

Supporting Those Who Care

Partners in Depression National Program Outcomes



EVERYMIND

This report was developed by **Everymind** (formerly the Hunter Institute of Mental Health) based on an independent national evaluation of the program conducted by Dr Deanna Pagnini.

This national evaluation was made possible through the generous support and funding of **nib foundation**.

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Without the national facilitators and the thousands of people who have completed the *Partners in Depression* program, this report would not be possible.

Thank you to Todd R Heard, Tania Ewin and Elise Clark who contributed to writing and editing this report.

This report and other evaluation reports are available online at **www.everymind.org.au/partners-in-depression**

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Supporting Those Who Care

A Word from the National Patron

When a special person enters our life – a partner, child or good friend – we make a promise to love and care for them. This unconditional love can be challenged and challenging.

Caring and loving someone with depression is not easy. *Partners in Depression* is here to help you on the journey.

As National Patron I am very proud of my association with *Partners in Depression* and the great work that has been done in providing support to people who love and care for someone experiencing depression across Australia. I welcome this program, which reflects the strong evidence-based approach adopted by **Everymind**.

The premise of the program is based on self-care and knowledge. We cannot be caring and supportive of others if we do not look after ourselves first. Many of us on this journey do not know where to start, what resources are available and how to provide real assistance. The *Partners in Depression* program helps us to do this. These feelings of helplessness are not good for our own mental health and can increase the risk of us developing our own mood disorders.

The *Partners in Depression* program is one way of addressing the current gap in information and support services.

Critical to the program design is the formal and independent evaluation process. This report is the outcome of that process, illustrating the impact of this program on many Australians. We now know that *Partners in Depression* has made a real difference to the lives of this vulnerable population across Australia.

We hope this report assists in raising awareness of the need for prevention approaches and support options for the many thousands of Australians that love, live with and care for people with depression every day.



Lucy Brogden

National Patron, *Partners in Depression*





Everymind

Our Vision

A world where all people and communities are mentally healthy and live well.

Who We Are

Everymind was established locally in Newcastle NSW in 1992 and has been delivering best-practice mental health and suicide prevention programs for over 25 years.

How We Work

Everymind is committed to the work that we do, but also pride ourselves on the way that we go about doing it. We have a diverse and passionate team who are dedicated to the prevention of mental ill-health, the prevention of suicide, and the promotion of mental health and wellbeing.

Key Objectives:

1. Improve the mental health of individuals and communities;
2. Reduce the incidence, prevalence and impact of mental health problems and mental illnesses;
3. Reduce the incidence of suicide, the prevalence of suicidal behaviours and their impact;
4. Build the evidence for promotion and prevention approaches in mental health and suicide prevention;
5. Build organisational strength, reputation and sustainability.

Everymind acknowledges Aboriginal and Torres Strait Islander peoples as the traditional owners of the land, and that we live and work on Aboriginal and Torres Strait Islander land.

Visit us at www.everymind.org.au



Everymind would like to acknowledge the funding support from **nib foundation**. Their investment from 2009 – 2013 has allowed Institute to complete the program, develop a national workforce and build the evidence base.

Find out more about **nib foundation**
www.nibfoundation.com.au

Putting Prevention First

A Word from **Everymind**

Nationally we have acknowledged the role of carers in service delivery for their family member or friend. There has however, been a worrying lack of attention given to the increased risk of mental ill-health that this caring role brings. The specific needs of people who love, live with or care for one million Australians affected by depression each year has also been missing.

Everymind embarked on developing the *Partners in Depression* program and disseminated it nationally to ensure that people who care for someone with depression had access to support, information, knowledge and the necessary skills to support their role.

Data presented in this report indicates that the mental health and wellbeing of those who love, live with and care for someone with depression should be a concern for us all.

Over 70% of people entering the *Partners in Depression* program reported levels of psychological distress that suggested an immediate risk of mental ill-health. They also highlighted experiencing challenges with their relationships, poor physical and mental health and reduced social participation.

We know from research that investing in the promotion of mental health and wellbeing and the prevention of mental ill-health leads not only to a more efficient use of mental health resources, it also has a flow-on effect to a range of other health and community outcomes.

Indeed, this snapshot from the national evaluation of *Partners in Depression* shows that psychoeducation programs for people who care for someone with depression can lead to improvements in mental health and wellbeing, improvement with relationships and promotes early help seeking behaviours for mental health problems.

We now have a national agenda that recognises, at least in theory, the rights of the carer to be involved in service delivery for their family member or friend. In releasing this report, I now call on a national agenda that also recognises the rights of those in caring roles to have timely and equitable access to interventions that enhance their wellbeing and prevent the onset of mental ill-health.



Jaelea Skehan
Director, **Everymind**





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Supporting Those Who Care

Report Snapshot

About the national evaluation

The *Partners in Depression* intervention is a six session group-based program which provides those who love, care for or live with a person experiencing depression with support, information, knowledge and the necessary skills to support their role as a carer and to improve their own mental health and wellbeing. The program was developed by **Everymind** (formerly the Hunter Institute of Mental Health) and is delivered to participants by program partners working in community-based mental health services across Australia.

Before the course I used to call 'me' time self-indulgent and now I call it self-care.

The national evaluation of *Partners in Depression* will be published as a series of four summary reports. This report ***Supporting those who care: Partners in Depression National Program Outcomes*** summarises the characteristics of those who entered the program, and their learning and mental health outcomes upon program completion and at six month follow-up.

Characteristics of those who care

The majority of program participants reported providing care and support to their partner or their child and approximately two-thirds lived with the person with depression, which meant that they experienced their caring/support role on a daily basis.

Nearly two-thirds of participants reported that the person with depression had other physical or mental health problems in addition to depression and nearly half the participants were providing support to more than one person.

Over half of all participants felt that the care and support role had a negative impact on their ability to engage in social activities and on the quality of their relationships. However, participants also reported that the experience had also led them to find greater meaning in their relationships.

Over half of all participants felt that providing support to the person experiencing depression has had a negative impact on their own mental health and wellbeing.

Upon entering the program a large proportion (70%) of program participants scored in the medium to high/very high range of psychological distress, with these reported levels being significantly higher than the general population.

***Partners in Depression* is an education and support program for families and friends who love, live with or care for a person experiencing depression. The program is conducted over six weekly sessions of one to two hours, delivered by local facilitators across Australia. www.everymind.org.au/partners-in-depression**

Outcomes for those who care

The program significantly increased participant understanding of depression and the caring experience and these individuals rated the program as effective in meeting its learning goals.

Most program participants were confident or extremely confident that they would be able to apply what they learnt in their own lives, with many already implementing changes at post-program and six month follow-up.

Participants reported improvements in their self-assessed mental and physical health and improvements in their family and social relationships following their involvement in the program.

**Over 70%
of program
participants
reported levels
that suggested
the likely
presence of a
mental disorder**

Standardised clinical mental health measures indicated that at program entry, participants were experiencing levels of psychological distress much higher than the general population.

Implications for those who care

There is a real need for interventions targeted at people who love, live with or care for someone experiencing depression. These interventions should address information needs, build skills and address the social isolation and relationship stress that many carers experience.

Given the high levels of psychological distress reported in people entering the program, those who love, live with or care for someone with depression need timely access to evidence-based primary prevention interventions.

The *Partners in Depression* program contributes to immediate and sustained improvements in mental health and wellbeing.

Program participants reported significant reduction in the levels of psychological distress at the completion of the program and at the six month follow-up.

The *Partners in Depression* program is effective in supporting participants to increase their understanding of the various aspects of depression and contributes to improved family relationships and social participation.

The effectiveness of the *Partners in Depression* program for priority populations requires exploration.

Further research is needed to assess the longevity of outcomes, to track the recovery of the person with depression and to assess the cost-benefits of the program to the health service.



1. Introduction to Partners in Depression

1.1 Program rationale

Depression affects one million Australians every year, and it is estimated that up to 20% of Australians will experience depressive symptoms at some stage in their life¹². Depression is the leading cause of non-fatal disability in Australia³ and is predicted to be the world's biggest health problem by 2020⁴. Depression accounts for more days lost in the workplace than almost any other physical or mental disorder⁵.

Given the prevalence of depression in Australia, families and friends are the largest providers of care and support for people living with depression. This support provided by Australian families and friends includes:

- Assisting their loved ones to manage their illness (e.g. identifying symptoms, working out symptom management strategies and facilitating access to treatment);
- Providing practical assistance to support their loved one's daily functioning (e.g. taking on more household, financial or employment responsibilities);
- Giving ongoing emotional support to their loved ones (e.g. being available to listen, organising mutually enjoyable activities and letting them know they are loved).

Families, carers and friends of people experiencing depression may also face many challenges themselves. These include working out the best way to support the person with depression, dealing with stigma and being able to manage their own mental health and wellbeing needs whilst in this support role.

Families, carers and friends often report not feeling comfortable in discussing their concerns with their loved one's mental health care professionals, believing the primary concern of treating clinicians should be for the person with depression

Furthermore, few mental health or counselling services specifically target the information or support needs of carers.

There are many documented benefits of programs which focus on the information and support needs of families, carers and friends of people experiencing a mental illness such as depression. These include: reducing the risk of the individual in the support role themselves developing a mental health problem, and improved treatment outcomes for the person living with a mental health issue, over and above standard care⁶.

Families and friends are the largest providers of care and support for people living with depression in Australia.

***Partners in Depression* is delivered to participants by program partners working in community-based mental health services across Australia.**

1.2 Program development

Partners in Depression was developed to increase access to evidence-based information and support for family members, carers and friends of people experiencing depression and to prevent the onset of mental health issues in this potentially vulnerable population. The program was developed by **Everymind** with funding and professional support from *beyondblue*: the national depression initiative, *nib foundation* and the program's National Reference Group.

Stage 1: Concept Development – 2006

Partners in Depression was originally developed and piloted independently by **Everymind**. The program was initially developed as a four week program and conducted in Newcastle NSW. Based on feedback and evaluation, the program was then re-developed in the current six session group format.

Stage 2: Local Pilot – 2007 – 2008

beyondblue supported a small scale pilot of the train-the-trainer program approach in the Hunter New England area of NSW. This program was delivered by a range of health and community professionals trained by **Everymind**. The outcomes showed that the program was relevant, meaningful and significantly improved participants' mental health and wellbeing at the completion of the program, as measured by the Kessler Psychological Distress Scale (K10) and the Depression Anxiety Stress Scale (DASS).

Stage 3: National Dissemination – 2009 – 2013

Following the pilot, *nib foundation* funded a national dissemination of *Partners in Depression*. Through this funding, workforce training was provided to more than 400 health and community mental health professionals from the public, non-government and private sectors across Australia.

Trained professionals, known as 'facilitators', were also provided with a range of free clinical and administrative supports to deliver the *Partners in Depression* program in their local communities. The aim was to assist facilitators to deliver a minimum of three groups in their community while also managing the clinical integrity of the program's delivery and outcomes.

1.3 Program approach: addressing a national gap

The *Partners in Depression* intervention is a six session group-based program which provides support to those who love, care for or live with a person experiencing depression through sharing information, knowledge and the necessary skills to support their role as a carer and to improve their own mental health and wellbeing.

Partners in Depression is delivered to participants by program partners working in community-based mental health services across Australia. Partner organisations are provided with extensive workforce development, clinical and implementation support to ensure that program participants across Australia benefit equally from attending the program.

Partners in Depression supports national policies, reports and recommendations in relation to families, carers and friends of people experiencing depression:

- **National Mental Health Policy 2008:** 2.2 Mental Health Promotion; 2.3 Preventing mental health problems and mental illness, and reducing suicide risk; 2.4 Early Intervention; 2.5 Carers; 2.6 Workforce; 2.9 Quality Outcomes; 2.10 Building and using evidence.
- **National Report Card on Mental Health and Suicide: A Contributing Life:** Include families and support people in care.
- **Recognition and Respect Mental Health Carers Report 2012:** Issue 1 - Listen and Respect Carers; Issue 3 - More and better trained staff at all levels; Issue 4 - Knowledge and information for carers; Issue 6 - Support systems and processes established for carers; Issue 11 - Physical and mental health of carers.

Core Components of the Program Include:

1. Introductions and building awareness of the program;
2. Developing an insight into the care and support role and the symptoms and treatments for depression;
3. Validating the care and support experience;
4. Introduction to cognitive behaviour therapy and the support role;
5. Suicidality and strategies for communicating with the person living with depression;
6. Help-seeking, support and future planning.



Facilitator case study: Jenice

As a Mental Health Promotion Co-ordinator I take an active role in raising awareness of, and promoting, positive mental health in our community. I work in collaboration with other health workers and service providers.

Our service knew there was a gap in what we were providing. *Partners in Depression* offered an evidence-based program to specifically support families, friends and carers of our clients experiencing depression.

The resources, content and support provided by the *Partners in Depression* project team is invaluable. Participants realise that they are not alone and have the opportunity to share their personal stories and experiences with others in similar situations. People involved in the program also acquire practical skills and learn the basics of how to implement self-care strategies in their daily lives.

When you see someone in the program “get it” – whatever “it” is for them – is the most memorable part of the program for me as a facilitator.

For some participants, it’s recognising and accepting the value of self-care, for others it’s a realisation that they are not alone or it may be learning a particular communication tip that they can see will work for them. Sometimes it’s when the person gains a better understanding of depression and how it’s affecting the person they care for. It can also be as simple as seeing them accept that depression isn’t a choice.

Participants who complete the *Partners in Depression* program have a better sense of hope for the future and an improved understanding of the impact of depression on their family members or friends.

It is an exciting process to watch people develop their skills and capabilities and have a renewed sense of positivity about their role in caring and supporting someone with depression.



For more information on the workforce development benefits of the *Partners in Depression* program please refer to the summary report titled: **Developing a workforce to support those who care: *Partners in Depression* Workforce Development Analysis** at www.everymind.org.au/partners-in-depression

1.4 Program logic

Partners in Depression is a **cost-effective, evidence-based** education and support program for families, carers and friends who love, live with or support a person experiencing depression. The program is able to build, support and sustain a **national workforce** to deliver community

outcomes. Research shows that *Partners in Depression* improves the mental health, wellbeing, help-seeking behaviours, relationships and social participation of families.

The program is able to **build, support and sustain a national workforce to deliver community outcomes.**



2.The National Evaluation

2.1 The national evaluation

The national evaluation of *Partners in Depression* will be published as a series of four summary reports, based on the logic outlined in Figure 1 right. The four evaluation reports are available online from www.everymind.org.au/partners-in-depression and include:

- Working together to support those who care: *Partners in Depression* Stakeholder Engagement Analysis
- Developing a workforce to support those who care: *Partners in Depression* Workforce Development Analysis
- Supporting effective program delivery for those who care: *Partners in Depression* Program Delivery Analysis
- Supporting those who care: *Partners in Depression* National Program Outcomes (available printed and online).



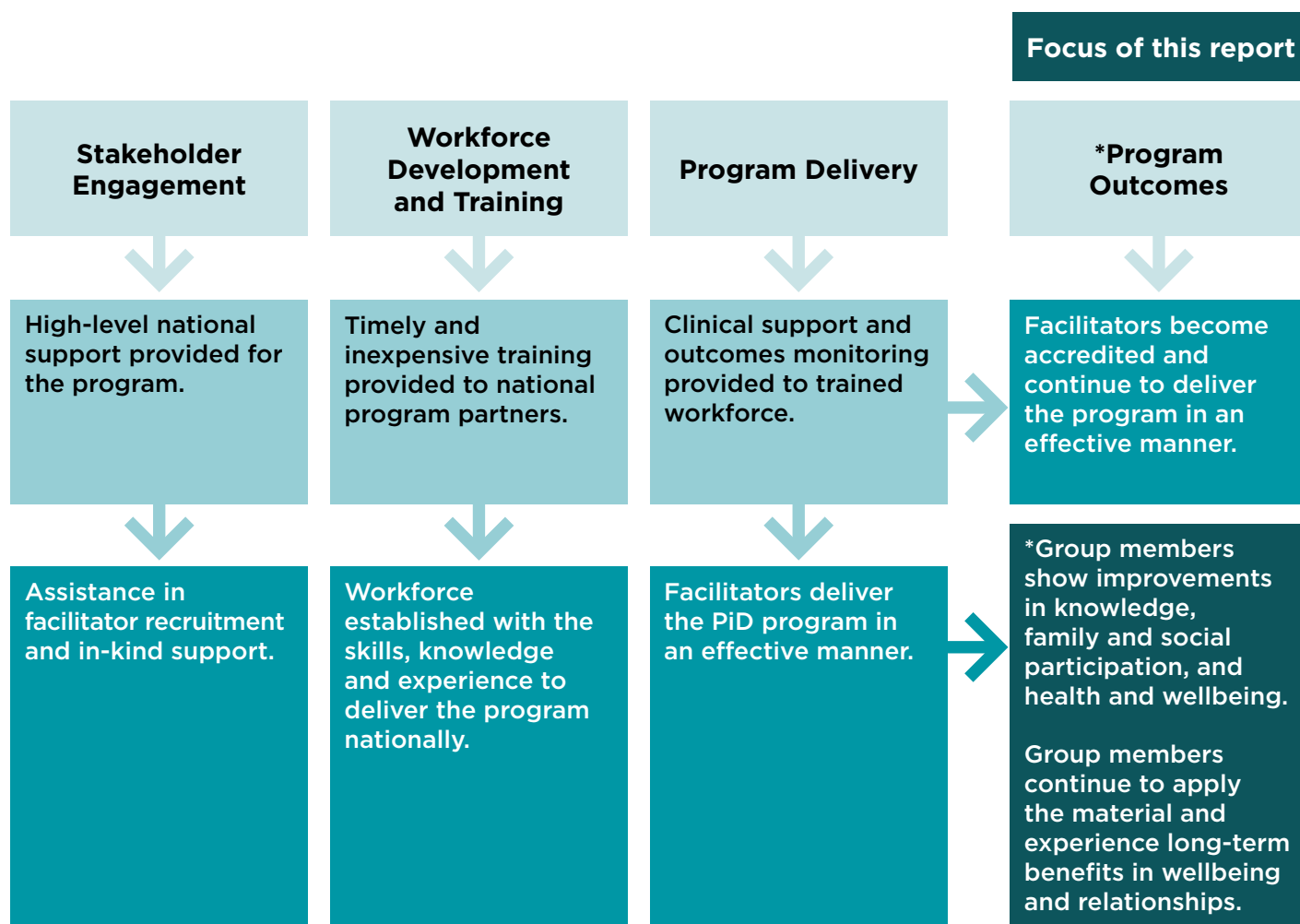


Fig 1. Overview of the program evaluation areas and expected outcomes.

* This report will focus on evaluation findings pertaining to the immediate and long-term impacts of the program on the mental health and wellbeing of families, carers and friends of people experiencing depression.

The remainder of this document will focus on the methodology, outcomes and recommendations emerging from the national evaluation of program outcomes.

This report will focus on evaluation findings pertaining to the immediate and long-term impacts of the program.



3.Evaluation Methodology

3.1 Aims

The primary aim of the evaluation was to investigate the effectiveness of the *Partners in Depression* program, in terms of the following:

1. Did the program deliver benefits to the mental health and wellbeing of program participants in terms of reducing their levels of psychological stress and increasing their self-assessed health and wellbeing?
2. Did the participants report improved social participation following the program's completion, both in the short and long-term?
3. Did the participants observe any improvements in their family relationships following the programs completion, both in the short and long-term?

3.2 Measures and procedures

High standards of ethical practice and program participant confidentiality were maintained throughout all stages of the program evaluation. The program content and evaluation methods were approved by the Hunter New England Research Ethics Committee (09/12/16/5.10).

To meet the aims of the evaluation, a cross-sectional mixed methods design was utilised. When constructing the evaluation methods, standard measures were utilised where possible to increase comparability of results with other existing secondary data sources (as outlined below in Table 1).

Table 1. Evaluation methods and measures

Participant questionnaires (baseline)	<p>All program participants were invited to complete baseline questionnaires prior to commencing the program. These questionnaires sought to obtain information including:</p> <ul style="list-style-type: none">• Demographic data about participants (age, gender, cultural background and languages spoken at home);• Details about the person they support with depression (length of caring role, relationship type);• Details about their own health and wellbeing (Kessler Psychological Distress Scale K10, physical health status);• Knowledge and attitudes towards depression and their role as a carer.
Participant questionnaires (post-program)	<p>At the completion of the six sessions, all program participants were invited to complete post-program questionnaires which included:</p> <ul style="list-style-type: none">• Repeated Participant Questionnaire - Baseline;• Participants' satisfaction with program information and structure, facilitators, benefits of attending for both themselves and the person they care for;• Knowledge and attitudes towards depression and their role as a carer (for comparison to baseline data);• Suggestions for improvements to the program.

Participant questionnaires (six month follow-up)	<p>Six months following the completion of the program, all consenting participants were invited to participate in a follow-up questionnaire which included:</p> <ul style="list-style-type: none"> • Repeated Participant Questionnaire – Post-Program; • Additional modules concerning help-seeking behaviours.
Focus groups (post program)	<p>Focus groups of participants were held in a range of locations (metropolitan and rural) to gain detailed qualitative feedback about their experience of the program. Participants who had previously consented were invited to participate in the focus groups, which were held six to twelve months following the completion of the program. Focus groups were conducted by an external evaluator and were structured in a manner that was consistent with the Participant Questionnaire – Six Month Follow up.</p>
Telephone interviews (six month follow-up)	<p>Within one-month following the completion of the program, consenting participants were contacted to participate in an in-depth telephone interview. The content of the telephone interviews were based on the Participant Questionnaire – Baseline.</p>
Secondary data analysis	<p>Existing population-based data sources⁷ were used to compare the characteristics of the program participants with national averages of people the same age.</p>

3.3 Analysis

Quantitative data was extracted from a purpose built *Partners in Depression* database, with all inferential statistics analysed using SPSS V16. Missing values on each variable were excluded from all analysis. Data were analysed using both independent and paired samples t-tests, and one way ANOVAs where indicated. Statistics were considered significant where $p < 0.05$.

Thematic analysis techniques were applied to the qualitative data to identify patterns in the data. This included data from open-ended questions in the questionnaires and transcripts from the focus groups and telephone interviews.

3.4 Response rate

While data collection is ongoing for the *Partners in Depression* program, data used in this report was collected from 1st May 2009 to 30th April 2012. Over this period, a total of 1220 people who love, care for or support a person experiencing depression participated in the program. The response rate for the program components are outlined in Table 2.

Table 2. Evaluation response rates

Program Method	Number	Response Rate
Participant questionnaire (baseline)	1220	100%
Participant questionnaire (post-program)	959	78.6%
Participant questionnaire (six month follow-up)	119	9.75%
Focus groups	92	N/A
Follow-up telephone interviews	40	N/A

4. Participant Characteristics and Experiences

4.1 Demographic data

A total of 136 *Partners in Depression* groups were conducted over the data collection period (01/05/2009 to 30/04/2012), with groups run in every state and territory across Australia. The majority (79.6%) of program participants were female, aged over 40 years (84.9%) and born in Australia (75%). Just over half of program participants were employed on a full-time or part-time basis and nearly three-quarters were married or in a de facto relationship. Details relating to the demographics of those who participated in the program are summarised in Table 3.

Table 3. Demographic data of those who participated in the program

Characteristic		Percent	Characteristic		Percent
Sex	Male	20.4%	Employment status	Full-time	26.3%
	Female	79.6%		Part-time	27.0%
Age	<20	0.4%		Studying	6.0%
	20-29	3.6%		Volunteer	10.0%
	30-39	11.1%		Retired	25.2%
	40-49	22.2%	Marital and relationship status	Single, never married	7.1%
	50-59	30.5%		Partner, living apart	3.1%
	60-69	23.4%		Married or de facto	72.8%
	70+	8.8%		Divorced or separated	12.0%
Born in Australia		75.3%		Widowed	4.7%
Indigenous		2.0%	English the only language spoken at home		88.1%

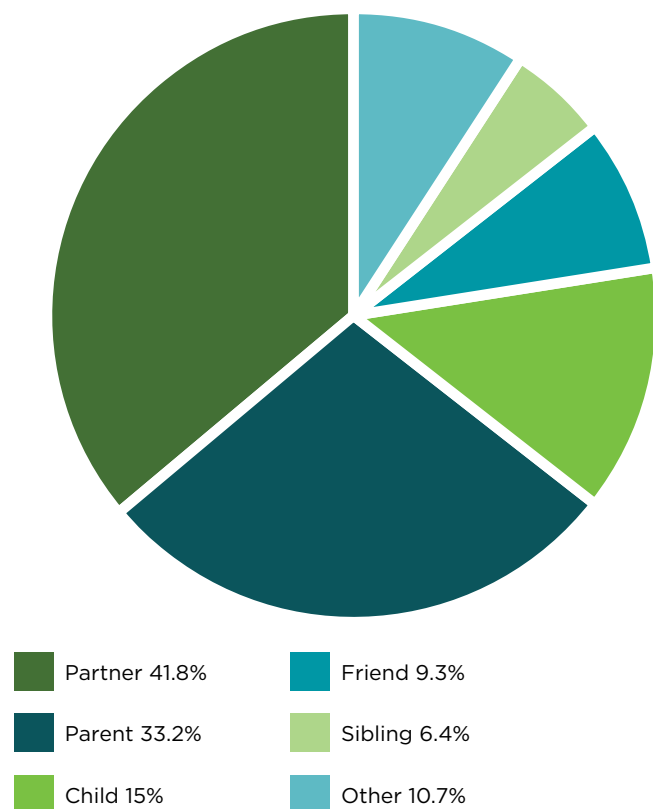


Fig 2. Relationships of participant to person experiencing depression

4.2 Relationship to the person experiencing depression

As illustrated in Figure 2, the majority (75%) of those who participated in the program reported providing care and support to their partner (41.8%) or their parent (33.2%), with a smaller proportion (15%) of participants providing care and support to their child. As many of the individuals in this study provided care or support to more than one person, the percentages for each sector of the pie chart shown in Figure 2 summate to a value greater than 100.

Over 90% of the people experiencing depression had been formally diagnosed by a health professional.

Approximately two-thirds (65.1%) of the participants lived with the person with depression, which meant that they were required to assume their caring/support role on a daily basis. Even during periods where the person with depression was not experiencing any of the symptoms, participants indicated that they still experienced the stress of wondering when or if the person would become unwell again. As one father said:

You don't know where your loved one's depression or illness is going, so while we're thinking ok, we are ok, you've always got in the back of your mind what if she gets sicker or what if she relapses, what if she gets better and then gets worse, or what if this is for the rest of her life or what if, what if, what if...

Those individuals who didn't live with the person with depression experienced similar concerns. According to one of the mothers who participated:

I think what happens is, you ring a couple of times and you think, oh well, they just want to be left alone, and then you think, or do they, or have they done something silly, or is there something wrong. And then the more you ring, I know the more upset my son gets and then he gets quite annoyed with me.

Nearly two-thirds of participants (64.6%) reported that the person with depression had other physical or mental health problems in addition to the depression itself. Some wondered whether the depression led to the other problems, or whether the other health or mental health problems helped trigger the depression, as one partner reported:

My husband has depression. It seemed to be multi-faceted and with a lot more investigation of his health issues, it has turned out that he actually has got a fairly complicated set of health matters. Not quite sure which came first – the health issues or the depression, but he has had depression for a long, long time and the problem has been I think it was unrecognised. For me it's been a huge learning curve.

Nearly half the participants (47.5%) were in multiple care roles, providing support to more than one person (either with a physical illness, mental illness or who were aged and frail).

4.3 Social Participation and Relationships

Table 4 shows the percentage of people in the program who agreed or strongly agreed that providing support to the person experiencing depression had a negative impact on their social interactions and relationships. Over half of all participants felt that the care and support role had a negative impact on their ability to engage in social activities and on the quality of their relationships with the person experiencing depression and other family and friends.

Table 4. Self-reported negative impacts of support role on relationships and social life

Aspect	Percent agreeing or strongly agreeing
Quality of my relationship with the person experiencing depression	57.4%
Quality of my relationships with other people in my life	51.6%
Ability to engage in social activities	55.0%

Although much research has focused on the negative aspects of supporting someone with depression, carers have often acknowledged that there are positive aspects as well.

When asked to describe any positive aspects of providing support to a loved one, many participants reported the experience had led them to find greater meaning in their relationship with the person with depression as well as in their own abilities to provide that support.

Their support role was reported to highlight the importance of ensuring that their own mental health needs were being addressed, for example:

[The] experience has been rewarding in many ways – has led me to grow into a more empathetic person. We have a much closer relationship. It has enabled me to do programs like this one and I have learnt so much and am more interesting and have met great people.

Nearly half the participants (47.5%) were in multiple care roles, providing support to more than one person.

4.4 Wellbeing

When asked, over half of all participants entering the program felt that providing support to the person experiencing depression has had a negative impact on their own wellbeing. This includes their physical and mental health, financial independence and their capacity to undertake daily activities (see Table 5 below).

Section 6 of this document will provide additional data on baseline, post-program and six month follow-up psychological distress scores for participants, as measured by the Kessler Psychological Distress Scale (K10). At baseline, the results suggest that a large proportion (70%) of program participants scored in the medium to high/very high range of psychological distress, with reported levels of psychological distress being significantly higher than the general population.

Table 5. Self-reported negative Impact of support role on wellbeing

Aspect	Percent agreeing or strongly agreeing
Mental health and wellbeing	61.5%
Physical health and wellbeing	51.2%
Finances	52.4%
Day-to-day responsibilities	60.7%

Snapshot: Participant characteristics

The majority of program participants reported providing care and support to their partner or their child.

Approximately two-thirds of the participants lived with the person with depression, which meant that they experienced their caring/support role on a daily basis.

Nearly two-thirds of participants reported that the person with depression had other physical or mental health problems in addition to depression.

Nearly half the participants were in multiple care roles, providing support to more than one person.

Over half of all participants felt that the care and support role had a negative impact on their ability to engage in social activities and the quality of their relationships. However, participants also reported the experience had led them to find greater meaning in their relationship.

Over half of all participants felt that providing support to the person experiencing depression has had a negative impact on their own mental health and wellbeing.

A large proportion (70%) of program participants scored in the medium to high/very high range of psychological distress, with reported levels of psychological distress being significantly higher than the general population.

Participant case study: Lyn

To wake each day with hope in your heart, rather than a burden on your chest and shoulders is a gift most of us take for granted. In 1992 my husband was made redundant from a senior position in a telecommunications project, and he became severely depressed. We made some significant changes to our life, including the purchase of a farm which was approximately a three hour drive from Sydney.

I continued to work and commute each week for approximately seven years until December 1999, when I found my 58 year old husband had a stroke. The following six months was consumed by intensive care and rehabilitation programs, after which I was allowed to take my broken husband home to our farm. He was unable to walk or talk or do even the most basic tasks.

My husband had been a physically strong man, highly motivated and a high achiever. Following his redundancy he experienced depression, high blood pressure, loss of self-esteem and then the stroke. It all had a traumatic effect on our family and friends.

Many could not manage the change and disappeared from our lives. Others rallied to support us but as we returned home from hospital, rural isolation compounded our situation. A key lesson for me has been to learn patience in the face of adversity and to accept a situation I cannot easily change. Adapting to it was my key to survival.

The next few years were marked by gradual recovery for both of us. I had to give up my job in Sydney and we faced financial losses and debt. I initially took on full responsibility for the management of our farm and growing herd of cattle, but age and physical strength were critical factors for my being able to continue in this role and I eventually had to call it a day. We sold the farm, the cattle and the lifestyle we loved to return to Sydney.

I have been a “carer” all of my life. I have looked after my children, my parents, thousands of students as a secondary English teacher and senior lecturer at University, and since 2000 my husband following his stroke. Attending the Partners in Depression group helped me to explore opportunities to resume some aspects of my former life. It has helped me regain a sense of me as more than just my caring role. The process has also helped my husband change from being very self-focused, to prompting him to do more for himself and accept my need to do things I enjoy.

Partners in Depression has opened doors in my own awareness and understanding that I am not alone on this journey. I do count my blessings. Although much has been lost, much has also been gained. I sincerely thank those who understood our journey and regret there are those who do not.





5. Learning Outcomes

5.1 Perceived effectiveness of the program

The program had ten key learning goals. On the post-program questionnaire, program participants were asked to rate how effective they thought the program was in meeting these goals, based on a six point scale, ranging from very poor (1) to excellent (6).

My husband was really impressed that I was going because he didn't even know what was going on.

The mean levels of effectiveness are presented in Table 6, with scores closer to 6 indicating higher participant rated effectiveness. Program participants agreed that the program was effective in meeting its expected learning outcomes, with the majority (90%) of respondents providing a score of five or higher.

It's ok to be frustrated with the situation. It's ok to be tired of it. It's ok to ask for help. I am not responsible for my partner's depression.

To further explore participants' perceptions about the program, individuals were asked what they felt were the main benefits of *Partners in Depression*. Examples listed by participants include:

- Learning/realising that they are not alone in their experiences;
- To be able to talk openly about depression;
- The importance of self-care;
- To ask for help when they need it for themselves;
- More accurate information about depression;
- Effective communication skills;
- To step back/set boundaries;
- Separating the person from the illness;
- To maintain hope.

Table 6. Mean participant rated effectiveness of *Partners in Depression*.

Aspect	Mean
Increasing your knowledge of the symptoms, diagnosis and treatment of depression	5.09
Increasing your awareness of the impact of depression on relationships	5.15
Providing information about and increasing your skills in effective communication strategies	5.05
Facilitating communication with others about the experience of supporting a person with depression	5.01
Developing awareness of strategies for accessing effective treatment for a person with depression	4.92
Increasing your awareness of the personal impact on your emotional and physical wellbeing of supporting a person with depression	5.19
Providing education and strategies for self-care and coping techniques	5.16
Providing education and increased awareness of the services and resources available to support people supporting a person with depression	5.06
Providing encouragement for you to increase help seeking behaviours for yourself and the person with depression	5.19
Meeting the needs you had prior to attending the program	5.02

Table 7. Comparison of baseline and post-program participant-rated knowledge.

Statements	Percent agreeing or strongly agreeing			Desired outcome
	Baseline	Post Program	Six month follow-up	Positive or Negative
I have a good understanding of the causes, symptoms and treatments for depression	48%	93%*	94%*	Positive
I have a good understanding of the service system available to support a person experiencing depression	38%	90%*	86%*	Positive
I talk with others about what it's like to support a person with depression	47%	70%*	70%*	Positive
I feel others don't understand what it's like to support a person with depression	62%	68%*	67%*	Negative
Due to my role supporting a person with depression, I feel a strong sense of isolation	43%	37%*	33%*	Positive
I am confident in my ability to communicate effectively with the person in my life with depression	42%	67%*	67%*	Positive
There is good communication between myself and the person in my life with depression	47%	60%*	59%*	Positive
I know what helps promote my own mental health	68%	92%*	91%*	Positive
I believe it is important to take time out and look after myself	90%	98%*	98%*	Positive
I make sure I take time out to look after myself and engage in self care activities regularly	58%	83%*	78%*	Positive
I have been able to access the support I need	41%	74%*	63%*	Positive
The person in my life experiencing depression has been able to access the support and treatment that they need	47%	64%*	66%*	Positive

*Note. * Indicates that significant change in score relative to baseline measure.*

5.2 Participant knowledge

Program participants were asked how strongly they agreed or disagreed with a series of statements relating to their experiences and levels of understanding about various aspects of depression itself and the caring experience. Table 7 shows the percentage of participants either agreeing or strongly agreeing with each statement at both baseline and post-program evaluation.

The analysis indicated a profound improvement across all statement areas, with the exception of “I feel others don’t understand what it’s like to support a person with depression.” In all cases, independent samples *t*-tests^A showed that the observed increases were statistically significant[^].

Meeting people I can relate to and the support provided through ‘like’ experiences was invaluable.

A total of 84% indicated that they had already applied program information and this increased to 93% at six month follow-up.

A A paired samples t-test is not used because these are unlinked data.

5.3 Participant application of program materials

In order for the program to induce meaningful changes in the participants’ lives, they need to be able to take what they have learned in the *Partners in Depression* group and apply the knowledge, concepts and skills in their own lives. At the end of the program, 80% of participants were confident or extremely confident that they would be able to apply this material. Only one person from the sample indicated that they were not at all confident.

Before the course I used to call ‘me’ time self-indulgent and now I call it self-care.

A total of 84% indicated that they had already applied program information and this increased to 93% at six month follow-up. During the focus groups and telephone interviews program participants most commonly reported applying the following lessons:

- Setting boundaries/stepping back;
- Changing the way they communicated/reacted to situations;
- Taking time for themselves;
- Discussing the material with the person with depression;
- Encouraging discussions about potential changes in treatment;
- Disclosing their experience of depression to others.

Snapshot: Learning outcomes

Program participants agreed that the program was effective in meeting its expected learning outcomes.

The program significantly increased participant understanding of depression and the caring experience.

The majority of participants were confident or extremely confident that they would be able to apply what they learnt in their own lives, with many already implementing changes at post-program and six month follow-up.

Participant case study: Kim

I have officially been supporting my wife for the past seven years, but I know I've been a carer for a lot longer than that. It was a major concern that there was something wrong, but you can't always put a name to it straight away.

There are still ups and downs and still worrying times. I don't think this is a situation where you can say it's sorted, because it changes all the time. You have to adapt to the mood swings, and as she gets better or gets sick you have to adapt to that too.

One of the things I've always had in my mind and I said from the start, "I'm not going anywhere". And I keep saying to my wife "our relationship will not end and I will not be leaving". It's what she needs to know because sometimes she doesn't know what is going to happen next and she needs to know I'm there to back her up. I hope that makes it a little easier for her.

Attending the *Partners in Depression* group made a huge difference. Knowing you aren't alone and connecting with people who can say "I know you're having the same problem as I'm having. It can be dealt with". It halves the worry and breaks it down.

Initially it can be very difficult to go into a group. Sometimes it's easier to talk one on one but you have to have someone you can talk with. I was down at a local club with my brother, who went to the *Partners in Depression* group before I did, and we were talking about things. This young bloke behind us came up and said "I know exactly what you're talking about. I've been through it", but he had no one to talk to.

I'm very open, but now my wife and I have more to talk about. Since the group we both have more information. The more information you've got, the more you can talk about it, and the more things come out - stuff that would never have come out in the first place.

I do get low sometimes, but that comes from years ago. I know have to deal with it, and relax. I'm 60 now. I'm going to make the most of all my years left with my wife.



6. Mental Health and Wellbeing Outcomes

6.1 Psychological distress

As indicated in previous sections, over half of all participants reported that providing support to the person experiencing depression had a negative impact on their mental health and wellbeing, their physical health, their finances and their capacity to undertake daily activities. This component of the evaluation aimed to investigate whether the program had directly contributed to improvements in the participants' mental health and wellbeing.

I learnt that it is not selfish to be healthy and happy. In fact, it can make it easier to continue caring.

To investigate the potential benefits of the program, participants were asked to complete the Kessler Psychological Distress Scale (K10). The K10 is a standardised measure of psychological distress and is commonly used in large scale population health surveys. The K10 has frequently been utilised to screen for the presence of mental disorders within the population, with scores >19 indicating the likely presence of a mental disorder. Participants were asked to complete the K10 at three time points including: at the commencement of the program, at the completion of the program and six months following the program. For the purpose of this report, K10 scores have been grouped into three categories i.e. Low 10-15, Medium 16-29 and High/Very High 30-50.

The results of the baseline assessment suggest that a large proportion (70%) of program participants scored in the medium to high/very high range of psychological distress at the commencement of the program. As outlined in Figure 3 below, their reported levels of psychological distress observed in the participants were significantly higher than the general population (when compared to data from a national survey⁸).

70%
of group participants reported high/very high levels of psychological distress.

This suggests that participants may themselves be experiencing levels of psychological distress sufficient to warrant clinical diagnosis prior to their entry into the program.

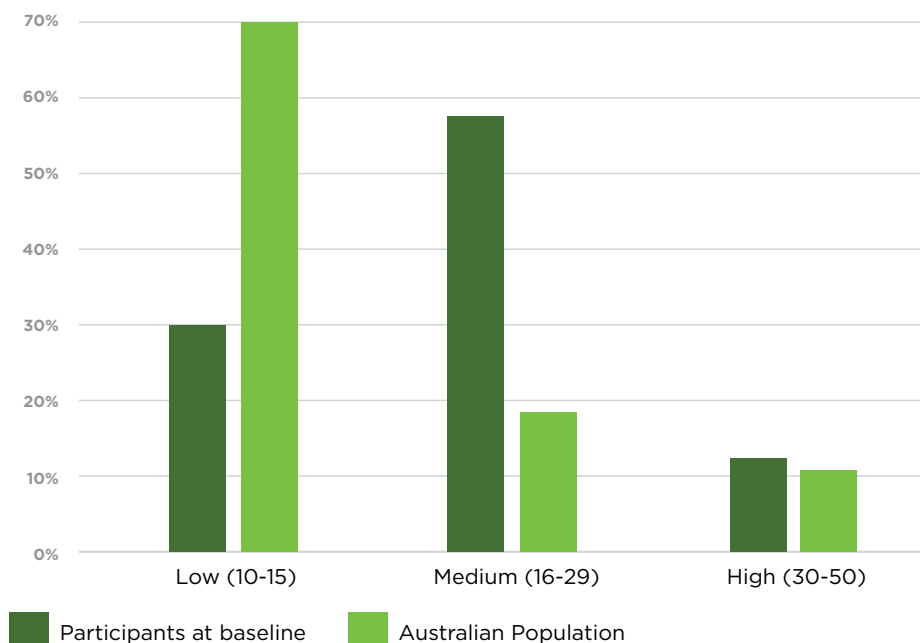


Fig 3. Levels of psychological distress (K10) observed in participants (at baseline) compared to the national average.

Table 8. Comparison of psychological distress levels between baseline and program's end

Level of psychological distress	Baseline	Post-program	Six month follow-up	National Health Survey ¹
Low (10-15)	30.0%	43.0%	48.7%	70.1%
Medium (16-29)	57.6%	50.9%	43.4%	18.4%
High/Very High (30-50)	12.4%	6.1%	8.0%	10.8%

Changes in psychological distress were analysed across baseline, program end and at six month follow-up with results represented in Table 8 above.

Paired sample *t*-tests indicated that relative to baseline, those who participated in the program showed significant (all $ps < 0.001$) reductions in their levels of psychological distress, which was observed at both the completion of the program and then again at six month follow-up. Whilst the program achieved significant reductions in the level of psychological distress for participants, levels of psychological distress remained slightly higher than the general population. Note that a smaller number of participants completed the K10 at six month follow-up.

6.2 Self-assessed health and wellbeing

To investigate the impact of *Partners in Depression* on their wellbeing, participants were asked to rate their level of agreement with the statements regarding whether the program improved their: overall physical and mental health, and ability to perform everyday tasks. The data presented in Table 9 shows changes across baseline, program end and six month follow-up.

On average, participants rated their overall physical and mental health and their ability to perform everyday tasks as good to very good at each time point. There was a small but significant increase from baseline to post program for self-reported ratings of overall mental health ($t(617)=4.07, p=.001$). This was not maintained in the repeated measures ANOVA across the three time points, but ratings for overall mental health approached significance ($F(2, 78)= 3.11, p=.05$).

Table 9. Self-assessed mental and physical health

Aspect	Mean rating		
	Baseline	Post-program	Six month follow-up
Overall physical health	4.04	4.11	3.96
Overall mental health	3.97	4.10	3.88
Ability to perform everyday tasks (e.g. at home, at work, studying, shopping, looking after yourself)	4.54	4.57	4.30

6.3 Relationships and social connection

I feel stronger mentally, enabling me to focus on stronger and good quality relationships based on equality. We are in a good place at the moment and can work together when things are not good.

Participants were asked to rate how effective they thought the program was for improving their relationships with family members, close friends and the person with depression. Ratings were based on a six point Likert scale, ranging from very poor (1) to excellent (6). The mean levels of effectiveness are presented in Table 10 below.

There was little change between baseline, post-program and six month follow-up ratings of relationships with family and friends. However, a paired samples t-test indicated that participants self-reported significant improvements in their relationships with the person in their life with depression from baseline to post-program measures ($t(583)=5.465, p<0.001$). This effect, however, was not observed at the six month follow-up period.

Table 10. Self-assessed improvement to relationships

Aspect	Mean rating		
	Baseline	Post-program	Six month follow-up
Overall relationship with your family and close friends	4.46	4.52	4.44
Relationship with the person in your life with depression	3.93	4.14	4.02

“We now have a greater willingness to speak openly about depression and how it affects daily routines, family relationships and our outlook on life.”

Consistent with the data presented previously, 81.7% of program participants reported that attendance had led to improvements in their relationships with family members and close friends and the person in their life with depression post program.

When asked, participants specifically described the following types of impacts:

- A better understanding of the other’s perspective;
- Separating the person from the illness;
- Better communication (including using “I” statements);
- Appreciation of the carer for doing the course;
- More patience;
- More open communication (e.g. willingness to raise difficult issues);
- In some cases, the participant disengaging from the person with depression.

To investigate the potential impact of the program in terms of increasing the social participation of participants, six month follow-up questions were asked to ascertain whether they had any contact with the other participants or their facilitators since the completion of the program.

- Half of the respondents reported that they had kept in touch with either another group member (74.6%) or one or both of their program facilitators (49.2%).
- The types of contact ranged from incidental meetings (e.g. in the supermarket) to organised get-togethers/follow-up programs.

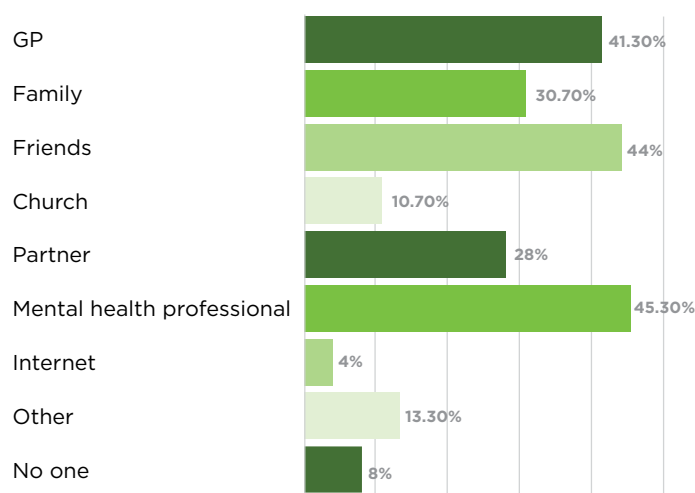


Fig 4. Who respondents turned to for help with their own mental health or wellbeing (%)

6.4 Impact on help-seeking behaviours

The importance of seeking help early for participants’ own issues was an important element of the program. When asked, two thirds of participants (at the six month follow up) reported that they felt they needed help with their own mental health or wellbeing. Participants with mental health concerns were asked who they had turned to for help with these concerns. As shown in Figure 4, program participants were most likely to have sought help from a mental health professional, GP or friend.

“I feel stronger and confident when bringing up sensitive issues.”



Snapshot: Mental health outcomes

The majority of program participants experienced levels of psychological distress significantly higher than the general population upon entry into the program. Levels of psychological distress reported suggest an increased risk of developing a mental health problem.

Program participants reported significant reductions in the level of psychological distress they experienced at the programs completion and six months following the program end.

Program participants reported improvements in their self-assessed mental and physical health and improvements in their family and social relationships following the program.



7. Implications

The current report *Supporting Those Who Care: Partners in Depression National Program Outcomes* suggests the following:

- **There is a need for interventions targeted at people who love, live with or care for someone experiencing depression.**

The majority of program participants reported providing care and support to their partner or their child, with a large proportion caring for more than one person and someone with complex comorbid physical and mental health problems.

- **Interventions targeted at people who love, live with or care for someone with depression need to address the social isolation and relationship stress that many carers experience.**

The majority of program participants felt that the care and support role had a negative impact on their life, including their ability to engage in social activities and the quality of their relationships.

- **Those who love, live with or care for someone with depression need timely access to evidence-based primary prevention interventions.**

Standardised clinical mental health measures indicated that at program entry participants were experiencing levels of psychological distress much higher than the general population. Over 70% of program participants reported levels that suggested the likely presence of a mental disorder. This is particularly worrying given the essential caring role participants play across Australia.

- **The *Partners in Depression* program contributes to immediate and sustained improvements in mental health and wellbeing.**

Program participants reported a significant reduction in their levels of psychological distress at the completion of the program and at the six month follow-up.

- **The *Partners in Depression* program is effective in supporting participants to increase their understanding of the various aspects of depression.**

In addition, the program provided practical strategies and sufficient instructions to program participants to support the later implementation of these strategies into their day-to-day lives.

- **The *Partners in Depression* program is effective in contributing to improved family relationships and social participation.**

People who love, live with or care for someone in depression reported improvements in their relationships with the person experiencing depression.

- **The effectiveness of the *Partners in Depression* program for priority populations requires exploration.**

Given the low uptake of the program by a number of priority populations, it is important to consider how the benefits of the program can be shared with these demographics, including: Men; Aboriginal and Torres Strait Islander peoples; young people; people from culturally and linguistically diverse backgrounds; and lesbian, gay, bisexual, transgender and intersex people and families.



- **Further research is needed.**

There is strong evidence to support the conclusion that the *Partners in Depression* program is driving the reported benefits to program participants. It would however, be important to investigate this conclusion via a study design using a waiting list control comparison group or a randomised control trial.

Future studies should consider tracking the recovery of the person with depression in order to investigate how their recovery impacts on the carer and whether carer program attendance impacts the recovery trajectory of the person with depression.

More evidence is required regarding the longevity of program benefits to the carer and whether the program contributes directly to a reduced need for mental health services for people who love, care for or support a person experiencing depression and the person with depression.

Additional analysis of the *Partners in Depression* evaluation data has been co-funded by **Everymind** and *beyondblue*.

A summary of these studies are available at **www.everymind.org.au/partners-in-depression** and will be published in peer-reviewed journals in the near future to ensure dissemination of research evidence.

“My husband **was really impressed that I was going ‘cause he didn’t even know what was going on.”**

“I feel stronger mentally, enabling me to focus on stronger and good quality relationships based on equality. We are in a good place at the moment and can work together when things are not good.”

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Families and friends
are the largest providers
of care and support for
people living with
depression in Australia.

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