# 6 Care Experience Survey summary of results

## 6.1 Survey aims and methodology

The Care Experience Survey was designed to elicit client and family perspectives of:

- level and areas of need for assistance
- the extent to which needs were met before joining a pilot project
- project effectiveness in meeting previously unmet needs
- the standard of aspects of service delivery
- the suitability of projects for providing care at home over the longer term.

The survey questionnaire was designed according to the recommendations of Cooper and Jenkins (1998) to find out about positive and any negative aspects of service delivery. The questionnaire was reviewed by a clinical psychologist and was piloted among staff at the AIHW and their older relatives and a small number of early clients in the North East Dementia Innovations Demonstration project at Austin Health who did not take part in the evaluation. The draft questionnaire was sent to service providers in the Pilot for comment. Feedback from the review and piloting was used to fine tune the instrument.

Project coordinators in the Dementia Pilot issued the Care Experience Survey questionnaire to each participating client/carer, having allowed for a client to have been receiving services for at least 4 weeks. Respondents completed the questionnaire and mailed it to the AIHW evaluation team by reply paid post. The Survey was anonymous. While responses can be linked to client profile and assessment data using the unique client identification code recorded by the project coordinator on the front of each questionnaire before issue, names and addresses or other identifying information were not requested.

The questionnaire includes a combination of closed, limited response and open-ended questions. Respondents were asked to compare the care received from a project to the clients' 'usual care' (before the project) and to report on whether the project met or is meeting previously unmet need for assistance across a range of areas covering health care, social care and ADL support. Respondents were also able to comment on specific aspects of service delivery such as care planning and coordination; continuity of care; the range and availability of services; choice; convenience; privacy and security; and the physical environment. Carers and family members were asked to assess the support and assistance they receive to assist them in their caring role and whether they believe that the project provides a suitable long-term care option for the care recipient.

A copy of the questionnaire is available on request to the AIHW Ageing and Aged Care Unit.

Analysis of completed questionnaires received by 31 January 2005 is summarised below. The data were analysed with frequency and cross-tabulation procedures in the SPSS computer package.

## 6.2 Response rates

A total of 249 questionnaires were distributed and 135 questionnaires were returned by 31 January 2005 (Table A6.1). Response rates for individual projects range between 29% and 71%, with an overall response rate of 54%.

**Table A6.1: Care Experience Survey, surveys distributed and received, and response rates by project**

| Project (approved provider) | Number of surveys distributed | Number of surveys received | Response rate (per cent) | Per cent of total response |
|---|---|---|---|---|
| Dementia Behaviour Assessment and Management Service (Southern Area Health Service, NSW Health, Wagga Wagga) | 39 | 13 | 33.3 | 8.9 |
| Dementia Rehabilitation at Home (North Coast Area Health Service, NSW Health, Northern Rivers) | 31 | 21 | 67.7 | 14.4 |
| Flexible Care Service (*annecto—the people network*, Melbourne) | 24 | 7 | 29.2 | 4.8 |
| North East Dementia Innovations Demonstration (Austin Health, Melbourne) | 14 | 9 | 64.3 | 6.2 |
| RSL Care Innovative Dementia Pilot (RSL Care Queensland, Brisbane) | 32 | 14 | 43.8 | 9.6 |
| South Brisbane & Gold Coast Pilot (Islamic Women's Association, Brisbane and Gold Coast) | 26 | 16 | 61.5 | 11.0 |
| Ozcare Innovative Dementia Care Packages (Ozcare, Rockhampton/Gladstone and Bundaberg) | 35 | 25 | 71.4 | 17.1 |
| Dementia Care in Alternative Settings (Southern Cross Care WA, Perth) | 33 | 20 | 60.6 | 13.7 |
| The Sundowner Club (ECH Incorporated, Adelaide) | 15 | 10 | 66.7 | 6.8 |
| **Total** | **249** | **135** | **54.2** | **100.0** |

### 6.2.1 Respondent identity

Respondents were asked to indicate who completed the Care Experience Survey on the first page of the questionnaire. More than one respondent could be identified on each questionnaire, for example, where a carer assists the client to complete a questionnaire, both 'client' and 'carer' is recorded. Respondent identities varied across the projects (Table A6.2).

**Table A6.2: Care Experience Survey, respondent identities by project**

| | Respondent identity | | | | | |
|---|---|---|---|---|---|---|
| **Project** | **Client** | **Carer** | **Other relative** | **Project coordinator** | **Other advocate** | **Total** |
| | | | **(number)** | | | |
| Dementia Behaviour Assessment and Management Service | 2 | 9 | 2 | — | 3 | 16 |
| Dementia Rehabilitation at Home | 3 | 18 | — | — | 2 | 23 |
| Flexible Care Service | 1 | 7 | 2 | — | — | 10 |
| North East Dementia Innovations Demonstration | — | 9 | 1 | — | — | 10 |
| RSL Care Dementia Pilot | 3 | 14 | 3 | — | — | 20 |
| South Brisbane & Gold Coast Pilot | 4 | 8 | 1 | 5 | 6 | 24 |
| Ozcare Innovative Dementia Pilot | 5 | 21 | 3 | — | 1 | 30 |
| Dementia Care in Alternative Settings | 1 | 16 | 3 | — | — | 20 |
| The Sundowner Club | 8 | 3 | — | 1 | — | 12 |
| **Total** | **27** | **105** | **15** | **6** | **12** | **165** |
| | | | **(per cent)** | | | |
| Dementia Behaviour Assessment and Management Service | 12.5 | 56.3 | 12.5 | — | 18.8 | 100.0 |
| Dementia Rehabilitation at Home | 13.0 | 78.3 | — | — | 8.7 | 100.0 |
| Flexible Care Service | 10.0 | 70.0 | 20.0 | — | — | 100.0 |
| North East Dementia Innovations Demonstration | — | 90.0 | 10.0 | — | — | 100.0 |
| RSL Care Innovative Dementia Care Pilot | 15.0 | 70.0 | 15.0 | — | — | 100.0 |
| South Brisbane & Gold Coast Pilot | 16.7 | 33.3 | 4.2 | 20.8 | 25.0 | 100.0 |
| Ozcare Innovative Dementia Care Packages | 16.7 | 70.0 | 10.0 | — | 3.3 | 100.0 |
| Dementia Care in Alternative Settings | 5.0 | 80.0 | 15.0 | — | — | 100.0 |
| The Sundowner Club | 66.7 | 25.0 | — | 8.3 | — | 100.0 |

*Note:* Multiple responses permissible.

— Nil.

Twenty-seven questionnaires were completed with the involvement of clients and 120 with the input of carer and/or other family members. Respondent identity was not indicated on three questionnaires.

Project coordinators were asked to encourage completion of the questionnaire by each client with or without assistance from a carer or other involved family member, wherever possible. This was not always possible and five clients received assistance from project staff.

Circumstances that led to staff involvement included, for example, lack of a carer or other close relative or friend, poor eyesight, impaired fine motor skills, or difficulty with written English. As the purpose of the survey was to gather views of the projects from the point of view of clients and their families, surveys completed by project staff (seven forms) were excluded from analysis of questions directly relating to satisfaction with project implementation, for example, satisfaction with staffing arrangements, convenience of project services, and project planning and coordination.

## 6.3 Coding framework

The AIHW engaged a consultant to develop a coding framework for responses to open-ended questions and perform analysis of completed forms in their entirety.

Development of the coding framework was an iterative process. The consultant completed a thematic analysis of a selection of hand-written responses to five key open-ended questions. The first two of these questions focus on needs and expectations. Two initial lists of 20 to 30 recurring themes were constructed, one by the consultant and one by the AIHW evaluation team. A high level of agreement was apparent and the process of cross-referencing the two lists produced a set of core themes for the initial coding framework. This list was further expanded and refined to accommodate responses to three more open-ended questions on the adequacy and quality of the project services and staffing.

The AIHW evaluation team reviewed the resulting set of codes. A number of additional codes were subsequently added to the framework until it was shown that responses to the five key open-ended questions in 50 completed questionnaires could be coded satisfactorily. The final coding framework consists of:

- 30 core themes
- 10 themes specifically associated with how the projects meet or fail to meet client needs
- nine themes that deal specifically with staffing issues
- nine themes associated with aspects of the Pilot that attract positive feedback from respondents
- nine themes associated with aspects of the Pilot that attract negative feedback from respondents
- 15 themes to cover general comments, both positive and negative.

Over 80 themes were identified for the coding framework and used in the interim analysis. The framework has been designed so that specific themes can be combined into more general categories for reporting purposes.

Inter-rater reliability of coding according to the global coding framework and responses to the most commonly answered open-ended questions was tested on a random sample of 20 questionnaires. A total of 23 categories from the coding framework featured in this analysis. Ten categories had perfect agreement and a further eight categories only deviated very slightly. The intra-class correlation coefficient for agreement between independent raters was 0.967, indicating a very high level of inter-rater reliability.

## 6.4 Summary of results

The Care Experience Survey revealed that projects have targeted clients with a wide range of needs, most commonly in the areas of domestic assistance, personal assistance, behaviour management, community access and social support. Approximately 28% of clients who responded to the survey (or on whose behalf a response was submitted) are reported as not having received assistance, either formal or informal, in the 6 months prior to starting with a project (Table A6.3). The most common source of assistance with everyday activities was family, friends and/or neighbours. Around 57% of respondents reported receiving assistance from a community organisation prior to the pilot (Table A6.4).

The areas mentioned by most respondents in relation to prior unmet need include domestic assistance, social support and nursing care at home. Assistance to manage the behavioural and psychological symptoms of dementia stood out as the most common area of unmet need—67% of respondents indicated that they needed help but were not receiving any assistance in this area prior to the project (Table A6.5).

These results accord with results from the baseline assessment of clients, which show that many clients displayed behavioural and psychological symptoms of dementia, and that most clients were partially or wholly dependent on the assistance of others for self-care and domestic activities.

Negative comments about service delivery mostly related to communication between the project coordinator and clients/carers, for example, returning telephone calls and checking up on things; access to aids and equipment; and limited hours of assistance. The few criticisms made were levelled mainly at the long-term care package services. Better or more frequent communication was desired by some of the family carers in DCAS and RSL Care Pilot and several carers with a relative in the Ozcare Packages project mentioned limited availability of aids and equipment. Comments about insufficient hours of assistance indicated gratitude for the amount of assistance received but also highlighted that more assistance was often needed. Comments from some carers in the RSL Care Pilot suggest that assistance to their care recipients was capped at 10–12 hours per week, which they felt was insufficient to meet their needs.

Across all projects, respondents made many more positive comments than negative comments when asked about aspects of the project they particularly liked and disliked. The most common single service type most liked was services and support for carers, including respite care (22 responses), though the majority of positive comments related to intangible benefits of the projects (77 responses) (Table A6.12). The most common criticism on these items was a lack of information and communication from the project team (six responses) (Table A6.13).

Carers and family members report benefiting from the information and support services provided by the projects (67–85% of those who responded in each project). The majority of carers and family members who received respite were happy with the nature, amount and quality of respite service provided (approximately 60–70% of those who responded). The survey also identified gaps in the awareness of carers and family members of people with dementia relating to Australian Government support services available to them, with approximately 50-60% those who responded unaware of four key sources of information and support.

Ninety-one of the 110 carers and family members who completed section C (83%) believe the Innovative Pool Dementia Pilot project delivered a level of service that could be expected to support their relative or friend for the foreseeable future (Table A6.15). Eight respondents

(7%) across four projects stated that the project would be an unsuitable form of longer term care. Eight respondents (7%) across six projects were unsure about the suitability of the project as a longer term care option. Comments from carers and family members illustrate their gratitude for the assistance provided through the projects. Where carers and family members expressed doubts over whether the project would be suitable in the longer term, they generally cited high carer strain, need for supervision or higher level care than the project could provide, or concerns about whether project services would be sufficient to cope with needs which may increase in the future.

A sample of responses to selected open-ended questions, taken from several projects, follows.

*To the question of client and family expectations of the projects:*

‘Personal care—emotional support, education about medication and dementia.’

‘Same hours per day, seven days. More respite.’

‘I am a widow and working fulltime as this is necessary for my family. I am an only child. I hope to keep my parents at home as long as possible. They would be so stressed out of their home environment. I go around at least once a day.’

‘I was receiving no help, no care except that from my wife. I hoped the program would be able to get me out to do and see different things and give my wife some time out.’

‘Assistance, support and respite in caring for my mother in my home.’

‘I had no expectations of help, but am pleasantly surprised with the help and advice forthcoming.’

*To the question of how the project helps or doesn't help to meet needs and aspects most liked, clients, carers and relatives say:*

‘As soon as my husband started the program, life changed for us.’

‘Somebody can speak the language and understand our culture. My husband doesn't want [to go to] residential care.’

‘I think the first weeks were great with two visits a day. The one hour a day has not been so good.’

‘Respite at home in the house.’

‘The staff carry out their tasks in a caring and professional manner.’

‘The quality support that is provided for a person with dementia and cerebrovascular disease. The documented service delivery plan provided by the provider.’

‘This is a wonderful program. [The provider] is exceptional and they have made a great difference to my parents' life and mine.’

‘Pilot program has been the best thing for [client] in years. Program workers get 100% mark from me as family member/carer.’

‘Program has given me peace of mind.’

‘The program delivers in all areas but one. It is not possible to place Mum into a respite centre when I need a break, so it would be wonderful if in-house respite was available for the occasional weekend off.’

‘The program has reduced the “frazzled” element for me by about 90%.’

‘Excellent.’

'It has been of great help.' [emphasis original]

*Comments on experience in accessing community care before the Innovative Pool Dementia pilot:*

'[client] had never received any help prior to this program except a man who came to mow the lawn.'

'My family was very deprived we don't have any idea of service. This pilot project changed our lives.'

'Help received [through a CACP] only 10 hours [per week], which is too little, but now better.'

'Before the program it was difficult to get help as family member was very uncooperative.'

'We needed to get into the "system" of care…as we had no information on where to go. Through the team organising these things for me I was able to get help.'

'Bloody hopeless!! Three local doctors—no help!!! One said "there's nothing wrong with your husband — you spoil him and he's lazy".'

'The pilot program opened doors for me to know where to get help. Before the program I was at the end of my endurance, without hope. I don't need sympathy (it's nice) or [to be] loaded with guilt—need sound day-by-day help and that's what the program gave me.'

'I felt lost. I didn't know where to turn for help. I had Mum and Dad to look after, we lived on a farm and it took 1 hour to the nearest town for the doctors, and 2 ½ hours [to the specialist]…we had a lot on our plates with the drought also.'

' "Commonwealth Carers Respite Centres" this is a JOKE!! It only caters for Emergency Respite to carers. It's very misleading and incorrect.' [emphasis original]

'Didn't like to overburden the family.'

## 6.5 Tabulated responses

### 6.5.1 Previous sources of assistance

Forty-one of the 135 respondents indicated that they had not been receiving assistance with everyday activities (personal care, meal preparation, taking medication, mobility, and transport) from any source in the 6 months prior to entering the project (Table A6.3). The most common source of assistance with everyday activities was family, friends and/or neighbours (77 respondents); 60 respondents reported that they were receiving assistance from either the organisation delivering the Innovative Pool services or another organisation.

**Table A6.3: Care Experience Survey, sources of assistance prior to entering the pilot**

| Source of assistance | Responses | Per cent |
|---|---|---|
| No-one | 41 | 30.4 |
| Family, friends and/or neighbours | 77 | 57.0 |
| Organisation delivering the pilot | 27 | 20.0 |
| Another organisation | 23 | 17.0 |
| District nursing service | 12 | 8.9 |
| Home care service | 7 | 5.2 |
| Other | 25 | 18.5 |

*Note:* Multiple responses permissible.

Around 47% of respondents reported not having received service or assistance from community organisations in the 12 months prior to entering the pilot (63 respondents) (Table A6.4). Domestic assistance (47 respondents), personal assistance (33 respondents), transport to appointments (29 respondents) and in-home respite care (26 respondents) were the most common types of assistance received from community organisations.

**Table A6.4: Care Experience Survey, assistance received from community organisations prior to entering the pilot**

| Assistance type | Responses | Per cent |
|---|---|---|
| Not applicable/no previous assistance | 63 | 46.7 |
| Domestic assistance | 47 | 34.8 |
| Personal care | 33 | 24.4 |
| Transport to appointments | 29 | 21.5 |
| In-home respite care | 26 | 19.3 |
| Medication management | 22 | 16.3 |
| Advice to find required aids/equipment | 20 | 14.8 |
| Behaviour management | 17 | 12.6 |
| Day centre respite care | 15 | 11.1 |
| Respite care in a residential aged care facility | 15 | 11.1 |
| Home maintenance | 11 | 8.1 |
| Assistance with manual handling | 10 | 7.4 |
| Help managing financial affairs | 10 | 7.4 |
| Home nursing | 8 | 5.9 |

*Note:* Multiple responses permissible.

## 6.5.2 Identified needs

Responses to question 3 give an indication of respondents' views of how well clients' needs in each of 13 areas were being met prior to entering the project.

The highest numbers of clients with any level of need for assistance (including unmet, partially met and fully met need) were in the areas of domestic assistance (102 respondents), personal assistance (93 respondents), behaviour management (92 respondents), and transport to appointments and social events (90 respondents) (Table A6.5).

The areas of need where respondents more frequently indicated adequate assistance was received prior to the project are: transport to appointments and social events (59% of clients with need were receiving adequate assistance prior to entering the Pilot), help to get to a doctor when needed (59% of clients with need were receiving adequate assistance), medication management (56% of clients with need were receiving adequate assistance). Forty-three clients were receiving some personal assistance, but not enough to meet their needs (46% of clients with identified need). Other common areas of need where assistance was being provided at inadequate levels include domestic assistance (37% of clients with identified need), and nursing care at home (35% of clients with identified need).

Behaviour management is the area with the highest level of identified previously unmet need—62 of the 92 clients (67%) with identified need for assistance with behavioural and psychological symptoms of dementia were not receiving any assistance in this area prior to the Pilot. Other areas where assistance was needed but was not being received prior to the Innovative Pool projects include physiotherapy (59% of clients with identified need), continence management (43% of clients with identified need) and nursing care at home (42% of clients with identified need). Across all areas, at least 20% of clients with identified need were not receiving any assistance prior to the Pilot.

‘Not applicable’ was most often recorded against mobility assistance (85 respondents), physiotherapy (79 respondents), continence management (70 respondents), and nursing care at home (70 respondents), though at least 65 clients identified a need in each of these areas.

These results accord with results from the baseline assessment of clients which show that many clients display behavioural and psychological symptoms of dementia, and that most clients were partially or wholly dependent on the assistance of others for self-care and domestic activities.

## Table A6.5: Care Experience Survey, assessment of the adequacy of assistance received from all sources prior to the pilot

| Assistance type | Had enough help | Had help, more needed | Did not have help, help needed | Number with identified need | Number reporting unmet need | Not applicable/ did not need help(a) | Total |
|---|---|---|---|---|---|---|---|
| | | | | (number) | | | |
| Personal assistance | 27 | 43 | 23 | 93 | 66 | 42 | 135 |
| Continence management | 16 | 21 | 28 | 65 | 49 | 70 | 135 |
| Mobility assistance | 21 | 16 | 13 | 50 | 29 | 85 | 135 |
| Help to get to a doctor when necessary | 51 | 14 | 22 | 87 | 36 | 48 | 135 |
| Medication management | 45 | 15 | 21 | 81 | 36 | 54 | 135 |
| Domestic assistance | 42 | 38 | 22 | 102 | 60 | 33 | 135 |
| Home maintenance | 34 | 16 | 22 | 72 | 38 | 63 | 135 |
| Transport to appointments and social events | 53 | 19 | 18 | 90 | 37 | 45 | 135 |
| Assistance to source aids/equipment | 31 | 14 | 25 | 70 | 39 | 65 | 135 |
| Accompaniment at home | 41 | 29 | 19 | 89 | 48 | 46 | 135 |
| Nursing care at home | 15 | 23 | 27 | 65 | 50 | 70 | 135 |
| Physiotherapy | 13 | 10 | 33 | 56 | 43 | 79 | 135 |
| Behaviour management | 10 | 20 | 62 | 92 | 82 | 43 | 135 |
| | | | | (per cent)(b) | | | |
| Personal assistance | 29.0 | 46.2 | 24.7 | . . | . . | . . | 100.0 |
| Continence management | 24.6 | 32.3 | 43.1 | . . | . . | . . | 100.0 |
| Mobility assistance | 42.0 | 32.0 | 26.0 | . . | . . | . . | 100.0 |
| Help to get to a doctor when necessary | 58.6 | 16.1 | 25.3 | . . | . . | . . | 100.0 |
| Medication management | 55.6 | 18.5 | 25.9 | . . | . . | . . | 100.0 |
| Domestic assistance | 41.2 | 37.3 | 21.6 | . . | . . | . . | 100.0 |
| Home maintenance | 47.2 | 22.2 | 30.6 | . . | . . | . . | 100.0 |
| Transport to appointments and social events | 58.9 | 21.1 | 20.0 | . . | . . | . . | 100.0 |
| Assistance to source aids/equipment | 44.3 | 20.0 | 35.7 | . . | . . | . . | 100.0 |
| Accompaniment at home | 46.1 | 32.6 | 21.3 | . . | . . | . . | 100.0 |
| Nursing care at home | 23.1 | 35.4 | 41.5 | . . | . . | . . | 100.0 |
| Physiotherapy | 23.2 | 17.9 | 58.9 | . . | . . | . . | 100.0 |
| Behaviour management | 10.9 | 21.7 | 67.4 | . . | . . | . . | 100.0 |

(a) Includes missing values (assumed to be 'not applicable').

(b) Number of responses as a percentage of number of respondents who indicated the service was needed.

. . Not applicable.

### 6.5.3 Hopes and expectations on joining a project

- Thirty respondents either stated that they had no prior expectations of the project or were unsure of what to expect, or did not provide any comment (Table 6.6).
- Of the 153 statements of expectation related to specific areas of assistance, carer services and support was the most commonly cited service type (45 responses), followed by domestic assistance (42 responses).
- Seventy-five statements of expectation related to intangible benefits, with increased participation the most commonly cited (27 responses).
- Forty-two statements of expectation related to improved service quality and value, the most common of which was enhanced service (15 responses).

**Table A6.6: Care Experience Survey, respondents' hopes and expectations of projects, analysis of open-ended responses**

| Theme | Responses |
|---|---|
| **Specific instrumental assistance/services** | |
| Carer services and support | |
| Respite care | 28 |
| Assistance for carer | 17 |
| *Total carer services and support* | *45* |
| Domestic assistance | |
| Domestic assistance | 20 |
| Assistance with meals | 14 |
| Assistance with shopping | 8 |
| *Total domestic assistance* | *42* |
| Personal assistance | 25 |
| Behaviour management | 12 |
| Nursing support | 9 |
| Transport | 7 |
| Continence management | 5 |
| Other specific instrumental assistance/services | 8 |
| *Total specific instrumental assistance/services* | *153* |
| **Intangible benefits** | |
| Participation | 27 |
| Safety | 16 |
| Confidence/reassurance | 16 |
| Independence | 13 |
| Other intangible benefit | 3 |
| *Total intangible benefits* | *75* |

*(continued)*

**Table A6.6 (continued): Care Experience Survey, respondents' hopes and expectations of projects, analysis of open-ended responses**

| Theme | Responses |
|---|---|
| **Improved service quality/value** | |
| Enhanced service | 15 |
| General positive | 13 |
| Enhanced quality of care | 5 |
| Other improved service quality/value | 9 |
| *Total improved service quality/value* | *42* |
| No expectations, unsure, no comment | 30 |

*Note:* Multiple responses permissible.

## 6.5.4 Quality and appropriateness of services

The majority of respondents (84%) believed that their project had addressed or was addressing previously unmet needs (Table A6.7). Eighteen respondents across seven projects stated that their project was addressing some areas of unmet need, but not to the extent that they had hoped. Just one respondent indicated that the project was not addressing some important needs.

**Table A6.7: Care Experience Survey, respondents' beliefs about whether the projects meet previously unmet needs, by project**

| Project | Yes | Partly | No | Missing | Total |
|---|---|---|---|---|---|
| | | | (number) | | |
| Dementia Behaviour Assessment and Management Service | 12 | 1 | — | — | 13 |
| Dementia Rehabilitation at Home | 19 | 1 | — | 1 | 21 |
| Flexible Care Service | 6 | 1 | — | — | 7 |
| North East Dementia Innovations Demonstration | 9 | — | — | — | 9 |
| RSL Care Innovative Dementia Care Pilot | 9 | 4 | 1 | — | 14 |
| South Brisbane & Gold Coast Pilot | 14 | 2 | — | — | 16 |
| Ozcare Innovative Dementia Care Packages | 21 | 3 | — | 1 | 25 |
| Dementia Care in Alternative Settings | 13 | 6 | — | 1 | 20 |
| The Sundowner Club | 10 | — | — | — | 10 |
| **Total** | **113** | **18** | **1** | **3** | **135** |

*(continued)*

**Table A6.7 (continued): Care Experience Survey, respondents' beliefs about whether the projects meet previously unmet needs, by project**

| Project | Yes | Partly | No | Missing | Total |
|---|---|---|---|---|---|
| | | | (per cent) | | |
| Dementia Behaviour Assessment and Management Service | 92.3 | 7.7 | — | — | 100.0 |
| Dementia Rehabilitation at Home | 90.5 | 4.8 | — | 4.8 | 100.0 |
| Flexible Care Service | 85.7 | 14.3 | — | — | 100.0 |
| North East Dementia Innovations Demonstration | 100.0 | — | — | — | 100.0 |
| RSL Care Innovative Dementia Care Pilot | 64.3 | 28.6 | 7.1 | — | 100.0 |
| South Brisbane & Gold Coast Pilot | 87.5 | 12.5 | — | — | 100.0 |
| Ozcare Innovative Dementia Care Packages | 84.0 | 12.0 | — | 4.0 | 100.0 |
| Dementia Care in Alternative Settings | 65.0 | 30.0 | — | 5.0 | 100.0 |
| The Sundowner Club | 100.0 | — | — | — | 100.0 |
| **Total** | **83.7** | **13.3** | **0.7** | **2.2** | **100.0** |

*Note*: Excludes six surveys completed with the assistance of project coordinators.

— Nil.

Most respondents rated the quality of the health and personal care and the home and community care services delivered by their project as satisfactory or good to very good (Tables A6.8 and A6.9). Weekend and emergency assistance and home modifications were the areas of service delivery most often rated as unsatisfactory across the projects (six respondents each), followed by personal assistance and food services (five respondents each).

### Table A6.8: Care Experience Survey, respondents' ratings of the quality of project health and personal care services

| Service | Good to very good | Satisfactory | Less than satisfactory | Not applicable[(a)] | Total |
|---|---|---|---|---|---|
| | | | (number) | | |
| Personal assistance | 74 | 17 | 5 | 39 | 135 |
| Continence management | 37 | 21 | 2 | 75 | 135 |
| Mobility assistance | 37 | 20 | 3 | 75 | 135 |
| Medication management | 40 | 17 | — | 78 | 135 |
| Weekend/evening emergency assistance | 24 | 13 | 6 | 92 | 135 |
| Provision of aids and equipment | 37 | 8 | 4 | 86 | 135 |
| Nursing care | 22 | 9 | — | 104 | 135 |
| Behaviour management | 57 | 30 | 3 | 45 | 135 |
| Physiotherapy and occupational therapy | 19 | 12 | 1 | 103 | 135 |
| | | | (per cent) | | |
| Personal assistance | 54.8 | 12.6 | 3.7 | 28.9 | 100.0 |
| Continence management | 27.4 | 15.6 | 1.5 | 55.6 | 100.0 |
| Mobility assistance | 27.4 | 14.8 | 2.2 | 55.6 | 100.0 |
| Medication management | 29.6 | 12.6 | — | 57.8 | 100.0 |
| Weekend/evening emergency assistance | 17.8 | 9.6 | 4.4 | 68.1 | 100.0 |
| Provision of aids and equipment | 27.4 | 5.9 | 3.0 | 63.7 | 100.0 |
| Nursing care | 16.3 | 6.7 | — | 77.0 | 100.0 |
| Behaviour management | 42.2 | 22.2 | 2.2 | 33.3 | 100.0 |
| Physiotherapy and occupational therapy | 14.1 | 8.9 | 0.7 | 76.3 | 100.0 |

(a) Includes missing values (assumed to be 'not applicable').

*Note:* Excludes six surveys completed with the assistance of project coordinators.

— Nil.

**Table A6.9: Care Experience Survey, respondents' ratings of the quality of home and community services**

| Service | Good to very good | Satisfactory | Less than satisfactory | Not applicable[(a)] | Total |
|---|---|---|---|---|---|
| | | | (number) | | |
| Domestic assistance | 50 | 19 | 4 | 62 | 135 |
| Food service | 40 | 11 | 5 | 79 | 135 |
| Home linen/laundry service | 26 | 9 | 1 | 99 | 135 |
| Home maintenance | 11 | 3 | 4 | 117 | 135 |
| Home modifications | 22 | 14 | 6 | 93 | 135 |
| Social support | 44 | 9 | 2 | 80 | 135 |
| Transport | 41 | 13 | 1 | 80 | 135 |
| Day centre programs | 28 | 13 | 1 | 93 | 135 |
| Interpreting service | 17 | 3 | | 115 | 135 |
| | | | (per cent) | | |
| Domestic assistance | 37.0 | 14.1 | 3.0 | 45.9 | 100.0 |
| Food service | 29.6 | 8.1 | 3.7 | 58.5 | 100.0 |
| Home linen/laundry service | 19.3 | 6.7 | 0.7 | 73.3 | 100.0 |
| Home maintenance | 8.1 | 2.2 | 3.0 | 86.7 | 100.0 |
| Home modifications | 16.3 | 10.4 | 4.4 | 68.9 | 100.0 |
| Social support | 32.6 | 6.7 | 1.5 | 59.3 | 100.0 |
| Transport | 30.4 | 9.6 | 0.7 | 59.3 | 100.0 |
| Day centre programs | 20.7 | 9.6 | 0.7 | 68.9 | 100.0 |
| Interpreting service | 12.6 | 2.2 | 0.0 | 85.2 | 100.0 |

(a) Includes missing values (assumed to be 'not applicable').

*Note:* Excludes six surveys completed with the assistance of project coordinators.

— Nil.

At question 9 respondents were asked to list services they believed were unsatisfactory and to provide reasons that service delivery did not meet expectations. Across the projects, respondents identified a total of 34 services or aspects of projects as less than satisfactory (Table A6.10). Limited availability of service and unidentified 'other' factors were most commonly identified as the reasons services were less than satisfactory. Cost does not feature prominently as a reason for dissatisfaction; poor ratings are more likely to be related to limited availability or other unspecified factors.

**Table A6.10: Care Experience Survey, aspects of project rated unsatisfactory and stated reasons**

| Service rated less than satisfactory | Responses | Reasons |
|---|---|---|
| Emergency assistance after hours and weekends | 4 | Limited availability<br>Other factors |
| Personal assistance | 4 | Limited availability<br>Problems with staff<br>Other factors |
| Home modifications | 3 | Limited availability<br>Other factors |
| Home maintenance | 3 | Problems with staff<br>Other factors |
| Domestic assistance | 3 | Limited availability<br>Other factors |
| Assistance with meals | 3 | Problems with staff<br>Other factors |
| Provision of aids and equipment | 2 | Limited availability<br>Too costly<br>Other factors |
| Amount of assistance from the pilot inadequate | 2 | Limited availability |
| Day programs | 1 | Limited availability |
| Management of behavioural symptoms of dementia | 1 | Inconvenient |
| Medication management | 1 | Other factors |
| Mobility assistance | 1 | Problems with staff |
| Physiotherapy and occupational therapy | 1 | Limited availability<br>Other factors |
| Assistance with shopping | 1 | Other factors |
| Social contact | 1 | Problems with staff |
| More mental stimulation needed | 1 | Other factors |
| Unspecified | 1 | Limited availability |

*Examples of written responses to question 9:*

‘Bathroom needs modification, have yet to access this service.’

‘Meals on wheels meals not liked and a lot went to waste.’

‘More stimulation needed mentally.’

‘Personal care—Dad will not allow it.’

‘Looking into day programs but haven’t heard back yet.’

‘Showering—wife objects to service so I do it now.’

‘12 hours per week is too little.’

Over three-quarters of respondents rated the staffing arrangements of their project as good to very good (Table A6.11). Three respondents stated that staffing arrangements were unsatisfactory.

**Table A6.11: Care Experience Survey, ratings of project staffing arrangements, by project**

| Project | Good to very good | Satisfactory | Less than satisfactory | Missing | Total |
|---|---|---|---|---|---|
| | | | (number) | | |
| Dementia Behaviour Assessment and Management Service | 10 | — | — | 3 | 13 |
| Dementia Rehabilitation at Home | 17 | 3 | — | 1 | 21 |
| Flexible Care Service | 6 | 1 | — | — | 7 |
| North East Dementia Innovations Demonstration | 7 | 2 | — | — | 9 |
| RSL Care Innovative Dementia Care Pilot | 9 | 5 | — | — | 14 |
| South Brisbane & Gold Coast Pilot | 16 | — | — | — | 16 |
| Ozcare Innovative Dementia Care Packages | 16 | 8 | 1 | — | 25 |
| Dementia Care in Alternative Settings | 14 | 4 | 2 | — | 20 |
| The Sundowner Club | 9 | 1 | — | — | 10 |
| **Total** | **104** | **24** | **3** | **4** | **135** |
| | | | (per cent) | | |
| Dementia Behaviour Assessment and Management Service | 76.9 | — | — | 23.1 | 100.0 |
| Dementia Rehabilitation at Home | 81.0 | 14.3 | — | 4.8 | 100.0 |
| Flexible Care Service | 85.7 | 14.3 | — | — | 100.0 |
| North East Dementia Innovations Demonstration | 77.8 | 22.2 | — | — | 100.0 |
| RSL Care Innovative Dementia Care Pilot | 64.3 | 35.7 | — | — | 100.0 |
| South Brisbane & Gold Coast Pilot | 100.0 | — | — | — | 100.0 |
| Ozcare Innovative Dementia Care Packages | 64.0 | 32.0 | 4.0 | — | 100.0 |
| Dementia Care in Alternative Settings | 70.0 | 20.0 | 10.0 | — | 100.0 |
| The Sundowner Club | 90.0 | 10.0 | — | — | 100.0 |
| **Total** | **77.0** | **17.8** | **2.2** | **3.0** | **100.0** |

*Note:* Excludes six surveys completed with the assistance of project coordinators.

—- Nil.

Of the 135 respondents[3], 119 (88.1%) stated that project services are delivered in a manner that is always or mostly convenient, both in terms of getting to and from service locations, and having staff come to the home. Four respondents stated that service delivery is sometimes inconvenient, and one respondent reported that services are often inconvenient. A rating was not given by 11 respondents.

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[3] Excluding the six questionnaires completed with the assistance of project coordinators.

Question 13 asked respondents to specify aspects of their project which they particularly liked. Respondents provided a total of 223 positive comments, 77 of which mention intangible benefits, with increased participation (17 responses) and confidence/reassurance (16 responses) the most frequent (Table A6.12). Sixty-six responses relate to specific types of assistance, most commonly respite care (12 responses) and carer support and domestic assistance (10 responses each). Fifty-five comments relate to service quality and value, with enhanced service cited most often (12 responses).

**Table A6.12: Care Experience Survey, aspects of service delivery viewed favourably by survey respondents**

| Theme | Responses |
|---|---|
| **Intangible benefits** | |
| Increased participation | 17 |
| Confidence/reassurance | 16 |
| Optimises/maintains wellbeing | 12 |
| Pilot helps— non-specific | 10 |
| Safety | 8 |
| Other intangible benefits | 14 |
| *Total intangible benefits* | *77* |
| **Specific instrumental assistance/services** | |
| Respite care | 12 |
| Carer support | 10 |
| Domestic assistance, meals and shopping | 10 |
| Personal assistance | 9 |
| Language/interpreter service | 8 |
| Other specific instrumental assistance/support | 17 |
| *Total specific instrumental assistance/services* | *66* |
| **Improved service quality/value** | |
| Enhanced service | 12 |
| Flexibility of project | 8 |
| Increased information | 8 |
| Enhanced quality of care | 7 |
| Project is culturally/traditionally aware | 5 |
| Other improved service quality/value | 15 |
| *Total improved service quality/value* | *55* |

*(continued)*

**Table A6.12 (continued): Care Experience Survey, aspects of service delivery viewed favourably by survey respondents**

| Theme | Responses |
|---|---|
| **Staff characteristics** | |
| Personal qualities | 12 |
| Work ethics | 7 |
| Other staff characteristics | 5 |
| *Total staff characteristics* | *25* |
| **Total positive comments** | **223** |
| Negative comments | 2 |
| No comment, unsure | 18 |

*Note:* Multiple responses permissible.

Question 14 asked respondents to specify aspects of their project which they particularly disliked. Twenty-one negative comments related to eight aspects of service delivery (Table A6.13). The most common criticism is lack of communication and information about the project (six responses). Twenty-four (24) respondents specifically stated that there were no aspects of the project that they did not like, and another 94 did not respond to the question.

**Table A6.13: Care Experience Survey, negative comments about service delivery: summary table of thematic analysis**

| Theme | Responses |
|---|---|
| Lack of information/communication needs improving | 6 |
| Understaffing issues | 4 |
| Inflexible service provision | 3 |
| Costs | 3 |
| No weekend/evening services | 2 |
| Fails to meet social needs | 1 |
| Limited hours/not enough time | 1 |
| Duty of care issues | 1 |
| **Total negative comments** | **21** |
| Positive comments | 1 |
| No, none at all | 24 |
| No comment/answer made | 94 |

*Note:* Multiple responses permissible.

### 6.5.5 Information and support provided to carers and family members

The section of the questionnaire reserved for carers or other involved family members was completed by 118 respondents.

Carers and family members were asked about their awareness of a range of Australian Government carer support and information services:

- 70 (59.3%) had never heard of or contacted Commonwealth Carelink
- 65 (55.1%) had never heard of or contacted a Commonwealth Carer Resource Centre
- 58 (49.2%) had never heard of or contacted a Commonwealth Carer Respite Centre
- 69 (58.5%) had never heard of or contacted the Dementia Helpline.

The survey asked carers and family members to indicate who, prior to the Pilot, they had approached about getting help to care for their relative or friend. More than half the respondents nominated an Aged Care Assessment Team or general practitioners (Table A6.14). Twenty per cent said that they had not previously sought advice about getting assistance. Government departments and information services, community organisations and hospitals were also identified as organisations approached for advice on receiving assistance with the caring role.

**Table A6.14: Care Experience Survey, persons and organisations previously approached for advice on obtaining assistance in providing care at home**

| Nominated source of advice or assistance | Number of responses | Per cent of responses |
|---|---|---|
| Aged Care Assessment Team | 77 | 65.3 |
| General practitioner | 66 | 55.9 |
| Family, friends | 38 | 32.2 |
| No-one | 24 | 20.3 |
| Government department | 23 | 19.5 |
| Community organisation | 23 | 19.5 |
| District nursing | 19 | 16.1 |
| Hospital emergency department | 14 | 11.9 |
| Government information service | 11 | 9.3 |
| Community health clinic | 7 | 5.9 |
| **Total responses** | **118** | **100.0** |

Carers and family members were asked about the information and support provided to them by the project:

- 80 (67.8%) believed that being involved with the project had increased their understanding of dementia, 23 (19.5%) did not believe that their understanding of dementia had been improved, and 13 were undecided
- 101 (85.6%) reported that the project had increased their awareness of the support services available to them, 11 did not believe that the project had improved their awareness, and four were undecided

- 94 (79.7%) believed that the project provided enough help to support them in their caring role, 10 did not believe that the support provided by the project was sufficient, and two were undecided.

Carers and family members recorded their opinions of the respite services offered by Dementia Pilot projects:

- 81 (68.6%) believed the respite care options provided by the project were suitable, eight reported that the respite care options provided were not suitable, and 12 were undecided
- 71 (60.2%) judged the amount of respite care they received through the project to be adequate, 14 said that they were not receiving enough respite care, and 10 were undecided
- 74 (62.7%) rated the quality of the respite care provided by the project as good to very good, and 18 rated the quality of respite care as satisfactory. No carers or family members rated the quality of respite care as unsatisfactory.

Overall, carers and family members reported benefiting from the information and support services provided by the projects, and the majority of carers and family members who received respite were happy with the nature, amount and quality of respite service provided. The survey also identified gaps in the awareness of carers and family members of people with dementia relating to Australian Government support services available to them.

## 6.5.6 Innovative Pool model as a long-term care option

Carers and other relatives were asked to assess the suitability of their project as a long-term care option for the care recipient (Table A6.15). Overall, 91 respondents (82.7%) believed the project delivered a service that could be expected to support their relative or friend for the foreseeable future. Eight respondents (7.3%) across four projects stated that the project would be unsuitable as a form of longer term care.

**Table A6.15: Care Experience Survey, carers' and other relatives' assessment of the project suitability as a long-term care option for the care recipient**

| Pilot project | Yes | No | Unsure | Not applicable[(a)] | Total |
|---|---|---|---|---|---|
| | | | (number) | | |
| Dementia Behaviour Assessment and Management Service | 9 | — | 1 | 1 | 11 |
| Dementia Rehabilitation at Home | 14 | 2 | — | 2 | 18 |
| Flexible Care Service | 6 | — | 1 | — | 7 |
| North East Dementia Innovations Demonstration | 8 | — | — | 1 | 9 |
| RSL Care Innovative Dementia Care Pilot | 12 | — | 2 | — | 14 |
| South Brisbane & Gold Coast Pilot | 8 | — | — | — | 8 |
| Ozcare Innovative Dementia Care Packages | 18 | 1 | 2 | 1 | 22 |
| Dementia Care in Alternative Settings | 13 | 3 | 2 | — | 18 |
| The Sundowner Club | 3 | — | — | — | 3 |
| **Total** | **91** | **6** | **8** | **5** | **110** |
| | | | (per cent) | | |
| Dementia Behaviour Assessment and Management Service | 81.8 | — | 9.1 | 9.1 | 100.0 |
| Dementia Rehabilitation at Home | 77.8 | 11.1 | — | 11.1 | 100.0 |
| Flexible Care Service | 85.7 | — | 14.3 | — | 100.0 |
| North East Dementia Innovations Demonstration | 88.9 | — | — | 11.1 | 100.0 |
| RSL Care Innovative Dementia Care Pilot | 85.7 | — | 14.3 | — | 100.0 |
| South Brisbane & Gold Coast Pilot | 100.0 | — | — | — | 100.0 |
| Ozcare Innovative Dementia Care Packages | 81.8 | 4.5 | 9.1 | 4.5 | 100.0 |
| Dementia Care in Alternative Settings | 72.2 | 16.7 | 11.1 | — | 100.0 |
| The Sundowner Club | 100.0 | — | — | — | 100.0 |
| **Total** | **82.7** | **5.5** | **7.3** | **4.5** | **100.0** |

(a) Includes missing values (assumed to be 'not applicable').

— Nil.

*Respondents who believe that the project is a suitable care option for the longer term commented:*

'My wife is aged 81 years—she has had mental breakdowns for over 50 years since the birth of our first daughter. Over the years she had at least 20 breakdowns requiring hospital treatment (three in the last 4 years), her daily medication is 9 tablets per day plus her hip replacement and the other one not done, her mobility is very limited.'

'I would suggest that doctors should advise patients of help available to them, as my husband's doctor for 5 years considered only his medication but his new doctor is much more helpful.'

'Once again, we appreciate what we receive and it makes it possible for mum to stay at home. More hours would provide respite for Dad, but we understand that's unlikely.'

'Provided that service is adjusted to changing needs.'

'However just recently my mother's condition has deteriorated to the point where home care would no longer be suitable. I have found the responsiveness and flexibility of the coordinator to meet my mother's changing needs wonderful. It would be great to have this program continue. Had Mum's condition not changed so much we would have been very happy to have the program and staff continue for the long term. I have nothing but praise and appreciation for this program. Thank you.'

'Certainly the program is of great value as a long-term solution. However once [client] becomes bed-ridden the program would be of little use as [client] would need nursing home care.'

'Yes please! Could not get by without it.'

'But would be much better if more than 12 hours a week was available. It's very hard to try and help someone at home 7 x 24 [sic], doing everything by yourself with only 12 hours a week help.' [emphasis original]

*Respondents who believe that the project is not a suitable care option in the longer term commented:*

'No, if he was home I would have found it too hard to manage I myself 73 years old all day [sic]. Waiting for knee reconstruction also have diabetes (33 years on insulin).'

'[Client] wants to stay in her home for as long as possible but needs all the care and help she can get. [My husband] and I are unable to give this kind of care as I have high blood pressure and he has to do the things I can't do in our own home.'

'If the dementia and health of my mother worsened, she would require more care, possibly the presence of someone in the house the whole time. I (the carer) am at work. This would equate to approximately 8t hours per day on those days I am casual teaching.'

'They have been assessed as needing long-term residential care (Mum and Dad).'

'Client would need 24 hour 7 day a week care in the near future for her safety and that of carer.'

'The client's specific psychological difficulties in conjunction with the client's circumstances are the reason for the "no" answer rather than any aspects of the pilot program.
(1) Client lives alone, since husband died on isolated, large rural property. I think the pilot would provide appropriate long-term assistance for people who live with another person in urban accommodation. (2) For the program to work long-term, the client needs insight into his/her difficulties and a willingness to accept help. The client resents help from carers, can act with much resistance, is suspicious, blames others and can be verbally abusive. The client is unhappy and does not consider companionship from carers to be appropriate. *However,* as the client's only child I have found the program extremely valuable to me. I could not have coped as long as I have without it, and in my objective opinion the client was more unhappy before the program started. It has been of great short-term (about 9 months so far) assistance to me and my wife.' [emphasis original]

'With the client's deteriorating condition it can be forseen that 24 hours care/supervision will become necessary before too long.'

'Having been the main carer for 7 to 8 years, feel unable to continue indefinitely.'

*Respondents who were unsure whether the project is a suitable care option in the longer term commented:*

'One option canvassed was for my sister to move permanently in with my wife and I at our home with continuing support (bathing etc.) from program. Whilst this may have worked successfully for a limited period, it was felt by all concerned to be impractical in the long term for following reasons: (1) stress in our home/relationship and extra workload on my wife. (2) distance travelled by program staff and friends.'

'If more services were introduced it could be of long-term assistance.'

'Unsure of the future.'

# 7 Conclusion

Innovative Pool Dementia Pilot projects were found to be targeting older people with very high dementia-related care needs. Over 80% of care recipients who participated in the national evaluation were aged 75 years and over and almost one-third were aged 85 years or over at the time. High levels of ADL and cognitive impairment recorded for the evaluation are consistent with the fact that most clients had ACAT approval for high level residential aged care by the time they started to receive Pilot services.

Care from relatives and friends was the main source of assistance for most clients and was the main reason that most Pilot recipients were still living at home before joining a project. Over 90% of community-based care recipients who participated in the evaluation were either living with a primary carer (most often a relative) or were receiving ongoing daily care from a relative or friend. Only 7% of the group were living alone and did not have a primary carer. Most projects required a person referred for services to have a carer calling in at least daily.

In addition to informal care, some care recipients were receiving formal services before joining the Pilot. Just over half the group (53%) had both a primary carer and assistance from government-funded community care services; 38% had a primary carer and were not receiving government-funded assistance; 4% received assistance from formal services only. The remaining 5% of community-based care recipients reported having had no previous sources of assistance (4%) or previous assistance is not known (1%). Approximately 21% of clients had been receiving a care package service before the Dementia Pilot, usually a CACP.

Assessment data recorded for the evaluation reveal concerning levels of carer strain and a statistically significant association was found between measures of carer strain and self-reports of psychological symptoms. Many carers reported strong negative reactions to the behavioural and psychological symptoms of dementia in their care recipient. These reports were not limited to what might be thought of as the more severe forms of behavioural disturbance, for example, aggression, but were also reported in connection with memory loss and emotional responses in the person with dementia—symptoms that typically emerge in the early stages of dementia.

The Dementia Pilot has offered a new choice to those people who had not formerly used government-funded services or any type of formal assistance by providing the opportunity for formal service intervention. Most of the 21% of community-based care recipients who had been receiving a care package before the Pilot were receiving CACP services (46 care recipients). Pilot providers noted that people had been transferred from a CACP to a Pilot package because a CACP is not usually adequate to support a high care dementia client. In addition, around 18% of care recipients who were previously receiving formal services had been accessing multiple aged care programs. Some service providers with access to multiple sources of funding use this as a way to increase service levels to high needs clients.

Areas of unmet need that have been targeted by Pilot projects include:

- limited access to high level community care—a CACP does not usually provide enough hours of care per week to adequately help family carers to maintain a person with high dementia-related needs at home

- a limited supply of community care with a dementia-specific focus—greater flexibility needs to be built into service delivery for staff to be able to respond to the needs of individual clients
- difficulty in achieving timely diagnosis of dementia and, hence, early intervention
- difficulty in obtaining and maintaining service for people with severe behavioural and psychological symptoms.

Three of the Pilot projects demonstrated a strong clinical component to service delivery in a short-term (8–12 weeks) intervention model. The Dementia Behaviour Advisory and Management Service addressed the problems of staff shortages in a large regional/rural area through an outreach behaviour assessment service that provides intensive clinical work-up in an intermediate care unit. This highly innovative service offered in-place behaviour management for care recipients living in the community and in residential aged care services. Dementia Rehabilitation At Home also addressed the challenges of regional and rural Australia for community care delivery, but via the use of Telehealth technology. This project has brought people with dementia into contact with clinical specialists for the purpose of diagnosis of dementia and co-morbidities and has linked people into the network of community services. Telehealth has been found both here and overseas to reliably assess dementia patients (Loh et al. 2005) and shows enormous potential for reducing the difficulties in accessing specialist services that are faced by people in rural and remote locations. A third short-term care project, North East Dementia Innovations Demonstration, provided an interface between hospital and home for patients at Austin Health in Melbourne and offered a new referral option for Aged Care Assessment Services in the region. The location of this service within a large acute and sub-acute care service maximises the chances for people with dementia to return and remain at home after a period in hospital.

One short-term care project, Flexible Care Service, is considered more similar to the long-term care projects on the basis of the type of assistance offered. This project and the long-term care projects in Queensland (RSL Care Dementia Pilot, South Brisbane and Gold Coast Innovative Dementia Pilot, and Ozcare Innovative Dementia Packages) and Western Australia (Dementia Care in Alternative Settings) focused on providing dementia-specific care packages that offer significantly higher hours of care per week than more widely available mainstream care packages. This greater flexibility enabled providers to address the needs of a care recipient and their carer (sometimes, entire families) more adequately through the provision of in-home ADL support, high level carer support including flexible respite care, and intensive case management and service coordination. The South Brisbane and Gold Coast Pilot catered exclusively to the needs of people from culturally and linguistically diverse backgrounds and their carers, for whom dementia and the use of community services often present special challenges that require a culturally sensitive approach and bilingual support. Other projects also offered culturally-specific care services to clients, for example, RSL Care, NEDID and FCS.

The Sundowner Club is distinguished from the rest of the projects as a respite care and socialisation program rather than being a care package program with case management. Sundowner Club clients and their carers benefit from a truly novel form of respite care that would complement other community care services for people with dementia and function as a useful early intervention.

Project coordinators experienced difficulties in some areas, most often related to recruiting and retaining suitably qualified staff, and occupancy management and exit strategies in the short-term care projects.

Carers expressed overwhelming support and gratitude for the services that they received through the Dementia Pilot. Approximately 83% of respondents to the Care Experience Survey indicated that they regarded the type of assistance received to be an appropriate form of care for their care recipient for the foreseeable future. Many carers reported reduced carer strain in parallel with receiving Pilot services and those who responded to the survey directly attributed their feelings of improved wellbeing to receipt of pilot services. Case study reports provide further solid evidence that Pilot services have made significant contributions to the quality of life of care recipients and their family carers.

More than half of the clients in short- and long-term care projects were still living at home when follow-up completed in mid-2005. Those people who had been admitted to residential aged care did so after a trial of care at home that helped to maximise function and delay admission for as long as possible. Carers of people admitted to residential aged care received support in the transition and were able to make a fully informed decision having had the opportunity to trial high level community care.

All nine projects appeared to be meeting their stated objectives with the overall aim of improving the quality of life of people with dementia and their carers and enabling people with dementia to live longer in the community.