Care Planning Sub-Program Stakeholder Survey 2008

Centre for Health Service Development

September, 2008
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Suggested citation

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<td>Table 15</td>
<td>Responses to Question 15</td>
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<td>Table 16</td>
<td>Responses to Question 16</td>
<td>9</td>
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<tr>
<td>Table 17</td>
<td>Responses to Question 17</td>
<td>9</td>
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<tr>
<td>Table 18</td>
<td>Responses to Question 18</td>
<td>10</td>
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<tr>
<td>Table 19</td>
<td>Responses to Question 19</td>
<td>10</td>
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<td>Responses to Question 21</td>
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<td>Responses to Question 22</td>
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<td>Table 23</td>
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<td>12</td>
</tr>
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</table>
1 Background

The Centre for Health Service Development (CHSD) has been appointed as the National Evaluation Team (NET) to undertake a formative and summative evaluation of the Care Planning Sub-Program – a Sub-Program of the Local Palliative Care Grants Program (LPCGP). The Care Planning Evaluation Framework developed by CHSD included an undertaking to conduct interviews with key informants and stakeholders (Section 3.7), to complement the common and customised evaluation tools and processes being utilised across both the individual project and sub-program levels.

2 Survey Aims

The focus of the stakeholder interviews was to consider the following issues: delivery, impact, sustainability, capacity building, generalisability and dissemination. The aim was to gather perspectives on these issues from an overall sub-program level, rather than the experience at the individual project level. In addition, views of stakeholders and informants were sought on their awareness and/or involvement in the sub-program and/or with the projects, as well as effective ways to communicate progress and findings from the projects and the sub-program.

3 Method

Given the broad range of stakeholders and informants who might have a perspective on the sub-program, it was decided that the most expedient means of soliciting their views was through an online survey. The online survey tool chosen was ‘SurveyMonkey.com’, because of its ability to customise surveys, and its ease of use. This tool has been used previously by CHSD and feedback from users has been positive.

A list of 46 stakeholders and informants was compiled in consultation with the Department of Health and Ageing (DoHA), including representatives from the primary, palliative, acute and specialist health care sectors, as well as aged care sector, government, consumers and carers, and professional groups.

The survey was piloted primarily to test for wording and ‘spam title’, and the final survey was conducted during February to April 2008. The survey was introduced with a brief outline of the Care Planning Sub-Program.

4 Results

Thirty responses were received to the survey, representing a 65% response rate. Not all respondents answered every question on the survey, with response rates for individual questions ranging from 27-28 out of 30 (questions 1, 2, 3, 4 & 7 – awareness and involvement) to 11-15 out of 30 (questions 9, 11, 13 – sustainability and capacity building).

The results of the survey are presented thematically in the discussion that follows. A full set of responses is attached at Appendix 1.

5 Key themes

5.1 Awareness and Involvement

The first eight questions sought perspectives of respondents regarding their awareness of the projects and sub-program, as well as an indication of their level of involvement. These questions received the most responses (90-94%).
The majority of respondents (75%) had heard about the Care Planning Sub-Program, mostly through the workshop, website or grant advertisement (43%). Others became aware of the sub-program through meetings they had attended (21%) while a further 17% became aware of the sub-program through the survey.

Almost half of respondents (48%) had a role with a project funded under the sub-program. Of these, 39% of these involved in project governance and a further 31% were involved in contract management, submission coordination or evaluation of projects.

Almost 60% of respondents knew about the projects. A number of respondents provided commentary about their level of knowledge, with most being supportive of the projects. In contrast, one respondent commented that there ‘was a lot of duplication’, while another indicated there was tension between the project and existing service/program staff which would have implications for the project’s sustainability.

### 5.2 Impact and Sustainability

Questions 9 and 10 of the survey looked at issues of project impact and sustainability. Response rates to these questions were lower than for the initial part of the survey, with only 14/30 responding to question 9, and 11/30 to question 10.

Of those who responded to question 9, most believed that the projects would continue to have an impact after the funding had finished (71%). However, the remainder indicated that additional funding would need to be found to continue the outcomes.

Approximately a third of the respondents to question 10 commented on sustainability strategies used, which included education modules for carers and service providers, shared knowledge, carer support initiatives, incorporating project strategies into organisational practice, and linking in with existing programs and services.

### 5.3 Capacity Building and Generalisability

Questions 11 and 12 looked at capacity building. Fourteen respondents addressed the first question, and five respondents provided examples under question 12.

Half of the respondents indicated that they had been involved in capacity building strategies. Strategies included workshops, successful funding submissions, contributing to the CareSearch website, working collaboratively with service providers, hospitals and relevant organisations to strengthen palliative care services.

Question 13 looked at generalisability issues. The majority of respondents agreed that the projects had been designed to provide useful information for other regions, services or organisations (71%), while just over half agreed that the project outcomes could be replicated elsewhere.

### 5.4 Dissemination

Questions 14-22 of the survey sought feedback regarding the dissemination of project and sub-program findings. Response rates varied for these questions, with better rates for key questions (20 – 25/30) than for optional follow-up questions.

In order to consider appropriate dissemination strategies, respondents were asked to provide information regarding the level of involvement of their organisation in palliative care (question 19). As expected, respondents were involved in palliative care at a number of different levels and undertook a broad range of activities. A third of respondents were involved in the direct support of patients and carers. Many of the organisations represented by respondents were also involved in
other support through providing information referral and counselling services, working to improve services, lobbying and representation at both state and national levels.

Just over half of the respondents indicated they had been informed about the progress of the sub-program &/or projects (question 14). This was mainly through attendance at meetings and through email contact. A smaller proportion had been informed through project newsletters.

A number of questions were asked about the most effective way to communicate with stakeholders in the future, specifically regarding the final outcomes of the sub-program and projects. Responses included: newsletter articles; website/webpage articles; conference presentations; and, journal articles.

Respondents were asked if they would be interested in attending a final workshop of the Care Planning Sub-Program that showcased the projects (question 21). Of those that responded, two-thirds expressed an interest, with all wanting to know about the projects' outcomes; the strategies and resources that worked (40% of responses); recommendations and plans for the future (30%); and, how to engage consumers, carers and service providers (20%).

6 Discussion

The survey provided the opportunity for the NET to gauge perspectives of key stakeholders and informants regarding the Care Planning Sub-Program. The overall response rate was disappointing, given that the stakeholders were individually emailed the information, and prompted three times for their responses.

6.1 Awareness and Involvement

The level of awareness of the sub-program by stakeholders was high, however this is not surprising given that palliative care is a relatively small and emerging field of health care. As often happens in these circumstances, a small number of key players often drive the field, with a strong emphasis on garnering support, and establishing coherence, which usually includes tight communication about and engagement in related initiatives.

While the majority of comments about the sub-program were positive, two specific comments were raised as a concern by respondents. The first was the apparent duplication between the projects, which echoes the observations made by the NET at the outset of our involvement in the sub-program. Consequently, the NET has spent considerable effort to align similar projects or elements of projects (eg, literature reviews) to prevent duplication of effort, and encourage the use of consistent evaluation tools. Similarly, the issue raised by one respondent concerning the 'considerable tension' between two projects and existing related services, 'neither of which I felt warranted funding as there were many issues around implementation and sustainability', was consistent with the experiences of a number of projects. This highlights the importance of sound engagement of local service networks prior to the development of new initiatives such as these.

6.2 Impact and Sustainability

Approximately one third of respondents were not convinced that the project outcomes could be sustainable without additional funding. This is consistent with feedback from project officers, a number of whom have already commenced negotiations with management and potential funding bodies to continue implementing the project outcomes once the project ceases. Two projects have already received funding to extend their project at the time of writing, with at least another half dozen indicating this would be pursued in the latter part of their project.

6.3 Capacity Building and Generalisability

Only half the survey respondents indicated that they had assisted Care Planning projects to implement capacity building strategies. This is surprising given that those surveyed were key
stakeholders of a relatively small and emerging field. Of the five respondents who provided examples, the activities included presenting at a project workshop, provision of information, and facilitating networks. It is possible that the influence is under-rated, as projects may have accessed resources on websites or staff at the ‘ground-level’ of these organisations, who may have had more involvement with and detailed knowledge of the projects.

6.4 Dissemination

A key finding from this part of the survey was that only just over half of the respondents indicated they had been informed about the progress of the sub-program &/or projects. This is despite the efforts of individual projects at the local level, and the NET at the systemic level, to make the findings and resources known. For example, as part of its contractual obligations, the NET has undertaken to ‘disseminate/make available a range of materials - relevant presentations; useful resources identified by projects and the CHSD; information bulletins relevant to the Sub-Program; and details of protocols/guidelines and resources developed projects’ (Section 4.1 Care Planning Sub-Program Communication Plan). We have done this through a variety of methods, including posting them on the CHSD web-site under the heading, ‘care planning’; making them available via the Knowledge Network; discussing the distribution of this information with PCA; and, taking opportunities to present at relevant conferences and workshops.

It is likely that the focus of effort by projects to date has been on the development and implementation of resources/models etc, rather than promotion or dissemination activities, which are more likely to occur when there is a ‘finished product’ or project results. Respondents indicated a high level of interest in hearing of project findings.

7 Conclusion

While there is a reasonable degree of awareness of the Care Planning Sub-Program and projects, the survey results suggests that there are missed opportunities to maximise engagement of key stakeholders and the sector more broadly. A likely reason for this is that the focus of effort by individual projects has been on developing and implementing their projects, and working with their local networks. This is certainly the perception of the NET through our dealings with the projects, undertaking site visits and reviewing progress reports.

The response to the survey, and anecdotal feedback from the sector, supports this focus of effort, as it appears that the sector is more interested in hearing about project ‘products’, rather than project ‘processes’. That said, however, there are clear lessons to be learnt from the projects about the ‘processes’ they have been involved in – the positives, as well as the negatives – which can influence policy and program development within the sector in the future. The NET has sought to do this through its activities outlined in the Communication Plan. There may also be opportunities for the Department of Health and Ageing, as funders and administrators of the Care Planning Sub-Program, to take a more active role in engaging key stakeholders and informants around the objectives, opportunities and processes – as well as outcomes - of the sub-program. This would facilitate a receptive context to the work being undertaken at the local level by individual projects, and enhance the potential for project outcomes to be sustained beyond the life of the sub-program.
8 Appendix: Care Planning Sub-Program – Stakeholder survey results

Question 1: Have you heard of the Care Planning Program?

Table 1 Responses to Question 1

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>75.0</td>
<td>21</td>
</tr>
<tr>
<td>No</td>
<td>25.0</td>
<td>7</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100.0</td>
<td>28*</td>
</tr>
</tbody>
</table>

Two respondents did not answer these first two questions

Three quarters of the respondents had heard of the Care Planning Program and over 78% had heard of the program more than a month before the survey was conducted and almost 43% had heard of the program more than a year ago.

Question 2: When did you first hear about the Care Planning Program?

Table 2 Responses to Question 2

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>This is the first I have heard of it</td>
<td>21.4</td>
<td>6</td>
</tr>
<tr>
<td>Within the last month</td>
<td>0.0</td>
<td>0</td>
</tr>
<tr>
<td>Within the last 6 months</td>
<td>25.0</td>
<td>7</td>
</tr>
<tr>
<td>Within the last year</td>
<td>10.7</td>
<td>3</td>
</tr>
<tr>
<td>More than a year ago</td>
<td>42.9</td>
<td>12</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100.0</td>
<td>28*</td>
</tr>
</tbody>
</table>

* Two respondents did not answer these first two questions

Question 3: How did you hear about the Care Planning Program?

Table 3 Responses to Question 3

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Through this survey</td>
<td>17.9</td>
<td>5</td>
</tr>
<tr>
<td>Word of mouth</td>
<td>7.1</td>
<td>2</td>
</tr>
<tr>
<td>Newsletter</td>
<td>7.1</td>
<td>2</td>
</tr>
<tr>
<td>Staff meeting or other type of meeting</td>
<td>21.4</td>
<td>6</td>
</tr>
<tr>
<td>Health service memo</td>
<td>3.6</td>
<td>1</td>
</tr>
<tr>
<td>Other (eg, website, grant advertisement)</td>
<td>42.9</td>
<td>12</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100.0</td>
<td>28*</td>
</tr>
</tbody>
</table>

* Two respondents did not answer this question

The most common way of hearing about the Care Planning Program was though a meeting or workshop (32%). A number of respondents had only found out about the Care Planning Program through receiving the survey (21.4%). Some respondents knew of the program from seeing it advertised and applying for a grant (14.3%) and other heard of it by word of mouth (14.3%).

Question 4: Do you have a role in the Care Planning Program?

Table 4 Responses to Question 4

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>48.1</td>
<td>13</td>
</tr>
<tr>
<td>No</td>
<td>51.9</td>
<td>14</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100.0</td>
<td>27*</td>
</tr>
</tbody>
</table>

* Three respondents did not answer this question
Question 5: If you answered Yes to Q4, what is your role?

Table 5  Responses to Question 5

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was involved in the project selection process</td>
<td>7.7</td>
<td>1</td>
</tr>
<tr>
<td>I am involved with the communication process with DoHA</td>
<td>15.4</td>
<td>2</td>
</tr>
<tr>
<td>I am on a project governance committee</td>
<td>38.5</td>
<td>5</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>38.5</td>
<td>5</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100.0</td>
<td>13*</td>
</tr>
</tbody>
</table>

* Seventeen respondents did not answer this question

Other (please specify)
- Evaluation role.
- Supporting the contract management process.
- Co-ordination of project submissions and a role in the review process of the proposals.
- Member of the Palliative Care Advisory Committee.

The majority of respondents (51.9%) did not have a role in the Care Planning Program. Those that did were mostly involved in project governance (38.5%) or had a role external to an actual project such as contract management, submission coordination or evaluation (30.8%).

Question 6: If you answered No to Q5, what role could you have in the Care Planning Program?

Table 6  Responses to Question 6

<table>
<thead>
<tr>
<th>Response text</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gather information on how the program was implemented from different community care specialist committees. Advice and support. As a National peak body, we could publicise the program through our member bodies as well as through our national e-newsletter and website. Contract management. As an advisory phone line worker … I am (now) able to give the information to callers. Promoting and advising on the benefits. <em>(Our service)</em> provides respite funding for carers of a person who is palliative. The health and wellbeing of the carer is essential in planning the needs of the care recipient. Partner in support to family members and carers of people needing palliative care e.g. counselling, group sessions, return to work etc. I attend meetings of the <em>(projects in my State)</em> to offer any assistance I can. <em>(Provide a link between …. program and PCOC)</em>.</td>
</tr>
</tbody>
</table>

* Eleven respondents answered this question, while nineteen respondents did not answer this question

Roles that respondents not currently involved in the Care Planning Program thought they could have included communication, project support, direct support to patients and carers and an external role such as contract management or evaluation.

Question 7: Do you know about any of the projects that were selected for the Care Planning program?

Table 7  Responses to Question 7

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>59.3</td>
<td>16</td>
</tr>
<tr>
<td>No</td>
<td>40.7</td>
<td>11</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100.0</td>
<td>27*</td>
</tr>
</tbody>
</table>

* Three respondents did not answer this question
Question 8: If you answered Yes to Q7, please comment on the projects that were selected, especially those related to your role or 'your patch'.

Table 8 Responses to Question 8

<table>
<thead>
<tr>
<th>Response text</th>
<th>Response themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lots of overlap and duplication.</td>
<td>Project specific</td>
</tr>
<tr>
<td>I am responsible for overseeing (a) project which among other things is designed to get earlier palliative care referrals through General Practice, developing tools both for GPs and for Carers.</td>
<td>Project specific</td>
</tr>
<tr>
<td>I am now not in this role and therefore can not remember the specific projects.</td>
<td>Moved on</td>
</tr>
<tr>
<td>I have a limited knowledge of all the projects within the Care Planning program and a more specific knowledge of the project through (local service provider).</td>
<td>Project specific</td>
</tr>
<tr>
<td>A project that focused on promoting the care of palliative patients to GP’s and exploring educational interventions appropriate to support the carer to better manage the caring role. Only from a contract management perspective.</td>
<td>Project specific</td>
</tr>
<tr>
<td>Palliative care in the residential aged care sector and addressing the particular needs of the Indigenous client group. Very relevant for me as I manage aged and community care in (similar) region. These projects were finished when I started work in the palliative care section, so my knowledge of their substance is very minimal.</td>
<td>Program level knowledge</td>
</tr>
<tr>
<td>I have a general knowledge of the 10 projects.</td>
<td>General knowledge</td>
</tr>
<tr>
<td>Our project. Supporting and educating carers in palliative care project.</td>
<td>General knowledge</td>
</tr>
<tr>
<td>(State-specific) project developing care management plans.</td>
<td>Project specific</td>
</tr>
<tr>
<td>I have some understanding of 2 projects in particular, neither of which I felt warranted funding as there were many issues around implementation and sustainability. There was considerable tension between state health dept staff and some project personnel. (The project) will be important and hopefully will continue to have legs once the funding finishes but there will be little or no ongoing ability for the service to support the e-side of it without appropriate resources - such is the nature of projects.</td>
<td>Project specific – fundamental issues</td>
</tr>
</tbody>
</table>

* Thirteen respondents answered this question, while seventeen respondents did not answer this question

Almost 60% of respondents knew about projects that were selected for the Care Planning program. Of those who commented about the care planning projects 47% gave details of a project they were involved with. Most were supportive of the projects although one recipient felt there was a lot of duplication happening and another indicated there was tension between project and program staff and that the project was not sustainable.

Question 9: What do you think is the goal for the Care Planning projects after the program ends?

Table 9 Responses to Question 9

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) The projects will be over and its impact will end soon after</td>
<td>0.0</td>
<td>0</td>
</tr>
<tr>
<td>b) The projects will be over but it will keep having an impact</td>
<td>71.4</td>
<td>10</td>
</tr>
<tr>
<td>c) By the time the funding ends the host organisation will have found other ways to keep the projects going</td>
<td>28.6</td>
<td>4</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100.0</td>
<td>14*</td>
</tr>
</tbody>
</table>

* Sixteen respondents did not answer this question

No respondents thought that the project would just end along with no ongoing impact after the Care Planning Program ended. The majority thought that the project would end but the impact would continue (71.4%), however, over 28% thought that they would be able to find another source of funding to continue the project. A number of respondents (45.5%) indicated that they were working towards implementing sustainability strategies while another 18% were implementing strategies such as shared knowledge, education modules, and carer support and incorporating project strategies into normal practice. One respondent did not think the project was sustainable.
Question 10: If you chose b) or c) please explain any strategies you have implemented or will be implementing to help the projects achieve sustainability beyond the life of the program.

Table 10  Responses to Question 10

<table>
<thead>
<tr>
<th>Response text</th>
<th>Response themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working through the sustainability tool and discussing strategies with project officers. These strategies are in the process of development through the aegis of various working groups and stakeholder fora. The integration of the outcomes of the Project with current practice depends also on linkages with existing and developing programs and practices. It also requires the engagement of the Government processes that are in place.</td>
<td>Working towards</td>
</tr>
<tr>
<td>There will be a shared knowledge that can be used by the broader palliative care community. Many of the projects appear to be investigating processes that could be utilised in services as part of usual practice. Carer’s needs are being explored and as information becomes available as to what is appropriate for carers of palliative care clients, the carer’s association will respond to those needs. Included sustainability strategies in the contracts.</td>
<td>Implementing – shared knowledge  Working towards</td>
</tr>
<tr>
<td>I don't really know - I'm not involved at a close enough level. We now have a suite of education modules for carers and service providers that we provide as an information session upon request and within resources. We now have resources to support palliative care carers we are in contact with through the Carers Telephone Line.</td>
<td>Implementing – education modules and carer support  Working towards</td>
</tr>
<tr>
<td>The materials produced from this project will be reviewed and updated as required by the (State health palliative care) Clinical Management Committee. Subject to resources additional management plans will be developed. The goal will be either b) or c) but realistically many are likely to cease when funding ends and the impacts slowly lost. It will be promoted within the community workforce as our resource and will be use I hope as a base for our correspondence round clinical practice. The problem will be keeping it up to date!</td>
<td>Not working towards  Implementing</td>
</tr>
</tbody>
</table>

* Eleven respondents answered this question, while nineteen respondents did not answer this question

Question 11: Has your organisation assisted any Care Planning projects to implement capacity building strategies?

Table 11  Responses to Question 11

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>50.0</td>
<td>7</td>
</tr>
<tr>
<td>No</td>
<td>50.0</td>
<td>7</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100.0</td>
<td>14*</td>
</tr>
</tbody>
</table>

* Sixteen respondents did not answer this question

Question 12: If you answered yes to Q11, please describe.

Table 12  Responses to Question 12

<table>
<thead>
<tr>
<th>Response text</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>[Project Worker] presented a workshop in (major city), also we presented info to DoHA … which resulted in funding being provided for network meetings in each state. We have provided some of the projects with information about what has happened previously. We are working with DoHA to capture the findings of the program and make them available more broadly through the CareSearch website. Capacity building strategies have been implemented through working collaboratively with Carers Association, GPs and Palliative Care. Partnerships with (local) Commonwealth carer respite services including 5 hospitals, 3 palliative care services and a broad range of other community care services. Please note materials are still being developed.</td>
<td></td>
</tr>
</tbody>
</table>

* Five respondents answered this question, while twenty-five respondents did not answer this question

Half of the respondents indicated that their projects had been involved in capacity building strategies. Strategies included workshops, successful funding submissions, contributing to the CareSearch website, working collaboratively with service providers, hospitals and relevant organisations to strengthen palliative care services.
Question 13: Do you believe the project(s) implemented in your area:

Table 13 Responses to Question 13

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were designed to meet needs in your area only</td>
<td>28.6</td>
<td>4</td>
</tr>
<tr>
<td>Were designed to provide useful information for other regions/services/organisations</td>
<td>71.4</td>
<td>10</td>
</tr>
<tr>
<td>Were designed so that project outcomes could be replicated elsewhere</td>
<td>57.1</td>
<td>8</td>
</tr>
<tr>
<td>TOTAL</td>
<td>#</td>
<td>14*</td>
</tr>
</tbody>
</table>

* Sixteen respondents did not answer this question
# Respondents could tick multiple responses for this question

Over 70% of respondents agreed that the projects were designed to provide useful information for other regions/services/organisation and 57% thought that the projects were designed so that outcomes could be replicated elsewhere.

Question 14: Have you been informed about the progress of the program and/or projects?

Table 14 Responses to Question 14

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>52.0</td>
<td>13</td>
</tr>
<tr>
<td>No</td>
<td>48.0</td>
<td>12</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100.0</td>
<td>25*</td>
</tr>
</tbody>
</table>

* Five respondents did not answer this question

Just over half (52%) had been informed about the progress of projects and the Care Planning Program with the majority being informed via meetings (72.7%) or email (54.5%). Of those who had not been informed 100% said that email would be the best way to inform them with half and half indicating meetings and newsletters as an appropriate method of communication.

Question 15: If you answered Yes to Q14, how are you informed about progress?

Table 15 Responses to Question 15

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meetings</td>
<td>72.7</td>
<td>8</td>
</tr>
<tr>
<td>Newsletter</td>
<td>18.2</td>
<td>2</td>
</tr>
<tr>
<td>Emails</td>
<td>54.5</td>
<td>6</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>11*</td>
</tr>
</tbody>
</table>

* Eleven respondents answered this question, while nineteen respondents did not answer this question
# Respondents could tick multiple responses for this question

Question 16: If you answered No to Q14, would you like to be informed about:

Table 16 Responses to Question 16

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Care Planning Program</td>
<td>0.0</td>
<td>0</td>
</tr>
<tr>
<td>Care Planning projects in my area</td>
<td>0.0</td>
<td>0</td>
</tr>
</tbody>
</table>

* Thirty respondents did not answer this question

Question 17: How would you like to be informed?

Table 17 Responses to Question 17

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meetings</td>
<td>50.0</td>
<td>2</td>
</tr>
<tr>
<td>Newsletter</td>
<td>50.0</td>
<td>2</td>
</tr>
<tr>
<td>Emails</td>
<td>100.0</td>
<td>4</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>4*</td>
</tr>
</tbody>
</table>

* Four respondents answered this question, while twenty-six respondents did not answer this question
Question 18: Please enter details of most appropriate contact method.

Table 18 Responses to Question 18

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Postal address</td>
<td>50.0</td>
<td>3</td>
</tr>
<tr>
<td>Email</td>
<td>100.0</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>0.0</td>
<td>0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>6*#</td>
<td></td>
</tr>
</tbody>
</table>

* Six respondents answered this question, while twenty-four respondents did not answer this question
# Respondents could tick multiple responses for this question

Question 19: What is your organisation's involvement in Palliative Care?

Table 19 Responses to Question 19

<table>
<thead>
<tr>
<th>Response text</th>
<th>Response themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have evaluated several palliative care projects.</td>
<td>External State level representation National level representation</td>
</tr>
<tr>
<td><em>(Our service)</em> is the Peak body representing all palliative care agencies, those interested in and those in need of or receiving palliative care ... National peak body.</td>
<td></td>
</tr>
<tr>
<td>My role now is research and education within a new national association. I sit on an alliance committee which includes palliative care Australia (CEO). The members of our organisation are involved through being national and international researchers, educators, industry partners. Research, education and service improvement. At the national level, we have had no involvement. I can't speak for individual member associations in each of the states and territories. We are a national online information and evidence repository.</td>
<td>Indirect support No involvement</td>
</tr>
<tr>
<td>Supporting carers of palliative care clients. Funder. Providing Funding contracts. <em>(State/Territory based peak body)</em> deal primarily with the carers of individuals in palliative care providing practical and emotional support during this difficult time and the period following the death of the care recipient. <em>(State/Territory based peak body)</em> and Palliative Care Australia is the peak body in Australia concerned with all aspects relating to Palliative Care including policy development, education &amp; awareness, and delivery - at all levels from Government to the Community generally.</td>
<td>Indirect support Direct support Funding support Funding support Direct support</td>
</tr>
<tr>
<td>Education. Promoting new programs or tools. <em>(Service)</em> works closely with Palliative care teams to give Carers a respite break when supporting a loved one who is palliative. Funding is provided for these supports to give Carers a respite break. <em>(Service)</em> had specific funding in the past to provide this function but now have only general funding. This has resulted in respite being available to these Carers but more limited than before. <em>(Service)</em> is able to broker registered nurses when this is also required. Our service provides support to family members and carers including those supporting people needing palliative care. Support includes: information, referral to appropriate services, counselling, support groups, buddy/mentoring programs, employment services, family advocacy etc. We are the peak body <em>(State/Territory based)</em>.</td>
<td>Indirect support Supports Pall Care services and funds respite care. Direct support – patients, carers</td>
</tr>
<tr>
<td>Education and training. Provide resources to carers and service providers through the Carer Line, website, counselling, newsletters. Member of Palliative care advisory committee. <em>(State/Territory Department)</em> has contracted with the Aust Government to undertake the project. Developing a data set to be collected nationally by specialist palliative care services on a voluntary basis. The ...Palliative care service is the main provider of specialist palliative care <em>(in region)</em> <em>(We are)</em> Specialist Palliative Care service in the <em>(State/Territory)</em>. Have 12 bed hospice, consult at all hospitals in the <em>(region)</em>. Remote, rural and urban visiting service. <em>(State/Territory)</em> based community organisation linked to PCA. Lobbying state government on palliative care issues, disseminating information on Palliative care.</td>
<td>State and National representation Indirect support Direct support, hospice service and state level representation</td>
</tr>
</tbody>
</table>

* Twenty-one respondents answered this question, while nine respondents did not answer this question

Respondents were involved in palliative care at a number of different levels and undertook a broad range of activities. A third of respondents were involved in the direct support of patients and carers. Many of the organisations represented by respondents were also involved in other support through providing information referral and counselling services, working to improve services, lobbying and representation at both state and national levels.
Question 20: What would be the most effective way(s) for others to learn about the progress and final outcomes of the Care Planning projects and program?

Table 20 Responses to Question 20

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff development meetings</td>
<td>43.5</td>
<td>10</td>
</tr>
<tr>
<td>Workshops</td>
<td>56.5</td>
<td>13</td>
</tr>
<tr>
<td>Newsletter articles</td>
<td>91.3</td>
<td>21</td>
</tr>
<tr>
<td>Journal articles</td>
<td>60.9</td>
<td>14</td>
</tr>
<tr>
<td>State conference presentations</td>
<td>69.6</td>
<td>16</td>
</tr>
<tr>
<td>National conference presentations</td>
<td>65.2</td>
<td>15</td>
</tr>
<tr>
<td>Website/webpage articles</td>
<td>82.6</td>
<td>19</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>23*</td>
</tr>
</tbody>
</table>

* Seven respondents did not answer this question

Respondents were most likely to recommend newsletter articles (91.3%), website/webpage articles (82.6%) and state conference presentations (69.6%) as the most effective ways to learn about the final outcomes of the Care Planning Program and the projects it funded.

Question 21: Would you like to attend a final workshop on the Care Planning program which could showcase the projects?

Table 21 Responses to Question 21

<table>
<thead>
<tr>
<th>Answer options</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>66.7</td>
<td>16</td>
</tr>
<tr>
<td>No</td>
<td>33.3</td>
<td>8</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100.0</td>
<td>24*</td>
</tr>
</tbody>
</table>

* Six respondents did not answer this question

Question 22: If you answered Yes to Q21, what would you like included in the workshop?

Table 22 Responses to Question 22

<table>
<thead>
<tr>
<th>Response text</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opportunity for projects to present findings, discussions about sustainability.</td>
</tr>
<tr>
<td>Summary packet of the major findings. Implications at the service level. Whether learnings are transferable. Also what didn't work so we don't keep repeating it. What we can do now. What we need to still solve and/or research. Strategies included in individual programs and if they worked, barriers in meeting outcomes, a portal for sharing resources developed during program.</td>
</tr>
<tr>
<td>I guess the usual rundown of the program, what achievements it has made, improvements that will be taken into account in the future and possible a list of relevant numbers for palliative care. All relevant information. A summary of how the Program came about, what it has achieved and where to from here if it is now in final stages. Understanding of projects - especially local projects. What they achieved especially with reference to support for families and carers. Understanding of how these projects connect with or could connect with other organisations in providing short or long-term support to families of people needing palliative care. Summaries of programs, what worked.</td>
</tr>
</tbody>
</table>

* Ten respondents answered this question, while twenty respondents did not answer this question
A third of respondents indicated that they would like to attend a final workshop on the Care Planning Program that could showcase the projects. Respondents most wanted to know about the projects’ outcomes (100%), what strategies and resources worked (40%), what recommendations and plans are there for the future (30%), how to engage consumers, carers and service providers (20%).

**Question 23:** If you have anything further to say about the Care Planning sub-program or the Care Planning projects please enter your comments in the box below.

**Table 23 Responses to Question 23**

<table>
<thead>
<tr>
<th>Response text</th>
<th>Response themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>We have employed a Project Officer to implement and manage this project. It is she who would attend any post-project meeting. The Project has provided a “connection point” for all (State/Territory) based projects and this in itself has been a very useful initiative.</td>
<td>Benefits from project – employment, communication</td>
</tr>
<tr>
<td>I'm sorry that I don't know more about the program. I suggest you contact our state and territory member organisations to get a carer perspective on the Program. While there is local knowledge about many of the projects, there appears to be a lack of ongoing information. Even a sheet on each project would have been useful. It has been very successful so far in linking palliative care ‘carers’ to the (peak body) so we are able to give support through counselling, respite and education. Expand education project. In (State/Territory) the project materials are still being developed. Therefore wide communication with other stakeholders has not yet occurred.</td>
<td>Little knowledge of program More communication/information about projects needed Success in linking carers to support Expand education project Project still developing</td>
</tr>
</tbody>
</table>

* Eight respondents answered this question, while twenty-two respondents did not answer this question

Of those respondents who had additional comments communication, information and education were given as aspects of a successful project or needed to improve project impact and outcomes. Other benefits of participating in the projects were the ability to employ staff and link carers with more help.