

Evaluation of the Lifekeeper Memory Quilt Project: Participant perceptions

Final Report

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Bereavement Support

Submitted by:

Dr Kath Peters RN, BN (Hons), PhD

Alan Staines OAM (Envoy)

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1. EXECUTIVE SUMMARY

1.1 Introduction

Suicide is a leading cause of premature deaths internationally and is responsible for the loss of over 2000 deaths per year in Australia (Australian Bureau of Statistics (ABS), 2010). Despite the acknowledgement that family and friends bereaved by suicide are at risk of complicated grief which increases their risk of suicide, limited postvention strategies exist to support survivors of suicide (Aguirre & Slater, 2010). This report presents the evaluation of an intervention (the Lifekeeper Memory Quilt Project) initiated by The Salvation Army, Suicide Prevention Bereavement and Support Services, that aimed to support those bereaved by suicide.

1.2 Background

The Lifekeeper Memory Quilt aims to memorialise those who have died, to provide comfort and support to those bereaved, and to raise public awareness of suicide. Further, by ‘putting a face’ on suicide, the Quilt serves as a reminder that real people and not just statistics are affected by suicide. The specific goals of the Lifekeeper Memory Quilt Project were to:

1. Provide an opportunity for friends and families to honour and remember their loved ones in a unique and special way.
2. Provide families with an opportunity to share their thoughts and feelings about their loved one, with other family members as well as a broader group of empathetic people.
3. Demonstrate to families that there are people within the community who join with them in their grief.
4. Raise awareness about the extent and impact of suicide in Australia and in particular the ripple effect of a suicide death through families, friends, associates and the broader community.

Since the Lifekeeper Memory Quilt was initiated in 2008, a total of 150 people bereaved by suicide, from 4 Australian states have had the opportunity to commemorate their loved one

on a Quilt. Anecdotal evidence has shown that participants found the Quilt Project to be a valuable support measure whilst navigating their grief, however a formal evaluation has not previously been conducted.

Methods

A mixed method design was used to evaluate the Lifekeeper Memory Quilt Project. All 150 people who had participated in the Quilt Project were invited to complete a questionnaire to provide feedback on various aspects of the Quilt Project. After completing the questionnaire, participants were invited to participate in an interview to elaborate on their experiences.

1.3 Summary statements

- The response rate for the questionnaire, approximately 55% and 91% of respondents were women.
- Telephone interviews averaging 30 minutes in duration were conducted with 30 participants.
- 65.8% of respondents had lost a child, 12.7% a spouse, 13.9% a sibling, and 6.3% a parent, to suicide.
- 22% of participants found out about the Quilt Project from a friend, 38% from a Salvation Army contact, and 40% were notified via support groups.
- Approximately 80% of respondents participated in the Quilt Project a year or more after they became bereaved; however a substantial amount of these indicated they would have preferred earlier involvement.
- Overall satisfaction with the Quilt Project was very high.
- 98% of respondents acknowledged that raising public awareness of suicide was part of their motivation for participating in the Quilt Project.
- 99% of respondents indicated that the Quilt effectively enabled them to remember and memorialise their loved one, while 95% of participants reported that participating in the Quilt Project assisted them in their grief journey.

- 96% of respondents conveyed that participating in the Quilt Project increased their feelings of connectedness with other bereaved families and enhanced family dialogue.
- Overall satisfaction with the appearance of the quilt was high, ranging from 4.23-4.33/5 for relevant items.
- Participants conveyed a desire for the Quilts to be better publicised to increase awareness in the community and for them to be more accessible for the bereaved to view.

1.4 Recommendations

- The overwhelmingly positive evaluation of the Quilt Project suggests that this is an effective intervention in supporting those bereaved by suicide, and further opportunities for suicide survivors to participate should be provided.
- There is a need to make Quilts more accessible to participants. As there are financial implications associated with providing such access for people in diverse geographical areas, further funding may be required.
- A clear plan needs to be devised for how the Quilts may be used in raising public awareness of suicide.
- Planning of future Quilts should include times and venues for the unveiling and showcasing of Quilts.
- Further strategies are required to ensure family dialogue about the bereaved is encouraged.
- Potential participants could be advised of a standard photo size and quality required for inclusion on Quilt panels, and provided with a choice of colours to be used.

2. INTRODUCTION

2.1 Background

The incidence of suicide in Australia increased from 2054 deaths in 2007, to 2191 in 2008 (ABS, 2010). This equates to around one Australian life being lost to suicide every 5 hours and in 2006, more people died to suicide than on the nation's roads (Hope for Life, 2008). For every person that dies by suicide, there are at least six people that will experience intense grief (Clark & Goldney, 2000). The literature that addresses the experiences of those bereaved by suicide suggests that it impacts negatively on the overall well-being of bereaved individuals/friends/families and carries significant personal and social costs (Mitchell, Kim, Prigerson & Mortimer, 2005; Hawton & Simkin, 2003). Previous research has shown that suicide survivors receive substantially less support than those bereaved by other causes (Faberow, Gallagher-Thompson, Gilewski & Thompson, 1992). Additionally, family members bereaved by suicide are at higher risk of suicide themselves (DoH, 2010; Qin, Agerbo, & Mortensen, 2002).

The risks of suicide in survivors are increased due to a number of reasons, which include stresses before the suicide occurred such as relationship difficulties, the funeral and settling of affairs, and of course the suicide itself (Aguirre & Slater, 2010). The survivor's grieving process plays a crucial role in defining the risk for suicide in survivors and is influenced by feelings of hopelessness that occur during the loss of a loved one, feelings of abandonment and rejection by the deceased, the stress created by striving to make sense of why their loved one had committed suicide, and shame associated with the stigma attached to death by suicide (Aguirre & Slater, 2010). The grieving process often demands that an individual who has survived suicide to emotionally and psychologically wade through feelings of stigma, shame, isolation, self-blame, guilt, anger at the deceased, a crisis of values, which all contribute to an intolerable psychological stress (otherwise termed 'psychache') (Aguirre & Slater, 2010; Wilson & Marshall, 2010). Such factors cultivate the risk of depression and/or post-traumatic stress disorder, which in turn increases the risk of developing complicated grief and of survivor suicide particularly in light of the strong association between suicide and depression (Aguirre & Slater, 2010; Kausch & Amer, 2007; Ram, Darshan, Rao, Honagodu, & A.R., 2012).

The relationship between psychache, social stigma and perception surrounding suicide, and the higher risk of suicide among those bereaved by suicide, emphasises the importance of creating and developing postvention strategies. The primary goal of postvention is to alleviate 'psychache' and assist suicide survivors in navigating their grief, as there is often no socially acceptable manner in which to grieve suicide (Aguirre & Slater, 2010; Maple, 2010). Whilst there is some evidence to suggest that family focused suicide postvention programs may be effective in reducing psychological symptoms and mental distress (Szumilas & Kutcher, 2011), research in this area remains limited.

2.2 The Lifekeeper Memory Quilt Project

Recently, the Salvation Army initiated the Lifekeeper Memory Quilt Project (LMQP). The LMQP was designed as a memorial to people who have died by suicide. Traditionally, quilts were made to chronicle the life of a family, as records of marriages, births and deaths (King, 2001). Quilt making is a tool that can help survivors navigate their way through the grieving process (Kausch & Amer, 2007). Quilt panel making also provides a lasting memory of the deceased and a continuing bond with them, which creates a lasting presence of the deceased (Kausch & Amer, 2007; Wood, Byram, Gosling, & Stokes, 2012). The idea is that the Quilt serve as a creative outlet for survivors' grief as well as a touching, visual reminder of the people who have died. By putting a 'face' on suicide, these quilts help to raise awareness about suicide and personalising the message. They also help to convey the message that suicide awareness is not just about lowering statistics, but also about the need for stronger community support in understanding and caring for families who have been bereaved by suicide.

The specific goals of the project were to:

1. Provide an opportunity for friends and families to honour and remember their loved ones in a unique and special way.
2. Provide families with an opportunity to share their thoughts and feelings about their loved one, with other family members as well as a broader group of empathetic people.

3. Demonstrate to families that there are people within the community who join with them in their grief.
4. Raise awareness about the extent and impact of suicide in Australia and in particular the ripple effect of a suicide death through families, friends, associates and the broader community.

In the United States, a similar quilt program was established by Sandy Martin, a mother who lost her son to suicide in 1997. These programs have spread across the U.S.A. with positive results. Producing a quilt piece can facilitate external and internal connections with the deceased whether it be positive, negative, or as a way to cope with the loss (Wood, et. al, 2012). The memory quilt pieces are displayed online and the quilt itself is displayed at conferences and postventions to unite those who have lost a loved one to suicide.

Participants of the Salvation Army LMQP have quilt pieces made for them after a registration of interest via email. The online nature of participation means that a geographically diverse population is able to participate in the project (Feigleman, Gorman, Beal, & Jordan, 2008). This is important as in Australia, suicide mortality is greater in rural or remote areas and being located at a significant distance from urban areas can mean that support is difficult to access. Although anecdotal evidence suggests that the Salvation Army LMQP is effective, it has not been formally evaluated. This limits the ability of the project to inform further interventions and the capacity for gaining support for future related initiatives.

2.3 Aim

The aim of this project was to evaluate the Lifekeeper Memory Quilt Project (LMQP) to explore participants' perception of its effectiveness as a support strategy for those bereaved by suicide and in raising awareness of the extent and impact of suicide in Australia. The knowledge gained through this research will assist in providing guidance in designing and implementing future interventions that could assist people bereaved by suicide and raise public awareness regarding suicide prevention in the community.

3. METHODOLOGY

3.1 Research Design

A mixed method approach was chosen to evaluate the effectiveness of the Lifekeeper Memory Quilt as it is useful in enhancing the validity of results through triangulation of the data (Polit & Beck, 2010). Furthermore, in this study, qualitative data was collected in addition to quantitative data for the purpose of explicating the meaning of quantitative descriptions (Polit & Beck, 2010). The project consisted of three distinct phases. Phase 1 comprised the adaptation of an existing questionnaire (with permission from Hawton et al, 2011, 2012) and new item generation for the evaluation tool to be distributed in Phase 2. Phase 3 involved the collection of qualitative data from participants via interviews.

3.2 Phase 1

As no instrument existed to specifically evaluate the LMQP, with the permission of the authors, Phase 1 included the adaptation of the 'Help is at Hand' questionnaire (Hawton et al, 2011, 2012) to reflect participant satisfaction with the Quilt Project. New item generation was informed by the literature, and by a panel of experts. Face and content validity of the questionnaire was established using the Delphi technique described in previous literature (see for example, Courtney, O'Reilly, Edwards & Hassall, 2011; Cross, 2005; Polit & Beck, 2010). This involved sending the questionnaire to a panel of experts several times for their opinions for the purpose of progressively refining questions until consensus was reached regarding the validity of the instrument. All panel members had extensive experience in working with bereaved people to ensure the provision of expert opinion on content. Also, due to the sensitive nature of the topic, expert panellists were able to provide advice regarding phrasing of the questions to avoid causing undue distress to the bereaved.

3.3 Research participants

Participants recruited for the purpose of Phase 2 & 3 were aged 18 years or above, were bereaved by suicide of a friend or family member and had actively participated in the Lifekeeper Memory Quilt Project.

3.4 Phase 2

Recruitment:

A package including an introductory letter, a participant information sheet, and the questionnaire developed in Phase 1, was emailed and/or posted to all individuals who participated in the LMQP.

Data Collection

Participants had the option of completing a hard copy of the questionnaire and returning it in a postage paid envelope or logging on to the UWS Qualtrics™ site and completing the questionnaire online. The questionnaire pursued both quantitative and qualitative responses from participants regarding their overall satisfaction with the LMQP as a support strategy for those bereaved by suicide.

Data analysis:

Online questionnaire data were downloaded from Qualtrics™ and entered into Microsoft Excel spreadsheets. Both this and the hardcopy questionnaire data were then exported into SPSS 15™. Data were analysed using descriptive statistics.

3.5 Phase 3

Recruitment:

Individuals who participated in Phase 2 of the study were also given the option to participate in Phase 3. The final page of the questionnaire distributed in Phase 2 asked whether participants would be willing to be interviewed either online, over the telephone or face to face. Those who expressed such a wish were asked to provide their contact details and the best time for them to be contacted. They were then contacted by a member of the research team who provided them with further information about what is required for participation in Phase 3.

Data Collection:

In depth interviews were utilised to explore participants' experiences of being involved in the LMQP. Participants chose whether they preferred to attend face to face interviews or whether they preferred a telephone or online interview. Face-to-face and telephone interviews were digitally recorded and transcribed verbatim.

Table 1 *Interview questions*

Initial question:

1. Can you tell me about your experience of participating in the Lifekeeper Memory Quilt Project?

Prompt questions:

2. Can you tell me why you decided to participate in the Quilt Project?
3. Can you tell me what you found helpful about the Quilt Project?
4. Can you tell me what you found difficult about the Quilt Project?
5. Have your thoughts and opinions about the Quilt changed over the last few years?
6. Has your involvement in the Quilt Project impacted on your grief journey? If so how?
7. How do you view the Quilt Project impacting on your family?
8. Did the Quilt Project assist in communication with members of your community?
9. Tell me how you would like to see the Quilt used.

Data Analysis:

Transcribed and downloaded data was entered into NVivo9™ for management of the data and analysed using thematic analysis.

3.6 Ethical Issues

Prior to recruitment, ethical approval was gained from the University of Western Sydney Human Research Ethics Committee. Prior to completing the questionnaire, participants were asked to read the participant information sheet and a further attachment that informed them of free counselling resources to access should they become distressed. Prior to being interviewed, participants gave informed consent and were advised of their right to cease the interview at any time and/or withdraw from the study. If a participant became

distressed, the interviewer stopped the interview and reminded them of their right to cease the interview at any time, withdraw from the study, and of the availability of an experienced independent counsellor and support services

4. RESULTS/FINDINGS

4.1 Introduction

There was a 55% response rate to the questionnaire (82/150) with 72 submitting the online version and 10 completing hard copies and returning via mail. Throughout this report, descriptive data is presented in terms of the number of responses to individual questions, as not all participants answered all questions. Subsequent to completing questionnaires, 30 people participated in telephone interviews between 10 and 67 minutes in duration (average 30 minutes). There was substantial consensus between the quantitative and qualitative data collected. The results are presented in four sections:

- 1) Demographic data;
- 2) Perceptions of how helpful the Quilt Project was;
- 3) Satisfaction with the look of the quilt and;
- 4) Suggestions for the use of the quilt.

4.2 Demographic data

Descriptive results from the questionnaire data show that 91% (n=71) of respondents were female, and almost 80% of participants were aged 46 years or over. The age range of the deceased was 13-76 years (mean 32.24, Standard deviation 14.45) and 83.5% were male. The majority of respondents (65.8%) had lost a child, with 12.7% losing a spouse, 13.9% a sibling, and 6.3% a parent, to suicide.

Table 2 *Participant gender*

Gender of Participant	n	%
Male	7	9
Female	71	91
Total	78¹	100

¹ Only 78 of the 82 participants provided a response to this question.

Table 3 *Participant age*

Age of Participant	n	%
18-25	1	1.3
26-35	4	5.1
36-45	11	13.9
46-55	27	34.2
56-65	25	31.6
66+	11	13.9
Total	79²	100

Table 4 *Gender of the deceased*

Gender of Deceased	n	%
Male	66	83.5
Female	13	16.5
Total	79²	100

Table 5 *Age range of the deceased*

Age range of Deceased	Mean	SD
13-76 years	32.24	14.45

² Only 79 of the 82 participants provided a response to this question.

Table 6 Relationship of deceased to participant

Relationship of Deceased	n	%
Spouse/Partner	10	12.7
Child	52	65.8
Sibling	11	13.9
Parent	5	6.3
Other	1	1.3
Total	79²	100

Seventeen (22%) participants found out about the Quilt Project from a friend, thirty (38%) from a Salvation Army contact, with the majority (40%, n= 32) being notified via support groups. Approximately 80% of respondents participated in the Quilt Project a year or more after they became bereaved, however only around 50% of respondents agreed this timeframe was ideal.

Figure 1 Notification about Quilt Project

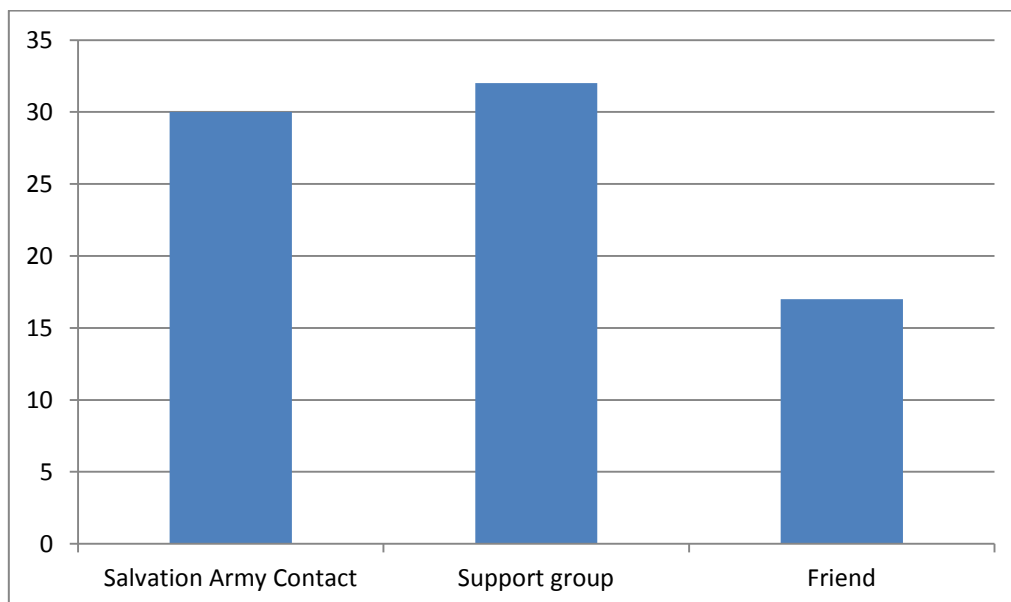
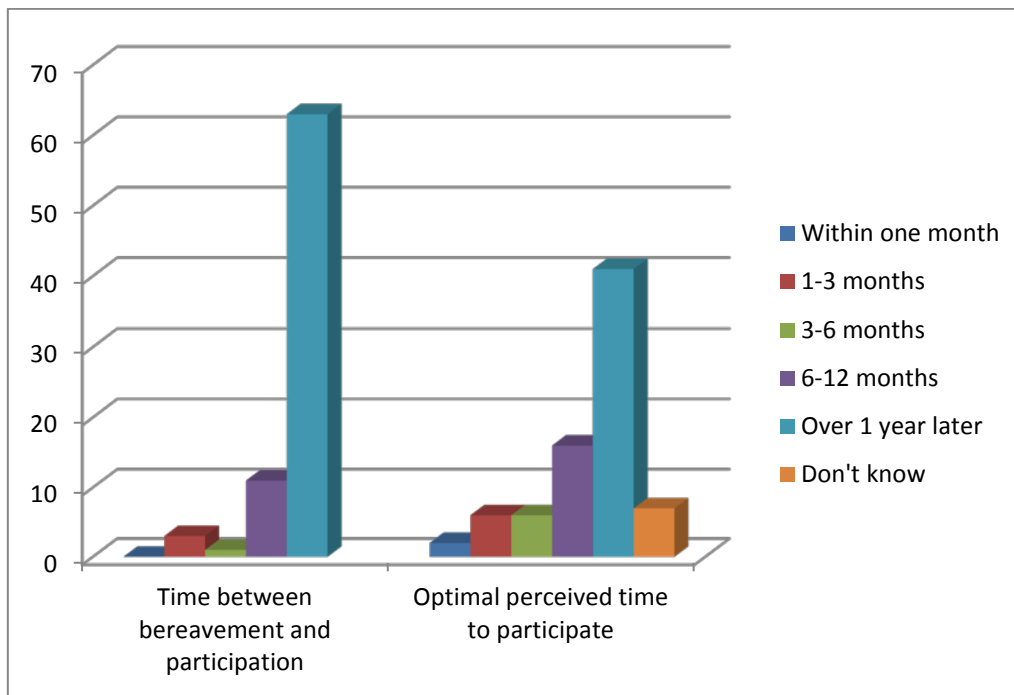


Figure 2 Time between bereavement and participation in the Quilt Project



4.3 Perceptions of how helpful the Quilt Project was

Over 90% of respondents agreed that overall, participating in the Quilt Project was helpful or extremely helpful to them with the majority indicating they felt a sense of community with other bereaved families. For the section of the questionnaire that elicited information regarding how helpful the Quilt Project was, agreement with individual items ranged from 3.74 - 4.84 / 5 (presented in Figure 4). Similar items for this section were also grouped together and are presented under the following headings:

- a) Public awareness as motivator,
- b) Remembering and memorialising loved ones,
- c) Assistance with the bereavement journey and,
- d) Assistance with family dialogue and sense of community.

Figure 3 Overall efficacy of the Quilt Project

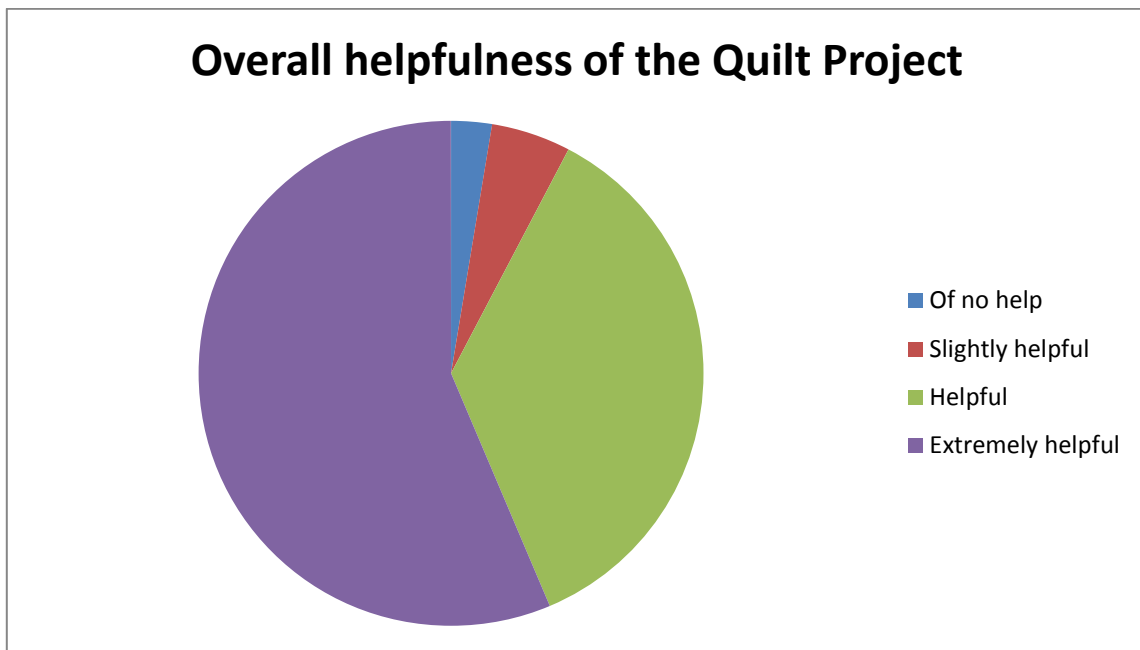


Figure 4 Level of agreement with individual items

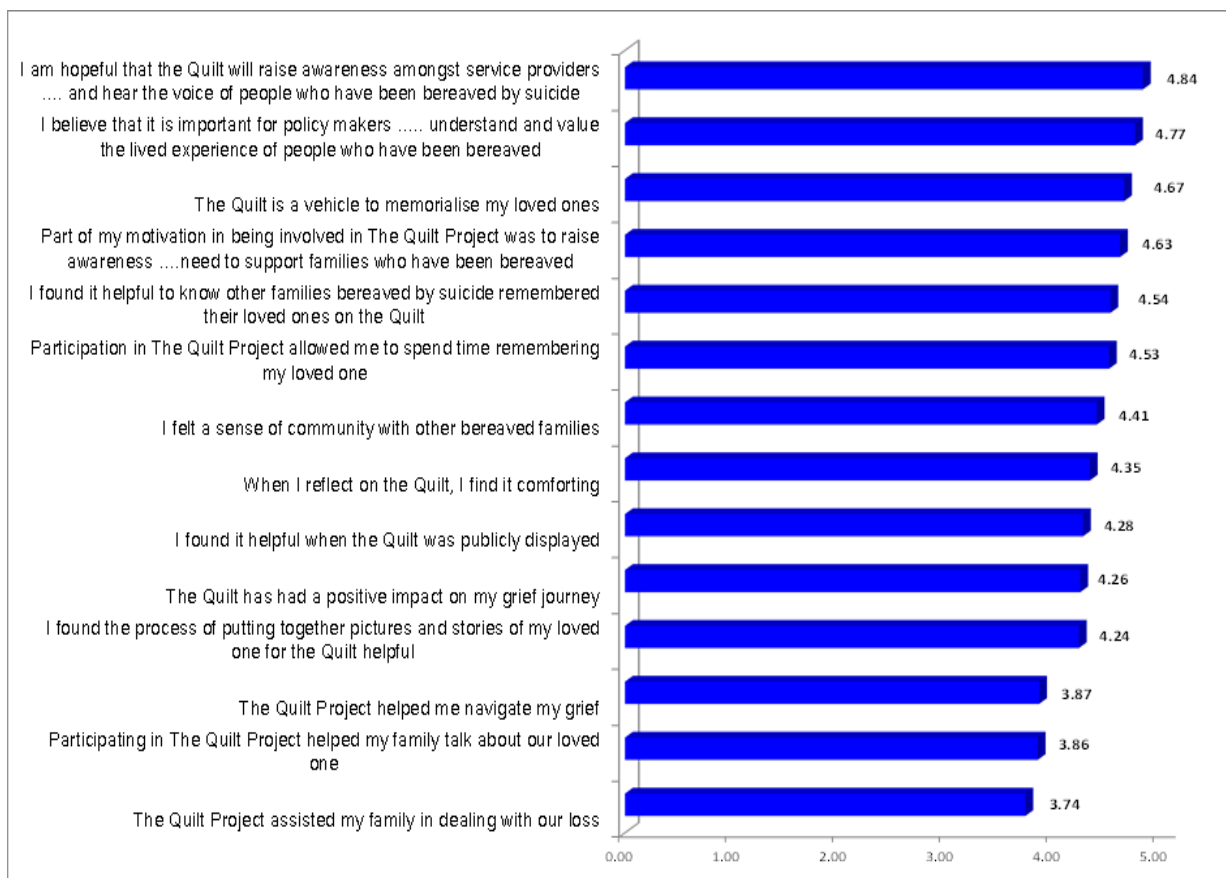
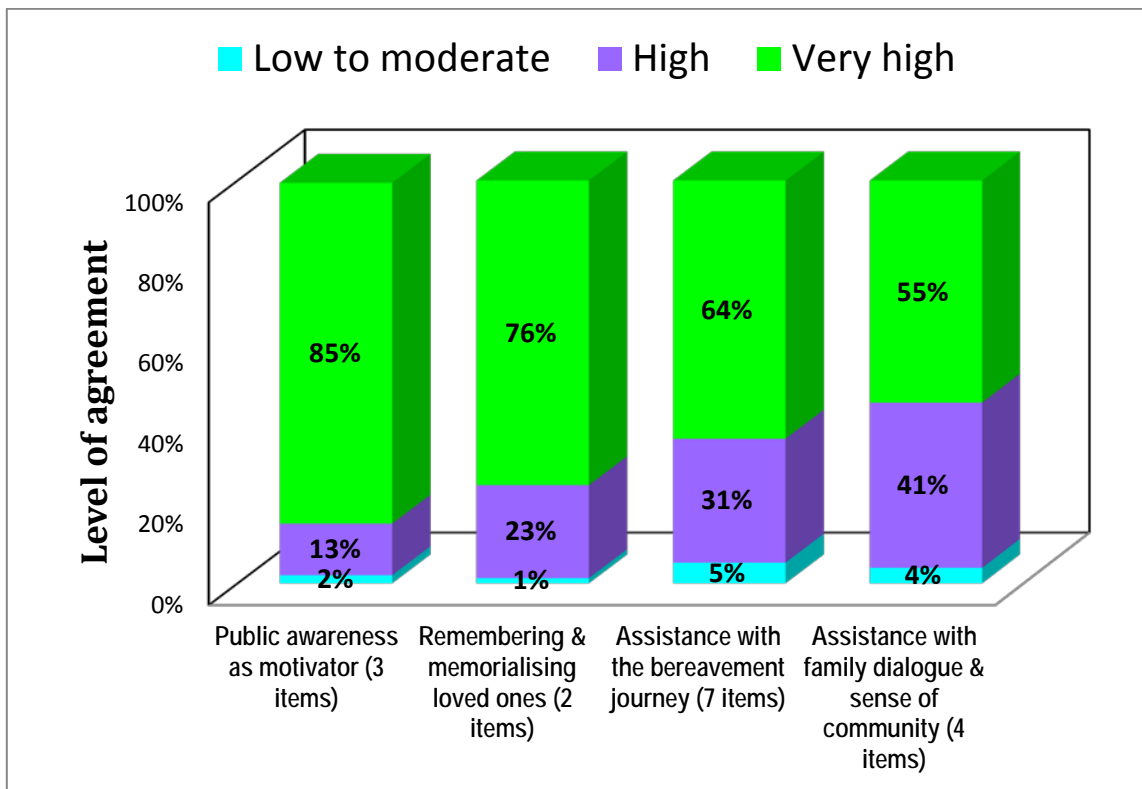


Figure 5 Level of agreement with grouped items



4.3.1 Public awareness as motivation for participation

Ninety-eight percent of respondents of the questionnaire agreed that part of their motivation for participating in the Quilt Project was to raise awareness of suicide amongst the community, service providers and policy makers and the need to support families who have been bereaved. This resonates with qualitative responses given by interview participants that highlight participants engaged in the quilt program for altruistic as well as personal reasons.

I saw it as a great opportunity to inform the public that it's just ordinary people that take their own lives. That by having [my daughter's] photograph on a quilt along with the others, that people can realise that those that take their own life are daughters, sons, brothers, sisters, fathers, mothers anybody. They're from many walks of life and from many creeds and religion. So it's just to get that out. (Participant 13)

I think at that point I wanted to be a part of something, and I still do want to be a part of something that we raise the awareness. We raise the idea that suicide is such a big thing. It's

just as big as cancer and just as big as everything else that's out there. You need to highlight it more and I thought, well this is the first step. (Participant 15)

I guess by having the quilts on display is evidence that all these faces are someone's husband, mother, father, brother, son, daughter, that no family is immune and if just one family gets help or support or comfort from that then it's a positive thing. (Participant 6)

Participants conveyed they wanted the Quilt to be used to make a difference, and whilst acknowledging that the future use of the quilt required much thought and sensitivity, they perceived greater publicity was required for the intervention to have a broader impact.

Yes, I'd like to see it used in - I guess when there is training on about - training on about maybe suicide prevention and to bring things out into these are real people and real stories and real life. (Participant 1)

I'd like to see it used in public. In public and TV programs, special documentations and people to see all these poor people's faces and all these beautiful young people and these older people and how badly they must have felt to take their own lives. So that it [suicide] doesn't keep happening. I'd like it to be advertised so that people know what it's about. (Participant 8)

4.3.2 Remembering and memorialising loved ones

Participants articulated the importance of not just remembering their loved one, but securing a record of their very existence. There was very strong agreement with 99% of questionnaire respondents indicating that the quilt effectively enabled them to remember and memorialise their loved one. Again, there was high congruency between the questionnaire and interview data, which is illustrated in the following participants' accounts.

It gave us something to focus on and to think about and to think of a way we could immortalise, I guess, for want of a better word, [my daughter's] memory. So it's not just us remembering her, because other people will tend to, not forget I suppose, but it's just off the front page for them a little bit so if there's something there that people can see, then I think that's good. (Participant 23)

I think just saying, here he is [on the quilt], he's not going to be forgotten, he's not going to be ignored. For many people who die by suicide, because you're not allowed to talk about it, it feels like you're ignoring that person existed. (Participant 4)

4.3.3 Assistance with the bereavement journey

The Quilt Project was perceived as effective in assisting participants with their bereavement journey with 95% of questionnaire respondents indicating high to very high levels of agreement with the relevant grouped items. Narrative data gained from the interviews also implied that the quilt was a valuable strategy in supporting those bereaved by suicide.

Again, it's so unifying, it's cathartic and you know, I look at it and I feel the same strong sense of emotion when I see my daughter there. It's just - it reaches into my heart and my soul. (Participant 3)

But I just found the project - the Quilt Project as a healing project and a very supportive project in being able to do it. I didn't find the process difficult at all. (Participant 19)

4.3.4 Assistance with family dialogue and sense of community

The responses from the questionnaire illustrate the perception that participation in the Quilt Project assisted in encouraging family dialogue and a sense of connectedness to other bereaved families. That is 55% indicated very high level and 41% a high level of agreement with relevant items. The qualitative data concurred with survey data regarding the sense of connectedness reported by participants.

I think the main thing was it made you feel like you were a part of something, that there were other people that had experienced the same thing. (Participant 7)

But I think there were lots of positives and I think to connect with others to experience the same bereavement is always very good. There was a lovely connection there [at the unveiling] with people and, yes, you realise that you're not alone. (Participant 19)

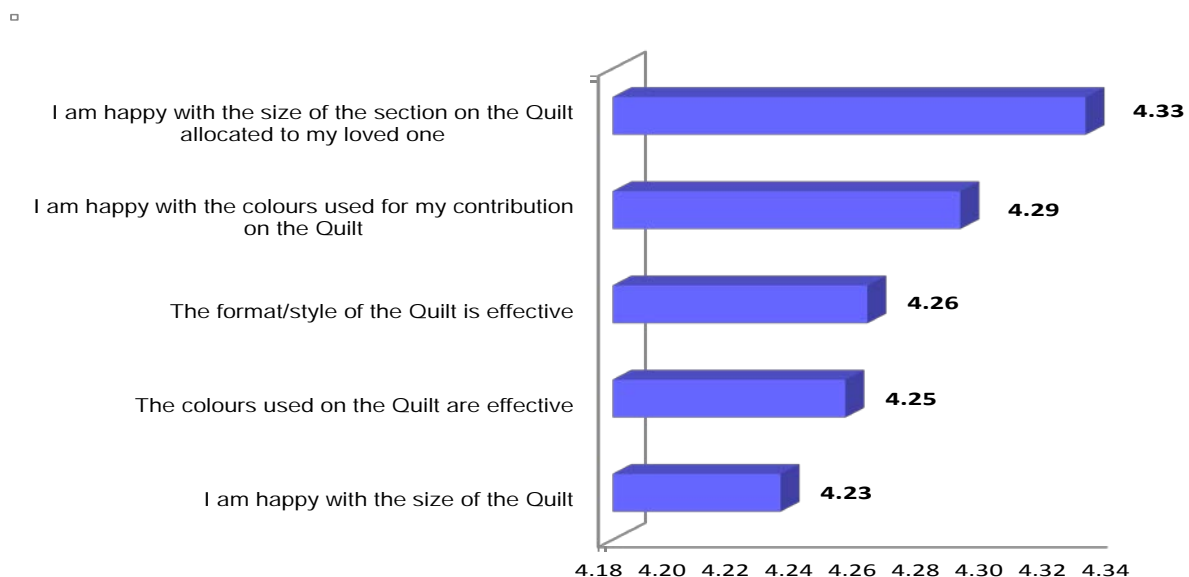
While there was reference to the effectiveness of the Quilt Project in encouraging family dialogue in some narratives, it was not a strong theme in the interview data. The following quote represents the few participants who disclosed that the Quilt positively contributed to family relationships.

The number one thing would be that it served as quite a nice connection for me and mum - mum and I to do something together with it. I think probably in the end I ended up doing it more than she did but she was quite - and that's more of an IT literacy thing I think. I've got to be able to do that. So she helped look at it and helped pick the quote and helped pick the photo but I was doing the IT bits of it and I think that was a positive thing for us. (Participant 17)

4.4 Satisfaction with the appearance of the quilt

The level of satisfaction with the aesthetics of the quilt itself was high, ranging from 4.23-4.33/5 for relevant items (see Figure 6). Some participants had not seen the finished product of the actual quilt so were either unable to give feedback on this aspect of the evaluation or gave feedback on the photo of the quilt they had received. The majority of those who had seen the quilt were happy with the way it looked.

Figure 6 Satisfaction with appearance of the Quilt



Qualitative responses from the questionnaire were mainly positive for example; *“The preparation and presentation was beautiful and made with love, what more would one want to change when so much care has been taken. Thank you”* and *“I just loved the quilt and everything about it”*. However, participants also suggested some ways in which the Quilt may be improved and conveyed *“I think it would be good to design our own pieces of the quilt but I also realize this would create a logistical nightmare”*. Further suggestions included asking the participant *“what colour he or she would like for the background of the photo and poem for their loved one”*.

Although not a common experience, one participant reported experiencing negative emotions as a result of the size of the photo used for her son’s space on the quilt.

I expected my photo to be larger. I saw other parents’ photos of their child, and they were bigger than my photo, and as silly as it sounds, I felt jealous, because it was as if my son was not as important as theirs ... I felt upset that my son was not recognised as much. I know that was not the case, but that is where my emotions took me.

4.5 Suggestions for improving the Quilt Project

Open ended questions on the questionnaire elicited the following responses from participants regarding how they perceived the Quilt Project could be improved. Many participants were happy with all aspects of the project and offered comments such as *“I don’t think you can improve something that is already perfect”* and *“I found the experience a positive one - no real improvements to suggest”*. However, around 20% of respondents identified issues related to the accessibility of the Quilt. As the initial unveiling of the Quilts was held in New South Wales, participants from other states highlighted difficulties they encountered due to financial constraints.

I found it very difficult to participate in the launching as it was held in Sydney. This was prohibiting not only in cost but in the transport difficulty. I would have participated had it have been held in Melbourne.

Some participants also reported that while they were happy overall with most processes, communication with the Quilt organisers could be improved by *‘informing families when the Quilt will be visiting their State or Territory so they can see the Quilt in person’*, and *“Informing the families what happens to the quilt after it is unveiled at the conference”*. Participants also expressed a wish for a picture of the Quilt to be *“quickly available on the Internet after it is unveiled”*.

The following excerpt highlights the perception that enhanced communication may have alleviated some of the dissatisfaction experienced by those who perceived they were disadvantaged in accessing the quilt.

When the planning to do the quilt was organised, dates for unveiling in all states should have been planned at the same time so that those people who could not attend the Sydney conference would know they were going to see it.

Further, some participants were unable to attend the unveiling due to work commitments and identified strategies to enhance opportunities for viewing the Quilt for example, *“I work during the day so being able to come to an event in the evening would have meant I could have come to a viewing of the quilt”* and *“To have the quilt displayed at different times and venues if possible”*.

Additional strategies suggested by participants to improve the Quilt Project included providing greater opportunity for the bereaved to talk about their loss with others who understand.

I would like to be able to talk about my girl and tell others how important it is to treasure the memories and let others learn to know her.

5. DISCUSSION AND RECOMMENDATIONS

The response rate for the questionnaire and interest in participating in the interviews indicates that participants of the Quilt Project were highly invested in the Quilt and in promoting suicide awareness and prevention. Responses from both questionnaire and narrative data strongly suggest that participation in the Quilt Project was helpful in supporting those bereaved by suicide throughout their grief journey. Participants overwhelmingly agreed that the Quilt Project was a positive and supportive experience that assisted them in their bereavement, which indicates that this intervention has the potential to contribute to the prevention of the sequelae of completed suicide.

Participants were hopeful that the Quilts would raise public awareness about suicide and therefore expressed a desire to know where the quilts were going to be stored and how they were going to be used. Whilst the use of the Quilts requires careful consideration, there is a need to make them more accessible to participants, and a clear plan for how they may be used in raising public awareness devised. As there are financial implications associated with providing such access for people in diverse geographical areas, further funding may be required.

Communication regarding where completed Quilts can be initially viewed is of utmost importance as poor communication impacts negatively on the experiences of participants. Therefore planning of future Quilts should include times and venues for the unveiling and showcasing of Quilts.

The qualitative data alluded to further strategies being required to ensure all members of bereaved families are supported and dialogue about the bereaved encouraged.

Whilst most feedback from the appearance of the Quilt was positive, some participants experienced negative emotions after viewing it. Although in the minority, these comments should be taken into consideration when planning future Quilts to mitigate distress to the bereaved. In particular, potential participants could be advised of a standard photo size and quality required for inclusion on Quilt panels and if possible, be given the option of choosing colours for their panel.

6. CONCLUSION

Findings related to the participants' experiences, reflect overwhelming agreement that the Quilt Project was a therapeutic experience. While participants identified some issues related to the accessibility of the Quilt, they perceived the project as a positive intervention that assisted them in honouring and remembering their loved one and helping them with their grief journey. Qualitative findings suggest that further strategies may be required to ensure family dialogue is increased surrounding the loss of a loved one to suicide. Participants were hopeful that the images and stories of their loved ones on the quilt would create a tangible connection, and therefore increase awareness of suicide in the community. For this reason they expressed a desire for the quilt to be exposed to a wider audience.

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8. APPENDICES

Lifekeeper Memory Quilt Project

INTERVENTION FOR PEOPLE BEREAVED BY SUICIDE

Thank you for giving us your views on *The Lifekeeper Memory Quilt Project*.

If you would prefer, an electronic version of this questionnaire may be completed online at the link provided -

http://uwsnm.us.qualtrics.com/SE/?SID=SV_3CB0RG6a5UwLXtW

Please read the Participant Information Sheet prior to completing this questionnaire.

NOTE: Completion and return/submission of this survey implies consent to use the data collected for research purposes

It might be helpful for you to read through the questions before you begin to answer them.

ABOUT YOU

Please tick (✓) one box for each question.

1. **Gender** ¹ Male ² Female
2. **Age group** ¹ 18-25 years ² 26-35 years ³ 36-45 years
- ⁴ 46-65 years ⁵ 66+ years

ABOUT THE PERSON WHO DIED

3. **How was the person who died related to you? Please specify their relationship to you, eg. Child, friend, partner, parent etc. Please do NOT state the name of the person.**

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4. **How old were they at the time of their death? (in years)**
5. **Their gender** ¹ Male ² Female

ABOUT THE QUILT PROJECT

6. **How did you find out about *The Quilt Project*?**

¹ From a Salvation Army contact ² From a friend ³ Other

If other, please specify

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7. How long after the bereavement did you participate in *The Quilt Project*?

- Within one month One to three months
 More than three to six months More than six to twelve months
 Over a year later Other

If other, please specify

.....

8. When would have been the best time for you to have participated in *The Quilt Project*?

- Within one month of the death One to three months after
 More than three to six months after More than six to twelve months after
 Over a year after Other

If other, please specify

.....

ABOUT HOW HELPFUL *THE QUILT PROJECT* WAS

9. Overall, how helpful did you find *The Quilt Project*?

- Of no help Slightly helpful Helpful Extremely helpful

Instructions: Please indicate the extent to which you agree with the following statements about *The Quilt Project* by circling the number corresponding to your responses.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
10. <i>The Quilt Project</i> helped me navigate my grief	1	2	3	4	5
11. The Quilt is a vehicle to memorialise my loved one	1	2	3	4	5
12. The Quilt has had a positive impact on my grief journey	1	2	3	4	5
13. Participation in <i>The Quilt Project</i> was a waste of time	1	2	3	4	5
14. I found the process of putting together pictures and stories of my loved one for the Quilt helpful	1	2	3	4	5
15. I did not find the approach used in the Quilt project to express my grief helpful	1	2	3	4	5
16. Participation in <i>The Quilt Project</i> allowed me to spend time remembering my loved one	1	2	3	4	5

Instructions: Please indicate the extent to which you agree with the following statements about *The Quilt Project* by circling the number corresponding to your responses.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
17. When I reflect on the Quilt, I find it comforting	1	2	3	4	5
18. My grief is still raw after participating in <i>The Quilt Project</i>	1	2	3	4	5
19. <i>The Quilt Project</i> assisted my family in dealing with our loss	1	2	3	4	5
20. I found it helpful to know other families bereaved by suicide remembered their loved ones on the Quilt	1	2	3	4	5
21. I felt a sense of community with other bereaved families	1	2	3	4	5
22. Participating in <i>The Quilt Project</i> helped my family talk about our loved one	1	2	3	4	5
23. I found it helpful when the Quilt was publically displayed	1	2	3	4	5
24. I was overwhelmed with pain when the Quilt was publically displayed	1	2	3	4	5
25. I found the process of putting together pictures and stories of my loved one for the Quilt difficult	1	2	3	4	5
26. Participation in <i>The Quilt Project</i> did not lessen my pain from grief	1	2	3	4	5
27. I would recommend that other families bereaved by suicide participate in <i>The Quilt Project</i>	1	2	3	4	5
28. Part of my motivation in being involved in <i>The Quilt Project</i> was to raise awareness of the issue of suicide and the need to support families who have been bereaved	1	2	3	4	5
29. I believe that it is important for policy makers and service providers to understand and value the lived experience of people who have been bereaved	1	2	3	4	5
30. I am hopeful that the Quilt will raise awareness amongst service providers and policy makers of the need to listen to the stories and hear the voice of people who have been bereaved by suicide	1	2	3	4	5

31. We would like to know how to improve *The Quilt Project*. Could you please tell us anything else that you found helpful and what would have made it more helpful?

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ABOUT THE PRESENTATION OF THE QUILT

Instructions: Please indicate the extent to which you agree with the following statements about *The Quilt Project* by circling the number corresponding to your responses.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
32. I am happy with the colours used for my contribution on the Quilt	1	2	3	4	5
33. The colours used on the Quilt are effective	1	2	3	4	5
34. The format/style of the Quilt is effective	1	2	3	4	5
35. I would have chosen different colours for my contribution to the Quilt	1	2	3	4	5
36. I would have liked to have a choice in the colours used for my contribution to the Quilt	1	2	3	4	5
37. I am happy with the size of the Quilt	1	2	3	4	5
38. I am happy with the size of the section on the Quilt allocated to my loved one	1	2	3	4	5

39. Are there any additional changes you would suggest for the appearance and style of The Quilt?

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40. **Are there any other comments or suggestions you would like to make about *The Quilt Project* or any other information resources that you think may be helpful for families bereaved by suicide?**

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Thank you for your time and help in completing this questionnaire.

Please return the completed questionnaire in the postage paid envelope provided to:

Dr Kath Peters
School of Nursing & Midwifery
University of Western Sydney
Locked Bag 1797
Penrith NSW 2751

NB: This questionnaire was adapted (with permission from the authors) from the Evaluation of Help is at Hand: A resource for people bereaved by suicide and other sudden, traumatic death; by Hawton, K., Sutton, L., Simkin, S., Walker, D-M., Stacey, G., & Waters, K.

Are you interested in participating in an interview?

We are interested in hearing more about your experiences of participating in the Quilt Project.

- Please email or phone Dr Kath Peters (details below) if you would like to participate in an interview to share your story or if you require further information about the interview.
- Alternatively, you may enter your details below and Dr Peters will contact you.

Interviews can be held via telephone, online or face to face at a time that is convenient for you.

Dr Kath Peters

Phone: 02 46203567

Email: k.peters@uws.edu.au

Yes I am interested in participating in an interview.

Name: _____

Contact details (Phone/email): _____

Best day/time to contact: _____