The way back Information Resources Project:

Final Report

Prepared by **Everymind**

May 2014

EVERYMIND

beyondblue
Depression. Anxiety.

Proudly funded by donations from
The Movember Foundation

Acknowledgements

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We gratefully acknowledge the people with lived experience of suicide attempt(s) and the family members and friends who spoke with us during the consultation. Thank you for sharing your story and your insights.

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CONTENTS

SUMMARY

In May 2013, *beyondblue* funded **Everymind** to develop evidence-informed information resources for people following a suicide attempt. These were to include resources for:

- People who had attempted suicide;
- Family and close friends of people who had attempted suicide;
- Aboriginal and Torres Strait Islander people (including family members and close friends) following a suicide attempt.

This report focuses on the development and pilot dissemination of the resources for the general community. A separate report outlines the development of the resource for Aboriginal and Torres Strait Islander peoples.

Key project achievements

- New national evidence-informed resources (developed as two A5 practical information booklets) for people who have attempted suicide and their family members and friends.
- Scan of existing evidence, policies and complementary resources to inform the development of *The way back* information resources.
- Proactive engagement and consultation with over 30 sector stakeholders to ensure resource content was consistent with and complementary of best practice.
- Consultation with nearly 40 people with lived experience of suicide attempt(s) about their information needs and their views about what should be taken into account in the development of the resources.
- Testing of the viability and fit of the general community resources in hospital and community mental health settings via a pilot in four services.
- Stakeholder feedback from over 20 people to inform future development, evaluation and dissemination of the resources.
- Clear actions identified about how to progress our understanding and improve the effectiveness of information resources for people who have attempted suicide and their family members and friends.

Evidence base and consultation

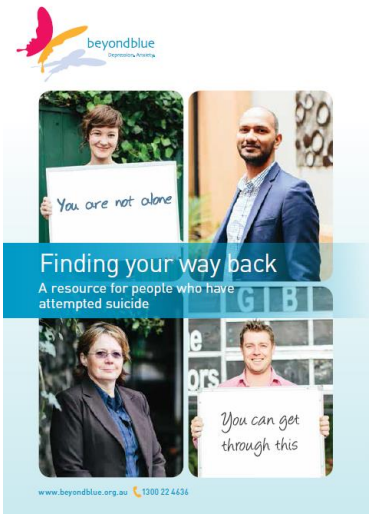
To ensure the resources were informed by the latest research and the collective wisdom of stakeholders, including people with lived experience of suicide attempt(s), the project undertook:

- A scan of academic evidence regarding the nature and efficacy of interventions and information resources for people who have attempted suicide and their family and friends;
- A scan of relevant government and professional association policies and guidelines;
- A scan of existing resources for people who have attempted suicide and their family and friends;
- Consultations with stakeholders including academics, service providers and peak professional body representatives;
- In-depth interviews with community members who had attempted suicide and family members, friends and carers of people who had attempted suicide.

The scan highlighted that while people who have attempted suicide are known to be at higher risk of suicide, and there is diverse research into the effectiveness of different types of support for this target group, there is a lack of evidence about the efficacy of providing information resources for people following a suicide attempt. Nevertheless, the scan and consultations showed that pamphlets, brochures and web-based information are used widely in the sector and sought by individuals, family and friends through formal and informal sources.

Resource development

Drawing from the scans and consultations, two resources were drafted by **Everymind,** reviewed by a panel of academics and other experts, and layout and design managed by *beyondblue*.



'Finding your way back: A resource for people who have attempted suicide' and 'Guiding their way back: A resource for people who are supporting someone after a suicide attempt' are short, A5 booklets that cover information about understanding the medical response, common reactions to a suicide attempt,

staying safe, talking about what has happened and looking after yourself. The resources also contain information about national crisis and support services.

Quotes from people with lived experience are used throughout the resources. These comments were recorded during the consultation process and were used to convey hope for the future. For example:

> *"After my suicide attempt six years ago, I kept remembering a quote from Winston Churchill: 'When you are going through hell…just keep going'. This gave me great faith that somehow I would find a way out. Which I did and I'm really enjoying life now."* (Male who has attempted suicide)

Pilot dissemination

The printed resources were piloted for four to six weeks in four hospital and community based mental health services in the Hunter Valley, New South Wales and Darwin, Northern Territory. Due to a range of reasons, only a comparatively small number of resources were distributed during the pilot and limited data was obtained to assess the resources' acceptability to stakeholders or effectiveness of dissemination in such settings. The available results did, however, indicate that staff and managers felt that the resources met the information needs of service users and that they would be appropriate for distribution in a range of health and community services in the future. For example:

> *"I think overall it's a great and much needed resource"* (Pilot participant)

Stakeholder feedback

An online survey was also used to invite external stakeholders to provide comments and feedback about the resources. Twenty-one completed responses were received, and although this was a comparatively low response rate, responses were generally positive and indicated that the resources were well regarded and considered suitable for their intended audiences.

Next steps

The development of these resources provides an important opportunity to provide people who have attempted suicide and their family members and friends with quality evidence-informed information that is designed to help people navigate the issues that arise after a suicide attempt. The resources would be strengthened by ongoing evaluation from the target audience, consideration of how online media can complement the written materials, further research into the benefits of information resources for people who have attempted suicide and a proactive dissemination strategy.

CHAPTER 1: PROJECT BACKGROUND

1.1 Background

It is conservatively estimated that approximately 65,000 Australians make a suicide attempt each year. These individuals can experience a range of physical, psychological, emotional and social challenges following the event and are at much higher risk of a further attempt or death by suicide. Many of the issues faced by someone who has attempted suicide, such as feelings of guilt and shame, can also be shared by close family members, friends and carers. However, few resources are presently available for either group of people. In May 2013, *beyondblue* funded **Everymind** to work with them to develop evidence-informed information resources for people who have attempted suicide and their family and friends.

1.2 Project aims

The two main aims of the project were:

1. To produce information resources for people who have attempted suicide;
2. To produce information resources for family and close friends of people who have attempted suicide.

The development of the resources was informed by the evidence including findings from:

- A scan of existing academic evidence on the nature and efficacy of interventions and information resources targeting people who have attempted suicide and their significant others;
- A scan of relevant government and professional association policies and guidelines;
- A scan of existing resources for people who have attempted suicide and their significant others;
- Consultations with sector stakeholders, including academics, service providers and peak bodies;
- In-depth interviews with community members who had attempted suicide and family, friends and carers of people who had attempted suicide.

1.3 Project management and staff

Project planning and resource development was overseen by a Project Working Group composed of senior staff from *beyondblue* and **Everymind**, and two community members with lived experience of suicide attempt(s). Day-to-day operation of the project was overseen by the Program Manager of the Families, Workplaces and Targeted Prevention team at **Everymind.** One Senior Project Officer was employed full-time to work on the project and additional staff were engaged around peak workload times, such as conducting in-depth interviews with people with lived experience of suicide attempt(s).

1.4 Phases of the project

The project was composed of five phases and these are outlined below in Figure 1.

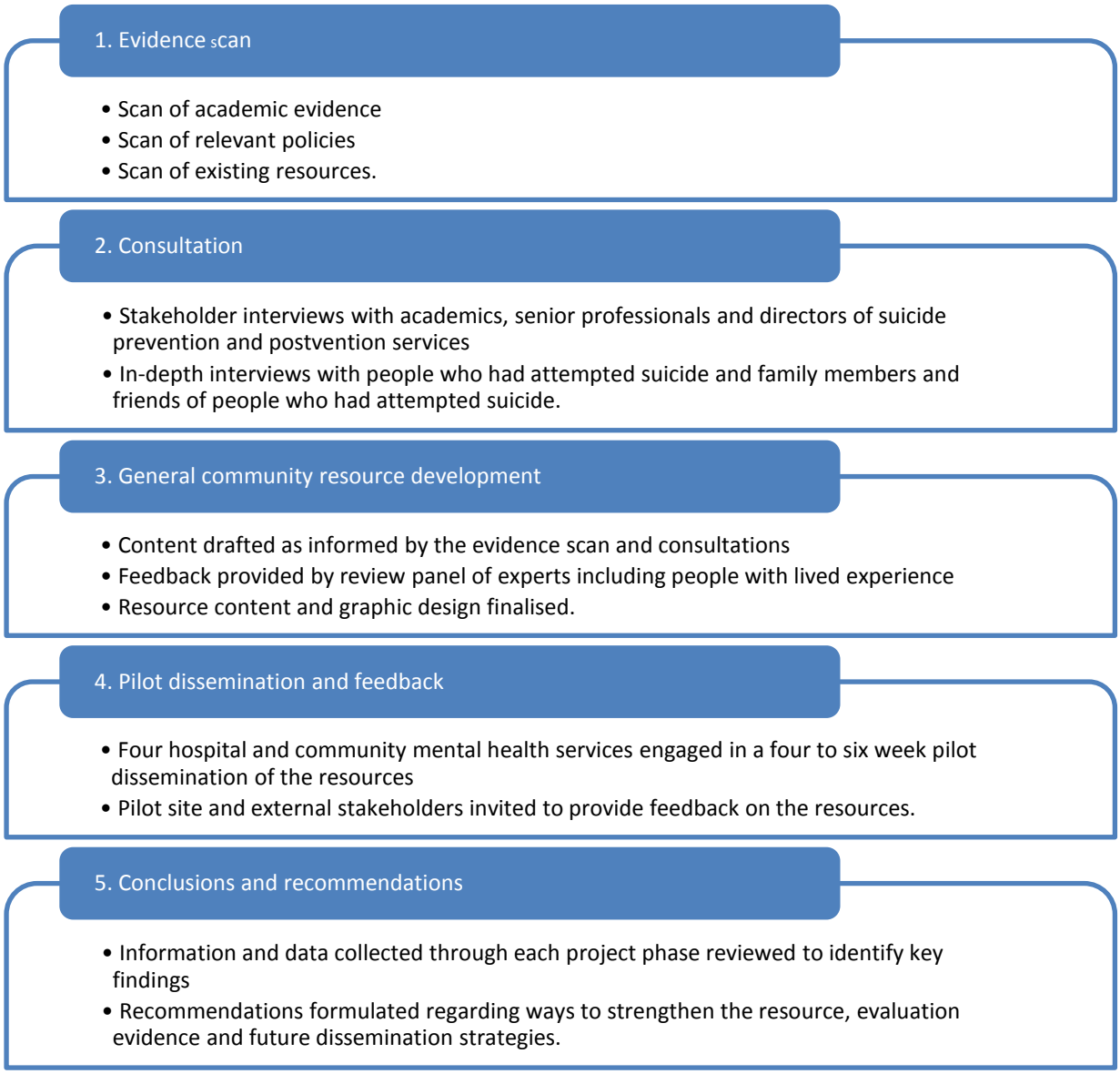


Figure 1: Project phases

1.5 Report overview

This report has been prepared by **Everymind** and provides a summary of the work undertaken by the project team from May 2013 until May 2014. Details about the work completed in each phase are provided. A separate report outlining the development of the resource for Aboriginal and Torres Strait Islander peoples is also available.

This report concludes with a series of recommendations for *beyondblue* regarding further development of the resource, future dissemination and strategies for evaluation of the general community resources.

CHAPTER 2: EVIDENCE, POLICY AND RESOURCE SCANS

Phase one of the project involved a review of the academic evidence, relevant federal and state policies and a scan of existing resources for people who had attempted suicide and their family and friends. This section provides a summary of the aims and key findings of these reviews as well as the recommendations that informed subsequent development of the resources.

Although each scan articulated and followed a prescribed methodology, it is important to note that time and resources did not permit comprehensive systematic reviews to be undertaken and it may be that other relevant material existed that was not identified.

2.1 Evidence scan

The purpose of the evidence scan was to identify research that could be used to inform the type, nature and delivery of the resources to be developed. Specifically, the scan aimed to:

- Identify the types of post-discharge support that has been found to be effective for people who have attempted suicide;
- Review evidence on the efficacy of psychoeducation for the target groups;
- Identify relevant self-help and self-care approaches;
- Scan other relevant research and literature.

Key findings

Individuals who have attempted suicide

The evidence base highlighted the range of risk factors for suicide attempts, including proximal risk factors (e.g. extreme distress, relationship difficulties, drug and alcohol use, etc.), distal or non-modifiable risk factors (e.g. gender, past sexual abuse, etc.) and specific population groups with higher rates of suicide attempt (e.g. people with mental illness). The evidence also highlighted the potential role of impulsivity.

Studies investigating the help-seeking behaviours of people who had attempted suicide highlighted that there was a large proportion of people who did not seek help from any services, and those who did seek help were seen by hospitals, general practitioners and mental health services. Engagement with service providers after an initial presentation was generally low; and it was suggested that people's engagement with services may have been affected by staff response at initial presentation.

Interventions that targeted people who had attempted suicide differed with regard to:

- Primary intended outcomes e.g. increased engagement with follow up services, reduced recurrence of suicidal behaviours;
- Settings e.g. hospital, community;
- Duration e.g. brief (one-off), longer term (multiple settings);
- Type e.g. information provision (e.g. support numbers), referral process, phone calls, letters/ postcards, therapy.

Because of the limited evidence base and the diversity of what had been investigated, it was difficult to draw firm conclusions about what sorts of interventions/ supports were likely to be effective in reducing suicidal behaviour or increasing engagement with support services for people who had attempted suicide. Nevertheless, the available evidence suggested that:

- Brief interventions, including regular contact by mail or information sessions coupled with regular phone contact, may be helpful in reducing repetition of suicidal behaviour;
- Brief interventions, including enhanced referral procedures within the same institution and proactive phone contact, may be helpful in improving engagement with follow-up services;
- Longer term therapies (including cognitive behavioural therapy, motivational approaches, psychodynamic therapy, dialectic behavioural therapy, problem solving treatments, mindfulness-based cognitive therapy) have some evidence of efficacy with people who have attempted suicide compared to treatment as usual or other approaches;
- Self-help/ self-paced web interventions are showing some promising efficacy.

Qualitative research directly involving people who had attempted suicide was also limited, however the few available published studies highlighted that common coping strategies included talking to others and seeking companionship, positive thinking, engaging with spirituality and religious practices, and seeking help from treatment providers.

Family and friends of people who have attempted suicide

Studies involving people who had attempted suicide and their families highlighted the important role that family members and significant others can play in providing support and helping to establish a safe environment. Many family members identified that they would have (or were) interested in engaging with professional support (e.g. counselling). In a focus group conducted in Australia, relatives of people who had made a suicide attempt identified a range of unmet personal support needs and a sense that they were disengaged from the treatment staff and process (Leggatt & Cavill, 2010). They identified that they were not provided with information about suicide, how to recognise suicidal behaviour, how to provide support to someone who has made an attempt or what actions to take if the suicidal behaviour recurs.

References

Leggatt M. & Cavill M. (2010). Carers' Experience of the Mental Health System in Relation to Suicide, *The Australian Journal on Psychosocial Rehabilitation,* Autum.

2.2 Policy scan

The purpose of the policy scan was to identify Australian policies and guidelines that guide clinical practice with regard to people who have attempted suicide and their families.

Key findings

There was a high level of consistency across jurisdictions with respect to suicide prevention policies. Governments at state levels had adopted the National Suicide Prevention Strategy objectives outlined in the LIFE Framework and taken on 'whole of government' approaches.

There was less consistency at the state level between health and mental health services with regard to policies and procedures for the delivery of services to people who have attempted suicide, and their family members and friends. Where policies or guidelines did exist, they were heavily orientated to risk assessment and management and only provided a brief focus on discharge planning (generally to the extent of confirming that a referral or appointment had been made).

The national professional associations (e.g. Australian Psychological Society; Australian College of Mental Health Nurses, etc.) had developed policies and standards that stressed the need for engagement, ongoing treatment and monitoring of a person who has attempted suicide and their family members.

2.3 Resources scan

The purpose of the resource scan was to identify existing information or self-help resources that specifically targeted, or were aimed at supporting, people who had attempted suicide and their families, in order to identify typical content, style and any evidence of efficacy or evaluation that had not been identified in the academic scan.

Key findings

While there were some information resources available in the public domain targeting people who had attempted suicide and their families, no evaluation reports were identified regarding their effectiveness in terms of reach, relevance or helpfulness. There was little or no information about the steps that had been taken by organisations to develop their resources.

Information resources were most typically available for people who had attempted suicide and their families in the form of a pamphlet or booklet, in hard copy or online. There were also a range of other online resources including information websites, blogs, forums, online videos, online meetings and an online assessment and self-help course; as well as mobile phone apps.

Content typically covered by the resources included:

- Information about risk factors for suicide with the aim of encouraging people with risk factors to seek help early and to assist family members and friends to support early help-seeking;
- For people who had attempted suicide - ways to stay safe (e.g. triggers, safety plans);
- For family members of people who had attempted suicide - communication strategies including how to talk with the person after a suicide attempt and how to communicate concern to support services;
- What to expect from treatment services (e.g. emergency departments);

- Self-help and self-care strategies to help manage stress and improve wellbeing;
- Information about support services for people who had attempted suicide and their carers.

2.4 Key conclusions from evidence, policy and resource scans

For the purposes of developing resources for people who have attempted suicide and their family and friends, the main conclusions and recommendations that were developed from the three scans are outlined below.

- There is an evidence gap regarding efficacy and acceptability of information resources targeted to people who have attempted suicide and their families.
- The different information needs of people who have attempted suicide and their families should guide what specific content should be included in the resources for each group.
- There are consistent topics currently covered in information resources for people who have attempted suicide and their families, which are informed by the evidence base. This resource should be comparable in terms of content, as well as address any gaps (as identified from stakeholder consultation).
- In light of patterns of help-seeking and coping behaviours reported by people who have attempted suicide, it would be appropriate to develop a resource that supports self-help and self-management.
- The information resources should seek to encourage and support people to connect with formal and informal supports.
- The settings and contact points that appear to offer most opportunity for effective dissemination include: emergency departments, acute mental health services and community mental health services.

CHAPTER 3: CONSULTATIONS WITH STAKEHOLDERS

During July 2013, **Everymind** contacted over 30 individuals and organisations identified as significant stakeholders in the suicide prevention and support service sector at the national level and invited them to participate in consultations to inform the development of *The way back* resources.

Individuals were asked to provide responses to set questions concerning:

- The importance of resources for individuals and their family and friends following a suicide attempt;
- Awareness of the types of resources that presently exist;
- What information they believed should be provided to the target group(s);
- Recommendations for how and where resources should be distributed.

Stakeholders could elect to provide responses by telephone interview or through completion of an online survey. Responses were collated and then subjected to thematic analysis.

3.1 Key findings

Are written resources important?

All stakeholders affirmed the importance of providing information resources to people following a suicide attempt. They identified a number of reasons why this was important.

- People who have attempted suicide are a high-risk group for further suicide attempts.
- A suicide attempt can be an incredibly stressful and distressing time for people, which can also be associated with experiencing a range of conflicting thoughts and emotions. Information and support can help a person make sense of what is happening and assist them in making informed choices about how to move forward.
- Many people who attempt suicide do not seek help and it is critical that they have information about the services available and be encouraged to use them.

All stakeholders identified the importance of providing resources to family and friends of people who had attempted suicide and reasons why they believed this to be important.

- Family and friends can bear the brunt of care at home for people who have attempted suicide and can be terrified that they will do something wrong. They are frequently desperate for information.
- Carers are likely to have their own support needs and the more information they have the better able they will be able to look after themselves as well as support the person who has attempted suicide.

What resources are presently available?

Stakeholders varied considerably in their knowledge about existing resources for individuals who had attempted suicide. For example, those who worked in hospital emergency departments did not know of any resources whilst others involved in community mental health promotion indicated that there were too many generalist information brochures. There were queries raised about national (as opposed to local) credibility, relevance and fit of existing resources and whether it would be better to develop resources for specific 'at-risk' audiences (e.g. young people) or particular settings (e.g. schools).

In contrast to the diverse responses concerning existing resources for individuals who had attempted suicide, virtually all stakeholders were unable to identify any existing resources for family and friends of people who had attempted suicide.

What content should be included in resources to be developed by this project?

Stakeholders provided a range of suggestions about the types of information to include in resources for individuals who had attempted suicide and they emphasised the importance of presenting it in a non-patronising manner. Key themes are outlined below.

- Information should be positive, normalise feelings and provide hope for the future.
- Practical information is important e.g. tips for how to talk about what has happened.
- Information about how to manage the recurrence of suicidal thoughts should be included.
- Information should encourage people to engage with services and peer support groups.
- People should be provided with a list of services that are available and what to expect from them.

Stakeholders also provided a range of suggestions about the types of information to include in resources for family members and friends of people who had attempted suicide. Key themes are summarised below.

- Practical information is needed on what to do and say to clinicians in terms of being involved in treatment and care plans for the person who has attempted suicide.
- Information is needed about how to have constructive conversations after a suicide attempt. This should include how to create safe environments and routines for the person at home.
- Information should include strategies to assist understanding of what has happened, typical reactions of others and dealing with any feelings of guilt.
- People should be provided with information about where people can get support for themselves including options for peer support.

Distribution of the resources

A variety of suggestions were made by stakeholders about where the best places to distribute the resources would be. Suggestions ranged from emergency departments and general practice clinics to organisations where 'at-risk' people may go (such as relationship and financial counsellors, pharmacies etc.) and public places such as the internet, libraries, community centres, cinemas and supermarkets.

Stakeholders also made comments about possible barriers that may impact on the resources being distributed in different organisational settings and these related to complexity, time constraints and staff rotations of various services (for example, emergency departments) as well as staff attitudes, knowledge and comfort when engaging with clients that have attempted suicide. Other barriers to distribution of information that were identified included: myths and stigma around suicide in the community; and cultural and language barriers.

3.2 Key conclusions from stakeholder consultations

- Information resources for people who have attempted suicide and their family members and friends are important.
- There was variable awareness of what resources were available for people who had attempted suicide and their family and friends.
- There was a range of consistent content identified by stakeholders as important to include in resources.
- The distribution of the resources should be wide and there will be specific barriers to overcome in different settings.

CHAPTER 4: VIEWS OF PEOPLE WITH LIVED EXPERIENCE

To supplement the findings from the background scans and consultations with the service sector, the project team conducted a consultation with people with lived experience of suicide attempt(s) to obtain their views and recommendations. A separate consultation report with more detailed information has been developed and is available. This section of the final report provides a summary of outcomes from the consultation with people with lived experience of suicide attempt(s).

4.1 Participants and methodology

Everymind worked with *beyondblue's* blueVoices and Suicide Prevention Australia to invite community members in their networks to participate in the consultation. To be eligible, participants needed to be aged over 18 years, not currently experiencing symptoms of mental distress, and the suicide attempt (by individuals or that of their family member or friend) had to have occurred more than 12 months prior.

Following a screening process, interviews were held with a total of 37 people of whom 22 were individuals who had attempted suicide, nine were family members or friends of a person who had attempted suicide and six were people who fell into both categories. Participants had an average age of 40 years (range 18-79 years) and the majority were female.

Interviews were conducted by tertiary qualified staff at **Everymind** who had either a social work or psychology background. All interviews were conducted by telephone and followed a five question semi-structured interview script that included:

1. How important do you think it is to talk about suicide and attempted suicide in the community?
2. What types of conversations or information about suicide or attempted suicide are occurring or available in the community?
3. What things do you think make it hard for people to talk about suicide or attempted suicide?
4. What things if any, do you think would make it easier to talk about suicide or attempted suicide?
5. If information was available for people immediately after a suicide attempt, what do you think would be most helpful?

The research was approved by the Hunter New England Health Research Ethics Committee.

4.2 Key findings

Driven by a strong desire to tell their story, participants shared intensely personal aspects of their lives that included descriptions of past feelings of absolute hopelessness, despair and experiences of their world being 'turned upside down'.

In addition to themes that emerged in response to specific questions, there were two major themes that emerged across all of the questions.

1. **Suicide and suicide attempts are highly stigmatised in the community.**

Participants spoke about the stigma as stemming from societal institutions such as religions (suicide as a sin), the law (suicide as a crime), medicine (suicide as a mental illness) as well as general cultural beliefs that value 'toughness' when people are facing adversity.

> *"People don't know how to react … They don't know whether or not to talk about it … There's definitely still a stigma."* (Female, 35, who had attempted suicide)

2. **People who are suicidal can be reluctant to disclose their feelings and seek help.**

Participants described that people who are suicidal can be reluctant to disclose their feelings and seek help because of expectations that others will respond with stigmatised and poorly informed views, or will be unable to assist.

> *"I was desperate to speak to someone, anyone, about how I was feeling. And I felt I couldn't and this made it really hard."* (Female, 35, who had attempted suicide)

When asked what type of information would be helpful for people after a suicide attempt, four key themes emerged.

1. Information explaining that suicide attempts are not uncommon and affect people from all walks of life.
2. Personal stories of how people have lived through their suicide attempt(s) could be helpful.
3. Information to help family members, friends and the community understand why a person may contemplate suicide.
4. Practical information and strategies to help people navigate the issues that come up after a suicide attempt.

> *"To be able to provide people who are friends or carers with factual information about why and the reasons behind it. I think that's really important."*
>
> (Female, 45, who had attempted suicide and was a family member)

Participants also emphasised that the primary role of information resources should be to support people in having constructive and supportive personal conversations, and that they would have greatest impact when provided in the context of non-judgemental attitudes about suicide.

4.3 Key conclusions

Consultations were conducted with people with lived experience of suicide attempt(s) to inform the development of *The way back* resources, but broader conclusions can also be drawn.

- It is possible to systematically investigate the needs and views of people with lived experience of a suicide attempt in a safe and supportive way and partner with them in the design and delivery of suicide prevention initiatives.
- People with lived experience identify a range of barriers to talking about suicide, suicide attempts and seeking support. These barriers were generally related to stigmatised or poorly informed views about suicide that exist in the community and a lack of understanding about what people may be going through when they are suicidal.
- People with lived experience could benefit from data about the number of people affected by suicide attempts, information that assists friends, family members and the community to understand why a person may contemplate suicide and practical information that helps people navigate issues that come up following a suicide attempt.
- People with lived experience suggested that hearing the personal stories of others who had attempted suicide may have important benefits. For individuals, it may help them to understand what has happened, see that they are not alone and have hope for the future. They felt it may also help the broader community understand what individuals experience before and after an attempt.
- People with lived experience of suicide attempt(s) are important partners in suicide prevention.

CHAPTER 5: RESOURCE DEVELOPMENT

5.1 Resource development and review process

Drawing from the collective results of background scans, consultations with stakeholders and in-depth interviews with people with lived experience of suicide attempt(s), the project staff prepared drafts of one resource for individuals who had attempted suicide and one for family members and friends of people who had attempted suicide.

Drafts were circulated initially to Project Working Group members and their feedback was incorporated and re-circulated. This process was repeated until the Reference Group approved the circulation of the latest version to other sources for feedback. An external review panel was established composed of academics, senior stakeholders in suicide prevention, mental health and carers sectors as well as two individuals with lived experience and professionals with specialised knowledge of particular demographic groups, such people from culturally and linguistically diverse backgrounds. After the feedback was incorporated, *beyondblue* engaged an external editor to review the documents and managed the design and layout of the resources to align with *beyondblue* corporate branding.

The title and main graphic of a maze (to represent the complex paths navigated by target audiences) was proposed by a member of the Project Working Group who had lived experience of suicide attempt. The titles for the two resources were developed and finalised:

a) 'Finding your way back: A resource for individuals who have attempted suicide';
b) 'Guiding their way back: A resource for people who are supporting someone after a suicide attempt'.

The final versions were approved by the Project Working Group and during November 2013, a small quantity was printed for the purposes of conducting the pilot dissemination.

5.2 Resource overview

The content of the resource was primarily aimed at covering information that would:

- Help people manage the issues that are typically associated with a suicide attempt;
- Encourage connection with others (informal and formal supports) and build people's capacity to have constructive conversations after a suicide attempt;
- Describe actions that promote safety and wellbeing.

The content was designed to be practical and straightforward. The information sits within two short A5 booklets. The family resource uses a workbook style approach and both resources have space for people to write down contact details of their personal supports. Both resources acknowledge the difficulties associated with a suicide attempt while communicating a hopeful view of the future.

The content covered by each resource includes:

- Understanding the medical response;
- Common reactions to a suicide attempt;
- Things to do in the short term;
- Talking about what has happened to others;
- What to do if thoughts about suicide return;
- Looking after yourself;
- The future;
- Resources and other information.

Quotes from people with lived experience are used throughout the resources. These were recorded during the consultation process and used with permission.

> *"After my suicide attempt six years ago, I kept remembering a quote from Winston Churchill: 'When you are going through hell…just keep going'. This gave me great faith that somehow I would find a way out. Which I did and I'm really enjoying life now."* (Male, who had attempted suicide)

CHAPTER 6: STAKEHOLDER RESOURCE FEEDBACK SURVEY

6.1 Development of online survey

In order to gather feedback about the resources and how they may be best distributed, during January 2014, **Everymind** developed an online survey for stakeholders to complete. The main aim of the survey was to obtain respondents' views about the tone, content and layout of each resource as well as their suggestions on where it should be disseminated and if they anticipated any barriers to its distribution.

6.2 Participants and methodology

beyondblue sent a link to electronic copies of the resources to a distribution list of approximately 100 stakeholders in the suicide prevention sector and invited them provide feedback about the resources. Stakeholders included academics, senior executives, project staff and some direct service providers. A reminder invitation was sent in late January and members of the Project Working Group also extended individual invitations to associates in their networks with permission to further circulate the invitation to other relevant individuals.

A total of 51 online surveys were started with around half of the submitted surveys only partially completed. Two individuals submitted answers to questions directly by email. Thus, the key findings are drawn from the responses to questions about the resources (n=21). It is important to keep in mind the small sample size and response rate when drawing conclusions from this data about the acceptability of the resources to sector stakeholders.

Respondents included a mix of project workers and direct service providers, managers of suicide prevention and postvention support services, national bodies and a small number of community members with lived experience of a suicide. Most participants identified they were from either Victoria or New South Wales.

6.3 Key findings

Content, tone, and design of the resources

Figure 2 provides an overview of the pattern of responses to different aspects of the resource and a selection of free text comments are also provided below.

In general, responses were very positive. The highest levels of agreement were about the individual resource covering useful content (96% agreed) and the family resource being easy to read (95% agreed). The lowest level of agreement (in the order of 10% lower agreement compared to other items) was for the individual resource having an engaging design style (75% agreed).

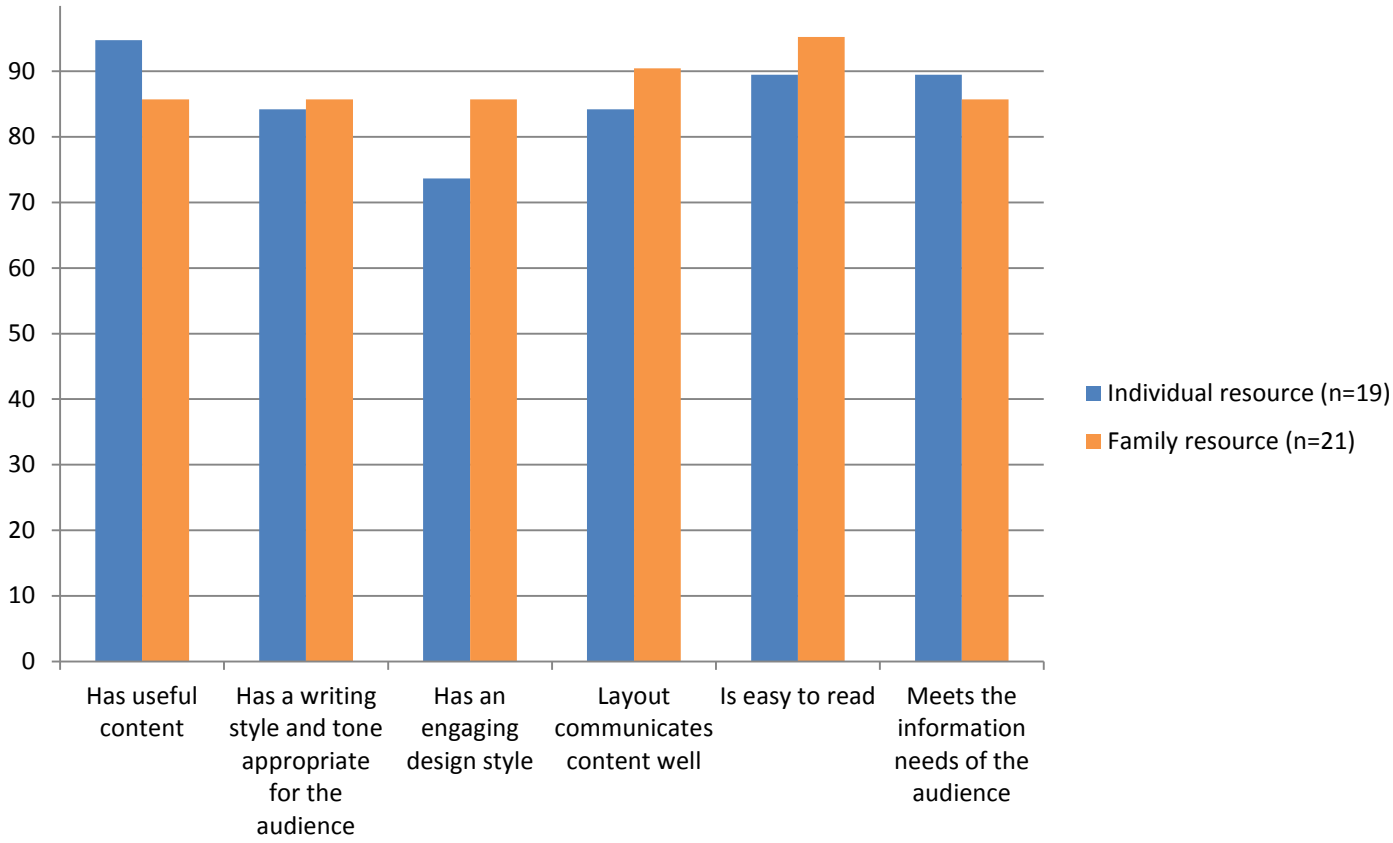


Figure 2: Percentage of respondents who agreed or strongly agreed with the statement
(note: remainder of sample were neutral or disagreed)

Where should the resources be distributed?

The majority of respondents indicated that the resources should be distributed in:

- Acute mental health services (81%);
- Community mental health services (81%);
- Community Health Services (81%);
- Primary care and GP services (77%);
- Hospital emergency departments (77%);
- Online (69%).

Free text comments emphasised the importance of making the resources available across a range of community (and non-health) settings.

Barriers to distribution

When asked if they anticipated any barriers to distributing the resources, half responded 'yes' and half responded 'no'. Comments referred to the following barriers:

- Attitudes of health and community professionals may influence interest or willingness to support dissemination (n=3);
- Cost of printing enough resources for them to be widely available (n=2);

- The importance of having the information resources supported with face-to-face or individual personal support (n=2).

Further comments about the 'Finding my way back' resource

A number of respondents provided additional comments about the booklet 'Finding my way back: A resource for people who have attempted suicide'. For example:

> *"I think it's a great and much needed resource however in some places the language used is a little technical - not the kind of language everyday people use. Also it could be more succinct and clear. This would also cut down on the overall length which would be good as it is quite long."*

> *"I'm not sure about the title - "Finding your way back" implies that you want to get back to where you have been which for many people is not necessarily true or possible. I think finding your way through would be better and also fits with the Maze image."*

> *"I found the style to be reasonable mostly, but somewhat patronising."*

> *"I like the quotes - short and succinct and yet powerful and personal."*

> *"It is very wordy and people with poor literacy may have trouble with it."*

> *"A more engaging friendly tone with some graphics would work better."*

> *"We don't really know at what point a person is going to handed this - 24 hours after a suicide attempt, a week, a month a year? Organising the document via a timeframe (Short, Medium and Long Term) - so that the person could refer to parts as they progress through the next few weeks, months and years as a developmental process."*

> *"Overall it is excellent …My only concern is that someone who is angry that they are still alive and thinking they will try to kill themselves again may not connect with it. Perhaps add a section (including quote) in the front that speaks to the person who is not happy to be alive and acknowledges this may be the case for them right now but the experiences of others who have attempted suggest that this will change with time."*

Further comments about the 'Guiding their way back' resource

A number of respondents also provided additional comments about 'Guiding their way back: A resource for people who are supporting someone after a suicide attempt' and these included:

> *"Could be less technical, shorter and in places and more succinct."*

> *"It is superb - many congratulations! Have you considered writing an 'easy read' version - a type of exec summary to be given to people immediately after a suicide attempt of a loved one as this is wonderful but its comprehensiveness may make some people reluctant to read it - if they are incredibly distressed. I have been told by people that they feel like their head is 'mashed up' in the immediate aftermath of a suicide attempt by someone they love. Perhaps just with the aim of compassionately instilling hope and signposting them to the full resource?"*

"Not sure about the title - Guiding their way back just feels a bit like it's on the support person to ensure that they make it, and to where? Helping guide them through feels more neutral or Guiding their way through."

"Why are there notes pages for supporters but not for the person affected?"

"I really like the space to write in the guide and all the practical tips. It's a shame similar space and practical elements were not included in the guide for the person who attempted as they make the guide more accessible and engaging. Overall, the guide is excellent."

6.4 Key conclusions

Across the respondents, feedback about the resources was largely positive. Suggestions for improvement included that attractiveness and accessibility could be improved by making the language simpler and the overall length shorter. Contrary to advice provided by one review panel member, there was some support from survey respondents to use a workbook style format in the resource for individuals. All settings were identified as relevant and appropriate with no clear indication of a preferred setting.

In light of the small number of respondents, ongoing evaluation and further feedback from stakeholders would strengthen confidence in the conclusions drawn from the sector stakeholder survey.

CHAPTER 7: PILOT DISSEMINATION

7.1 Aim of the pilot

The primary aim of the pilot was to evaluate the feasibility and effectiveness of distributing the resources through hospital and community mental health settings. The pilot also sought to obtain feedback from staff about whether they felt the resources were suitable and useful to their clients.

7.2 Participating organisations and methodology

Two services in the Hunter Valley, New South Wales and two services in Darwin, Northern Territory agreed to take part in the pilot dissemination of the resources.

Both of the Hunter sites were part of the Hunter New England Local Health District. One of the sites was a hospital-based mental health service in Newcastle providing acute psychiatric care. The other service was a mixed hospital and community-based service in a regional area providing triage and assessments for the emergency department, an inpatient ward and a community mental health service. The pilot proceeded in the two Hunter Valley sites from December 2013 – January 2014.

The Northern Territory sites were both based in Darwin and consisted of a hospital-based crisis service and a private counselling service that specialised in suicide prevention. Their pilots were conducted from mid-April to mid-May 2014.

A series of briefing discussions were held with service management in each site to explain the aims of the research and what would be required of a pilot site. After agreeing to take part in the pilot, where possible, Institute staff also provided an overview of the pilot to other team members.

Although some minor procedural differences occurred in each site, it was agreed that people should be offered a resource if they presented to a service for assistance with a stated intention to die AND an act of self-injury (regardless of severity). It was understood that staff would need to use clinical judgement to distinguish suicide attempts from other forms of distress and non-suicidal self-harm. Written guidelines clarifying eligibility were provided to staff before pilot commencement.

Staff piloting the resources were asked to complete a record distribution sheet for each eligible client that presented for assistance. This record included whether the client was offered either of the resources and when a booklet was not offered, and why (e.g. 'client too distressed' or 'offer when admitted to ward'). If a client was offered a booklet but declined to accept it, this was also to be recorded (with a brief explanation if possible).

Management and staff were briefed and provided with a form to record any adverse events or unintended outcomes that occurred during the distribution of resources (e.g. if a client became agitated or suffered a negative event after being provided with a resource).

Each site was provided with folders containing all relevant record sheets and staff guidelines for each of the different work units in their services. They were also provided with posters to display in main work/ traffic areas reminding staff to distribute the resources to eligible clients.

The main forms of data sought were:

- The number of resources offered and issued to patients (as recorded by site staff);
- Staff views about the resources and their experiences of being involved in the pilot (obtained through survey forms);
- Any other general information about the service, the distribution strategy used and barriers and opportunities anticipated and experienced (obtained through group discussions).

The pilot dissemination research projects were approved by the Hunter New England Research Ethics Committee and the Northern Territory Research Ethics Committee.

7.3 Key findings

Resource record distribution and adverse events

One New South Wales site provided 10 completed record sheets and the other provided one and we therefore relied on verbal estimates made by staff at a group discussion to determine that around a total of 20 resources were distributed across the two sites in that state. From completed records sheets from the New South Wales sites, results showed that:

- Six resources for individuals and three resources for family members had been distributed;
- Six males and two females received either or both of the resources;
- Four resources were distributed between 7am and 3pm, two were distributed between 3pm and 11pm and one was distributed between 11pm and 7am.

One Northern Territory site provided information about the number of resources they distributed verbally in a phone discussion and the other provided details by email. Based on these sources, a total of 20 resources were distributed across the two sites in the Territory. This included 15 resources for individuals and five resources for family and friends (details about the gender of recipients and time of distribution were not available).

These numbers were less than those which had been predicted in planning meetings across all pilot sites. For example, one New South Wales site had estimated that at least 10 presentations related to a suicide attempt occurred each week. Similarly, one Northern Territory site estimated they would see approximately 100 clients per month with suicidal thoughts and plans.

No adverse events or unintended outcomes were recorded or reported from any pilot sites.

Group discussions

Group discussions were held with staff and management from the New South Wales pilot sites following their distribution periods. Follow-up telephone discussions or email communications occurred with the managers of Northern Territory sites following the conclusion of their pilots in mid-May 2014.

All sites acknowledged the small number of booklets distributed and this was considered at one site to be due to an unusually quiet period in terms of clients presenting for assistance following a suicide attempt. Another service also considered this to be the case but added that only a comparatively small number of clients would typically present for assistance following an attempted suicide (compared to presenting because of suicidal ideation). They indicated that this was a consequence of people

presenting to other services after a suicide attempt and suicide attempts specifically being a less common reason for presentation than suicidal ideation or non-suicidal self-injury.

One manager advised that it was often difficult to embed any change in staff work practices and hence staff participation in the pilot had been contingent on 'pushing them' to hand out the resources. The manager also said that not all eligible service users would have been offered a booklet mainly because staff forgot, particularly when they were busy. This was also part of a broader problem that occurred at times with the distribution by staff of other resources.

No sites identified any other problems or challenges with undertaking the pilot generally or specific aspects such as determining who would be an eligible client, how to complete the record distribution sheets and/or adverse events records. One staff member raised a question about being unable to know for certain that when an individual was given both booklets if the one for family and friends would actually be passed on to them.

At one site there was a general discussion about the risks of negative consequences if the booklets were issued to people incorrectly. A concern was raised about the potential risk of resource distribution 'normalising' suicide attempt as being a good way to deal with extreme distress/ crisis. The concern was noted and there was agreement that the concern did not disregard the many positive reasons why it could be important to distribute information resources to those in need.

Without disregarding concerns about the resources being incorrectly given to people, all sites considered that staff felt the information in the booklets was beneficial for clients and carers and a number had received unsolicited positive feedback from clients and carers who accepted the booklets. All sites also stated that the resource should continue to be distributed within services such as theirs as well as other settings such as general practitioners waiting rooms, private psychologists, general community health centres, counselling services and services for specific demographic groups such as headspace.

Staff survey

Each pilot site was provided with hard copies of a two-page staff survey and given the option of doing an online version if preferred. Across all four sites, 12 surveys were completed and/or partially completed and returned. It is estimated that sites had a combined staff (including managers) of approximately 85 people. This would mean that the overall response rate for the staff survey was about 14%. However, there was large site variability in response rate (from 3% to 80%) potentially indicative of the different levels of staff engagement with the pilot.

Out of the 12 surveys obtained, only seven participants stated that they had handed out either of the booklets and each of these estimated they had distributed one to five copies during the four week pilot period. Most estimated that this represented about half of clients who would have presented following a suicide attempt or were a family member/friend of someone who had attempted suicide. Only one respondent stated that all eligible clients were given a resource.

When asked why they didn't give out any resources or only gave them to some clients, respondents either did not provide a reason, or indicated that they:

- Did not see any eligible clients during the pilot period;

- Worked across different sites and the resources were not available at that site;
- Considered the resources were not suitable for a client who was from a culturally and linguistically diverse background;
- Considered the resources were not suitable for a client who had previously been given many resources;
- Had forgotten during a busy work period.

In terms of staff's views about the resources, the majority agreed that the resources had:

- Useful content (8/11);
- A writing style and tone appropriate to the audience (7/11);
- An engaging design style (6/11);
- Were easy to read (8/11);
- Met the information needs of the audience (7/11).

Only a few free text comments were provided by pilot site participants in the survey. One respondent made the following comments:

> *"Clients reported that the "Guiding their way back" assisted in starting conversations with family members following their suicide attempt which had previously felt too difficult."*
>
> *"Personal comments from a client on the "Finding my way back resource" were that they found it helpful to have information condensed into one document and that it introduced new ideas to them."*
>
> *"Based on feedback from clients, it seems one of the most needed times for this to be distributed is immediately following a suicide attempt (e.g. Emergency Departments and acute mental health services). Family members described these times as being overwhelming and often leaving them feeling as though they do not have adequate information on 'what to do next'. Whilst I believe the resources would be useful in other mental health services, I see them as having the most benefit giving them to people in the acute phase."*

Other comments included:

> *"The resources are good to hand out. It's nice to have resources that are appropriate and helpful."*
>
> *"We would be happy to continue distribution…the booklets are a valuable tool for people to have."*

7.4 Key conclusions

In general, the feedback from pilot sites suggested that the resources were perceived as relevant and useful and were viewed positively.

However, this did not result in many resources being distributed. The lack of engagement of some staff in the pilot dissemination (despite initial apparent interest and multiple reminders) highlights the substantial barriers that can arise when trying to integrate information distribution into large systems with multiple contact points.

CHAPTER 8: CONCLUSIONS AND NEXT STEPS

Within a 12-month period, the project team at **Everymind** conducted an evidence, policy and resource scan, consulted with service providers and those with lived experience of suicide attempt(s), drafted and reviewed two resource booklets and piloted them with ethics approval in four sites across two states and territories.

Without question, it is crucial to provide all possible support and information to individuals and their family and friends following a suicide attempt. The key challenge is ensuring that the support and information provided is useful and responsive to peoples' needs at the time. The consultations conducted with people who had lived experience of suicide attempt(s) indicated that many had experienced poor responses when seeking assistance and there was a strong and universal view among people with lived experience that suicide is highly stigmatised and that an effective suicide prevention strategy would be to change community attitudes about suicide. Information resources can play a role in this.

Based on the evaluative data collected, the indications are that *The way back* information resources are meeting some of the information needs of individuals, family members and friends following a suicide attempt. The resources were largely well received with positive feedback and no major issues arose during the pilot or as identified through stakeholder feedback. Feedback did however suggest that there was some room for improvement, particularly with regard to language style and overall length of the resources.

The project itself has been undertaken within the context of limited academic research into the efficacy of written information resources generally or formal evaluations of resources currently being distributed in the sector. Similarly, the findings from the pilot suggest that a number of workplace barriers affect the degree to which information resource distribution will be distributed or used in different organisational settings and workplaces. These contextual issues help inform what should be the next steps for these resources and more generally what may be useful for the suicide prevention sector to further explore.

The thorough and reflective approach taken to the development of these resources mean a range of conclusions can be drawn from the findings and the experiences of the project team and provide a solid foundation for moving forward.

8.1 Key conclusions

- **People with lived experience of suicide attempt(s) (including family members and friends) are an important target group for suicide prevention activities.**
- **People with lived experience of suicide attempt(s) (including family members and friends) can and should be involved in the development and/ or delivery of suicide prevention strategies, including engagement in consultation which can be done in a safe and sensitive way.**
- **Addressing and combating stigma and community discomfort in talking about suicide is an important suicide prevention activity.**
- **People with lived experience of suicide attempt(s) (including family members and friends) value information resources that can support people to have a better understanding of suicide, which provide hope and enable people to have helpful and constructive conversations generally and in times of crisis.**
- **Personal stories about experiences of suicide attempt can play an important role in suicide prevention and there are increasing and emerging opportunities to support this through online communities and social media.**
- **There is a need for ongoing evaluation and research into the effectiveness of information resources as a suicide prevention and wellbeing strategy.**
- **The distribution of information resources for people who have attempted suicide and their family members and friends should be part of a broader strategy that empowers people, communities and health services to better support people following a suicide attempt.**

8.2 Next steps

Drawing on the pilot evaluation, stakeholder feedback and other components of the project, the following recommendations are provided to the funding body.

The usefulness of the resources for the intended audience has not been examined in appropriate detail. Despite best efforts to obtain feedback from pilot site staff, only limited data was obtained and only a small number of stakeholders completed the online survey. While positive responses were provided from these small samples, there were indications that some found the resources too long and that shorter versions using more plain English would be suitable. It was also suggested that the resource for individuals could be improved by including spaces for users to write down their thoughts and actions similar to the 'workbook' style used in the resource for family and friends.

Recommendation 1: That further structured consultations be conducted with a demographically representative sample of community members with lived experience of suicide attempt(s) to obtain their feedback about the resources.

Recommendation 2: That consideration is given to developing a shorter version (possibly a pamphlet) of the present resources using very plain English.

Recommendation 3: That a series of online videos by people with lived experience are developed to complement the written resources. The videos should include discussion about how they got through the attempt (i.e. personal stories of hope) as well as highlighting relevant components of the content covered in the printed resources.

Given the limited academic evidence regarding the usefulness of written information resources for either individuals who have attempted suicide or family and friends of people who have attempted suicide, it would then be useful and appropriate to conduct a formal evaluation of the resources.

Recommendation 4: That a research study (e.g. a randomised control trial with staged roll out) be conducted to evaluate the effectiveness of the written resources. This evaluation should include research about the manner in which people obtain the resources (for example from a worker, the internet, etc.) and whether this impacts on utility and outcomes associated with having received the resource.

In acknowledgement of the wide availability and general use of information resources in Australia, even without efficacy data, widespread dissemination of the resources may be appropriate. The following recommendations are made about how dissemination can be approached to ensure most likelihood of engagement and effectiveness.

Recommendation 6: That the availability of the resource(s) be proactively promoted with stakeholders, with access points also directly available to the general public.

Recommendation 7: That dissemination of the resources be supported by other strategies that build sector and community capacity to address stigma about suicide and which enable people to have constructive and helpful conversations after a suicide attempt.