



Advance Care Planning Australia National Advisory Service Evaluation Report 2019

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Acknowledgements

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Advance Care Planning Australia provides expertise in advance care planning practice, health professional education, translational research, information resources and advisory services. Our purpose is to build the foundation for a national collaborative approach to advance care planning.

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Introduction

This report details the evaluation of the Advance Care Planning Australia (ACPA) National Advance Care Planning Advisory Service, covering the period 1 January 2019 to 31 December 2019. The report describes the key achievements, including enquiry statistics, service satisfaction, case studies, data management, and volunteer hours. The report provides an overall assessment and discussion regarding the reach of the program, program quality, program sustainability, and program learning. It also makes recommendations for ongoing improvement of the advisory service.

Background

The ACPA National Advance Care Planning Advisory Service (including phone, email and online) is designed to provide information and resources to support Australians with advance care planning. Advance care planning is a process of planning for future health and personal care whereby an individual's values, beliefs and preferences are made known to guide future medical decision-making in the event a person no longer has decision-making capacity.

The phone and email advisory service is available five days per week, Monday to Friday, 9am to 5pm AEST. The advisory service provides free advice to individuals, the health and aged care workforce and organisations across a range of topics, including:

- how to make sure their goals, values and preferences are heard;
- advice on how to choose a Substitute Decision-Maker;
- completing an Advance Care Directive; and
- accessing relevant forms in each state and territory.

The ACPA National Advisory Service performance indicators include:

- reaching a minimum of 1000 unique contacts per annum; and
- completion of an evaluation report annually.

In 2017, an innovative pilot successfully demonstrated that a volunteer-led Advance Care Planning National Advisory Service can maintain similar, if not higher levels of satisfaction as a health professional model. Following the completion of this pilot, a number of ACPA Volunteer Community Ambassadors were recruited, trained, mentored and evaluated to provide national advance care planning advisory services and deliver the role of advisor operator.

Methods

The evaluation of the ACPA National Advance Care Planning Advisory Service involved both quantitative and qualitative data collection and analysis for the period of 1 January to 31 December 2019. Ethics approval for this evaluation was provided by Austin Health Human Research Ethics Committee with the reference number HREC/18/Austin/267.

National enquiries analytics were collected and managed within Zoho CRM a customer relationship management system. Zoho CRM provided a secure (password protected) and centralised system to record enquiries, information about each individual contact, task allocation, resolutions and responses. Enquiry analytics included the number of, reasons for, characteristics of service users including consumer versus workforce, and call location by jurisdiction and/or country.

National enquirer satisfaction with the advisor and/or service received was evaluated via electronic or hardcopy survey. The survey evaluation period was 1 June to 31 December 2019. Zoho CRM distributed electronic surveys at the start of each month for enquiries received during the previous month, to enquirers with email addresses. For enquirers without an email address, hard copy surveys were posted with a return envelope. Hardcopy survey responses were entered into Zoho Survey manually by a project staff member. Evaluation processes included data cleaning, extraction, analysis and reporting.

Volunteer hours were recorded using the Better Impact volunteer management software. The secure system allowed for the tracking of volunteer activities and hours, and data management of key volunteer documents.

Case studies were developed using the detailed information recorded in Zoho CRM. The development of case studies was used to demonstrate outcomes, best practice and areas for further improvement.

Findings

During 1 January to 31 December 2019, 1687 enquirers utilised the ACPA National Advance Care Planning Advisory Service. Whilst, the enquirer survey evaluation was conducted for a seven month period during 1 June to 31 December 2019 and involved 56 responses from 282 surveys distributed (RR 20%).

Key Achievements

Key achievements of the national advance care planning advisory service included:

- the resolution of 1678 enquiries, thereby exceeding by over 60% the performance target of 1000 unique contacts per annum (on average, 140 enquiries per month).
- a 10% increase in enquiries from the previous year (2018).
- the recruitment, onboarding and training of a new Deputy Program Director and Project Officer to manage the team of volunteers and the national advisory service.
- the review and re-development of a comprehensive volunteer recruitment process.
- the review and update of a comprehensive six-day training program totaling 42 hours of committed time per volunteer.
- the recruitment, training, and on-boarding of 9 new volunteers, expanding the volunteer team to comprise 20 volunteers.
- 282 surveys sent to enquirers, with 56 survey responses received (response rate 20%) and 98% reported they strongly agreed/agreed that they were satisfied with the service they received.

Enquiries

Over the period 1 January 2019 to 31 December 2019:

- the predominant users of the service were consumers making enquiries for themselves (26%) and health professionals (22%). Further details regarding service users each month are recorded in Appendix 1.
- Victoria, New South Wales, and then Queensland recorded the highest number of enquiries. Further details regarding the total number of enquiries per month and per jurisdiction are recorded in Appendix 2.
- the predominant enquiry source was the 1300 number, representing 71% of all enquiries.

Further details regarding the total number of enquiries per month and per enquiry source are recorded in Appendix 3.

- the primary reasons for people contacting the national advisory service were requests for documents/resources, education/training, and advice completing ACP forms. Further details regarding the primary reasons for people contacting the service each month are recorded in Appendix 4 and summarised in Table 1.

Table 1. Reason for enquiry

Reason for Enquiry	Number of Enquiries
Documents/Resources	605 (36%)
Other	274 (16%)
Education/Training	243 (14%)
Advice on completing ACP	185 (11%)
Volunteering	126 (8%)
Legal/Legislation Information	120 (7%)
Implementation Advice	65 (4%)
Media and Events	53 (3%)
Research/Reports	7 (1%)
Prevalence Study	0 (0%)

Service Satisfaction

Results from the 56 national advance care planning advisory service survey responses included:

- 98% of respondents strongly agreed/agreed that they were satisfied with the service they received.
- 98% of respondents strongly agreed/agreed that the operator was knowledgeable.
- 98% of respondents strongly agreed/agreed that the operator was easy to understand.
- 91% of respondents strongly agreed/agreed that the operator directed them to useful resources.
- 84% of respondents strongly agreed/agreed that the resources they were directed to were useful (if applicable).

- 98% of respondents strongly agreed/agreed that the operator provided them with the advance care planning information that they required.
- following their encounter with ACPA, respondents expressed that they felt confident:
 1. having advance care planning conversations with family and friends (77%)
 2. completing a written advance care directive specifying particular treatments they do/don't want (64%)
 3. completing a written advance care directive specifying their values (55%)
 4. appointing a Substitute Decision-Maker via a form (54%)
- The top three outcomes of an interaction with the national advisory service were:
 1. increased knowledge about advance care planning (49%)
 2. increased knowledge about how to complete an advance care directive (40%)
 3. increased knowledge about what having an advance care planning conversation involves (40%)

Volunteer Hours

The advisory service aimed to be predominantly volunteer-operated. In mid-2019, nine new volunteers were recruited and trained to deliver the national advance care planning advisory service. There was an increase in volunteer-led advisor operations with the percent of shifts being covered by volunteers in October, November and December at 91%, 90% and 87%, respectively.

Case Studies

The following three case studies highlight the varying and often complex nature of enquiries received and resolved by the national advance care planning advisory service.

Health professional

In October 2019, a General Practitioner from Victoria contacted the ACPA national phone advisory service regarding advice on completion of an advance care directive (ACD) for a patient with capacity issues. The GP had significant concerns about her patient's mental health and level of understanding of the consequences of her decisions, given that the patient's ACD specified that they did not want to receive any medical intervention under any circumstances, including minor procedures. The GP had accessed some of the resources available on the ACPA website but was keen to discuss her concerns further to guide her practice. The volunteer operator escalated the enquiry for ACPA staff involvement. An ACPA staff member advised the GP that she was under no obligation to sign the patient's ACD if she had concerns that the patient did not fully understand the consequences of her directive. It was also recommended that she consider referring her patient to a psychiatrist for a formal assessment of capacity, particularly given the patient was not a regular patient of her

practice. The GP was then re-directed to the ACPA website to refer her to the range of supporting documents and resources available for health professionals, including relevant e-learning modules. The GP was very grateful for the advice and information provided and was encouraged to contact the service again if she had any further questions.

Consumer

In October 2019, the advisory service assisted an individual from Tasmania requesting the Tasmanian ACD form. The caller was elderly and was not computer literate. She explained to the operator a complex social background, whereby a previous appointment of an Enduring Guardian had caused significant distress amongst her children, who all live interstate or overseas and appeared to have limited understanding of the advance care planning process and responsibilities as an Enduring Guardian. The advisor operator advised that as this previous appointment had been revoked, she needed to appoint someone to the guardian role for them to have legal authority to make medical treatment decisions on her behalf. The caller was already familiar with the Office of the Public Guardian, as she had already spoken with them at length. The operator recommended that she did not sign the ACD with her doctor until she had sufficient time to have conversations with important others about her medical care preferences, and discussed the possibility of reappointing her friend as her Enduring Guardian. The operator also offered to post an information resource pack. The operator was able to provide reassurance and advice during the call where the enquirer was clearly distressed and worried.

Complex

Increasingly during 2019, the advisory service has received complex enquiries and the trained volunteers and staff have been able to resolve these successfully. The range of enquiries received is extensive, including queries regarding capacity, responsibilities and exemptions for health care workers in relation to implementation of advance care directives, and legislation based questions.

In November 2019, a health professional (CEO of a disability and aged care provider) from NSW contacted the advisory service to seek advice on the obligations on his support staff regarding ACDs. The organisation was in the process of developing a policy and the caller was particularly interested in the responsibilities of non-registered care workers in implementing ACDs in emergency situations. Due to the complexity of this enquiry, it was escalated to ACPA staff to ensure an accurate and comprehensive response. The enquirer was informed of the limitations and current gaps in legislation for non-registered health professionals. It was acknowledged that this is a very difficult scenario for disability and aged care organisations given that at this point in time, only registered health practitioners are obliged under NSW common law to follow / implement an ACD once a person loses capacity to make their own medical treatment decisions. There are no obligations

within law for non-registered support staff to follow or to not follow someone's ACD that may include a DNR order.

The ACPA staff member advised that ACPA has advocated that organisations and non-registered staff uphold the person's autonomy and preferences for care where this is clearly stated in an ACD. It was also emphasized to the caller that ACPA continues to highlight this gap in law and policy, and are hoping the revised National Framework for ACDs will address this. ACPA has also raised the issue with the Australian Aged Care Quality and Safety Commission.

In summary, the ACPA national advisory service is highly regarded by users demonstrated by consistent and increasing utilization as well as ongoing high user satisfaction and acceptability. It provides a unique and comprehensive national advisory service to consumers, the health and aged care workforce, and organisations.

Limitations

This evaluation identified a number of limitations including:

- The email address field in the CRM is not a mandatory field and therefore email addresses are not routinely recorded. This had implications for the number of surveys that could be sent to people accessing the service. In response to this challenge, the volunteers have been reminded to ask enquirers for this information where possible.
- ACPA staff identified the need to more accurately record volunteer hours, including the documentation of volunteer activities pertaining to resource collating sessions, team meetings, training and mentoring, community presentations and work on the advisory service. As such, there have been some amendments to the Better Impact system and how it is being used, including additional activity fields to more accurately capture the range of activities the volunteers may engage in as part of their role.
- During 1 January – 31 May 2019, evaluation surveys were not circulated due to ACPA staff changes and resource limitations. The monthly distribution of evaluation surveys recommenced from 1 June 2019.
- Survey responses are recorded against the month they were received, but cannot be directly linked to the date/month that the enquiry was made.
- Enquiries received via the ACPA website previously did not include the jurisdiction field. This resulted in a high proportion of enquiries being recorded with the jurisdiction field as 'unknown'. As a result, additional contact with the enquirer was required to confirm their

jurisdiction to ensure the advice and resources provided were relevant to their location. The enquiry form on the website has since been updated to include the jurisdiction.

Discussion

Program Reach

- The ACPA program has established reach across all jurisdictions of Australia. It achieved extensive reach in Victoria, with enquiries from Victoria representing approximately 43% of all calls. NSW and QLD have also demonstrated good reach representing 17% and 12%, respectively. Only 13 calls were recorded from the Northern Territory (0.8%) indicating that ACPA reach in the Northern Territory is limited. Other states that require further focus include Tasmania and the ACT.
- The advisory phone line continues to be the preferred method for contacting the national advisory service for both health professionals and consumers, representing 71% of all enquiries.
- Requests for documents and resources continue to be the most common reason for contacting the service (36%). Consumers contacting the service require hard-copy mail outs as they are unable to access and/or download and print resources themselves.

Program Quality

- Responses received via the evaluation survey indicate a very high degree of satisfaction with the quality of the service and the support provided. The most common responses received via this survey were that the advisor operator was “knowledgeable” and “very helpful”. For example, one enquirer commented “excellent information and service – very pleasant and knowledgeable operator.”
- A number of respondents indicated that the amount of information included in the information packs is daunting and overwhelming. A review has been completed to ensure that only essential documents are included.
- The ACPA website enquiry form for the national advisory service now includes a mandatory field for enquirers to select their state / territory. This will greatly improve the efficiency and accuracy of advice provided by ACPA staff and volunteers, given that legislation and terminology around advance care planning differs significantly across Australia.

Program Sustainability/Volunteer Model

- Volunteer recruitment in 2019 outweighed attrition, with the volunteer team expanding by 9 members. Following the recruitment and training of 9 additional volunteers in mid-2019, the advisory service steadily increased the number of enquiries managed by volunteers, with the months October, November and December recording volunteer-led operation at 91%, 90% and 87% respectively. This is the highest level of volunteer-led operation that the advisory service has achieved since its inception.
- In 2019, the Standard Operating Procedure has been reviewed and updated to ensure volunteers have the most accurate information available to support them in their role. This included the addition of scripts for sensitive topics including Voluntary Assisted Dying. Annual review of this important resource ensures ongoing consistency with the advice provided and recorded by the volunteers.

Recommendations

The evaluation of the ACPA National Advance Care Planning Advisory Service provided the following recommendations:

- Consider need for more flexible hours for volunteers to improve sustainability, recognizing that volunteers often hold multiple volunteer roles as well as other personal commitments and responsibilities including paid work, study and carer duties.
- Consider undergraduate students for future recruitment campaigns, in particular psychology students who may be interested in undertaking volunteer duties which would align with their chosen career pathway.
- Highlight requirement for 12 month commitment to volunteer role in position description and group information sessions during the annual recruitment campaign to improve volunteer retention.
- Explore technology options to allow an automated diversion process for the national advisory service to the individual mobile phones provided to the volunteers.
- Provide formal communication skills training to the volunteer team to assist them in responding to difficult or complex conversations.
- ACPA Advisory Service staff to complete Volunteering Australia CPD program to further develop volunteer management skills and achieve formal recognition for this qualification.
- Collaboration with external partners and organisations to promote the ACPA National Advisory Service to further improve reach and community awareness.

Conclusion

ACPA continues to provide a high quality national advance care planning advisory service that provides valuable information and resources to a range of audiences. This service continues to demonstrate the impact that volunteers have on increasing awareness and uptake of advance care planning within the wider community. Evaluation findings and recommendations will support continuous quality improvement of this advisory service.

Appendix 1. National Advisory Service Enquirers (January – December 2019)

Enquirer	Jan-19	Feb-19	Mar-19	Apr-19	May-19	Jun-19	Jul-19	Aug-19	Sep-19	Oct-19	Nov-19	Dec-19	Total
Health Professional	44	26	41	32	27	15	28	31	30	45	33	17	369
Substitute Decision-Maker	2	1	0	0	1	1	3	3	0	2	0	0	13
Individual	22	41	31	53	50	25	25	44	30	31	39	37	428
Family/Friend	8	14	14	18	15	19	19	16	16	25	19	16	199
None	25	45	49	75	85	114	51	51	51	33	30	12	621
Unknown	5	5	9	10	8	3	2	2	2	1	1	0	48
Total	106	132	144	188	186	177	128	147	129	137	122	82	1678

Appendix 2. National Advisory Service Enquiries (1 January – 31 December 2019)

Jurisdiction	Jan-19	Feb-19	Mar-19	Apr-19	May-19	Jun-19	Jul-19	Aug-19	Sep-19	Oct-19	Nov-19	Dec-19	Total
ACT	7	3	2	5	3	7	5	5	9	4	0	1	51
NSW	20	20	36	31	24	26	19	23	22	25	22	16	284
NT	0	0	2	2	0	1	2	0	3	1	2	0	13
QLD	13	16	22	22	17	15	16	20	19	19	13	8	200
SA	3	20	3	16	11	7	7	7	11	8	6	11	110
TAS	2	1	5	5	7	3	3	2	3	6	2	2	41
VIC	48	56	52	70	90	77	58	63	44	64	59	33	714
WA	8	4	10	11	12	9	7	15	7	9	11	7	110
International	2	4	0	4	0	2	1	1	2	0	0	0	16
Unknown	3	8	12	22	22	30	10	11	9	1	7	4	139
Total	106	132	144	188	186	177	128	147	129	137	122	82	1678

Appendix 3. National Advisory Service Enquiry Source (January – December 2019)

Source	Jan-19	Feb-19	Mar-19	Apr-19	May-19	Jun-19	Jul-19	Aug-19	Sep-19	Oct-19	Nov-19	Dec-19	Total
1300 Advisory Service	67	84	107	138	126	98	103	109	89	107	94	74	1196
ACPA email	15	16	7	13	7	6	4	6	6	8	4	0	92
ACPA office phone	2	0	0	3	3	1	0	2	0	21	1	0	33
Other	0	1	0	1	3	3	0	1	0	1	2	1	13
ACPA website	22	31	30	33	46	69	21	29	31	0	21	7	340
ACPA newsletter	0	0	0	0	1	0	0	0	0	0	0	0	1
Staff personal work email	0	0	0	0	0	0	0	0	2	0	0	0	2
ACPA learning website	0	0	0	0	0	0	0	0	1	0	0	0	1
Total	106	132	144	188	186	177	128	147	129	137	122	82	1678

Appendix 4. National Advisory Service Enquiry Reason (January – December 2019)

Enquiry Reason	Jan-19	Feb-19	Mar-19	Apr-19	May-19	Jun-19	Jul-19	Aug-19	Sep-19	Oct-19	Nov-19	Dec-19	Total
Advice on completing ACP	12	10	11	13	15	11	16	18	19	21	21	18	185
Documents/Resources	24	52	59	92	64	48	43	53	47	49	45	29	605
Education/Training	36	32	20	32	19	13	18	20	16	16	15	6	243
Implementation Advice	5	3	3	5	7	7	5	7	4	11	6	2	65
Legal/Legislation Information	7	6	5	8	5	5	15	15	7	21	16	10	120
Media and Events	7	9	15	0	1	3	1	4	6	3	1	3	53
Unknown	0	0	0	0	0	0	0	0	0	0	0	0	0
Other	13	16	28	31	43	33	22	24	26	11	13	14	274
Prevalence Study	0	0	0	0	0	0	0	0	0	0	0	0	0
Research and Reports	0	1	0	1	0	0	1	1	0	2	1	0	7
Volunteering	2	3	3	6	32	57	7	5	4	3	4	0	126
Total	106	132	144	188	186	177	128	147	129	137	122	82	1678

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