interview (specify reason) _____

ONE WEEK AFTER LETTER SENT – PARTICIPANT AND NOMINATED PERSON

INTERVIEWER CHECK S2 ANSWER ON p1 AND CIRCLE WHO TO ASK FOR:

1. PARTICIPANT
2. NOMINATED PERSON (Specify name & relationship _____)

Good morning/afternoon/evening, my name is I am calling on behalf of the Lifetime Care and Support Authority.

Could I please speak to [PARTICIPANT/ NOMINATED PERSON]?

I called you about a week ago in regards to a survey the L/ifetime Care and Support is conducting. We resent the letter.

A. Have you received it yet?

1. Yes – GO TO “PARTICIPANT’ OR ‘NOMINATED PERSON’ SECTION’
2. No – GO TO B

B. IF NO LETTER RECEIVED: Would you like me to organise another replacement letter, or can I organise an interview time with you now?

1. Organise interview time - GO TO “PARTICIPANT’ OR ‘NOMINATED PERSON’ SECTION’
2. Replacement letter – GO TO C

C. What is the best address to send the letter to?

The letter should be with you in the next couple of days and I will call you again in one week.

IF APPROPRIATE: Can I organise a time to call back?

RECORD: DATE _____ TIME: _____ (put it in your diary)

THANK AND CLOSE. RECORD ON CALLSHEET AND SEND DETAILS TO SANDRA IMMEDIATELY FOR REPLACEMENT LETTER TO BE SENT.

Z. ASK ALL – RE: NOMINATED PERSON INITIAL (NPI)

IF SPEAKING TO CURRENT NOMINATED PERSON: I have just one more thing I would like to ask. We would like to ask a few questions of the family member or friend who helped [participant's name] when he/she first joined the scheme. This is most likely when [participant's name] was in hospital. Is that person yourself or someone else?

1. Same CONTINUE TO QUESTIONNAIRE OR REPEAT APPOINTMENT & CLOSE
2. Different /someone else GO TO Z1

IF SPEAKING TO PARTICIPANT: I have just one more thing I would like to ask. We need to ask a few questions of the family member or friend who helped you when you first joined the scheme. This is most likely when you were still in hospital. Can you tell me who that person was?

1. Same as current nominated person IF SAME AND DON'T HAVE NOMINATED PERSON DETAILS THEN ASK: Do they live with you there? IF YES THEN ASK: Can you please give me their name? _____ THEN CONTINUE TO QUESTIONNAIRE.
2. Different to current nominated person /someone else GO TO Z1
3. Don't have current nominated person (Participant only interview): Specify relationship/ name of initial nominated person _____ GO TO Z1.
4. Don't know REMIND OF INTERVIEW TIME "That's OK, I will just do your interview on [date] at [time]." Or CONTINUE TO QUESTIONNAIRE as appropriate.

Z1 IF DIFFERENT: Would it be OK if I got their name and phone number so I could contact them to ask them the 4 questions. It is just important that we ask someone who was around you / [participant's name] in the initial part of the process.

1. Yes – GO TO Z2
2. No / REFUSED – REMIND OF INTERVIEW TIME "That's OK, I will just do your interview on [date] at [time]." Or CONTINUE TO QUESTIONNAIRE as appropriate.

Z2. Do they live in the same household as you?

1. Yes – GO TO Z3
2. No – GO TO Z4

Z3. I'd like to continue to interview you now, so what would be a good time to call them/ (name) back?

1. Refused/ DK
2. Provide details / call back later

Name: _____

Phone number check: _____

Good time to call (if possible) _____

Z4. Can you please give me their details so I can contact them?

1. Yes – RECORD DETAILS BELOW
2. No / refused - REMIND OF INTERVIEW TIME "That's OK, I will just do your interview on [date] at [time]." Or CONTINUE TO QUESTIONNAIRE as appropriate.

Name: _____

Phone number: _____

Good time to call (if possible) _____

Z5: IF CONTACTING SEPARATE INITIAL NOMINATED PERSON:

Good morning/afternoon/evening, my name is I am calling on behalf of the Lifetime and Support Authority. I am part of an independent research organization that is conducting a on behalf of the Lifetime Care and Support Authority to find out what people think about the Sc and ways it could be improved to better meet the needs of clients.

[Participant's Name/ Nominated Person's Name] has given me your contact details and I would to ask you 4 questions about your experience with (Participant's Name) when he/she started w Lifetime Care and Support Scheme.

May I interview you briefly now or make a time with you for another day?

1. Yes – Now GO TO Main Questionnaire: Page 9 – C6(a) to C6(d) inclusive.

2. Yes – Appointment RECORD DATE, TIME AND NAME/S BELOW

DATE _____ TIME: _____ (put it in your diary)

3. No/refused interview (specify reason) _____

IF INTERVIEW IS 3 OR MORE DAYS AWAY: I will call you the day before the interview to cor the time still suits.

Name of 'nominated person initial' being interviewed? _____
