

Frequent Users of Crisis Helplines
Who are they and why do they continue to call?

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Abstract

Crisis helplines were established in the 1950s to provide an immediate telephone response to anyone in an acute crisis. They now operate around the world, and Lifeline is recognised as one of Australia's largest national crisis helpline services. A disproportionate number of calls to crisis helplines come from frequent users, who make multiple calls over an extended period of time. It has long been thought that frequent users are isolated individuals who call about non-crisis related issues; however, this assumption has never been investigated. Service providers struggle in knowing how to respond to frequent users while still addressing the needs of other callers. An evidence-based approach is required.

Aim

The aim of this thesis was to investigate the socio-demographic characteristics of frequent users of crisis helplines and the factors driving their frequent use. Specifically, it answered the research questions:

1. What is the socio-demographic profile of frequent users of crisis helplines?
2. What are the reasons for frequent users' continued use of crisis helplines and how do they differ to those of other callers?
3. What are the health service use patterns of frequent users of crisis helplines?

Methods

Three studies were conducted to address the research questions. Study 1, a brief survey of callers to Lifeline, investigated the socio-demographic characteristics of frequent users and differences in their reasons for calling compared with episodic and one-off callers. Quantitative analyses were conducted using ordered logistic regression. Study 2 involved interviews with Lifeline frequent users. Inductive thematic analysis was used to generate common themes to understand why some users may call crisis helplines frequently. Study 3, a longitudinal analysis of data from the *diamond* study, examined the relationship between frequent use of crisis helplines and health service use patterns over time. Crisis helpline use was measured at 3, 6, 9, and 12 months and analysed using ordered logistic regression.

Results

Compared to other callers, frequent users were more socially isolated individuals and lacked people to turn to in moments of despair. They had come to rely on crisis helplines for support; although, this was not the only factor driving them to call. They also reported disabling and chronic mental health issues, physical illnesses, and ongoing crises. The circumstances under which they called varied, but there was evidence to suggest that the current service model was not meeting their long-term needs and may in fact reinforce their calling behaviour. Frequent users also visited the general practitioner, psychiatrist, psychologist, and the emergency department at rates higher than other callers; yet, they were less satisfied with their access to these services.

Conclusions

Frequent users have a genuine need for crisis support, yet, they use crisis helplines in a manner different from their intended use. They account for a substantial number of callers to crisis helplines and service providers may benefit from recognising frequent users as a legitimate group of service users. This might have implications to how counsellors approach these users and may require a change in the operation of crisis helplines.

Declaration

- *The thesis comprises only original work towards the Doctor of Philosophy except where indicated in the preface.*
- *Due acknowledgment has been made in the text to all other material used.*
- *The thesis is fewer than 100,000 words, exclusive of tables, bibliographies and appendices.*

Signed:

A handwritten signature in black ink, appearing to read 'Amiddleton', written over a horizontal line.

Aves Primula Audrey Middleton

Preface

This body of work comprises of a thesis with publication. It was completed as per the University of Melbourne requirements, the empirical studies are presented in Chapters 5 to 7 as published manuscripts. These studies were undertaken as part of a broader project: *Frequent and Continuing Contacts to Lifeline Crisis Support Services*. The broader project included a systematic literature review and four empirical studies with a core group of researchers (Professor Jane Pirkis, Professor Jane Gunn, Dr. Bridget Bassilios, and myself). Additional support was sought for specific studies, when required. In terms of the systematic literature review, I led the review into frequent users of crisis helplines, which included identifying the papers, extracting relevant information from each paper, analysing the data, and drafting the final manuscript. Jane Pirkis and Jane Gunn conceptualised the approach taken in the review and along with Bridget Bassilios provided critical comment. Extracts from this systematic literature review are included in Chapter 3 and the published manuscript is included as Appendix 2. The citation of the manuscript is:

- o Middleton A., Gunn J., Bassilios B., Pirkis J. (2014). Systematic review of research into frequent callers to crisis helplines. *Journal of Telemedicine and Telecare*, 20(2), 89-98. doi:10.1177/1357633X14524156

I was also involved in the four empirical studies of the broader project. I led the development, implementation, and analysis of two of these studies, which form the empirical research of this thesis.

Chapter 5 presents Study 1, which investigated the differences in the socio-demographic characteristics and reasons for calling between frequent users and other callers to crisis helplines. Included in this chapter is the manuscript: *How do frequent users of crisis helplines differ from other users regarding their reasons for calling? Results from a survey with callers to Lifeline, Australia's national crisis helpline service*, which is published in the journal *Health and Social Care in the Community*. I led the development of this manuscript, with Jane Gunn, Jane Pirkis, Bridget Bassilios, and Alan Woodward as co-authors. Jane Pirkis and Jane Gunn conceptualised the initial study. Alan Woodward and I collected the data. I developed the research question, conducted data analysis, and

drafted the manuscript with critical comment from the co-authors. All authors approved its submission, cited as:

- o Middleton A., Woodward A., Gunn J., Bassilios B., Pirkis J. (2017). How do frequent users of crisis helplines differ from other users regarding their reasons for calling? Results from a survey with callers to Lifeline, Australia's national crisis helpline service. *Health and Social Care in the Community*, 25(3), 1041-1049. doi:10.1111/hsc.12404

Chapter 6 presents Study 2, which investigated why some users call crisis helplines frequently. This chapter included the manuscript: *The experiences of frequent users of crisis helplines: A qualitative interview study*, published in the journal *Patient Education and Counseling*. As primary author of the manuscript, I developed the interview guide, conducted the interviews, led the analysis, and drafted the manuscript with input from the other authors. Co-authors, Jane Gunn and Jane Pirkis, conceived the original idea for the study, oversaw its successful completion, and along with Bridget Bassilios, provided input into the draft. All authors read and approved the final manuscript, cited as:

- o Middleton A., Gunn J., Bassilios B., Pirkis J. (2016) The experiences of frequent users of crisis helplines: A qualitative interview study. *Patient Education and Counseling*, 99(11), 1901-1906. doi:10.1016/j.pec.2016.06.030

Chapter 7 presents Study 3, which investigated the relationship between frequent use of crisis helplines and health service use patterns over time. This chapter included the manuscript: *The health service use of frequent users of telephone helplines in a cohort of general practice attendees with depressive symptoms*, published in *Administration and Policy in Mental Health and Mental Health Services Research*. I was the primary author, and Jane Gunn, Jane Pirkis, Bridget Bassilios, and Patty Chondros were co-authors. Jane Gunn was the chief investigator on the *diamond* study and Patty Chondros was a co-investigator. I developed the research question, conducted data analysis with guidance from Patty Chondros, and drafted the manuscript with critical comment from the other authors. All authors read and approved the final manuscript, cited as:

- o Middleton A., Pirkis J., Chondros P., Bassilios B., Gunn J. (2015). The health service use of frequent users of telephone helplines in a cohort of general practice attendees with depressive symptoms. *Administration and Policy in Mental Health*

and Mental Health Services Research, 43(5), 663-674. doi:10.1007/s10488-015-0689-7

The remaining studies of the broader project were led by Matthew Spittal and Bridget Bassilios, respectively, who conducted the analysis and wrote the manuscripts. I provided critical comment on each of these manuscripts. Findings from these manuscripts are not part of the original work of this thesis but are included in the literature regarding frequent users of crisis helplines (Chapter 3). The citations for these manuscripts are:

- o Spittal M., Fedyszyn I., Middleton A., Bassilios B., Gunn J., Woodward A., Pirkis J. (2015) Frequent callers to crisis helplines: Who are they and why do they call? *Australian and New Zealand Journal of Psychiatry*, 49(1), 54-64. doi:10.1177/0004867414541154
- o Bassilios B., Harris M., Middleton A., Gunn J., & Pirkis J. (2015) Characteristics of people who use telephone counselling: findings from secondary analysis of a population-based study. *Administration and Policy in Mental Health and Mental Health Services Research*, 42(5), 621-632. doi:10.1007/s10488-0140595-8

A manuscript summarising the whole project was prepared by Jane Pirkis, which outlined the literature review, the four empirical studies, and considered the overall findings of the project. I was responsible for undertaking the literature review, collecting and analysing data for the survey/interview study with frequent users of Lifeline, and preparing and analysing data from the *diamond* study with the assistance of Patty Chondros). I read and approved the final manuscript. This manuscript is referenced in Chapter 9 of this thesis and is cited as:

- o Pirkis J., Middleton A., Bassilios B., Harris M., Spittal M., Fedyszyn I., Chondros P., & Gunn J. (2016) Frequent callers to telephone helplines: New evidence and a new service model. *International Journal of Mental Health Systems*, 10:43. doi:10.1186/s13033-016-0076-4.

Conference Presentations

During my candidature I presented my research findings at two conferences including, a national Australian conference and an international conference in Canada:

- o Middleton A., Davidson S., Pirkis J., Gunn J. (2014) Predictors of an adequate healthcare response for primary healthcare patients at risk of suicide, The National Suicide Prevention Conference, 23-25 July 2014, Perth, Australia. [Oral presentation]
- o Middleton A., Gunn J., Basilios B., Pirkis J. (2014) Systematic review of research into frequent callers to crisis helplines. The National Suicide Prevention Conference, 23-25 July 2014, Perth, Australia. [Poster presentation]
- o Middleton A., Pirkis J., Chondros P., Basilios B., Gunn J. (2015) Does suicidality predict the frequent use of telephone helplines in a general practice cohort with depressive symptoms? 28th World Congress of the World Association of Suicide Prevention, 16-20 June 2015, Montreal, Canada. [Oral presentation]

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Thank you to everyone who read through and provided comment on specific chapters. It was hard for me to reach out and ask for your feedback but all of your comments enhanced the quality of this submitted dissertation. In addition to my two supervisors, I would like to thank Amy Coe, Adrian Laughlin, Emily Habgood, Kristi Milley, Marianne Webb, Nicholas Zia, Patty Chondros, and Rebecca Bergin. I am also grateful for the support from Karen Dacy from Academic Skills, University of Melbourne who provided me writing advice and support throughout my PhD.

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Table of Contents

Introduction	1
1.1 Study context	1
1.1.1 The establishment of crisis helplines.....	2
1.1.2 The structure of crisis helplines.....	4
1.1.3 Frequent users of crisis helplines.....	5
1.2 Problem statement.....	8
1.3 Aim and scope	9
1.4 Significance of the study.....	10
1.5 Thesis overview	11
The evolution of crisis helplines.....	15
2.1 The early crisis helplines	15
2.1.1 The Samaritans, United Kingdom	16
2.1.2 Los Angeles Suicide Prevention Centre, USA	17
2.1.3 Lifeline, Australia.....	19
2.1.4 A comparison of the early crisis helplines.....	20
2.2 Structure of the crisis helpline service model	22
2.2.1 Short-term support.....	23
2.2.2 Staff and volunteers	25
2.2.3 Caller autonomy	27
2.3 Factors leading to the strengthening and expansion of crisis helplines	28
2.3.1 Increasing demand.....	29
2.3.2 Crisis intervention theory	31
2.3.3 Technological advancements.....	32
2.4 Effectiveness of crisis helplines.....	34
2.5 Crisis helplines in Australia.....	37
2.5.1 Lifeline 13 11 14	39

2.6	Chapter summary	42
	Frequent Users of Crisis Helplines	43
3.1	Frequent users of crisis helplines	43
3.1.1	Why are frequent users a concern to crisis helplines?	44
3.1.2	Current approaches to frequent users	45
3.2	Overview of the empirical literature on frequent users of crisis helplines	46
3.2.1	Defining frequent users of crisis helplines	47
3.2.2	Study methodologies	48
3.2.3	Frequent users calling patterns	57
3.3	Characteristics of frequent users of crisis helplines based on findings from the empirical research	60
3.3.1	Socio-demographic characteristics	60
3.3.2	Reasons for calling	62
3.3.3	Health service use	65
3.4	Research gaps	66
3.5	Chapter summary	67
	Methods	69
4.1	Thesis aim and research questions	69
4.1.1	Thesis aim	70
4.1.2	Research questions	70
4.2	Methodological overview	70
4.2.1	Choice of analytical methods	70
4.2.2	A convergent mixed methods approach	73
4.3	Empirical studies	77
4.3.1	Study 1: Survey of Lifeline callers	77
4.3.2	Study 2: Interviews with Lifeline frequent users	84
4.3.3	Study 3: Longitudinal analysis of data from the diamond study	87

4.4	Chapter summary	93
	Study 1: Survey of Lifeline callers	95
5.1	PDF of manuscript	95
5.2	Chapter summary	105
	Study 2: Interviews with Lifeline frequent users.....	107
6.1	PDF of manuscript	107
6.2	Additional analysis – healthcare use	114
6.3	Chapter summary	114
	Study 3: Longitudinal analysis of data from the diamond study.....	117
7.1	Additional background information.....	117
7.2	PDF of manuscript	119
7.3	Chapter summary	132
	Integration and interpretation of findings.....	133
8.1	Using a convergent approach to interpret findings from the empirical research 133	
8.1.1	The socio-demographic profile of frequent users of crisis helplines.....	135
8.1.2	Reasons for frequent users’ continued use of crisis helplines and how they differ to those of other callers.....	136
8.1.3	Factors driving the frequent use of crisis helplines	137
8.2	Interpretation of the key findings.....	138
8.2.1	Socio-demographic characteristics	138
8.2.2	Factors driving the frequent use of crisis helplines	139
8.3	Convergent mixed methods approach.....	142
8.4	Chapter summary	143
	Addressing the issue of frequent use of crisis helplines.....	145
9.1	Strengths and limitations of this thesis	145
9.1.1	Strengths	145
9.1.2	Limitations.....	148

9.2	Recognising frequent users of crisis helplines as legitimate callers	150
9.2.1	Implications to the operation of Lifeline	153
9.2.2	Opportunities for future research.....	154
9.3	Conclusion	156
	References	159
	Appendices	181
	Appendix 1: Literature search criteria used to identify the empirical studies that investigated frequent users of crisis helplines	183
	Appendix 2: Systematic review PDF.....	187
	Appendix 3: Ethics approval to undertake Study 1 and Study 2	199
	Appendix 4: Study 1 – Screener for survey of Lifeline callers	203
	Appendix 5: Study 1 – Survey of Lifeline callers	207
	Appendix 6: Study 2 – Interview schedule with Lifeline frequent users	211
	Appendix 7: Study 2 – Detailed characteristics of interview participants	215
	Appendix 8: Study 3 – List of explanatory measures taken from the diamond study outlining how they were coded and the time points they were measured	219
	Appendix 9: Study 3 – diamond surveys.....	223

List of Tables

Table 1: Similarities and differences between the Samaritans, Los Angeles Suicide Prevention Centre, and Lifeline.....	22
Table 2: Overview of the empirical studies reporting on frequent users of crisis helplines	50
Table 3: The number of calls and callers by call frequency in those studies where sufficient information was provided.....	59
Table 4: Phases of thematic analysis	72
Table 5: Distinction between the role of the counsellor and the research interviewer for data collection purposes.....	80
Table 6: Comparison of the setting, study population, research question and methods of the three empirical studies	134

List of Figures

Figure 1: Chronological evolution of the telephone with crisis helpline	34
Figure 2: Lifeline Crisis Support Practice Model.....	41
Figure 3: Visual overview of the three empirical studies.....	76
Figure 4: Recruitment of participants for Study 1 and Study 2.....	78
Figure 5: Recruitment of Study 2 participants	85
Figure 6: Study 3 response rate over the first 12-months of follow up	89

List of Abbreviations

CATI	Computer Assisted Telephone Interviewing
<i>diamond</i>	Diagnosis, Management, and Outcomes of Depression in Primary Care
GP	General Practitioner
IFOTES	International Federation of Telephone Emergency Services
Lifeline	Lifeline Australia (13 11 14), 24-hour telephone crisis helpline
NMHW	National Mental Health and Wellbeing survey conducted in Australia in 2007
RI	Research Interviewer
TCS	Telephone Crisis Support
UK	United Kingdom
USA	United States of America

1

Introduction

Crisis helplines were established in the 1950s to provide immediate, one-off crisis support. They continue to receive a disproportionate number of calls from frequent users, a group of callers who make multiple calls over an extended period of time. Frequent users challenge the crisis helpline service model with their repeated use and little is known about why they call. The aim of this thesis was to investigate the socio-demographic characteristics of frequent users of crisis helplines and the factors driving their use. This chapter provides the background into why research into frequent users of crisis helplines is needed. It begins by describing the development of crisis helplines over the last 60 years and highlights the intended nature of the support offered by these services. Frequent users have long been identified as a group of callers to crisis helplines and it has been assumed that they are isolated individuals calling about non-crisis related issues. This assumption has never been investigated. Research in this area is needed as service providers have finite resources and struggle in responding to frequent users while maintaining contact with other callers. An exploration of the needs of frequent users would benefit from an evidence-based approach.

1.1 Study context

This section provides the background into why research into frequent users of crisis helplines is needed. It begins by outlining three independent crisis helplines that were established more than 60 years ago in the United Kingdom (UK), the United States of America (USA), and Australia. The structures of these services are described, which formed the foundation of the crisis helpline service model that has since been adopted around the world. Frequent users have been identified by many of these services. Limited research has been undertaken into frequent

users of crisis helplines and further investigation is needed into their socio-demographic characteristics and the factors driving their use.

1.1.1 The establishment of crisis helplines

Crisis helplines were established at a time when suicide prevention was considered to be the role of psychiatric services (Hvidt, Ploug, & Holm, 2016; Taylor, Kingdon, & Jenkins, 1997). Knowledge about suicidal behaviour was minimal and stigma surrounding the issue made it difficult for people to seek help (World Health Organisation, 2014). When people did reach out, limited understanding existed around the support they needed (Mann et al., 2005). As recognition of the global importance of suicide increased, suicide prevention became a broader public health challenge (Hawton, 2014). Non-psychiatric services became interested in seeing how they could contribute to reducing suicide rates (Hvidt et al., 2016; World Health Organisation, 2012). Crisis helplines were one such solution. There is still much to be learned about suicide prevention but crisis helplines have come to be considered to have a role in suicide prevention (World Health Organisation, 2014).

The first crisis helpline was established in the 1950s out of a church in central London. Reverend Chad Varah, an Anglican minister, wanted to understand why three people were dying by suicide each day (Varah, 1988). He hoped to speak to people who had suicidal tendencies but realised the difficulties in identifying people who engaged in suicidal behaviours (Varah, 1988). Instead, he created a widely publicised service that was accessible, day and night, to people considering suicide (Varah, 1988). Known as “*The Samaritans*”, this service became internationally recognised as the first 24-hour suicide prevention helpline (Lester, 2000). After the Samaritans branch opened in London in 1953, additional branches opened across the UK (Fox, 1962). In the ten years after the establishment of the Samaritans, similar, yet, independent helplines were established in the USA and Australia. Similar to the Samaritans, these new services were designed to provide an immediate response to anyone experiencing a personal crisis (Lester, 2000). The USA-based helpline was established in 1958 by a group of mental health professionals working at a Los Angeles hospital (Shneidman, Farberow, & Litman, 1994). Known as the Los Angeles Suicide Prevention Centre, this helpline had a focus on helping people in a suicide crisis (Shneidman et al., 1994). In contrast, the Australian helpline opened in 1963 in Sydney by Sir Alan Walker, a Methodist minister (Walker, 1967). Known as Lifeline, this service was focused more broadly on supporting

people experiencing emotional crises, which may have included suicidal behaviours (Walker, 1967). Lifeline grew to become one of Australia's national 24-hour crisis helplines (Barber, Blackman, Talbot, & Saebel, 2004). Together with the Samaritans, the Los Angeles Suicide Prevention Centre and Lifeline are considered the early international helpline organisations to operate in English-speaking countries (Lester, 2000). These three services are referred throughout the thesis as the "early" crisis helplines. The International Federation of Telephone Emergency Services (IFOTES) was established in Europe around the same time as these early crisis helplines, however this organisation is considered outside the scope of this thesis.

A central component of the early helpline services was their ability to reach out to people with the greatest need. These helplines evolved out of a need for services that were immediately available to people at risk of suicide (Rosenbaum & Calhoun, 1977). Independently, the founders established a telephone based service that could reach people engaging in suicidal behaviours (Hvidt et al., 2016). To maximise the reach, these services were designed to immediately respond to a wide spectrum of callers (Dew, Bromet, Brent, & Greenhouse, 1987); be available 24-hours a day (Coman, Burrows, & Evans, 2001); be accessible without a referral from other services (Coveney, Pollock, Armstrong, & Moore, 2012); and provide a service at minimal or no cost to users (Coman et al., 2001). These features formed the foundation of the crisis helpline service model.

Shortly after the early crisis helplines were established, similar services emerged around the world. Some of the new services were branches of the early helplines; yet, many new independent services. These services offered support that was similar to Lifeline in that it addressed a range of emotional issues rather than just suicide prevention. For example, some of these services focused on supporting people experiencing depression, eating disorders, and substance abuse (Leach & Christensen, 2006).

Crisis helplines now operate around the world in different forms, each with their own focus. They operate as independent services or as part of various health and mental healthcare services (Mishara & Daigle, 2001). In Australia alone, there are over 115 crisis helplines (Urbis Keys Young, 2002). These services are referred to by a range of names, as illustrated in Box 1; however, the term *crisis helpline* is used throughout this thesis.

The ability of crisis helplines to identify individuals at imminent risk of suicidal behaviour and offer support during that moment of crisis remains a primary focus of these services (Gould et al., 2016). They have gained international recognition for their contribution in supporting people during suicidal crises (World Health Organisation, 2014). The proportion of callers to crisis helplines reporting a

Box 1: Other names for “*crisis helplines*”

Crisis (help)line
Crisis support service
Helpline
Suicide prevention centre
Crisis intervention service
Emergency telephone advisory
Hotline
Telephone helpline

suicidal crisis varies from service to service, but has been estimated in the United States to be between 3% and 57% (Ramchand et al., 2016). Counsellor’s compliance of enquiring about suicidal behaviours varies widely, which contributes to the difficulty of identifying the precise number of callers reporting a suicidal crisis (Ramchand et al., 2016).

1.1.2 The structure of crisis helplines

Crisis helplines were initially intended to provide one-off support to people in an acute crisis. They were designed to address a need for services that were accessible to people in need. The support offered by crisis helplines focused on addressing the individual’s immediate crisis but was offered differently by each service. Service providers were primarily concerned about alleviating the caller’s immediate distress, strengthening their personal coping strategies, and providing pathways through which they could access other services (Barber et al., 2004; Kalafat, Gould, Munfakh, & Kleinman, 2007). The delivery of this support varied between services and ranged from a non-directive active listening approach (Varah, 1988) through to a directive approach where strategies and advice were offered to the caller (Mishara et al., 2007). Evidence indicates that each of these approaches may led to different outcomes, with an empathetic and collaborative problem solving approach thought to lead to greater reductions in an individual’s suicidal thoughts (Mishara et al., 2007).

From early on, crisis helplines were staffed by volunteers who lacked formal mental health training. Initially, Varah operated the Samaritans with the assistance of a single secretary but quickly found it difficult to respond to the demand (Varah, 1988). He noticed that most of the callers did not require in-depth mental health treatment but rather needed an empathetic ear (Varah, 1988). This prompted him to hand over the responsibility of answering calls to a group of trained, lay volunteers, within a year of establishing the helpline and took on a more

consultative role himself (Varah, 1988). He minimized staffing costs by using volunteers to answer calls, which was important as the service relied on funding from external donors and resources were limited (Varah, 1988). A similar approach was adopted by the founders of the Los Angeles Suicide Prevention Centre and Lifeline, in that lay volunteers were also trained to answer calls (Litman, Farberow, Shneidman, Heilig, & Kramer, 1965; Walker, 1967). These services were still supported by mental health professionals, who acted as consultants rather than directly answering the phones (Hvidt et al., 2016). While the use of volunteers has continued to be a core component of the crisis helpline service model, some services have employed paid professionals in recent years (Lifeline Australia, 2015a). Around the world, crisis helplines are now staffed by a variety of paid professionals, unpaid professionals, trained volunteers, and lay volunteers (Bassilios, Harris, Middleton, Gunn, & Pirkis, 2015; Kalafat et al., 2007). Each helpline has their own protocol for who can answer calls and refers to them by different names; for example, Lifeline refers to these individuals as Telephone Crisis Supporter (TCS). For ease of reference the term *counsellor* is used throughout this thesis.

The crisis helpline service model was also designed to respond to the needs of the caller without placing any restrictions on their use. Callers could call about their own issue or on behalf of another person (Farberow et al., 1966). There was no distinction to what may constitute a “crisis”, which could differ from person-to-person. Rather, service providers were of the view that if an individual made the effort to call they were considered to be in a crisis (Rosenbaum & Calhoun, 1977), regardless of whether the counsellor perceived it as a “crisis”. This approach raised concerns among counsellors who found they were continually talking to callers who did not appear to be in an immediate crisis (Imboden, 1980; Tarran, 1982). Instead, these callers were seen to be isolated and calling about non-crisis related issues (Tarran, 1982). Many of these “isolated individuals” would call multiple times over an extended period of time (Haywood, 1980). Often known as frequent users, the calls made by these users were sometimes perceived by service providers and counsellors as an inappropriate use of the service.

1.1.3 Frequent users of crisis helplines

Service providers have struggled with the issue of frequent users over the last 50 years and remain unclear about who these callers are. The first study on frequent users, published in 1964, described these users as confused, intoxicated, psychotic, and chronically suicidal individuals

who could absorb the counsellor's time if permitted (Litman et al., 1965). Since this first study, 18 additional studies have empirically investigated frequent users of crisis helplines. A variety of terms were used to refer to this group of callers, including frequent (Leuthe & O'Connor, 1980), regular (Coveney et al., 2012), chronic (Imboden, 1980) or repeat (Kinzel & Nanson, 2000); the term *frequent user* is used throughout this thesis. The precise number of calls made by frequent users is unclear as definitions vary. As an example, Spittal et al. (2015) found that 60% of calls to Lifeline were made by 3% of callers who called more than 20 times in a month. This equated to 247,547 of the 411,725 calls analysed over an 18-month period (Spittal et al., 2015). Other types of callers have also been identified that present challenges for crisis helplines, notably unwelcome callers, who accounted for nearly 2% of calls to Lifeline (Spittal et al., 2015). The observation that a small number of people account for a large proportion of calls has been documented in the UK, the USA, and Australia (Litman et al., 1965; Watson, McDonald, & Pearce, 2006) and highlight the need for the proposed doctoral research.

Frequent users challenge the crisis helpline service model with their repeated calls. Firstly, their nature of the calls was considered problematic as they were seen to only be calling about non-crisis related issues (Tarran, 1982). Crisis helplines were never intended to provide ongoing general support (Kinzel & Nanson, 2000). Furthermore, crisis helplines have finite resources, which make it difficult for these services to answer all of the calls they receive. For example, in 2015 the average call answer rate for Lifeline was 85% (Lifeline Australia, 2015a). Concern exists among service providers that by responding to frequent users, calls from people in an immediate crisis may be left unanswered (Watson et al., 2006). Secondly, counsellors have often expressed feelings of frustration in their attempts to respond to frequent users (Greer, 1976) and find themselves providing the similar responses over multiple calls (Kinzel & Nanson, 2000). This may leave counsellors feeling ineffective as they do not see any progress in the issues presented by frequent users (Kinzel & Nanson, 2000) and in many cases may lead to counsellor burnout (Cyr & Dowrick, 1991).

Crisis helplines have considered different ways to respond to frequent users, which includes restricting the number and length of the calls frequent users can make to the crisis helpline (Barmann, 1980; Hall & Schlosar, 1995). These approaches were developed without empirical research and little evidence exists to support their effectiveness in addressing the needs of frequent users. Furthermore, there has been no research into whether any of these approaches

may trigger a further crisis (Haywood, 1980). Instead, counsellors have responded to frequent users in an ad hoc manner. The use of crisis helplines by frequent users would benefit from evidence-based research that considers their specific needs.

Most of the research into frequent users of crisis helplines is dated and lacks rigor. There are 19 studies that have investigated frequent users of crisis helplines. Most of these studies were conducted before 2000 and nearly half were based in the USA. It is acknowledged that the characteristics of callers may differ between services and countries (Lester, 2000). An inconsistent definition of frequent use was employed across the 19 studies, and in the majority of cases categorised frequent users as calling more than once. It is expected that people may call back at least once after their initial call (Gould, Kalafat, Harris Munfakh, & Kleinman, 2007) and thus such a definition may not accurately represent frequent users (Johnson & Barry, 1978). Furthermore, the type of study impacted on the quality of findings, with studies being of two kinds: audits and purpose-designed surveys. The audits were often a review of routinely collected call data, allowing for a large sample of callers to be examined, but limited the type of data available for analysis. In contrast, a wider range of variables were examined in the purpose-designed surveys, however the sample size in these studies was often smaller. The number of frequent users investigated in most studies was less than 100, irrespective of the type of study. The variation in study design brings into question the representativeness of the findings across different services. More up-to-date and rigorous research into frequent users of crisis helplines is needed.

The socio-demographic characteristics of frequent users in an Australian setting requires clarification. Research into frequent users of crisis helplines has explored differences in the age, alcohol and/or drug use, employment status, ethnicity, living arrangements, physical illness, and marital status of frequent users compared with other callers. However, these variables were inconsistently investigated and findings varied across studies, irrespective of the methodology used, definition employed, time-period, or setting. Furthermore, only four of the 19 studies were conducted in an Australian setting.

Clarification is also needed around the reasons frequent users call crisis helplines. Most research has investigated frequent users' reasons for calling by examining at the problems raised during their call. The findings from these studies were inconclusive, some reported that frequent users called to discuss issues related to social support (Burgess, Christensen, Leach,

Farrer, & Griffiths, 2008; Watson et al., 2006), whereas, other studies reported that frequent users called about mental health issues (Bassilios et al., 2015; Burgess et al., 2008; Coveney et al., 2012; Ingram et al., 2008; Spittal et al., 2015). Furthermore, these issues were often not examined in the same study. In terms of mental health issues, depression and anxiety were reported as the most common mental health issues experienced by frequent users (Bassilios et al., 2015; Burgess et al., 2008; Kalafat et al., 2007; Mishara & Daigle, 1997), arguably at rates higher than other callers. Frequent users were just as likely as other callers to engage in suicidal behaviours (Bassilios et al., 2015; Lester & Brockopp, 1970; Mishara & Daigle, 1997; Sawyer & Jameton, 1979; Spittal et al., 2015). From the current research, it remains unclear whether frequent users are more likely to call crisis helplines about issues related to social support or mental health issues and which mental health issues were experiencing.

The health service use of frequent users is also poorly understood. It is widely viewed that frequent use of crisis helplines is a result of poor access to healthcare services (Gould et al., 2007; Kalafat et al., 2007). Although, the empirical research did not support this view but reported that frequent users visited healthcare services in addition to calling crisis helplines (Bassilios et al., 2015; Burgess et al., 2008; Farberow et al., 1966; Greer, 1976; Lester & Brockopp, 1970; Sawyer & Jameton, 1979). Bassilios et al. (2015) investigated callers' health service use and found that in an Australian population, frequent users were more likely to visit a GP for emotional wellbeing compared with other callers. Bassilios et al. (2015) was unable to investigate what happened in these visits and whether these individuals called the helplines because their needs were not adequately met by the GP. The health service use patterns of frequent users' needs to be understood to determine whether their use of crisis helplines is a result of unmet need.

1.2 Problem statement

Crisis helplines were established over 60 years ago to provide immediate one-off crisis support to anyone in need. However, a disproportionate number of calls come from frequent users. These users were first identified in 1963 and were categorised as making multiple calls over an extended period of time. Frequent users challenge the crisis helpline service model with their repeated use and service providers struggle in knowing how to best respond to frequent users while addressing the needs of other callers. It has long been assumed that frequent users are

isolated individuals calling about non-crisis related issues. There are concerns that the finite resources available to crisis helplines may mean that calls made by one-off callers, assumed to be in an immediate crisis, are missed while the counsellor responds to frequent users. Furthermore, feelings of frustration have been expressed by counsellors in their attempts to respond to the recurring issues experienced by frequent users. Service providers have called for an evidence-based approach that takes into consideration the needs of frequent users, yet, the current research is of highly variable quality with inconsistent findings across studies. Most of this research is dated and lacks rigor.

Further investigation into frequent users of crisis helplines is required. Research gaps relate to: (1) the uncertainty around the characteristics of frequent users of crisis helplines in an Australian setting; (2) the lack of clarity around the reasons for frequent users' calls to crisis helplines and whether the assumption that these users call for non-crisis related support is accurate; and, (3) not understanding the health services accessed by frequent users and whether their use of crisis helplines is a result of unmet need. Once these research gaps are addressed, an evidence-based approach could be developed that considers the specific needs of frequent users.

1.3 Aim and scope

The aim of this thesis is to investigate the socio-demographic characteristics of frequent users of crisis helplines and the factors driving their frequent use. It will primarily seek to address the three research gaps identified in the literature on frequent users of crisis helplines.

The focus of this thesis is limited to crisis helplines, targeted at the adult population for generalised emotional support, which includes suicide prevention. This is opposed to other services, which may offer a telephone helpline component but are primarily focused on a specialised population, for example, young people or a specific health issue. Over 100 crisis helplines operate in Australia; however, this thesis primarily focuses on Lifeline, which is recognised as one of Australia's largest national 24-hour crisis helpline services. The Samaritans in the UK and the Los Angeles Suicide Prevention Centre in the USA are mentioned throughout, which along with Lifeline are recognised internationally as the early crisis helpline organisations across English-speaking countries. The similarities and differences of these two

crisis helplines are explored in relation to Lifeline with the intention of understanding the generalisability of the findings from this thesis to other services.

The investigation into frequent users of crisis helplines in this thesis was limited to those callers who made multiple calls and were thought to be calling for non-crisis related support. Currently no universal definition of frequent use exists and the definition varies between studies. In most studies, frequent users were not accurately distinguished from other callers. Lifeline's current operational definition was used throughout this thesis to identify frequent users (i.e., those people who called the helpline 20 times or more in a month). This approach was taken to give relevance of the findings to Lifeline. This definition was also used in the study by Spittal et al. (2015). In the event that the data available for analysis prevented such a definition from being used, the most comparable definition was chosen.

Callers who rang the crisis helpline regularly but categorised as unwelcome callers were excluded from this research. These callers include people who call for sexual gratification (known as "masturbators") and may have a history of becoming abusive. The nature of these calls can be confronting for counsellors. Even though unwelcome callers may also call regularly, they were considered beyond the scope of this thesis. The nature of how these callers use crisis helplines would require a different type of study and it was therefore decided to exclude "unwelcome" callers from this study.

1.4 Significance of the study

This thesis presents the first mixed method investigation of the socio-demographic characteristics of frequent users and the factors driving their use in an Australian population of callers to crisis helplines. The majority of the previous research into frequent users was conducted before 2000 and reported on crisis helplines based in the USA. The findings from these studies were inconsistent and their relevance to an Australian context is unclear. In contrast, a contemporary approach was taken in this thesis to look at the issue of frequent users of crisis helplines and drew on data from multiple sources. A convergent mixed method approach (Fetters, Curry, & Creswell, 2013) was used to bring together the findings during the interpretation phase. The implications of these findings, in light of previous research, are that frequent users have a genuine need for support, yet they use crisis helplines in a manner that is

different from their intended use. Service providers may benefit from recognising frequent users as legitimate callers.

1.5 Thesis overview

Chapter 1 provides an overview of the need for research into frequent users of crisis helplines. Chapter 2 explores the development of crisis helplines over the last 60 years. It begins by describing the three independent helplines that were established in the 1950s and 1960s. These services all shared similar components, which became the foundation of the crisis helpline service model now implemented around the world. The factors that led to the rapid expansion of crisis helplines in the 1960s are explained. This chapter concludes with an exploration of crisis helplines in Australia and identifies Lifeline as one of the more widely used crisis helpline services.

Chapter 3 presents an overview of the literature published on frequent users of crisis helplines. It begins with a summary of how frequent users are described in the literature. A brief overview is presented of the 19 studies that have empirically investigated frequent users of crisis helplines. The findings from these studies are summarised under the headings: socio-demographic characteristics, reasons for calling, and health service use. The chapter concludes with outlining three research gaps that still need to be addressed.

Chapter 4 provides an overview of the methods used to conduct the empirical research of this thesis. This chapter begins by restating the thesis aim and the three research questions developed to address the research gaps. Three empirical studies were undertaken as part of this thesis. Study 1 was a brief survey completed by callers to Lifeline at the end of their call and investigated the socio-demographic profile of frequent users and differences in their reasons for calling compared with other callers. Study 2 was an in-depth interview study conducted with a sub-group of Lifeline callers who completed the brief survey (Study 1) and sought to understand why some users may call crisis helplines frequently. Study 3 analysed data from the *diamond* study, a longitudinal cohort of general practice attendees with depressive symptoms, to examine the relationship between frequent use of crisis helplines and health service use patterns over time. The findings from these studies were brought together during the interpretation phase using a convergent mixed methods approach. The three studies are

presented in Chapters 5 to 7. These studies were all prepared as journal manuscripts and have been accepted for publication in peer-reviewed journals. The published version of these manuscripts is included in the relevant chapter.

Chapter 5 presents Study 1, a survey completed by 315 callers to Lifeline at the end of their call between February and July 2015. Survey participants reported on reasons for their current call, the number of times they called Lifeline in the past month and their socio-demographic characteristics. Participants were categorised as frequent, episodic, and one-off users. The socio-demographic profile of frequent users and differences in their reasons for calling compared with other callers was investigated using ordered logistic regression. Included in this chapter is the manuscript: *How do frequent users of crisis helplines differ from other callers regarding their reasons for calling?*, which has been published in *Health and Social Care in the Community*.

Chapter 6 presents Study 2, an in-depth interview study conducted with 19 callers to Lifeline who completed the brief survey (Study 1) and reported calling Lifeline 20 times or more in the past month. Semi-structured interviews were undertaken with callers to explore in more detail why some users may call crisis helplines frequently. Inductive thematic analysis was used to examine the interview data. The manuscript *The experiences of frequent users of crisis helplines: A qualitative interview study*, published in *Patient Education and Counselling* is included in this chapter.

Chapter 7 presents Study 3, secondary analysis of data from the *diamond* study, a longitudinal cohort of 789 general practice attendees with depressive symptoms. Using ordered logistic regression, this study sought to examine the relationship between frequent use of crisis helplines and health service use patterns over time. The results from this study were presented in the manuscript: *The health service use of frequent users of telephone helplines in a cohort of general practice attendees with depressive symptoms*, published in *Administration and Policy in Mental Health and Mental Health Services Research*.

Chapter 8 uses a convergent mixed method approach to bring together the findings from the three studies presented in Chapters 5 to 7. This chapter begins with a summary of the main findings in relation to how they address the research questions outlined in Chapter 4. Building on what is already known about frequent users of crisis helplines, the findings from this thesis

confirm that frequent users have a genuine need for support, but their needs and reasons for calling differ to what service providers initially intended crisis helplines to address. The chapter concludes with a review of what constitutes a convergent mixed method approach and the strengths and weaknesses of using this methodological approach, specific to this research.

Chapter 9 discusses the significance of the findings in terms of addressing the issue of frequent users of crisis helplines. It begins with a discussion of the strengths and limitations of the methods. The implications of the finding that service providers may benefit from recognising frequent users as legitimate service users are explored, particularly in relation to the operation of Lifeline and opportunities for future research. This chapter concludes with a summary of the thesis.

2

The evolution of crisis helplines

To appreciate the significance of the challenges presented by frequent users of crisis helplines, it is important to understand the evolution of these services over the last 60 years and the contribution that crisis intervention theory had to their growth. This chapter begins by providing more information into the establishment of the early crisis helplines across three separate continents that. These services were designed to offer short-term support, involved counsellors who were often volunteers without professional mental health training, and allowed for the caller to end the call at any point. The number of crisis helplines rapidly expanded from the 1960s onwards around the world and this growth has been attributed to increasing in demand from the community, the introduction of crisis intervention theory, and technological advancements. This growth occurred without evidence demonstrating their effectiveness in reducing suicide rates. This chapter concludes with an overview of crisis helplines in Australia and identifies Lifeline as one of the largest national crisis helpline services.

2.1 The early crisis helplines

Crisis helplines were established to provide an immediate, short-term response to people in an acute crisis. Initially, three independent helplines were established across three continents: the Samaritans in the UK, the Los Angeles Suicide Prevention Centre in the USA, and Lifeline in Australia. Despite being independent, these helplines shared the goal of providing short-term immediate crisis support over the telephone. The nature of the support varied as a result of the different professional qualifications of the founders. Both the UK and Australian helplines were established by Christian ministers and offered non-directive support. In contrast, the USA helpline was established by three mental health professionals and offered direct advice and suggestions. These services are outlined below.

2.1.1 The Samaritans, United Kingdom

As already mentioned in Section 1.1.1, the Samaritans was the first crisis helpline, established in a church in central London. The idea for this service was inspired by London's '999' emergency service, which began in 1937 and allowed people in London to call an "easy to remember number" during an emergency and automatically be put through to police, ambulance, or fire services (Holland, 2010). No such service existed for people in a suicidal crisis, which Reverend Chad Varah felt required a similar response to the emergency services (Varah, 1992). Varah considered himself to be the most appropriate person to operate such a service as he had been providing counselling through the Church since 1935 (Varah, 1988). After sharing his idea with the Church leaders, Varah moved to a church in central London with minimal ministerial duties and dedicated his time to the suicide prevention service (Fox, 1962).

The service began on 2 November 1953 with a telephone helpline and drop-in centre (Varah, 1988). It was advertised in the papers, and journalists coined the name "*the Samaritans*" (Varah, 1988). Even though Varah was a Christian minister, the service was promoted as being non-denominational to ensure it remained accessible to the entire population regardless of religious beliefs (Varah, 1988). A secretary was employed to assist with the expected workload; however, within a year this two-person team found it difficult to respond to the growing demand (Varah, 1988). It was at this point that Varah brought on a group of volunteers to help make the clients comfortable while they waited for their appointment. It quickly became apparent that many of these clients would feel better and leave before their appointment (Varah, 1992). Varah attributed improvements to the clients mood as a result of having an opportunity to talk to someone who listened empathetically (Lester, 2000). In fact, Varah estimated that in the first year only 12% of people who used the service required formal counselling (Varah, 1992). The other individuals were looking for someone with whom they could share their distress (Varah, 1992).

On reflection of the first year of operation, Varah changed the structure of the service. With the success of the volunteers and the lack of serious mental health issues among clients, volunteers were placed in charge of answering the phones from 2 February 1954 (Lester, 2000). Varah continued to oversee the operation of the helpline and recruited the volunteers; yet, he was no longer directly involved with clients. His focus shifted towards formally creating a

voluntary-based organisation where people without professional qualifications, but with an empathetic nature, were trained to support people at risk of suicide over the telephone (Fox, 1962). The support offered by the service was meant to assist the caller to move beyond their current crisis and give them the confidence to access appropriate services in their community (Fox, 1962). Underpinning the service model was a primary focus on suicide prevention. The responsibility of the call remained with the caller and was referred to as “self-determination” (Pollock et al., 2010). For this reason, Varah considered it inappropriate for the volunteers to instruct callers on how to act on their suicidal thoughts (Varah, 1988). Rather, the volunteers were trained to “befriend” the caller and provide confidential and non-judgemental support (Samaritans, 2016a). Offering non-directive support became synonymous with the Samaritans model of care, which remains a distinguishing feature of the helpline today from other services (Pollock, Armstrong, Coveney, & Moore, 2010).

2.1.2 Los Angeles Suicide Prevention Centre, USA

The Los Angeles Suicide Prevention Centre was co-founded in 1958 by Edwin Shneidman, Norman Farberow, and Robert Litman (Litman, Shneidman, & Farberow, 1961). Before establishing the Los Angeles Suicide Prevention Centre, these three clinically trained mental health researchers were involved in investigating suicides across the Los Angeles County over a ten-year period (Shneidman & Farberow, 1956). Their research focused on understanding the psychological factors that may contribute to suicide by analysing data from psychiatric case histories, psychological test results, suicide notes, and health service use (Shneidman & Farberow, 1956). This work concluded that *“calling upon professional psychiatric, psychological, and social service specialists for the treatment of a potentially suicidal person may mean the difference between life and death”* (Shneidman & Farberow, 1956, p. 114). However, they did not identify any agencies that provided an immediate response to someone in a suicidal crisis (Farberow & Shneidman, 1961).

Based on these findings, the Suicide Prevention Centre was established at the Los Angeles County Hospital. This centre was designed to evaluate and refer hospital patients when they were discharge after a suicide attempt (Shneidman et al., 1994). Initially, the centre was available from 9:00am to 5:00pm, Monday to Friday, staffed by physicians, psychologists, social workers, and nurses (Litman et al., 1961). It was intended to act as the pilot for similar services to be established across the USA. Specifically, the goals of the Suicide Prevention

Centre were to: 1) demonstrate the relationship between a Suicide Prevention Centre and other community mental health agencies; 2) serve as a pilot project for other communities interested in establishing a suicide prevention program; and 3) collect hitherto unobtainable research data on the etiology, meaning, and prevention of self-destruction (Litman et al., 1961). A telephone helpline component was not initially included (McGee, 1974).

The Suicide Prevention Centre evolved into a telephone service after people began making contact outside of business hours. Despite being established as a discharge service, staff at the Suicide Prevention Centre noticed a high volume of calls were coming from people engaging in suicidal behaviours in the community (McGee, 1974). Most of these calls were in the evening (Litman et al., 1965). Staff felt they could no longer ignore these calls so, in April 1963 the model of care was redesigned to include a telephone crisis helpline component (Farberow et al., 1966). This helpline was available 24-hours a day and available to the entire population (Litman et al., 1965). There were no restrictions on what the caller could speak about (Shneidman et al., 1994). The helpline offered counselling support and referrals to community services (Shneidman et al., 1994), which was intended to act as an immediate resolution to individuals in crisis and operate as part of a network of community resources (Litman et al., 1965). The support was directive and offered a collaborative problem-solving approach between the counsellor and caller (Litman et al., 1965). Initially, mental health professionals were resistant to providing crisis support over the telephone; yet, the popularity of the service demonstrated the benefits of using the telephone to enable desperate people to readily seek help that may otherwise be unavailable (Shneidman et al., 1994).

The redesign of the Suicide Prevention Centre raised concerns about how to staff the helpline without requiring additional funds. When the centre began operating outside of business hours, it was difficult to find clinicians who were willing to work throughout the night (Shneidman et al., 1994). Even if the staff were available, the costs were too high (Farberow et al., 1966). Instead, alternative ways to staff the helpline were considered (Farberow et al., 1966). As the Samaritans had already successfully moved to a model where volunteers staffed the helpline, a similar approach was trialled. After the careful selection, training, and close supervision of a group of non-professional volunteers, this approach was adopted by the Suicide Prevention Centre (Lester, 2000; Shneidman et al., 1994). Many of the volunteers were students

completing a mental health related training who were yet to obtain their formal qualifications (Litman et al., 1965).

2.1.3 Lifeline, Australia

Lifeline was established as an independent service in 1963. As mentioned in Section 1.1.1, Lifeline was founded by Reverend Dr. Sir Alan Walker, a Methodist minister, in Sydney (Lifeline Australia, 2015b). A public announcement was made in the Sydney Morning Herald before the centre opened where Walker shared his vision for a new service and the name “*Telephone Life Line*” was coined (Henderson, 1981). The first call was answered on 16 March 1963 (Henderson, 1981) and from the outset, Lifeline operated as a 24-hour telephone helpline. It was staffed by lay volunteers, trained to support anyone experiencing an emotional crisis (Walker, 1967). The helpline was available to the whole community. Lifeline was established differently to the Samaritans and the Los Angeles Suicide Prevention Centre, with the differences explored below.

In 1958, Alan Walker was appointed the minister of the Sydney Central Methodist Mission. As part of his ministry duties, Walker was to enhance the church’s presence in providing institutional care in the community (Henderson, 1981). In his first ten years of leadership, Walker made several contributions towards community-related activities, one of which was the establishment of Lifeline, Sydney’s first 24-hour emergency counselling service (Henderson, 1981). This service was part of his greater vision to create an organisation that could meet human need, known as “*The Mantle of Christ*” (Walker, 1967). In particular, Walker wanted to establish an organisation that responded to the issues faced by people living in the city, which he often attributed to loneliness (Henderson, 1981). He had noticed through his ministerial work that people were moving away from the church and had nowhere to turn for help when faced with emotional, psychological, financial, and spiritual issues (Walker, 1967). Despite many of these people arriving at the central Methodist mission in times of need, Walker felt it would be more appropriate if they could reach out for help from their own familiar environment (Walker, 1967). He identified that people living in the bush were able to access medical support through the Royal Flying Doctor Service (Royal Flying Doctor Service, 2016). This service was established in 1928 by Dr John Flynn as a “*Mantle of Safety*” for people in rural Australia (Walker, 1967) and provided aeromedical support across large distances. Walker adapted this

concept for an urban setting and thus conceptualised the “*Mantle of Christ*”, which included a crisis helpline component.

From the outset, Lifeline differed to the other crisis helplines as the intention was to offer support for a broad range of issues. Instead of solely focusing on suicide prevention, Walker hoped to meet the needs of individuals before they reached the point of crisis (Wight, 1997). He intended to provide support for matters related to mental health issues, marriage guidance, financial assistance, and spiritual issues (Walker, 1967). He was of the view that if these issues were not addressed then an individual could enter into a crisis state (Walker, 1967). A strong Christian philosophy underpinned the support offered by Lifeline (Walker, 1967). This was most evident in the underlying pro-life philosophy of the service, which saw counsellors being trained to guide callers away from engaging in any life threatening behaviours (Walker, 1967). Walker drew on religious insights to understand how to respond to human need (Henderson, 1981). This strong Christian philosophy was strikingly different from the Samaritans where the support was intended to be non-denominational and maintain the self-determination of callers. Varah (1988) described Lifeline as a “*rival concept in the antipodes*” (p. 20) that deliberately went against his view on the underlying principles of such a service. These services remain independent of each other.

The selection of Lifeline counsellors differed to the other helplines in that Walker only recruited volunteers from among members of a Christian congregation (Walker, 1967). This criterion was used to ensure the counsellors only offered support that was firmly based in Christian beliefs (Walker, 1967). A group of volunteers were recruited and trained by Walker over a period of nine months before the helpline officially opened (Walker, 1967).

2.1.4 A comparison of the early crisis helplines

The similarities and differences between the early crisis helplines are presented in Table 1. It is important to understand the differences between these services as they represent the three early helpline organisations in English-speaking countries.

The Samaritans, Los Angeles Suicide Prevention Centre, and Lifeline were established within ten years of one another across three separate continents. The formation of these helplines was largely dependent on the founders’ professional interests. As already mentioned, the Samaritans and Lifeline were founded by Christian ministers and the Los Angeles Suicide

Prevention Centre was founded by three mental health researchers. These individuals had different views on the type of support to be offered. In particular, the two Christian-based helplines took a non-directive approach by offering active listening. The Samaritans had a strong focus on befriending while Lifeline had a large Christian focus. In contrast, the American helpline was more directive and offered specific advice and suggestions to callers. Also the primary focus of the services differed, in that support offered by the Samaritans and the Los Angeles Suicide Prevention Centre was primarily focused on suicide prevention, whereas Lifeline had a broader focus on providing emotional support, which included suicide prevention. Another difference between these services was their primary function; namely, the two Christian helplines were established to provide a service to the community; whereas, the American helpline was intended to act as a pilot site for future crisis support services to be established across the USA. The different functions of these services had implications on the information collected on callers. From the outset, the American helpline kept comprehensive records of all of the calls received (Litman et al., 1961) while similar data were not collected by the Samaritans or Lifeline. The difference in the data collected is one reason why the majority of empirical research on crisis helplines has originated from the USA.

Despite these differences, three similar components were identified across the services: (1) they were all designed to provide short-term or one-off support to callers; (2) they were staffed by volunteers who did not have any professional mental health training; and (3) they had a strong emphasis on ensuring callers' autonomy was maintained throughout the encounter. These components form the foundation of the crisis helpline service model, which is explored in more detail in Section 2.3.

Table 1: Similarities and differences between the Samaritans, Los Angeles Suicide Prevention Centre, and Lifeline

	The Samaritans	Los Angeles Suicide Prevention Centre	Lifeline
First established	1953	1958	1963
Country of origin	United Kingdom	United States of America	Australia
Founders' professional background	Anglican minister	Clinical psychiatrists and psychologists	Methodist minister
Primary function	Service provision	Pilot site for future services	Service provision
Focus	Suicide prevention	Suicide prevention	Emotional support
Nature of support	Befriending (final decision left to the caller)	Directive and collaborative problem solving	Active listening (pro-life)
Duration of support	Short-term/one-off	Short-term/one-off	Short-term/one-off
Staffed by	Volunteers	Volunteers	Volunteers
Professional training of staff	Lay individuals	Lay individuals (often in professional training)	Lay individuals (members of a Christian congregation)
Hours of operation	24-hours	24-hours	24-hours

2.2 Structure of the crisis helpline service model

Crisis helplines were designed to respond to people in an immediate crisis. Before their establishment, people in a crisis would seek help from healthcare services, including the local general practitioner (GP), psychiatrist, or psychologist. These services were designed to provide ongoing treatment, preventative healthcare, and chronic disease management to the individual (Seddon, Marshall, Campbell, & Roland, 2001). Yet, they lacked the capacity to immediately respond to people in an acute crisis (i.e., people engaging in suicidal behaviours)

as costs were associated with accessing care, structured consultation times, long waiting times, and location of services (Farrer, Christensen, Griffiths, & Mackinnon, 2011). The need for a service that provided short-term, immediate support for people in an acute crisis became apparent in the 1950s (Shneidman & Farberow, 1956).

Crisis helplines were designed to operate separately to, but complement the support offered by healthcare and psychiatric services. A less medicalised model of service delivery was adopted by providing a brief response, specific to the crisis (Kalafat et al., 2007) that could appeal to people who were resistant to seeking help from medical or psychiatric services. There was no scope to offer in-depth psychological treatment (Watson et al., 2006). Instead, components were included that enabled short-term support to be offered to people in an acute crisis. Firstly, the support offered by the helpline was designed to be short-term and specific to the current crisis, which was in contrast to general practice services that provided ongoing treatment (Seddon et al., 2001). Secondly, the helplines were staffed by volunteers who often did not have any professional mental health training. Thirdly, importance was given to maintaining the caller's autonomy throughout the entire encounter, which differs to general practice care where the individual remains dependent on the health professional. These components were similar across the three early helplines and were incorporated into the service model in an attempt to address the barriers that prevented people from accessing immediate support from healthcare services. These components have been maintained as the crisis helpline service model spread across the world and are described below.

2.2.1 Short-term support

Crisis helplines were designed to provide a unique form of support that addressed many of the barriers encountered when accessing healthcare services. Integral to the support offered by crisis helplines was their ability to be immediately available, which addressed a concern that people were not accessing healthcare services in times of need (Rosenbaum & Calhoun, 1977). By using the telephone to connect with people in a crisis, these services removed several of the barriers that may have previously prevented people from accessing support. In particular, financial barriers were removed as the services were available at minimal or no cost to callers (Coman et al., 2001); the services were not bound by geographical barriers and could be accessed from the privacy of one's own home (Coman et al., 2001); they were made largely

accessible as they were available 24-hours a day (Coman et al., 2001); and could be accessed without a referral (Coveney et al., 2012).

In addition to being immediately available, the support offered by crisis helplines was intended to be short-term. These services were intended to provide a complementary crisis support service that was accessible to be people in need rather than replicate the support offered by healthcare services (Morgan, Chakkalackal, & Cyhlarova, 2012). The short-term nature meant that the response needed to be brief and specific to the current crisis (Kalafat et al., 2007). The interaction was usually limited to the duration of the phone call, which prevented the development of an ongoing relationship between the counsellor and the caller. There was no scope to offer in-depth psychological treatment, which was seen to be the role of healthcare services (Watson et al., 2006).

The short-term nature of the encounter needed to be sufficient to assist the person to return to a stable state. This made it difficult to provide any formal mental health treatment, which might require several structured sessions (Leach & Christensen, 2006). Instead, the support focused on assisting the individual to draw on their own internal resources and problem-solving skills so that, at the end of the conversation, they would be safe (Slem & Cotler, 1973). These services developed into a listening service that offered emotional and psychological support to individuals in distress (Hvidt et al., 2016). The focus of the support was restricted to alleviating the caller's immediate distress, strengthening their personal coping strategies, and providing pathways through which they could access other services (Barber et al., 2004; Kalafat et al., 2007).

Initially, crisis helplines were established to support people engaging in suicidal behaviours but their focus quickly broadened to include a wider range of emotional issues. This shift was first seen in Lifeline, which targeted people experiencing any form of emotional crisis (Walker, 1967). Later helplines were established to support people experiencing depression, eating disorders, and substance abuse (Leach & Christensen, 2006). This shift occurred after it was identified that many people were reaching out to crisis helplines with emotional issues that were not specific to suicide (Day, 1974). Crisis helplines now provide general emotional support, but continue to maintain an underlying emphasis on suicide prevention (Hvidt et al., 2016).

As mentioned in Section 2.1.4, the support offered by crisis helplines differed between services. This ranged from a non-directive active listening approach (Varah, 1988) through to a directive approach where strategies and advice were offered (Mishara et al., 2007). Evidence indicates that when counsellors took an empathetic and supportive approach by using collaborative problem solving techniques more positive outcomes resulted among callers (Mishara et al., 2007). Merely providing a service that offers active listening was not found to have an effect on call outcomes (Mishara et al., 2007).

2.2.2 Staff and volunteers

From the outset, crisis helplines were staffed by volunteers. As demonstrated above, an important distinction between crisis helplines and healthcare services was the need for crisis helplines to be available at the time of the crisis and thus, they were available 24 hours a day. Ensuring this availability required the service to be constantly staffed. The costs associated with staffing such a service with paid professionals might have been unmanageable (Heilig, Heilig, Farberow, Litman, & Shneidman, 1968). Callers were not charged to use the service so funding had to come from external sources. The lack of profit often meant that resources were scarce. To overcome these financial barriers, service providers had to find a financially viable way to staff a 24-hour service. The solution was lay volunteers. Section 2.1.1 illustrated how Varah recruited a group of volunteers within the first year of operation to assist with the workload. These volunteers came with no formal mental health training but were upskilled to support callers for the duration of the phone call. Using lay volunteers to answer calls was also adopted by the founders of the Los Angeles Suicide Prevention Centre and Lifeline.

Each of these services had their own criteria that specified the desired skills of counsellors. This criterion was aligned with the perspective of the helpline founders. Specifically, Varah wanted to ensure the Samaritans remained a non-denominational service and was less inclined to recruit individuals who were overtly religious (Varah, 1988). In contrast, Walker wanted to create a Christian organisation that could respond to human need and only recruited members of Christian congregations (Walker, 1967). The founders of the Los Angeles helpline took an entirely different approach and recruited young trainees who were interested in entering a mental health profession but had not yet completed their clinical training (Litman et al., 1965). Despite these differences, there was a strong emphasis across all of the services to recruit individuals who were empathic and able to listen without judgement (Litman et al., 1965;

Paterson, Reniers, & Völlm, 2009; Varah, 1988; Walker, 1967). These qualities were important as the support offered by the helplines tended to focus more on active listening than specific mental health treatment.

Empathy and altruism have been identified as key factors that drive an individual to volunteer for crisis helplines. Research has found that the people who are most likely to volunteer for crisis helplines are driven by their personal characteristics rather than past experiences (Paterson et al., 2009). Empathy has been identified as the most prevalent characteristic among helpline counsellors (Paterson et al., 2009). This may occur as a by-product of service providers being inclined to recruit people who are empathetic. Other characteristics such as self-actualisation and having a greater sense of openness have also been found to be more prevalent among counsellors than the general population (Tapp & Spanier, 1973), along with volunteers being driven by a sense of altruism (Tapp & Spanier, 1973). These characteristics can mean that counsellors may have selfless concern for the wellbeing of others and may try to help callers in whatever way possible. This is a necessary trait when people are being asked to support people in difficult times. However, it is also important to point out here, that in some instances this selfless concern could lead to a counsellor going beyond the crisis intervention role. To overcome this challenge, service providers have provided counsellors with appropriate training.

From the outset, all counsellors were required to undertake a comprehensive training program before answering calls. Not only were these training programs important in ensuring the counsellors provided the appropriate type of support, they were also necessary to ensure a consistent model of care was offered across the service (Stein & Lambert, 1984). Usually, the focus of such training programs was on developing the lay volunteers' skills so that they could provide crisis intervention over the telephone in a single encounter (Stein & Lambert, 1984). This was often based around assisting counsellors develop non-judgemental supportive listening skills (McLennan, Culktn, & Courtney, 1994). These training programs were usually facilitated by mental health professionals who provided ongoing supervision to the counsellors (Kinzel & Nanson, 2000). In multiple cases, it has been found that the quality of support offered by lay volunteers after receiving appropriate training was equivalent to having mental health professionals answer the calls (Heilig et al., 1968; Rosenbaum & Calhoun, 1977). This has been questioned in a recent study that found a correlation between counsellors who are paid

and spend more hours answering calls having an increased confidence in handling imminent risk with callers (Gould et al., 2016).

Many helplines now employ a combination of paid professionals, unpaid professionals, and volunteers (Bassilios et al., 2015; Kalafat et al., 2007; Ramchand et al., 2016). More paid staff and professionals were brought on as each service evolved and adopted a stronger mental health presence (Knowles, O'Cathain, Turner, & Nicholl, 2014). Potential benefits in employing mental health professionals to answer calls were identified as services found it increasingly difficult to recruit appropriate volunteers to respond to callers (Cyr & Dowrick, 1991; Kinzel & Nanson, 2000). The drop-out of volunteers among crisis helpline services is also high (Cyr & Dowrick, 1991; Kinzel & Nanson, 2000). Lifeline has continued to increase over the years the number of mental health professionals and paid staff it employs as counsellors (Lifeline Australia, 2015a).

2.2.3 Caller autonomy

Crisis helplines were established to meet the needs of the caller. They were designed to ensure access to the greatest number of people (Slem & Cotler, 1973). This was achieved by removing as many potential barriers as possible. Importance was given to maintaining the autonomy of callers. It was believed that people may not reach out to crisis helplines for support if they feared that they could not control the situation (Rosenbaum & Calhoun, 1977). To counteract this fear, crisis helpline were structured in a way that ensured the autonomy of callers was maintained throughout the encounter (Rosenbaum & Calhoun, 1977). This was ensured by three components related to callers to crisis helplines: 1) callers were the ones who decided when to call the helpline and could end the conversation at any stage (MacKinnon, 1998); 2) callers were able to remain anonymous throughout the entire encounter and were only required to provide information about themselves that might assist in that moment (Coman et al., 2001); 3) the decision of how to act after the call was left to the caller (MacKinnon, 1998).

Related to caller autonomy was the need to allow callers to select the issues to be discussed during the phone call. The focus of the call was to remain centred on the caller over the entire encounter (Pollock, Moore, Coveney, & Armstrong, 2012). Anyone who perceived themselves to be in a crisis was encouraged to use the service, including people calling about their own issue or on behalf of someone else (Farberow et al., 1966). The interpretation of what may

constitute a “crisis” differed from person to person as there was no distinct definition (Paterson et al., 2009). Counsellors were trained to recognise that if an individual made the effort to call the service then they are considered to be experiencing a crisis (Rosenbaum & Calhoun, 1977), regardless of whether the counsellor perceived the issue as a “crisis”. This resulted in counsellors having to respond to a wide spectrum of callers (Dew et al., 1987). Counsellors often felt that many of these calls were not an appropriate use of the service (Pollock et al., 2012; Watson et al., 2006), yet they could do little about altering the way in which these callers used the service.

Frequent users were considered to be of particular concern to counsellors and service providers. These callers were identified as calling repeatedly about similar issues over an extended period of time (Haywood, 1980). In many of the encounters with frequent users it was perceived that their issues were not related to an immediate crisis (Hall & Schlosar, 1995). Instead, frequent users were seen to be isolated individuals who were calling repeatedly seeking non-crisis related support (Tarran, 1982); although, this assumption has not been investigated. These users were identified as absorbing a substantial amount of the counsellors time (Litman et al., 1965). Service providers became concerned that by responding to frequent users they may be preventing other callers from getting through (Kinzel & Nanson, 2000; MacKinnon, 1998). Providers were also concerned that if they approached frequent users differently they may remove the callers’ autonomy, which was outlined above as being integral to the crisis helpline service model. Frequent users are the focus of this thesis and are explored further in Chapter 3. These callers are mentioned here as to highlight that not everyone who uses crisis helplines does so in the manner intended by service providers.

2.3 Factors leading to the strengthening and expansion of crisis helplines

From the late 1960s the crisis helpline service model rapidly spread throughout the world. Many of the new helplines were branches of the early crisis helplines, while others were new and independent services. Growth was attributed to the communities increasing demand for crisis helplines, the influence of the promotion of crisis intervention theory, and technological advancements. Crisis helplines have continued to grow and evolve over the last 60 years and the factors leading to their growth are described below.

2.3.1 Increasing demand

Within the first year of operation, the founders of the three early helplines identified a dramatic increase in the number of people calling. This demand exceeded their expectations and led to the expansion of the service model (Lester, 2000). Initially, the founders attempted to increase the capacity of the centre by bringing on more counsellors but were restricted by the physical size of the space available (Varah, 1988). To overcome this challenge, additional centres were opened, which led to the eventual spread of the service model around each respective country (Lester, 2000). Similar expansion was seen across all three of the helplines, which is described below.

The Samaritans quickly grew in popularity and still operates today, albeit in an expanded format. Within the first 20 years of operation, the Samaritans went from answering an average of 250 calls a year from the sole branch in central London (Wilkins, 1969) to operating 143 branches across the UK and an additional nine international branches (Day, 1974). The Samaritans continued to grow over the last 60 years and now operates over 201 branches in the UK (Samaritans, 2016a). Collectively, these branches answer close to three million calls a year (Pollock et al., 2010). This number of calls is reported to have remained relatively stable since the early 1990s (Pollock et al., 2010). An additional five million calls are categorised as “snap calls”, lasting less than 5 seconds (Pollock et al., 2010). Email, SMS, face to face contact are also available through the service, however 85% of contacts are via the telephone (Pollock et al., 2010). The service is accessible from either a national number, available across all of the UK, which directly links the caller to a counsellor or by directly calling the number of a specific branch (Samaritans, 2016b). Eighty percent of calls are made to the local branch number (Lunn, 2006). The Samaritans’ model of care has also grown outside of the UK and in 2001 it was estimated that close to 350 international branches were operating in over 40 countries (Mishara & Daigle, 2001). These helplines drew on the framework of the London branch but have made adapted it over the years based on the needs of the population.

The Los Angeles Suicide Prevention Centre was always intended to act as a pilot site for future services. Within a short period of time, several new centres were established across the USA (McGee, 1974). These centres maintained the key principles of the Los Angeles Suicide Prevention Centre but their focus varied based on the needs of the community. In particular, most of the centres extended their focus beyond suicide prevention to include crises related to

drug and alcohol abuse, rape, sexual abuse, and domestic violence (James & Gilliland, 2013). Similar to the Suicide Prevention Centre, it was acknowledged that crisis helplines could not function in isolation from other services and therefore a close collaboration was maintained between these new helplines and other community-based services (James & Gilliland, 2013). In the USA, crisis helplines now operate within a national network where calls to a single toll-free number are routed to the nearest centre (Substance Abuse and Mental Health Services Administration, 2016). These helplines are available to anyone in a suicidal or emotional crisis across the USA (Substance Abuse and Mental Health Services Administration, 2016).

The success of the Sydney centre led to the growth of the crisis helpline service model in other Australian cities. The Sydney branch received 10,000 calls in its first year of operation from people with issues related to marital problems, drug and alcohol abuse, pregnancy, gambling, and suicidal behaviours (Walker, 1967). These calls were underpinned by the theme of loneliness, which Walker (1967) attributed to a result of the ills of living in an overcrowded urban environment. The helpline was promoted around Australia, and by 1966, Lifeline centres were operating in 16 Australian cities (Wight, 1997). Initially, these centres were established as separate services but were modelled on the Sydney centre (Wight, 1997). A degree of autonomy existed between the centres until it became apparent in 1966 that coherence was needed and thus, Lifeline International was established (Wight, 1997). Representatives from each of the Lifeline centres were members of this new organisation, which developed an overarching code of practice (Wight, 1997). After this new code of practice was introduced, the centres began operating with a sense of coherence and additional centres were established in Australia and the rest of the world. Forty-one Lifeline centres now operate across Australia as part of a national network. Calls to a single number are answered by the next available counsellor (Barber et al., 2004; Lifeline Australia, 2015b).

Demand for crisis helplines has continued to grow over the years, so much so that these services now find it difficult to respond to all callers (Watson et al., 2006). Long wait times and difficulties getting through have often been reported by callers (Morgan et al., 2012). For example, Lifeline reported in 2015 that their call answer rate was 85% (Lifeline Australia, 2015a). Crisis helplines continue to have finite resources, which makes it difficult to further increase their capacity to answer more calls (Morgan et al., 2012). Instead, there has been a recent push to understand more about the characteristics of callers and whether opportunities

exist for improving the efficiency of the services (Gould et al., 2016; Hvidt et al., 2016; Watson et al., 2006). In particular, frequent users have received significant attention in regards to whether the proportion of calls they make can be reduced, as already mentioned in Section 1.3 (Hall & Schlosar, 1995).

2.3.2 Crisis intervention theory

The early crisis helpline services were not developed within a clear theoretical framework. Rather, as already mentioned, a model of care evolved out of an attempt by several individuals to establish a service that responded immediately to people at risk of suicide. Initially, the basis of the new service model was not supported by strong evidence, yet the services continued to expand as demand increased. It was not until ten years after the first Samaritans branch was established that a new theory was proposed that supported the crisis helpline model of care (Bleach & Claiborn, 1974). The introduction of this new theory has been associated with strengthening the crisis helpline service model with a brief description of this theory provided below.

Crisis intervention theory was proposed by Gerald Caplan in 1964. This theory was considered the best approach for crisis intervention growing as an area of interest among healthcare professionals during the late 1950s and early 1960s (Parad, 1965). Caplan (1964) proposed that a crisis could be anything that may disrupt an individual's emotional equilibrium. He estimated that a crisis would last a short period of time, between four to six weeks, and could be addressed by offering an individual timely support that focused on their immediate crisis (Caplan, 1964). The importance of focusing on improving the individual's acute psychological disturbances rather than other aspects of their life was emphasised (Moore, 2016). It was assumed that if the individual received the appropriate support during the crisis they would return to a state of emotional equilibrium (Parad, 1965). Important to Caplan's theory was the understanding of how people act during emotional disequilibrium. Caplan (1964) argued that it is at the moment of disequilibrium that humans are most vulnerable and may act irrationally. Conversely, he felt that it was at this moment of vulnerability that people are the most receptive to new perspectives and are distinctively open to receiving support from others (Caplan, 1964). This disequilibrium could be regarded as a growth promoting experience (Parad, 1965), in that the individual was provided with the opportunity to move towards a new emotional understanding that they may otherwise find nearly impossible at any other time (Caplan, 1964). If the crisis was not resolved

within a timely manner, issues could manifest into a mental health condition (Caplan, 1964). With the potential to prevent mental health conditions, it became critical that the individual could access appropriate support networks at the exact time of the emotional disequilibrium (Caplan, 1964). Once appropriate support was provided, the individual in crisis would return to a new stable emotional state.

Despite Caplan's theory being proposed after the early crisis helplines were established, it became a basis to promote the crisis helpline model of care. Crisis helplines were already operating in a manner that ensured immediate support was offered in a timely manner to those in crisis (Farberow et al., 1966). With these similarities, crisis helplines and crisis intervention theory became widely promoted (Hvidt et al., 2016). Over the years, several alternative theories have been proposed that have attempted to redefine the meaning of "crisis" (Parad, 1965; Poal, 1990; Rapoport, 1965). However, the theory put forward by Caplan has remained widely recognised (Poal, 1990). Some of these theories are mentioned in Section 2.5.1 in relation to the theories that influenced the Lifeline service model. Some of these other theories are touched upon in Section 2.5.1 in relation to the theories that have influenced the Lifeline service model.

2.3.3 Technological advancements

Invented in 1844, the telephone was initially used by commercial and professional communities (Arson, 1977). Telephone access became more affordable to the general population after World War II as technology improved (Mercer, 2006). Telephone connections in every household became the "norm" and by the 1980s it was estimated that close to 90% of households in the USA had their own connection (Rutter, 1987). In the same period, close to 78% of UK households had a telephone connection (de Sola Pool, 1977) and 85% of households in Australia (Australian Bureau of Statistics, 1984). Cost was attributed as the main reason why some households did not have a telephone connection (Australian Bureau of Statistics, 1984).

The uptake of mobile technology in the early 2000s changed how people used the telephone. Mobile phones allowed people to communicate with one another without needing to be at home (Mercer, 2006). When mobile technology was first introduced, in the 1970s, it was extremely expensive in comparison to the household telephone (May & Hearn, 2005). But by the late 1990s, systems were put in place to make mobile technology affordable and more people had their own personal device (May & Hearn, 2005). Built within the mobile phone technology

was the ability to interact with other people via the short message service (SMS) (Kim, Park, & Oh, 2008). Mobile telephones have become widespread and in 2014 it was estimated that over 7.2 billion mobile devices were in operation worldwide (Boren, 2014). Mobile technology has continued to advance, with the introduction of the iPhone in 2007 giving further impetus to its development (Apple Inc., 2016).

The evolution of the telephone was integral to the growth of crisis helplines. These services were established around the same time telephones became a common household item (Berman, 1991). The value of using telephones to immediately connect with another individual was starting to be recognised, and crisis helplines were structured with this ability in mind (Cherry, 1977). The number of calls to crisis helplines has continued to increase as telephone technology improved over the last 60 years (Kitchingman, Wilson, Woodward, Caputi, & Wilson, 2016). This increase can be demonstrated with the example of Lifeline, which went from answering 10,000 calls in its first year of operation at a single centre (Walker, 1967) to answering 831,744 calls in 2015-2016 across 41 centres (Lifeline Australia, 2016). Service providers have continued to incorporate the technological developments in the telephone into the operation of crisis helplines (Kitchingman et al., 2016). This can be seen more recently with the introduction of online chat services and SMS communication by crisis helpline services (Luxton, June, & Kinn, 2011). These new models are beyond the scope of this thesis. However, the characteristics of people using crisis helplines may have changed as new technology made these services more accessible. Figure 1 presents a brief chronological outline of the development of the telephone in relation to the early crisis helplines.

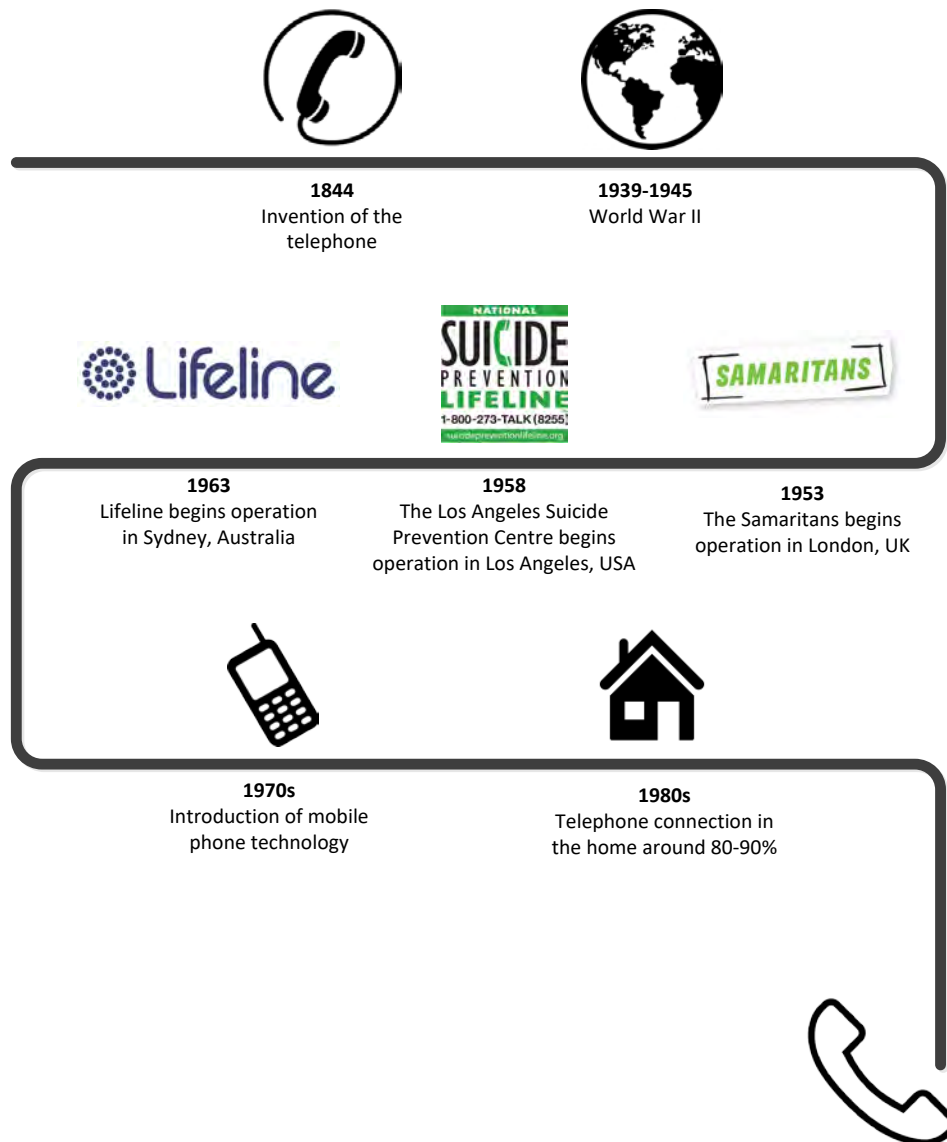


Figure 1: Chronological evolution of the telephone with crisis helpline

2.4 Effectiveness of crisis helplines

The growth of crisis helplines occurred without corresponding evidence to demonstrate their effectiveness in suicide prevention. In fact, demonstrating the effectiveness of crisis helplines has proven to be difficult (Hvidt et al., 2016). These difficulties arise from the anonymous and confidential nature of these services, which was mentioned in Section 2.2.3 as an important element to encourage service use. Limited information is collected on callers and the outcome

of the call is usually not known. Instead, records tend to be kept based on the notes made by counsellors. This requires accurate record keeping (Coveney et al., 2012). In reality this information is often hindered by substantial missing data (Watson et al., 2006). Furthermore, these services were established at a time when the use of randomised controlled trials for proving effectiveness of models of service were not common—a practice which is now more widely acceptable. In an attempt to overcome these limitations, other approaches have been used to investigate the effectiveness of crisis helplines. Approaches include comparing changes in suicide rates in the community, changes during the call, and measuring both the caller and counsellors' satisfaction with the encounter.

Changes in suicide rates were first used to demonstrate the effectiveness of the Samaritans by comparing the suicide rates between towns in the UK with and without a helpline branch. Bagley (1968) compared the suicide rates of 15 towns where a Samaritans branch had operated for at least two years with 15 towns that did not have a Samaritans branch. In this study, Bagley (1968) reported a 20% decrease in the suicide rates in those towns with a Samaritans branch. No such difference was found in the 15 control towns (Bagley, 1968). This difference was attributed to the presence of the crisis helpline (Varah, 1988). Since this study, several attempts were made to replicate the methods used by Bagley (1968) both in the UK and other localities where crisis helplines operate, but similar distinctions were not observed (Lester, 1997). Two systematic reviews evaluated these studies and reported that the findings were inconsistent. It was concluded that there is no evidence to show that crisis helplines have an effect on reducing suicide rates (Dew et al., 1987; Lester, 1997).

Even though little evidence exists to demonstrate the effectiveness of crisis helplines, these services remain important to suicide prevention. It may be that other factors related to suicidal behaviour have a stronger influence on suicide rates compared to the influence of crisis helplines. This could include factors related to individual behaviours (e.g., people not reaching out to crisis helplines) and the presence of other suicide prevention strategies in a community (e.g., restriction of means) (Lester, 1997). Such an explanation is not meant to detract from the importance of crisis helplines, but rather highlight that crisis helplines are not the only strategy required in suicide prevention (Mann et al., 2005). Often several suicide prevention strategies occur at the same time in one locality, making it difficult to isolate the specific effect of one approach (Hvidt et al., 2016). The low base rate of suicide also makes this a difficult area to

investigate. Demonstrating the effectiveness of any specific strategy to reduce rates of suicide is an ongoing challenge in suicide prevention research (Mann et al., 2005). Instead, other factors related to the effectiveness of crisis helplines have been investigated.

The short-term outcome of callers is another approach used to demonstrate the effectiveness of crisis helplines. Two studies, conducted in the USA and Canada, investigated whether changes occurred in callers' emotional states by the end of their call to the helpline (Gould et al., 2007; Kalafat et al., 2007; Mishara & Daigle, 1997). In the study by Mishara and Daigle (1997), external research assistants were employed to silently monitor the calls and noted any changes during the call. In contrast, in the study by Kalafat et al. (2007) and Gould et al. (2007) a group of callers were assessed, identified as either non-suicidal and suicidal callers, and followed-up after their initial call. Although these studies used different methods, both identified a reduction in callers' distress levels from the start to the end of the call (Gould et al., 2007; Kalafat et al., 2007; Mishara & Daigle, 1997). These reductions were more common among callers who were identified as suicidal at the start of the call (Gould et al., 2007; Mishara & Daigle, 1997). This finding suggests that crisis helplines may be effective in reducing an individuals' immediate suicidal risk. However, as already mentioned in Section 2.2.1, it may be the type of support offered that leads to this reduction, as it was observed by Mishara and Daigle (1997) that more significant decreases in the callers' distress levels occurred when counsellors used a structured and collaborative approach, as opposed to active listening. It is unclear whether similar results would be found among callers to either the Samaritans or Lifeline, as these services take a more passive approach compared to the North American-based helplines.

The effectiveness of crisis helplines has also been examined by exploring caller's satisfaction. This method was first used by Speer (1971) to justify that people who called back after their initial call did so because they were satisfied with the service. This approach was criticised by Apsler and Hoople (1976) because it relied on counsellors accurately knowing who had called before. Instead, Apsler and Hoople (1976) directly asked callers about their prior use of the helpline and found that 63% of callers reported calling previously; rates of re-use were associated with specific socio-demographic characteristics. Underpinning both of these studies was the assumption that recurring calls to the crisis helpline were an indication of satisfaction. Neither studies investigated whether frequent users called back because they were unsatisfied with the previous encounter (Apsler & Hoople, 1976; Speer, 1971). Coveney et al. (2012)

addressed this assumption by specifically asking callers in an online survey how they rated their previous encounter and found that, overall, participants were positive about their past encounter and felt better after the call. They rated the overall helpfulness of their last encounter highly (Coveney et al., 2012). Despite demonstrating that callers were satisfied with their access to crisis helplines, these studies were unable to explore whether crisis helplines were, in fact, effective in reducing an individual's risk of suicide.

As already mentioned, explicit differences may exist in the outcomes of crisis helplines across each country, making it difficult to form any conclusive findings. Differences may be a result of variations in the nature of the support offered by each service and the characteristics of callers across localities (see Section 2.1.4). Different caller characteristics may mean that research conducted among callers to the Los Angeles Suicide Prevention Centre, or in the USA more generally, may not reflect the population of callers to Lifeline in Australia. To date, the majority of research into crisis helplines, including their effectiveness, has been based in the USA. A focus on the USA occurred as a result of these helplines having, from the outset, an emphasis on the collection of data for research purposes (Litman et al., 1961); a feature that was not included in either the Samaritans or Lifeline's service model. Such differences may mean that inconclusive findings will continue to arise when comparing research on the effectiveness of crisis helplines across multiple localities. There is merit in looking specifically at the situation in one setting and then understanding whether these findings can be translated to other helpline services.

2.5 Crisis helplines in Australia

Suicide is the 14th leading cause of death in Australia and in 2014 accounted for over 2,500 deaths (Australian Bureau of Statistics, 2014). Crisis helplines are identified as one service that can offer early care to and support those in need (Department of Health and Ageing, 2007). They are available at times when healthcare services may not be available and are often used by healthcare professionals to assist their clients outside of business hours (Coveney et al., 2012; Farrer et al., 2011). As previously described, these services were designed to overcome the barriers faced by people in a crisis accessing general practitioners. In particular, crisis helplines are available at times when general practice and mental healthcare services are closed (Coman et al., 2001).

Since the opening of the Lifeline branch in Sydney in 1963, the crisis helpline service model has spread across the country. In 2002, it was estimated that over 115 services were operating in Australia that included some form of telephone crisis support (Urbis Keys Young, 2002). The precise number of services is unknown, as there is no comprehensive list of all crisis helplines operating in Australia. The number of services has likely increased since this review was conducted 15 years ago.

In Australia, crisis helplines operate at different geographical levels (i.e., national, state, local), and each service has its own focus (Coman et al., 2001). Many of these services maintained a strong emphasis on suicide prevention. Some of the commonly known 24-hour toll-free national crisis helplines include:

- *Lifeline 13 11 14*: As mentioned earlier, this was the first crisis helpline to be established in Australia and provides confidential crisis support service to all Australians experiencing a personal crisis or thinking about suicide (Lifeline Australia, 2016b). Further details related to Lifeline are provided below;
- *Kids Helpline*: This is a confidential counselling service for kids and young Australians between five and 25 years of age (Kids Helpline, 2016);
- *MensLine*: This is a telephone and online support, information and referral service for men with family and relationship concerns (MensLine Australia, 2014); and,
- *Suicide Call Back Service*: This is a professional telephone and online counselling service for people affected by suicide (Suicide Call Back Service, 2016).

Crisis helplines were included in a recent review of all Australian mental health services. This review, completed in 2014, by the National Mental Health Commission explored the nature of mental health programmes and services in Australia and identified opportunities for improvements (National Mental Health Commission, 2014a, 2014b). A major finding from the review was the large extent of duplication that existed among crisis helpline services operating in Australia (National Mental Health Commission, 2014a). This duplication was seen to cause confusion among consumers of mental health services, with several potential funding implications (National Mental Health Commission, 2014a). The review highlighted that many of these services were operating as separate organisations and could benefit from being consolidated into fewer services (National Mental Health Commission, 2014a). The Australian Government provided a response to this review, and in terms of crisis helplines, concluded that

a new digital mental health gateway should be established that *“will bring together and streamline access to existing evidence-based information, advice and digital mental health treatment and will connect people to services they need through a centralised telephone and web portal”* (Department of Health, 2015, p. 12). It was proposed that Lifeline could act as an entry point to this gateway (Department of Health, 2015), which is expected to be established by 2017 (Department of Health, 2015).

2.5.1 Lifeline 13 11 14

Lifeline 13 11 14 has become one of Australia’s largest national crisis helpline services (Barber et al., 2004; Watson et al., 2006). Lifeline now operates as a national network with 41 centres across Australia (Lifeline Australia, 2015a). It considers itself as a leading provider of suicide prevention services and offers a point of contact for people considering suicide (Lifeline Australia, 2015a). As the service evolved over the last 60 years, the strong Christian emphasis, highlighted in Section 2.1.3, is no longer evident. Rather, the service now aims to support all Australians in times of crisis and equip the community to be resilient and suicide-safe (Lifeline Australia, 2014). The support focuses on connecting people to counselling, learning programs and providing relevant information, as required (Lifeline Australia, 2015b). Primarily, the service operates as a 24-hour crisis helpline (Lifeline Australia, 2015b), but more recently has included an online chat component. It also operates a Suicide Hot Spot phone crisis line and various training programs (Lifeline Australia, 2015b).

Lifeline has continued to maintain a focus on assisting individuals through a suicidal crisis and answers approximately 50 calls each day from people engaging in suicidal behaviours (Lifeline Australia, 2013). Other calls come from people experiencing personal crises, anxiety, depression, loneliness, abuse and trauma, work-related stresses, familial or societal pressures, and seeking information for friends or family (Lifeline Australia, 2015b). Lifeline operates as a national charity and relies on external financial support. In 2015, Lifeline received over AUD\$22 million from government grants, corporate support, and community and individual donations (Lifeline Australia, 2015a). Half of this income went towards the operation of the 24-hour helpline service (Lifeline Australia, 2015a). The service operates independently to other crisis helplines and healthcare services in Australia, however, general practitioners and mental health professionals are known to often refer their patients to call Lifeline when they are not available (Morgan et al., 2012).

Lifeline is staffed by trained counsellors, including both volunteers and paid staff (Barber et al., 2004). In 2015, over 1,000 staff and 11,000 volunteers were employed (Lifeline Australia, 2015a). It is only in recent years that Lifeline has begun paying a group of counsellors to work the overnight and weekend shifts as these shifts were difficult to fill with volunteer staff (Lifeline Australia, 2015a). In 2015, the paid counsellors answered approximately 20% of calls to the service (Lifeline Australia, 2015a). All counsellors go through an extensive selection and training process before they begin answering calls. They are trained to enquire about suicidal behaviours during each call.

Lifeline's approach to suicide prevention has continued to evolve over the years and has incorporated theories on suicidal behaviour. Underlying the service's approach is the belief that it is possible to intervene early in a suicidal crisis by offering help to individuals experiencing difficulties in their lives. This rationale is in line with the crisis intervention theory proposed by Caplan (1964) and is further supported by the work undertaken by the founders of the Los Angeles Suicide Prevention Centre (Shneidman et al., 1994). Theories, such as the one proposed by Joiner (2002) relating to the view that mental health issues contribute largely to the distorted thinking and dysfunctional response to situations that occur in suicidal thinking and acts, have also underpinned the Lifeline service model. It is understood that by offering compassionate help and practical support a person's trajectory towards a suicidal act can be interrupted (Joiner, 2002). The service has developed its own crisis support practice model, which draws on these theories and guides service provision. This model was published in the study by Kitchingman et al. (2015) and is presented in Figure 2. It includes five stages: 1) connect with the caller, 2) focus the call, 3) relieve distress, 4) enable coping, and 5) decide next steps. This model has been shown to be implemented by Lifeline counsellors but its use in other settings is yet to be demonstrated (Kitchingman et al., 2015).

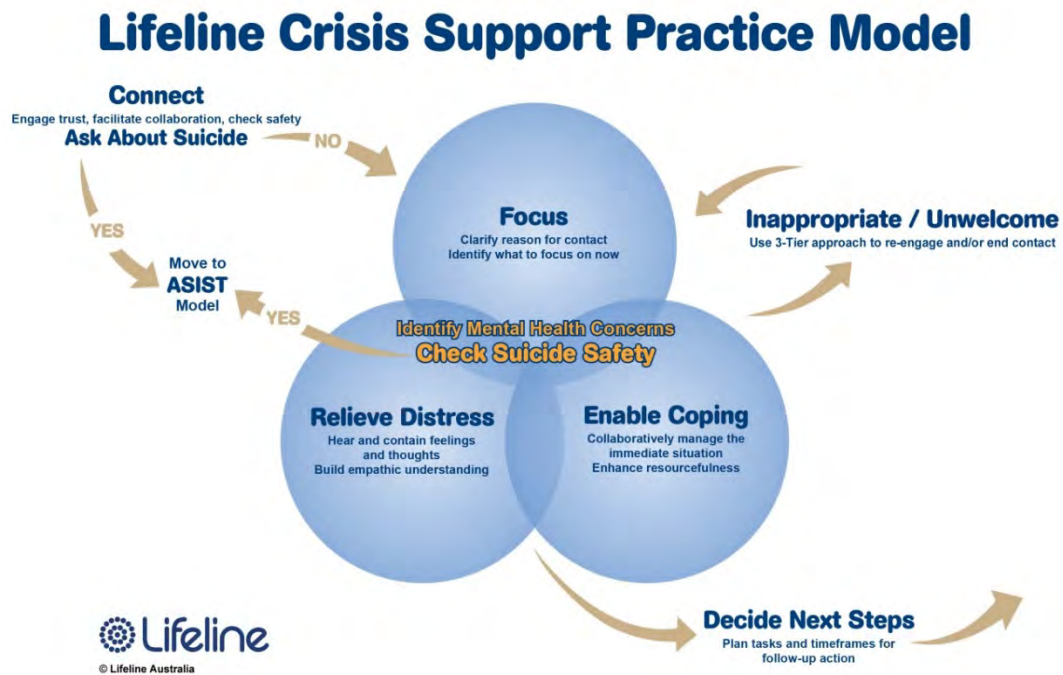


Figure 2: Lifeline Crisis Support Practice Model

Each year, Lifeline receives a growing number of calls. In the last ten years, this number almost doubled from 450,000 calls in 2005-2006 (Lifeline Australia, 2006) to over 820,000 calls in 2014-2015 (Lifeline Australia, 2015a). Similar to other crisis helplines, callers to Lifeline remain anonymous and each call is treated as a unique encounter, with no follow-up between calls (Barber et al., 2004). Calls are answered across the national network with each call allocated to the next available counsellor, regardless of geographical location (Lifeline Australia, 2015a). This differs to the other helplines, which still have a local number for each branch (Pollock et al., 2010). In 2015, 73% of calls came from people in a crisis, with suicide being discussed in 70% of these calls (Lifeline Australia, 2015a). Other topics included, family and relationships (25%), mental health (19%), and loneliness (19%) (Lifeline Australia, 2015a). Referrals to other support, including mental health and e-mental health services, were provided in over half of these calls (Lifeline Australia, 2015a). In the same period, the greatest number of calls were received from people aged 45-54 years (30%), and nearly 60% of calls came from females (Lifeline Australia, 2015a). Callers to Lifeline can be categorised as one-off, episodic, or frequent users. As already mentioned, Lifeline defines frequent users as those who call 20 times or more in a month (Spittal et al., 2015).

2.6 Chapter summary

The chapter described the worldwide growth of crisis helplines and the lack of evidence demonstrating their effectiveness. These services were established without a formal theoretical framework, but service providers drew on the crisis intervention theory proposed by Caplan in 1964 in an attempt to justify the need for these services. As demand for crisis helplines grew and they became more popular, the service model quickly expanded around the world. Crisis helplines can be distinguished from healthcare services by providing short-term support that is specific to the crisis, often offered by volunteers without any formal mental health training, and focused on maintaining callers' autonomy. This differs to healthcare services, which were designed to provide ongoing treatment. The nature of the support offered by crisis helplines has evolved over the last 60 years as telephone technology revolutionised the way people engage with one another. Despite crisis helplines around the world sharing many similarities, there are explicit differences between each service, which may influence the characteristics of the caller. Therefore, any research into the characteristics of crisis helpline users' needs to be specific to the service under investigation. The focus of this thesis is on Lifeline, which employs a model of care that focuses on assisting individuals through a suicidal crisis and takes a multi-faceted approach to suicide prevention, which is encapsulated within the training of counsellors and service procedures. For Lifeline, as for many crisis helplines, frequent users have been identified as a group of callers to the service and are the focus of the next chapter.

3

Frequent Users of Crisis Helplines

Chapter 3 provides an overview of the literature published on frequent users of crisis helplines over the last 60 years and is presented in four parts. The first part describes the use of the term frequent user in the literature and how these users are perceived by service providers and counsellors. The second part introduces the empirical research published on frequent users of crisis helplines and outlines the definitions of frequent use, the different study methodologies, and calling patterns. The third part presents the findings from this empirical literature in regards to the socio-demographic characteristics of frequent users, mental health issues, their reasons for calling and health service use patterns. The final part of the chapter outlines the current research gaps regarding frequent users of crisis helplines and highlights opportunities for further research.

3.1 Frequent users of crisis helplines

The previous chapter described how crisis helplines were established over 60 years ago to provide one-off support to individuals in an immediate crisis. These helplines were designed to complement healthcare services and were intended to provide short-term support. This was reflected in the fact that each call to the crisis helpline was treated as a unique encounter with no follow-up between calls (Coman et al., 2001). A significant number of calls have been identified to come from users who make multiple calls over an extended period of time (Leuthe & O'connor, 1980). Frequent users are common to many crisis helplines and the appropriateness of their calls remains a concern for service providers (Imboden, 1980). Counsellors have begun to respond differently to frequent users compared to other callers, without considering their individual needs.

3.1.1 Why are frequent users a concern to crisis helplines?

Frequent users make a disproportionate number of calls to crisis helplines. They are estimated to represent between one and five percent of callers (Wilkins, 1969) but account for up to 60% of calls (Spittal et al., 2015). The precise number of calls is unclear as each service defines frequent users differently (Johnson & Barry, 1978). For example, Lifeline (see Section 2.1.3) defines frequent users as calling 20 times or more in a month (Spittal et al., 2015), whereas, the Samaritans (see Section 2.1.1) considers those who make more than one call a regular user (Coveney et al., 2012). Crisis helplines continue to report that a small group of frequent users account for a significant number of the calls. The frequency, nature and appropriateness of the calls made by frequent user's presents a unique challenge to service providers who struggle to meet the needs of all callers with finite resources.

A long-standing assumption has been that frequent users call crisis helplines because they are isolated and looking for non-crisis related support (Haywood, 1980; Tarran, 1982) rather than being in an immediate crisis (Hall & Schlosar, 1995). Calling about non-crisis related issues is considered outside of the scope of the crisis helpline service model (Kinzel & Nanson, 2000). MacKinnon (1998) even suggested that frequent users may invent a crisis to continue their dialogue with the counsellor. As mentioned in Section 2.3.1, crisis helplines have finite resources and struggle to answer every call. Service providers are concerned that if a substantial number of calls are made by frequent users, and their calls are not urgent, then they may prevent callers in an immediate crisis from getting through (MacKinnon, 1998; Pollock et al., 2012). Conversely, there is uncertainty around whether calls from frequent users are actually non-crisis related as this assumption was based on the views of service providers rather than evidence from the empirical research. It may actually be that for many frequent users, the simple act of calling prevents a future crisis (MacKinnon, 1998). It has also been proposed that frequent users might call because they find the support helpful (Apsler & Hoople, 1976; Speer, 1971) and lack access to healthcare services (Apsler & Hoople, 1976; Gould et al., 2007; Kalafat et al., 2007). If this is the case then these callers cannot simply be dismissed as an "inappropriate" or "nuisance" callers, which is how they are sometimes described in the literature (Hall & Schlosar, 1995; Leuthe & O'connor, 1980; Watson et al., 2006).

The significance and nature of the calls by frequent users has been recognised to impact on counsellors. Frequent users are seen to call about recurring issues (Imboden, 1980) and

counsellors find themselves giving similar advice each time (Farberow et al., 1966). Discernible changes are not seen between calls (Rosenfield, 1996) and the lack of progress has been attributed to frequent users ignoring the advice offered by counsellors (Kinzel & Nanson, 2000). Counsellors have also reported feeling as though they lack insight into how to respond to frequent users (Greer, 1976; Kinzel & Nanson, 2000), which may lead to feeling that their efforts are ineffective (Farberow et al., 1966; Greer, 1976; Ingram et al., 2008; Wilkins, 1969). Counsellors' experiences with frequent users have been linked with them becoming suspicious of the legitimacy of other callers, or in extreme cases, counsellor burnout and resignation (Cyr & Dowrick, 1991). Counsellors have also expressed concerns that they receive inadequate training to know how to respond to frequent users (Pollock et al., 2010). To improve role satisfaction, service providers have identified a need to address these negative experiences among counsellors (Gilat & Rosenau, 2011; MacKinnon, 1998; Pollock et al., 2012).

3.1.2 Current approaches to frequent users

Several suggestions have been made about how service providers could better respond to frequent users. An early solution was for counsellors to respond sympathetically, firmly, and consistently (Litman et al., 1965). More recent suggestions include: limiting the number (Hall & Schlosar, 1995; Imboden, 1980; Leuthe & O'Connor, 1980) and length of calls (Barmann, 1980; MacKinnon, 1998); allocating frequent users to a specific counsellor who calls at a predetermined time (Barmann, 1980); developing a personalised management plan for each frequent user (Imboden, 1980; Tarran, 1982); increasing referrals to healthcare services (Leuthe & O'Connor, 1980); and encouraging frequent users to write letters to the helpline instead of calling (Brunet, Lemay, & Belliveau, 1994). These suggestions were not based on empirical research; rather they were based on the perceptions of service providers and counsellors. In 2002, when the Samaritans underwent a rebranding the service began to provide more pre-emptive forms of support. In particular, it considered how the service could respond to frequent users, among other callers who are considered to make inappropriate use of the service (Pollock et al., 2010).

Many of the current approaches to the management of frequent users does not consider their individual needs. Whether these approaches may trigger a further crisis among frequent users or have any other negative effect has not been investigated (Haywood, 1980). Furthermore, there is the question about whether limiting frequent users access to crisis helplines removes

their autonomy, which was already described in Section 2.2.3 as an underlying principle of the crisis helpline service model (Rosenbaum & Calhoun, 1977). The issue also exists that the current approaches to frequent users focus on reducing the negative impact these callers have on counsellors; these approaches do not address the underlying issues that may be driving frequent users to call so often. Therefore, frequent users could benefit from the development of an evidence-based approach that is based on empirical research.

3.2 Overview of the empirical literature on frequent users of crisis helplines

Nineteen studies have published empirical research on frequent users of crisis helplines. These studies were identified using a systematic approach that is outlined in Appendix 1. The 19 studies are described in Table 2, with a summary presented below. The study by Litman et al. (1965) provides the earliest reference to frequent users, which reports on the first year of the Los Angeles Suicide Prevention Centre operating as a 24-hour helpline. Litman et al. (1965) found that 4% of callers rang the helpline more than once, and were classified as frequent users. These users were described as taking up a substantial amount of the counsellor's time with their physical and mental health issues (Litman et al., 1965). No comparisons were made between the characteristics of frequent users and other callers, making it difficult to determine how these callers differed. Since this first study, an additional 20 articles have been published with empirical research on frequent users of crisis helplines. These 21 articles represent 19 separate studies as Litman et al. (1965) and Farberow et al. (1966) presented findings from the Los Angeles Suicide Prevention Centre, and Gould et al. (2007) and Kalafat et al. (2007) reported on an evaluation of caller outcomes at eight crisis helpline sites in the USA.

Studies that were not published in academic journals were excluded from this review, which meant non-peer reviewed literature that also explored the issue of frequent use of crisis helplines was excluded. This included the report prepared by the research group at the University of Nottingham (Pollock et al., 2010) on a two-year evaluation of the telephone and email emotional support services of the Samaritans. This evaluation began in January 2008 and was undertaken to develop evidence about the impact of the services provided, and to better understand the needs and expectations of those who use them (Pollock et al., 2010). It incorporated quantitative and qualitative elements and broadly investigated crisis helpline use

rather than restricting their investigation to that of frequent users (Pollock et al., 2010). Two manuscripts have been published from this study (Pollock et al., 2012, Coveney et al., 2012). Regular users, who reported calling the Samaritans more than once, were identified in the study by Coveney et al. (2012) and included in the literature review. The report on the broader research project was not included in Section 3.3 as it was not published in an academic journal but is considered in other sections throughout the thesis.

3.2.1 Defining frequent users of crisis helplines

Frequent users were defined differently across the 19 studies. Most commonly, frequent users were defined as calling more than once (Apsler & Hoople, 1976; Bassilios et al., 2015; Coveney et al., 2012; Farberow et al., 1966; Gould et al., 2007; Ingram et al., 2008; Kalafat et al., 2007; Litman et al., 1965; Mishara & Daigle, 1997; Murphy, Wetzel, Swallow, & McClure, 1969; Ramchand et al., 2016; Speer, 1971; Watson et al., 2006). Other studies categorised frequent users based on the number of calls made over a set period of time. Definitions ranged from three (Burgess et al., 2008) to 20 calls over one month (Spittal et al., 2015), ten calls over one (Brunet et al., 1994), six (Bartholomew & Olijnyk, 1973) or eight (Lester & Brockopp, 1970) months or 19 calls over two years (Greer, 1976). The study by Johnson and Barry (1978) identified six categories of frequency of calls, which were: single call to the centre, single call to centre with follow-up calls, multiple calls to centre—two-day period or less, multiple calls to centre—first week only, multiple calls to centre—multi-incident/same problem/over more than one week, and multiple calls to centre—multiple problems/over more than one week. Four studies provided no specific definition of frequent use but described them as making multiple calls (Barmann, 1980; Hall & Schlosar, 1995; Sawyer & Jameton, 1979; Wilkins, 1969).

The lack of a universal definition meant that frequent users were categorised differently between studies. Usually, frequent users were categorised using an arbitrary number (Johnson & Barry, 1978), which in most cases consisted of simply defining frequent users as calling more than once. This approach does not align with how service providers distinguish frequent users from other callers (Johnson & Barry, 1978). Nor does it acknowledge the fact that many callers make at least one follow-up call to the helpline after their initial crisis call (Gould et al., 2007; Speer, 1971). Eighty-five percent of respondents to the online survey considered contacting the Samaritans again, of which 503 (54%) had already reported using the helpline more than once (Coveney et al. 2012). People who may call the crisis helpline two or three

times are not the users that service providers are most concerned about. Rather, it is those callers who may ring an “inappropriate” number of times often about non-crisis related issues. In response to this distinction, Johnson and Barry (1978) highlighted the need for a definition that not only included the number of calls made but also considered the time over which these calls occurred and whether each call was related to the same issue or multiple issues. However, the proposed six categories of frequency of calls may not be a practical option to apply to the limited data that tends to be available on callers to crisis helplines. It is also unclear whether frequent users are similar across each service.

A more consistent definition of frequent use is needed that is relevant to service providers. As explained above, the definition needs to do more than compare one-off callers with people who call more than once. Yet, there is currently little consensus on what the definition could be. The first step in developing a consistent definition may benefit from looking at how service providers currently categorise frequent users. For example, Lifeline defined frequent users as calling 20 times or more in a month. This definition was recently used in a study investigating frequent users of Lifeline between 2011 and 2013 (Spittal et al., 2015). Based on the above exploration regarding the need for a consistent definition and as the focus of this thesis was on callers to Lifeline, Lifeline’s definition of frequent use was used. This approach ensured the findings from this research remained relevant to Lifeline.

3.2.2 Study methodologies

Different methods were used across the 19 studies to investigate frequent users of crisis helplines. Methods varied by study design, sampling strategies and data analysed. Of the 19 studies, 13 were audits of routinely collected data and six reported on purpose-designed surveys. Fifteen studies included a representative sample of callers, in which comparisons were made in ten studies between frequent users and other callers. Findings related to frequent users varied from the number of calls made through to a detailed report of their socio-demographic characteristics, reasons for calling, and health service use patterns.

The 13 audit studies were based on the analysis of data previously collected for administrative purposes. Most of the audits were completed before 1980, primarily in the USA (Farberow et al., 1966; Greer, 1976; Johnson & Barry, 1978; Lester & Brockopp, 1970; Litman et al., 1965; Sawyer & Jameton, 1979; Speer, 1971; Wilkins, 1969). Three audits were conducted in an

Australian setting, all with callers to Lifeline (Bartholomew & Olijnyk, 1973; Spittal et al., 2015; Watson et al., 2006). As explained in Chapter 2 (see Section 2.1.4), differences may exist between the characteristics of callers across different services, making it difficult to attribute findings from the older American studies to a contemporary Australian population. Furthermore, five of the audits included an analysis of all calls to the helpline during a specified time period; seven were conducted on a representative sample of calls; and, one study reported only on frequent users. In most studies, the average sample was around 1,000 calls, apart from the three most recent studies that each analysed over 100,000 calls (Ingram et al., 2008; Spittal et al., 2015; Watson et al., 2006). The larger sample may be a reflection of the increasing number of calls received by crisis helplines or indication of an inherent difference between these studies with the older studies. As the audit studies drew on routinely collected data they examined a larger sample of callers compared with the purpose-designed surveys. However, the variables available for analysis were dependent on the data originally collected. This limitation was most evident in the variety of approaches taken to define frequent use, which ranged from categorising frequent users as calling the helpline twice through to calling 20 times or more in a month.

Six studies used a purpose-designed survey methodology to investigate frequent users. Four of these studies were conducted after 2000 and one reported on callers to Lifeline (Burgess et al., 2008). Most of the studies were conducted as one-off surveys (Apsler & Hoople, 1976; Burgess et al., 2008; Coveney et al., 2012; Murphy et al., 1969), with other studies following up callers over a period of time (Gould et al., 2007) and reviewing crisis helpline use from a population-based mental health survey (Bassilios et al., 2015). The latter study, by Bassilios et al. (2015), was conducted outside of a specific crisis helpline service and addressed the user rather than the provider experience. Compared with the audit studies, a wider range of variables were examined in these studies, however the sample size tended to be smaller due to limitations with the recruitment process. Only a sample of callers were included in the analysis, of which three studies were considered to include a sample that was representative of all callers. More than half of the survey studies defined frequent users as calling more than once (Apsler & Hoople, 1976; Coveney et al., 2012; Gould et al., 2007; Kalafat et al., 2007; Murphy et al., 1969).

Table 2: Overview of the empirical studies reporting on frequent users of crisis helplines

Study	Year	Country	Helpline service	Sample size	Study design	Data collection	Was the sample representative of all callers?	Frequent user definition	Data reported for frequent users	Were comparisons made between frequent users and other callers?
Litman et al. (1965)	1963-1964	USA	Los Angeles Suicide Prevention Centre	1,336 callers	Audit	Record of evening calls.	Y	Calls > 1	Number of frequent users and their socio-demographic profile	N
Farberow et al. (1966)	1963-1964	USA	Los Angeles Suicide Prevention Centre	2,675 calls	Audit	Record of all calls.	Y	Calls > 1	Number of frequent users, number > 6 calls Profile of frequent users Prior treatment	N
Wilkins (1969)	1967	USA	Chicago Call for Help Clinic	200 callers	Audit	Call record used to identify a random sample of 200 callers.	Y	Definition unclear	Number of frequent users, number making 6 or more calls	N

Study	Year	Country	Helpline service	Sample size	Study design	Data collection	Was the sample representative of all callers?	Frequent user definition	Data reported for frequent users	Were comparisons made between frequent users and other callers?
Murphy et al. (1969)	1967	USA	Suicide Prevention, Inc. of St Louis	73 callers	Survey	Sub-set of callers interviewed.	N	Calls > 1	Number of frequent users History of suicide attempt (Y/N), Previous psychiatric treatment (Y/N) Followed advice (Y/N)	N
Lester and Brockopp (1970)	1968-1969	USA	Suicide Prevention and Crisis Service of Erie County	2,128 callers	Audit	All frequent users compared with a random sample of callers.	Y	Calls > 10 x 8 months	Number of calls Age, gender, marital status, ethnicity, children, living arrangements Prior treatment, suicidal history and risk	Y
Greer (1976)	1970s	USA	San Jose (California) Suicide and Crisis Centre	63 callers	Audit	All frequent users compared with a random sample of callers.	Y	Calls > 19 x 2 years	Age, gender, marital status Call duration Suicide history & risk, mental health history, drug & alcohol use, prior treatment, referrals	Y

Study	Year	Country	Helpline service	Sample size	Study design	Data collection	Was the sample representative of all callers?	Frequent user definition	Data reported for frequent users	Were comparisons made between frequent users and other callers?
Sawyer and Jameton (1979)	1970s	USA	Cleveland Suicide Prevention Centre	67 callers	Audit	All frequent users compared with a random sample of callers.	Y	Definition unclear	Age, gender, marital status, ethnicity, employment Mental health diagnosis, suicide history, prior treatment, referrals	Y
Speer (1971)	1971	USA		2,459 callers	Audit	Record of all calls.	Y	Call > 1	Number of calls	N
Bartholomew and Olijnyk (1973)	1971	Australia	Lifeline	8 callers	Audit	Record of frequent users.	N	Calls > 10 x 6 months	Age, gender, marital status Number of calls, common time of call Presenting problems, previous psychiatric treatment	N
Apsler and Hoople (1976)	1972-1973	USA	Project Place Hotline, Boston	11,703 calls	Survey	One-off standardized questionnaire (start of call) with sample of callers.	Y	Calls > 1	Age, gender, employment, ethnicity	Y

Study	Year	Country	Helpline service	Sample size	Study design	Data collection	Was the sample representative of all callers?	Frequent user definition	Data reported for frequent users	Were comparisons made between frequent users and other callers?
Johnson and Barry (1978)	1973-1974	USA	Crisis Intervention of Greenville, South Carolina	100 callers	Audit	Random sample of callers.	Y	6 calling patterns	Person who made call, number of calls, calling pattern	N
Mishara and Daigle (1997)	1988-1990	Canada	Suicide-Action Montreal and Carrefour Intervention Suicide	263 callers	Audit	Random sample of calls monitored by an external research assistant.	Y	Calls > 1	Number of frequent users Changes over the call (depression, suicide urgency level) Creation of contracts, intervention style	Y
Ingram et al. (2008)	2001-2005	USA	Girls and Boys Town National Hotline	349,464 callers	Audit	Record of all calls.	Y	Calls > 1	Age, gender Number of frequent users, reason for call, call duration	Y
Watson et al. (2006)	2003	Australia	Lifeline	90,128 calls	Audit	Record of calls with available data.	N	Calls > 1	Duration of use	N

Study	Year	Country	Helpline service	Sample size	Study design	Data collection	Was the sample representative of all callers?	Frequent user definition	Data reported for frequent users	Were comparisons made between frequent users and other callers?
Gould et al. (2007)	2003-2004	USA	Los Angeles Suicide Prevention Centre	380 callers	Survey	Suicidal callers were assessed and invited to a follow-up study.	N	Calls > 1	Number of frequent calls, referral follow-ups	N
Kalafat et al. (2007)	2003-2004	USA	8 telephone crisis services (7 were part of the national 1-800-SUICIDE network)	801 callers	Survey	Crisis callers assessed and invited to a follow-up study (excluded frequent users excluded).	N	Calls > 1	Number of frequent calls Suicidal thoughts, Profile of Moods States – Modified (POMS-M)	N
Burgess et al. (2008)	2006	Australia	Lifeline	270 callers	Survey	One-off 60-item questionnaire (end of call) with sample of all callers.	Y	Calls $\geq$ 3/month	Age, gender, relationship status Self-reported problems, mental health measures, mental health assistance (past month)	Y

Study	Year	Country	Helpline service	Sample size	Study design	Data collection	Was the sample representative of all callers?	Frequent user definition	Data reported for frequent users	Were comparisons made between frequent users and other callers?
Bassilios et al. (2015)	2007	Australia	NA	8,841 individuals	Survey	Population based health survey.	Y	Calls > 1	Relationship status, living arrangement, suicidality, gender, age, education, employment, psychological distress, health service use.	Y
Coveney et al. (2012)	2008-2009	UK	The Samaritans	1,308 callers	Survey	Online survey.	N	Calls > 1	Reason for last call, overall perception of helpfulness	Y
Spittal et al. (2015)	2011-2013	Australia	Lifeline	411,725 calls by 98,174 callers	Audit	Record of all calls.	Y	Calls $\geq$ 20 per month	Gender, age, relationship status Call duration Safety assessment for suicide, self-harm, mental health, crime, domestic violence, child protection	Y

Study	Year	Country	Helpline service	Sample size	Study design	Data collection	Was the sample representative of all callers?	Frequent user definition	Data reported for frequent users	Were comparisons made between frequent users and other callers?
Ramchand et al. (2016)	2014	USA	10 suicide prevention hotlines in California	241 calls	Audit	Monitored random sample of calls to 10 crisis helplines in California.	Y	Calls > 1	Number of frequent users	N

3.2.3 Frequent users calling patterns

Few studies reported on the interaction of frequent users' with crisis helplines. In particular, these studies looked at the period of time over which frequent users had called the helpline, the proportion of callers who were identified as frequent users compared with other callers, the duration of each call made by frequent users, and the outcome of these calls. These factors are described below.

Length of calling helpline

Three studies explored the length of time that frequent users had been calling the helpline (Greer, 1976; Sawyer & Jameton, 1979; Watson et al., 2006). All of these studies reported that at least half of the frequent users had been calling for more than one year. More specifically, Watson et al. (2006) found that at least 80% of frequent users had been calling for a few months. This finding supports the perception that frequent users call crisis helplines for an extended period of time.

Proportion of frequent users compared with other callers

Thirteen studies provided sufficient information to calculate the number of calls made by frequent users in comparison to other callers. Table 3 outlines these studies in terms of the number of calls, the number of callers, the number of callers making two or more calls, and the number making 20 or more calls. Together these studies reported on over 1.4 million calls to nine separate services.

Duration of call

Inconsistent findings were reported across the two more recent studies that investigated whether frequent users make longer calls to crisis helplines compared with other callers. In the studies by Ingram et al. (2008) and Spittal et al. (2015), it was reported that frequent users called for a shorter period of time compared with other callers. More specifically, Ingram et al. (2008) estimated that the average call for frequent users lasted 6.57 minutes. In comparison, Spittal et al. (2015) provided evidence to suggest that longer calls were associated with increase odds of being a frequent user, which was most evident for calls between 20 and 30 minutes (Spittal et al., 2015). The variation in call duration seen across these studies may be a result of inherent differences between the services rather than differences among frequent users.

Call outcome

Four studies investigated the outcome of calls made by frequent users (Gould et al. 2007; Greer et al., 2007; Mishara & Diagle, 1997; Sawyer & Jameton, 1979). The study by Gould et al. (2007), based in the USA, reported that a referral to mental health professionals was given to 52% of frequent users but only 16% followed through. In contrast, Mishara and Daigle (1997) investigated whether the counsellor made a contract with the caller at the end of their call and found this occurred more often with frequent users. Once again, it may be the inherent differences of these services that led counsellors to take a variety of approaches with frequent users. However, the findings from these studies highlight that counsellors may attempt to provide frequent users with alternative pathways of seeking help, yet frequent users may not follow through with these suggestions. Whether this occurs may also be dependent on the crisis helpline service model, with some services more inclined to provide referrals compared to others.

The different study designs, sampling strategies, definitions of frequent users, and methods made it difficult to combine the data. However, the studies addressed similar issues relating to frequent users allowing the findings to be presented around common themes.

Table 3: The number of calls and callers by call frequency in those studies where sufficient information was provided

	Study description		Number of calls by call frequency					Number of callers by call frequency				
	Duration	Total calls	Calls analysed^	Calls by those who called ≥ 2		Calls by those who called ≥ 20		Callers analysed^	Callers who called ≥ 2		Callers who called ≥ 20	
	(months)	N	N	n	%	n	%	N	N	%	n	%
Farberow et al. (1966) and Litman et al. (1965)	12	1,607	1,607	326	20	-	-	1,336	55	4	3	0.2
Murphy et al. (1969)	3	281	111	62	56	-	-	73	24	33	-	-
Lester and Brockopp (1970)	12	3,910	3,910	3,519	90	394	10	2,218	1,819	82	6	0.3
Speer (1971)	2	3,536	3,536	1,495	42	730	21	2,459	418	17	17	0.7
Apsler and Hoople (1976)	12	11,703	-	-	-	-	-	-	-	37	-	-
Johnson and Barry (1978)	12	1,235	462	319	69	-	-	100	36	36	-	-
Mishara and Daigle (1997)	36	617	617	420	68	-	-	263	66	25	-	-
Ingram et al. (2008)	60	499,066	349,464	167,743	48	-	-	-	-	-	-	-
Burgess et al. (2008)	1	1,404	1,117 ^{`</sup>	894* <sup>`}	80	-	-	270	119* [`]	44	-	-
Coveney et al. (2012)	12	-	-	-	-	-	-	1,309	707	54	-	-
Bassilios et al. (2015)	1	8,841 [?]	-	-	-	-	-	90	48	53	-	-
Spittal et al. (2015)	18	850,344	411,725	336,363	82	247,547	60	98,174	22,812	23	2,594	3
Ramchand et al. (2016)	> 1	273	241	84	35	-	-	-	-	-	-	-

- this information was not reported in the article

^ not all calls received by the crisis helpline were analysed in the calculation of the total number of calls and callers, as some studies only analysed a sample of callers

[`] the total number of calls was estimated from the data available in the article

* study defined categories as 1-2 calls and 3-9 calls

3.3 Characteristics of frequent users of crisis helplines based on findings from the empirical research

The degree of information reported on frequent users of crisis helplines varied extensively across the 19 studies. Four studies simply reported on the number of calls made by frequent users compared with other callers (Johnson & Barry, 1978; Litman et al., 1965; Ramchand et al., 2016; Speer, 1971; Wilkins, 1969) and are therefore not included in this section. The study by Bartholomew and Olijnyk (1973) is also excluded from this section as it only reported on the socio-demographics of eight frequent users without making any comparisons to other callers. The remaining 14 studies are included, as they all reported, to some extent, on the socio-demographic characteristics of frequent users compared with other callers, their reasons for calling, and health service use. A summary of the findings from these studies are presented under these three broad themes with the intention of understanding what is already known about frequent users of crisis helplines. In particular, the findings from the four Australian-based studies are highlighted (Bassilios et al., 2015; Burgess et al., 2008; Spittal et al., 2015; Watson et al., 2006) as it is important to understand the characteristics of callers specific to a setting (see Section 2.4). The research gaps are also highlighted.

3.3.1 Socio-demographic characteristics

The socio-demographic characteristics of frequent users were compared with other callers in nine of the 19 studies. This included looking at differences in the sex, age, marital status, ethnicity, employment status, living arrangements, and physical health of frequent users compared with other callers. Only sex, age, and marital status were consistently investigated in these studies, with varied results. This variation may be a result of the different study designs, definition of frequent use, times, or settings. Additionally, as only a few of these studies were conducted in an Australian setting, the socio-demographic characteristics between frequent users and other callers to crisis helpline remains uncertain.

Sex

Sex was compared between frequent users and other callers in eight of the studies, with inconsistent findings (Apsler and Hoople, 1976; Bassilios et al., 2015; Burgess et al.,

2008; Greer, 1976; Ingram et al., 2008; Lester & Brockopp, 1970; Sawyer & Jameton, 1979; Spittal et al., 2015). Spittal et al. (2015) reported that frequent users were more likely to be male compared with other callers. The other three recent studies provided no evidence to support an association between frequent use and sex (Bassilios et al., 2015; Burgess et al., 2008; Ingram et al., 2008). Instead, these studies reported that around 60% to 70% of callers were female irrespective of frequent use (Bassilios et al., 2015; Burgess et al., 2008; Ingram et al., 2008).

Age

The average age of frequent users varied across the studies with no clear patterns (Apsler & Hoople, 1976; Bassilios et al., 2015; Burgess et al., 2008; Greer, 1976; Ingram et al., 2008; Lester & Brockopp, 1970; Sawyer & Jameton, 1979; Spittal et al., 2015). The two studies conducted in an Australian setting in the last ten years showed that frequent use increased with age (Burgess et al., 2008; Spittal et al., 2015). Two additional studies provided no evidence to support an association between frequent use and age (Bassilios et al., 2015; Ingram et al., 2008). Bassilios et al. (2015) was conducted in Australia and drew on a population sample to compare one-off and repeat callers; a definition which was highlighted in Section 3.2.2 to not accurately represent frequent users.

Marital status

Callers' marital status was investigated in seven studies (Bassilios et al., 2015; Burgess et al., 2008; Greer, 1976; Lester and Brockopp, 1970; Sawyer & Jameton, 1979; Spittal et al., 2015). Evidence from the two recent Australian studies conducted specifically with callers to Lifeline (Burgess et al., 2008; Spittal et al., 2015) indicated an association between frequent use and being unmarried. Bassilios et al. (2015) found no evidence of an association between frequent use and marital status.

Ethnicity

Ethnicity was investigated in three studies, all conducted in the 1970s and based in the USA, with inconsistent findings. Ethnicity was not investigated in any of the Australian-based studies and as the cultural mix in Australia differs to the USA (Stratton & Ang, 1994) these findings may have little relevance to an Australian setting.

Employment status

Some evidence exists to suggest that frequent users were more likely to be unemployed compared with other callers. Bassilios et al. (2015) reported that 72% of frequent users were unemployed compared with 36% of other callers.

Living alone

Two studies investigated whether frequent users were more likely to live alone than other callers, but neither study found evidence to support this association (Bassilios et al., 2015; Lester & Brockopp, 1970). Specifically, Bassilios et al. (2015) found no difference between frequent users and other callers in rates of living alone.

Alcohol and/or drug use

Contradictory findings were reported in five studies about whether frequent users experience problems related to alcohol and/or drug use (Bassilios et al., 2015; Burgess et al., 2008; Farberow et al., 1966; Greer, 1976; Sawyer & Jameton, 1979). The Australian study by Burgess et al. (2008) reported that frequent users were less likely than other callers to drink alcohol. In contrast, Bassilios et al. (2015) reported that 35% of frequent users had a substance use disorder on the ICD-10, however this was not significantly different from other callers.

Physical illness

Physical illness was only investigated in one Australian based study and showed that frequent users were more likely than other callers to report problems related to a physical illness (Burgess et al., 2008). This was assessed by asking callers at the end of their call how much several potential problems were currently causing difficulties in their life, of which one was physical illness (Burgess et al., 2008).

3.3.2 Reasons for calling

Minimal research has been undertaken into investigating the reasons for frequent users' calls to crisis helplines. Of these studies, large discrepancies exist between whether frequent users were more likely to call in regards to issues related to social support (Burgess et al., 2008; Coveney et al., 2012; Watson et al., 2006) or mental health issues (Bassilios et al., 2015; Burgess et al., 2008; Coveney et al., 2012; Ingram et al., 2008; Spittal et al., 2015). Coveney et al. (2012) reported that frequent users called for complex,

varied reasons that go beyond mental health issues and social support. These callers used crisis helplines as part of their support network (Coveney et al., 2012).

Most of the research on the reasons for calling considered the issues raised during the call rather than asking frequent users why they had called. In fact, only in the study by Coveney et al. (2012) were callers specifically asked about the main reason for their last call. In that study, frequent users were more likely than other callers to report calling about mental health issues, self-harm, and sexual abuse (Coveney et al., 2012). First-time callers tended to report being more generally sad or low or indicated that they called about relationship problems (Coveney et al., 2012). However, 60% of the respondents to this survey reported email as their last method of contact, and only half reported contacting the service in the last month (Pollock et al., 2010). In addition, there has not been an emphasis in the research conducted on frequent users to collect data on their experience of calling crisis helplines, even though one of the common assumptions about frequent users is that they call because they are isolated and looking for someone to talk with about non-crisis related issues (see Section 3.1.1). The social support and mental health issues reported by frequent users are explored below.

Social Support

Social support was measured in three studies by whether callers reported issues related to loneliness or isolation, with inconsistent findings. It was reported in the study by Burgess et al. (2008) that 76% of frequent users reported loneliness caused difficulties in their life compared to 50% of other callers. Whereas, in the study by Coveney et al. (2012) a similar proportion of frequent users and other callers, around 5%, reported calling the helpline about loneliness and/or isolation. However, when frequent users were asked for the reason for their multiple contacts, 55% reported calling because they felt lonely and isolated (Coveney et al., 2012). No comparisons were made between frequent users and other callers in the study by Watson et al. (2006), instead it was reported that 16% of calls were related to social support. Even though it is clear from these studies that social support is a reason for many frequent users calls to crisis helplines, the inconsistent methods used in these studies makes it difficult to determine the proportion of frequent users experiencing social support issues among frequent users and how it may differ to other callers.

Mental health issues

The mental health issues experienced by frequent users was explored in six of the 19 studies, and included:

- Anxiety (Bassilios et al., 2015; Burgess et al., 2008; Kalafat et al., 2007) ;
- Confusion and overall distress (Kalafat et al., 2007);
- Depression (Bassilios et al., 2015; Burgess et al., 2008; Greer, 1976; Kalafat et al., 2007; Sawyer & Jameton, 1979);
- Panic attacks (Burgess et al., 2008);
- Personality disorders (Farberow et al., 1966);
- Possible psychosis (Farberow et al., 1966);
- Schizophrenia (Sawyer & Jameton, 1979);
- Social and simple phobias (Burgess et al., 2008); and/or
- Suicidal behaviours (Bassilios et al., 2015; Greer, 1976; Kalafat et al., 2007; Lester & Brockopp, 1970; Litman et al., 1965; Mishara & Daigle, 1997; Murphy et al., 1969; Sawyer & Jameton, 1979; Spittal et al., 2015).

Different methods were used in each of these studies to elucidate information regarding mental health issues. Methods ranged from reviewing the notes taken by the counsellor during the call (Greer, 1976; Spittal et al., 2015) through to surveying calls using validated measures (Bassilios et al., 2015; Burgess et al., 2008; Kalafat et al., 2007; Mishara & Daigle, 1997). The variation in methods has implications regarding the quality of information collected, with the findings elicited via the use of validated measures considered to be more precise as it is not the role of counsellors to diagnose a caller's mental health issues (Watson et al., 2006). Only anxiety, depression, and suicidal behaviours were examined using validated measures. The findings from these studies are reported below.

The prevalence of anxiety among callers was explored in three studies where an association with higher rates of anxiety was consistently found among frequent users compared to other callers. In the study by Burgess et al. (2008), it was reported that frequent users had significantly higher anxiety scores compared with other callers, as measured on the Goldberg Anxiety Scale (GAS). The Profile of Mood States (POMS) scale was used in the study by Kalafat et al. (2007), where frequent users were found to

be more anxious compared with other callers. Bassilios et al. (2015) reported an increase in the odds of an anxiety disorder diagnosis for frequent users on the ICD-10 criteria. Even though a different measure was used in each of these studies to identify anxiety, an association was found in all of them. The consistent result provides strong evidence to suggest an association exists between frequent use and anxiety.

Depression was also found in multiple studies to be experienced by frequent users, however, it was most likely experienced at rates similar to other callers. Validated measures were used in three studies to explore the rates of depression among callers with no difference found between frequent users and other callers (Bassilios et al., 2015; Burgess et al., 2008; Kalafat et al., 2007). Specifically, it was reported in the study by Bassilios et al. (2015) that 53% of frequent users compared with 40% of other callers were diagnosed with an affective disorder on the ICD-10. In the study by Burgess et al. (2008), the mean depression score on the Goldberg Depression Scale (GDS) was between five and six for all callers, irrespective of the number of times they called. Furthermore, Kalafat et al. (2007) found a trend towards higher levels of depression among frequent users on the POMS scale, but this difference was not statistically significant.

Frequent users were found to be just as likely as other callers to engage in suicidal behaviours. Two recent studies reported that a high proportion of frequent users disclosed engaging in suicidal behaviours around the time of calling the crisis helpline and studies reported an association between frequent use and suicidal behaviours (Kalafat et al., 2007; Spittal et al., 2015). This finding indicates that suicidality is still an issue for this group of callers.

3.3.3 Health service use

It has been assumed that frequent users called crisis helplines because they lacked access to healthcare services, yet this assumption was not supported by the empirical research. More recently, Kalafat et al. (2007) explicitly assumed that frequent users have limited access to healthcare services and therefore rely on crisis helplines for support. This study did not investigate the health service use patterns of frequent users, but rather used this assumption to justify why service providers can not turn frequent users away (Kalafat et al., 2007). Conversely, it has been reported in two recent Australian studies that most frequent users were receiving mental health treatment at the time of calling the helpline (Bassilios et al., 2015; Burgess et al., 2008;). Furthermore, it was found that frequent

users were not only visiting healthcare professionals at the time of calling the crisis helpline, they were most likely using these services at rates higher to other callers (Bassilios et al., 2015; Burgess et al., 2008). It is unclear why frequent users access both crisis helplines and healthcare services, as crisis helplines were only designed to complement healthcare services and act as a safety net when other services were not available (see Section 2.2). The Australian population-based study by Bassilios et al. (2015) reported that frequent users were more likely than other callers to visit their GP for emotional wellbeing in the past 12 months and suggested this may be occurring because their needs were not being met by the healthcare services. However, no research has been undertaken into exploring the health service use patterns of frequent users and whether their use of crisis helplines is an indication of their needs not being adequately met by other services. Further investigation is needed to explore the way in which frequent users access healthcare services and whether patterns can be found to explain why they access these services in addition to calling crisis helplines.

It is important to also acknowledge that not all frequent users of crisis helplines may be in contact with healthcare services. There may be a proportion of frequent users who lack access to any healthcare services, which was estimated in the study by Sawyer and Jameton (1979) to be around 11%. Further research is needed to accurately identify this group as they may have different needs to those frequent users who accessing healthcare services in addition to calling crisis helplines.

3.4 Research gaps

Empirical research into frequent users of crisis helplines is limited and of highly variable quality. Only three characteristics were consistently investigated across the 19 studies. The study design often restricted the variables available for analysis. In the audit studies, which drew on routinely collected data, there was a reliance on data that had been collected for administrative purposes and often had large amounts of missing data. In contrast, a wider range of variables were investigated in the purpose-designed surveys but these studies were less likely to include a representative sample of callers. If comparisons are to be made between the findings from each the studies there needs to be consistency in variables examined. Additionally, an improved definition of frequent use is required to ensure the same callers are being examined across studies. Currently, frequent users are

most often defined as calling the helpline more than once, which does not accurately distinguish frequent users from other callers. More consistency is needed around the variables examined and the way in which frequent users are identified.

A further limitation of the research into frequent users of crisis helplines is the uncertainty around whether the findings are reflective of an Australian population. Over half of the studies were dated and based in the USA. As telephone technology has dramatically advanced over the last 50 years (see Section 2.3.3), findings from over half of the studies may not be reflective of the modern frequent user. Compared to the 1960s and 1970s, when most of the research into frequent users was conducted, the number of people with access to a telephone has more than doubled. Changes in the use of telephones may also impact on the type of person calling the helpline. Furthermore, the nature of the support offered by Lifeline differs to those helplines based in the USA (see Section 2.4), which may lead to inherent differences in the characteristics of frequent users between these settings. Further research is needed into callers to crisis helplines in an Australian context. Specific research gaps in relation to the socio-demographic characteristics of frequent users, their reasons for calling and health service use need to be addressed.

3.5 Chapter summary

The aim of this chapter was to review the literature on frequent users of crisis helplines over the last 60 years. This chapter began by demonstrating that frequent users account for a substantial number of calls to crisis helplines and are thought to call about non-crisis related issues. This assumption has left service providers concerned about whether responding to frequent users prevents other callers in an immediate crisis from getting through. Furthermore, counsellors have reported feelings of frustration in their repeated attempts to respond to frequent users. These feelings have led service providers to consider different ways to approach frequent users but these approaches are not evidence-based nor do they consider the individual needs of frequent users. Nineteen studies were identified in a systematic review into the empirical literature published on frequent users of crisis helplines. The definition of frequent use varied across these studies and often did not reflect the group of callers that service providers were most concerned about. These studies were of two kinds: audits of routinely collected data and purpose-designed surveys. Many of these studies were dated and based in the USA, which may not reflect

the Australian context. Several characteristics were found to be related to frequent users of crisis helplines, yet the findings were inconsistent. Three main areas for future research were identified and included: (1) confirming the socio-demographic characteristics of frequent users in an Australian setting; (2) clarifying the reasons for frequent users calls to crisis helplines and determining whether the assumption that they call for non-crisis related support is accurate; and (3) understanding the health services accessed by frequent users and whether their use of crisis helplines is a result of unmet need. Addressing these research gaps will assist service providers develop an evidence-based approach that is designed to respond to the needs of both frequent users and other callers.

4

Methods

Chapter 4 provides an overview of the methods used in this thesis. This chapter begins with a review of the thesis aim and outlines the three research questions. These questions were developed to address the research gaps identified in Chapter 3 and required the use of both quantitative and qualitative methods. A convergent mixed methods approach was identified as an appropriate method. Three empirical studies were undertaken: Study 1 – a survey of Lifeline callers, Study 2 – interviews with Lifeline frequent users, and Study 3 – secondary analysis of data from the *diamond* study, a cohort of general practice attendees with depressive symptoms. The findings from these studies were brought together during the interpretation phase using a convergent mixed methods approach.

4.1 Thesis aim and research questions

In the previous chapter, it was demonstrated that frequent users present a unique challenge to service providers. Crisis helplines were designed to provide one-off support to callers, yet, a disproportionate number of calls come from users who call often. Minimal research has been undertaken over the last 60 years into frequent users of crisis helplines. This has meant that many aspects relating to frequent users remains unknown and service providers are unclear about how to respond to these callers. As outlined in Section 3.4, the outstanding research gaps relating to frequent users of crisis helplines concern the uncertainty around the socio-demographic profile of frequent users and their reasons for calling. This thesis sought to address these research gaps. The thesis aim and corresponding research questions are outlined below.

4.1.1 Thesis aim

The aim of this thesis was to investigate the socio-demographic characteristics of frequent users of crisis helplines and the factors driving their frequent use. This aim was operationalised through three research questions.

4.1.2 Research questions

1. What is the socio-demographic profile of frequent users' of crisis helplines?
2. What are the reasons for frequent users' continued use of crisis helplines and how do they differ to those of other callers?
3. What are the health service use patterns of frequent users of crisis helplines?

4.2 Methodological overview

The varying nature of the research questions required the use of both quantitative and qualitative methods. Three distinct studies were identified as potential ways to address these research questions. The findings would be brought together during the interpretation phase using a convergent mixed methods approach. The choice of analytical methods and use of a convergent mixed methods approach are described below.

4.2.1 Choice of analytical methods

Research question 1 sought to understand the socio-demographic profile of frequent users of crisis helplines. This required an exploration of the socio-demographic characteristics reported by frequent users and other callers. Previous research addressed similar questions by analysing administrative data (Ingram et al., 2008; Spittal et al., 2015; Watson et al., 2006). However, the validity of these findings has been criticised based on the considerable amount of missing data (Watson et al., 2006) and variations in the definition of frequent use (Johnson & Barry, 1978). A more suitable approach for investigating the socio-demographic profile of frequent users may be through the use of data collected for the specific purpose of answering the research question. As many of the socio-demographic characteristics remained stable over time (i.e., gender) they could be measured at a single time point. Quantitative data collected at a single time point was adequate to address research question 1 as it sought to understand the association of certain socio-demographic characteristics (explanatory measures) with frequent use (outcome of interest) (Liamputtong, 2010).

The outcome variable would need to distinguish frequent users from other callers, as mentioned in Section 3.2.1. For the case of callers to crisis helpline, this required a variable with several categories, most likely in some form of categorical order. Ordered logistic regression is an extension of logistic regression and is an appropriate method to use with ordered categorical outcome data (Kirkwood & Sterne, 2003). The parameters of ordered logistic regression represent the exposure odds ratios for being the highest j categories compared with the lowest ($k-j$) categories (Kirkwood & Sterne, 2003). Underlying the model is the assumption that the effect of exposure is the same for all splits of categories of the outcome variable (Kirkwood & Sterne, 2003), known as the proportional odds assumption. Namely, group 1 is compared with group 2 and group 3, and then group 1 and group 2 are compared with group 3. The final analysis is a combined estimate odds ratio (OR) demonstrating the measures of association (Hosmer, Lemeshow, & Sturdivant, 2013). Built into the statistical program STATA is the Brant test command (StataCorp, 2013), which tests whether the OR is equally distributed between groups. In the case where the proportional odds assumption is not met, other analytical methods may be more appropriate (Vittinghoff, Glidden, Shiboski, & McCulloch, 2012). To answer research question 1, a suitable outcome variable could include three ordered categories that investigates crisis helpline use based on the number of calls made to the helpline and distinguishes frequent users from other callers.

Research question 2 explored the reasons why frequent users called crisis helplines so often and how these reasons differed to other callers. This type of question lends itself to both quantitative and qualitative approaches. A quantitative approach could be used to gather insight into the types of reasons frequent users call and whether these reasons differ from other callers. This approach has been used in previous research to explore the problems raised during frequent users' calls to crisis helplines (Burgess et al., 2008). Yet, these studies did not include any questions that elucidated information from callers about their specific reasons for calling. These questions were excluded as the data had previously been collected for other purposes. Collecting data that could answer this question might have been more appropriate in this situation, which is similar to the approach taken in the study by Coveney et al., (2012). However, this information may still provide little insight into why frequent users call crisis helplines so often. The in-depth experience of a selected group of frequent users could provide information on "why" these users call often. Inductive qualitative thematic analysis is an appropriate

method to investigate user experiences (Liamputtong, 2010). Analysis is inductive as the themes emerge from the data rather than applying a pre-determined theoretical framework to the data, known as deduction (Thomas, 2006). Inductive thematic analysis includes six distinct phases, outlined in Table 4. Data for qualitative research needs to be collected for the specific purpose of research, as it allows the researcher to have more control over the quality of data collected and refine the interview schedule as data collection progresses (Creswell & Clark, 2011). This requires identifying a group of frequent users who are willing to be interviewed. One way to achieve this could be by first surveying a group of callers and then recruiting a manageable number of callers who report frequent use to participate in a follow-up interview. Linking in with the methods used to collect data to answer research question 1 could provide access to such a population.

Table 4: Phases of thematic analysis

Phase	Description of the process
1. Familiarisation with the data	Can involve the transcription of data, reading, and re-reading the data, noting down initial ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic ‘map’ of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back to the analysis of the research question and literature, producing a scholarly report of the analysis.

This table has been adapted from the one provided in Braun and Clark (2006)

Research question 3 sought to identify the health service use patterns of frequent users. Previous research struggled to identify the health service use patterns of frequent users of

crisis helplines as it was usually based on a small sample of callers and only examined data from a single time-point. A longitudinal component could be important to include as the use of healthcare services can be transitory and vary over short periods of time (Bhandari & Wagner, 2006). It could investigate the types of healthcare services used by frequent users and see whether patterns emerge over time. However, the difficulties in collecting socio-demographic information from callers has been highlighted, suggesting that it may be more difficult to collect detailed information on callers' health service use over multiple time points. Data collection could become expensive and processes to reduce attrition rates might be needed (van Weel, 2005). If suitable data were available that had previously been collected, this could address many of the challenges faced when trying to answer this research question.

Accessing a data set suitable to answer research question 3 was made possible via the *diamond* study. The *diamond* study is a longitudinal cohort study that investigated the health service use patterns of general practice attendees with depressive symptoms over ten years (see Section 4.3.3). Study 3 involved the secondary analysis of data from the *diamond* study. Even though the data used from the *diamond* study was collected 10 years ago and was not specifically collected to answer the research questions of this thesis, it provides insight into callers who visited the GP, a group who has previously been shown to be sizeable (see Section 3.3.3), and have depressive symptoms. This approach has its limitations, but based on the importance of this research gap, could provide substantial insights into an issue that is vexing for service providers.

4.2.2 A convergent mixed methods approach

Mixed methods research is a well-recognised approach used to integrate quantitative and qualitative methods. It draws upon the combined strengths of both methods (Creswell, 2015) and is appropriate when one analysis method alone provides insufficient insights into the problem. Creswell and Clark (2011) defined mixed methods research as:

“A research design with philosophical assumptions as well as methods of inquiry. As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis of data and the mixture of qualitative and quantitative approaches in many phases in the research process. As a method, it focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or series of studies. Its

central premise is that the use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone.” (p. 5)

Underlying mixed method research is the assumption that by combining quantitative and qualitative data, the collective strength of this information provides a better understanding of the problem than either form of data alone (Creswell, 2015). This assumption is based on the fact that research methods have both strengths and limitations and by combining methods, the strengths of both methods can be drawn together (Fetters et al., 2013). For example, quantitative methods provides an opportunity for generalisation of findings and precision (Fetters et al., 2013), whereas, qualitative methods offers an in-depth analysis of individuals' experiences (Liamputtong, 2010). Thus by using mixed methods, different perspectives on the same issue can be investigated and the findings can be more comprehensive than one method alone (Creswell & Clark, 2011).

Specific scientific techniques need to be followed when conducting mixed methods research (Creswell & Clark, 2011). Firstly, rigorous methods required by either quantitative or qualitative approaches must be maintained. Secondly, data needs to be integrated based on predetermined methods. Several mixed methods designs exist, which are selected based on the timing, weighting, and mixing of the quantitative and qualitative methods (Creswell & Clark, 2011).

One design, known as a convergent approach, was suited to this thesis as it allowed for quantitative and qualitative studies to be conducted separately and then merged the findings at the time of interpretation. The merging of the data allows the problem to be investigated from multiple perspectives, which may provide different insights if data were looked at separately (Creswell, 2015). As each study (described above in Section 4.2.1) addressed a specific research question, the findings could be brought together at the interpretation phase. The studies could be conducted in parallel as the results from each study would not impact on the other studies.

Using a convergent mixed methods approach is not without its limitations, which often relate to merging data. Data needs to be consistent between studies so that when findings are merged they can be compared and contrasted in a meaningful manner. It was outlined in Section 4.2.1 that the research questions could be addressed using three distinct studies.

A consistent definition of frequent use was required across the three studies. In Section 3.2.1, it was proposed that Lifeline's definition of frequent use (i.e., categorising those who called 20 times or more in a month as frequent users) would be suitable for use in this thesis. However, in the case of Study 3, it was not possible to use this definition as the data had already been collected. Instead, the most comparable definition was used and noted as a study limitation. The use of different definitions was addressed at the interpretation phase of the analysis, when the findings from the three studies were merged together. Greater weight was given to the findings from Study 1 and Study 2. Figure 3 presents a visual overview of how a convergent mixed methods approach was used to bring together the three studies in this thesis.

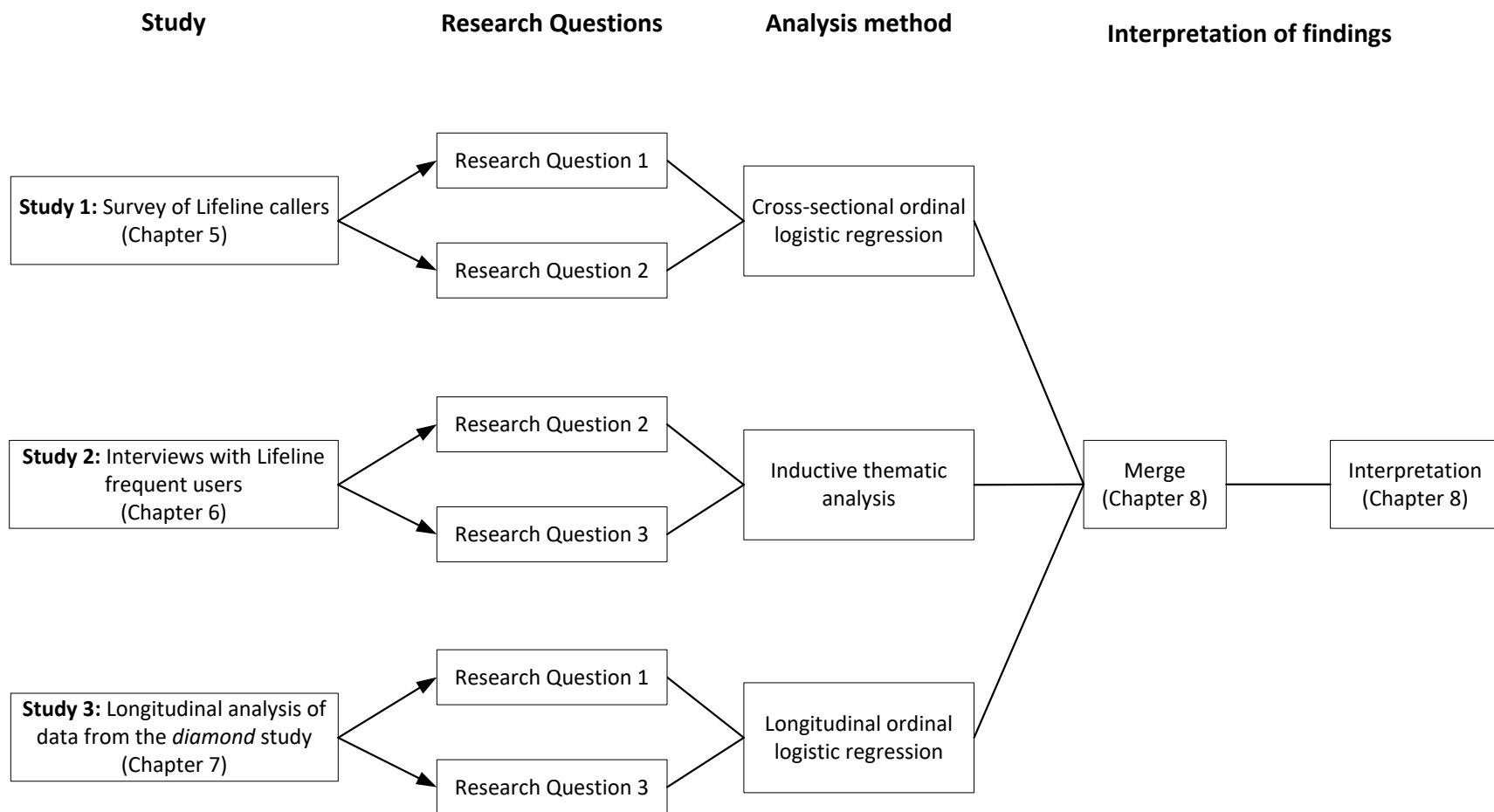


Figure 3: Visual overview of the three empirical studies

4.3 Empirical studies

As already mentioned, three empirical studies were undertaken as part of this thesis to address the research questions. Study 1 addressed research question 1 and research question 2, Study 2 addressed research question 2 and research question 3, and Study 3 addressed research question 1 and research question 3. These studies were completed as part of a broader project investigating frequent users of crisis helplines. Each study was prepared as a manuscript, which have been published. The broader project was led by Professor Jane Pirkis at the University of Melbourne. The research team included a core group of experienced health services researchers at the university (Professor Jane Pirkis, Professor Jane Gunn, Dr. Bridget Bassilios, and the PhD candidate), who were all independent to Lifeline. Mr. Alan Woodward, the Executive Director of the Lifeline Research Foundation, was also involved in the boarder project and used the survey to recruit participants for research related to his own PhD. The project was funded by Servier Australia through a competitively awarded project grant from the Lifeline Research Foundation. No funding body had a role in the study design; collection, analysis, and interpretation of data; writing of the manuscripts; or the decision to submit the manuscripts for publication.

The studies that informed the research presented in this thesis were undertaken as part of a PhD that satisfied all requirements. Strict protocols were implemented in the broader project to ensure that the PhD candidate led the research. This included the candidate conducting the literature review that formed the basis of Chapter 3, with the published review presented in Appendix 2; developing, implementing and analysing data from the survey of Lifeline callers (Study 1), the interviews with the Lifeline frequent users (Study 2), and data from the *diamond* study (Study 3).

4.3.1 Study 1: Survey of Lifeline callers

Study 1 was a brief survey administered to Lifeline callers at the end of their call between February and July 2015. A group of callers who completed the survey were also invited to take part in an in-depth interview (Study 2), described below. Figure 4 outlines the recruitment of participants into Study 1 and Study 2. The University of Melbourne Human Research Ethics Committee approved these two studies (Reference number: 1441987X), with the approval letter provided in Appendix 3. Research question 1 and research

question 2 were addressed by investigating the socio-demographic profile of frequent users and differences in their reasons for calling compared with those of episodic and one-off callers. Quantitative analyses were conducted using ordered logistic regression.

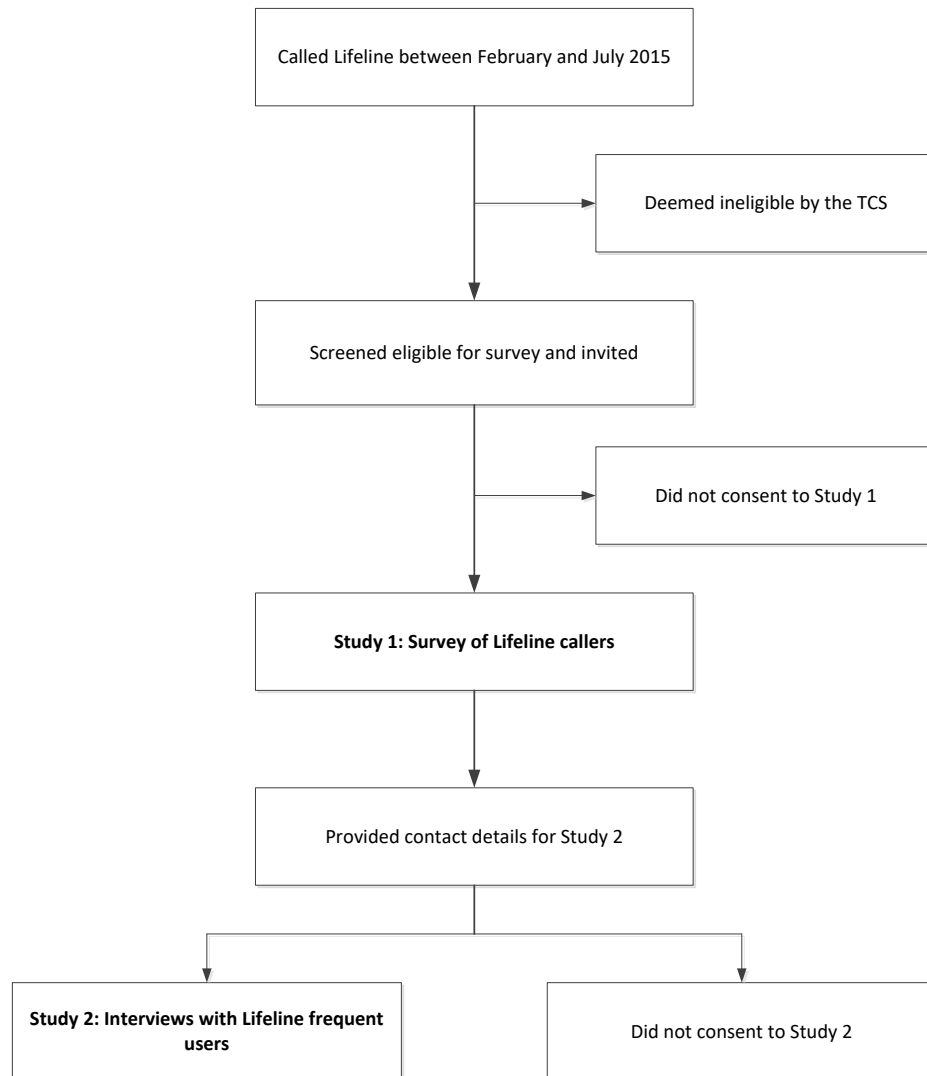


Figure 4: Recruitment of participants for Study 1 and Study 2

The brief survey was designed in a similar manner to the approach taken by Burgess et al. (2008), who also surveyed Lifeline callers at the end of their call. However, the approach used in this study was altered slightly based on feedback from the previous study. The survey was administered by Lifeline-employed supervisors rather than independent research assistants and the number of questions included in the survey was reduced. The study protocol was developed in close collaboration with staff at Lifeline, including national managers, clinical advisors, centre managers, and supervisors. Staff provided feedback on the study design and piloted components of the survey. Lifeline

staff were included to ensure the process of requesting caller participation in the research was done in a respectful, appropriate, and safe manner. The recruitment of participants is described below along with information on the variables examined, including the outcome measure.

Participants

Between 1 February and 31 July 2015, callers to two Lifeline centres were invited to complete a brief survey at the end of their call. The two centres, Harbour to Hawkesbury and Northern Beaches, both located in Sydney, New South Wales, were selected based on their capacity to answer a large volume of calls. Calls to these centres came from across the country on a randomised basis as Lifeline operates within a national network where calls are allocated to the next available answer point. The survey was administered to eligible callers over 54 randomly selected four-hour shifts. These shifts were pre-determined based on the availability of research interviewers (see below) and occurred over a range of times and days.

During each data collection shift, a trained Lifeline supervisor acted as a research interviewer and worked with a team of at least two counsellors. The research interviewers and counsellors had distinct roles: the research interviewer administered the survey, while the counsellor screened each caller for eligibility and invited them to complete the survey. The reason for distinguishing between the research interviewer and counsellor's role was to ensure callers saw a clear distinction between their crisis call and their participation in the research. Table 5 describes the roles of the counsellor and the research interviewer. For each shift, the research interviewer was specifically employed for research purposes and had no other service delivery responsibilities. In contrast, the counsellor worked in their usual crisis support role but silently screened callers during each call, using a screening template (provided in Appendix 3).

Callers were ineligible if the counsellor deemed them to be in an immediate crisis, verbally abusive, or in an unstable mental state. The screening template was used to ensure the caller was not in an immediate crisis or at risk of harming themselves. It also enabled the identification of callers who could not provide informed consent (i.e., due to intoxication or insufficient proficiency in English). For eligible callers, the counsellor introduced the study, sought their interest, and checked if they had previously completed the survey. Interested callers were passed onto the research interviewer who obtained

verbal consent and administered the survey (see Appendix 5). The whole process took around five minutes. It is important to note that even though the counsellor was provided with a screening template, they still acted as gatekeepers and had to use some subjective judgement in deciding who to invite to participate in the survey. This may have inherently excluded some eligible callers.

Table 5: Distinction between the role of the counsellor and the research interviewer for data collection purposes

Explicitly, the role of the counsellor in administering the survey was to: • Use a screening template to assess callers' eligibility. • Inform callers about the study and invite them to hear more. • Pass the phone to the research interviewer who administered the survey to eligible and interested callers. • Keep a record of the number of callers screened and invited to the study.
The role of the research interviewer in administering the survey was to: • Be employed exclusively for the study during the census period (i.e., NOT to undertake any operational supervisor or counsellor functions during the relevant shifts). • Be co-located next to the desk/phone of the counsellor (to ensure minimal disruption to normal operations). • Administer the survey once the phone was handed to them by the counsellor. • Enter the survey data into a password-protected online platform. • Briefly explain Study 2 at the end of the survey and obtain contact details from interested participants.

Six supervisors across the two centres acted as research interviewers for the duration of the study. Before data collection began, a training manual was developed and used to train the research interviewers. The training focused on the development of research interview skills and administration of the survey. The manual was first piloted during an introductory face-to-face session held at the two centres on 22 December 2014. Five supervisors from each centre attended this session and provided feedback on the study design. Minor changes were made to the protocol, which mainly reflected the functioning of these centres. These sessions also provided an opportunity to build rapport between the

researchers and the Lifeline staff. A two-hour training session was then held with a wider group of potential research interviewers and counsellors on 29 and 30 January 2015, respectively. Those who attended this session were invited to express interest in participating in data collection. The centre manager selected the final group of research interviewers and counsellors. This recruitment process was chosen in an attempt to ensure only people who were supportive of the research process were involved—a small amount of resistance was noticed from some staff. Data collection formally began on 1 February 2015 and lasted for six months. A debrief session was held at the end of data collection at the two centres, on 14 August 2015, where a preliminary summary report of the findings was presented to the centre manager, research interviewers, and counsellors.

Throughout data collection, regular communication was maintained between the researchers and the study sites. This included sending regular progress reports to the centres, detailing the spread of the data collection shifts and the number of surveys completed. These reports were used as an opportunity to prompt the centres to continue scheduling regular data collection shifts and provide feedback on the administration of the survey. This reminder was important as from time to time the number of data collection shifts was reduced and some time slots were missed.

The survey

The survey included six brief questions, four of which related to participants' socio-demographic characteristics, one to participants' use of Lifeline in the past month, and one to participants' reasons for calling on that occasion. The survey was developed specifically for this study using a systematic process. Firstly, in terms of socio-demographic characteristics, a list was made of all questions included in previous research that were shown to be associated with frequent use along with a list of the characteristics investigated in the *diamond* study (see Section 3.3.1). The main socio-demographic characteristics were selected from these lists and included. Secondly, a list was made of all previous questions that asked about the number of calls made to the helpline. The question included in the study by Burgess et al. (2008), regarding number of calls made, was chosen as it included the same categories needed to apply the Lifeline definition of frequent use (see Section 3.2.1). Thirdly, in terms of questions about reasons for calling, it was found that no such measure had been included in previous research. Therefore, a question specific to this study was developed that elicited this information and included

eight potential statements based on previously suggested reasons for frequent users calls to crisis helplines. These questions were piloted with the staff at Lifeline and minor revisions were made to the wording of the questions.

Research interviewers accessed the survey via REDCap (Research Electronic Data Capture), an online platform. REDCap is maintained at the University of Melbourne (Harris et al., 2009) and is a secure, web-based application designed to support data capture for research studies, providing: 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources. Each research interviewer was provided with a unique password, which allowed them to access the online survey and enter data. The website where data were stored was also password-protected and only accessible by the University of Melbourne research team. The online platform allowed the researchers to track the progress of data collection in real time and address any issues with data collection as they arose. This database was also used to identify potential participants for Study 2 (described below in Section 4.3.2).

Outcome variable

The first question of the survey asked participants about how often they had called Lifeline in the past month with six response options available: once/just today, twice, 3-5 times, 6-10 times, 11-19 times, and 20 or more times. Participants were then categorised into three groups based on their response to this question: one-off users (once/just today), episodic users (2-19 times), and frequent users (≥ 20 times).

Explanatory measures

Data on the following socio-demographic characteristics were collected: gender, age, language, Aboriginal or Torres Strait Islander origin, usual living arrangements, and employment status. Gender responses were male, female, and intersex; however, intersex was dropped in the analysis as it was only reported by one participant. Age was categorised into four groups: <25 years, 25-44 years, 45-65 years, and >65 years. Primary language was measured by whether participants reported English as their first language (yes/no). Aboriginal and/or Torres Strait Islander origin was summarised as a binary variable (yes/no). The brief nature of the survey prevented the inclusion of any detailed questions regarding callers' ethnicity. Instead, only those callers who were of Aboriginal

and/or Torres Strait Islander origin were identified as little is known about whether these individuals call crisis helplines. Usual living arrangements were classified in terms of whether participants reported living alone or not. Employment status in a usual week was summarised as: employed/studying (full/part time employment, studying, self-employed), not in paid employment (home duties with no paid work, retired, unemployed/looking for work), or being unable to work due to sickness or disability.

Regarding reasons for calling, participants were asked what prompted their call to Lifeline on that occasion. Eight potential statements were provided and participants could select all that applied. As already mentioned, the eight statements were developed specifically for this study and were informed by the literature (Bassilios et al., 2015; Burgess et al., 2008; Coveney et al., 2012; Middleton, Pirkis, Chondros, Bassilios, & Gunn, 2016; Watson et al., 2006). The draft set of statements were first developed and then refined after feedback from Lifeline personnel. The final statements were: 1) my usual health professional was not available; 2) a health professional suggested I call Lifeline; 3) a family member or friend suggested I call Lifeline; 4) I was in an immediate crisis; 5) I have been feeling very nervous, anxious or depressed; 6) I did not have a lot of hope about the future; 7) there was nobody else I could talk to; and 8) I regularly call Lifeline to talk about how I am feeling. An “other” response with a free text option was also provided, which was re-coded during data cleaning.

Data analysis

Ordered logistic regression was used to examine the association between frequency of use and reasons for calling in both univariate and multivariate models. Callers were categorised into three groups: one-off callers (called once in the past month); episodic callers (called 2-19 times in the past month); and frequent users (called >20 times in the past month). Age, sex, employment status, and living arrangements were adjusted for in the multivariate model. English as the first language and Aboriginal and/or Torres Strait Islander origin were not included in the multivariate model as there was limited variance in the responses to these questions. Estimates for the associations were reported as cumulative odds ratios with 95% confidence intervals. The ordered logistic regression model relies on the proportional odds assumption, which assumes that the odds ratios are constant for each of the splits of the categories in the outcome (that is, comparing the odds of “Frequent users and Episodic users” to “One-off users”, and “Frequent users” to

“Episodic users and One-off users” for each sub-group of the explanatory variables to a reference group). This assumption was satisfied for all explanatory variables as assessed by the Brant test. All statistical analyses were conducted using STATA version 13 (StataCorp, 2013).

4.3.2 Study 2: Interviews with Lifeline frequent users

Study 2 was an in-depth interview study conducted with a sub-group of Lifeline callers who completed the brief survey for Study 1. Nineteen semi-structured interviews were undertaken with callers who reported in the brief survey to have called Lifeline 20 times or more in the past month and provided their contact details. Research question 2 was addressed in this study by examining the interview transcripts to explore why some users may call crisis helplines frequently. Research question 3 was also investigated by asking participants about their use of healthcare services. Transcripts were analysed using inductive thematic analysis to generate common themes.

Participants

Potential participants were identified from a question included at the end of the survey (Study 1) that asked callers whether they were interested in participating in an in-depth study looking at their experience with Lifeline (see Appendix 5). Interested participants were required to provide their contact details (name and either a phone number or email address). This information was saved into REDCap and checked at the start of each day. Participants who expressed interest in participating in the follow-up interview, reported calling 20 times or more in the past month, and provided their contact details were included in the study.

Potential participants were contacted and interviewed between February and August 2015. Eligible callers were contacted within one day of completing the survey and provided with additional information about the study. A plain language statement was sent out after a mailing address was obtained from interested callers. These callers were recontacted one week later to answer any questions and confirm their participation. For those who were interested, a time was scheduled for the interview to be conducted over the telephone. On the day of the interview, before starting the interview, the key requirements of the study were read and verbal consent was obtained. All interviews were conducted over the telephone, allowing for a maximum number of participants to be reached within the study period. All interviews were audio recorded and transcribed

verbatim. A limitation of this study was that only participants who had completed the survey were eligible to participate, which may have excluded some callers. As callers were required to initially provide basic personal information to the research interviewer, some may have been deterred even though confidentiality was assured.

Sixty-nine participants completed the survey (Study 1) and reported frequent use. Thirty-four of these participants provided their contact details and were approached for Study 2. Of these participants, 19 were interviewed, eight could not be contacted after multiple attempts, and seven declined participation. Reasons for non-participation included being too busy, no longer being interested, and, in one case, not being able to provide informed consent. Figure 5 presents the recruitment of participants into this study. All participants who had completed Study 1, reported frequent use, provided their contact details, and consented to the study, were interviewed. No differences were observed between the socio-demographic characteristics of participants who were interviewed and those who declined participation. Interview duration ranged from 19 to 91 minutes, with an average of 38 minutes.

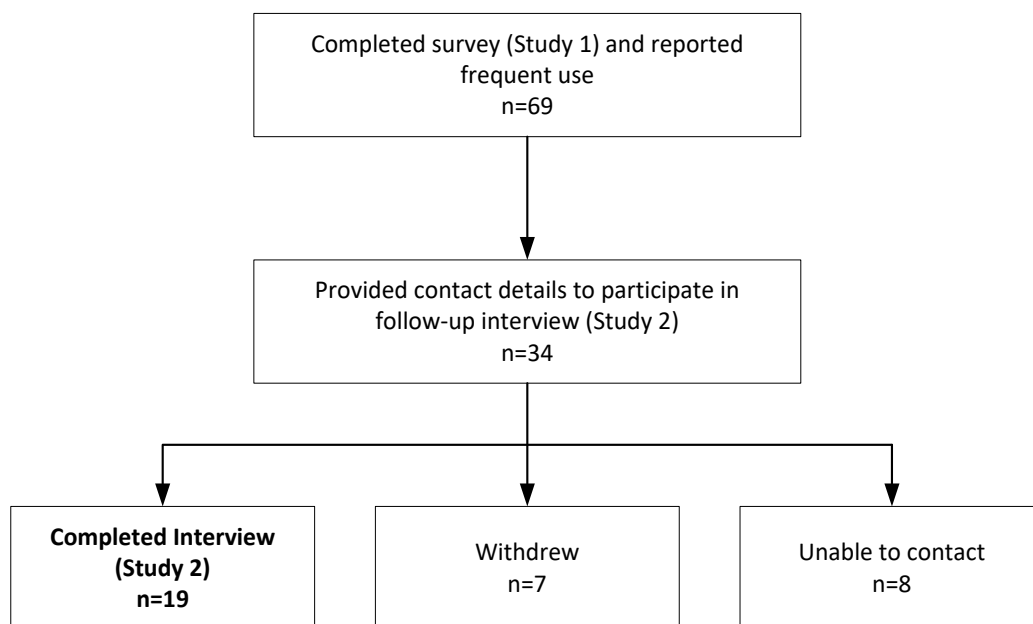


Figure 5: Recruitment of Study 2 participants

Interview schedule

Interviews were semi-structured and guided by an interview schedule (see Appendix 6). This schedule was developed using appropriate methods outlined in the literature (Denzin & Lincoln, 2011). Based on this method, other studies that involved interviews

about participants' experience with using a healthcare service were considered. Questions were worded in a way to encourage open-ended responses rather than yes/no responses and kept broad enough to capture a range of experiences (Denzin & Lincoln, 2011).

The interview schedule went through several iterations before being finalised. Firstly, a draft interview schedule was developed by the research team using other studies as an example. Secondly, the schedule was shown to several staff at Lifeline who provided their feedback. Thirdly, the schedule was revised by the research team and submitted to the ethics committee as part of the study ethics application, which was approved with minor revisions. Fourthly, the transcripts from the first two interviews were reviewed by the research team who made no further changes. The final schedule included 27 questions, which asked participants about what prompted them to call Lifeline, how they used the service, and their experience of calling. Participants were also asked about their use of other helplines and healthcare services. The survey concluded with asking participants to share a story of their recent experience with calling Lifeline in an attempt to capture any information which may have been missed in the interview.

Data analysis

Inductive thematic analysis was used in Study 2 to explore why some users call crisis helplines frequently (Braun & Clarke, 2006; Pope, Ziebland, & Mays, 2000). Transcripts were anonymised and imported into NVivo 11 Software (QSR International Pty Ltd., 2015). Each transcript was analysed in its entirety and emerging themes were constantly compared across transcripts to ensure interpretation remained grounded in the data. Data analysis was conducted with the support of the wider research team (outlined in Section 4.3). Initially, five transcripts were coded and the emerging themes were discussed with the other researchers. The research team identified three overarching themes from the data and developed a conceptual framework. These themes centred on participants' reasons for calling, the response they received from Lifeline, and the calling behaviours they described. Using this framework, an additional five transcripts were coded and no new themes were found. The conceptual framework was then reviewed by the research team who independently applied it to the first five transcripts. Minor coding discrepancies were resolved through discussions among the team. The conceptual framework was slightly revised and this version was used to recode all of the transcripts. All interviews were included in the analysis; there were no disconfirming cases

4.3.3 Study 3: Longitudinal analysis of data from the *diamond* study

Study 3 was a secondary analysis of data from the Diagnosis, Management, and Outcomes of Depression in Primary Care (*diamond*) study. Data were taken from the first year of follow up, collected in 2006, at three month intervals. At each time point, participants reported on their use of healthcare services, which included use of crisis helplines, along with information on their socio-demographic characteristics, mental and physical health. Research question 3 was addressed by identifying the relationship between frequent use of crisis helplines and health service use patterns over time, particularly use of general practice services. This decision was made on the grounds that GPs provide the majority of mental healthcare in Australia and specialist services are, for the most part, only accessible through referrals from GPs (Sikorski, Lupp, König, van den Bussche, & Riedel-Heller, 2012). Research question 1 also considered the characteristics of participants. Crisis helpline use (no use, non-frequent use, frequent use) was measured at 3, 6, 9, and 12 months and analysed using ordered logistic regression.

diamond was a longitudinal cohort of general practice attendees with depressive symptoms. The study began in 2005 and after ten years of follow-up data collection concluded in 2016. It was the largest and longest running prospective study of general practice attendees with depressive symptoms in Australia, and one of the largest in the world, making it a unique resource. *diamond* provides comprehensive information about people with depressive symptoms in Australian primary healthcare and the response from general practice. The aim of *diamond* was to document the experiences, health outcomes, treatment, and service use of a cohort of general practice patients identified by a depression screening process (Gunn et al., 2008). *diamond* was led by Professor Jane Gunn at the University of Melbourne. The research team included investigators from the University of Melbourne, the University of Liverpool, the University of Newcastle, and Swinburne University of Technology. The *diamond* study was initiated with pilot funding from the *beyondblue* Victorian Centre of Excellence in Depression and Related Disorders and the main cohort was funded through project grant funding from the Australian National Health and Medical Research Council (IDs 299869, 454463, 566511, and 1002908). *diamond* was approved by the University of Melbourne Human Research Ethics Committee (Reference number: 030613X).

Before starting this doctoral research, the PhD candidate worked full-time as a research assistant on *diamond* since June 2010 and was responsible for coordination and day-to-day management. Responsibilities included management of the participant tracking system, overseeing the casual research assistants, coordinating team meetings, participation in the data collection process, preparing and facilitating study communication and dissemination, and ongoing research support. While undertaking this doctoral research, the PhD candidate continued to be involved with data collection as a casual research assistant and administered the telephone interview with study participants.

Participants

Seven hundred and eight-nine general practice attendees with depressive symptoms were recruited in 2005 from 30 general practices in Victoria, Australia. Participants were required to be aged between 18 and 75 years of age and visited their GP in the past year. Participants were screened for depressive symptoms using the Centre for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977) and recruited if they scored 16 or above on this scale. They were followed at baseline, 3, 6, 9, and 12 months, and annually thereafter. At each time point participants were required to complete a written survey and a computer assisted telephone interview (CATI).

As outlined in Figure 6, minimal attrition was observed over the first year of follow up. Briefly, of the 789 participants who were recruited into the *diamond* cohort at baseline, useable surveys were returned by 668 participants at three-months, 634 participants at six-months, 612 participants at nine-months, and 563 participants at 12-months. Loss to follow-up in the first year was associated with not being able to manage on their available income, screening positive for panic syndrome on the PHQ, or reporting childhood abuse.

Outcome variable

The outcome was frequency of telephone helpline use over a three-month period. The question was included as part of the Client Service Receipt Inventory that assesses mental health service use and was adapted for use in the general practice setting (Chisholm et al., 2000). Specifically, participants were asked at each time point “*how often they had used telephone helplines for depression, stress or worries in the past three months*”. This outcome was measured at 3, 6, 9, and 12 months in the first year (see Appendix 9, 3-month survey question E9). Participants reported their telephone helpline use on a five-

point scale (never, rarely, monthly, a few times a month, once a week or more), which was categorised at each time point into three ordered categories: (i) no use (never); (ii) non-frequent use (rarely, monthly or a few times a month); (iii) frequent use (once a week or more). These categories were selected as based on the data available from the *diamond* study they were the most comparable to the definition used in Study 1 and Study 2.

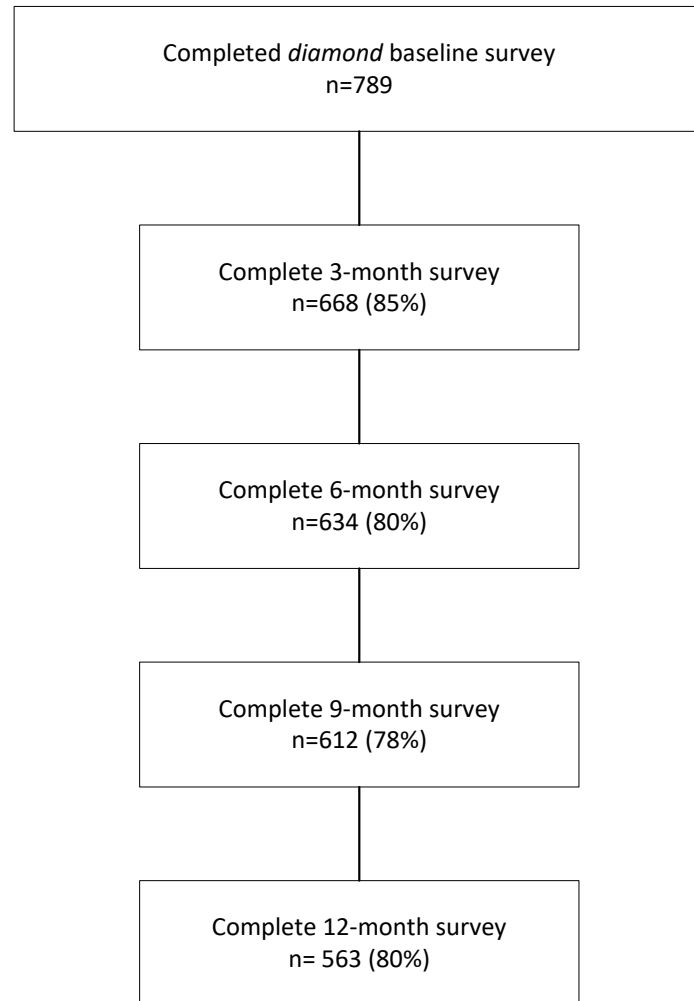


Figure 6: Study 3 response rate over the first 12-months of follow up

Explanatory measures

In this study, only data from the first year of follow-up was considered as it was collected at three-month intervals. A range of socio-demographic characteristics and clinical factors reported by study participants were examined at baseline and at each time-point. The explanatory measures included in this study were selected based on those variables that were available in the *diamond* study and had previously been examined in research into frequent users of crisis helplines or were known to be relevant to health service use

patterns. These factors included socio-demographic characteristics, physical and mental health factors, medication related items, and health service use variables (see Appendix 9). Explanatory variables were measured at different time points: some were only measured once (usually at baseline) and did not vary, called time-independent variables; while other variables, which were measured at each time point and could vary over time, called time-dependent variables. Time-dependent explanatory variables were measured at the same time point as the outcome variable. The list of variables, the way they were coded, and the time-point at which they were measured is presented in Appendix 8, with a brief description presented below.

Socio-demographic characteristics included age, gender, living arrangements, ability to manage on available income, and social support. Gender and age in years were measured at baseline. Age was categorised into three groups: 18-34, 35-54, and 55-76 years. Usual living arrangements were assessed at each time point and identified those who lived alone (yes/no). Ability to manage on available income was measured on a five point Likert scale at baseline and categorised to a dichotomous variable: difficult some of the time/difficult all of the time/impossible to manage, and, easily/not bad to manage. Social support was measured at baseline using a question taken from the psycho-social stressors module in the Patient Health Questionnaire (PHQ) (Spitzer, Kroenke, & Williams, 1999). This question identified participants who were “*bothered by having no one to turn to when they had a problem*” with three response options: not at all bothered, bothered a little, and bothered a lot.

Measures of physical health included chronic disease and self-rated health. Chronic disease was measured at baseline by asking participants whether they had any long-term illness, health problem or disability, which limited their daily activity or the work they could do (including problems due to old age). This question was taken from the 2001 UK Census (Sturgis, Thomas, Purdon, Bridgwood, & Dood, 2001) and reported as a binary (yes/no) variable. Self-rated health was measured at each time point using a question from the Short-Form 12 survey (SF-12) (Ware, Kosinski, & Keller, 1998). The question was “*in general, would you say your health is...?*” and included five response options, which were dichotomised into a binary variable: poor/fair, good/very good/excellent.

Mental health factors included anxiety, major depressive syndrome, personality disorder, and suicidal thoughts. The PHQ was used to measure both anxiety and major depressive

syndrome (Spitzer et al., 1999). Anxiety was measured at baseline using the 6-item PHQ other anxiety module and assessed using an algorithm that follows the DSM-IV criteria for Generalised Anxiety Disorder (Spitzer et al., 1999) and included those participants who reported being bothered by feeling nervous, anxious, on edge, or worried a lot about different things in the past four weeks. Major depressive syndrome was measured using the PHQ-9 (Spitzer et al., 1999), which is scored via the algorithm method that dichotomises responses into two categories: no major depressive syndrome, and major depressive syndrome. Participants were screened for the probability of meeting criteria for a personality disorder at 3-year follow up. Unlike the other variables, the Standardised Assessment of Personality – Abbreviated Scale (SAPAS) (Moran et al., 2003), validated for use in routine clinical settings, was not administered in the first year. However, previous research has shown that personality disorder symptoms begin in late childhood, so using this screener after the outcome variable was considered a reasonable means of identifying most people with a high probability of meeting criteria for a personality disorder (Lieb, Zanarini, Schmahl, Linehan, & Bohus, 2004). Suicidal thoughts were used as a proxy measure for suicide risk, which was assessed via item nine of the PHQ-9 (Spitzer et al., 1999) at each time point. This item enquired whether over the past two weeks the participant was “*bothered by thoughts that they would be better off dead or of hurting themselves in some way*”. The four response choices were dichotomized into: no suicidal thoughts (not at all), suicidal thoughts present (several days/more than half the days/nearly every day).

Medication related items were identified from responses provided at each time point to the question “*During the past 3 months, what medications have you been prescribed for your emotional wellbeing?*” Medication names had previously been coded by a research pharmacist into larger medication categories that included antidepressants and antipsychotics. The prescription of these two medication types were reported as binary (yes/no) variables.

Questions specific to health service use were developed by the *diamond* research team to capture participants’ use of healthcare services and measured at 3, 6, 9, and 12-month time points. These questions were based on the Client Service Receipt Inventory (see page 88) (Chisholm et al., 2000). Participants were asked whether they had visited a GP (yes/no), a psychologist (yes/no), a psychiatrist (yes/no), or the emergency department

(yes/no) in the past three months. Based on the responses to these four questions a composite variable was created that identified participants who had visited the GP and one or more of the other health professionals in the past three months vs. only visited the GP. People who did not report visiting the GP in the past three months were excluded from this composite variable. A five-point Likert scale was used to assess participants' satisfaction with access to health services, measured at each time point. This question was taken from the WHOQoL-Bref (Hawthorne, Herrman, & Murphy, 2006) and responses were sorted into three categories: very satisfied/satisfied, neither satisfied nor dissatisfied, and very/fairly dissatisfied.

Details about visits to the GP were measured for those participants who reported visiting the GP in the past three months. This included the number of GPs visited (count), the number of visits made to their usual GP (count), the number of visits made to the GP for any reason (count), and the number of visits to the GP for emotional wellbeing (count). The average length of visit was reported as a categorical variable with three categories: $\leq$ 6 minutes, 7 – 19 minutes, or $\geq$ 20 minutes, which aligned with standard Medicare Benefits Schedule item numbers for general practice visits in Australia (Department of Health, 2014b). The survey also enquired whether participants changed their usual GP in the past three months (yes/no) and whether they reported that their GP had done any of the following in the past three months: provided reassurance, encouragement, and explanation (yes/no); given them a chance to talk about how they were feeling (yes/no); helped them talk through their problems (yes/no); given them information (leaflets, booklets or videos) about depression, stress or worries (yes/no); or made a suggestion or referral for them to see another health professional for their emotional wellbeing (yes/no). The helpfulness of the GP in addressing their emotional wellbeing was measured using a five-point Likert scale and reported as a categorical variable: not at all helpful, slightly/moderately helpful, very/extremely helpful.

Data analysis

Data were analysed for participants who completed the telephone helpline use question at least once over the first year (3, 6, 9, and 12 months). The frequency of telephone helpline use was ordered and summarised at each time point. Ordered logistic regression was used to examine the association between telephone helpline use and each explanatory variable. Quantitative data can be clustered at several levels and needs to be accounted

for in the analysis (Rabe-Hesketh & Skrondal, 2012). In the case of this study, data were clustered at both the level of recruitment (i.e., 30 general practices across Victoria, Australia) and at the level of the individual, as the measures were repeated over the first year of analysis. Therefore, the time point that the outcome was measured was included as a fixed effect in the model. In addition, generalised estimating equations (GEEs) with the individual as the cluster were used to account for the correlation of data from repeated measures on the same individual (Nauhaus, 1992). Estimates for the associations were reported as cumulative odds ratios with 95% confidence intervals. The ordered logistic model relies on the proportional odds assumption, which assumes that the odds ratios are constant for each of the splits of the categories in the outcome (that is, comparing the odds of “Frequent use and Non-frequent use” to “No use of telephone helplines”, and “Frequent use” to “Non-frequent use and No use of telephone helplines” for each subgroup of the explanatory variable to a reference group). This assumption was satisfied for all explanatory variables when tested using the Brant test. All statistical analyses were conducted using STATA version 13.1 (StataCorp, 2013).

4.4 Chapter summary

This chapter provided an overview of the methods used in the empirical research conducted as part of this thesis. It began with the thesis aim and research questions, which were developed to address the research gaps established in Chapter 3. Three studies were conceived to address the research questions, which included both quantitative and qualitative methods. Study 1 was a brief survey of Lifeline callers that investigated the socio-demographic profile of frequent users and differences in their reasons for calling compared with other callers. Study 2 was an interview study conducted with a sub-group of callers to Lifeline who completed the brief survey and drew on inductive thematic analysis to understand why some users may call crisis helplines frequently. Study 3 included a longitudinal analysis of data from the *diamond* study and used ordered logistic regression to examine the relationship between frequent use of crisis helplines and health service use patterns over time. A convergent mixed methods approach was used to bring together the findings from these studies during the interpretation phase of analysis. Each of these studies was prepared as a journal manuscript and published in peer-reviewed journals. The published versions of these manuscripts are presented in the next three chapters with the findings from the three studies brought together in Chapter 8.

5

Study 1: Survey of Lifeline callers

Chapter 5 presents Study 1, a brief survey completed by callers to Lifeline at the end of their call between February and July 2015. Survey data were used to investigate the socio-demographic profile of frequent users of crisis helplines and differences in their reasons for calling compared with other callers. The main findings from this study were presented in the manuscript titled: *How do frequent users of crisis helplines differ from other users regarding their reasons for calling? Results from a survey with callers to Lifeline, Australia's national crisis helpline service*. This manuscript was published in *Health and Social Care in the Community* and is included here. The chapter concludes with a summary of the key findings related to research question 1 and research question 2, which were addressed in this study.

5.1 PDF of manuscript

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How do frequent users of crisis helplines differ from other users regarding their reasons for calling? Results from a survey with callers to Lifeline, Australia's national crisis helpline service

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What is known about this topic

- Frequent users account for a significant proportion of calls to crisis helplines.
- Service providers are unclear about how they should respond to frequent users of crisis helplines.
- Frequent users may be calling about social support and/or mental health issues but this has not previously been specifically investigated.

What this paper adds

- This is the first study to identify that frequent users are more likely than other users to call because they are seeking ongoing emotional support.
- Frequent users call crisis helplines for reasons that are at odds with the one-off service model.
- A better understanding of why frequent users seek ongoing emotional support from crisis helplines is needed.

Abstract

Crisis helplines are designed to provide short-term support to people in an immediate crisis. However, there is a group of users who call crisis helplines frequently over an extended period of time. The reasons for their ongoing use remain unclear. The aim of this study was to investigate the differences in the reasons for calling between frequent and other users of crisis helplines. This was achieved by examining the findings from a brief survey completed by callers to Lifeline Australia at the end of their call between February and July 2015. In the survey, callers reported on their socio-demographics, reasons for their current call and number of calls made in the past month. Survey respondents were categorised as frequent, episodic and one-off users, and analyses were conducted using ordered logistic regression. Three hundred and fifteen callers completed the survey, which represented 57% of eligible callers. Twenty-two per cent reported calling 20 times or more in the past month (frequent users), 51% reported calling between 2 and 19 times (episodic users) and 25% reported calling once (one-off users). Two per cent were unable to recall the number of calls they made in the past month. Frequent users reported similar reasons for calling as other users but they were more likely to call regularly to talk about their feelings [OR = 6.0; 95% CI: 3.7–9.8]. This pattern of service use is at odds with the current model of care offered by crisis helplines which is designed to provide one-off support. There is a need to investigate further the factors that drive frequent users to call crisis helplines regularly.

Keywords: crisis helplines, crisis resolution, frequent users, health service research, survey research

Introduction

Crisis helplines lie at the forefront of community crisis support services (Gould *et al.* 2012, Knowles *et al.* 2014). They offer short-term 24-hour telephone support to individuals experiencing a personal crisis (Farrer *et al.* 2011, Coveney *et al.* 2012). This support is designed to assist callers to strengthen their personal coping strategies, alleviate immediate distress and provide pathways to access other relevant services (Barber *et al.* 2004, Kalafat *et al.* 2007). It is intended to complement traditional

healthcare services (Gould *et al.* 2012) and to be a one-off or single session service (Coman *et al.* 2001, Kalafat *et al.* 2007). However, crisis helplines around the world have identified that some individuals use these services on a frequent basis (Middleton *et al.* 2014).

Frequent users of crisis helplines are of particular concern as they account for a significant proportion of calls (Gilat & Rosenau 2011, Spittal *et al.* 2015). The precise number of calls made by frequent users is unclear; however, one recent study found that 60% of calls to a national crisis helpline service were made by individuals who called 20 times or more in the preceding month (Spittal *et al.* 2015). Frequent users' pattern of service use is considered by many service providers as inappropriate and is associated with feelings of frustration (Kinzel & Nanson 2000, Gilat & Rosenau 2011) and burnout (Cyr & Dowrick 1991) among crisis helpline counsellors. However, service providers struggle to know how to best respond to the needs of frequent users (Leuthe & O'Connor 1980, Hall & Schlosar 1995, Middleton *et al.* 2014) as it is unclear what support they are seeking (Kinzel & Nanson 2000, Gilat & Rosenau 2011). An improved understanding of the reasons why frequent users call crisis helplines and whether alternative service models might better meet their needs is required.

Previous research has presented conflicting explanations regarding the reasons for frequent users' calls to crisis helplines. Some studies found that frequent users call seeking social support (Bartholomew & Olinyk 1973, Watson *et al.* 2006, Burgess *et al.* 2008), whereas other studies reported that frequent users call about their mental health issues (Burgess *et al.* 2008, Ingram *et al.* 2008, Coveney *et al.* 2012, Bassilios *et al.* 2015, Spittal *et al.* 2015). Each of these reasons would require a different response from service providers. However, only one of these studies was specifically designed to investigate the reasons why frequent users call (Coveney *et al.* 2012). This study used an online survey methodology asking respondents to report on a previous call to a crisis helpline, such a method introduces the possibility of recall bias (Coveney *et al.* 2012). There is a need for research that specifically investigates the reasons driving frequent users to call crisis helplines.

This study aimed to investigate the differences in the reasons for calling between frequent and other users of crisis helplines. These differences were investigated among a group of callers to Lifeline 13 11 14, the largest national crisis helpline service in Australia (Barber *et al.* 2004, Watson *et al.* 2006). Lifeline consists of 41 centres that operate within a national network (Coman *et al.* 2001, Lifeline Australia 2015) and

is staffed by a combination of trained volunteers and paid employees who act as Telephone Crisis Supporters (TCSs) (Barber *et al.* 2004, Spittal *et al.* 2015).

Methods

Design

Individuals who called Lifeline between February and July 2015 were invited to complete a survey at the end of their call. The survey was administered during 54 randomly selected 4-hour shifts at two Lifeline centres. These centres were selected based on their capacity to answer a large volume of calls. The Lifeline service operates within a national network that allocates calls to the next available answer point, ensuring callers were approached for the research study on a randomised basis. Six supervisors at the two centres acted as research interviewers for the duration of the study. Research interviewers were trained by AM and AW in research interviewing skills and administration of the survey. The research interviewers worked with a team of at least two TCSs during each shift to recruit callers.

At the end of each call, the TCS screened callers and invited eligible callers to complete a brief survey about their experiences with Lifeline. Callers were ineligible if the TCS deemed them to be in an immediate crisis, verbally abusive or in an unstable mental state. The exclusion criteria were developed to ensure the safety of vulnerable and distressed callers. Callers were also excluded if they were under 18 years of age or unable to converse in English. Callers who reported they had not previously completed the survey and were interested were then passed on to the research interviewer who obtained their verbal consent and administered the survey, which is may be found under supporting information.

This survey was conducted as part of a larger study investigating the outcomes for users of Lifeline and to explore the factors that influence these outcomes. Ethics approval was granted by The University of Melbourne's Human Research Ethics Committee (ID: 1441987.2).

Classification of crisis helpline users

Respondents were asked how often they had contacted Lifeline in the past month with six response options available: once/just today; twice; 3–5 times; 6–10 times; 11–19 times; and 20 or more times. Based on their response to this question, respondents were categorised into three groups: one-off users (once/just today); episodic users (2–19 times); and frequent

users (≥ 20 times). These categories were selected as they reflect Lifeline's current classification of users; in particular, Lifeline defines a frequent user as someone who calls the service 20 times or more in a month (Spittal *et al.* 2015).

Socio-demographic characteristics

The survey collected data on the following socio-demographic characteristics: gender, age, language, Aboriginal or Torres Strait Islander origin, usual living arrangements and employment status. Gender responses included male, female and intersex; however, intersex was dropped in the analysis as it was reported by only one respondent. Age was categorised into four groups: <25 years, 25–44 years, 45–65 years and >65 years. Primary language was measured by whether respondent's reported English as their first language (yes/no). The brief nature of the survey prevented us from including a detailed question regarding caller's ethnicity. Instead, we were specifically interested in identifying those callers who were of Aboriginal and/or Torres Strait Islander origin as these individuals are at increased risk of suicide (Sveticic *et al.* 2012). Aboriginal and/or Torres Strait Islander origin was summarised as a binary variable (yes/no). Usual living arrangements were classified in terms of whether respondents reported living alone or not. Employment status in a usual week was summarised as: employed/studying (full-/part-time employment, studying, self-employed), not in paid employment (home duties with no paid work, retired, unemployed/looking for work), or being unable to work due to sickness or disability.

Reasons for calling Lifeline

The survey asked respondents about the reasons that prompted their call to Lifeline on that occasion. They were provided with eight potential statements and were able to select all that applied. The eight statements were developed specifically for this study and were informed by the literature (Watson *et al.* 2006, Burgess *et al.* 2008, Coveney *et al.* 2012, Bassilios *et al.* 2015, Middleton *et al.* 2016). We first developed a draft set of statements which were later refined based on feedback from several Lifeline personnel. The final statements included: (i) my usual health professional was not available; (ii) a health professional suggested I call Lifeline; (iii) a family member or friend suggested I call Lifeline; (iv) I was in an immediate crisis; (v) I have been feeling very nervous, anxious or depressed; (vi) I did not have a lot of hope about the future; (vii) there was nobody else I could talk to;

and (viii) I regularly call Lifeline to talk about how I am feeling. An 'other' response with a free text option was also provided, which was re-coded during data cleaning.

Statistical analysis

Ordered logistic regression was used to examine the association between frequency of use and reasons for calling in both univariate and multivariate models. Age, sex, employment status and living arrangements were adjusted for in the multivariate model. English as the first language and Aboriginal and/or Torres Strait Islander origin were not included in the adjusted model due to the limited variance in responses. Estimates for the associations are reported as cumulative odds ratios with 95% confidence intervals. The ordinal logistic regression model relies upon the proportional odds assumption, which assumes that the odds ratios are constant for each of the splits of the categories in the outcome (i.e. comparing the odds of 'Frequent users and Episodic users' to 'One-off users', and 'Frequent users' to 'Episodic users and One-off users' for each sub-group of the explanatory variables to a reference group). This assumption was satisfied for all explanatory variables when tested using the Brant test. All statistical analyses were conducted using Stata version 13 (StataCorp 2013).

Results

A total of 2,977 calls were answered across the two centres during the 54 shifts (see Figure 1). Of these calls, the TCSs screened 990 callers, of whom 417 (42%) were deemed to be ineligible, 244 (25%) declined to participate, and 329 (33%) provided consent. Reasons for non-participation included: previously completing the survey ($n = 43$; 4%); not interested ($n = 183$; 18%); and the need to wait due to lack of research interviewer immediate availability ($n = 18$; 2%). Of the 329 callers who agreed to participate, 14 (4%) withdrew before completion and 315 (96%) completed the survey. Fifty-seven per cent of eligible callers completed the survey.

Classification of crisis helpline users

Of the 315 respondents who completed the survey, 69 (22%) were classified as frequent users, 162 (51%) as episodic users and 79 (25%) as one-off users. Five respondents were unable to recall the number of times they called in the past month. The distribution of callers by user group is presented in Figure 2.

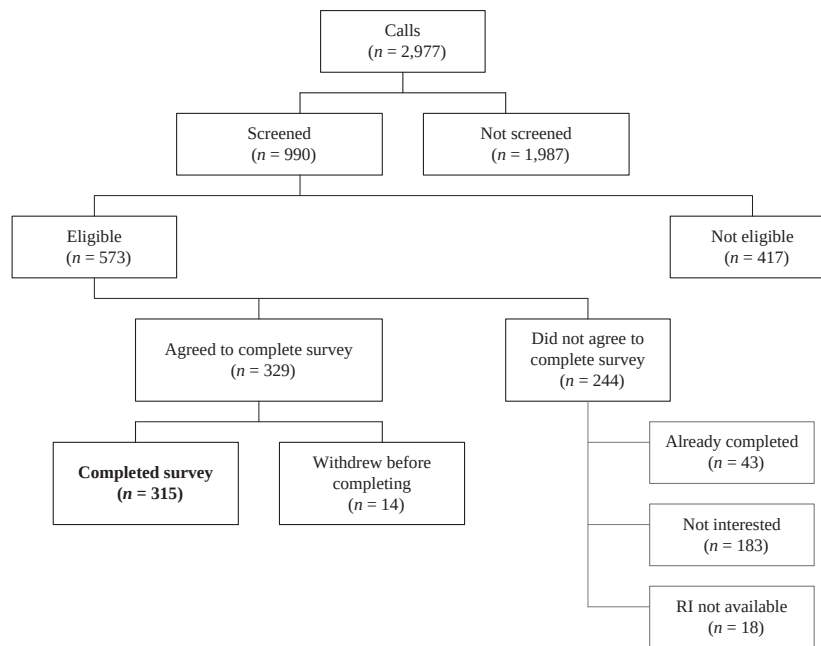


Figure 1 Flow chart of recruitment of Lifeline callers. RI = Research interviewer.

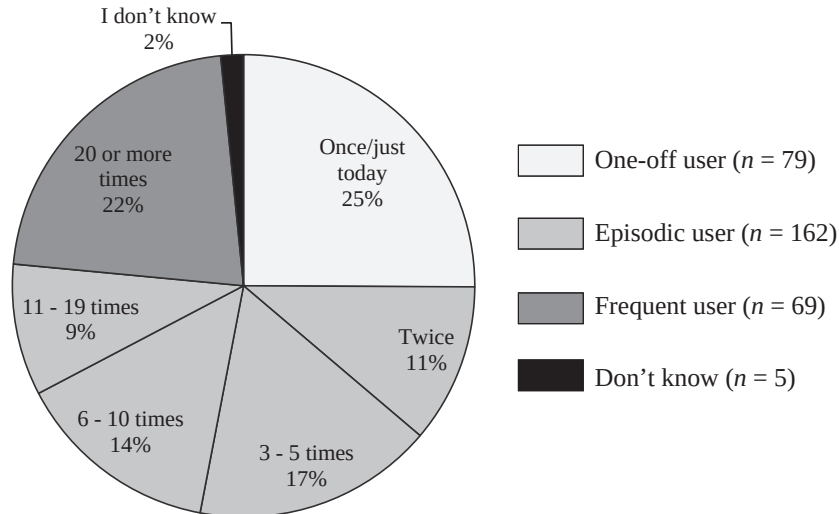


Figure 2 Classification of crisis helpline users based on reported use in the past month ($n = 315$).

Socio-demographic characteristics of crisis helpline users

Table 1 presents the socio-demographic characteristics of respondents. Forty-five per cent of frequent users were male compared to 31% of episodic and 37% of one-off users. Nearly half of the respondents in each user group were aged between 45 and 65 years. Around 90% of respondents in each user group

reported English as their first language. No frequent users and only 4% of episodic and one-off users reported Aboriginal and/or Torres Strait Islander origin. Sixty-one per cent of frequent users reported living alone compared to 57% of episodic and 38% of one-off users. Over half of the frequent users (55%) reported being unable to work due to sickness or disability, compared to 35% of episodic and 19% of one-off users.

Table 1 Socio-demographic characteristics by crisis helpline user classification

	Total (<i>n</i> = 315)* <i>n</i> (%)	Frequent (<i>n</i> = 69)* <i>n</i> (%)	Episodic (<i>n</i> = 162)* <i>n</i> (%)	One-off (<i>n</i> = 79)* <i>n</i> (%)
Gender				
Male	112 (36)	31 (45)	51 (31)	29 (37)
Female	199 (63)	38 (55)	108 (67)	49 (62)
Age				
<25 years	16 (5)	1 (1)	7 (4)	8 (10)
25–44 years	83 (26)	15 (22)	44 (27)	23 (29)
45–65 years	164 (52)	42 (61)	83 (51)	37 (47)
>65 years	48 (15)	9 (13)	27 (17)	10 (13)
English as their first language				
No	32 (10)	7 (10)	15 (9)	10 (13)
Yes	281 (89)	60 (87)	147 (91)	69 (87)
Aboriginal or Torres Strait Islander origin				
No	301 (96)	68 (99)	152 (94)	76 (96)
Yes	10 (3)	0	7 (4)	3 (4)
Live alone				
No	149 (47)	27 (39)	70 (43)	49 (62)
Yes	166 (53)	42 (61)	92 (57)	30 (38)
Employment				
Employed/studying	91 (29)	14 (20)	41 (25)	36 (46)
Unemployed	105 (33)	16 (23)	58 (35)	28 (35)
Unable to work due to sickness or disability	112 (36)	38 (55)	57 (35)	15 (19)

*Denominators vary due to missing data.

Reasons for calling Lifeline

Table 2 presents a summary of the number of reasons reported for calling Lifeline on that occasion. Two per cent of respondents reported that none of the reasons applied, 18% reported that only one reason applied, 60% reported that between two and four reasons applied, and 19% reported that five or more reasons applied. There were 40 respondents who reported calling for a reason other than the eight statements of which 13 could not be re-coded.

The association between crisis helpline use and each of the reported reasons for calling is presented in Table 3. The four most common reasons reported by all users included: having nobody else to talk to (68%); feeling nervous, anxious or depressed (66%); regularly calling to talk about their feelings (58%); and being in an immediate crisis (36%). Fifteen per cent of respondents reported all four of these reasons, 80% reported at least one (but not all four) and 5% did not report any. Of these reasons, regularly calling to talk about their feelings was the sole reason

Table 2 Total number of reasons reported for calling Lifeline on that occasion, by crisis helpline user classification

Reasons for calling Lifeline	Total number of respondents (<i>n</i> = 315) <i>n</i> (%)	Frequent (<i>n</i> = 69) <i>n</i> (%)	Episodic (<i>n</i> = 162) <i>n</i> (%)	One-off (<i>n</i> = 79) <i>n</i> (%)
No reason	6 (2)	0	3 (2)	3 (4)
1 reason	58 (18)	15 (22)	24 (15)	16 (20)
2 reasons	74 (23)	9 (13)	37 (23)	27 (34)
3 reasons	70 (22)	16 (23)	40 (25)	13 (16)
4 reasons	46 (15)	12 (17)	26 (16)	8 (10)
5+ reasons	61 (19)	17 (25)	32 (20)	12 (15)
Mean (SD)	2.9 (1.4)	Mean (SD) 3.1 (1.5)	Mean (SD) 3.0 (1.4)	Mean (SD) 2.5 (1.4)
Median (IQR)	3 (2–4)	Median (IQR) 3 (2–4)	Median (IQR) 3 (2–4)	Median (IQR) 2 (2–4)

SD, standard deviation; IQR, interquartile range.

Table 3 Association between crisis helpline use and reasons for calling based on ordinal logistic regression

Reason for calling Lifeline	Total number of respondents (<i>n</i> = 315)* <i>n</i> (%)	Frequent (<i>n</i> = 69)* <i>n</i> (%)	Episodic (<i>n</i> = 162)* <i>n</i> (%)	One-off (<i>n</i> = 79)* <i>n</i> (%)	Unadjusted [†] OR (95% CI)	Adjusted ^{†,‡} OR (95% CI)
Nobody else to talk to	215 (68)	41 (59)	122 (75)	49 (62)	1.0 (0.6–1.6)	1.0 (0.6–1.6)
Feeling nervous, anxious or depressed	207 (66)	48 (70)	105 (65)	53 (67)	1.2 (0.8–1.9)	1.2 (0.7–1.9)
Regularly call to talk about how they are feeling	183 (58)	59 (86)	102 (63)	19 (24)	6.0 (3.7–9.8)	6.8 (4.0–11.4)
In an immediate crisis	113 (36)	27 (39)	59 (36)	27 (34)	1.2 (0.8–1.9)	1.3 (0.8–2.0)
No hope for the future	88 (28)	21 (30)	43 (27)	24 (30)	1.1 (0.7–1.7)	1.1 (0.7–1.8)
Suggested by health professional	53 (17)	13 (19)	31 (19)	9 (11)	1.5 (0.9–2.6)	1.6 (0.9–2.9)
Usual health professional not available	52 (17)	9 (13)	32 (20)	11 (14)	0.9 (0.5–1.3)	0.9 (0.6–1.4)
Suggested by family member/friend	23 (7)	5 (7)	9 (6)	8 (10)	0.6 (0.3–1.5)	1.0 (0.4–2.5)

*Individual reasons are not mutually exclusive.

[†]Cumulative odd ratios (ORs) and their 95% confidence intervals (95% CI) calculated using ordinal logistic regression modelling increasing frequency of use.

[‡]Adjusted for age, sex, live alone and employment status.

endorsed by 26 respondents, 9 of whom were frequent users.

The most common reason reported by frequent users was to talk regularly about their feelings (86%). For episodic users, the most common reason was having nobody else to talk to (75%) and for one-off users it was that they felt nervous, anxious or depressed (67%). Calling Lifeline because a family member or friend had suggested it was the least common reason for all users, reported by less than 10% of users. In the univariate analysis, reporting more frequent use was associated with regularly calling to talk about their feelings [OR = 6.0; 95% CI: 3.7–9.8] and remained significant in the multivariate model [OR = 6.8; 95% CI: 4.0–11.4]. This was the only reason that was significantly associated with crisis helpline user category in both the univariate and multivariate analysis.

Discussion

In this study, frequent users accounted for nearly one-quarter of all crisis helpline users. They were distinguished from other users by their need to regularly talk about their feelings. However, this was not the only reason they reported calling; they also called about mental health issues, having nobody else to talk to and being in an immediate crisis. These reasons were reported at similar rates to other users.

The findings from this study build on previous research that has investigated frequent users of crisis helplines. It is evident from this study that the reasons driving frequent users to call crisis helplines may be associated with their need for regular emotional support as well as seeking help with their mental health issues. This differs to previous research that

reported frequent users were only calling about social support (Bartholomew & Olijnyk 1973, Watson *et al.* 2006, Burgess *et al.* 2008) or mental health issues (Burgess *et al.* 2008, Ingram *et al.* 2008, Coveney *et al.* 2012, Bassilios *et al.* 2015, Spittal *et al.* 2015) but not a combination of both reasons. This difference may be a result of the variation in methods used, as this is the only study to specifically ask crisis helpline users why they called the service on that occasion. Furthermore, the socio-demographic characteristics of frequent users were similar across these studies (Burgess *et al.* 2008, Bassilios *et al.* 2015, Spittal *et al.* 2015). In addition, whether callers are of Aboriginal and/or Torres Strait Islander origin has not previously been investigated and the limited variance in responses supports the perspective that these individuals have fewer contacts with mental health services prior to suicide (Sveticic *et al.* 2012). Specifically, no frequent user reported being of Aboriginal and/or Torres Strait Islander origin.

Strengths and limitations

This is the first study to ask frequent users of crisis helplines directly about the reason for their call immediately after the encounter. This approach removes the possibility of recall bias which has affected previous studies (Coveney *et al.* 2012). This methodology also removes the difficulties in following up users after the initial contact (Kalafat *et al.* 2007, Coveney *et al.* 2012) and ensuring the analysis was exclusive to Lifeline callers. Some previous studies have been unable to confirm respondents were actual users of a specific helpline (Coveney *et al.* 2012, Bassilios *et al.* 2015, Middleton *et al.* 2016).

Furthermore, the study was conducted over a 6-month period which ensured the participation rates were maximised among respondents. A robust statistical method was also used to compare the differences between user groups.

There are some limitations to this study that need to be considered. First, the survey was not offered to all callers, even though all callers were considered for the study during the randomised shifts. This is because the TCS screened each caller for their eligibility and may not have offered the survey to some callers out of concern of their safety. This may have reduced the representativeness of the sample. However, the fact that nearly 60% of screened callers were considered eligible for the study suggests a wide spectrum of the caller population was approached. Second, the self-report nature of the survey required users to accurately report whether they had previously completed the survey and the number of times they called in the past month. Previous studies have suggested that some users may underreport the number of times they call, so some users may have been misclassified (Burgess *et al.* 2008). Third, the brief nature of the survey meant we could only investigate a limited number of socio-demographic characteristics. Future research may benefit from including more questions but needs to ensure this does not deter people from completing the survey. Fourth, even though we investigated the reasons for calling, this was the first occasion on which the eight statements were used and hence could not be compared to the results of other studies. However, these statements most likely represent a comprehensive list as very few respondents selected the 'other' option and could not be re-coded. Nevertheless, there is a possibility that providing pre-specified reasons for calling may lead to respondents to only select those reasons.

Future studies may benefit from examining the reasons frequent users report calling using other methods. This could involve only asking about the most important reason for calling; however, this would lack depth in understanding all of the reasons they call. Another option would be to include an unstructured question rather than options but may not extract all of the reasons for calling. We suggest using in-depth qualitative methods to explore the reasons why some users call crisis helplines frequently.

Implications for policy and practice

Frequent users are driven to call crisis helplines for many reasons, including their mental health issues and their need for crisis support. However, they have an additional need for ongoing emotional support.

This pattern of service use differs to the current model of care offered by crisis helplines which is designed to provide one-off support. Instead, frequent users may be better suited to a model of care that is designed to provide ongoing support. If such a model were offered, a 'whole system approach' would be suitable as previous research has shown that frequent users already receive mental healthcare from a general practitioner (Bassilios *et al.* 2015, Middleton *et al.* 2016) and mental health professionals (Burgess *et al.* 2008, Middleton *et al.* 2016). Such an approach would involve integrating clinical and professional services with an ongoing non-clinical service that specifically addresses the need for emotional support and occasional crisis support. This would first require a better understanding of the needs of frequent users and why they are seeking ongoing emotional support from crisis helplines (Finch *et al.* 2008). This is worth exploring in more in-depth research and is part of additional work that has been undertaken with a subsample of respondents (Middleton *et al.* In press). Once this is understood, service providers would need to consider ways to complement rather than duplicate the work of healthcare professionals in ways that ensure these users receive optimal care while reducing their continuing use of crisis helplines (Segar *et al.* 2013).

Conclusion

Frequent users of crisis helplines present a unique dilemma to service providers. They call crisis helplines seeking support for a variety of reasons, including their mental health issues, crisis support and ongoing emotional support. However, the current model of care prevents service providers from being able to offer any form of ongoing support across calls. There is a need to investigate further why frequent users are seeking ongoing support from crisis helplines.

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No funding body had a role in the study design; the collection, analysis and interpretation of data; the writing of the manuscript; or the decision to submit the manuscript for publication.

Conflict of interest

AW has dual roles in the project, being a PhD student and the Executive Director of Lifeline Research. The Lifeline Research Foundation funded this project as it has a genuine interest in improving Lifeline's service and in no way sought to influence the results. AW role in Lifeline is separate from service operations and was established for the purpose of research and the translation of research findings for service improvement. Furthermore, a MOU has been written between Lifeline Australia and The University of Melbourne which clearly articulates AW's role on this study which is distinct and non-overlapping to his professional involvement with Lifeline Research.

All other authors (AM, JG, BB, JP) declare that there is no conflict of interest.

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Supporting Information

Additional supporting information may be found in the online version of this article at the publisher's web-site.

5.2 Chapter summary

Study 1 sought to understand the socio-demographic profile of frequent use of crisis helplines (research question 1) and explore the reasons for frequent users' continued use of crisis helplines and how these reasons differ to other callers (research question 2). Three hundred and fifteen callers to Lifeline completed the survey, of which 69 (22%) were identified as frequent users. In relation to research question 1, it was found that nearly half of the frequent users were male and aged between 45 and 65 years of age. Nearly all spoke English as their first language and none reported being of Aboriginal or Torres Strait Islander origin. Over two-thirds of frequent users lived alone and more than half reported being unable to work due to sickness or disability. In relation to research question 2, the reasons for frequent users' calls to Lifeline did not greatly differ to other callers apart from reporting that they called more often to talk about how they were feeling. Compared with other callers, frequent users called about mental health issues, crisis-related issues, and seeking ongoing emotional support. As frequent users appear to call crisis helplines for reasons similar to other callers, further investigation is needed to understand why they call so often.

6

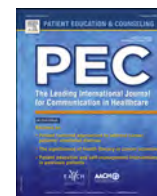
Study 2: Interviews with Lifeline frequent users

Chapter 6 presents Study 2, an interview based study conducted with 19 callers to Lifeline who completed the brief survey (Study 1) and reported calling Lifeline 20 times or more in the past month. In-depth semi-structured interviews were used to explore the reasons why some users may call crisis helplines frequently. Inductive thematic analysis was used to explore why these 19 frequent users called Lifeline so often. The main findings were presented in manuscript titled: *The experiences of frequent users of crisis helplines: A qualitative interview study*. This manuscript was published in the journal *Patient Education and Counselling*. Additional analysis related to the use of healthcare services as reported by participants during the interview is also presented in this chapter. An overview of the characteristics of the 19 participants who completed the interviews is presented in Appendix 7. The chapter concludes with a summary of the key findings related to research question 2 and research question 3, which were addressed in this study.

6.1 PDF of manuscript

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The experiences of frequent users of crisis helplines: A qualitative interview study



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ABSTRACT

Objective: To understand why some users call crisis helplines frequently.

Methods: Nineteen semi-structured telephone interviews were conducted with callers to Lifeline Australia who reported calling 20 times or more in the past month and provided informed consent. Interviews were audio-recorded and transcribed verbatim. Inductive thematic analysis was used to generate common themes. Approval was granted by The University of Melbourne Human Research Ethics Committee.

Results: Three overarching themes emerged from the data and included reasons for calling, service response and calling behaviours. Respondents called seeking someone to talk to, help with their mental health issues and assistance with negative life events. When they called, they found short-term benefits in the unrestricted support offered by the helpline. Over time they called about similar issues and described reactive, support-seeking and dependent calling behaviours.

Conclusion: Frequent users of crisis helplines call about ongoing issues. They have developed distinctive calling behaviours which appear to occur through an interaction between their reasons for calling and the response they receive from the helpline.

Practice implications: The ongoing nature of the issues prompting frequent users to call suggests that a service model that includes a continuity of care component may be more efficient in meeting their needs.

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1. Introduction

Telephone helplines diversify the way people access healthcare [1]. Helplines reach a wide spectrum of the population [1,2] and support people with cancer [3], smoking cessation [4] and acute crises such as suicidality [5]. Numerous helplines operate in Australia [6,7] and crisis helplines account for the majority of them [8]. Crisis helplines provide anonymous 24-h support to people experiencing an immediate crisis [8–10]. They are staffed by either volunteer or paid personnel who vary in their degree of professional training [11]. Lifeline is recognised as the national 24-h crisis helpline in Australia and is staffed by trained Telephone Crisis Supporters (TCSs) [12]. Lifeline aims to support Australians in times of crisis and equip individuals and communities to be resilient and suicide-safe [13].

Lifeline's current model of care is based around providing short-term support [11,14]. Each call is treated as a unique encounter [8].

However, a disproportionately high number of calls are from individuals seeking ongoing support [15]. A previous study found that 60% (or 247,547) of calls to Lifeline were from individuals who called 20 times or more in a month and represented 3% of all service users [16]. The high volume of calls made by frequent users creates the need to understand why these users continue to call. Frequent users of crisis helplines are neither unique, nor new, to Lifeline and were first recognised in an American study in the 1960s [17].

Previous studies used quantitative methods to investigate the differences among users of crisis helplines [16,18–24]. These studies found that frequent users are more likely than non-frequent and non-users of crisis helplines to present with poor physical health, chronic disease, mental health issues and lack other social supports [11,15,16,18,19,24]. The socio-demographic characteristics of frequent users vary between studies. This has been attributed to differences in the way frequent users are defined and the variables investigated [15]. However, several studies found that frequent users are more likely to be male [16,19–21,23] and unmarried [16,19,20,23]. They are also more likely than other users and non-users to visit health professionals, including general

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practitioners, psychiatrists, psychologists and present more often to the emergency department [18,24]. Yet, frequent users are less satisfied with their current access to healthcare services [24]. These findings suggest that frequent users may be calling in search of a service that can better meet their needs. Further investigation is needed to understand whether this is the only reason driving the frequent use of crisis helplines.

The aim of this study was to understand why some users call crisis helplines frequently. This was investigated from the perspective of self-identified frequent users of Lifeline Australia.

2. Methods

2.1. Study setting and sampling

This study was part of a larger study investigating the experiences of, and outcomes for, callers to Lifeline. The larger study included a sample of 315 callers who completed a brief survey at the end of their call to Lifeline between February and July 2015 [25]. Callers were eligible to complete the survey if the TCS deemed them to be over 18 years of age, able to converse in English and not in an immediate crisis. Callers in an immediate crisis were excluded to ensure the safety of those who were vulnerable and distressed. All respondents who reported in the brief survey that they called Lifeline 20 times or more in the past month (considered frequent users according to Lifeline's current operational definition [16]) and provided their contact details were invited to this study. Ethics approval was granted by The University of Melbourne's Human Research Ethics Committee (ID: 1441987.2).

2.2. Data collection

Study data were collected and managed using REDCap electronic data capture tools at The University of Melbourne [26]. Respondents were contacted and interviewed between February and August 2015 by A.M., who is a trained and experienced research interviewer and independent of Lifeline. All eligible callers were contacted at least one day after completing the survey. Interested participants were sent a plain language statement, by post or email, at least one week prior to the interview. Before the start of the interview, the key requirements were read out by the interviewer and respondents provided informed verbal consent. All interviews were conducted over the telephone which allowed for a maximum number of respondents to be reached within the study period. Furthermore, respondents were already familiar with discussing their experiences over the phone as they were recruited from a telephone service. Interviews were audio recorded and transcribed verbatim by A.M.

Interviews were semi-structured and guided by an interview schedule (see Appendix). During the interview, respondents were asked what prompted their call to Lifeline, how they used the service and their experience of calling. They were also asked about their use of other helplines and healthcare services. These questions were specifically developed by the authors for the purpose of this study. All authors reviewed the first two interviews and decided no changes were required to the interview schedule.

Sixty-nine respondents completed the brief survey and reported frequent use [25]. Thirty-four of these respondents provided their contact details and were approached. Of these respondents, 19 were interviewed, eight could not be contacted after multiple attempts and seven declined participation. Reasons for non-participation included being too busy, no longer interested, and in one case having a long term brain injury. No differences were observed between the socio-demographic characteristics of respondents who were interviewed and those who declined

participation. Interview duration ranged from 19 to 91 min, with an average of 38 min.

2.3. Analysis

Respondents' socio-demographic characteristics were analysed using STATA version 13 [27] and reported as frequencies. An inductive thematic analysis [28,29] approach was used to understand why some users call crisis helplines frequently. Transcripts were anonymised and imported into QSR International's NVivo 11 Software [30]. Each transcript was analysed in its entirety and emerging themes were constantly compared across transcripts to ensure interpretation remained grounded in the data. Initially, A.M. coded five transcripts and discussed the emerging themes with J.G. They identified three overarching themes from the data and developed a conceptual framework. These themes centred on respondents' reasons for calling, the response they received from Lifeline and the calling behaviours they described. Using this framework, A.M. coded an additional five transcripts and found no new themes. The other authors then reviewed the conceptual framework and independently applied it to the first five transcripts. Minor coding discrepancies were resolved through discussions among all authors. The conceptual framework was slightly revised and A.M. used this revised framework to recode all of the transcripts. All interviews were included in the analysis; there were no disconfirming cases.

3. Results

3.1. Characteristics of respondents

Table 1 presents the socio-demographic characteristics of the 19 respondents. Twelve respondents were female and 11 were between 45 and 65 years of age. Seventeen respondents reported English as their first language and 13 lived alone. No respondent reported being of Aboriginal and/or Torres Strait Islander origin. Only one respondent reported being employed with the remaining either unable to work ($n = 15$) or unemployed ($n = 3$).

Table 1
Socio-demographic characteristics of respondents ($n = 19$).

	Respondents n (%)
Gender	
Male	7 (37)
Female	12 (63)
Age	
<25 years	1 (5)
25–44 years	5 (26)
45–65 years	11 (58)
>65 years	2 (11)
Employment	
Employed/studying	1 (5)
Not employed/not in paid employment	3 (16)
Unable to work due to sickness/disability	15 (79)
Lives alone	
Yes	14 (74)
No	5 (26)
English as first language	
Yes	17 (89)
No	2 (11)
Aboriginal or Torres Strait Islander Origin	
No	19 (100)

Respondents first called Lifeline about a legitimate issue, however, over time they found themselves calling frequently, as exemplified by the following quote: “[the] first time I called . . . was because it was the first time I had suicidal thoughts . . . when it started five years ago I would call them . . . once a month . . . I became dependent on them, like I can’t get better without calling them . . . [in] the last year . . . I’ve been calling . . . everyday, more often . . . three to five times a day” [Caller 07; Male (M); 18–25yo]. A few respondents had begun calling frequently in the last few months, whereas, the majority were calling frequently for over two years.

Frequent use was related to three interrelated components, namely; reasons for calling, service response and calling behaviours. Reasons for calling were closely related to the response they received from Lifeline, which one caller described as: “well I do have a trauma history . . . when you talk to some counselling services they want you to stay a victim . . . whereas . . . Lifeline . . . talk to people about hard issues . . . they know how to . . . pull you out of that, and that . . . is what makes them so good to talk to, because you don’t feel like you’re a victim . . . they are very pragmatic and understanding” [Caller 10; F; 25–44yo]. Such a response would then drive their calling behaviour because Lifeline “were happy to talk to you even if you rang back several times within the day, and they’re still happy to talk to you . . . when you’re friends . . . get busy and . . . can’t talk . . . so I am a bit more reliant on Lifeline” [Caller 16; F; 45–65yo]. The calling behaviours were also linked to their reason for calling, as demonstrated by: “when I get upset or [have a] problem, that’s when I reach out” [Caller 13; M; ≥65yo]. A conceptual framework illustrating how these components are interrelated is shown in Fig. 1 and a description of each component is provided below.

3.2. Reasons for calling

Respondents indicated that they called Lifeline seeking: someone to talk to, help with their mental health issues, and assistance with past and present negative life events. These reasons remained the same over time, with one respondent stating

he “used to call . . . 50 years ago . . . it was the same problem” [Caller 08; M; ≥65yo].

3.2.1. Someone to talk to

Over half of the respondents mentioned calling for social connection, advice and a listening ear. One respondent justified calling because she “just wanted . . . somebody to talk to, somebody to help sort things out with” [Caller 16; F; 45–65yo]. Often, respondents kept calling because they had “no family support” [Caller 15; F; 45–65yo] and there was “no-one else to turn to” [Caller 02; F; 25–44yo]. Lifeline provided an opportunity for human interaction, as exemplified by the following: “I call Lifeline because I need a human connection” [Caller 07; M; 18–34yo]. For many, Lifeline is their first point of contact when needing someone to talk to, with one caller stating: “I just feel comfortable calling them first . . . I just sort of feel like it’s a familiar friend I can call and count on that is always there” [Caller 12; F; 45–65yo].

3.2.2. Help with mental health issues

Nearly all respondents reported calling because they experienced a mental health issue of varying severity. One caller explained, “I call [Lifeline] for support because I have a mental illness” [Caller 11; F; 24–44yo]; whereas, another caller commented that “if I didn’t have a mental illness I wouldn’t need to ring Lifeline” [Caller 13; M; >65yo]. Depression and anxiety were the most commonly reported mental health issues; however, schizophrenia, panic attacks and having a “nervous breakdown” were also mentioned by a few respondents.

Suicidality was another issue for many respondents, with one respondent stating, “I was calling when I got suicidal . . . to get some help” [Caller 19; F; 45–65yo]. For three of these respondents, they first called Lifeline “because it was the first time [they] had suicidal thoughts” [Caller 07; M; 18–24yo]. However, suicidality was not an issue for all respondents with four explicitly stating that they “never had thoughts of suicide” [Caller 03; F; 45–65yo] and “would rather . . . they didn’t ask [about suicidal thoughts but] . . . wait for the caller to bring it up” [Caller 05; M; 45–65yo].

3.2.3. Assistance with past and present negative life events

Respondents also called about past and present negative life events which included childhood abuse, domestic violence, loss of a loved one, separation from a partner and/or a major accident. Many of these events occurred several years ago but were still affecting the individual. For example, one male respondent aged over 65 stated that, he was “not able to socialise in our society . . . because I came to this country at age of eight and . . . I was abused at school, verbally and physically by the other kids and it made it impossible for me to live a normal life” [Caller 08]. For many respondents, the issues they called about were ongoing and one respondent stated that despite seeking help from a psychiatrist, she called Lifeline because she was “still having difficulties with all of those issues . . . I mentioned initially” [Caller 12; F; 45–65yo].

3.3. Response from Lifeline

In general, respondents preferred Lifeline over other helplines in Australia due to the response they received. A typical remark was: “occasionally I would call [other helpline] . . . but I don’t call . . . anymore, I usually call Lifeline” [Caller 01; F; 45–65yo]. This preference was attributed to the: provision of non-specific support, availability of the service and the variety of counsellors. However, this response only provided short-term benefits, with one caller stating “they give me about half an hour . . . that gives me a little bit of space . . . then I might wait two or three hours and phone again” [Caller 04; M; 45–65yo].

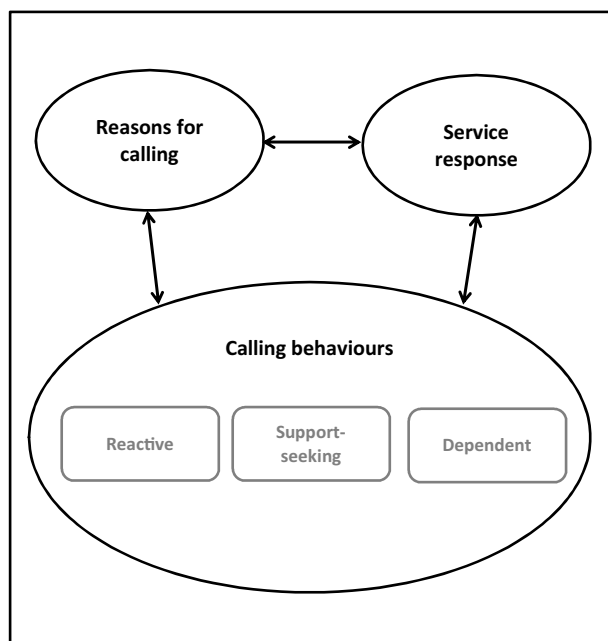


Fig. 1. Conceptual framework depicting the interaction between the factors contributing to the frequent use of crisis helplines.

3.3.1. Non-specific support

Lifeline offered non-specific generalised support, which was unlike many other helplines that focused on specific issues. One caller described the difference as, *“I have [tried other helplines] but Lifeline is not as specific”* [Caller 10; F; 25–44yo]. Some callers were turned away from other helplines because they did not *“fit into the categories”* [Caller02; F; 25–44yo]. By contrast, the generalised support offered by Lifeline allowed callers to discuss anything that was on their mind without being turned away. This was important for one caller who reported, *“I don’t have anything specific I want to talk about”* [Caller01; F; 45–65yo]. However, other callers perceived that the counsellor did not see their issues as genuine and reported being told *“don’t waste our time; there’s other people in more need”* [Caller17; M; 45–65yo].

3.3.2. Availability

Over half of the respondents mentioned the importance of Lifeline always being available. The 24-h operation of Lifeline meant they could *“pick up the phone and call any time of day or night”* [Caller12; F; 45–65yo]. If the line was busy, they would stay on hold until the call was answered. This was unlike other services where respondents had to *“keep dialling because they didn’t have a call waiting system”* [Caller19; F; 45–65yo]. One caller summarised Lifeline’s availability as, *“compared to a lot of other services . . . [Lifeline] is so easy to contact . . . get through to . . . their number’s really easy to remember”* [Caller10; F; 25–44yo].

Despite being easy to contact, each call was usually restricted to 30-min. Many felt this was insufficient time to *“explain what’s going on and express everything”* [Caller10; F; 25–44yo]. One caller felt that she *“can tell when they are trying to get me off the phone . . . when they are winding down the talk and I’d rather talk”* [Caller01; F; 45–65yo]. However, such restrictions were not of a major concern to respondents as they knew they could easily call back. In fact, respondents continued to call because the TCSs would *“tell [them] to call back whenever [they] want”* [Caller05; M; 45–65yo]. One respondent recently commenced calling frequently after a suggestion from one TCS: *“I was calling when I got suicidal . . . and a counsellor suggested . . . instead of waiting for it to culminate in feeling suicidal . . . if you can recognise the warning symptoms, ring up when you’re feeling [down]”* [Caller19; F; 45–65yo].

3.3.3. Variety of counsellors

Having a variety of counsellors available was mentioned by nearly all respondents as an incentive to call frequently. A common remark was *“some of them [TCSs] are good, some . . . are downright rude”* [Caller03; F; 45–65yo]. A positive calling experience was reported when the TCS would *“listen and give some advice”* [Caller04; M; 45–65yo] as opposed to when they *“just paused indefinitely . . . and not say anything”* [Caller01; F; 45–65yo]. However, negative responses were uncommon in comparison to positive responses, with a typical comment about the ratio being: *“mostly I’d say 85% positive . . . there is about 15% of calls that I’ve had where it has been hopeless”* [Caller01; F; 45–65yo]. When respondents encountered a negative response, they would hang up and call back again hoping to find a different counsellor *“because [Lifeline] is Australia-wide, the chances of finding the same person again are very low”* [Caller16; F; 45–65yo]. However, this also meant during each call they had *“to re-explain everything . . . [because] you’re speaking to someone different all the time”* [Caller10; F; 25–44yo].

Respondents also called looking for a TCS who *“forgot the rules . . . ask you how you’re feeling . . . tell you about themselves”* [Caller07; M; 18–24yo]. This was mentioned by half of the respondents when specifically asked how Lifeline could improve its service. They felt that rules made it difficult to build rapport

with the TCSs, with one caller explaining: *“when you are having a two-way conversation it is nice to be two-ways”* [Caller05; M; 45–65yo]. Respondents also felt the TCS should *“have . . . a pseudo name . . . they don’t have to use their real name”* [Caller19; F; 45–65yo] so they can address them personally.

3.4. Calling behaviours

Respondents described three distinctive behaviours which drove their frequent calls and included reactive, support-seeking and dependent calling behaviours. Each of these behaviours were prompted by different reasons and varied in regularity.

3.4.1. Reactive behaviours

Nine respondents reported calling after an incident triggered feelings of anxiety and/or depression. This was categorised as a reactive calling behaviour and is exemplified by the following response: *“if I’ve got nothing that’s stressing me out . . . I’m not likely to ring . . . but . . . if I’ve got things that are stressing me out, or making my anxiety play up, then I’ll ring”* [Caller09; F; 25–44yo]. Reactive calling behaviour was directly related to events that were happening in their lives, which one caller described as: *“there’s no real pattern . . . if I’m around toxic environment it will be quite regularly, as much as 5 times a day . . . if I’m totally away from all the triggers . . . very little”* [Caller17; M; 45–65yo].

3.4.2. Support-seeking behaviours

Support-seeking calling behaviours were identified among nine respondents who would call when they needed emotional support. Five of these respondents also described a reactive calling behaviour at other times. The support-seeking calling behaviour was described by one respondent as calling *“to discuss my day or something because I’ve got no one else to . . . talk to”* [Caller19; F; 45–65yo]. Respondents reported a sense of *“desperation . . . I just need someone to talk to that understands”* [Caller13; M; ≥65yo]. Similar to the reactive calling behaviour, there was no distinctive calling pattern associated with the support-seeking behaviour; instead, respondents described *“there [are] long periods [I call] and then I stop because things are fine and then when things aren’t fine that’s when I keep [calling]”* [Caller14; F; 45–65yo].

3.4.3. Dependent behaviours

Dependent calling behaviour, described by six respondents was not related to a specific trigger. Instead, calling had become part of their daily routine. One respondent described this behaviour as: *“it’s like an addiction, that’s why I keep calling . . . part of my lifestyle . . . so I just keep calling . . . I don’t have anything to do, so I call Lifeline”* [Caller07; M; 18–34yo]. Respondents indicated that each time they called, their narrative was similar, often ruminating over a past event, with one caller reporting, *“I told her the exact same story a hundred times over”* [Caller04; M; 45–65yo]. Dependent behaviour was associated with daily calls to Lifeline regardless of life circumstances and a typical response was: *“well I just like ringing every night . . . I get bored and lonely cause I’ve got no-one else to talk to”* [Caller18; M; 25–44yo].

4. Discussion and conclusion

4.1. Discussion

This is the first study to investigate why some users call crisis helplines frequently. Using a qualitative approach, we identified that frequent use was connected to three interrelated components. Firstly, respondents called seeking someone to talk to, help with their mental health, and assistance with past and present negative life events. Secondly, respondents indicated that the response they

received from Lifeline helped to meet their short-term needs and the ability to call regularly without restrictions was favourably viewed. Thirdly, respondents described three distinctive calling behaviours which were classified as reactive, support-seeking and dependent. These calling behaviours appeared to develop over time and were closely related to respondents' reasons for calling and the response they received.

The current crisis helpline service model is designed to provide one-off support rather than ongoing support to individuals who experience chronic and complicated crises, even though these individuals make a large proportion of calls. Frequent users call about issues that are ongoing in their lives. However, the current model of care makes it difficult for crisis helpline staff to adequately address frequent users' needs in a single encounter. Furthermore, frequent users are sometimes dissatisfied with the response they receive and call back looking for a TCS with a different approach. This mismatch between the model of care offered by crisis helplines and the support frequent users are seeking suggests that they may benefit from more continuous care over a period of time.

The service model of crisis helplines also requires callers to retell their story each time they ring as prior encounters are not recognised. Repeating their story may frustrate frequent users with a reactive or support-seeking behaviour; however, this also enables users with dependent calling behaviours to ruminate about past experiences which may prolong their depression and anxiety [31]. A service model which reduces the need for frequent users to repeat their story during each encounter and includes a continuity of care component might lead to more efficient use of the service and offer benefits in building resilience in frequent users over time.

A major strength of this study was the use of interviews with self-identified frequent users of crisis helplines. No previous study has done this. The health issues experienced by respondents in this study were similar to those reported in previous quantitative studies [15,16,18,24] and there were no differences in the demographics between frequent callers who agreed and declined to be interviewed, suggesting that our findings may be generalizable beyond our interview sample. Furthermore, respondents were heterogeneous in their experience of calling Lifeline.

Some limitations of this study are that callers were required to provide their contact details to be invited to this study. Callers who were in an immediate crisis or wished to maintain their anonymity were excluded from the study, which may have biased the results. We also relied on callers accurately reporting the number of times they called in the past month, thus excluding callers who may have under-reported their calls. Due to privacy, we were unable to verify respondents' self-reported calls with their actual call data.

4.2. Conclusion

Frequent users call crisis helplines about ongoing issues and find short-term benefits in the response they receive from the helpline. Over time frequent users develop reactive, support-seeking and dependent calling behaviours which appear to be interrelated to their reasons for calling and the response they receive. The ongoing nature of frequent users' issues suggests that a model of care that includes a continuity of care component may better suit their needs. Over time this may lead to more efficient use of the helpline and improved mental health for frequent users.

4.3. Practice implications

There may be more efficient ways for crisis helpline providers to address the needs of frequent users while reducing the number of calls they make to the service. This may include offering a parallel

telephone service to frequent users that includes a continuity of care component. Such a model of care would allow helpline staff to understand the calling behaviours of each frequent user and develop a personalised management plan. This would reduce the need for frequent users to repeat their story each time. However, there are a number of factors that need to be considered before such a model is implemented. Firstly, callers' use of other healthcare services needs to be acknowledged so that the support offered by the helpline complements, rather than duplicates, any face-to-face care. The difference between these services would be that crisis helpline staff could address the calling behaviours of frequent users whereas face-to-face treatment could focus on their underlying social, mental and physical health issues. Secondly, processes need to be put in place to discourage any further dependency on the helpline. This could be done by focusing on the development of self-management techniques that assists frequent users to address their own issues in the long-term. This new model of care would need to be tested to see whether it has other unintended consequences before being introduced into routine practice.

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Conflicts of interest

No funding body had a role in the study design; the collection, analysis and interpretation of data; the writing of the manuscript; or the decision to submit the manuscript for publication.

Author contributions

J.P. and J.G. conceived the study and oversaw its successful completion. A.M. conducted the interviews with study participants and led the analysis. J.G., B.B. & J.P. provided input to the analysis. A. M. drafted this manuscript, with input from all other authors. All authors read and approved the final manuscript.

I confirm all personal identifiers have been removed or disguised so the persons described are not identifiable and cannot be identified through the details of the story.

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Appendix A

Interview schedule

1. Can you tell me a bit about the circumstances under which you called Lifeline in the past few months?
2. What was happening for you that prompted your initial call?
3. If you called more than once, what made you continue to call?
4. What made you call Lifeline in particular?
5. Did you consider making contact with any other telephone services?

- a. If not, why not?
- b. If so, why did you call Lifeline as well?
6. Was the decision to call Lifeline entirely your own, or did someone else suggest it (e.g., a friend or a family member, a health professional)?
7. People call Lifeline in all sorts of different ways. Some people call only once and don't call again. Some people call more episodically, maybe making a few calls over a short period and then not calling again for some time. Still others call regularly and often, sometimes over a longer period. How would you describe your own calling patterns?
8. This might be a difficult question to answer, but can you explain why you have a particular calling pattern or why you call in the way you do?
9. What happens for you between calls?
10. What prompts you to call again?
11. How do you feel that Lifeline continues to provide you with support for your emotional wellbeing?
12. Some people see a range of health professionals for their emotional well being as well as calling Lifeline. Are you seeing any health professionals for your emotional well being?
13. Do you get different things from these health professionals compared with what you get from calling Lifeline?
14. How did you find the experience of calling Lifeline?
15. Did you find it easy to get through?
16. Did you feel as though the telephone crisis supporter listened to you?
17. Did he or she say things that were useful in helping you think through your issues and how you might deal with them?
18. Can you tell me more about the support you received from Lifeline?
19. What did you find helpful about the support provided by Lifeline?
20. How do you feel Lifeline could improve its service to meet the needs of callers like yourself?
21. How did you feel after calling Lifeline?
22. What, if any, action did you take after calling Lifeline?
23. What has happened for you since calling Lifeline?
24. I'm interested to know whether things have changed for you. Thinking back to what you told me about what prompted your initial call, would you say that things have got better, got worse or stayed the same?
25. If they've changed at all, would you attribute any of this change to Lifeline?
26. I've asked you a lot of questions, but I'm wondering if you might like to tell the story of your recent contact with Lifeline in your own words, taking me through from beginning to end. You can speak in general terms if that's easier for you.
27. Are there any other comments you'd like to make?

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6.2 Additional analysis – healthcare use

Participants were explicitly asked in the interview about their use of healthcare services in addition to calling crisis helplines and whether they visited a general practitioner. Responses to this question did not emerge as a specific theme around reasons for frequent users' calls but are briefly mentioned here as research question 3 sought to identify the health service use patterns of frequent users. Out of the 19 participants, 16 reported having a regular GP whom they saw often, and nine of these participants reported talking to the GP about their emotional wellbeing. This finding highlights that of this sample, the majority of frequent users regularly visited their GP and saw them for issues related to their emotional wellbeing. Furthermore, many of these participants also visited other healthcare professionals regularly, including psychologists, psychiatrists, and counsellors. Only two participants explicitly reported not having a regular healthcare professional at the time of the interview. This finding highlights that a group of service users who are familiar with the healthcare system and use these services often in conjunction with calling crisis helplines. The relationship between frequent use of crisis helplines and health service use patterns was explored further in Study 3, reported in Chapter 7.

6.3 Chapter summary

Study 2 explored the reasons for frequent users' continued use of crisis helplines (research question 2) by examining the transcripts of 19 in-depth semi-structured interviews conducted with frequent users of Lifeline. Inductive thematic analysis was used to identify three overarching themes from these interviews that related to why frequent users call so often. These themes included the reasons for frequent users calls to crisis helplines, the response they received when they called, and the way in which they called. Reasons for calling related to seeking someone to talk to, help with mental health issues and assistance with negative life events, many of which occurred several years ago but continued to impact on their lives. When frequent users called, they found short-term benefits in the unrestricted support offered by the helpline. Over time frequent users called about similar issues and described reactive, support-seeking, and dependent calling behaviours. The findings from this study challenged previously held views about why frequent users call crisis helplines; rather than simply calling about mental health issues

or seeking social support. The findings also identified that frequent users developed distinctive calling behaviours, which appeared to occur through an interaction between their reasons for calling and the response they receive from the helpline. These factors have not been examined in previous research, which relied on quantitative methods, to the same depth as in this study. Instead by using a qualitative methodology, the experience of frequent users' calling crisis helpline could be investigated. The health service use patterns of frequent users (research question 3) were also briefly examined, where it was found that nearly all participants visited their GP regularly as well as other healthcare professionals.

7

Study 3: Longitudinal analysis of data from the *diamond* study

Chapter 7 presents Study 3, an analysis of data from the *diamond* study, a longitudinal cohort of 789 general practice attendees with depressive symptoms. The relationship between frequent use of crisis helplines and health service use patterns was examined over the first year of follow up at three-month intervals. This chapter begins with background information related to the appropriateness of drawing on data from a general practice cohort to examine frequent users of crisis helplines. The results from this study are presented in the enclosed published version of the manuscript: *The health service use of frequent users of telephone helplines in a cohort of general practice attendees with depressive symptoms*. This manuscript was published in *Administration and Policy in Mental Health and Mental Health Services Research*. The chapter concludes with a summary of the key findings related to research question 1 and research question 3, which were addressed in this study.

7.1 Additional background information

In Australia, GPs are considered the cornerstone of the healthcare system. They are intended to provide generalist patient-centred care, accessible to all Australians. Yet, this is not always the case, particularly for those living in rural areas who face significant health disadvantages compared to those living in urban centres (McGrail & Humphreys, 2009). Individuals living in rural areas have reduced accessibility to GP services due to health and medical workforce shortages (McGrail & Humphreys, 2009). General practice is subsidized by the Australian Federal Government's Medicare rebate, which reduces the costs of visits and treatments for patients, making it a universal service (Department of Human Services, 2014). In practice the system is not always equitable, particularly in

terms of access to mental health services (Meadows, Enticott, Inder, Russell, & Gurr, 2015). Eighty three percent of Australians consulted a GP in 2009-2010 (Younes et al., 2013). Individuals are able to select their own GP and visit them for most of their generalist healthcare needs (Schoen et al., 2007). General practice provides continuity of care and forms the foundation of the Australian healthcare system (Seddon et al., 2001). GPs are the gatekeepers to specialist medical providers, providing referrals to these services that are otherwise inaccessible (Sikorski et al., 2012). Using data from a population-based survey, Bassilios et al. (2015) reported that frequent users of crisis helplines are more likely to visit a GP for their emotional wellbeing compared with other callers and those who had not called a helpline in the past year. Furthermore, the interview data collected as part of this thesis showed that nearly all 19 frequent users of Lifeline reported having a regular GP whom many saw for their emotional wellbeing (see Section 6.2). It can be concluded from these findings that a high proportion of frequent users regularly visited their GP, making it appropriate to look at a subgroup of frequent users of crisis helplines who also visit the GP.

In addition to visiting the GP, a substantial number of frequent users may experience depression. As outlined in Section 3.3.2, rates of depression among frequent users were similar to other callers, estimated to be around half of the calling population. This is no surprise, as depression is recognised as the single largest cause of disability burden (Mathers, Vos, Stevenson, & Begg, 2000). It is estimated that one in six Australians experience depression at some stage in their life (Mathers et al., 2000). Every year this equates to over 1 million Australian adults experiencing depression (Australian Bureau of Statistics, 2008). In Australia, depression is mainly managed in general practice (Australian Institute of Health and Welfare, 2013) and depression screening tools have been used to identify that between 24-55% of people in general practice waiting rooms are probably depressed (Herrman et al., 2002). Investigating the health service use patterns of a group of frequent users of crisis helplines who also visit the GP and screen positive for depressive symptoms gives insight into what may be happening for these individuals.

7.2 PDF of manuscript

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The Health Service Use of Frequent Users of Telephone Helplines in a Cohort of General Practice Attendees with Depressive Symptoms

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Abstract We examined the relationship between frequent use of telephone helplines and health service use over time in a cohort of 789 general practice attendees with depressive symptoms. Telephone helpline use (no use, non-frequent use, frequent use) was measured at 3, 6, 9 and 12 months and analysed using ordered logistic regression. Sixteen participants (2 %) reported frequent use of telephone helplines. Reporting frequent use was associated with visiting multiple general practitioners, using emergency services and visiting mental health specialists in the previous 3 months. Despite this pattern of service use, there was evidence that these services were not meeting the needs of frequent users of telephone helplines, as they were also more likely to report dissatisfaction with their access to health services compared to non-frequent and non-users of telephone helplines. Our findings suggest that a model of care which addresses the complex needs of frequent users of telephone helplines is needed.

Keywords Depression · General practice · Telephone helplines · Health service use

This paper has not been presented at a meeting but components of it were presented at the 28th World Congress of the International Association for Suicide Prevention in June 2015 in Montreal, Canada by the lead author.

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Introduction

Telephone helpline services provide timely short-term crisis support and are designed to respond to users who call once or only a few times (Kalafat et al. 2007). In Australia, there are a number of 24-h telephone helpline services that operate at a national level each with their own focus. Individuals can call these helplines without any sort of referral, although general practitioners (GPs) and other mental healthcare providers sometimes recommend these services to their patients (Morgan et al. 2012). Examples of such telephone helplines include Lifeline, which is the largest generalised service, MensLine and the Suicide Call Back Service (National Mental Health Commission 2014). Common to many of these services are a group of callers that seek ongoing support and use telephone helplines differently to their original purpose of providing short-term crisis support (Kalafat et al. 2007). These callers make multiple calls over an extended period of time (Middleton et al. 2014) and, for the purposes of this paper, are called frequent users. In Australia, approximately 3 % of telephone helpline callers are frequent users and their calls account for around 60 % of all calls received (Spittal et al. 2015). Frequent users place a heavy burden on telephone helplines even though they represent a small proportion of the caller population.

Frequent users present a number of challenges to telephone helpline service providers. Firstly, services struggle in striking a balance between providing support to frequent users and addressing the needs of other callers (Barmann 1980). Telephone helpline services have finite resources, thus responding to frequent users can mean that calls from other users are left unanswered (Watson et al. 2006). In 2014, the average call answer rate at Lifeline Australia, the national 24-h telephone helpline was 85 % (Lifeline

Australia 2014). Concerns have been raised that unanswered calls may be from people in an immediate crisis who are being missed while telephone helpline operators speak with frequent users (Farberow et al. 1966; Kalafat et al. 2007; Watson et al. 2006). Secondly, telephone helpline operators express feelings of frustration towards frequent users and perceive a lack of control over their calling patterns (Greer 1976; Kinzel and Nanson 2000). These feelings develop over time as operators repeatedly try to address the recurring and complex problems experienced by frequent users (Farberow et al. 1966; Greer 1976; Ingram et al. 2008; Wilkins 1969). These challenges have led to requests for research that sheds light on the factors associated with the frequent use of telephone helplines (Middleton et al. 2014).

Since the 1970s studies in the USA (Apsler and Hoople 1976; Greer 1976; Ingram et al. 2008; Kalafat et al. 2007; Lester and Brockopp 1970; Murphy et al. 1969; Sawyer and Jameton 1979), Canada (Mishara and Daigle 1997) and Australia (Bartholomew and Olijnyk 1973; Bassilios et al. 2015; Burgess et al. 2008; Spittal et al. 2015) have investigated the socio-demographic and psychological characteristics of frequent users. All but one of these studies (Kalafat et al. 2007) were cross-sectional and the use of validated measures were limited (Middleton et al. 2014). These studies used different definitions of frequent use and varied widely in their methodologies, yet, they all concluded that frequent users have complex social, physical and mental health needs. Collectively, they suggest that frequent users are more likely to be male and unmarried compared to non-frequent users (Middleton et al. 2014), and that frequent users have an array of psychological problems, including depression (Bartholomew and Olijnyk 1973; Kalafat et al. 2007; Mishara and Daigle 1997), anxiety (Bassilios et al. 2015; Burgess et al. 2008; Kalafat et al. 2007), personality disorders (Farberow et al. 1966), suicidal thoughts and behaviours (Bassilios et al. 2015; Kalafat et al. 2007; Lester and Brockopp 1970; Mishara and Daigle 1997; Sawyer and Jameton 1979; Spittal et al. 2015), and feelings of hopelessness (Kalafat et al. 2007). A lack of social supports and feelings of loneliness are also reported by many frequent users (Bartholomew and Olijnyk 1973; Burgess et al. 2008; Coveney et al. 2012).

The complex health needs of frequent users mean that they are likely to require a range of healthcare services, yet their health service use patterns are poorly understood. Some authors have suggested that frequent users have an inappropriate reliance on telephone helplines and they continue to call because their needs are not being met by other areas of the healthcare system (Gould et al. 2007; Kalafat et al. 2007). If this is true, then improving the response local healthcare services provide to frequent users might decrease their calls to telephone helplines. However,

the evidence indicates that frequent users are making use of other parts of the healthcare system. Several studies have found that frequent users commonly report receiving current or prior treatment from professionals who provide mental healthcare in a range of settings (Bartholomew and Olijnyk 1973; Bassilios et al. 2015; Burgess et al. 2008; Farberow et al. 1966; Greer 1976; Lester and Brockopp 1970; Sawyer and Jameton 1979). Our own previous study in this area shows that repeat callers of telephone helplines are more likely to have received mental healthcare from a GP in the past year than those who called only once or did not call at all (Bassilios et al. 2015). However, whether these healthcare services are able to meet the needs of frequent users of telephone helplines requires further investigation.

These findings suggest that the factors associated with frequent use may be more nuanced than originally suggested, and that there may be an association between frequent users' particular characteristics, treatment needs, and the type of healthcare they use. The current study aims to examine the relationship between frequent use of telephone helplines and health service use patterns over time. In particular, we focus on the use of GP services because they are the providers from whom mental healthcare is most frequently sought in Australia (Australian Institute of Health and Welfare 2013) and specialist services are, for the most part, only accessible through referrals from a GP (Sikorski et al. 2012).

Methods

Sample and Procedure

We conducted the analysis using the Diagnosis, Management and Outcomes of Depression in Primary Care (*diamond*) study. *Diamond* is a longitudinal, prospective cohort study of people with depressive symptoms which began in 2005. The design, methods and sample size calculations have been previously reported (Gunn et al. 2008). Briefly, 789 people who screened positive for depressive symptoms on the Centre for Epidemiologic Studies Depression Scale (CES-D ≥ 16) were recruited into the cohort. Participants were randomly selected from the patient lists of 30 GPs in Victoria, Australia, were aged between 18 and 75 years, and had visited the GP at least once in the past year. Ethics approval was granted by The University of Melbourne's Human Research Ethics Committee (ID: 030613X).

The current study reports on data from the first year of follow up, during which participants completed postal surveys at 3 months intervals. Each survey collected data on participants' socio-demographic characteristics, physical and mental health status and their health service use.

Questions specific to health service use were developed by the research team to capture participants' use of a variety of healthcare services. These questions were based on the Client Service Receipt Inventory (CSRI) that assesses mental health service use and has been adapted for use in the general practice setting (Chisholm et al. 2000).

Primary Outcome

The outcome was frequency of telephone helpline use over a 3 month period. As part of the CSRI, participants were asked how often they had used telephone helplines for depression, stress or worries in the past 3 months. This outcome was measured at 3, 6, 9 and 12 months in the first year. Participants reported their telephone helpline use with a five-point scale (never, rarely, monthly, a few times a month, once a week or more) which we categorised at each time point into three ordered categories: (i) no use (never); (ii) non-frequent use (rarely, monthly or a few times a month); (iii) frequent use (once a week or more). These categories were selected based on a modified definition that we used in a previous study. In that study, we defined frequent users of telephone helplines as those who called 20 times or more in the past month (Spittal et al. 2015). The data available from the *diamond* study did not allow us to use quite the same definition, but we chose one that was as comparable as possible.

Explanatory Variables

Details about self-reported socio-demographic, physical and mental health, medication related and health services use variables are described below. Appendix (Table 4) outlines how the variables were coded and when they were measured. Explanatory variables that were only measured once (usually at baseline) or did not vary over the year were considered to be time-independent variables, whereas variables measured at each time point and could vary over time were considered to be time-dependent variables. Time-dependent explanatory variables were measured at the same time point as the outcome variable.

Socio-demographic Factors

Socio-demographic factors included age, gender, living arrangements, ability to manage on available income and social support. Gender and age in years were measured at baseline. Age was categorised into three groups: 18–34, 35–54 and 55–76 years. Usual living arrangements were assessed at each time point and identified those who lived alone (yes/no). Ability to manage on available income was measured on a five-point Likert scale at baseline and categorised to a dichotomous variable: difficult some of the

time/difficult all of the time/impossible to manage, easily/not bad to manage. Social support was measured at baseline using a question taken from the psycho-social stressors module in the Patient Health Questionnaire (PHQ) (Spitzer et al. 1999). This question identified participants who were bothered by having no one to turn to when they had a problem with three response options: not at all bothered, bothered a little, bothered a lot.

Physical Health Factors

Measures for physical health included chronic disease and self-rated health. Chronic disease was measured at baseline by asking participants whether they had any long-term illness, health problem or disability, which limits their daily activity or the work they can do (including problems due to old age). This question was taken from the UK Census in 2001 (Sturgis et al. 2001) and reported as a binary (yes/no) variable. Self-rated health was measured at each time point using a question in the Short-Form 12 survey (SF-12) (Ware et al. 1998). The question includes five response options which we dichotomised into a binary variable: poor/fair, good/very good/excellent.

Mental Health Factors

Mental health factors included anxiety, major depressive syndrome, personality disorder and suicidal thoughts. The PHQ was used to measure both anxiety and major depressive syndrome (Spitzer et al. 1999). Anxiety was measured at baseline using the 6-item PHQ other anxiety module. Anxiety was calculated based on an algorithm that follows the DSM-IV criteria for Generalised Anxiety Disorder (Spitzer et al. 1999) and included those participants who reported being bothered by feeling nervous, anxious, on edge or worried a lot about different things in the past four weeks. Major depressive syndrome was measured using the PHQ-9 (Spitzer et al. 1999), which is scored via the algorithm method that dichotomises responses into two categories: no major depressive syndrome, major depressive syndrome. Participants were screened for the probability of meeting criteria for a personality disorder at 3-year follow up. Unlike the other variables, the Standardised Assessment of Personality-Abbreviated Scale (SAPAS) (Moran et al. 2003) which has been validated for use in routine clinical settings was not administered in the first year. However, previous studies have shown that personality disorder symptoms begin in late childhood, so using this screener after the outcome variable was assessed was considered reasonable as a means of identifying the majority of people with a high probability of meeting criteria for a personality disorder (Lieb et al. 2004). Suicidal thoughts were used as a proxy

measure for suicide risk and were assessed via item nine of the PHQ-9 (Spitzer et al. 1999) at each time point. This item enquires whether over the past 2 weeks the participant has been bothered by thoughts that they would be better off dead or of hurting themselves in some way. The four response choices were dichotomized into: no suicidal thoughts (not at all), suicidal thoughts present (several days/more than half the days/nearly every day).

Medication Related Items

Medication related items were identified from responses provided at each time point to the question “During the past 3 months, what medications have you been prescribed for your emotional wellbeing?” Medication names were then coded by a research pharmacist into larger medication categories which included antidepressants and antipsychotics. We reported on the prescription of both of these medication types as binary (yes/no) variables.

Health Service Use Factors

The use of healthcare services was measured at 3, 6, 9 and 12 month time points. Participants were asked whether they had visited a GP (yes/no), a psychologist (yes/no), a psychiatrist (yes/no) or the emergency department (yes/no) in the past 3 months. Based on the responses to these four questions we created a composite variable that identified participants who had visited the GP and one or more of the other health professionals in the past three months vs. only visited the GP. People who did not report visiting the GP in the past three months were excluded from this composite variable. Participants used a five-point Likert scale to rate how satisfied they were with their access to health services measured at each time point. This question was taken from the WHOQoL-Bref (Hawthorne et al. 2006) and responses were sorted into three categories: very satisfied/satisfied, neither satisfied nor dissatisfied, and very/fairly dissatisfied.

Details about visits to the GP were measured for those participants who reported visiting the GP in the past 3 months. This included the number of visits to the GP for any reason (count) and the number of visits to the GP for emotional wellbeing (count) in the past 3 months. Furthermore, we measured the number of GPs visited (count) and the number of visits made to their usual GP (count) in the past 3 months. The average length of visits to the GP was reported as a categorical variable with three categories: ≤ 6 min, 7–19 min, or ≥ 20 min which aligned with standard Medicare Benefits item numbers for general practice visits in Australia (Department of Health 2014). We also measured whether participants had changed their usual GP in the past 3 months (yes/no) and whether they reported that the GP had done any of the following in the past

3 months: provided reassurance, encouragement and explanation (yes/no); given them a chance to talk about how they were feeling (yes/no); helped them talk through their problems (yes/no); given them information (leaflets, booklets or videos) about depression, stress or worries (yes/no); or made a suggestion or referral for them to see another health professional for their emotional wellbeing (yes/no). The helpfulness of the GP in addressing their emotional wellbeing was measured using a five-point Likert scale and reported as a categorical variable: not at all helpful, slightly/moderately helpful, very/extremely helpful.

Statistical Analysis

Analysis used data provided by participants who completed the telephone helpline use question at least once over the first year (3, 6, 9 and 12 months). The frequency of participants' use of telephone helplines was ordinal and summarised at each time point from available data. Ordered logistic model was used to examine the association between telephone helpline use and each explanatory variable. Time that the outcome was measured was included as a fixed effect in the model. In addition, robust standard errors with the individual as the cluster were used to account for the correlation of data from repeated measures on the same individual. Estimates for the associations were reported as cumulative odds ratios with 95 % confidence intervals. The ordinal logistic model relies upon the proportional odds assumption, which assumes that the odds ratios are constant for each of the splits of the categories in the outcome (that is comparing the odds of “Frequent use and Non-frequent use” to “No use of telephone helplines” and “Frequent use” to “Non-frequent use and No use of telephone helplines” for each sub-group of the explanatory variable to a reference group). This assumption was satisfied for all explanatory variables when tested using the Brant test. All statistical analyses were conducted using STATA version 13.1 (StataCorp 2014).

Results

Of the 789 participants who were recruited into the *diamond* cohort at baseline, useable surveys were returned by 668 participants at three-months, 634 participants at six-months, 612 participants at nine-months and 563 participants at 12-months. Loss to follow-up in the first year was more common among those who were unable to manage on their available income, had panic syndrome on the PHQ or reported childhood abuse. Seven hundred and thirteen (90 %) of the *diamond* participants responded to the question about telephone helpline use at least once over the

Table 1 Patterns of participation in the diamond cohort study over the first year of follow up outlining responses to the use of telephone helplines question (n = 713)

	Time point				Frequency	Percent (%)
	3 months	6 months	9 months	12 months		
Participants with no missing values	x	x	x	x	479	67.2
Participants with one missing value	x	x	x	.	134	18.8
	x	x	.	x		
	x	.	x	x		
	.	x	x	x		
Participants with two missing values	x	x	.	.	59	8.3
	x	.	x	.		
	x	.	.	x		
	.	x	x	.		
	.	x	.	x		
	.	.	x	x		
	.	.	.	.		
Participants with three missing values	x	.	.	.	41	5.8
	.	x	.	.		
	.	.	x	.		
	.	.	.	x		

There are 76 observations with all missing values. The percentage is calculated with the total of 713 instead of 789 (as this only includes participants who responded to the telephone helpline use question)

(x) indicates that telephone helpline use was recorded at that time point; (.) indicates that telephone helpline use was missing at that time point

first year (at 3, 6, 9 or 12 months). Of these participants, 479 (67 %) responded at all four time points, 134 (19 %) at three time points, 59 (8 %) at two time points and 41 (6 %) at one time point. The patterns of participation in the *diamond* cohort study over the first year of follow up for those who responded to the question about use of telephone helplines is given in Table 1.

Table 2 describes the frequency of use of telephone helplines over the first year of follow up. In total, 654 (92 %) participants reported no use of a telephone helpline at every follow-up time point, 43 (6 %) reported only non-frequent use at one or more follow-up time points, and 16 (2 %) reported frequent use at least once in a three month follow-up period. Of the 16 participants who reported frequent use, 10 reported frequent use at one time point only and six reported frequent use at two or more time points.

Table 3 shows the strength of the association between telephone helpline use and each of the explanatory variables. A worked example on interpreting Table 3 is given using the live alone variable. This time-dependent variable was measured at the same time point as telephone helpline use. A total of 552 observations were identified over the four time points (3, 6, 9 and 12 months) where an individual reported living alone. A total of 178 participants (25 %) in the sample accounted for these 552 observations (100 %: n = 713). The unadjusted odds ratio

of being a frequent user was 2.4 times greater for people who lived alone compared to those who did not live alone. We are 95 % confident that the true odds ratio lies between 1.3 and 4.5. The key findings from Table 3 are described below.

Frequent use of telephone helplines was associated with younger age (18–34 years), living alone, difficulties managing on available income and being bothered a lot by not having a confidant. The odds of reporting frequent use compared to non-frequent use and no use of telephone helplines was also higher for those who had a chronic disease and/or rated their health as poor or fair. In relation to mental health factors, anxiety at baseline, major depressive syndrome, a high probability of personality disorder, suicidal thoughts and the use of antipsychotic medications was strongly associated with frequent use of telephone helplines.

Frequent use of telephone helplines was also associated with visits to a psychologist, psychiatrist, and/or the emergency department in the previous 3 months. An association was also found between the number of GPs visited in the 3 month period and the likelihood of being a frequent user of telephone helplines. In addition, participants who reported changing their usual GP in 3 months and that the GP gave them a chance to talk about their feelings; talk through their problems or gave them information about depression, stress or worries had a greater

Table 2 Frequency of use of telephone helplines over the first year (3, 6, 9 and 12 months) of follow up (n = 713)

	Total		
	n/N	%	(95 % CI)
No use of telephone helplines by time point			
3 months	643/668	96.3	(94.5–97.6)
6 months	616/634	97.2	(95.5–98.3)
9 months	590/612	96.4	(94.6–97.7)
12 months	533/563	94.7	(92.4–96.4)
No use of telephone helplines at any time point ^a	705/713	98.9	(97.8–99.5)
No use of telephone helplines at every time point ^a	654/713	91.7	(89.5–93.6)
Non-frequent use of telephone helplines by time point			
3 months	19/668	2.8	(1.7–4.4)
6 months	13/634	2.1	(1.1–3.5)
9 months	15/612	2.5	(1.4–4.0)
12 months	21/563	3.7	(2.3–5.6)
Non-frequent use of telephone helplines at any time point ^b	48/713	6.7	(5.0–8.8)
Non-frequent use of telephone helplines at any time point without reporting frequent use at any time point ^b	43/713	6.0	(4.4–8.0)
Frequent telephone use of telephone helplines by time point			
3 months	6/668	0.9	(0.3–1.9)
6 months	5/634	0.8	(0.3–1.8)
9 months	7/612	1.1	(0.5–2.3)
12 months	9/563	1.6	(0.7–3.0)
Frequent use of telephone helplines at any time point ^c	16/713	2.2	(1.3–3.6)
Number of time points where frequent use of telephone helplines was reported ^c			
One time point	10/713	1.4	(0.7–2.6)
Two or more time points	6/713	0.8	(0.3–1.8)

^a Identified for those who reported no use of telephone helplines at any time point (3, 6, 9 or 12 months)

^b Identified for those who reported non-frequent use of telephone helplines at any time point (3, 6, 9 or 12 months)

^c Identified for those who reported the frequent use of telephone helplines at any time point (3, 6, 9 or 12 months)

odds of being a frequent user compared to non-frequent users and non-users of telephone helplines. Furthermore, reports of the GP referring them to another health professional for their emotional wellbeing and dissatisfaction with their access to health services was more likely for frequent users compared to non-frequent users and non-users of telephone helplines.

Discussion

This is the first study to examine in-depth the health service use patterns of frequent users of telephone helplines. In this cohort, the number of visits to the GP was similar for frequent users compared to non-frequent and non-users of telephone helplines. However, frequent users were more likely than non-frequent and non-users to report that, in the past 3 months, they had consulted multiple GPs, visited a mental health professional, and/or were dissatisfied with

their access to these healthcare services. Consistent with previous research in this area (Middleton et al. 2014), significant life challenges, such as social isolation, financial difficulties, poor general health and serious and disabling mental illness, were also associated with the frequent use of telephone helplines.

The findings from this study demonstrate that frequent users access face-to-face healthcare services in addition to calling telephone helplines. This finding is in contrast to previous studies suggesting that frequent users inappropriately relied on telephone helplines for support instead of accessing mental health services (Gould et al. 2007; Kalafat et al. 2007). Instead, frequent users may be accessing a range of healthcare services because they are unable to find one service that can adequately meet their complex needs. This could not be investigated in the current study. However, the increased likelihood of frequent users in this study to report dissatisfaction with access to healthcare services and to consult multiple GPs

Table 3 Association between telephone helpline use (modelling probability of frequent telephone helpline use) and the explanatory variables of interest based on ordinal logistic regression reporting unadjusted cumulative odds ratio (OR) and their 95 % confidence interval (95 % CI) (n = 713)

	No. of observations N = 2477 ^a	Frequency ^b	OR (95 % CI) ^c
Socio-demographic factors			
Age ^d			
18–34 years	424	18	3.0 (1.2–7.9)
35–54 years	1250	50	2.0 (0.9–4.5)
55–76 years	803	32	1.0
Female ^d	1753	71	1.8 (0.9–3.8)
Live alone ^e	552	25	2.4 (1.3–4.5)
Difficult/impossible to manage on available income ^d	1348	56	3.1 (1.6–6.0)
Bothered by not having a confidant ^d			
Not bothered	970	39	1.0
Bothered a little	835	35	1.7 (0.8–3.7)
Bothered a lot	655	27	3.0 (1.4–6.4)
Physical health factors			
Chronic disease ^d	1264	53	3.2 (1.7–5.9)
Poor/Fair self-rated health ^e	997	57	1.9 (1.1–3.3)
Mental health factors			
Baseline anxiety ^d	488	20	4.8 (2.7–8.7)
PHQ-9 major depressive syndrome ^e	565	42	4.4 (2.6–7.5)
High probability of a personality disorder ^f	567	31	3.9 (2.0–7.5)
Suicidal thoughts ^e	673	42	4.4 (2.7–7.3)
Medication related items			
Antidepressant use ^e	858	44	1.5 (0.9–2.6)
Antipsychotic use ^e	109	5	11.3 (5.5–23.2)
Health service use in the past three months			
Visited a GP ^e	1923	96	1.6 (0.9–2.9)
Visited a psychologist ^e	208	17	5.1 (2.7–9.6)
Visited a psychiatrist ^e	258	16	6.1 (3.3–11.4)
Visited the emergency department ^e	197	20	4.5 (2.3–8.5)
Visited the GP and other health professionals ^e	1401	81	4.3 (2.4–7.6)
Satisfaction with access to health services ^e			
Very/fairly dissatisfied	191	18	4.0 (2.2–7.2)
Neither satisfied or dissatisfied	353	31	1.2 (0.6–2.3)
Very satisfied/satisfied	1933	92	1.0
GP related health service use in the past three months			
Number of visits to the GP—all reasons mean(SD) ^{e,g}	2023	3.3 (3.1)	1.1 (1.0–1.2)
Number of visits to the GP—emotional wellbeing mean(SD) ^{e,g}	2010	1.1 (2.2)	1.2 (1.0–1.4)
Number of GPs visited mean(SD) ^{e,g}	1994	1.4 (0.7)	1.7 (1.3–2.2)
Number of times visited usual GP mean(SD) ^{e,g}	2010	2.6 (2.9)	1.1 (1.0–1.1)
Average length of visit ^{e,g}			
<6 min	182	19	1.0
7–19 min	1197	76	0.7 (0.3–1.9)
≥20 min	537	42	1.3 (0.5–3.8)
Changed usual GP ^{e,g}	288	27	1.9 (1.1–3.1)
Reported that the GP provided reassurance, encouragement and explanation ^{e,g}	1272	80	2.3 (1.0–5.0)
Reported that the GP gave them a chance to talk about their feelings ^{e,g}	1209	77	2.1 (1.1–3.8)
Reported that the GP gave them a chance to talk through their problems ^{e,g}	634	50	2.9 (1.7–5.2)

Table 3 continued

	No. of observations N = 2477 ^a	Frequency ^b	OR (95 % CI) ^c
Reported that the GP gave them information about depression, stress or worries ^{e,g}	199	23	2.3 (1.3–4.1)
GP suggested/referred to another health professional for emotional wellbeing ^{e,g}	217	22	3.3 (1.8–6.1)
Helpfulness of the GP in addressing emotional wellbeing ^{e,g}			
Not at all helpful	292	28	0.9 (0.4–2.2)
Slightly/moderately helpful	601	50	1.1 (0.6–2.0)
Very/extremely helpful	840	59	1.0

^a Number of observations (repeated measures) as used in the analysis (total number of observations = 2477)

^b Frequency = the unweighted percentage of individuals in the study sample (100 %: n = 713). May not equal 100 % for time-dependent variables as participant could respond differently at each time point. Categorical variables are reported as percentages and continuous variables are reported as mean (SD)

^c Unadjusted ORs and 95 % confidence intervals calculated using ordered logit model. Robust standard errors were used to adjust for correlation of responses due to repeated measures on individuals over time. Base outcome was “no use”. Value of 1.0 indicates reference category

^d Explanatory variable measured at baseline (time-independent)

^e Explanatory variable measured at the same time point as the outcome variable (time-dependent)

^f As this explanatory variable was measured later this was a sub-analysis for the 438 individuals that had data available had 3 years

^g Sub-analysis conducted for those who visited the GP in the past three months at each time measured

indicates that the needs of frequent users may remain unmet. Therefore, the solution to reducing the number of calls made by frequent users is unlikely to be achieved by simply linking them into clinical services, as has previously been suggested (Gould et al. 2007). If the aim of telephone helpline service providers is to reduce the number of calls made by frequent users and to better meet their health care needs, it is important to understand the extent to which the health care needs of frequent users are being met by the various services they currently use.

GPs were more likely to refer frequent users to other services. This suggests that GPs find it difficult to manage frequent users alone, which is not surprising considering the complex needs of these users. It is likely that a multi-disciplinary approach is required if the health needs of frequent users are to be met. It also seems likely that frequent users seek different types of support from different service providers. It may be that frequent users are looking for an empathetic form of support from telephone helplines to assist them with their social isolation. Telephone helplines certainly focus on these elements of support rather than on clinical and psychosocial interventions that are offered elsewhere (Coman et al. 2001). It may also be that frequent users are looking for immediate support outside of standard office hours (Bassilios et al. 2015; Coman et al. 2001). Further research could provide insights into understanding the type of support that frequent users are seeking from telephone helplines and explore the circumstances under which they call.

The model of care available to frequent users could be enhanced to better meet their needs. Currently, the management of patients between different service providers within the Australian healthcare system is fragmented (Yen et al. 2011). Principles from the Assertive Case Management model (Bond et al. 2001), developed to manage patients with serious mental health illnesses in the community, could be used to guide healthcare services in providing complementary support to frequent users. This could include strengthening communication and collaboration between GPs, mental health professionals and telephone helplines and devising care management plans (Bond et al. 2001). It could occur at the level of the individual, although the anonymity of telephone helplines may make this difficult. It also might be done at a system level, with, for example, GPs or the bodies that represent them (e.g., Primary Health Networks in Australia) and representatives of telephone helplines sharing information with each other.

Strengths

This study uses the *diamond* data, which allowed us to examine the use of telephone helplines across four data collection time points. Retention rate of respondents in comparison to published longitudinal studies was similar (Bellón et al. 2010; Lamers et al. 2012) and the likelihood of recall bias was minimised because surveys were conducted every three months over a one year period. Unlike most previous studies that have investigated the

characteristics of frequent users (Middleton et al. 2014), the current study used validated instruments to identify the presence of mental health issues (Gunn et al. 2008), and examined the use of GPs and other mental health providers and services in an in-depth fashion.

The socio-demographic, physical and mental health profile of frequent users in our cohort were similar to previous studies of telephone helpline frequent users (Middleton et al. 2014). This suggests that even though our sample is taken from a general practice cohort with depressive symptoms, the factors found to be associated with frequent use is likely to be representative of frequent telephone helpline users.

Limitations

Our study had several limitations. Firstly, we relied on self-reported data that may have resulted in misclassifying participants as frequent users, non-frequent users and non-users of telephone helplines. We were unable to distinguish whether calls were to the same helpline service or multiple services. Secondly, the measures available to us were limited to those collected as part of the *diamond* study. There was a clear case for the inclusion of the socio-demographic, physical and mental health variables that we considered, and there were not many additional factors that we would have desirably included. However, there were temporal issues with some, particularly those that were measured at a single time point (e.g., anxiety), which may have changed over the year but were only measured at baseline. Thirdly, very few people reported the frequent use of telephone helplines over 3 months at any one time point; however, by including the repeated measures on the same individual over the 12 month period increased study precision. Fourthly, as our study focused on frequent users of telephone helplines, we were not in a position to comment on the extent to which telephone helpline services are providing adequate support to all callers. It is likely that telephone helplines provide an important and beneficial

service for many of their callers (Lester 1997), however, it appears in our study that the complex needs of frequent users remain unmet.

Conclusions

The frequent use of telephone helplines by primary care attendees with depressive symptoms does not appear to be driven by a lack of access to face-to-face healthcare services. These individuals access a larger range of healthcare services in comparison to non-frequent and non-users of telephone helplines, but their more complex health needs appear to remain unmet. The development of a model of care that aims to better meet the needs of these users is required. This would require understanding whether GPs and other mental health services find it difficult to manage these patients and the type of support frequent users perceive telephone helplines provide them.

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Appendix

See Table 4.

Table 4 List of explanatory variables included in the regression model with details on how they were coded and the time points at which they were measured

Explanatory variable	Coding	Time point
Socio-demographic factors		
Age	2 = 18–34 years 1 = 35–54 years 0 = 55–76 years	Baseline
Gender	0 = Male 1 = Female	Baseline
Live alone	0 = No 1 = Yes	3, 6, 9, 12 months

Table 4 continued

Explanatory variable	Coding	Time point
Ability to manage on available income	0 = Easily/Not too bad 1 = Difficult/impossible	Baseline
Bothered by not having a confidant	0 = Not bothered 1 = Bothered a little 2 = Bothered a lot	Baseline
Physical health factors		
Chronic disease	0 = No 1 = Yes	Baseline
Self-rated health	0 = Good/Very Good/Excellent 1 = Poor/Fair	3, 6, 9, 12 months
Mental health related factors		
Anxiety at baseline	0 = No 1 = Yes	Baseline
PHQ-9 major depressive syndrome	0 = No major depressive syndrome 1 = Major depressive syndrome	3, 6, 9, 12 months
High probability of a personality disorder	0 = No 1 = Yes	3 years
Suicidal thoughts	0 = No 1 = Yes	3, 6, 9, 12 months
Medication related items		
Antidepressant use	0 = No 1 = Yes	3, 6, 9, 12 months
Antipsychotic use	0 = No 1 = Yes	3, 6, 9, 12 months
Health service use in the past three months		
Visited a GP	0 = No 1 = Yes	3, 6, 9, 12 months
Visited a psychologist	0 = No 1 = Yes	3, 6, 9, 12 months
Visited a psychiatrist	0 = No 1 = Yes	3, 6, 9, 12 months
Visited the emergency department	0 = No 1 = Yes	3, 6, 9, 12 months
Visited the GP and other health professionals	0 = Only visited the GP 1 = Visited GP and one or more health professional (psychologist/psychiatrist/ER)	3, 6, 9, 12 months
Satisfaction with access to health services	0 = Very/fairly dissatisfied 1 = Neither satisfied or dissatisfied 2 = Very satisfied/satisfied	3, 6, 9, 12 months
GP related health service use in the past three months		
Number of visits to the GP—any reason	Continuous	3, 6, 9, 12 months
Number of visits to the GP—emotional wellbeing	Continuous	3, 6, 9, 12 months
Number of GPs visited	Continuous	3, 6, 9, 12 months
Number of times visited usual GP	Continuous	3, 6, 9, 12 months
Average length of visit to the GP	0 = ≤6 min 1 = 7–19 min 2 = ≥20 min	3, 6, 9, 12 months
Changed usual GP	0 = No 1 = Yes	3, 6, 9, 12 months

Table 4 continued

Explanatory variable	Coding	Time point
GP provided reassurance, encouragement and explanation	0 = No 1 = Yes	3, 6, 9, 12 months
GP gave a chance to talk about how were feeling	0 = No 1 = Yes	3, 6, 9, 12 months
GP helped talk through problems	0 = No 1 = Yes	3, 6, 9, 12 months
GP gave information (leaflets, booklets or videos) about depression, stress or worries	0 = No 1 = Yes	3, 6, 9, 12 months
GP suggested or referred them to see another health professional for their emotional wellbeing	0 = No 1 = Yes	3, 6, 9, 12 months
Helpfulness of the GP in addressing emotional wellbeing	0 = Not at all helpful 1 = Slightly/moderately helpful 2 = Very/extremely helpful	3, 6, 9, 12 months

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7.3 Chapter summary

Study 3 sought to understand the socio-demographic profile of frequent use of crisis helplines (research question 1) and the health service use patterns of frequent users of crisis helplines (research question 3) by examining data from the *diamond* study over the first year of follow up. Frequent users of crisis helplines investigated in this study represented a group of general practice attendees with depressive symptoms. Though this sample may have excluded some callers, it provided insights into the health service use patterns of a group of frequent users. Until now this has been a largely under-researched area. The socio-demographic profile of frequent users in this study was similar to the profile reported in Study 1, suggesting that the findings from this study may be representative of the wider population of frequent users of crisis helplines. The findings also highlighted that a large proportion of frequent users access healthcare services, including general practice, psychology, psychiatry, and the emergency department, at rates higher than other callers and non-users of crisis helplines. Despite their high service use, they remain dissatisfied with their access to these services. It may be that their complex health needs make it difficult for their needs to be met by a single service, which in turn may explain why they continue to use crisis helplines in addition to healthcare services. There is a need to look at supporting these individuals differently so that their complex needs may be addressed.

8

Integration and interpretation of findings

Chapter 8 begins by bringing together the findings from the three studies in relation to how they address the research questions. Consideration is given to the extent of convergence and divergence between the findings of these studies. The meaning of these findings, in light of previous research into frequent users of crisis helplines, is explored. The chapter concludes with a brief review of the use of a convergent mixed methods approach in this research to address the thesis aim.

8.1 Using a convergent approach to interpret findings from the empirical research

As outlined in Chapter 4, three empirical studies were undertaken to investigate the research questions this thesis sought to address. More broadly, it explored the socio-demographic characteristics of frequent users of crisis helplines and the factors driving their frequent use. These empirical studies were conducted in parallel, and at the time of interpretation a convergent mixed methods approach was used to bring together the findings. To assist with this interpretation, an assessment was made of the similarities and differences between the three studies and the extent to which the studies were comparable. Table 6 compares the three studies in terms of study population, setting, research question, and timing. A summary of the key findings from the three empirical studies is presented in relation to the three research questions, taking into consideration the degree of convergence.

Table 6: Comparison of the setting, study population, research question and methods of the three empirical studies

	Study 1: Survey of Lifeline callers	Study 2: Interviews with Lifeline frequent users	Study 3: Longitudinal analysis of data from the <i>diamond</i> study
Setting	Lifeline Australia		30 general practice clinics in Victoria, Australia
Study population	Calls received at two Lifeline centres over 54 randomly selected four-hour shifts	Sub-group of callers who participated in Study 1 and reported frequent use and provided their contact details	A cohort of general practice attendees with depressive symptoms
Sample	N=315	N=19	N=713
	69 reported frequent use	19 reported frequent use	16 reported frequent use
Inclusion criteria	Deemed by the counsellor to not be: in an immediate crisis, verbally abusive, or in an unstable mental state; Provided informed consent.	Completed Study 1; Expressed interest in the interview; Reported frequent use; Provided contact details.	Aged between 18 and 75 years of age; Visited the GP in the past year; Screened positive for depressive symptoms (scored ≥ 16 on the CES-D).
Question used to identify frequent use	How often have you called Lifeline in the past month? <i>Once/just today, twice, 3-5 times, 6-10 times, 11-19 times, 20 times or more.</i>		How often have you used telephone helplines for depression, stress or worries in the past three months? <i>Never, rarely, monthly, a few times a month, once a week or more.</i>
Outcome variable	<i>One-off users</i> (once/just today) <i>Episodic users</i> (2-19 times) <i>Frequent users</i> (≥ 20 times)		<i>No use</i> (never) <i>Non-frequent use</i> (rarely, monthly, a few times a month) <i>Frequent use</i> (once a week or more)
Time of data collection	February to August 2015		2005-2006
Methodology	Brief survey	Semi-structured in-depth interview	Written survey and CATI
Time period	Cross-sectional	One-off interview	Longitudinal (baseline, 3, 6, 9, and 12-months)
Analysis method	Ordered logistic regression	Inductive thematic analysis	Ordered logistic regression

**similarities between studies are marked in green (convergence); differences are left white (divergence)*

As demonstrated in Table 6, differences and similarities existed between the three studies. Most notably, the population investigated in Study 3 was distinctively different from the population in Study 1 and Study 2. A different definition was used in Study 3 to categorise frequent users. This difference was unavoidable as the data in Study 3 was collected previously and the necessary information was not available to identify those who had called a crisis helpline 20 times or more in the past month; the definition used in Study 1 and Study 2. However, the analysis method used in Study 3 was similar to Study 1, and allowed for comparisons to be made between the two studies. Study 1 and Study 2 were more similar, particularly as Study 2 was a subset of Study 1. Respondents in both Study 1 and Study 2 were drawn from the same population and the same question was used to elicit crisis helpline use. A different analysis method, justified by the study methodology, was used in these two studies.

Despite variation between the three studies, they each provided insight into the issue of frequent use of crisis helplines. Study 1 and Study 2 looked at the issue within a group of callers to Lifeline, while Study 3 provided a unique opportunity to look at health service use over time among a population that included some individuals who had used crisis helplines. Such data were not available in either Study 1 or Study 2. By itself, Study 3 contributes to the research on frequent users of crisis helplines, but when merging the findings caution needs to be taken as the study methodology differs. To account for divergence, different weight was given to the findings from each study. As most similarities existed between the population in Study 1 and 2, the findings from these studies were given equal weight. The findings from Study 3 were used to supplement those of Study 1 and Study 2, when the findings of these studies did not adequately address the research question.

8.1.1 The socio-demographic profile of frequent users of crisis helplines

The use of different methods in previous research has resulted in inconsistent findings around the reported socio-demographic characteristics of frequent users. Research question 1 sought to document the socio-demographic profile of frequent users of crisis helplines in Australia. This question was addressed in Study 1 and Study 3, which drew on data from two different populations to examine differences between frequent users and other users and non-users of crisis helplines. Ordinal logistic regression was the analysis

technique used in both studies to examine these differences. Despite inherent differences between these two populations, some similarities were found regarding the socio-demographic profile of frequent users of Australian crisis helpline services.

In both studies, frequent users were more likely to report living alone and employment related issues. Differences were found between the two studies with regard to the association between age, gender, and frequent use suggesting that these factors are not strongly associated frequent use. Other factors found to be associated with frequent use, as reported in Study 3, included a poor to fair health rating, issues with chronic diseases, and being bothered a lot by not having a confidant. These factors were not examined in Study 1.

When the findings from these two studies were brought together, it appears that frequent users could be distinguished from other callers by their social isolation, likelihood of living alone, and high levels of unemployment or difficulties managing on available income.

8.1.2 Reasons for frequent users' continued use of crisis helplines and how they differ to those of other callers

Research question 2 sought to explore the reasons for frequent users' continued use of crisis helplines. This question was addressed in Study 1 and Study 2 with the use of both quantitative and qualitative methods. Study 1 employed a quantitative approach using ordinal logistic regression to investigate differences in the reasons for calling between frequent and other users of crisis helplines, whereas Study 2 used a qualitative approach with inductive thematic analysis to generate common themes from 19 semi-structured interviews.

The findings from Study 1 highlight that similar to other callers, frequent users call crisis helplines about mental health issues, social isolation, and crisis-related issues. However, they have an additional need for regular emotional support, which is a distinguishing feature. Their desire to call regularly to talk about their feelings was explored further among a sub-set of these frequent users in Study 2. The use of in-depth interviews gave insight into this need, which appears to be driven by an interaction between their reasons for calling and the short-term benefits they receive when they call. On closer examination,

three distinctive calling behaviours were identified that could be described as reactive, support-seeking, and dependent behaviours.

Even though it was not part of the initial study design, data were available in Study 3 that allowed for an exploration of the mental health issues associated with frequent use of crisis helplines. Anxiety, major depressive syndrome, personality disorder, suicidal thoughts, and the use of antipsychotic medications were all strongly associated with frequent use.

Drawing together the findings of these studies, it could be concluded that the reasons for frequent users' continued use of crisis helplines are a mix of complex crisis-related issues, mental health issues, and social isolation. It is also apparent that these callers have come to rely on crisis helplines as a source of regular emotional support, which distinguishes them from other callers. This reliance appears to develop as they identify short-term benefits in calling.

8.1.3 Factors driving the frequent use of crisis helplines

It has been suggested by Apsler and Hoople (1976) and Kalafat et al. (2007) that frequent users call crisis helplines because their access to healthcare services is limited. Research question 3 sought to identify the health service use patterns of frequent users of crisis helplines, which was addressed using both qualitative methods in Study 2 and quantitative methods in Study 3.

Study 2 asked interview respondents about the health professionals they saw for their emotional wellbeing and found that general practitioners were the most commonly mentioned health professional. This finding was examined in more detail in Study 3 by exploring differences between health service use patterns of frequent users, non-frequent users, and non-users of crisis helplines. Frequent users were more likely to report visiting multiple GPs, using emergency services, and visiting mental health professionals at rates higher than other callers and non-users of crisis helplines. Yet, frequent users were less satisfied than other callers and non-callers with their access to healthcare services, which suggests that their needs may remain unaddressed.

Bringing together the results from these two studies indicates that frequent users tend to draw on a range of healthcare services in addition to calling crisis helplines and may also be using these services at rates higher than other users.

8.2 Interpretation of the key findings

The findings of this research need to be considered in light of previous research into frequent users of crisis helplines. Several similarities exist between the socio-demographic profile of frequent users and the factors driving their frequent use. These are explored below.

8.2.1 Socio-demographic characteristics

Sufficient evidence now exists to suggest that frequent users are not simply a group of isolated individuals (Haywood, 1980; Tarran, 1982) who live alone and experience unemployment (Apsler & Hoople, 1976; Sawyer & Jameton, 1979). Frequent use may not be associated with a specific socio-demographic profile, in terms of gender or age, but these users are distinguished from other callers by their experience of a combination of social isolation (Burgess et al., 2008; Coveney et al., 2012; Middleton et al., 2016b; Middleton et al., 2017), long-term mental health issues (Bassilios et al., 2015; Burgess et al., 2008; Kalafat et al., 2007; Middleton et al., 2016a; Middleton et al., 2016b; Middleton et al., 2017), negative life events that continue to cause them distress (Coveney et al., 2012; Middleton et al., 2016b), and chronic physical health issues (Burgess et al., 2008; Middleton et al., 2016a).

Similarities were identified between the findings from this research and those studies previously undertaken in an Australian setting. In particular, unemployment was found to be associated with frequent use (Bassilios et al., 2015; Middleton et al., 2016b; Middleton et al., 2017) in those studies where it was investigated. Marital status was not investigated in this research, but was previously found to be associated with frequent use among callers to Lifeline (Burgess et al., 2008; Spittal et al., 2015). Living alone could be related to being unmarried, which was associated with frequent use in this research. Not having a partner/spouse was found by Bassilios et al. (2015) to distinguish those who call crisis helplines from those who do not call. Chronic disease was also reported in the Australian study by Burgess et al. (2008) to be associated with frequent use. Alcohol and drug use, which received inconsistent reports in previous research (Bassilios et al., 2015; Burgess et al., 2008), was not investigated in this research.

Trends in the similarities between these studies are interesting to note. In particular, the studies by Burgess et al. (2008) and Spittal et al. (2015) were both representative of callers

to Lifeline. However, frequent users were defined in the study by Burgess et al. (2008) to call the service 10 times or more in a month. Whereas, Bassilios et al. (2015) examined the issue of frequent use in a population-based study, thus covering a broader population than any of the other studies—however no distinction was made between episodic and frequent users. Despite these differences, similar socio-demographic characteristics were associated with frequent use. This supports the idea raised by Pollock et al. (2010) that frequent users may not be that distinctively different from episodic callers.

Mental health issues

Findings from this research support previous reports that frequent users experience a range of mental health issues. This similarity was found despite this research primarily being undertaken within the context of a group of general practice attendees who reported depressive symptoms. The likelihood of reporting mental health issues was increased in this population. The mental health issues experienced by frequent users in Study 3 were similar to those reported in previous research that also drew on standardised measures. In particular, rates of anxiety and depression were high among frequent users, consistent with previous research that used validated measures (Bassilios et al., 2015; Burgess et al., 2008; Kalafat et al., 2007). Similarly, it has consistently been reported that frequent users experience suicidal behaviours at rates similar to other callers (Bassilios et al., 2015; Kalafat et al., 2007; Mishara & Daigle, 1997; Spittal et al., 2015). Caution needs to be taken when assessing suicidal thoughts as a proxy for suicidal risk (Beck et al., 1999).

As association between frequent use and an increased probability of having a personality disorder was found in this research. The prevalence of personality disorders has only been investigated once before, in a study conducted nearly 50 years ago, where an association was reported (Farberow et al., 1966). People with personality disorders experience variations in their emotions and struggle to maintain relationships with others, which can often lead to emotional crises (National Institute for Health and Clinical Excellence, 2009). A higher rate of suicidal tendencies has been identified among people with a personality disorder (National Institute for Health and Clinical Excellence, 2009). This might benefit from further investigation.

8.2.2 Factors driving the frequent use of crisis helplines

It is becoming clear that the factors driving frequent users of crisis helplines are more complex than seeking social support, as was initially assumed (Hall & Schlosar, 1995).

The precise reason for calling appears to differ from person to person, but all of these users have come to rely on crisis helplines for emotional support. This includes social support and/or issues related to their mental health, but these are not the only reasons driving them to call. Based on the socio-demographic profile of frequent users established in light of this study and previous research, such as that by Bassilios et al. (2015), Burgess et al., (2008), Spittal et al. (2015), it is no surprise that frequent users have an additional need for emotional support as they lack other social supports. For many their friends and family appear to have turned away from them (Coveney et al., 2012). Part of this complexity may relate to the way in which frequent users learn to “play the system” and the way the system works to promote, if not encourage, dependency (Pollock et al., 2010). This suggests that service providers can not simply approach frequent users by focusing on the issue they present to the helpline with.

The findings from Study 2 also have some interesting similarities to those identified in Pollock et al. (2010) among the 48 callers who completed the in-depth interviews. In both studies, it was common for callers to provide a vague response about how often they called, how long they had been using the service, and why they called regularly (Middleton et al., 2016b; Pollock et al., 2010). Callers would go through periods of intense contact and then no contact with the helpline (Pollock et al., 2010). The callers in Study 2 had minimal support networks, whereas in the study by Pollock et al. (2010) wide variation was reported in the quality of their support networks, possibly a result of extending the study population beyond frequent users. However, a major point of difference between these studies was that the findings from Pollock et al. (2010) were not explicit to frequent users but rather included a broader group of callers to crisis helplines. Despite investigating different groups of callers, these studies both identified that a complex set of reasons were driving these callers to rely on crisis helplines for emotional support. This suggests that some commonalities may exist between frequent users across different countries. Findings related to frequent users of crisis helplines of different services may be more comparable than initially proposed.

Frequent use is unlikely to be a result of limited access to healthcare services. The findings from this research support the findings from Bassilios et al. (2015) that frequent users visited a range of healthcare services in addition to calling crisis helplines at rates higher to other callers and non-users of crisis helplines. It was suggested that the needs

of frequent users remained unmet despite their heavy service use (Bassilios et al., 2015). It was also reported by Pollock et al. (2010) that many respondents were in contact with a range of services at the time of contacting the crisis helpline, including specialised and professional services. The needs of callers seemed to be met in this study, as the majority of callers reporting being satisfied with their encounter (Pollock et al., 2010). Instead, it was the different understanding that existed between counsellors and callers, in terms of the purpose of the helpline, that created this sense of unmet need (Pollock et al., 2010). This difference in understanding highlights that callers may not necessarily share the same commitment as volunteers to “move on” (Pollock et al., 2010). Although crisis helplines wish to provide emotional support to persons in crisis, including those experiencing suicidal thoughts and feelings, in reality a relatively small number of callers are, even if self-defined, in a crisis when they call. Most of the callers in the study by Pollock et al. (2012) did not contact the helpline with the intention of moving on but rather saw the service as a regular source of support to contact when in need. Spittal et al. (2016) found that 60% of the calls are from frequent users and Pollock et al. (2010) found that over 85% of survey respondents (89% of who already used the service regularly) reported considering contacting the service again. This raises some interesting questions of: Who is the service for, and What is the role of user-defined needs in its development and assessment?

Crisis helplines were established around the principle of being a universally accessible service to those in need. The definition of a crisis is left up to the individual (Paterson et al., 2009). Frequent users seem to have identified that they can call crisis helplines with no restrictions, as reported in Study 2 and in the study by Pollock et al. (2010). Frequent users appear to define their needs in very different terms from the organisation, which wants to support a different clientele. This causes contention as the service model is built on the assumption of providing support for one-off calls, yet a substantial number of calls come from people who call more often. A misunderstanding has emerged between how frequent users’ understand the purpose of crisis helplines and the vision of the organisation. This misunderstanding is further supported by the notion, outlined in Pollock et al. (2010), of the “good caller” who experiences great difficulty or despair, if not actively suicidal, and leaves the counsellor feeling like they had made a significant difference in terms of how the caller was feeling by the end of the call. This is in comparison to the “good counsellor”, also identified in Study 2, who appears to be

genuinely concerned about the caller and gives them the space to control the topic of conversation and express their emotions (Middleton et al., 2016b; Pollock et al., 2010). An encounter with either of these ideal individuals is minimal within the current operation of crisis helplines (Kitchingman et al., 2017; Gilat & Rosenau, 2011; Pollock et al., 2012). New models of care could be specifically designed to take into consideration the calling behaviour model developed in Study 2. Such a model has not been proposed before.

8.3 Convergent mixed methods approach

The convergent mixed methods approach used in this thesis allowed for the question of frequent use of crisis helplines to be explored from multiple perspectives, which provided different insights into the issue compared to looking at data from the three separate studies (Creswell, 2015). The majority of previous research has looked at the issue of frequent use in individual studies. The findings from these studies were difficult to compare as different populations were investigated. In comparison, the studies in this thesis were designed in a way so that the findings could be brought together using a convergent mixed methods approach. This meant that both quantitative and qualitative analytical methods could be used to explore the research questions (Sale, Lohfeld, & Brazil, 2002).

The use of a convergent mixed methods approach is not without limitations, particularly in the context of this study. This approach requires that a consistent population is examined in each study to bring together the findings from multiple studies. This was not the case in Study 3, which explored the research questions in a sub-set of crisis helpline users and defined frequent users differently to Study 1 and 2. This variation was taken into consideration by giving the findings from Study 3 less weight; however, this did not completely address the issue of consistency. To clarify the accuracy of the findings from Study 3, this study would need to be replicated in a population that is representative of callers to crisis helplines. Secondly, the way the findings from the three studies were brought together could have been strengthened by merging the studies before the interpretation phase. This would have allowed for some of the gaps identified in Study 1 to be examined in the other studies. This was not possible in this research, as data were collected in parallel for Study 1 and Study 2. Thirdly, the use of other mixed method approaches could have been explored. For example, an explanatory design could have

been adopted that used quantitative methods to examine a problem and then qualitative to help explain the initial results in more depth (Creswell, 2015).

8.4 Chapter summary

The findings from the three empirical studies were brought together in this chapter using a convergent mixed methods approach. Data were merged in relation to how the findings from each study addressed the research questions. Findings from Study 1 and 2 were given equal weighting, whereas Study 3 provided additional analysis that could not be explored in the first two studies. These findings were explored in light of previous research, with many similarities identified suggesting that differences between services may not be as apparent as once proposed. Based on this, evidence is now developing to indicate that services providers may benefit from recognising frequent users as legitimate callers. This notion will be explored further in the following chapter.

9

Addressing the issue of frequent use of crisis helplines

Chapter 9 discusses the significance of the findings in terms of addressing the issue of frequent use of crisis helplines, particularly in terms of Lifeline. The chapter begins by outlining the strengths and limitations of this research. It then discusses the potential implications of service providers recognising frequent users as legitimate callers and opportunities for future research. The chapter concludes with a summary of the significance this research makes towards understanding frequent users of crisis helplines.

9.1 Strengths and limitations of this thesis

As already outlined, three empirical studies were undertaken using both quantitative and qualitative methods to investigate the socio-demographic characteristics of frequent users of crisis helplines and the factors driving their frequent use. The findings from these studies were brought together using a convergent mixed methods approach, drawing on the strengths of the methods used in each study. Integrating the findings from the three empirical studies in this manner has not been done previously. The strengths and limitations of this research are considered below.

9.1.1 Strengths

There are several strengths that relate to the methods used in this research. In particular, these relate to the use of: in-depth interview data, using data solely drawn from an Australian setting, the collaboration with Lifeline in implementing of the findings of this research, and the use quantitative and qualitative methods that were brought together using a convergent mixed methods approach. Each of these strengths is explored below.

This was the first study to use in-depth interviews with an identified group of frequent users of crisis helplines in an Australian context. Even though the problem of frequent

use was identified over 50 years ago, a dearth of research has sought to obtain the first-hand perspective of frequent users in a systematic way. Only the study by Pollock et al. (2010) was identified to have included in-depth interviews with callers to crisis helplines. However, as already mentioned (see Section 3.2), frequent users were not distinguished from other callers in this study. Qualitative methods allow for the experience of frequent users to be explored in more detail and provide insight into their calling behaviours.

The use of data specific to one crisis helpline service in Australia, namely Lifeline, can be considered both a strength and limitation. As a strength, by primarily considering data from Lifeline provided greater reassurance that the findings were representative of the same population. A limitation of previous research, as noted in Section 2.1.4, is the inability to compare the characteristics of callers across studies due to concerns with inherent differences between services. Furthermore, the findings from this research may be representative of other generalised crisis helpline services in Australia, and potentially other countries, as Lifeline is considered one of the largest helplines in Australia, receiving over 820,000 calls in 2014-2015 (Lifeline Australia, 2015a). However, callers to Lifeline may be distinctively different from other crisis helpline users, which may not reflect the broader population of frequent users. The methods undertaken in this thesis might benefit from being replicated in other settings, such as the UK and/or USA, to determine whether similarities exist between services. Similarities have already been identified between with findings from the study by Pollock et al. (2010).

Along with drawing on data from Lifeline, a process has begun with the service to explore how to implement the findings from this research into practice. From the outset, the research team of the broader project collaborated with staff at Lifeline to ensure the findings remained relevant to their service needs. The findings from the broader project were presented at the national Lifeline managers meeting in December 2015, where managers were given the opportunity to ask questions and provide feedback on the proposed model. The managers welcomed the research and were eager to consider the findings. The collaboration between the research team and Lifeline is a unique strength of this study and will continue to benefit the helpline into the future. Furthermore, the findings from the three empirical studies are already available in the public domain as they are published in peer-reviewed journals.

Another strength was the use of both quantitative and qualitative methods to address the research questions. Health services research is often not incorporated into routine practice as the applicability of the findings to other settings can be unclear (Ettelt & Mays, 2011). However, if consistent findings are reported across multiple studies investigating the same issue, the representativeness of the findings becomes more plausible (Lohr & Steinwachs, 2002). This is where the use of multiple methods can assist in improving the validity of the findings of health services research (Brazil, Ozer, Cloutier, Levine, & Stryer, 2005). In the case of this research, cross-sectional and longitudinal methods were drawn upon to explore the socio-demographic characteristics and factors driving frequent use with similar findings. Additionally, these factors were investigated with the use of standardised measurements, further strengthening the validity of the findings.

The way in which the findings from the three studies were brought together is worth mentioning despite being explored in detail in Chapter 8. A range of data sources and methodologies were used to seek answers to the same research questions. The findings from the three studies were integrated using a convergent mixed method approach. As already mentioned in Section 8.3, by merging the findings from the three studies during the interpretation phase a comprehensive review of the issue of frequent use was provided (Creswell, 2015). If the findings from different studies point in a similar direction then you can draw conclusions with a greater degree of certainty than if you had a single study, data source, or methodology. Study 3 has been identified to be inadvertently different from Study 1 and 2, particularly in relation to the timing of data collection, within a study of depression; the definition of frequent user; and the secondary analysis of data collected for a different purpose. A resolution to this difference was explored in Section 8.1, which meant the inclusion of data from the *diamond* study offered an opportunity to explore frequent use from a different perspective. It allowed for a longitudinal analysis that explored health service use patterns of frequent users of crisis helplines, a missing element in previous research. This research was undertaken among a cohort of general practice attendees with depressive symptoms, but included a group of callers to crisis helplines. This represents a pragmatic approach to overcome the limited resources and difficulties in collecting data, which are associated with completing doctoral research.

9.1.2 Limitations

This thesis is not without its limitations, which need to be considered when interpreting the findings. The limitations of this thesis relate to: the definition of frequent use, the small number of frequent users included in each study, the use of self-report data, the recruitment of callers into Study 1 and Study 2, the use of data from the *diamond* study, and the potential exclusion of some frequent users. Each of these limitations is explored below.

A limitation of this research was the lack of a consistent definition of frequent use. Despite the best efforts to ensure consistency between the three studies, it was not possible. The definition used in Study 1 and Study 2 categorised frequent users as calling the helpline 20 or more times in a month. Even though an arbitrary number, this cut-off reflected the definition used by Lifeline. The use of this definition was possible with the data available in Study 3, which made it difficult to compare findings with Study 1 and 2. This is a well-documented limitation of previous research into frequent users.

The small sample of frequent users investigated in each of the three studies is another limitation. Most previous research reported on data relating to less than 100 frequent users, bringing into doubt the representativeness of the findings. A similar limitation was encountered in this research. Effort was made to recruit the largest number of frequent users, but in both Study 1 and Study 3 frequent users made up less than 25% of the population. This highlights a difficulty in undertaking research into frequent users of crisis helplines. Even though a small number of frequent users were recruited, it was recruited in a systematic manner. This can be seen as a step to strengthen the representativeness of the findings. In particular, in Study 1 all eligible callers were invited over 54 shifts that occurred at different times of the day to participate. In terms of Study 3, data were drawn from a sample that included individuals who had both used and not used crisis helplines and was considered representative of a group of general practice attendees with depressive symptoms (Gunn et al., 2006).

This research also relied on self-report data, which may be considered a limitation. It is well recognised that the responses provided to self-report data may be affected by recall bias and participants may not be entirely honest out of fear of criticism (Bhandari & Wagner, 2006). Other methods, such as collection of observational data can reduce the degree of bias, but in the case of understanding how people engage with healthcare

services it would be difficult to collect observational data that includes all types of services (Drapeau, Boyer, & Diallo, 2011). Within certain parameters, self-report data has come to be considered an appropriate method of data collection in health services research (Drapeau et al., 2011). In particular, self-report data are considered appropriate when the follow-up time between the event and reporting the event is minimal. Recall bias was minimised in Study 1 by asking Lifeline callers at the end of their call about the encounter. In the case of Study 2, participants were asked more broadly about their experience with calling Lifeline, which would not have been appropriate to an observation methodology. For Study 3, participants were asked at three monthly intervals to report on the previous period. This is considered an acceptable period of time to recall past health service use (Bhandari & Wagner, 2006). Future research could address this limitation by comparing self-report health service use data of frequent users with observation data collected by health professionals to identify any discrepancies.

The recruitment of participants into Study 1 and Study 2 is another limitation. For Study 1, the counsellor acted as a gatekeeper and decided which callers were invited to complete the brief survey. This may have introduced bias into the recruitment process. Based on their discretion, the counsellor may have marked some callers as ineligible even though they may have been eligible, thus not informing them of the survey. To address this limitation, participation in data collection was voluntary for counsellors. This was to ensure the involvement of staff that were supportive of the process and more likely to follow the research protocol. Furthermore, in an attempt to reduce confusion about eligibility counsellors were provided with a template to screen calls. Eligibility to Study 2 was limited to callers who participated in the brief survey and provided contact information. This method of recruitment excluded callers who did not wish to participate in the survey or wished to maintain their anonymity with Lifeline.

Consideration also needs to be given to the inclusion of data from the *diamond* study in Study 3. Data were collected nearly ten years ago in which there have been several reforms to the Australian healthcare system, in particular to general practice and mental health services. These reforms may have changed the way people use healthcare services. For example, The Australian Federal Government introduced in 2006 the Better Access to Mental Health Professionals program, which aimed to provide better links between general practice services and mental health professionals by offering patients with a

mental health plan six visits to a psychologist per year (Department of Health, 2014a). However, the impact of this change on this research is unclear as, if anything, this program was meant to improve access to mental health professionals (Bassilios et al., 2016). The specific helpline used by participants was also not explicitly investigated in the *diamond* study. Instead, participants were asked more generally about their use of crisis helplines for their emotional wellbeing. As highlighted in Section 2.5, over 115 crisis helpline services operate in Australia increasing the likelihood of participants using other helplines. However, not all of these services operate at the national level and Lifeline is one of the larger services (Barber et al., 2004). The assumption was made in Study 3 that reporting positively to calling a crisis helpline for emotional wellbeing meant calling Lifeline, which at some stage was most likely true for participants. The population investigated in Study 3 was not limited to crisis helplines. Future research might benefit from examining differences that may exist between a general practice population and callers to crisis helplines, in particular the health service use patterns of frequent users.

The possibility that some frequent users may have been excluded from the analysis also needs to be considered. Even though processes were put in place to investigate a wide spectrum of callers to Lifeline, some users who called frequently may have been inadvertently missed in the analyses. In terms of Study 1 and Study 2, users who may have called frequently were excluded if they were considered to be in an immediate danger. For Study 3, users who called frequently but did not use general practice services in the past year or report depressive symptoms were excluded. In future research, it would be worth considering methods to reach these users, particularly as their needs may differ to the frequent users considered in this thesis.

9.2 Recognising frequent users of crisis helplines as legitimate callers

Consideration of this research and that of Pollock et al. (2010), Pollock et al. (2012), and Spittal et al. (2015) highlight that service providers may benefit from recognising frequent users as legitimate callers. This would require service providers to reconsider how they approach these callers and whether changes are required to the operation of crisis helplines. The implications of these changes are considered both broadly and specifically in regards to Lifeline.

Crisis helplines have been deliberating and experimenting with ways of responding to frequent users for many years. Past attempts at reducing calls from frequent users have not been very effective (Barmann, 1980; Brunet et al., 1994; Hall & Schlosar, 1995). This is partly because crisis helplines were designed to have low access barriers when compared with public or professional services. While strategies to reduce the numbers of calls from frequent users are largely untested, the same could be said for the effectiveness of the core service to those who call once at a point of acute crisis (Hvidt et al., 2016). Crisis helplines were established at a time when the use of randomised controlled trials for proving effectiveness of models of service use was not common and they grew as a result of increasing demand and popularity. The questions of popularity and increasing demand of crisis helplines and their effectiveness needs to be clearly distinguished. The effectiveness of crisis helplines was not the focus of this thesis but, as these services are now in widespread use, it is important to consider as part of their evolution. Rather than trying to reduce the number of calls made by frequent users, a common approach, service providers may consider extending the scope of crisis helpline beyond supporting those in an immediate crisis to include people requiring more regular support. Frequent users could be included within this latter category. This would require service providers recognise frequent users as legitimate callers to crisis helplines.

Recognising frequent users as a group of service users has implications to the functioning of these services. The current service model is designed for single call, crisis focused interventions, which differs from how frequent users approach these services. If crisis helpline services providers were to recognise frequent users as a legitimate service user, the role these services are seen to play within the community could change. They might no longer be recognised as only providing immediate crisis support but support a substantial number of regular users, whose needs differ to one-off users. Furthermore, no consistent approach is taken towards responding to these callers, rather it is left up to the counsellor to decide. Pollock et al. (2012) identified that counsellors often felt that they receive insufficient training on responding to frequent users. Formal recognition of these callers could give rise to the development of training programmes to better equip counsellors to address the needs of frequent users. This could help minimise any false expectations that may exist among counsellors about the callers they will support and among callers who may become frustrated with the response they receive from the service. A framework could be developed to assist services in approaching frequent users.

The calling behaviour model proposed in Study 2 could be drawn upon in the development of a new model of care (Middleton et al., 2016b).

Consideration could also be given to collaborating with professional mental health services, as a high proportion of frequent users are already using such services. Currently crisis helplines operate in isolation to healthcare services despite it being recognised that they offer complementary support. Greater improvements to an individual's health have been shown to occur in those situations where health professionals operate within a collaborative model of care (Bond, Drake, Mueser, & Latimer, 2001). By collaborating with one another, counsellors can ensure that the treatment they provide is supportive of the treatment being offered by healthcare professionals. Crisis helplines offer a unique type of service. They are available at times when healthcare services may not be accessible and can be used without any prior referrals. However, implementing these changes could lead to restructuring the operation of crisis helplines. Different agencies might explore the nature and dynamics of working together, which may implicate the reworking of existing professional roles, identities, and notions of trust (Segar, Rogers, Salisbury, & Thomas, 2013). Potential conflicts may also arise between varying professional roles and responsibilities (Segar et al., 2013). Callers would be required to relinquish their anonymity and the provision of short-term support would no longer be a distinguishing feature of such services. This could potentially be a cause of concern among service providers. The Samaritans have introduced the caller care system, in that care plans and call limits are created for those callers whose use is perceived to be outside the range of "appropriate" use; however, this has been a difficult system to implement (Pollock et al., 2010).

Research into frequent users of healthcare services could also be drawn upon when considering any changes to the crisis helpline service model. The issue of frequent use is not unique to crisis helplines and it has been well documented that there are frequent users of healthcare services, such as general practice (Smits et al., 2014) and the emergency department (Griffin et al., 2017; Norton et al., 2012; Thompson, Grootemaat, Morris, Owen, & Eagar, 2011). Research conducted in these settings, which includes a systematic review (Gill & Sharpe, 1999), found that by identifying and interviewing frequent users to understand their life situation and what may be driving them to use the service frequently, they could reduce their use of the service by working with these individuals

over time to educate them on how to use the service appropriately. This finding could be translated to the crisis helpline setting and include an aspect of education on the purpose of crisis helplines.

9.2.1 Implications to the operation of Lifeline

In Australia, work is underway to reconfigure the operation of crisis helplines. This change is taking place as part of the findings from the National Mental Health Commission review into mental health services in the country (National Mental Health Commission, 2014a). It was identified in this review that substantial duplication exists in the type of crisis helplines operating in Australia, making it difficult for individuals to navigate the system. The Australian Federal Government has begun considering changes to the operation of crisis helplines (Department of Health, 2015). Changes include the recent proposal to establish a digital mental health gateway that directs callers towards the most appropriate service (see Section 2.5). Implementing this new gateway will require careful consideration of frequent users' needs, otherwise they will simply become a part of the new system. The pending introduction of the new digital gateway provides a strategic opportunity to reconfigure the operation of crisis helplines. A service could be established that focuses on responding to frequent users and recognises they are not calling for immediate short-term support. When frequent users call through to the gateway they could be directed to that service.

An alternative model of care was proposed by Pirkis et al. (2016) as part of the broader project this thesis falls within. The model sought to offer an integrated and tailored service in which they were allocated to a dedicated and specially trained counsellor with specified times to call. The model also included the promotion of better linkages between crisis helplines and services that provided mental health care, in particular GPs and other primary care providers. The implementation of this model, or similar models, is most likely currently outside of the scope of what crisis helplines are able to deliver (Spittal et al., 2015) and would require a major change in the foundational structure of crisis helplines. However, plans are underway with Lifeline to pilot the proposed model of care, as outlined in the study by Pirkis et al. (2016). This was made possible by the collaborations that formed while undertaking the broader research project.

9.2.2 Opportunities for future research

The recognition of frequent users as a legitimate group of service users presents opportunities for future research. Foremost the way in which frequent users are defined needs clarification. Following on from this, additional research into the issue of frequent users of crisis helplines could be undertaken. This might benefit from looking at differences among frequent, episodic and one-off users, if such a definition is adopted. Other research could look at the perspective of counsellors, collect accounts rather than descriptions of behaviours, and investigate frequent use among “unwelcome callers”.

Current research, including this study, distinguishes frequent users from other callers by the number of calls made to the helpline. Categorisation is based on an arbitrary number, which is often selected either based on the data available or on a pre-selected cut-off number. In reality it is hard to justify that someone who makes 19 calls is markedly different from someone who reports making 20 calls. It is likely, as shown in the study by Pollock et al. (2010) that some callers may go through episodes or cycles of frequent use and thus it is not necessarily a fixed attribute. Instead, frequent use is more likely to be related to the length, nature, appropriateness, and period of time over which calls are made (Johnson & Barry, 1978). Scope exists for further research to be undertaken into the development of a more appropriate definition of frequent use that considers more than just the number of calls made.

Once a more acceptable definition of frequent use is developed, clarification could be sought around the socio-demographic profile of frequent users and the reasons for their calls. This research could be undertaken in both an Australian setting and in other countries to determine the representativeness of the findings. Emphasis could be given to look at characteristics that have received minimal interest in previous research, for example the probability of having a personality disorder and chronic disease.

One reason for not adopting a comprehensive definition of frequent use may relate to the difficulties in collecting such information. Most research into frequent users of crisis helplines has been limited based on the availability of data. Difficulties encountered in recruiting a representative sample of callers to crisis helplines have already been established in the literature. Particularly these relate to the anonymity of crisis helplines and ethical considerations due to the sensitive nature of the population. The question could then become about understanding how people use crisis helplines rather than trying

to find an ideal point of categorisation. This could be the focus of future research, which aims to collect data from a broad range of callers to crisis helplines, rather than limiting itself to frequent users.

If the development of a more robust definition is not possible, future research could focus on investigating whether distinctive differences exist between frequent, episodic and one-off users. In particular, the health service patterns could receive more attention. If an association is identified between frequent use and increased use of healthcare services, opportunities for collaboration between these services to address the issue of frequent use could be explored. This would be particularly useful in terms of educational programs, which as mentioned above (see Section 9.2.1) is one successful way to reduce the frequent use of healthcare services.

Ensuring future research continues to look at the issue of frequent use of crisis helpline from multiple perspectives is beneficial. In particular, this could include the perspective of counsellors, which is one element that was missing from this research, yet is important to consider in addressing the issue of frequent use. Work has already been undertaken in this regard in relation to the Samaritans in the United Kingdom (Pollock et al., 2010; 2012). Ethical considerations are also reduced when collecting information from counsellors as opposed to callers and may be one way to increase the sample size.

Future research could also give more attention to the status of data involving “accounts” rather than “descriptions” of behaviours and experience. This could either be in the form of using standardised measures or observing the behaviour of the caller during the actual call with the helpline, as undertaken by Mishara et al. (1997). This is important, as it has already been proposed that callers may create a story to engage the counsellor as they have learned that this will allow them to talk for longer (MacKinnon, 1998; Pollock et al., 2010). The same may be true for when they are asked to describe their engagement with crisis helplines. This was one benefit of including the data from Study 3 in the analysis as it included the collection of standardised measures to investigate mental health issues.

Frequent users who are considered as “unwelcomed” callers could also be included in future research. These callers are often described as being affected by severe mental health issues, seeking sexual gratification, they are chronically lonely and unhappy. Many of these callers fall within the category of frequent users. New arrangements have been

established in Australia where phone companies are able to suspend services to people who repeatedly make unwelcome calls to helplines (Australian Communications and Media Authority, 2017). Callers seeking sexual gratification were explicitly excluded from Study 1 and 2.

9.3 Conclusion

Crisis helplines were established to provide immediate one-off crisis support. Helplines originated in the UK, USA and Australia and even though their precise support differed, they were all designed in a similar manner. The crisis helpline service model emerged from the structure of these early helplines. These services now operate around the world and are considered to have a role in suicide prevention. Many of these services are faced with the issue of frequent use. These users challenge the service model with their repeated use and there is concern that they call for non-crisis related support while preventing individuals in an immediate crisis from getting through. Service providers have begun to consider managing these users differently, yet they lack an evidence-based approach. Minimal empirical research has investigated this group of service users. The absence of evidence is exacerbated by the anonymous and confidential nature of the service which precludes routine collection of outcome data. Furthermore, of the research that is available, inconsistent findings have been reported between studies and the relevance of these findings to an Australian setting is unclear. This thesis sought to provide clarity around the socio-demographic characteristics of frequent users of crisis helplines and the factors driving their use in an Australian context.

Three studies were undertaken to explore the issue of frequent use, two of which were designed specifically for the purpose of this research. The studies included a survey of Lifeline callers, interviews with Lifeline frequent users, and longitudinal analysis of data from the *diamond* study, a cohort of general practice attendees with depressive symptoms. A combination of quantitative and qualitative analytical methods were used, brought together using a convergent mixed methods approach.

The findings from this research highlight that frequent users were calling with a genuine need for emotional support, yet their needs were not being met. Their calling behaviours appear to occur as an interrelated interaction between their reasons for calling, the response they receive from the service and distinct calling behaviours that they develop

over time. They have come to rely on crisis helplines for ongoing support which is not in line with the original purpose of crisis helplines. They also access care from healthcare services. The use of the convergent mixed methods approach allowed for a nuanced investigation of frequent use of crisis helplines compared to previous research as it took into consideration the findings from several studies

The findings from this thesis make an empirical contribution to research by clarifying the socio-demographic profile of frequent users and the factors driving their frequent use in an Australian population. In particular, the findings offer in-depth knowledge about the potential calling behaviours of frequent users, which can be used to train counsellors and assist in the development of service models that can cater to the needs of frequent users and improve how crisis helplines approach their calling behaviours. Building on previous research there is evidence emerging to suggest that frequent users may be a legitimate group of service users. The issue of frequent use may arise as a misunderstanding that has developed between the role counsellors perceive themselves to have and how frequent users perceive the purpose of these services. The effectiveness of crisis helplines in suicide prevention is yet to be demonstrated, and it may be that these services have a broader role in supporting people through a range of emotional crises, not just those in an immediate crisis. Services providers may benefit from reconfiguring the nature of support offered by crisis helplines to include the needs of frequent users. Processes are already underway in Australia to investigate what an alternative model of care may potentially look like.

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Appendices

Appendix 1: Literature search criteria used to identify the empirical studies that investigated frequent users of crisis helplines

Articles were included in the review if they presented empirical data on frequent users of crisis helplines and were published in English between 1960 and June 2016. Brief case studies were excluded from this review. The articles were identified after comprehensive searches of two databases, Medline and ProQuest, in March 2013 and repeated in June 2016. Search terms included: (Suicide OR Depression OR Mental Health) AND (Emergency telephone advisory OR Helpline OR Hotline OR Crisis line OR Suicide prevention cent* OR Crisis intervention service OR Crisis support service) AND (Chronic OR Frequent OR Repeat) AND (Call* OR Use*). The reference lists of potentially relevant articles were searched to identify additional articles, which were then obtained. Titles and abstracts were reviewed to identify relevant articles and all duplicate records were removed. The full text article and citation of potentially relevant articles were downloaded into Endnote and read by myself. Where there was uncertainty, the article was discussed with my supervisors, Jane Gunn and Jane Pirkis, and decided whether to include or not. All articles which presented empirical data on frequent users of crisis helplines were included.

After identifying eligible papers, the information from each of the articles was collated information into an excel spreadsheet. The information collected included: authors, publication year, study aim, crisis helpline service and location, frequent users definition, sample selection and size, time and follow-up, data collection methods, variables measured, interventions, results, study limitations and conclusions. Data for each of these variables were categorised and then summarised. For the studies where information about the caller population was provided the ratio between calls and callers and the 95% confidence interval was calculated using Stata version 13.1 (StataCorp, 2013).

A total of 561 articles were identified from the database search and within text references after removing duplicate records. Four hundred and ninety-eight articles were excluded after reading the title and abstracts as they did not have crisis helplines as their primary focus. Of the 63 full text articles reviewed, an additional 29 articles were excluded as they were not relevant to frequent users of crisis helplines. Thirty-four articles discussed frequent users; however, on further review only 21 of these articles presented empirical data. The remaining articles comprised of opinion pieces and brief case studies (Figure 1). Thus 21 articles met the inclusion criteria. The 21 articles represented 19 separate studies as Farberow et al. (1966) and Litman et al. (1965) presented findings from the first study

of callers to the Los Angeles crisis helpline; and, Gould et al. (2007) and Kalafat et al. (2007) reported on an evaluation of crisis helpline outcomes at eight sites in the USA.

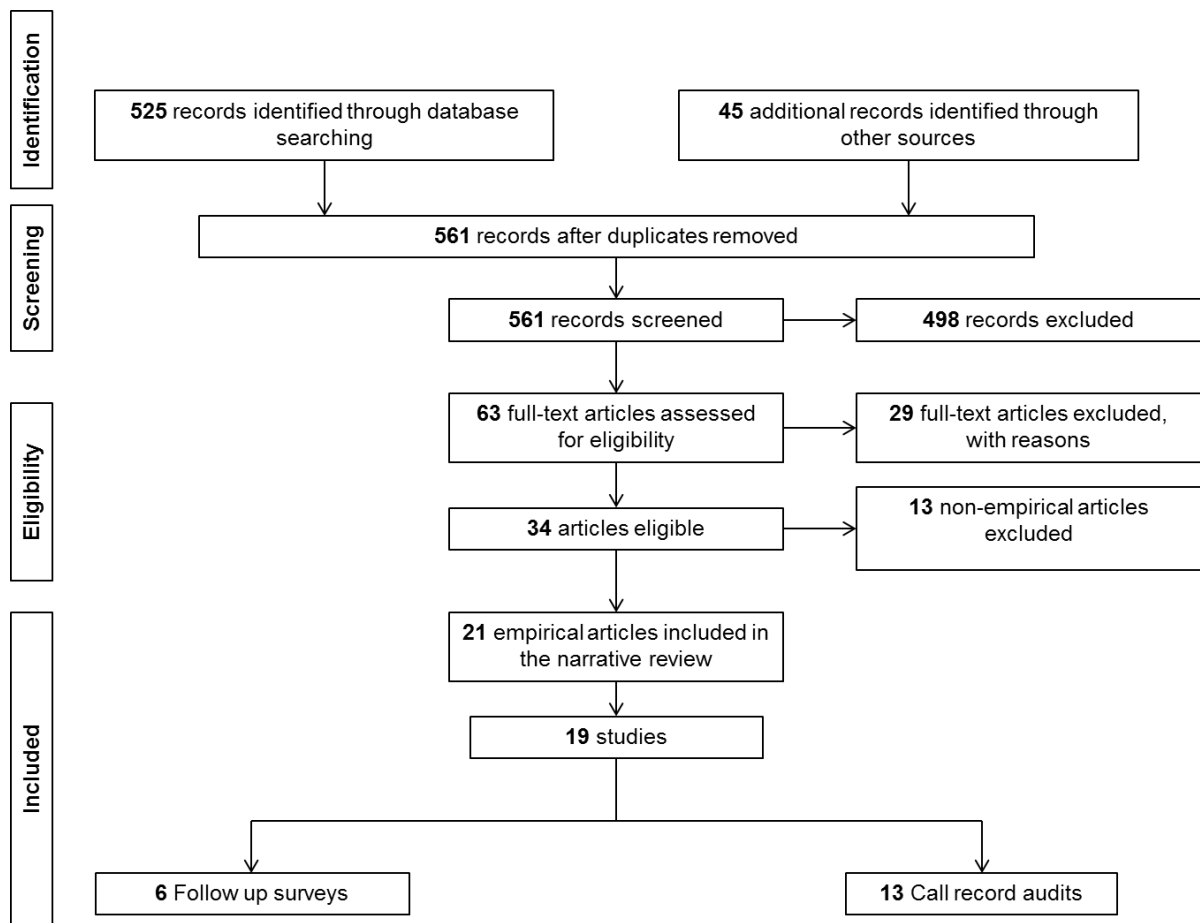


Figure 1: Flow diagram of articles included in the review of frequent users of crisis helplines

Appendix 2: Systematic review PDF

Systematic review of research into frequent callers to crisis helplines

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Summary

We conducted a systematic review of research into callers making multiple calls to crisis helplines. Two databases were searched, identifying 561 articles from 1960 until 2012, of which 63 were relevant. Twenty-one articles from 19 separate studies presented empirical data about callers making multiple calls to crisis helplines. Of the 19 studies, three were intervention studies, five were surveys of callers and 11 were call record audits. Most studies were conducted in the USA and defined frequent callers as people making two or more calls. Frequent callers were more likely to be male and unmarried compared to other callers. There were no reported differences between frequent callers and other callers with regard to age, mental health conditions or suicidality. Three studies tested interventions designed to better manage frequent callers. These studies, even though small, reported reductions in the number of calls made by frequent callers. Suggested techniques for responding to frequent callers included: limiting the number and duration of calls allowed, assigning a specific counsellor, implementing face to face contact, the service initiating contact with the caller instead of waiting for callers to contact the service, providing short term anxiety and depression treatment programmes by telephone, and creating a specific management plan for each frequent caller. Future work requires robust study design methods using larger sample sizes and validated measurements.

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Introduction

Crisis helplines for emotional wellbeing have existed since the 1950s,¹ each with their own purpose and target group.^{2–4} Most were established to provide timely assistance to people who were experiencing a crisis of suicidality or depression.⁵ The crisis helplines have used different service models, from a non-directive, listening approach to a more directive approach.^{2,4,6,7} Callers to crisis helplines typically remain anonymous, call at any time of the day, and speak to trained personnel who assist them to manage their crisis.^{2,5,8} The support provided is usually not of an ongoing nature.² A mixture of lay and professional personnel operate crisis helplines, some on a paid basis and some as volunteers.

Research suggests that people who make multiple calls to crisis helplines may be using the services inappropriately.^{9,10} These callers are commonly known as frequent,¹¹ chronic,¹⁰ multiple or repeat callers.¹² In this paper we refer to them as frequent callers. The first study of frequent callers to crisis helplines for emotional wellbeing was published in 1965 and described them as callers who took up a lot of time with complex physical and mental health problems.¹³

Crisis helplines struggle to know how to best respond to frequent callers as they challenge the conventional crisis model of care with their contacts.^{6,8,9,12,14} Frequent callers seek help regularly from crisis helplines and do not always appear to have an immediate crisis.^{10,12} They also take up

time, which prevents other crisis calls from being taken.^{8,11} Crisis helplines have begun to consider different ways to respond to frequent callers, including limiting their access.^{10,11} However, concern exists over whether limiting their access may trigger a further crisis.⁹ Currently, crisis helplines manage this subgroup of callers in an ad hoc manner. There is a need for an evidence-informed approach.

We have therefore carried out a systematic review of the literature about frequent callers to crisis helplines. The aims of the systematic review were to:

1. describe frequent callers, in terms of their socio-demographic and clinical characteristics, the nature and frequency of their calls, their use of other services and treatments, and the outcomes of their contact;
2. discuss the impact that frequent callers have on crisis helplines;

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3. identify potential interventions to respond to the needs of frequent callers.

Methods

Articles were included in the review if they presented empirical data on callers who made multiple calls to crisis helplines, and were published in English between 1960 and 2012. The exception was brief case studies, which were excluded.

Two databases, Medline and ProQuest, were searched in March 2013. The search terms included: (Suicide OR Depression OR Mental Health) AND (Emergency Telephone Advisory OR Helpline OR Hotline OR Crisisline OR Suicide Prevention Cent* OR Crisis Intervention Service OR Crisis Support Service) AND (Chronic OR Frequent OR Repeat) AND (Call* OR User). The reference lists of potentially relevant articles were searched to identify additional articles, which were obtained. Titles and abstracts were reviewed to identify relevant articles, and all duplicate records were removed. The full text article and citation of potentially relevant articles were downloaded into Endnote and read by one author. Articles about which there was uncertainty were discussed with the other authors and a decision was made about whether to include them. All articles which presented empirical data on callers who made multiple calls to crisis helplines were included.

After identifying eligible papers, information from each article was stored in a spreadsheet. The information included: authors, publication year, study aim, crisis helpline name and location, frequent callers definition, sample selection and size, time period and follow-up, data collection methods, variables measured, interventions, results, limitations and conclusion. Data for each of these variables were categorised and then summarised. The ratio between calls and callers and the 95% confidence interval was calculated using a standard package (STATA version 12¹⁵) for the studies that provided sufficient information about the caller population.

Results

A total of 561 articles were identified through the database search and from within text references, after duplicate records were removed. Four hundred and ninety-eight articles were excluded after reading the title and abstracts as they did not have crisis helplines as their primary focus. Of the 63 full text articles reviewed, an additional 29 articles were excluded as they did not relate to callers making multiple calls. Thirty-four articles discussed callers who made multiple calls; however on further review only 21 presented empirical data, and the remaining articles comprised opinion pieces and brief case studies (Figure 1). Thus 21 articles met the inclusion criteria, see Tables 1–3. The 21 articles represented 19 separate studies as Gould *et al.*¹⁶ and Kalafat *et al.*¹⁷ reported on an

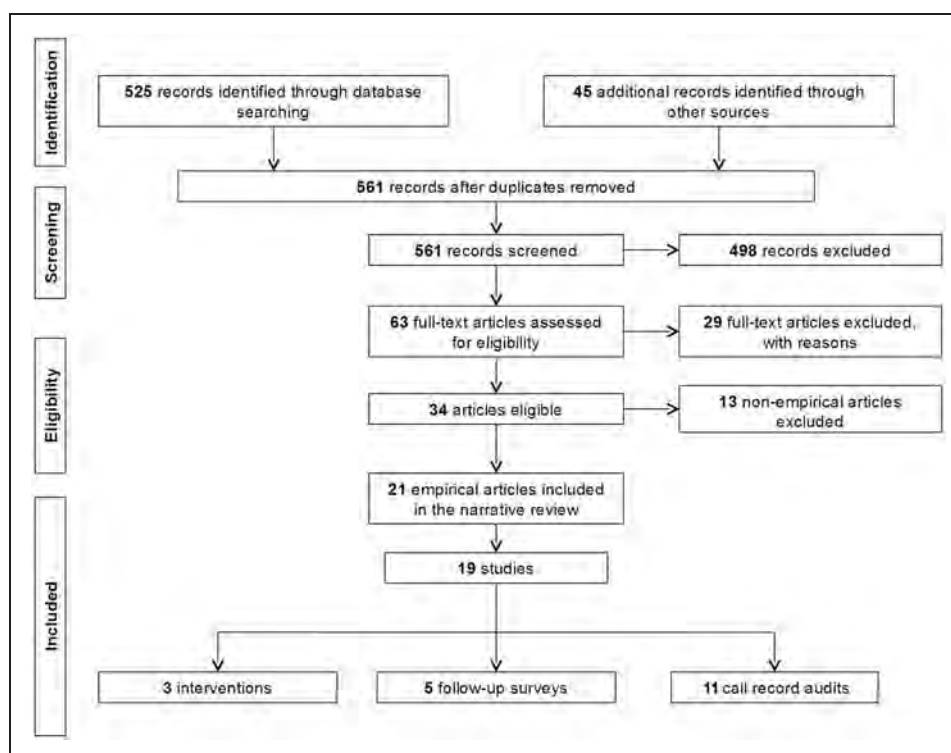


Figure 1. Flow diagram of studies included in the systematic review.

Table 1. Intervention studies included in the review.

Study	Year	Country	Data collection	Frequent caller definition	Intervention	Sample size	Outcome	Comparison groups
Barmann ¹⁹	1970s	USA	Recorded number of callers	No clear definition provided	A counsellor was assigned to each frequent caller who would call their "patient" once a week on the same day each week.	14 callers	Reduction in mean number of calls	Randomised Intervention vs. control group
Brunet ²⁰	1990s	Canada	Recorded number of callers	More than 10 calls/month	Each frequent caller was given the option of corresponding with an assigned counsellor through letters.	5 callers	Reduction in duration of calls	Non-randomised Before and after
Hall ²¹	1990s	Canada	Total number of calls	No clear definition provided	Limited frequent callers to a maximum of two calls per day of 15mins per call. They were unable to call between mid-night and 08:00.	1351 calls	Reduction in suicide risk and duration of calls	Non-randomised Before and after

evaluation of crisis helpline outcomes at eight sites in the US; and Farberow *et al.*¹⁸ and Litman *et al.*¹³ presented findings on a study of frequent callers to a Los Angeles crisis helpline. In the 21 articles included in this review, callers who made multiple calls to crisis helplines were referred to as frequent, chronic or repeat callers.

Of the 19 empirical studies, three were intervention studies^{19–21} (summarised in Table 1), five were surveys of crisis helpline callers^{16,17,22–25} (summarised in Table 2), and 11 were call record audits^{13,18,26–35} (summarised in Table 3). Studies varied in their data collection methods and definition of frequent callers. Nine studies compared frequent callers with other callers.^{22–24,27–32} The data reported for frequent callers varied from only reporting the number of calls made by frequent callers^{13,33} to a more detailed presentation of caller demographics, suicide history and prior treatment for frequent callers.^{23,26,27,30,32}

The intervention studies all took place in North America; two in Canada^{20,21} and one in the USA.¹⁹ All were restricted by a small sample size and only one study used a randomised controlled design. Brunet *et al.*²⁰ was the only intervention study to provide a specific definition of frequent callers.

A range of interview techniques were used in the studies that surveyed callers, with most completing one-off surveys.^{22–25} Nearly all of the survey studies defined frequent callers as making more than one call.^{16,17,22,24,25} Only the studies by Apsler²² and Coveney *et al.*²⁴ surveyed more

than 1000 callers. All studies analysed a sub-sample of callers to crisis helplines. The studies by Apsler,²² Burgess *et al.*²³ and Coveney *et al.*²⁴ compared frequent callers with other callers.

The majority of the call record audit studies were completed before 1980 in North America.^{13,18,27,29,30,32,33,35} Only the studies by Ingram *et al.*²⁸ and Watson *et al.*³⁴ were completed after 2000. These had the largest sample sizes of the audit studies. There was greater variation in the definition of frequent callers for the audit studies compared to the survey and intervention studies. More than half of the audit studies presented some comparison of frequent callers with other callers.^{27–32}

Of all the studies, nine defined frequent callers as callers who made more than one call to a crisis helpline.^{13,16–18,22,24,25,28,31,33,34} Other studies defined frequent callers as callers who made a specific number of calls over a period of time. These definitions ranged from three calls over one month,²³ 10 calls over one,²⁰ six²⁶ or eight³⁰ months or 19 calls over two years.²⁷ The study by Johnson and Barry²⁹ discussed the need for a definition of frequent callers to include not only the number of calls but also the pattern of calls and follow-up policy of the crisis helpline. Their definition separated callers into six types of calling patterns based on the number of calls made, the time period over which the calls occurred and whether each call was related to the same problem or multiple problems.²⁹ There were four studies that did not provide a specific definition of frequent callers but referred to

Table 2. Survey studies included in the review.

Study	Year	Country	Sample size	Data collection	Frequent caller definition	Data reported for frequent callers
Murphy ²⁵	1967	USA	73 callers	Interviewed a subset of callers.	More than one call	History of suicide attempt Previous psychiatric treatment Followed advice
Apsler ²²	1972-1973	USA	11,703 calls	Completed a standardized intake questionnaire with a sample of callers at the start of the call. Compared callers who made one call with callers who made more than one.	More than one call	Age Gender Employment Race
Gould ¹⁶	2003-2004	USA	380 callers	Assessed suicidal callers during their call and invited them to complete a survey with a follow-up interview.	More than one call	Number of frequent calls Referral follow-ups
Kalafat ¹⁷	2003-2004	USA	801 callers	Assessed crisis callers during their call and invited them to complete a survey with a follow-up interview (excluded frequent callers from initial cohort).	More than one call	Number of frequent calls Suicidal thoughts Profile of Moods States – Modified (POMS-M)
Burgess ²³	2006	Australia	270 callers	Completed a 60-item questionnaire with a sample of callers at the end of the call. Compared less frequent, frequent and very frequent callers.	More than 3 calls/month	Age, Gender, Relationship status Self-reported problems Mental health measures Mental health assistance (past month)
Coveney ²⁴	2008-2009	UK	1309 callers	Online survey comparing callers who made one call with callers who made more than one.	More than one call	Reason for last contact Overall perception of helpfulness

them as a subgroup of callers who made multiple calls.^{19,21,32,35}

Ten of the studies reported on a representative sample of all callers to crisis helplines,^{13,22–25,28–31,33} see Table 4. Together these studies reported on over 520,000 calls to ten separate crisis helplines. An example of the information presented in this table can be explained through the study by Lester and Brockopp.³⁰ Over one year this crisis helpline received 3910 calls from 2128 people (callers). All of the calls received in the year of follow-up were analysed in the study. Of the 3910 calls, 90% of calls were by people who called two or more times, and 17% of calls were made by people who called ten or more times. Of the 2128 separate callers, 82% called two or more times, and 1% called ten or more times. The ratio

between callers and calls was calculated to be one caller to 1.20 calls (95% CI 1.14–1.26).

The ratio between callers and calls in all of the studies was more than one call per caller. In the 2006 study by Burgess *et al.*²³ completed in Australia, the ratio between callers and calls was one caller to 4.14 calls (95% CI 3.90–4.39) for one month of follow-up. Due to the wide variation in the methods, sample size and follow-up time period the ratio calculated for these studies cannot be compared. The call ratio could not be calculated for three of the studies as insufficient information of the caller population was provided.^{22,24,28}

The different study designs, sampling strategies, definitions of frequent callers and methods made it difficult to combine the data or to undertake a formal meta-analysis of

Table 3. Call record audit studies included in the review.

Study	Year	Country	Sample size	Data collection	Frequent caller definition	Data reported for frequent callers
Litman ¹³	1963-1964	USA	1336 callers	Call record audit of all evening calls.	More than one call	Number of frequent callers
Farberow ¹⁸	1963-1964	USA	2675 calls	Call record audit of all calls to crisis helpline.	More than one call	Number of frequent callers Number making over 20 calls Prior treatment
Wilkins ³⁵	1967	USA	200 callers	Call record audit to identify a random sample of 200 callers.	No clear definition provided	Number of frequent callers Number making 6 or more calls
Lester ³⁰	1968-1969	USA	2128 callers	Call record audit to identify all frequent callers and compare them to a random sample of 1 time callers. Compared frequent callers with one off callers.	More than 10 calls in 8 months	Age, Gender, Marital status, Race, Number of children, Parenthood, Living arrangements Number of calls Prior treatment, Suicidal history and risk
Speer ³³	1971	USA	2459 callers	Call record audit of all calls.	More than one call	Number of calls
Bartholomew ²⁶	1971	Australia	8 callers	Call record audit of frequent callers.	More than 10 calls in 6 months	Age, Gender, Marital status Number of calls, Common time of call Presenting problems Previous psychiatric treatment
Greer ²⁷	1970s	USA	63 callers	Call record audit to identify frequent callers and compare to a random sample of all callers. Compared frequent callers with other callers.	More than 19 calls in 2 years	Age, Gender, Marital status Call duration Suicide history and risk, Mental health history, Drug and alcohol use, Prior treatment, Referrals
Johnson ²⁹	1973-1974	USA	100 callers	Call record audit to identify a random sample of all callers. Compared one call vs. one call with follow-up vs. multiple calls over two days vs. multiples calls in a week vs. multiple calls over more than one week	6 calling patterns	Mean age by gender and call category, Type of call (person who made the call) Number of calls, Calling pattern

(continued)

Table 3. Continued.

Study	Year	Country	Sample size	Data collection	Frequent caller definition	Data reported for frequent callers
Sawyer ³²	1970s	USA	67 callers	Call record audit of all calls to identify frequent callers and compare to a random sample of other callers. Compared frequent callers with other callers.	No clear definition provided	Age, Gender, Marital status, Race, Employment Active callers Mental health diagnosis, Suicide history, Prior treatment, Referrals
Mishara ³¹	1988-1990	Canada	263 callers	External research assistant monitored and coded a random sample of calls. Compared single calls with more than one call.	More than one call	Number of frequent callers Changes over the call (depression, urgency) Creation of contracts, Intervention style
Watson ³⁴	2003	Australia	90,128 calls	Call record audit of all calls.	More than one call	Duration of use
Ingram ²⁸	2001-2005	USA	349,464 callers	Call record audit of all calls. Compared single calls with more than one call.	More than one call	Age, Gender Number of frequent callers, Reason for call, Call duration

the intervention studies. However, the studies addressed similar problems relating to frequent callers allowing the findings to be presented around common themes.

Characteristics of frequent callers

Seven studies reported on the demographic characteristics of frequent callers.^{22,23,26-28,30,32} Of these studies, five compared frequent callers with other callers^{23,27,28,30,32} of which three reported on a representative sample.^{23,28,30} Based on the findings of these studies, frequent callers were more likely to be male^{23,27,28,32} and unmarried.^{23,26,27,32} It is unclear whether frequent callers differed from other callers in terms of age,^{22,23,26-28,30,32} ethnicity^{22,30,32} or employment status^{22,32} as few studies reported on these characteristics and there were inconsistent findings.

Frequent callers contacted crisis helplines because they were seeking social support,^{23,24,26,34} had mental health concerns,^{24,28} and/or experienced a physical illness.²³ Mental health concerns were identified in three studies as the main reason for contact from frequent callers.^{24,26,28} However, whether these problems were more commonly experienced by frequent callers compared to other callers is unknown.^{22,24,30}

In the five studies reporting on suicidal behaviour, at least half of frequent callers were identified as having a

history of suicidal behaviour.^{25-27,30,32} Frequent callers were more likely to have a history of suicidal behaviour than other callers in only three studies.^{17,26,27} The severity of suicidal behaviour was higher for frequent callers compared to other callers in the studies by Greer²⁷ and Sawyer and Jameton.³²

Frequent callers experienced mental health problems that included depression,^{17,26} panic attacks,²³ confusion and overall distress,¹⁷ and personality disorder problems.¹⁸ Frequent callers were also identified in some studies as having a diagnosis of schizophrenia,³² possible psychosis,¹⁸ or social and simple phobias.²³ These studies did not use validated measurements. The use of alcohol and drugs by frequent callers was unknown as only the studies by Greer²⁷ and Sawyer and Jameton³² found an association, but were completed in small samples in the 1970s. The study by Burgess *et al.*²³ found frequent callers in Australia in 2006 were less likely to drink alcohol than other callers.

Using validated measurements, frequent callers in the study by Burgess *et al.*²³ had significantly higher anxiety scores on the Goldberg Anxiety Scale (GAS). However, there was no difference between frequent and other callers on the Goldberg Depression Scale (GDS).²³ Using the Profile of Mood States (POMS) scale, the study by Kalafat *et al.*¹⁷ found that frequent callers experienced hopelessness and were more anxious compared to other

Table 4. Calls and call frequency in studies reporting on a representative sample.

Characteristics			Number of calls by call frequency						Number of callers by call frequency						Ratio between callers and calls				
Study	Duration months	Total calls N	Calls analysed [^]			Calls made by people who called more than twice			Calls made by people who called more than ten times			Callers analysed		Callers who called more than twice		Callers who called more than ten times		Ratio	95% CI
			N	%	n	%	n	%	N	n	%	n	%	n	%				
Litman ¹³	12	1607	1607	321	20	—	—	1336	53	4	—	—	—	—	—	—	—	1.20	1.14–1.26
Murphy ²⁵	3	281	111	62	56	—	—	73	24	33	—	—	—	—	—	—	—	1.52	1.25–1.83
Lester ³⁰	12	3910	3910	3519	90	665	17	2218	1819	82	21	1	1	1	1	1	1	1.76	1.71–1.82
Speer ³³	2	3536	3536	1485	42	849	24	2459	418	17	25	1	1	1	1	1	1	1.44	1.39–1.49
Apsler ²²	12	11,703	—	—	—	—	—	—	—	37	—	—	—	—	—	—	—	—	—
Johnson ²⁹	12	1235	462	319	69	—	—	100	36	36	—	—	—	—	—	—	—	4.62	4.21–5.06
Mishara ³¹	36	617	617	420	68	—	—	263	66	25	—	—	—	—	—	—	—	2.35	2.16–2.54
Burgess ²³	1	1404	1117 [*]	894 ³⁴	80	391	35	270	119 ³⁴	44	38	14	14	14	14	14	14	4.14	3.90–4.39
Ingram ²⁸	60	499,066	349,464	167,743	48	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Coveney ²⁴	12	—	—	—	—	—	—	1309	707	54	—	—	—	—	—	—	—	—	—

-this information was not reported in the article;

*study defined categories as 1–2 calls and 3–9 calls;

³⁴the total number of calls was estimated from the data available from the article;

[^]not all calls received by the crisis helpline were analysed in the calculation of the number of calls and callers, as some studies only analysed a sub-sample of callers.

callers. The study by Mishara and Daigle³¹ found frequent callers were less likely to have decreases in depression scores over time.

Four studies found that frequent callers were seeking help from several mental health professionals, with many already undergoing formal treatment.^{18,23,25,32} Up to 85% of frequent callers in the study by Murphy *et al.*²⁵ had a history of previous psychiatric treatment. However, in the study by Sawyer and Jameton³² there were some frequent callers (11%) who only used crisis helplines for support and reported no contact with other mental health services.

The duration of calls made by frequent callers were found in the studies by Greer²⁷ and Ingram *et al.*²⁸ to be shorter than the calls made by other callers. Contracts for follow-up and referrals were often arranged by crisis helplines to ensure further support for frequent callers.^{28,31} It is unknown whether these contracts were more likely to be prepared with frequent callers compared to other callers. However, it has been estimated that 16–50% of frequent callers follow through with the advice provided by the crisis helpline.^{16,25} Reductions in the level of urgency during crisis calls were less likely to be seen with frequent callers compared to other callers in the study by Mishara *et al.*³¹

The study by Apsler²² explicitly made the assumption that frequent callers found crisis helplines helpful because they continued to call. This assumption was supported by the findings of the study by Coveney *et al.*²⁴ that measured frequent caller's overall perception of helpfulness. This study found that frequent callers gave an average score of eight out of ten for helpfulness.²⁴

Impact of frequent callers on helplines

The studies in the present review did not formally measure the impact of frequent callers on crisis helplines. However, some studies commented on the frequency, nature and appropriateness of calls made by frequent callers as being problematic for crisis helplines.^{13,18,19,27,28,30,32,34,35} Frequent callers were described as time-wasters who took up a significant amount of time for crisis helplines, limiting the amount of time available for other callers.^{13,17,18,29,33,34} They were seen to contact crisis helplines continuously with recurring problems, without appearing to make discernable positive changes over time.^{18,27,28,35} In responding to frequent callers, crisis helpline workers were described as developing feelings of frustration and resentment²⁷ and experiencing an overall emotional drain.³² These feelings have been associated with crisis helpline workers thinking of themselves as ineffective counsellors.^{27,28} One study also described frequent callers being treated differently to other callers as a result of these feelings.²⁷

Managing frequent callers

Three intervention studies were identified in the review (Table 1). The study by Barmann¹⁹ tested different

responses to frequent callers. Fourteen frequent callers were identified from call records and seven were randomly assigned to the intervention. A counsellor was assigned to each caller with a limit on the amount of calling time they were permitted each week. If a crisis was experienced, callers were allowed to call at any time; however they were reminded of these restrictions. The mean number of calls for the intervention group reduced from 24 to 11 calls over a nine week period compared to 24 to 21 calls in the control group.¹⁹

The study by Hall and Schlosar²¹ limited frequent callers to a maximum of two calls per day for 15 minutes per call with no contact allowed between midnight and 08:00. Changes in suicide risk before and after the intervention were used to measure improvement, and a minor reduction in the suicidal behaviour of frequent callers was observed. The number of hours spent on the telephone by frequent callers reduced from 172 hours before the intervention to 82 hours five months after the intervention.²¹

The study by Brunet *et al.*²⁰ implemented a 6-month written correspondence intervention with 22 frequent callers. Callers were assigned a counsellor with whom they started written correspondence. No limitations were made on the number of calls they could make to the crisis helpline. Only 23% ($n=5$) of the frequent callers, all female, completed the trial.²⁰ Before the intervention the five frequent callers took up a mean total of 541 min over a three-month period compared to three months after the intervention where the mean total was 261 min.²⁰

Based on the findings in the survey and audit studies, suggested techniques for responding to frequent callers included: using a directive and rigid management technique,^{32,33} discouraging the caller from contacting the service,³⁰ limiting the call duration allowed,^{30,32} implementing face to face contact,³² the service initiating contact with the caller instead of waiting for callers to contact the service,³² providing short term anxiety and depression treatment programmes by telephone,²³ and creating a specific management plan for each frequent caller.³⁰

Discussion

The present systematic review found that the research into frequent callers to crisis helplines is limited and of highly variable quality. Frequent callers were more likely to be male and unmarried. There were no reported differences between frequent callers and other callers with regard to age, employment, ethnicity, mental health conditions and suicidality. No study reported data on the impact of frequent callers on crisis helpline staff. Responses to frequent callers could include limiting the number and duration of calls allowed, and/or assigning a specific counsellor. These responses were shown in three intervention studies to reduce the number of calls made by frequent callers.

The strength of this review is that we have conducted an extensive search of the literature and have synthesised the findings according to themes. We have documented the research techniques utilised by studies investigating frequent callers to crisis helplines and provided an analysis of frequent caller characteristics. Our review also provides a summary of the interventions for frequent callers and identifies areas for further research. The limitations of the review are that there are various definitional and methodological limitations with the studies included in it. The review includes studies from over 40 years ago when telephone access was limited, and therefore the characteristics of frequent callers may have subsequently changed.

A range of terms were used in the studies to refer to callers who made multiple calls to crisis helplines. Most of these terms referred to callers who made more than one call. However, it emerged that crisis helplines are more concerned about the callers who may be using the service inappropriately, rather than just callers who made multiple calls. The definition of calling more than once appeared to be used as a convenience definition to try and identify callers who may be using the service inappropriately. Crisis helplines are interested in understanding those who may call inappropriately so that they can respond to them more effectively.

In order to understand the callers who may be calling inappropriately, an improved definition of frequent callers is needed. Such a definition cannot simply be more than one call to crisis helplines, as one would expect people to commonly make a follow-up call after their initial crisis call. As suggested by Johnson and Barry²⁹ the definition needs to extend beyond the number of calls made to consider the length, nature, appropriateness and the period of time over which the calls are made. Having a definition that considers more than the number of calls made will assist crisis helplines in identifying the frequent callers in their caller population who may require a different response.

For crisis helplines to respond effectively to frequent callers they also need to understand the impact that frequent callers have on crisis helpline staff and how frequent callers differ from other callers in personal characteristics and mental health. In order to achieve this future research needs to include representative samples and validated measures. Crisis helplines could also explore a response that includes collaboration with external mental health professionals. This could be through referrals to mental health professionals or running telephone-based cognitive behavioural therapy programmes.

In conclusion, most callers to crisis helplines make more than one call. Future studies need a definition of frequent callers that considers more than the number of calls made. To understand how frequent callers affect crisis helplines and differ from other callers, robust study design methods using larger sample sizes and validated measurements are required. Once these differences are understood, crisis helplines will be able to respond appropriately to frequent callers.

Acknowledgements

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Appendix 3: Ethics approval to undertake Study 1 and Study 2

20 May 2014

Professor J.E. Pirkis
Melbourne School of Population and Global Health
The University of Melbourne

Dear Professor Pirkis

I am pleased to advise that the Health Sciences Human Ethics Sub-Committee approved the following Project:

Project title: **Experiences of and outcomes for callers to Lifeline**
Researchers: **A Middleton, Dr B Bassilios, Prof J M Gunn, Mr A Woodward, Prof J E Pirkis, Dr M J Spittal**
Ethics ID: **1441987**

The Project has been approved for the period: **20-May-2014 to 31-Dec-2014**

It is your responsibility to ensure that all people associated with the Project are made aware of what has actually been approved.

Research projects are normally approved to 31 December of the year of approval. Projects may be renewed yearly for up to a total of five years upon receipt of a satisfactory annual report. If a project is to continue beyond five years a new application will normally need to be submitted.

Please note that the following conditions apply to your approval. Failure to abide by these conditions may result in suspension or discontinuation of approval and/or disciplinary action.

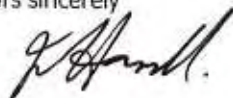
- (a) **Limit of Approval:** Approval is limited strictly to the research as submitted in your Project application.
- (b) **Variation to Project:** Any subsequent variations or modifications you might wish to make to the Project must be notified formally to the Human Ethics Sub-Committee for further consideration and approval. If the Sub-Committee considers that the proposed changes are significant, you may be required to submit a new application for approval of the revised Project.
- (c) **Incidents or adverse effects:** Researchers must report immediately to the Sub-Committee anything which might affect the ethical acceptance of the protocol including adverse effects on participants or unforeseen events that might affect continued ethical acceptability of the Project. Failure to do so may result in suspension or cancellation of approval.
- (d) **Monitoring:** All projects are subject to monitoring at any time by the Human Research Ethics Committee.
- (e) **Annual Report:** Please be aware that the Human Research Ethics Committee requires that researchers submit an annual report on each of their projects at the end of the year, or at the conclusion of a project if it continues for less than this time. Failure to submit an annual report will mean that ethics approval will lapse.
- (f) **Auditing:** All projects may be subject to audit by members of the Sub-Committee.

If you have any queries on these matters, or require additional information, please contact me using the details below.

Please quote the ethics registration number and the title of the Project in any future correspondence.

On behalf of the Sub-Committee I wish you well in your research.

Yours sincerely



Ms Jennifer Hassell - Secretary
Health Sciences HESC
Phone: 90353341, Email: hassell@unimelb.edu.au

cc: HEAG Chair - Population and Global Health

Appendix 4: Study 1 – Screener for survey of Lifeline callers

Experiences of and outcomes for callers to Lifeline 13 11 14 research study

Sheet A – Caller Eligibility Checklist

Please complete one form per caller

Step 1: Eligibility (DO NOT READ OUT)

Is the caller eligible to participate? By the end of the call is he/she ...

- | | | |
|--|------------------------------|-----------------------------|
| Over 18 years of age? | ☐ Yes | ☐ No |
| Proficient in English? | ☐ Yes | ☐ No |
| Not at an immediate risk to themselves or others? | ☐ Yes | ☐ No |
| Not experiencing a high a degree of distress? | ☐ Yes | ☐ No |
| Not verbally abusive? | ☐ Yes | ☐ No |
| In a suitable mental state to participate? (i.e. able to provide informed consent) | ☐ Yes | ☐ No |
| Other? (please specify: _____) | ☐ Yes | ☐ No |

NO to any? (Caller is not eligible. Complete the call)

All YES? (Caller is eligible. Proceed to step 2)

Step 2: Introducing the survey (READ OUT SCRIPT)

TCS: Before we end, I would like to invite you to take part in a confidential survey being conducted by a team from the University of Melbourne with Lifeline. The purpose of the survey is to understand callers' experiences with Lifeline. This will inform service improvements. The survey will take no more than 5 minutes to complete.

- Are you interested in completing the survey?

☐ Yes (Proceed to Q2)
☐ No (Thank the caller and end the call)
- Have you already completed this survey?

☐ Yes (Thank the caller and end the call)
☐ No (Proceed to Q3)
- If you agree, I will pass you on to an interviewer who will work through the survey with you. They are conducting the surveys on behalf of The University of Melbourne team. Before he/she begins, he/she will explain the survey to you in more detail and seek your verbal consent. Your participation is voluntary. Are you happy for me to pass you onto the interviewer?

☐ Yes (Pass the phone to the research interviewer)
☐ No (Thank the caller and end the call)

Office Use Only (TCS to complete)

Did the participant complete the survey?

☐ Yes	☐ No	☐ Not eligible
☐ Research interviewer not available		

TCS initials: _____

Lifeline Centre: _____ Northern Beaches

Date: ____/____/2015

Time: ____:____

To be completed by the TCS at the end of EACH crisis call during designated shifts

Appendix 5: Study 1 – Survey of Lifeline callers

Online survey

The survey is to be completed by the research interviewer and is accessible by a password protected online database. The link to the survey is: <http://j.mp/15i7LYq>

THE UNIVERSITY OF MELBOURNE Lifeline AUSTRALIA

Survey of Lifeline Callers

To be completed by the supervisor once the Telephone Crisis Supporter has ensured the caller is eligible and they agree to hear more about the survey.

Page 1 of 6

This research is being conducted by Lifeline Australia and the University of Melbourne. It has been granted ethics approval by the University of Melbourne's Health Sciences Human Ethics Sub-Committee (Ethics ID: 1441987.1).

The purpose of this research is to investigate the immediate impacts and longer term outcomes for one-off, episodic and frequent callers to Lifeline 13 11 14, and to explore the factors that influence these outcomes but your centre will only be involved in Part A. Part A takes the form of a brief cross-sectional survey administered to callers to Lifeline who agree to participate during a one-month census period; Part B involves an interview-based longitudinal study of a subset of callers from Part A.

Part A will collect data from callers to 13 11 14 using a brief telephone survey administered to eligible callers after a call on the caller's use of and reasons for contacting 13 11 14.

The survey will also collect basic caller demographic information. The survey will request caller consent for Part B which will involve quarterly interviews with callers over 12 months.

Callers who participate in the survey alone will remain anonymous; callers who agree to take part in the interview will be asked to provide their name, phone number and address so that they can be followed up by the interviewer.

Please contact the survey administrator: Ayes Middleton on a.middleton@unimelb.edu.au or (03) 90358014 if you are having any problems accessing this survey.

To access a new survey form please enter your unique password provided during training:

* must provide value

Next Page >>

REDCap Software - Version 5.7.0 - © 2014 University of Melbourne

Introduction

Hello, I will be conducting the survey today.

I will explain the survey to you and then seek your verbal consent.

This project is being conducted by a team from The University of Melbourne in collaboration with Lifeline. The purpose of the survey is to understand callers' experiences with Lifeline 13 11 14. This will inform service improvements.

If you agree to participate, I will ask you about your calls to Lifeline and some basic information about yourself. The survey will take no more than 5 minutes to complete. The information you provide is confidential and will not be kept by Lifeline.

You are free to stop at any time and if you do so, it will have no effect on the service you receive from Lifeline or from any other agency.

This project has been approved by the University of Melbourne Human Research Ethics Committee and if you have any concerns, I can provide you with their contact details.

Before we begin do you have any questions about the survey?

Do I have your verbal permission to continue with the survey?

☐ Yes

☐ No

*If the answer to this question is **No**, thank the caller for calling Lifeline and end the call.*

*If the answer is **Yes**, then proceed to the survey.*

Survey

1. In the past month, how often have you contacted Lifeline 13 11 14?
 - ☐ Once/just today
 - ☐ Twice
 - ☐ 3 – 5 times
 - ☐ 6 – 10 times
 - ☐ 11 – 19 times
 - ☐ 20 or more times
 - ☐ I don't know
2. Thinking about what prompted you to call Lifeline 13 11 14 today, do any of these following statements apply?

I have been feeling very nervous, anxious or depressed	☐ Yes
I did not have a lot of hope about the future	☐ Yes
A family member or friend suggested that I call Lifeline 13 11 14	☐ Yes
A health professional suggested that I call Lifeline 13 11 14	☐ Yes
My usual health professional was not available	☐ Yes
I was in an immediate crisis	☐ Yes
There was nobody else that I could talk to	☐ Yes
I regularly call Lifeline 13 11 14 to talk about how I am feeling	☐ Yes
Other (please specify): _____	

I would now like to ask you a few questions about yourself.

1. What gender do you identify with?
 - ☐ Male
 - ☐ Female
 - ☐ Intersex
 - ☐ Prefer not to answer
2. How old are you?
 - ☐ Under 25 years
 - ☐ 25 – 44 years
 - ☐ 45 – 65 years
 - ☐ over 65 years
 - ☐ Prefer not to answer
3. In a usual week, which of the following best describes you?
 - ☐ In full/part time employment
 - ☐ Studying
 - ☐ Home duties (with no paid work)
 - ☐ Self-employed
 - ☐ Unemployed/looking for work
 - ☐ Retired
 - ☐ Unable to work due to sickness or disability
 - ☐ Prefer not to answer
4. Who do you usually live with? (*can select more than one*)
 - ☐ Spouse/partner
 - ☐ Children
 - ☐ Parents
 - ☐ Unrelated flatmate or co-tenant
 - ☐ Alone

- ☐ Other
- ☐ Prefer not to answer

5. Is English your first language? ☐ Yes ☐ No ☐ Prefer not to answer

6. Are you of Aboriginal or Torres Strait Islander origin?
- ☐ Aboriginal but not Torres Strait Islander origin
 - ☐ Torres Strait Islander but not Aboriginal origin
 - ☐ Both Aboriginal and Torres Strait Islander origin
 - ☐ Neither Aboriginal or Torres Strait Islander origin
 - ☐ Prefer not to answer

Thank you, that brings us to the end of the survey today.

Invitation to Part B

Before you go I would like to tell you about an opportunity to participate in a more in-depth study looking at callers experience to Lifeline 13 11 14 with the researchers at The University of Melbourne. This will include being phoned by an interviewer from the University of Melbourne research team four times over the next year (now, in three, six and 12 months' time).

The information you provide is confidential and will not be linked to any previous or future information you provide to Lifeline. You are free to withdraw from this study at any time. If you decide not to participate, this will have no effect on any service you may receive from Lifeline or from any other agency. No personal information you provide will be held by Lifeline.

If you think you might be interested, I will ask you to give me your name and phone number or email address which I will pass onto the researchers. They will then send you some more detailed information about participating in the interviews, and a consent form that you will be asked to sign and send back.

Do you think might be interested in participating in the more detailed interviews? ☐ Yes ☐ No

*If **No**, reassure the caller that this is fine. If **Yes**, collect the callers' contact details:*

Caller's name: _____

Caller's phone number or email address: _____

That is the end of the survey today. Thank you for taking part.

Appendix 6: Study 2 – Interview schedule with Lifeline frequent users

1. Can you tell me a bit about the circumstances under which you called Lifeline in the past few months?
2. What was happening for you that prompted your initial call?
3. If you called more than once, what made you continue to call?
4. What made you call Lifeline in particular?
5. Did you consider making contact with any other telephone services?
 - a. If not, why not?
 - b. If so, why did you call Lifeline as well?
6. Was the decision to call Lifeline entirely your own, or did someone else suggest it (e.g., a friend or a family member, a health professional)?
7. People call Lifeline in all sorts of different ways. Some people call only once and don't call again. Some people call more episodically, maybe making a few calls over a short period and then not calling again for some time. Still others call regularly and often, sometimes over a longer period. How would you describe your own calling patterns?
8. This might be a difficult question to answer, but can you explain why you have a particular calling pattern or why you call in the way you do?
9. What happens for you between calls?
10. What prompts you to call again?
11. How do you feel that Lifeline continues to provide you with support for your emotional wellbeing?
12. Some people see a range of health professionals for their emotional well being as well as calling Lifeline. Are you seeing any health professionals for your emotional well being?
13. Do you get different things from these health professionals compared with what you get from calling Lifeline?
14. How did you find the experience of calling Lifeline?
15. Did you find it easy to get through?
16. Did you feel as though the telephone crisis supporter listened to you?
17. Did he or she say things that were useful in helping you think through your issues and how you might deal with them?
18. Can you tell me more about the support you received from Lifeline?
19. What did you find helpful about the support provided by Lifeline?

20. How do you feel Lifeline could improve its service to meet the needs of callers like yourself?
21. How did you feel after calling Lifeline?
22. What, if any, action did you take after calling Lifeline?
23. What has happened for you since calling Lifeline?
24. I'm interested to know whether things have changed for you. Thinking back to what you told me about what prompted your initial call, would you say that things have got better, got worse or stayed the same?
25. If they've changed at all, would you attribute any of this change to Lifeline?
26. I've asked you a lot of questions, but I'm wondering if you might like to tell the story of your recent contact with Lifeline in your own words, taking me through from beginning to end. You can speak in general terms if that's easier for you.
27. Are there any other comments you'd like to make?

Appendix 7: Study 2 – Detailed characteristics of interview participants

ID	Sex	Age	Duration of frequent use	Mental health issues	Calling behaviour
01	F	45-64	Long-term	Anxiety, panic attacks, schizophrenia	Reactive
02	F	25-44	~ 2 years	Anxiety, depression	Support-seeking
03	F	45-64	Few months	Schizophrenia	Dependent
04	M	45-64	~ 2 years	Anxiety, depression	Dependent
05	M	45-64	Long-term	Anxiety, depression	Dependent
06	F	45-64	Few months	Depression	Support-seeking
07	M	18-25	Long-term	Depression	Dependent
08	M	+65	Long-term	-	Dependent
09	F	25-44	Long-term	Anxiety	Reactive
10	F	25-44	~ 2 years	Depression	Reactive, support-seeking
11	F	25-44	Unable to recall	-	Support-seeking
12	F	45-64	Unable to recall	Depression	Reactive
13	M	+65	Long-term	Depression, nervous breakdown, schizophrenia	Support-seeking
14	F	45-64	Unable to recall	-	Reactive, support-seeking
15	F	45-64	Long-term	-	Reactive
16	F	45-64	Long-term	Depression	Reactive, support-seeking
17	M	45-64	Long-term	Anxiety, depression, schizophrenia	Reactive
18	M	25-44	~ 2 years	Nervous breakdown	Dependent
19	F	45-64	Long-term	Anxiety, depression	Reactive, support-seeking

**Appendix 8: Study 3 – List of explanatory measures taken from the
diamond study outlining how they were coded and the time points they were
measured**

Explanatory variable	Coding	Time point
<i>Socio-demographic factors</i>		
Age	2 = 18-34 years 1 = 35-54 years 0 = 55-76 years	Baseline
Gender	0 = Male 1 = Female	Baseline
Live alone	0 = No 1 = Yes	3, 6, 9, 12 months
Ability to manage on available income	0 = Easily/Not too bad 1 = Difficult/impossible	Baseline
Bothered by not having a confidant	0 = Not bothered 1 = Bothered a little 2 = Bothered a lot	Baseline
<i>Physical health factors</i>		
Chronic disease	0 = No 1 = Yes	Baseline
Self-rated health	0 = Good/Very Good/Excellent 1 = Poor/Fair	3, 6, 9, 12 months
<i>Mental health related factors</i>		
Anxiety at baseline	0 = No 1 = Yes	Baseline
PHQ-9 major depressive syndrome	0 = No major depressive syndrome 1 = Major depressive syndrome	3, 6, 9, 12 months
High probability of a personality disorder	0 = No 1 = Yes	3 years
Suicidal thoughts	0 = No 1 = Yes	3, 6, 9, 12 months
<i>Medication related items</i>		
Antidepressant use	0 = No 1 = Yes	3, 6, 9, 12 months
Antipsychotics use	0 = No 1 = Yes	3, 6, 9, 12 months

Explanatory variable	Coding	Time point
<i>Health service use in the past three months</i>		
Visited a GP	0 = No 1 = Yes	3, 6, 9, 12 months
Visited a psychologist	0 = No 1 = Yes	3, 6, 9, 12 months
Visited a psychiatrist	0 = No 1 = Yes	3, 6, 9, 12 months
Visited the emergency department	0 = No 1 = Yes	3, 6, 9, 12 months
Visited the GP and other health professionals	0 = Only visited the GP 1 = Visited GP and one or more health professional (psychologist/psychiatrist/ER)	3, 6, 9, 12 months
Satisfaction with access to health services	0 = Very satisfied/satisfied 1 = Neither satisfied or dissatisfied 2 = Very/fairly dissatisfied	3, 6, 9, 12 months
<i>GP related health service use in the past three months</i>		
Number of visits to the GP – any reason	Continuous	3, 6, 9, 12 months
Number of visits to the GP – emotional wellbeing	Continuous	3, 6, 9, 12 months
Number of GPs visited	Continuous	3, 6, 9, 12 months
Number of times visited usual GP	Continuous	3, 6, 9, 12 months
Average length of visit to the GP	0 = ≤ 6 minutes 1 = 7-19 minutes 2 = ≥ 20 minutes	3, 6, 9, 12 months
Changed usual GP	0 = No 1 = Yes	3, 6, 9, 12 months
GP provided reassurance, encouragement and explanation	0 = No 1 = Yes	3, 6, 9, 12 months
GP gave a chance to talk about how were feeling	0 = No 1 = Yes	3, 6, 9, 12 months

Explanatory variable	Coding	Time point
GP helped talk through problems	0 = No 1 = Yes	3, 6, 9, 12 months
GP gave information (leaflets, booklets or videos) about depression, stress or worries	0 = No 1 = Yes	3, 6, 9, 12 months
GP suggested or referred them to see another health professional for their emotional wellbeing	0 = No 1 = Yes	3, 6, 9, 12 months
Helpfulness of the GP in addressing emotional wellbeing	0 = Very/extremely helpful 1 = Slightly/moderately helpful 2 = Not at all helpful	3, 6, 9, 12 months

Appendix 9: Study 3 – *diamond* surveys

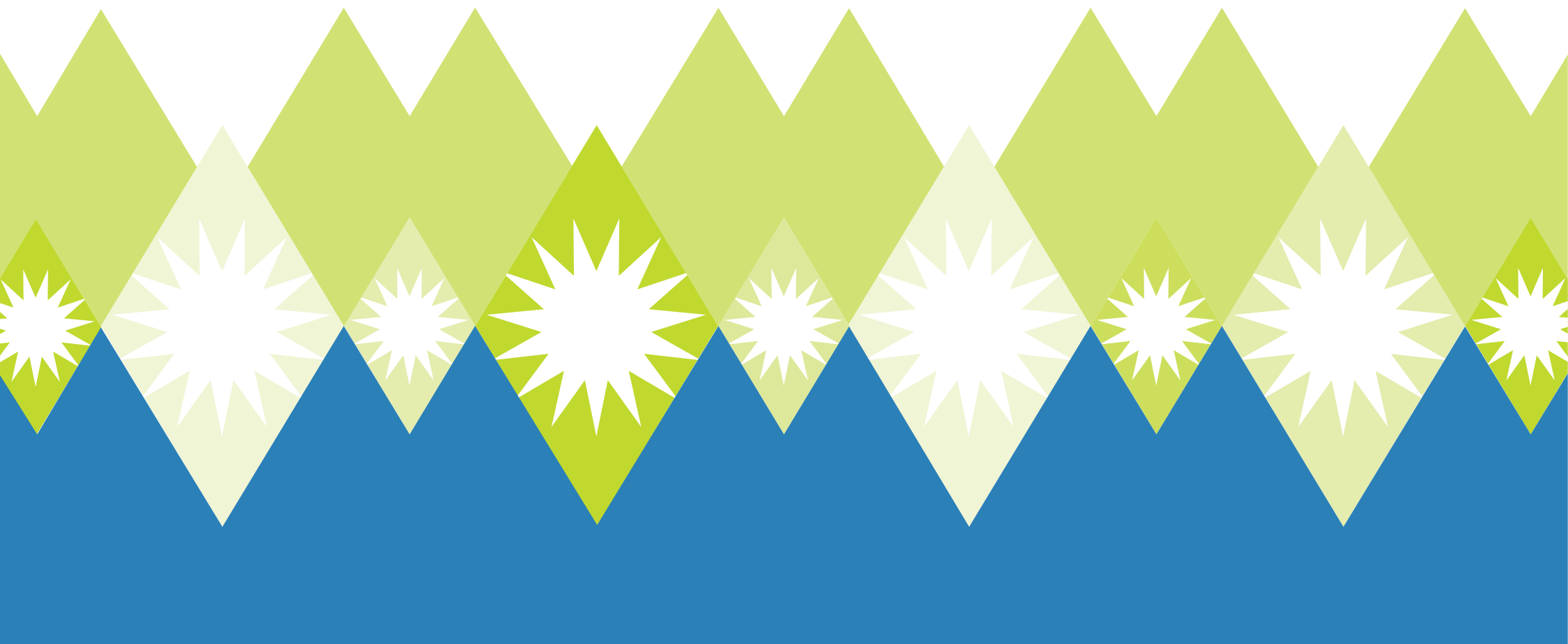
Baseline

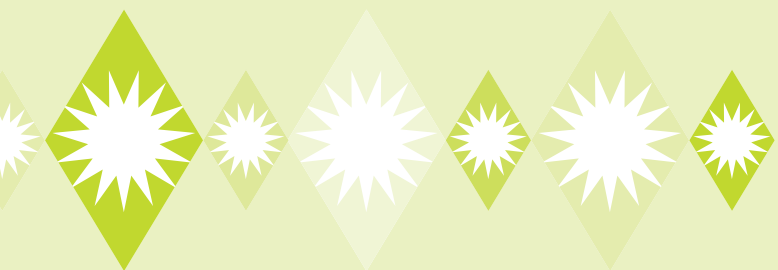
3, 6, 9 months

12 months

□ □ - □ □ □

diam**nd**





How to fill in the survey

Please read the questions carefully and follow the instructions. There are no right or wrong answers, just put what is right for you. Your answers will remain confidential.

Most of the questions can be answered by putting a **tick** in the box next to the answer that best applies to you. **Please tick only one box** per question, unless otherwise specified.

For example:

Is your usual GP male or female?

Male ☒ ₁

Female ☐ ₂

If you wish to write further comments, please do so on the blank page at the end of the survey or attach extra pages if you wish.



Welcome to the *diamond* project

Thank you for agreeing to take part in this project. Your responses to this survey will help us to build a better picture of the way general practitioners (GPs) or family doctors care for a person's emotional well-being. We are very interested in your own experiences of the care you receive.

This survey asks about your physical and emotional health and how issues such as lifestyle choices, intimate relationships, domestic violence and support networks may affect well-being. This survey will also give you a chance to report about the care you have received during the last 12 months.

All information you give us in this survey is **STRICTLY CONFIDENTIAL** and all findings from the project will be presented in anonymous form. We have tried it out with people and found that the survey takes around **30 minutes** to complete.

The **diamond** team is based at the Department of General Practice, The University of Melbourne. If you have any questions about the project, please call the **diamond** team on **03 8344 9719**.

This project is funded by the National Health and Medical Research Council and the Victorian Centre of Excellence in Depression and Related Disorders, an initiative between beyondblue and the State Government of Victoria.

A About yourself

This section asks about some background details. These questions are important because they allow your answers to be compared with those of other people with a similar background to you, without identifying anybody.

A1 Today's date is:

Day		Month		Year			

A2 What is your date of birth?

Day		Month		Year			

A3 a) Have you changed your usual general practitioner (GP) or family doctor you attend for your healthcare since you completed the first **diamond** survey?

Yes	☐	1
No	☐	0 (Go to question A4)

b) If Yes, what was your reason for changing GP?

(Please tick all that apply)

I have moved house	☐	1
The GP has left the clinic	☐	1
I was unhappy with my care	☐	1
The GP was always running late	☐	1
The GP didn't listen to me	☐	1
The GP was too expensive	☐	1
Other	☐	1

(Please specify)

A4 Do you have private health insurance for hospital and/or ancillary services, e.g., dental, physiotherapy?

(Please tick one box)

Hospital and ancillary ("extras")	☐	1
Ancillary ("extras") only	☐	2
Hospital only	☐	3
None of the above	☐	4

Income is very important to understand health, as it influences the health services someone has access to.

A5 How do you manage on your available income?

(Please tick one box)

Easy	☐	1
Not too bad	☐	2
Difficult some of the time	☐	3
Difficult all of the time	☐	4
Impossible	☐	5

A6 What was the total income (before tax) of your family in the last year?

\$20,000 or less	☐	1
\$20,001 - \$30,000	☐	2
\$30,001 - \$40,000	☐	3
\$40,001 - \$50,000	☐	4
\$50,001 - \$60,000	☐	5
\$60,001 - \$70,000	☐	6
More than \$70,000	☐	7

B About your quality of life

This section asks about your quality of life. Please answer all the questions. If unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks.

B Please read each question and assess your feelings, for the last 2 weeks, and tick the box for each question that gives the best answer for you.

(Please tick one box on each line)

	Very poor	Poor	Neither poor nor good	Good	Very good
B1 How would you rate your quality of life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

	Very dissatisfied	Fairly dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
B2 How satisfied are you with your health?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

B3 The following questions ask about how much you have experienced certain things in the last 2 weeks

(Please tick one box on each line)

	Not at all	A small amount	A moderate amount	A great deal	An extreme amount
To what extent do you feel that physical pain prevents you from doing what you need to do?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How much do you need any medical treatment to function in your daily life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How much do you enjoy life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
To what extent do you feel your life to be meaningful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How well are you able to concentrate?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How safe do you feel in your daily life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How healthy is your physical environment?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Do you have enough energy for everyday life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Are you able to accept your bodily appearance?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Have you enough money to meet your needs?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How available to you is the information you need in your daily life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

	Not at all	Slightly	Somewhat	To a great extent	Completely
To what extent do you have the opportunity for leisure activities?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

	Not at all	Slightly	Moderately	Very	Extremely
How well are you able to get around physically?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

B4 The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last 2 weeks *(Please tick one box on each line)*

	Very dissatisfied	Fairly dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your sleep?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

How satisfied are you with your ability to perform your daily living activities?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
--	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

How satisfied are you with your capacity for work?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
--	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

How satisfied are you with yourself?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
--------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

How satisfied are you with your personal relationships?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
---	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

How satisfied are you with your sex life?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
---	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

How satisfied are you with the support you get from your friends?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
---	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

How satisfied are you with the conditions of your living place?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
---	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

	Very dissatisfied	Fairly dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your access to health services?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

How satisfied are you with your transport?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
--	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

	Never	Infrequently	Sometimes	Frequently	Always
How often do you have negative feelings such as blue mood, despair, anxiety, depression?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

**We appreciate your time and effort.
Please continue to the next page**



C About your health

This section asks for your views about your health, how you feel and how well you are able to do your usual activities.

c1 In general, would you say your health is... ?

(Please tick one box)

- Excellent ☐₁
- Very good ☐₂
- Good ☐₃
- Fair ☐₄
- Poor ☐₅

c2 The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(Please tick one box on each line)

Yes,
limited
a lot

Yes,
limited
a little

No,
not limited
at all

- a) **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf ☐₁ ☐₂ ☐₃
- b) Climbing **several** flights of stairs ☐₁ ☐₂ ☐₃

c3 During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(Please tick one box on each line)

Yes No

- a) **Accomplished** less than you would like ☐₁ ☐₀
- b) Were limited in the **kind** of work or other activities ☐₁ ☐₀

c4 During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? (Please tick one box on each line)

Yes No

- a) **Accomplished less** than you would like ☐₁ ☐₀
- b) Didn't do work or other activities as **carefully** as usual ☐₁ ☐₀

c5 During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? (Please tick one box)

- Not at all ☐₁
- A little bit ☐₂
- Moderately ☐₃
- Quite a bit ☐₄
- Extremely ☐₅

- c6 **These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.**

How much of the time during the past 4 weeks:

(Please tick one box on each line)

All of the time Most of the time A good bit of the time Some of the time A little of the time None of the time

Have you felt calm and peaceful?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

Did you have a lot of energy?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

Have you felt down?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

- c7 **During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc)?**

(Please tick one box)

All of the time

☐₁

Most of the time

☐₂

Some of the time

☐₃

A little of the time

☐₄

None of the time

☐₅

If you have not been in paid employment in the past 3 months, please go to Question C9.

- c8 **In the past 3 months, how many days have you taken off work (include both short and long periods) for:**

(Please enter the total number of days in the boxes below)

a) physical health problems total number of days

b) emotional problems total number of days

- c9 **In the past 3 months, how many days were you unable to perform your home duties or study tasks due to:**

(Please enter the total number of days in the boxes below)

a) physical health problems total number of days

b) emotional problems total number of days

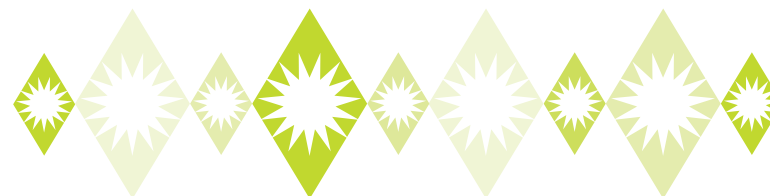
- c10 **In the past 3 months, how many days were you unable to participate in your usual leisure activities due to:**

(Please enter the total number of days in the boxes below)

a) physical health problems total number of days

b) emotional problems total number of days

**We appreciate your time and effort.
Please continue to the next page**



D About your lifestyle and life events

This section asks you about lifestyle issues that may affect your health.

D1 In a normal week, how many times do you engage in vigorous exercise lasting 20 min or more (i.e., exercise that makes you breathe harder or puff and pant, such as netball, squash, jogging, aerobics, vigorous swimming etc.)? *(Please tick one box)*

- Never ☐₀
- Once a week ☐₁
- Two or three times per week ☐₂
- Four, five or six times a week ☐₃
- Once every day ☐₄
- More than once every day ☐₅

D2 In a normal week, how many times do you engage in less vigorous exercise which lasts for 20 min or more (i.e., exercise that does not make you breathe harder or puff and pant, such as walking, gardening, swimming, and lawn bowling)? *(Please tick one box)*

- Never ☐₀
- Once a week ☐₁
- Two or three times per week ☐₂
- Four, five or six times a week ☐₃
- Once every day ☐₄
- More than once every day ☐₅

D3 For the following list, please indicate whether or not you have experienced these events in the past 12 months and if so, what impact the experience has had on you.

(Please tick one box on each line)

	NO, I haven't experienced this event in the past 12 months	YES and it has had an extremely negative impact on me	YES and it has had a slightly negative impact on me	YES but it has had no impact on me	YES and it has had a slightly positive impact on me	YES and it has had an extremely positive impact on me
Major personal injury or illness	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Major illness or injury of a parent, close family member or friend	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
The death of a spouse, parent, close family member or a friend	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Marriage	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Separation or divorce due to marital/ relationship difficulties or steady relationship breakdown	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Hit, slapped, kicked or otherwise physically hurt by partner/ ex partner	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Hit, slapped, kicked or otherwise physically hurt by someone other than partner/ex-partner	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Partner/ex partner forced you to have sexual activities	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Someone other than partner/ex-partner forced you to have sexual activities	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Serious problem with a close friend, neighbour or relative	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆

NO , I haven't experienced this event in the past 12 months	YES and it has had an extremely negative impact on me	YES and it has had a slightly negative impact on me	YES but it has had no impact on me	YES and it has had a slightly positive impact on me	YES and it has had an extremely positive impact on me
--	--	--	---	--	--

A major change in financial status (a lot better off, a lot worse off)

☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
-----------------------------	-----------------------------	-----------------------------	-----------------------------	-----------------------------	-----------------------------

Change in job/ workplace (including retirement, being sacked or made redundant)

☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
-----------------------------	-----------------------------	-----------------------------	-----------------------------	-----------------------------	-----------------------------

Pregnancy or partner's pregnancy

☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
-----------------------------	-----------------------------	-----------------------------	-----------------------------	-----------------------------	-----------------------------

E Your emotional well-being

This section asks about your emotional well-being, including your feelings and behaviours. Please answer all the questions even though some of them are similar, they allow us to compare your experiences with that of others.

E1 Below are a series of statements that may describe how you might have felt or behaved in the PAST WEEK. Please indicate how often you have felt this way during the past week.

Please ensure that you tick one box for each statement.

a) During the past week I was bothered by things that usually don't bother me

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
☐ _0	☐ _1	☐ _2	☐ _3

b) During the past week I did not feel like eating; my appetite was poor

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
☐ _0	☐ _1	☐ _2	☐ _3

c) During the past week I felt that I could not shake off the blues even with help from my family or friends

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
☐ _0	☐ _1	☐ _2	☐ _3

d) During the past week I felt I was just as good as other people

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
0	1	2	3

e) During the past week I had trouble keeping my mind on what I was doing

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
0	1	2	3

f) During the past week I felt depressed

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
0	1	2	3

g) During the past week I felt that everything I did was an effort

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
0	1	2	3

h) During the past week I felt hopeful about the future

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
0	1	2	3

i) During the past week I thought my life had been a failure

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
0	1	2	3

j) During the past week I felt fearful

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
0	1	2	3

k) During the past week my sleep was restless

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
0	1	2	3

l) During the past week I was happy

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
0	1	2	3

m) During the past week I talked less than usual

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
0	1	2	3

n) During the past week I felt lonely

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
0	1	2	3

o) During the past week people were unfriendly

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
0	1	2	3

p) During the past week I enjoyed life

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
☐ _0	☐ _1	☐ _2	☐ _3

q) During the past week I had crying spells

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
☐ _0	☐ _1	☐ _2	☐ _3

r) During the past week I felt sad

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
☐ _0	☐ _1	☐ _2	☐ _3

s) During the past week I felt that people dislike me

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
☐ _0	☐ _1	☐ _2	☐ _3

t) During the past week I could not "get going"

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
☐ _0	☐ _1	☐ _2	☐ _3

E2 During the last 4 weeks, how much have you been bothered by any of the following problems?

(Please tick one box on each line)

	Not bothered	Bothered a little	Bothered a lot
Stomach pain	☐ _0	☐ _1	☐ _2
Back pain	☐ _0	☐ _1	☐ _2
Pain in your arms, legs or joints (knees, hips, etc)	☐ _0	☐ _1	☐ _2
Menstrual cramps or other problems with your periods	☐ _0	☐ _1	☐ _2
Pain or problems during sexual intercourse	☐ _0	☐ _1	☐ _2
Headaches	☐ _0	☐ _1	☐ _2
Chest pain	☐ _0	☐ _1	☐ _2
Dizziness	☐ _0	☐ _1	☐ _2
Fainting spells	☐ _0	☐ _1	☐ _2
Feeling your heart pound or race	☐ _0	☐ _1	☐ _2
Shortness of breath	☐ _0	☐ _1	☐ _2
Constipation, loose bowels, or diarrhoea	☐ _0	☐ _1	☐ _2
Nausea, gas or indigestion	☐ _0	☐ _1	☐ _2

E3 Over the last 2 weeks, how often have you been bothered by any of the following problems? (Please tick one box on each line)

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things	☐ _0	☐ _1	☐ _2	☐ _3
Feeling down, depressed or hopeless	☐ _0	☐ _1	☐ _2	☐ _3
Trouble falling or staying asleep, or sleeping too much	☐ _0	☐ _1	☐ _2	☐ _3

E3 Over the last 2 weeks, how often have you been bothered by any of the following problems? (Please tick one box on each line)

	Not at all	Several days	More than half the days	Nearly every day
Feeling tired or having little energy	☐ _0	☐ _1	☐ _2	☐ _3
Poor appetite or overeating	☐ _0	☐ _1	☐ _2	☐ _3
Feeling bad about yourself, or that you are a failure, or have let yourself or your family down	☐ _0	☐ _1	☐ _2	☐ _3
Trouble concentrating on things, such as reading the newspaper or watching television	☐ _0	☐ _1	☐ _2	☐ _3
Moving or speaking so slowly that other people could have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual	☐ _0	☐ _1	☐ _2	☐ _3
Thoughts that you would be better off dead or of hurting yourself in some way	☐ _0	☐ _1	☐ _2	☐ _3

E4 Questions about anxiety. (Please tick one box on each line)

	No	Yes
In the last 4 weeks have you had an anxiety attack-suddenly feeling fear or panic?	☐ _0	☐ _1
If you ticked <u>No</u>, go to question E6		
Has this ever happened before?	☐ _0	☐ _1
Do some of these attacks come suddenly out of the blue - that is, in situations where you don't expect to be nervous or uncomfortable?	☐ _0	☐ _1
Do these attacks bother you a lot or are you worried about having another attack?	☐ _0	☐ _1

E5 Think about your last bad anxiety attack. (Please tick one box on each line)

	No	Yes
Were you short of breath?	☐ _0	☐ _1
Did your heart race, pound or skip?	☐ _0	☐ _1
Did you have chest pain or pressure?	☐ _0	☐ _1
Did you sweat?	☐ _0	☐ _1
Did you feel as if you were choking?	☐ _0	☐ _1
Did you have hot flashes or chills?	☐ _0	☐ _1
Did you have nausea or an upset stomach, or the feeling that you were going to have diarrhoea?	☐ _0	☐ _1
Did you feel dizzy, unsteady, or faint?	☐ _0	☐ _1
Did you have tingling or numbness in parts of your body?	☐ _0	☐ _1
Did you tremble or shake?	☐ _0	☐ _1
Were you afraid you were dying?	☐ _0	☐ _1

E6 Over the last 4 weeks, how often have you been bothered by any of the following problems?

(Please tick one box on each line)

	Not at all	Several days	More than half the days
Feeling nervous, anxious, on edge, or worrying a lot about different things	☐ _0	☐ _1	☐ _2
If you ticked <u>Not at all</u>, go to question E7			
Feeling restless so that it is hard to sit still	☐ _0	☐ _1	☐ _2
Getting tired very easily	☐ _0	☐ _1	☐ _2
Muscle tension, aches, or soreness	☐ _0	☐ _1	☐ _2
Trouble falling asleep or staying asleep	☐ _0	☐ _1	☐ _2
Trouble concentrating on things, such as reading a book or watching television	☐ _0	☐ _1	☐ _2
Becoming easily annoyed or irritated	☐ _0	☐ _1	☐ _2

E7 Questions about eating. (Please tick one box on each line)

Do you often feel that you can't control **what** or **how much** you eat?

No ☐_0 Yes ☐_1

Do you often eat, **within any 2-hour period**, what most people would regard as an unusually **large** amount of food?

☐_0 ☐_1

If you ticked No to either of the above, go to question E10

Has this been as often, on average, as twice a week for the last 3 months?

No ☐_0 Yes ☐_1

E8 In the last 3 months, have you often done any of the following in order to avoid gaining weight?

(Please tick one box on each line)

Made yourself vomit

No ☐_0 Yes ☐_1

Taken more than twice the recommended dose of laxatives

☐_0 ☐_1

Fasted (not eaten anything at all for at least 24 hours)

☐_0 ☐_1

Exercised for more than an hour specifically to avoid gaining weight after binge eating

☐_0 ☐_1

E9 If you ticked Yes to any of the above ways of avoiding gaining weight, were any as often, on average, as twice a week?

No ☐_0

Yes ☐_1

E10 In the last 4 weeks, how much have you been bothered by any of the following problems?

(Please tick one box on each line)

Worrying about your health

Not bothered ☐_0 Bothered a little ☐_1 Bothered a lot ☐_2

Your weight or how you look

☐_0 ☐_1 ☐_2

Little or no sexual desire or pleasure during sex

☐_0 ☐_1 ☐_2

Difficulties with husband/wife, partner/lover or boyfriend/girlfriend

☐_0 ☐_1 ☐_2

The stress of taking care of children, parents, or other family members

☐_0 ☐_1 ☐_2

Stress at work outside of the home or at school

☐_0 ☐_1 ☐_2

Financial problems or worries

☐_0 ☐_1 ☐_2

Having no one to turn to when you have a problem

☐_0 ☐_1 ☐_2

Something bad that happened recently

☐_0 ☐_1 ☐_2

Thinking or dreaming about something terrible that happened to you in the past - like your home being destroyed, a severe accident, being hit or assaulted, or being forced to commit a sexual act

☐_0 ☐_1 ☐_2

E11 Over the last 4 weeks, how often have you been bothered by repetitive intrusive thoughts, ideas, doubts, images or impulses that distress you and that you regard as unwanted or senseless?

Not at all ☐_0 Some days ☐_1 More than half the days ☐_2

Not at all _0 Some days _1 More than half the days _2

[illegible]

E14 Questions about menstruation, pregnancy and childbirth

(Please tick one box)

Periods are unchanged □₁

No periods because pregnant or recently gave birth ☐2

Periods have become irregular or changed in frequency, duration or amount ☐3

No periods for at least a year □₄

Having periods because taking hormone replacement (oestrogen) therapy or oral contraceptive ☐5

No (or does not apply)	Yes
------------------------------	-----

During the week before your period starts, do you have a **serious** problem with your mood- like depression, anxiety, irritability, anger or mood swings?

If **Yes**: Do these problems go away by the end of your period?

Have you given birth within the last 6 months? ☐_0 ☐_1

Have you had a miscarriage within the last 6 months? ☐_0 ☐_1

Are you having difficulty getting pregnant? ☐_0 ☐_1

24

F Your relationships

In this section we ask about your relationships because it is an important part of your life that may influence your health. We ask you about your experiences in adult intimate relationships. By adult intimate relationship we mean husband/wife, partner or boy/girl friend for longer than 1 month.

F1 Have you ever been in an adult intimate relationship?

(Since you were 16 years of age)

Yes ☐_1

No ☐_0 (If NO, go to question F6)

F2 Are you currently in an intimate relationship?

Yes ☐_1

No ☐_0 (If NO, please go to question F4)

F3 Are you currently afraid of your partner?

Yes ☐_1

No ☐_0

F4 Have you ever been afraid of any partner?

Yes ☐_1

No ☐_0

F5 We would like to know if you experienced any of the actions listed below and how often it happened during the past twelve months. If you were not with a partner in the past twelve months, could you please answer for the last partner that you had.

Please tick the appropriate box, which matches the frequency, over a twelve month period, that it happened to you. (Please tick one box on each line)

Actions	How often it happened					
	Never	Only once	Several times	Once/month	Once/week	Daily
My Partner:						
Told me that I wasn't good enough	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Kept me from medical care	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Followed me	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Tried to turn my family, friends and children against me	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Locked me in the bedroom	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Slapped me	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Raped me	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Told me that I was ugly	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Tried to keep me from seeing or talking to my family	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Threw me	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Hung around outside my house	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Blamed me for causing their violent behaviour	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Harassed me over the telephone	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6

Actions My Partner:	How often it happened						
	Never	Only once	Several times	Once/month	Once/week	Daily	
Shook me	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Tried to rape me	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Harassed me at work	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Pushed, grabbed or shoved me	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Used a knife or gun or other weapon	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Became upset if dinner/housework wasn't done when they thought it should be	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Told me that I was crazy	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Told me that no one would ever want me	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Took my wallet and left me stranded	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Hit or tried to hit me with something	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Did not want me to socialise with my female friends	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Put foreign objects in my vagina/anus	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Refused to let me work outside the home	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Kicked me, bit me or hit me with a fist	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Tried to convince my friends, family or children that I was crazy	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Told me that I was stupid	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Beat me up	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐

These next questions are about possible experiences you may have had as a child (before you were 16 years of age).

Please tick the most appropriate box for each question.

F6 When you were growing up, how often did any adult do any of the things on this list to you?

(Please tick one box on each line)

	Often	Sometimes	Rarely	Never	
Pushed, grabbed, or shoved you	☐ 1	☐ 2	☐ 3	☐ 0	☐
Threw something at you	☐ 1	☐ 2	☐ 3	☐ 0	☐
Slapped or spanked you	☐ 1	☐ 2	☐ 3	☐ 0	☐
Kicked, bit, or punched you	☐ 1	☐ 2	☐ 3	☐ 0	☐
Hit you with something	☐ 1	☐ 2	☐ 3	☐ 0	☐
Choked, burned, or scalded you	☐ 1	☐ 2	☐ 3	☐ 0	☐
Physically attacked you in some other way	☐ 1	☐ 2	☐ 3	☐ 0	☐

F7 When you were growing up, did any adult do any of these things to you against your will?

	Yes	No	
Exposed themselves to you more than once?	☐ 1	☐ 0	☐
Threatened to have sex with you?	☐ 1	☐ 0	☐
Touched the sex parts of your body?	☐ 1	☐ 0	☐
Tried to have sex with you or sexually attacked you?	☐ 1	☐ 0	☐



G About your community participation and social support

This section asks about various social and community activities that you may have participated in during the **past 12 months**.

G1 In the past 12 months, how often have you done the following social activities?

(Please tick one box on each line)

	Once a week or more	A few times a month	Monthly	A few times a year	Rarely	Never
Visited family/ family visit	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Visited friends/ friends visit	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Visited neighbours/ had neighbours visit	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Attended church or a religious group	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Gone to a social club	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Used the Internet for social communication	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Gone to a café or restaurant	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Gone to a club, pub or bar	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Gone to the cinema or theatre	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Gone to watch a sports event	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Gone to a party or dance	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0

G2 In the past 12 months, how often have you done the following sport, leisure or support activities?

(Please tick one box on each line)

	Once a week or more	A few times a month	Monthly	A few times a year	Rarely	Never
Played sport	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Had social contact through children's sport	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Gone to the gym or exercise class	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Self-help or support groups	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Singing, acting or played music in a group	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Been involved in a hobby group	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0
Gone to a class	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 0

G3 In the past 12 months, have you been involved in the following community or group activities?

(Please tick either 'Yes' or 'No' for each statement)

	Yes	No
School-related group	☐ 1	☐ 0
Service club (e.g. Lions, CWA)	☐ 1	☐ 0
Ethnic group (e.g. Croatian, Italian club)	☐ 1	☐ 0
Volunteer organisation or group	☐ 1	☐ 0

G4a Do you have any household pets?

Yes ☐1 No ☐0 (If NO, go to page 32)

b) If Yes, how attached are you to your pet/s? (Please tick one box)

Extremely attached	Moderately attached	A little attached	Not attached at all
☐ 1	☐ 2	☐ 3	☐ 0

Next are some questions about the support that is available to you.

The following questions ask about people in your environment who provide you with help or support. Each question has two parts.

For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the persons' initials and their relationship to you (see example). Do not list more than one person next to each of the numbers beneath the question.

Example

Who do you know whom you can trust with information that could get you into trouble?

No one 1) T.N. (brother) 4) T.N. (father) 7)
 2) L.M. (friend) 5) L.M. (employer) 8)
 3) R.S. (friend) 6) 9)

If you have had no support for a question, circle the words "No one", but still rate your level of satisfaction. Do not list more than nine persons per question.

For the second part, tick how satisfied you are with the overall support you have.

Example

How satisfied?

Very dissatisfied Fairly dissatisfied A little dissatisfied A little satisfied Fairly satisfied Very satisfied
☐₁ ☐₂ ☐₃ ☐₄ ☒₅ ☐₆

Please answer all the questions as best you can.

G5a) Whom can you really count on to be dependable when you need help?

No one 1) 4) 7)
 2) 5) 8)
 3) 6) 9)

b) How satisfied?

Very dissatisfied Fairly dissatisfied A little dissatisfied A little satisfied Fairly satisfied Very satisfied
☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

G6a) Who can you really count on to help you feel more relaxed when you are under pressure or tense?

No one 1) 4) 7)
 2) 5) 8)
 3) 6) 9)

b) How satisfied?

Very dissatisfied Fairly dissatisfied A little dissatisfied A little satisfied Fairly satisfied Very satisfied
☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

G7a) Who accepts you totally, including both your worst and best points?

No one 1) 4) 7)
 2) 5) 8)
 3) 6) 9)

b) How satisfied?

Very dissatisfied Fairly dissatisfied A little dissatisfied A little satisfied Fairly satisfied Very satisfied
☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

G8a) Who can you really count on to care about you, regardless of what is happening to you?

No one 1) 4) 7)
 2) 5) 8)
 3) 6) 9)

b) How satisfied?

Very dissatisfied Fairly dissatisfied A little dissatisfied A little satisfied Fairly satisfied Very satisfied
☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

G9a) Who can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

No one 1) 4) 7)
 2) 5) 8)
 3) 6) 9)

b) How satisfied?

Very dissatisfied Fairly dissatisfied A little dissatisfied A little satisfied Fairly satisfied Very satisfied
☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

G10a) Who can you count on to console you when you are very upset?

No one 1) 4) 7)
 2) 5) 8)
 3) 6) 9)

b) How satisfied?

Very dissatisfied Fairly dissatisfied A little dissatisfied A little satisfied Fairly satisfied Very satisfied
☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

H Health service use

This section asks about any of the doctors or health professionals you may have seen during the past 12 months regarding your own health. Please include any visits that were for check-ups or script repeats.

H1 How many times have you seen the following health professionals during the past 12 months? Please ensure that you tick a response for each health professional. If you have not seen the health professional please ensure that you tick the '0 times' box.

	0 times	1-2 times	3-4 times	5-6 times	7-11 times	12 or more times
General practitioner (GP)	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Hospital doctor	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Specialist doctor	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Physiotherapist	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Chiropractor	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Psychologist	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Counsellor	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Psychiatrist	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Nurse	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Social worker	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Alcohol or drug worker	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Domestic violence worker	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Family therapist	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Naturopath	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Homeopath	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Acupuncturist	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Other natural therapist	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆

H2a) During the past 12 months, have you...?

(Please tick either 'Yes' or 'No' for each statement)

Yes	No	If yes, how many times?
-----	----	-------------------------

Received help from an ambulance

☐ 1 ☐ 0 ☐

Been driven to hospital by an ambulance

☐ 1 ☐ 0 ☐

Attended a hospital emergency department or casualty ward

☐ 1 ☐ 0 ☐

Attended an outpatient clinic of a hospital for physical illness

☐ 1 ☐ 0 ☐

Attended an outpatient clinic of a hospital
for your emotional well-being

☐ 1 ☐ 0 ☐

b) If you ticked Yes to any of the above, please state the reason for using the service/s in the space below.

This image shows a single sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

H3a) During the past 12 months, have you been admitted at least overnight to ...?

(Please tick either 'Yes' or 'No' for each statement)

Yes	No	If yes, how many nights in total did you stay during all admissions?

A general hospital for physical illness

☐ 1 ☐ 0 ☐

A general hospital for your emotional well-being

1	0	
---	---	--

A psychiatric hospital

☐ 1 ☐ 0 ☐

If you have not been admitted to hospital during the past 12 months, please go to page 38.

b) If you ticked Yes to any of the above, please state why you were admitted to hospital in the space below.

H4 Did you use your private health insurance for this/ these stay/s in hospital?

Yes

1

No

10

Sections I-N ask in more detail about your use of some of the health professionals in question H1 during the past 12 months.

It is likely you will not have seen all the health professionals listed in sections I-N, therefore you do not need to complete the sections for the health professionals you have not seen. Each section will direct you to the next section if you have not seen the particular health professional to be discussed. Please follow the instructions at the start of each section carefully.

	Page
I Your visits to a GP	39
J Your visits to a Psychiatrist	43
K Your visits to a Psychologist	44
L Your visits to a Counsellor	45
M Your visits to professionals for problems related to alcohol and/or drug use	46
N Your visits to an alternative therapist	47

If you have not used any of the health professionals listed in Section I-N above in the past 12 months, please go to Section O about medication on page 49.

Everyone should complete Section P on page 55.

i Your visits to a GP

The following section asks in more detail about your visits to a GP during the past 12 months. If you have not seen a GP during this time, *please go to Section J on page 43*.

- 11 During the past 12 months, how many different GPs have you seen?** *(Please enter total number of GPs seen)*

total number of GPs seen

- 12 How many times did you visit a GP?** *(Please enter the total number of times in the box below)*

number of visits to GP during past 12 months

- 13 How many times did you visit your usual GP?** (Your usual GP is the GP that you see most of the time for your own health care).

(Please enter the total number of times in the box below)

number of times during past 12 months

- 14 How many of these visits to any GP were related to your emotional well-being such as stress, anxiety, or depression?**

(Please enter the total number of times in the box below)

number of visits

15 On average, how long did your visits with a GP take?

(Please tick the box that reflects the average length of visits)

Less than 6 minutes	7-19 minutes	20-39 minutes	40-60 minutes	More than 1 hour
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5

16 Where did the visits with a GP take place?

(Please tick all that apply)

In their rooms (surgery, clinic or shop)	In your home	At a community health clinic	At a drug or alcohol service	At a hospital outpatients (including accident or emergency)
☐ _1	☐ _1	☐ _1	☐ _1	☐ _1

17 How much did you usually pay out of pocket for each visit to a GP?

\$

18 Can you please describe the treatment or support that you have received for your emotional well-being from a GP during the past 12 months?

(Please write your response in the space below)

19 During your visits to a GP in the past 12 months, which of these forms of help did you receive? (Please tick all that apply)

GP provided reassurance, encouragement and explanation ☐_1

GP gave me the chance to talk about how I was feeling ☐_1

GP gave me information (leaflets, booklets, videos) about depression, stress or worries, their treatment, and available services ☐_1

GP prescribed medicine or tablets for depression, stress or worries ☐_1

GP helped me to talk through my problems ☐_1

GP provided family or marital counselling ☐_1

GP asked me about/suggested I cut down my use of alcohol and/or drugs/ GP gave me alcohol and/ or drug counselling ☐_1

GP taught me techniques such as relaxation or meditation ☐_1

GP hypnotised me ☐_1

GP encouraged me to exercise ☐_1

GP gave me advice about diet ☐_1

GP gave me advice on getting a good night's sleep ☐_1

GP suggested I see another health professional for help with my emotional well-being ☐_1

GP referred me to a health professional for help with my emotional well-being ☐_1

110 Overall, how helpful have you found the GP in addressing your emotional well-being during the past 12 months...?

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5

I11 During the past 12 months, have you received counselling from a GP in relation to your emotional well-being?

Yes ☐_1
No ☐_0 (If NO, go to Section J on page 43)

I12 During the past 12 months, how helpful have you found this counselling in addressing your emotional well-being...?

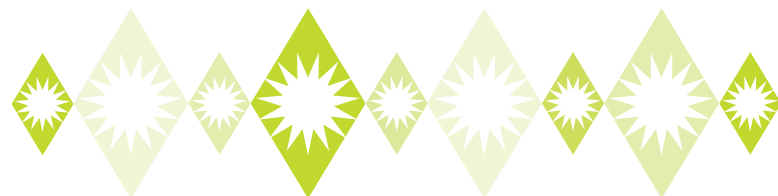
Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5

I13 During the past 12 months, have you ever seen a GP for a series of scheduled visits for your emotional well-being?

Yes ☐_1
No ☐_0 (If NO, go to Section J on page 43)

I14 During the past 12 months, how helpful have you found attending a GP for a series of scheduled visits in addressing your emotional well-being ...?

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5



J Your visits to a Psychiatrist



The following section asks in more detail about your visits to a Psychiatrist during the past 12 months. If you have not seen a Psychiatrist during this time, *please go to Section K on page 44*.

J1 During the past 12 months, how many times did you visit a Psychiatrist?

(Please enter the total number of times in the box below)

number of visits to Psychiatrist during past 12 months

J2 On average, how long did these visits to a Psychiatrist take? (Please tick the box that reflects the average length of visits)

Less than 6 minutes	7-19 minutes	20-39 minutes	40-60 minutes	More than 1 hour
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5

J3 Where did these visits with the Psychiatrist take place?

(Please tick all that apply)

In their rooms (surgery, clinic or shop)	In your home	At a community health clinic	At a drug or alcohol service	At a hospital outpatients (including accident or emergency)
☐ _1	☐ _1	☐ _1	☐ _1	☐ _1

J4 How much did you usually pay out of pocket for each visit to a Psychiatrist?

\$

J5 During the past 12 months, how helpful have you found the Psychiatrist in addressing your emotional well-being....?

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5

K Your visits to a Psychologist

The following section asks in more detail about your visits to a Psychologist during the past 12 months. If you have not seen a Psychologist during this time, *please go to Section L on page 45*.

K1 During the past 12 months, how many times did you visit a Psychologist?

(Please enter the total number of times in the box below)

number of visits to Psychologist during past 12 months

K2 On average, how long did the visits with a Psychologist take? (Please tick the box that reflects the average length of visits)

Less than 6 minutes	7-19 minutes	20-39 minutes	40-60 minutes	More than 1 hour
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

K3 Where did these visits with a Psychologist take place? (Please tick all that apply)

In their rooms (surgery, clinic or shop)	In your home	At a community health clinic	At a drug or alcohol service	At a hospital outpatients (including accident or emergency)
☐ ₁	☐ ₁	☐ ₁	☐ ₁	☐ ₁

K4 How much did you usually pay out of pocket for each visit to the Psychologist? (over and above you health insurance refund)

\$

K5 During the past 12 months, how helpful have you found the Psychologist in addressing your emotional well-being...?

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

For office use only

L Your visits to a Counsellor

The following section asks in more detail about your visits to a Counsellor for your emotional well-being during the past 12 months. If you have not seen a Counsellor during this time, *please go to Section M on page 46*.

L1 During the past 12 months, how many times did you visit a Counsellor? (Please enter the total number of times in the box below)

number of visits to Counsellor during the past 12 months

L2 On average, how long did the visits with a Counsellor take? (Please tick the box that reflects the average length of visits)

Less than 6 minutes	7-19 minutes	20-39 minutes	40-60 minutes	More than 1 hour
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

L3 Where did those visits with a Counsellor take place? (Please tick all that apply)

In their rooms (surgery, clinic or shop)	In your home	At a community health clinic	At a drug or alcohol service	At a hospital outpatients (including accident or emergency)
☐ ₁	☐ ₁	☐ ₁	☐ ₁	☐ ₁

L4 How much did you usually pay out of pocket for each visit to the Counsellor?

\$

L5 During the past 12 months, how helpful did you find the Counsellor in addressing your emotional well-being...?

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

For office use only

M Your visits to professionals for problems related to alcohol and/or drug use

The following section asks in more detail about your visits to professionals for problems related to alcohol and/or drug use during the past 12 months. If you have not had any treatment and support for problems related to alcohol and/or drug use during this time, *please go to Section N on page 47*.

M1 During the past 12 months, have you seen the following health professionals for problems related to alcohol and/or drug use? Please ensure that you tick a response for each health professional. If you have not seen the health professional please ensure that you tick the '0 times' box.

	0 times	1-2 times	3-4 times	5-6 times	7-11 times	12 or more times
General practitioner (GP)	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Hospital doctor	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Specialist doctor	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Psychiatrist	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Psychologist	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Alcohol worker/ counsellor	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Drug worker/ counsellor	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6

M2 During the past 12 months, have you been admitted to any of the following services for problems related to alcohol and/or drug use?

	Yes	No
Alcohol and drug unit of a hospital	☐ _1	☐ _0
Residential rehabilitation	☐ _1	☐ _0

N Your visits to an alternative therapist

The following section asks about your visits to any alternative therapist for your emotional well-being during the past 12 months. If you have not seen an alternative therapist for your emotional well-being, *please go to Section O on page 49*.

N1 During the past 12 months, how many times did you visit an alternative therapist for your emotional well-being? (Please enter the total number of times in the box below)

number of visits to an alternative therapist during the past 12 months

N2 During the past 12 months, which of the following alternative therapists have you visited for your emotional well-being? (Please tick all that apply)

Naturopath	☐ _1
Homeopath	☐ _1
Acupuncturist	☐ _1
Herbalist	☐ _1
Reiki therapist	☐ _1
Massage therapist	☐ _1
Aromatherapy therapist	☐ _1
Other (specify)	☐ _1

N3 On average, how long did the visits with the alternative therapist take?

(Please tick the box that reflects the average length of visits)

Less than 6 minutes	7-19 minutes	20-39 minutes	40-60 minutes	More than 1 hour
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5

N4 Where did those visits with alternative therapists take place? (Please tick all that apply)

In their rooms (surgery, clinic or shop)	In your home	At a community health clinic	At a drug or alcohol service	At a hospital outpatients (including accident or emergency)
☐ _1	☐ _1	☐ _1	☐ _1	☐ _1

N5 How much did you usually pay out of pocket for each visit to the alternative therapist for your emotional well-being?

\$

N6 During the past 12 months, how helpful have you found the alternative therapy in addressing your emotional well-being...?

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5

O Medication for your emotional well-being and/or for problems related to alcohol and/or drug use

The following section asks about any medication you may have been prescribed by a GP or Psychiatrist for your emotional well-being or for problems related to alcohol and/or drug use during the past 12 months. If you have not been prescribed any medication during this time, *please go to Section P on page 55*.

These questions ask you about any medication you may have been prescribed for your **emotional well-being**.

01 During the past 12 months, what medications have you been prescribed for your emotional well-being? Please can you check the details on your medication pack or bottle, and write the name of the medication and the dose you are taking in the boxes below. Complete a line for each medication you are being prescribed for your emotional well-being. *An example is shown in the table to help you.*

	Name of medication	Dose	Times per day taken
	Efexor	1 X 37.5mg tablet	Twice a day
1			
2			
3			

02 For each of the medications listed above, who first prescribed this/these medication/s to you?

(Please answer separately for each medication you have been prescribed in 01).

Medication 1	GP	☐ _1	Psychiatrist	☐ _2
Medication 2	GP	☐ _1	Psychiatrist	☐ _2
Medication 3	GP	☐ _1	Psychiatrist	☐ _2

03a) **How long have you been taking/did you take medication 1 for?**

Less than one month	1 month to less than 3 months	3 months to less than 6 months	6 months to less than 1 year	1 year to less than 2 years	2 years or more	Don't know
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6	☐ _7

b) **How long have you been taking/did you take medication 2 for?**

Less than one month	1 month to less than 3 months	3 months to less than 6 months	6 months to less than 1 year	1 year to less than 2 years	2 years or more	Don't know
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6	☐ _7

c) **How long have you been taking/did you take medication 3 for?**

Less than one month	1 month to less than 3 months	3 months to less than 6 months	6 months to less than 1 year	1 year to less than 2 years	2 years or more	Don't know
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6	☐ _7

04a) **During the past 12 months, how helpful have you found medication 1 in addressing your emotional well-being...?**

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5

b) **During the past 12 months, how helpful have you found medication 2 in addressing your emotional well-being...?**

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5

c) **During the past 12 months, how helpful have you found medication 3 in addressing your emotional well-being...?**

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5

05 **Are you still being prescribed/taking this medication?**

(Please answer separately for each medication you have been prescribed in O1).

Medication 1	Yes	☐ _1	No	☐ _0
Medication 2	Yes	☐ _1	No	☐ _0
Medication 3	Yes	☐ _1	No	☐ _0

If you are not still being prescribed/taking this medication, go to question 07

06 **Who currently prescribes this/these medication/s to you?**

(Please answer separately for each medication you have been prescribed in O1).

Medication 1	GP	☐ _1	Psychiatrist	☐ _2
Medication 2	GP	☐ _1	Psychiatrist	☐ _2
Medication 3	GP	☐ _1	Psychiatrist	☐ _2

The following questions ask you about any medication you may have been prescribed for **problems related to alcohol and/or drug use**.

07 **During the past 12 months, have you been prescribed medication from a GP or Psychiatrist for problems related to alcohol and/or drug use?**

Yes ☐_1

No ☐_0 (If NO, go to Section P on page 55)

- 08 **During the past 12 months, what medications have you been prescribed for problems related to alcohol and/or drug use?** Please can you check the details on your medication pack or bottle, and write the name of the medication and the dose you are taking in the boxes below. Complete a line for each medication you are being prescribed for problems related to alcohol and/or drug use. *An example is shown in the table to help you.*

	Name of medication	Dose	Times per day taken
	<i>Acamprosate</i>	<i>2 X 330mg tablets</i>	<i>Three times a day</i>
1			
2			
3			

- 09 **Who first prescribed this/these medication/s to you?**
(Please answer separately for each medication you have been prescribed in 08).

Medication 1	GP	☐ _1	Psychiatrist	☐ _2
Medication 2	GP	☐ _1	Psychiatrist	☐ _2
Medication 3	GP	☐ _1	Psychiatrist	☐ _2

- 010a) **How long have you been taking/did you take medication 1 for?**

Less than one month	1 month to less than 3 months	3 months to less than 6 months	6 months to less than 1 year	1 year to less than 2 years	2 years or more	Don't know
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6	☐ _7

- b) **How long have you been taking/did you take medication 2 for?**

Less than one month	1 month to less than 3 months	3 months to less than 6 months	6 months to less than 1 year	1 year to less than 2 years	2 years or more	Don't know
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6	☐ _7

- c) **How long have you been taking/did you take medication 3 for?**

Less than one month	1 month to less than 3 months	3 months to less than 6 months	6 months to less than 1 year	1 year to less than 2 years	2 years or more	Don't know
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6	☐ _7

- 011a) **During the past 12 months, how helpful have you found medication 1 in addressing your problems with alcohol and/or drug use...?**

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5

- b) **During the past 12 months, how helpful have you found medication 2 in addressing your problems with alcohol and/or drug use...?**

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5

- c) **During the past 12 months, how helpful have you found medication 3 in addressing your problems with alcohol and/or drug use...?**

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ _1	☐ _2	☐ _3	☐ _4	☐ _5

o12 Are you still being prescribed/taking this medication?

(Please answer separately for each medication you have been prescribed in O8).

Medication 1	Yes	☐ _1	No	☐ _0
Medication 2	Yes	☐ _1	No	☐ _0
Medication 3	Yes	☐ _1	No	☐ _0

If you are not still being prescribed/taking this medication, go to Section P on page 55

o13 Who currently prescribes this/these medication/s to you?

Medication 1	GP	☐ _1	Psychiatrist	☐ _2
Medication 2	GP	☐ _1	Psychiatrist	☐ _2
Medication 3	GP	☐ _1	Psychiatrist	☐ _2

P Your Experiences

Please complete this section only if you have experienced depression, stress or worries since you completed the last *diamond* survey.

P1 What has been the thing that has helped you most of all with depression, stress or worries during the past 12 months? *(Please write your response in the space below)*

P2 During the past 12 months, how would you describe your emotional health? *(Please write your response in the space below)*

We need your consent to be involved further in the *diamond* study

Before you can participate further in the *diamond* study we need your **consent**. Signing the consent form on page 57 indicates that you understand what *diamond* involves, how your privacy will be protected and that it is OK for us to continue contacting you. **The consent form will be removed from the booklet and stored separately from your completed survey.**

diagnosis, management and outcomes of depression in primary care

Consent form for participating further in the *diamond* project

Name of participant:

- 1 I consent to participate in the *diamond* project. This involves completing 4 postal surveys and participating in a one-hour telephone interview. This has been explained to me. A written copy of the information has been given to me to keep.
- 2 I acknowledge that:
 - a) I have been informed that I am free to withdraw from the project at any time without explanation or prejudice and to withdraw any unprocessed data previously supplied.
 - b) The project is for the purpose of research and not for treatment.
 - c) I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements.
 - d) The information that I provide may be used in future publications and that pseudonyms will be used to ensure no individual data is identified.
 - e) I have been informed that my doctor (GP) will care for me in the usual manner, whether I choose to participate in the project or not. My GP will not see the completed surveys or the responses I give.

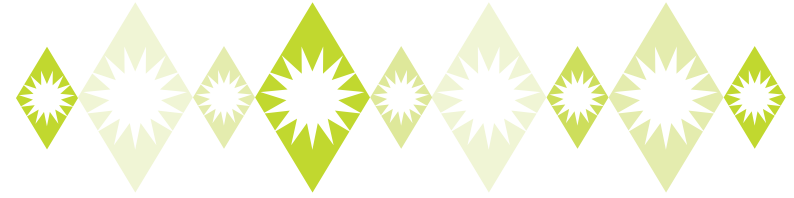
Signature

Date

(Participant)



[illegible]



Thank you very much for the time and effort you have taken in completing this survey.

Please use the reply paid envelope to send it back to us, together with the signed consent form on page 54 of this booklet. If no envelope was enclosed with your survey or you have mislaid it, please call a member of the **diamond** team on **(03) 8344 9719** and we will send you another one.

Or use our REPLY PAID return address (no stamp is required):

diamond Project
Department of General Practice
University of Melbourne
REPLY PAID 65443
200 Berkeley Street
Carlton VIC 3053

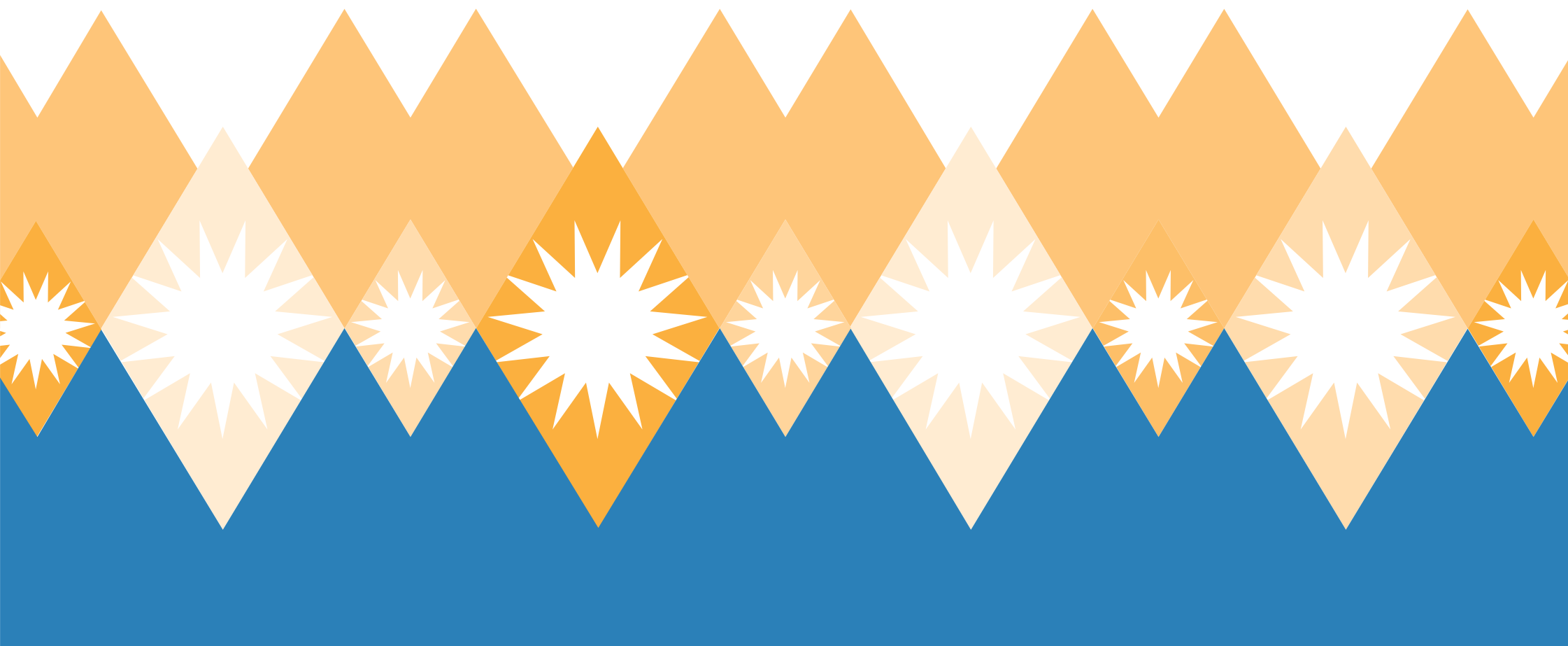
If you wish to talk to someone about any of the issues raised in this survey we have provided a card with phone numbers to call to access information. You can also contact the **diamond** project team on **(03) 8344 9719**.

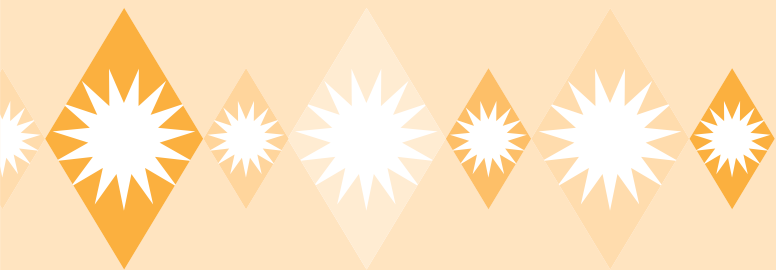
Many thanks,
The **diamond** team

This questionnaire includes:

- The WHOQOL GROUP (1998). Development of the World Health Organisation WHOQOL-BREF Quality of Life Assessment, Psychological Medicine, 28, 551-558.
- the SF-12® Health Survey, © 1994, 2000 QualityMetric Incorporated –all rights reserved SF-12® is a registered trademark of the Medical Outcomes Trust (MOT).
- The Centre for Epidemiologic Studies – Depression (CES-D) scale, Radloff LS.
- the PRIME MD PHQ developed by Drs RL Spitzer, JBW Williams, K Kroenke and colleagues. PRIME MD® is a trademark of Pfizer Inc. Copyright© 1999 Pfizer Inc.
- Composite Abuse Scale (1999) Hegarty K.
- MacMillan HL et al. Prevalence of Child Physical and Sexual Abuse in the Community: Results From the Ontario Health Supplement. JAMA 1997, 278 (2), 131-135.
- Baum et al. (2000). Epidemiology of participation: An Australian community study, JI Epidemiol Community Health, 54; p414-423

diamond





How to fill in the survey

Please read the questions carefully and follow the instructions. There are no right or wrong answers, just put what is right for you. Your answers will remain confidential.

Most of the questions can be answered by putting a **tick** in the box next to the answer that best applies to you. Please **tick only one box** per question, unless otherwise specified.

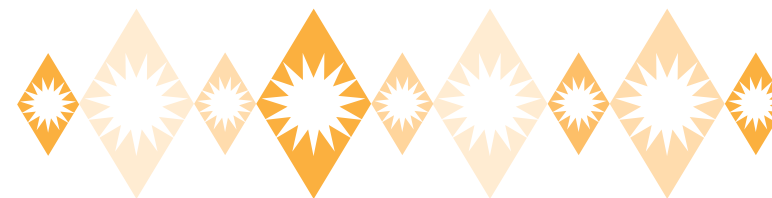
For example:

Is your usual GP male or female?

Male ☒ ₁

Female ☐ ₂

If you wish to write further comments, please do so on the blank page at the end of the survey or attach extra pages if you wish.



Thank you very much for the time and effort you have taken in completing this survey.

Please use the reply paid envelope to send it back to us. If no envelope was enclosed with your survey or you have mislaid it, please call a member of the **diamond** team on **(03) 8344 9719** and we will send you another one.

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Many thanks,
The **diamond** team

This questionnaire includes:

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- Baum et al. (2000). Epidemiology of participation: An Australian community study, JI Epidemiol Community Health, 54; p414-423



Thank you for your continued involvement in the *diamond* project

This survey asks about your current physical and emotional health. Completing this survey will give you a chance to tell us

- how you are and whether or not things have changed for you and,
- about the care you have received during the past 3 months.

Your responses to this survey will help us to build a better picture of the way general practitioners (GPs) or family doctors care for a person's emotional well-being. We are very interested in your own experiences of the care you receive.

All information you give us in this survey is **STRICTLY CONFIDENTIAL** and all findings from the project will be presented in anonymous form. We have tried it out with people and found that the survey takes around **20 minutes** to complete.

The *diamond* team is based at the Department of General Practice, The University of Melbourne. If you have any questions about the project, please call the *diamond* team on **03 8344 9719**.

This project is funded by the National Health and Medical Research Council and the Victorian Centre of Excellence in Depression and Related Disorders, an initiative between beyondblue and the State Government of Victoria.

A About yourself

This section asks about your background and some personal details.

A1 Today's date is:

				2	0		
Day		Month		Year			

A2 In a usual week, which of the following best describes you? (Please tick all that apply)

- | | | |
|---|--------------------------|---|
| In full-time paid work | ☐ | 1 |
| In part-time paid work or in casual paid work | ☐ | 1 |
| At school or in full-time education | ☐ | 1 |
| In part-time education | ☐ | 1 |
| Self-employed (e.g., in a family business) | ☐ | 1 |
| Home duties only – no paid work | ☐ | 1 |
| Unemployed – looking for work | ☐ | 1 |
| Unpaid voluntary work | ☐ | 1 |
| Unable to work due to sickness or disability | ☐ | 1 |
| Retired from paid work | ☐ | 1 |
| Other
(Please describe) | ☐ | 1 |

A3 Who do you usually live with?

(Please tick all that apply)

- | | | |
|--|--------------------------|---|
| I live alone | ☐ | 1 |
| Husband or wife | ☐ | 1 |
| Defacto partner | ☐ | 1 |
| My child/ren | ☐ | 1 |
| My partner's child/ren | ☐ | 1 |
| My parent/s | ☐ | 1 |
| Unrelated flatmate or co-tenant | ☐ | 1 |
| Other relationship
(Please specify) | ☐ | 1 |

The following question is about your 'usual' GP. Your usual GP is the GP that you see most of the time for your own health care.

A4 a) Have you changed your 'usual' general practitioner (GP) or family doctor you attend for your healthcare since you completed the last **diamond** survey around 3 months ago?

- | | | |
|-----|--------------------------|---|
| Yes | ☐ | 1 |
| No | ☐ | 0 |

b) If Yes, what was your reason for changing GP?

(Please tick all that apply)

- | | | |
|--------------------------------|--------------------------|---|
| I have moved house | ☐ | 1 |
| The GP has left the clinic | ☐ | 1 |
| I was unhappy with my care | ☐ | 1 |
| The GP was always running late | ☐ | 1 |
| The GP didn't listen to me | ☐ | 1 |
| The GP was too expensive | ☐ | 1 |
| Other
(Please specify) | ☐ | 1 |

B About your quality of life

This section asks about your quality of life. Please answer all the questions. If unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks.

B Please read each question and assess your feelings, for the last 2 weeks, and tick the box for each question that gives the best answer for you.

(Please tick one box on each line)

Very poor Poor Neither poor nor good Good Very good

B1 How would you rate your quality of life?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

Very dissatisfied Fairly dissatisfied Neither satisfied nor dissatisfied Satisfied Very satisfied

B2 How satisfied are you with your health?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

B3 The following questions ask about how much you have experienced certain things in the last 2 weeks

(Please tick one box on each line)

Not at all A small amount A moderate amount A great deal An extreme amount

To what extent do you feel that physical pain prevents you from doing what you need to do?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

How much do you need any medical treatment to function in your daily life?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

How much do you enjoy life?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

To what extent do you feel your life to be meaningful?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

Not at all Slightly Moderately Very Extremely

How well are you able to concentrate?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

How safe do you feel in your daily life?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

How healthy is your physical environment?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

Not at all Slightly Somewhat To a great extent Completely

Do you have enough energy for everyday life?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

Are you able to accept your bodily appearance?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

Have you enough money to meet your needs?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

How available to you is the information you need in your daily life?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

To what extent do you have the opportunity for leisure activities?

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

	Not at all	Slightly	Moderately	Very	Extremely
How well are you able to get around physically?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

B4 The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last 2 weeks (Please tick one box on each line)

	Very dissatisfied	Fairly dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your sleep?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

How satisfied are you with your ability to perform your daily living activities?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
--	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

How satisfied are you with your capacity for work?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
--	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

How satisfied are you with yourself?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
--------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

How satisfied are you with your personal relationships?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
---	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

How satisfied are you with your sex life?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
---	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

How satisfied are you with the support you get from your friends?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
---	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

How satisfied are you with the conditions of your living place?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
---	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

How satisfied are you with your access to health services?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
--	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

How satisfied are you with your transport?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
--	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

	Never	Infrequently	Sometimes	Frequently	Always
How often do you have negative feelings such as blue mood, despair, anxiety, depression?	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

B5 Over the last 2 weeks, how often have you been bothered by any of the following problems? (Please tick one box on each line)

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things	☐ ₀	☐ ₁	☐ ₂	☐ ₃

Feeling down, depressed or hopeless	☐ ₀	☐ ₁	☐ ₂	☐ ₃
-------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

Trouble falling or staying asleep, or sleeping too much	☐ ₀	☐ ₁	☐ ₂	☐ ₃
---	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

Feeling tired or having little energy	☐ ₀	☐ ₁	☐ ₂	☐ ₃
---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

Poor appetite or overeating	☐ ₀	☐ ₁	☐ ₂	☐ ₃
-----------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

Feeling bad about yourself, or that you are a failure, or have let yourself or your family down	☐ ₀	☐ ₁	☐ ₂	☐ ₃
---	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

Trouble concentrating on things, such as reading the newspaper or watching television	☐ ₀	☐ ₁	☐ ₂	☐ ₃
---	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

Moving or speaking so slowly that other people could have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual	☐ ₀	☐ ₁	☐ ₂	☐ ₃
--	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

Thoughts that you would be better off dead or of hurting yourself in some way	☐ ₀	☐ ₁	☐ ₂	☐ ₃
---	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

C About your health

This section asks for your views about your health, how you feel and how well you are able to do your usual activities.

c1 In general, would you say your health is... ?

(Please tick one box)

- Excellent ☐ ₁
- Very good ☐ ₂
- Good ☐ ₃
- Fair ☐ ₄
- Poor ☐ ₅

c2 The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(Please tick one box on each line)

Yes,
limited
a lot

Yes,
limited
a little

No,
not limited
at all

- a) **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf ☐ ₁ ☐ ₂ ☐ ₃
- b) Climbing **several** flights of stairs ☐ ₁ ☐ ₂ ☐ ₃

c3 During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(Please tick one box on each line)

Yes No

- a) **Accomplished** less than you would like ☐ ₁ ☐ ₀
- b) Were limited in the **kind** of work or other activities ☐ ₁ ☐ ₀

c4 During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? (Please tick one box on each line)

Yes No

- a) **Accomplished less** than you would like ☐ ₁ ☐ ₀
- b) Didn't do work or other activities as **carefully** as usual ☐ ₁ ☐ ₀

c5 During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? (Please tick one box)

- Not at all ☐ ₁
- Slightly ☐ ₂
- Moderately ☐ ₃
- Quite a bit ☐ ₄
- Extremely ☐ ₅

c6 **These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.**

How much of the time during the past 4 weeks:

(Please tick one box on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time	
Have you felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Did you have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐
Have you felt down?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐

c7 **During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc)?**
(Please tick one box)

All of the time	☐ 1	
Most of the time	☐ 2	
Some of the time	☐ 3	
A little of the time	☐ 4	
None of the time	☐ 5	

If you have not been in paid employment during the past 3 months, please go to Question C9.

c8 **During the past 3 months, how many days have you taken off work (include both short and long periods) for:**
(Please enter the total number of days in the boxes below)

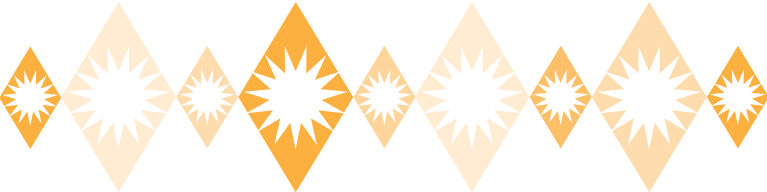
a) physical health problems		total <u>number</u> of days	☐ ☐ ☐
b) emotional problems		total <u>number</u> of days	☐ ☐ ☐

c9 **During the past 3 months, how many days were you unable to perform your home duties or study tasks due to:**
(Please enter the total number of days in the boxes below)

a) physical health problems		total <u>number</u> of days	☐ ☐ ☐
b) emotional problems		total <u>number</u> of days	☐ ☐ ☐

c10 **During the past 3 months, how many days were you unable to participate in your usual leisure activities due to:**
(Please enter the total number of days in the boxes below)

a) physical health problems		total <u>number</u> of days	☐ ☐ ☐
b) emotional problems		total <u>number</u> of days	☐ ☐ ☐



D Your emotional well-being

This section asks about your emotional well-being, including your feelings and behaviours. Please answer all the questions even though some of them are similar to those you have already answered. They allow us to compare your experiences with those of others.

D1 During the past 3 months, how would you rate your overall emotional well-being?

Excellent ☐1 Very good ☐2 Good ☐3 Fair ☐4 Poor ☐5

D2 During the past 3 months, would you consider your emotional well-being is....?

Better than usual ☐1
Same as usual ☐2
Worse than usual ☐3

**We appreciate your time and effort.
Please continue to the next page**

D3 Below are a series of statements that describe how you might have felt or behaved in the PAST WEEK. Please indicate how often you have felt this way during the past week.

Please ensure that you tick one box for each statement.

a) During the past week I was bothered by things that usually don't bother me

Rarely or none of the time (less than 1 day) ☐0 Some or a little of the time (1-2 days) ☐1 Occasionally or a moderate amount of time (3-4 days) ☐2 Most or all of the time (5-7 days) ☐3

b) During the past week I did not feel like eating; my appetite was poor

Rarely or none of the time (less than 1 day) ☐0 Some or a little of the time (1-2 days) ☐1 Occasionally or a moderate amount of time (3-4 days) ☐2 Most or all of the time (5-7 days) ☐3

c) During the past week I felt that I could not shake off the blues even with help from my family or friends

Rarely or none of the time (less than 1 day) ☐0 Some or a little of the time (1-2 days) ☐1 Occasionally or a moderate amount of time (3-4 days) ☐2 Most or all of the time (5-7 days) ☐3

d) During the past week I felt I was just as good as other people

Rarely or none of the time (less than 1 day) ☐0 Some or a little of the time (1-2 days) ☐1 Occasionally or a moderate amount of time (3-4 days) ☐2 Most or all of the time (5-7 days) ☐3

e) During the past week I had trouble keeping my mind on what I was doing

Rarely or none of the time (less than 1 day) ☐0 Some or a little of the time (1-2 days) ☐1 Occasionally or a moderate amount of time (3-4 days) ☐2 Most or all of the time (5-7 days) ☐3

f) During the past week I felt depressed

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

g) During the past week I felt that everything I did was an effort

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

h) During the past week I felt hopeful about the future

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

i) During the past week I thought my life had been a failure

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

j) During the past week I felt fearful

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

k) During the past week my sleep was restless

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

l) During the past week I was happy

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

m) During the past week I talked less than usual

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

n) During the past week I felt lonely

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

o) During the past week people were unfriendly

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

p) During the past week I enjoyed life

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

q) During the past week I had crying spells

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

r) During the past week I felt sad

Rarely or none of the time
(less than 1 day)
☐_0

Some or a little of
the time (1-2 days)
☐_1

Occasionally or a moderate
amount of time (3-4 days)
☐_2

Most or all of the time
(5-7 days)
☐_3

s) During the past week I felt that people dislike me

Rarely or none of the time
(less than 1 day)
☐_0

Some or a little of
the time (1-2 days)
☐_1

Occasionally or a moderate
amount of time (3-4 days)
☐_2

Most or all of the time
(5-7 days)
☐_3

t) During the past week I could not “get going”

Rarely or none of the time
(less than 1 day)
☐_0

Some or a little of
the time (1-2 days)
☐_1

Occasionally or a moderate
amount of time (3-4 days)
☐_2

Most or all of the time
(5-7 days)
☐_3

**We appreciate your time and effort.
Please continue to the next page**

E About your lifestyle and life experiences

**This section asks you about your lifestyle issues and
life experiences that may affect your health.**

**E1 In a normal week, how many times do you engage in
vigorous exercise lasting 20 min or more (i.e., exercise
that makes you breathe harder or puff and pant, such
as netball, squash, jogging, aerobics, vigorous swimming
etc.)? (Please tick one box)**

- Never ☐_0
- Once a week ☐_1
- Two or three times per week ☐_2
- Four, five or six times a week ☐_3
- Once every day ☐_4
- More than once every day ☐_5

**E2 In a normal week, how many times do you engage in
less vigorous exercise which lasts for 20 min or more
(i.e., exercise that does not make you breathe harder
or puff and pant, such as walking, gardening, swimming,
and lawn bowling)? (Please tick one box)**

- Never ☐_0
- Once a week ☐_1
- Two or three times per week ☐_2
- Four, five or six times a week ☐_3
- Once every day ☐_4
- More than once every day ☐_5

E3 During the past 3 months, how often have you done any of the following activities?

(Please tick one box on each line)

	Once a week or more	A few times a month	Monthly	Rarely	Never
Visited family/ family visit	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Visited friends/ friends visit	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Visited neighbours/ had neighbours visit	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Attended church or a religious group	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Gone to a social club	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Used the Internet for social communication	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Gone to a café or restaurant	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Gone to a club, pub, bar	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Gone to the cinema or theatre	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Gone to watch a sports event	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Gone to a party or dance	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Played sport	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Had social contact through children's sport	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Gone to the gym or exercise class	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Self-help or support groups	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Singing, acting or played music in a group	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Been involved in a hobby group	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Gone to a class	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
I have not done any of the above activities					☐ ₁

E4 During the past 3 months, how often have you tried any of the following for depression, stress or worries?

(Please tick all that apply)

	Once a week or more	A few times a month	Monthly	Rarely	Never
Exercise	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Yoga	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Counselling	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Hypnosis	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Depression medication (antidepressants)	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
St John's Wort	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Sedatives (sleeping medication)	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Acupuncture	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Relaxation/meditation	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Massage/touch therapy	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Aromatherapy	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Changed your diet	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Reduced your alcohol or drug intake	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Attended a self-help group for your emotional well-being	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Attended a self-help group for problems with alcohol or drugs	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Read a self-help book	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Prayer	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Educational or therapeutic websites on the internet	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Telephone help-line	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀
Talked to family or friends	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₀

I have not tried any of the above

☐₁

E5a) During the past 3 months, have you experienced any of the following and if so, what impact has the experience had on you?

(Please tick one box on each line)

	NO, I haven't experienced this in the past 3 months	YES and it has had an extremely negative impact on me	YES and it has had a slightly negative impact on me	YES but it has had no impact on me	YES and it has had a slightly positive impact on me	YES and it has had an extremely positive impact on me
Major personal injury or illness	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Major illness or injury of a parent, close family member or friend	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
The stress of taking care of children, parents, or other family members	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
The death of a spouse, parent, close family member or a friend	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Begun a new relationship	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Marriage	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Difficulties with husband/ wife, partner/lover or boyfriend/girlfriend	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Separation or divorce due to marital/relationship difficulties or steady relationship breakdown	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Been afraid of your partner	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
Hit, slapped, kicked or otherwise physically hurt by partner/ex partner	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆

NO, I haven't experienced this in the past 3 months

YES and it has had an extremely negative impact on me

YES and it has had a slightly negative impact on me

YES but it has had no impact on me

YES and it has had a slightly positive impact on me

YES and it has had an extremely positive impact on me

Hit, slapped, kicked or otherwise physically hurt by someone other than partner/ex-partner

☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

Partner/ex partner forced you to have sexual activities

☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

Someone other than partner/ex-partner forced you to have sexual activities

☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

Serious problem with a close friend, neighbour or relative

☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

A major change in financial status (a lot better off, a lot worse off)

☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

Stress at work, outside of the home or at school

☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

Change in job/ workplace (including retirement, being sacked or made redundant)

☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

Pregnancy or partner's pregnancy

☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆

b) In addition to the above list, during the past 3 months, have you experienced anything that has had a negative impact on you? (Please describe)

c) In addition to the above list, during the past 3 months, have you experienced anything that has had a positive impact on you? (Please describe)

	0 times	1-2 times	3-4 times	5-6 times	7-11 times	12 or more times
General practitioner (GP)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Hospital doctor	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Specialist doctor	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Physiotherapist	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Chiropractor	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Psychologist	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Counsellor	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Psychiatrist	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Nurse	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Social worker	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Domestic violence worker	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Alcohol or drug worker	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Family therapist	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Naturopath	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Homeopath	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Acupuncturist	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Other natural therapist	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

	Yes	No	If yes, how many times?
Received help from an ambulance	☐ _1	☐ _0	
Been driven to hospital by an ambulance	☐ _1	☐ _0	
Attended a hospital emergency department or casualty ward	☐ _1	☐ _0	
Attended an outpatient clinic of a hospital for physical illness	☐ _1	☐ _0	
Attended an outpatient clinic of a hospital for your emotional well-being	☐ _1	☐ _0	

This image shows a single sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

F3a) **During the past 3 months, have you been admitted at least overnight to ...?**
 (Please tick either 'Yes' or 'No' for each statement)

	Yes	No	If yes, how many nights in total did you stay during all admissions?
A general hospital for physical illness	☐ _1	☐ _0	
A general hospital for your emotional well-being	☐ _1	☐ _0	
A psychiatric hospital	☐ _1	☐ _0	

If you have not been admitted to hospital during the past 3 months, please go to page 25.

b) **If you ticked Yes to any of the above, please state why you were admitted to hospital in the space below.**

F4 **Did you use your private health insurance for any of the stays in hospital?**

Yes ☐_1

No ☐_0

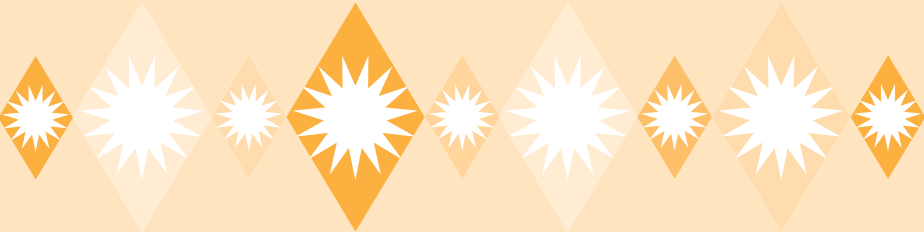
Sections G-L ask in more detail about your use of health professionals.

It is likely you will not have seen all the health professionals listed, therefore you do not need to complete the sections for the health professionals you have not seen. You will be directed to the next section if you have not seen a particular health professional. Please follow the instructions at the start of each section carefully.

	Page
G Your visits to a GP	26
H Your visits to a Psychiatrist	30
I Your visits to a Psychologist	31
J Your visits to a Counsellor	32
K Your visits to professionals for problems related to alcohol and/or drug use	33
L Your visits to an alternative therapist	34

If you have not used any of the health professionals listed in Section G-L above in the past 3 months, please go to Section M about medication on page 36.

Everyone should complete Section N on page 39.



G Your visits to a GP

This section asks in more detail about your visits to a GP during the past 3 months. If you have not seen a GP during this time, *please go to Section H on page 30.*

G1 During the past 3 months, how many different GPs have you seen?

(Please enter total number of GPs seen)

number of GPs seen during the past 3 months

G2 How many times did you visit a GP?

(Please enter the total number of times in the box below)

number of visits to GP during the past 3 months

G3 How many times did you visit your usual GP? (Your usual GP is the GP that you see most of the time for your own health care).

(Please enter the total number of times in the box below)

number of times during the past 3 months

G4 How many of these visits to any GP were related to your emotional well-being such as stress, anxiety, or depression?

(Please enter the total number of times in the box below)

number of visits during the past 3 months

For office
use only

G5 On average, how long did your visits with a GP take?

(Please tick the box that reflects the average length of visits)

Less than 6
minutes

☐ ₁

7-19
minutes

☐ ₂

20-39
minutes

☐ ₃

40-60
minutes

☐ ₄

More than
1 hour

☐ ₅

G6 Where did the visits with a GP take place?

(Please tick all that apply)

In their rooms
(surgery, clinic)

☐ ₁

In your home

☐ ₁

At a community
health clinic

☐ ₁

At a drug or
alcohol service

☐ ₁

At a hospital
outpatients
(including accident
or emergency)

☐ ₁

G7 How much did you usually pay out of pocket for each visit to a GP?

\$

G8 During the past 3 months, can you please describe the treatment or support that you have received for your emotional well-being from a GP?

(Please write your response in the space below)

G9 During your visits to a GP in the past 3 months, which of these forms of help did you receive? (Please tick all that apply)

GP provided reassurance, encouragement and explanation ☐ ₁

GP gave me the chance to talk about how I was feeling ☐ ₁

GP gave me information (leaflets, booklets, videos) about depression, stress or worries, their treatment, and available services ☐ ₁

GP prescribed medicine or tablets for depression, stress or worries ☐ ₁

GP helped me to talk through my problems ☐ ₁

GP provided family or marital counselling ☐ ₁

GP asked me about my use of alcohol and/or drugs/ suggested I cut down my use of alcohol and/or drugs/ gave me alcohol and/ or drug counselling ☐ ₁

GP taught me techniques such as relaxation or meditation ☐ ₁

GP hypnotised me ☐ ₁

GP encouraged me to exercise ☐ ₁

GP gave me advice on a healthy lifestyle ☐ ₁

GP gave me advice about diet ☐ ₁

GP gave me advice on getting a good night's sleep ☐ ₁

GP suggested I see another health professional for treatment for my emotional well-being ☐ ₁

GP referred me to a health professional for treatment for my emotional well-being ☐ ₁

I did not receive any of the above ☐ ₁

G10 Overall, how helpful have you found the GP in addressing your emotional well-being during the past 3 months?

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

G11 During the past 3 months, have you received counselling from a GP in relation to your emotional well-being?

Yes ☐ ₁
 No ☐ ₀ (If NO, go to question G13)

G12 How helpful have you found this counselling in addressing your emotional well-being...?

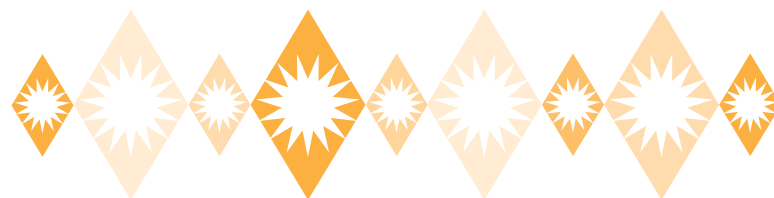
Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

G13 During the past 3 months, have you seen a GP for a series of scheduled visits for your emotional well-being?

Yes ☐ ₁
 No ☐ ₀ (If NO, go to Section H)

G14 How helpful have you found attending a GP for a series of scheduled visits in addressing your emotional well-being ...?

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅



H Your visits to a Psychiatrist

This section asks in more detail about your visits to a Psychiatrist during the past 3 months. If you have not seen a Psychiatrist during this time, please go to Section I on page 31.

H1 During the past 3 months, how many times did you visit a Psychiatrist?

(Please enter the total number of times in the box below)

number of visits to Psychiatrist during the past 3 months

H2 On average, how long did your visits with a Psychiatrist take? (Please tick the box that reflects the average length of visits)

Less than 6 minutes

☐ 1

7-19 minutes

☐ 2

20-39 minutes

☐ 3

40-60 minutes

☐ 4

More than 1 hour

☐ 5

H3 Where did the visits with the Psychiatrist take place?

(Please tick all that apply)

In their rooms (surgery, clinic)

☐ 1

In your home

☐ 1

At a community health clinic

☐ 1

At a drug or alcohol service

☐ 1

At a hospital outpatients (including accident or emergency)

☐ 1

H4 How much did you usually pay out of pocket for each visit to a Psychiatrist?

\$

H5 How helpful have you found the Psychiatrist in addressing your emotional well-being....?

Not at all helpful

☐ 1

Slightly helpful

☐ 2

Moderately helpful

☐ 3

Very helpful

☐ 4

Extremely helpful

☐ 5

For office use only

☐

I Your visits to a Psychologist

This section asks in more detail about your visits to a Psychologist during the past 3 months. If you have not seen a Psychologist during this time, please go to Section J on page 32.

I1 During the past 3 months, how many times did you visit a Psychologist?

(Please enter the total number of times in the box below)

number of visits to Psychologist during the past 3 months

I2 On average, how long did your visits with a Psychologist take? (Please tick the box that reflects the average length of visits)

Less than 6 minutes

☐ 1

7-19 minutes

☐ 2

20-39 minutes

☐ 3

40-60 minutes

☐ 4

More than 1 hour

☐ 5

I3 Where did the visits with a Psychologist take place?

(Please tick all that apply)

In their rooms (surgery, clinic)

☐ 1

In your home

☐ 1

At a community health clinic

☐ 1

At a drug or alcohol service

☐ 1

At a hospital outpatients (including accident or emergency)

☐ 1

I4 How much did you usually pay out of pocket for each visit to the Psychologist? (over and above your health insurance refund)

\$

I5 How helpful have you found the Psychologist in addressing your emotional well-being ...?

Not at all helpful

☐ 1

Slightly helpful

☐ 2

Moderately helpful

☐ 3

Very helpful

☐ 4

Extremely helpful

☐ 5

For office use only

☐

J Your visits to a Counsellor

This section asks in more detail about your visits to a Counsellor during the past 3 months. If you have not seen a Counsellor during this time, *please go to Section K on page 33.*

J1 During the past 3 months, how many times did you visit a Counsellor?

(Please enter the total number of times in the box below)

number of visits to Counsellor during the past 3 months.

J2 On average, how long did your visits with a Counsellor take? (Please tick the box that reflects the average length of visits)

Less than 6 minutes	7-19 minutes	20-39 minutes	40-60 minutes	More than 1 hour
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

J3 Where did the visits with a Counsellor take place?

(Please tick all that apply)

In their rooms (surgery, clinic)	In your home	At a community health clinic	At a drug or alcohol service	At a hospital outpatients (including accident or emergency)
☐ 1	☐ 1	☐ 1	☐ 1	☐ 1

J4 How much did you usually pay out of pocket for each visit to the Counsellor?

\$

J5 How helpful did you find the Counsellor in addressing your emotional well-being ...?

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

For office use only

K Your visits to professionals for problems related to alcohol and/or drug use

This section asks in more detail about your visits to professionals for problems related to alcohol and/or drug use during the past 3 months. If you have not had any treatment or support for problems related to alcohol and/or drug use during this time, *please go to Section L on page 34.*

K1 During the past 3 months, have you seen the following health professionals for problems related to alcohol and/or drug use? Please ensure that you tick a response for each health professional. If you have not seen the health professional please ensure that you tick the '0 times' box.

	0 times	1-2 times	3-4 times	5-6 times	7-11 times	12 or more times
General practitioner (GP)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Hospital doctor	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Specialist doctor	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Psychiatrist	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Psychologist	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Alcohol worker/ counsellor	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Drug worker/ counsellor	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

K2 During the past 3 months, have you been admitted to any of the following services for problems related to alcohol and/or drug use?

	Yes	No
Alcohol and drug unit of a hospital	☐ 1	☐ 0
Residential rehabilitation	☐ 1	☐ 0

For office use only

L Your visits to an alternative therapist

This section asks about your visits to any alternative therapist during the past 3 months. If you have not seen an alternative therapist during this time, *please go to Section M on page 36.*

L1 During the past 3 months, how many times did you visit an alternative therapist?

(Please enter the total number of times in the box below)

number of visits to an alternative therapist during the past 3 months

L2 During the past 3 months, which of the following alternative therapists have you visited?

(Please tick all that apply)

Naturopath	☐ ₁
Homeopath	☐ ₁
Acupuncturist	☐ ₁
Herbalist	☐ ₁
Reiki therapist	☐ ₁
Massage therapist	☐ ₁
Aromatherapy therapist	☐ ₁
Other (please specify)	☐ ₁

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☐

L3 On average, how long did your visits with the alternative therapist take?

(Please tick the box that reflects the average length of visits)

Less than 6 minutes	7-19 minutes	20-39 minutes	40-60 minutes	More than 1 hour
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

L4 Where did the visits with the alternative therapist take place? (Please tick all that apply)

In their rooms (surgery, clinic)	In your home	At a community health clinic	At a drug or alcohol service	At a hospital outpatients (including accident or emergency)
☐ ₁	☐ ₁	☐ ₁	☐ ₁	☐ ₁

L5 How much did you usually pay out of pocket for each visit to the alternative therapist?

\$

L6 How helpful have you found the alternative therapy in addressing your emotional well-being...?

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

M Medication for your emotional well-being

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The following section asks about any medication you may have been prescribed for your emotional well-being during the past 3 months. If you have not been prescribed any medication during this time, *please go to Section N on page 39.*

M1 During the past 3 months, what medications have you been prescribed for your emotional well-being? Please can you check the details on your medication pack or bottle, and write the name of the medication and the dose you are taking in the boxes below. Complete a line for each medication you are being prescribed for your emotional well-being. *An example is shown in the table to help you.*

	Name of medication	Dose	Times per day taken
	Efexor	1 X 37.5mg tablet	Twice a day
1			
2			
3			

M2 For each of the medications listed above, who first prescribed this/these medication/s to you?
(Please answer separately for each medication you have been prescribed in M1).

Medication 1	GP	☐	Psychiatrist	☐
Medication 2	GP	☐	Psychiatrist	☐
Medication 3	GP	☐	Psychiatrist	☐

M3a) How long have you been taking/did you take medication 1 for?

Less than one month	1 month to less than 3 months	3 months to less than 6 months	6 months to less than 1 year	1 year to less than 2 years	2 years or more	Don't know
☐	☐	☐	☐	☐	☐	☐

b) How long have you been taking/did you take medication 2 for?

Less than one month	1 month to less than 3 months	3 months to less than 6 months	6 months to less than 1 year	1 year to less than 2 years	2 years or more	Don't know
☐	☐	☐	☐	☐	☐	☐

c) How long have you been taking/did you take medication 3 for?

Less than one month	1 month to less than 3 months	3 months to less than 6 months	6 months to less than 1 year	1 year to less than 2 years	2 years or more	Don't know
☐	☐	☐	☐	☐	☐	☐

M4a) During the past 3 months, how helpful have you found medication 1 in addressing your emotional well-being...?

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐	☐	☐	☐	☐

b) During the past 3 months, how helpful have you found medication 2 in addressing your emotional well-being...?

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐	☐	☐	☐	☐

c) During the past 3 months, how helpful have you found medication 3 in addressing your emotional well-being...?

Not at all helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
☐	☐	☐	☐	☐

M5 Are you still being prescribed/taking this medication?

(Please answer separately for each medication you have been prescribed in M1).

Medication 1	Yes	☐	No	☐
Medication 2	Yes	☐	No	☐
Medication 3	Yes	☐	No	☐

If you are not still being prescribed/taking this medication, go to question M7

M6 Who currently prescribes this/these medication/s to you?

(Please answer separately for each medication you have been prescribed in M1).

Medication 1	GP	☐ ₁	Psychiatrist	☐ ₂
Medication 2	GP	☐ ₁	Psychiatrist	☐ ₂
Medication 3	GP	☐ ₁	Psychiatrist	☐ ₂

The following question asks you about any medication you may have been prescribed for **problems related to alcohol and/or drug use**.

M7a) During the past 3 months, have you been prescribed medication from a GP or Psychiatrist for problems related to alcohol and/or drug use?

Yes ☐₁ (If YES, go to question M7b)
 No ☐₀ (If NO, go to Section N on page 39)

b) During the past 3 months, what medications have you been prescribed for problems related to alcohol and/or drug use?

Please can you check the details on your medication pack or bottle, and write the name of the medication and the dose you are taking in the boxes below. Complete a line for each medication you are being prescribed for your emotional well-being. *An example is shown in the table to help you.*

	Name of medication	Dose	Times per day taken
	Acamprosate	2 X 330mg tablets	Three times a day
1			
2			
3			

N Your experiences



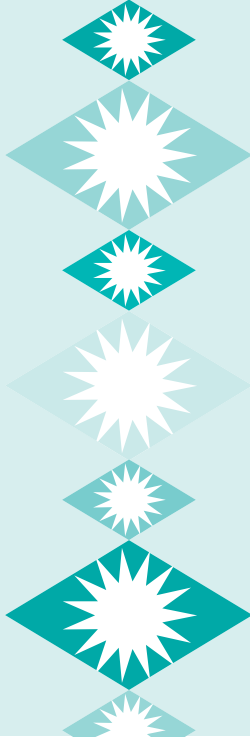
N1 During the past 3 months, what has been the thing that has helped you most of all with depression, stress or worries?

(Please write your response in the space below)

N2 During the past 3 months, how would you describe your emotional health? (Please write your response in the space below)

Comments

This image shows a full page of blank, lined paper. It features approximately 20 horizontal blue lines spaced evenly across the page, typical of notebook or composition paper. The lines are thin and light blue, set against a plain white background. There is no handwriting, printed text, or other markings on the page.

A vertical decorative element on the left side of the page, featuring a repeating pattern of teal diamonds with white starburst designs, set against a light teal background.

How to fill in the survey

Please read the questions carefully and follow the instructions. There are no right or wrong answers, just put what is right for you. Your answers will remain confidential.

Most of the questions can be answered by putting a **tick** in the box next to the answer that best applies to you. Please **tick only one box** per question, unless otherwise specified.

For example:

Is your usual GP male or female?

Male

☒ ₁

Female

☐ ₂

If you wish to write further comments, please do so on the blank page at the end of the survey or attach extra pages if you wish.



Thank you for your continued involvement in the *diamond* project

This survey asks about your current physical and emotional health. Completing this survey will give you a chance to tell us

- how you are and whether or not things have changed for you and,
- about the care you have received recently.

Your responses to this survey will help us to build a better picture of the way general practitioners (GPs) or family doctors care for a person's emotional well-being. We are very interested in your own experiences of the care you receive.

All information you give us in this survey is **STRICTLY CONFIDENTIAL** and all findings from the project will be presented in an anonymous form.

The **diamond** team is based at the Department of General Practice, The University of Melbourne. If you have any questions about the project, please call the **diamond** team on **03 8344 9719**.

This project is funded by the National Health and Medical Research Council and the Victorian Centre of Excellence in Depression and Related Disorders, an initiative between beyondblue and the State Government of Victoria.



DEPARTMENT OF
GENERAL
PRACTICE



THE UNIVERSITY OF
MELBOURNE

A About yourself

This section asks about your background and some personal details.

A1 Today's date is:

				2			
Day				Month		Year	

A2a) What is your date of birth?

Day				Month		Year	

b) How old are you?

Age (in years)	

A3 In a usual week, which of the following best describes you? (Please tick all that apply)

In full-time paid work	☐	☐
In part-time paid work or in casual paid work	☐	☐
At school or in full-time education	☐	☐
In part-time education	☐	☐
Self-employed (e.g., in a family business)	☐	☐
Home duties only – no paid work	☐	☐
Unemployed – looking for work	☐	☐
Unpaid voluntary work	☐	☐
Unable to work due to sickness or disability	☐	☐
Retired from paid work	☐	☐
Other (Please describe)	☐	☐

A4 **Who do you usually live with?**

(Please tick all that apply)

- I live alone ☐_1
- Husband or wife ☐_1
- Defacto partner ☐_1
- My child/ren ☐_1
- My partner's child/ren ☐_1
- My parent/s ☐_1
- Unrelated flatmate or co-tenant ☐_1
- Other relationship (Please specify) ☐_1

A5 **Do you have private health insurance for hospital and/or ancillary services, e.g., dental, physiotherapy?**

(Please tick one box)

- Hospital and ancillary ("extras") ☐_1
- Ancillary ("extras") only ☐_2
- Hospital only ☐_3
- None of the above ☐_4

Income is very important to understand health, as it influences the health services someone has access to.

A6 **How do you manage on your available income?**

(Please tick one box)

- Easily ☐_1
- Not too bad ☐_2
- Difficult some of the time ☐_3
- Difficult all of the time ☐_4
- Impossible ☐_5

A7 **What was the total income (before tax) of your family in the last year?**

- \$20,000 or less ☐_1
- \$20,001 - \$30,000 ☐_2
- \$30,001 - \$40,000 ☐_3
- \$40,001 - \$50,000 ☐_4
- \$50,001 - \$60,000 ☐_5
- \$60,001 - \$70,000 ☐_6
- More than \$70,000 ☐_7

A8 **What is your main source of income** (Please tick one box)

- Wage or salary ☐_1
- Any government pension or allowance or benefit ☐_2
- Child support ☐_3
- Superannuation/Annuity ☐_4
- Own business or share in a partnership ☐_5
- Rental investment ☐_6
- Dividends or interest ☐_7
- Other income ☐_8

B About your quality of life

This section asks about your quality of life. Please answer all the questions. If unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks.

B Please read each question and assess your feelings, for the last 2 weeks, and tick the box for each question that gives the best answer for you.

(Please tick one box on each line)

	Very poor	Poor	Neither poor nor good	Good	Very good
B1 How would you rate your quality of life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B2 How satisfied are you with your health?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

B3 The following questions ask about how much you have experienced certain things in the last 2 weeks.
(Please tick one box on each line)

To what extent do you feel that physical pain prevents you from doing what you need to do?

Not at all	A small amount	A moderate amount	A great deal	An extreme amount
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

cont. The following questions ask about how much you have experienced certain things in the last 2 weeks.
(Please tick one box on each line)

Not at all	A small amount	A moderate amount	A great deal	An extreme amount
------------	----------------	-------------------	--------------	-------------------

How much do you need any medical treatment to function in your daily life?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

How much do you enjoy life?

To what extent do you feel your life to be meaningful?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

How well are you able to concentrate?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

How safe do you feel in your daily life?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

How healthy is your physical environment?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

Not at all	Slightly	Somewhat	To a great extent
------------	----------	----------	-------------------

Do you have enough energy for everyday life?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

Are you able to accept your bodily appearance?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

Have you enough money to meet your needs?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

How available to you is the information you need in your daily life?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

To what extent do you have the opportunity for leisure activities?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

Not at all	Slightly	Moderately	Very	Extremely
------------	----------	------------	------	-----------

How well are you able to get around physically?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

B4

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last 2 weeks. (Please tick one box on each line)

	Very dissatisfied	Fairly dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your sleep?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How satisfied are you with your ability to perform your daily living activities?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How satisfied are you with your capacity for work?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How satisfied are you with yourself?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How satisfied are you with your personal relationships?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How satisfied are you with your sex life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How satisfied are you with the support you get from your friends?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How satisfied are you with the conditions of your living place?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How satisfied are you with your access to health services?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How satisfied are you with your transport?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
How often do you have negative feelings such as blue mood, despair, anxiety, depression?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

C About your health

This section asks for your views about your health, how you feel and how well you are able to do your usual activities.

c1 In general, would you say your health is... ?

(Please tick one box)

Excellent	☐ 1
Very good	☐ 2
Good	☐ 3
Fair	☐ 4
Poor	☐ 5

c2 The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(Please tick one box on each line)

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a) Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	☐ 3
b) Climbing several flights of stairs	☐ 1	☐ 2	☐ 3

c3 During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(Please tick one box on each line)

- a) **Accomplished** less than you would like Yes _1_ No _0_
- b) Were limited in the **kind** of work or other activities Yes _1_ No _0_

c4 During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? (Please tick one box on each line)

- a) **Accomplished** less than you would like Yes _1_ No _0_
- b) Didn't do work or other activities as **carefully** as usual Yes _1_ No _0_

c5 During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? (Please tick one box)

- Not at all _1_
- Slightly _2_
- Moderately _3_
- Quite a bit _4_
- Extremely _5_

c6 These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks:

(Please tick one box on each line)

- | | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time |
|----------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Have you felt calm and peaceful? | <input type="text"/> _1_ | <input type="text"/> _2_ | <input type="text"/> _3_ | <input type="text"/> _4_ | <input type="text"/> _5_ | <input type="text"/> _6_ |

Did you have a lot of energy?

- _1_ _2_ _3_ _4_ _5_ _6_

Have you felt down?

- _1_ _2_ _3_ _4_ _5_ _6_

c7 During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc)?

(Please tick one box)

- All of the time _1_
- Most of the time _2_
- Some of the time _3_
- A little of the time _4_
- None of the time _5_

If you have not been in paid employment during the past 3 months, please go to Question C9.

c8 **During the past 3 months, how many days have you taken off work (include both short and long periods) for:**
(Please enter the total number of days in the boxes below. If you have not taken time off work for either physical health or emotional problems please write '0' in the box(s) below)

a) physical health problems total number of days
 b) emotional problems total number of days

c9 **During the past 3 months, how many days were you unable to perform your home duties or study tasks due to:**
(Please enter the total number of days in the boxes below. If your home duties or study have not been affected by either physical health or emotional problems please write '0' in the box(s) below)

a) physical health problems total number of days
 b) emotional problems total number of days

c10 **During the past 3 months, how many days were you unable to participate in your usual leisure activities due to:**
(Please enter the total number of days in the boxes below. If your usual leisure activities have not been affected by either physical health or emotional problems please write '0' in the box(s) below)

a) physical health problems total number of days
 b) emotional problems total number of days

D Your emotional well-being

This section asks about your emotional well-being, including your feelings and behaviours. Please answer all the questions even though some of them are similar to those you have already answered. They allow us to compare your experiences with those of others.

D1 **During the past 3 months, how would you rate your overall emotional well-being?**

Excellent _1_ Very good _2_ Good _3_ Fair _4_ Poor _5_

D2 **During the past 3 months, would you consider your emotional well-being is....?**

Better than usual _1_
 Same as usual _2_
 Worse than usual _3_

**We appreciate your time and effort.
 Please continue to the next page**

d3 Below are a series of statements that describe how you might have felt or behaved in the PAST WEEK. Please indicate how often you have felt this way during the past week.

Please ensure that you tick one box for each statement.

- a) During the past week I was bothered by things that usually don't bother me
- | | | | |
|---|--|---|---------------------------------------|
| Rarely or none of the time
(less than 1 day) | Some or a little of
the time (1-2 days) | Occasionally or a moderate
amount of time (3-4 days) | Most or all of the time
(5-7 days) |
| ☐ _0 | ☐ _1 | ☐ _2 | ☐ _3 |
- b) During the past week I did not feel like eating; my appetite was poor
- | | | | |
|---|--|---|---------------------------------------|
| Rarely or none of the time
(less than 1 day) | Some or a little of
the time (1-2 days) | Occasionally or a moderate
amount of time (3-4 days) | Most or all of the time
(5-7 days) |
| ☐ _0 | ☐ _1 | ☐ _2 | ☐ _3 |
- c) During the past week I felt that I could not shake off the blues even with help from my family or friends
- | | | | |
|---|--|---|---------------------------------------|
| Rarely or none of the time
(less than 1 day) | Some or a little of
the time (1-2 days) | Occasionally or a moderate
amount of time (3-4 days) | Most or all of the time
(5-7 days) |
| ☐ _0 | ☐ _1 | ☐ _2 | ☐ _3 |
- d) During the past week I felt I was just as good as other people
- | | | | |
|---|--|---|---------------------------------------|
| Rarely or none of the time
(less than 1 day) | Some or a little of
the time (1-2 days) | Occasionally or a moderate
amount of time (3-4 days) | Most or all of the time
(5-7 days) |
| ☐ _0 | ☐ _1 | ☐ _2 | ☐ _3 |
- e) During the past week I had trouble keeping my mind on what I was doing
- | | | | |
|---|--|---|---------------------------------------|
| Rarely or none of the time
(less than 1 day) | Some or a little of
the time (1-2 days) | Occasionally or a moderate
amount of time (3-4 days) | Most or all of the time
(5-7 days) |
| ☐ _0 | ☐ _1 | ☐ _2 | ☐ _3 |

- f) During the past week I felt depressed
- | | | | |
|---|--|---|---------------------------------------|
| Rarely or none of the time
(less than 1 day) | Some or a little of
the time (1-2 days) | Occasionally or a moderate
amount of time (3-4 days) | Most or all of the time
(5-7 days) |
| ☐ _0 | ☐ _1 | ☐ _2 | ☐ _3 |
- g) During the past week I felt that everything I did was an effort
- | | | | |
|---|--|---|---------------------------------------|
| Rarely or none of the time
(less than 1 day) | Some or a little of
the time (1-2 days) | Occasionally or a moderate
amount of time (3-4 days) | Most or all of the time
(5-7 days) |
| ☐ _0 | ☐ _1 | ☐ _2 | ☐ _3 |
- h) During the past week I felt hopeful about the future
- | | | | |
|---|--|---|---------------------------------------|
| Rarely or none of the time
(less than 1 day) | Some or a little of
the time (1-2 days) | Occasionally or a moderate
amount of time (3-4 days) | Most or all of the time
(5-7 days) |
| ☐ _0 | ☐ _1 | ☐ _2 | ☐ _3 |
- i) During the past week I thought my life had been a failure
- | | | | |
|---|--|---|---------------------------------------|
| Rarely or none of the time
(less than 1 day) | Some or a little of
the time (1-2 days) | Occasionally or a moderate
amount of time (3-4 days) | Most or all of the time
(5-7 days) |
| ☐ _0 | ☐ _1 | ☐ _2 | ☐ _3 |
- j) During the past week I felt fearful
- | | | | |
|---|--|---|---------------------------------------|
| Rarely or none of the time
(less than 1 day) | Some or a little of
the time (1-2 days) | Occasionally or a moderate
amount of time (3-4 days) | Most or all of the time
(5-7 days) |
| ☐ _0 | ☐ _1 | ☐ _2 | ☐ _3 |
- k) During the past week my sleep was restless
- | | | | |
|---|--|---|---------------------------------------|
| Rarely or none of the time
(less than 1 day) | Some or a little of
the time (1-2 days) | Occasionally or a moderate
amount of time (3-4 days) | Most or all of the time
(5-7 days) |
| ☐ _0 | ☐ _1 | ☐ _2 | ☐ _3 |

i) During the past week I was happy

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

m) During the past week I talked less than usual

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

n) During the past week I felt lonely

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

o) During the past week people were unfriendly

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

p) During the past week I enjoyed life

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

q) During the past week I had crying spells

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

r) During the past week I felt sad

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

s) During the past week I felt that people dislike me

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

t) During the past week I could not "get going"

Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
_0	_1	_2	_3

**We appreciate your time and effort.
Please continue to the next page**



D4 During the last 4 weeks, how much have you been bothered by any of the following problems?

(Please tick one box on each line)

	Not bothered	Bothered a little	Bothered a lot
Stomach pain	☐ _0	☐ _1	☐ _2
Back pain	☐ _0	☐ _1	☐ _2
Pain in your arms, legs or joints (knees, hips, etc)	☐ _0	☐ _1	☐ _2
Menstrual cramps or other problems with your periods	☐ _0	☐ _1	☐ _2
Pain or problems during sexual intercourse	☐ _0	☐ _1	☐ _2
Headaches	☐ _0	☐ _1	☐ _2
Chest pain	☐ _0	☐ _1	☐ _2
Dizziness	☐ _0	☐ _1	☐ _2
Fainting spells	☐ _0	☐ _1	☐ _2
Feeling your heart pound or race	☐ _0	☐ _1	☐ _2
Shortness of breath	☐ _0	☐ _1	☐ _2
Constipation, loose bowels, or diarrhoea	☐ _0	☐ _1	☐ _2
Nausea, gas or indigestion	☐ _0	☐ _1	☐ _2

D5 Over the last 2 weeks, how often have you been bothered by any of the following problems? (Please tick one box on each line)

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things	☐ _0	☐ _1	☐ _2	☐ _3
Feeling down, depressed or hopeless	☐ _0	☐ _1	☐ _2	☐ _3
Trouble falling or staying asleep, or sleeping too much	☐ _0	☐ _1	☐ _2	☐ _3
Feeling tired or having little energy	☐ _0	☐ _1	☐ _2	☐ _3
Poor appetite or overeating	☐ _0	☐ _1	☐ _2	☐ _3
Feeling bad about yourself, or that you are a failure, or have let yourself or your family down	☐ _0	☐ _1	☐ _2	☐ _3
Trouble concentrating on things, such as reading the newspaper or watching television	☐ _0	☐ _1	☐ _2	☐ _3
Moving or speaking so slowly that other people could have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual	☐ _0	☐ _1	☐ _2	☐ _3
Thoughts that you would be better off dead or of hurting yourself in some way	☐ _0	☐ _1	☐ _2	☐ _3

D6 Questions about anxiety. (Please tick one box on each line)

	No	Yes
In the last 4 weeks have you had an anxiety attack-suddenly feeling fear or panic?	☐ _0	☐ _1
If you ticked <u>No</u>, go to question D8		
Has this ever happened before?	☐ _0	☐ _1
Do some of these attacks come suddenly out of the blue - that is, in situations where you don't expect to be nervous or uncomfortable?	☐ _0	☐ _1
Do these attacks bother you a lot or are you worried about having another attack?	☐ _0	☐ _1

D7 Think about your last bad anxiety attack.

(Please tick one box on each line)

	No	Yes
Were you short of breath?	☐ _0	☐ _1
Did your heart race, pound or skip?	☐ _0	☐ _1
Did you have chest pain or pressure?	☐ _0	☐ _1
Did you sweat?	☐ _0	☐ _1
Did you feel as if you were choking?	☐ _0	☐ _1
Did you have hot flashes or chills?	☐ _0	☐ _1
Did you have nausea or an upset stomach, or the feeling that you were going to have diarrhoea?	☐ _0	☐ _1
Did you feel dizzy, unsteady, or faint?	☐ _0	☐ _1
Did you have tingling or numbness in parts of your body?	☐ _0	☐ _1
Did you tremble or shake?	☐ _0	☐ _1
Were you afraid you were dying?	☐ _0	☐ _1

D8 Over the last 4 weeks, how often have you been bothered by any of the following problems?

(Please tick one box on each line)

	Not at all	Several days	More than half the days
Feeling nervous, anxious, on edge, or worrying a lot about different things	☐ _0	☐ _1	☐ _2
If you ticked <u>Not at all</u>, go to question D9			
Feeling restless so that it is hard to sit still	☐ _0	☐ _1	☐ _2
Getting tired very easily	☐ _0	☐ _1	☐ _2
Muscle tension, aches, or soreness	☐ _0	☐ _1	☐ _2
Trouble falling asleep or staying asleep	☐ _0	☐ _1	☐ _2
Trouble concentrating on things, such as reading a book or watching television	☐ _0	☐ _1	☐ _2
Becoming easily annoyed or irritated	☐ _0	☐ _1	☐ _2

D9 Questions about eating. (Please tick one box on each line)

	No	Yes
Do you often feel that you can't control what or how much you eat?	☐ _0	☐ _1
Do you often eat, within any 2-hour period , what most people would regard as an unusually large amount of food?	☐ _0	☐ _1

If you ticked No to either of the above, go to question D12

	No	Yes
Has this been as often, on average, as twice a week for the last 3 months?	☐ _0	☐ _1

FOR WOMEN ONLY (Men go to Section E)

D16 Questions about menstruation, pregnancy and childbirth

a) What best describes your menstrual periods?

(Please tick one box)

Periods are unchanged ☐ 1

No periods because pregnant or recently gave birth ☐ 2

Periods have become irregular or changed in frequency, duration or amount ☐ 3

No periods for at least a year ☐ 4

Having periods because taking hormone replacement (oestrogen) therapy or oral contraceptive ☐ 5

No
(or does
not apply)

Yes

b) During the week before your period starts, do you have a **serious** problem with your mood- like depression, anxiety, irritability, anger or mood swings? ☐ 0 ☐ 1

If **Yes**: Do these problems go away by the end of your period? ☐ 0 ☐ 1

c) Have you given birth within the last 6 months? ☐ 0 ☐ 1

d) Have you had a miscarriage within the last 6 months? ☐ 0 ☐ 1

e) Are you having difficulty getting pregnant? ☐ 0 ☐ 1

We appreciate your time and effort.
Please continue to the next page

E About your lifestyle and life experiences

This section asks you about your lifestyle issues and life experiences that may affect your health.

E1 In a normal week, how many times do you engage in vigorous exercise lasting 20 min or more (i.e., exercise that makes you breathe harder or puff and pant, such as netball, squash, jogging, aerobics, vigorous swimming etc.)? (Please tick one box)

Never ☐ 0

Once a week ☐ 1

Two or three times per week ☐ 2

Four, five or six times a week ☐ 3

Once every day ☐ 4

More than once every day ☐ 5

E2 In a normal week, how many times do you engage in less vigorous exercise which lasts for 20 min or more (i.e., exercise that does not make you breathe harder or puff and pant, such as walking, gardening, swimming, and lawn bowling)? (Please tick one box)

Never ☐ 0

Once a week ☐ 1

Two or three times per week ☐ 2

Four, five or six times a week ☐ 3

Once every day ☐ 4

More than once every day ☐ 5

E3 During the past 3 months, how often have you tried any of the following for depression, stress or worries?

(Please tick one box on each line)

	Once a week or more	A few times a month	Monthly	Rarely	Never
Exercise	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Yoga	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Counselling	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Hypnosis	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Depression medication (antidepressants)	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
St John's Wort	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Sedatives (sleeping medication)	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Acupuncture	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Relaxation/meditation	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Massage/touch therapy	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Aromatherapy	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Changed your diet	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Reduced your alcohol or drug intake	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Attended a self-help group for your emotional well-being	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Attended a self-help group for problems with alcohol or drugs	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Read a self-help book	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Prayer	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Educational or therapeutic websites on the internet	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Telephone help-line	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
Talked to family or friends	☐ _1	☐ _2	☐ _3	☐ _4	☐ _0
I have not tried any of the above					☐ _1

E4 Which of the following best describes your cigarette smoking? (Please tick only one box)

Never smoked ☐_0

Used to smoke ☐_1

Now smoke occasionally ☐_2

Now smoke regularly ☐_3

E5 How many cigarettes do you smoke a day?

(Please tick only one box)

I don't smoke ☐_0

Less than 10 ☐_1

Between 10 -19 ☐_2

20 or more ☐_3

E6 Questions about drinking



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The pictures above show the number of standard drinks for beer, wine and spirits. For example, 1 pot = 1 drink, 1 100ml glass of wine = 1 drink, 1 single spirit = 1 drink.

For the following questions please tick the answer that best applies.

MEN: How often do you have eight or more drinks on one occasion? (Please tick only one box)

WOMEN: How often do you have six or more drinks on one occasion? (Please tick only one box)

Never ☐_0

Less than monthly ☐_1

Monthly ☐_2

Weekly ☐_3

Daily or almost daily ☐_4

E7 **How often during the last year have you been unable to remember what happened the night before because you had been drinking?** (Please tick only one box)

Never ☐0
Less than monthly ☐1
Monthly ☐2
Weekly ☐3
Daily or almost daily ☐4

E8 **How often during the last year have you failed to do what was normally expected of you because of drinking?**

(Please tick only one box)

Never ☐0
Less than monthly ☐1
Monthly ☐2
Weekly ☐3
Daily or almost daily ☐4

E9 **In the last year has a relative or friend, or a doctor or other health worker been concerned about your drinking or suggested you cut down?** (Please tick only one box)

No ☐0
Yes, on one occasion ☐1
Yes, on more than one occasion ☐2

E10a) **During the past 3 months, have you experienced any of the following and if so, what impact has the experience had on you?**

(Please tick one box on each line)

	NO, I haven't experienced this in the past 3 months	YES and it has had an extremely negative impact on me	YES and it has had a slightly negative impact on me	YES but it has had no impact on me	YES and it has had a slightly positive impact on me	YES and it has had an extremely positive impact on me
--	---	---	---	------------------------------------	---	---

Major personal injury or illness	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
----------------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

Major illness or injury of a parent, close family member or friend	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
--	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

The stress of taking care of children, parents, or other family members	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
---	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

The death of a spouse, parent, close family member or a friend	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
--	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

Begun a new relationship	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
--------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

Marriage	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
----------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

Difficulties with husband/ wife, partner/lover or boyfriend/girlfriend	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
--	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

Separation or divorce due to marital/relationship difficulties or steady relationship breakdown	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
---	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

Been afraid of your partner	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
-----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

Hit, slapped, kicked or otherwise physically hurt by partner/ex partner	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
---	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

Hit, slapped, kicked or otherwise physically hurt by someone other than partner/ex-partner

Partner/ex partner forced you to have sexual activities

Someone other than partner/
ex-partner forced you to
have sexual activities

Serious problem with a close friend, neighbour or relative

A major change in financial status (a lot better off, a lot worse off)

Stress at work, outside of the home or at school

Change in job/ workplace
(including retirement, being
sacked or made redundant)

Pregnancy or partner's pregnancy

b) In addition to the above list, during the past 3 months, have you experienced anything that has had a negative impact on you? *(Please describe)*

c) In addition to the above list, during the past 3 months, have you experienced anything that has had a positive impact on you? *(Please describe)*

F1 During the past 3 months, how many times have you seen the following health professionals? Please tick a response for each health professional. If you have not seen the health professional please ensure that you tick the '0 times' box.

General practitioner (GP)	0 times	1-2 times	3-4 times	5-6 times	7-11 times	12 or more times
	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

General practitioner (GP)

Hospital doctor

Specialist doctor

Physiotherapist

Chiropractor

Psychologist

Counsellor

Psychiatrist

Nurse

Social worker

Domestic violence worker

Alcohol or drug worker

Family therapist

Naturopath

Homeopath

Acupuncturist

Other natural therapist

F2a) During the past 3 months, have you...?

(Please tick either 'Yes' or 'No' for each statement)

	Yes	No	If yes, how many times?
Received help from an ambulance	☐ _1	☐ _0	
Been driven to hospital by an ambulance	☐ _1	☐ _0	
Attended a hospital emergency department or casualty ward	☐ _1	☐ _0	
Attended an outpatient clinic of a hospital for physical illness	☐ _1	☐ _0	
Attended an outpatient clinic of a hospital for your emotional well-being	☐ _1	☐ _0	

b) **If you ticked Yes to any of the above, please state the reason for using the service/s in the space below.**

This image shows a blank sheet of white paper with ten vertical blue lines, resembling notebook paper. The lines are evenly spaced and run from the top to the bottom of the page. There is no text or other markings on the paper.

F3a) During the past 3 months, have you been admitted at least overnight to ...?

(Please tick either 'Yes' or 'No' for each statement)

	Yes	No	If yes, how many nights in total did you stay during all admissions?
A general hospital for physical illness	1	0	
A general hospital for your emotional well-being	1	0	
A psychiatric hospital	1	0	

If you have not been admitted to hospital during the past 3 months, please go to Section G.

b) **If you ticked Yes to any of the above, please state why you were admitted to hospital in the space below.**

F4 Did you use your private health insurance for any of the stays in hospital?

Yes ☐_1



Your visits to a GP

This section is about your visits to a general practitioner (GP) or family doctor.

The following question is about your 'usual GP'.
Your usual GP is the GP that you see most of the time for your own health care.

G1.a) Have you changed your usual general practitioner (GP) or family doctor you attend for your healthcare since you completed the last **diamond** survey?

Yes ☐_1

No ☐_0 (Go to question G2)

b) If Yes, what was your reason for changing GP?

(Please tick all that apply)

I have moved house ☐_1

The GP has left the clinic ☐_1

I was unhappy with my care ☐_1

The GP was always running late ☐_1

The GP didn't listen to me ☐_1

The GP was too expensive ☐_1

Other (Please specify) _____

The following questions ask about your 'usual GP clinic', the clinic that you usually visit.

G2 How do you rate the way you are treated by receptionists at your clinic?

Very poor ☐_1 Poor ☐_2 Fair ☐_3 Good ☐_4 Very good ☐_5 Excellent ☐_6

G3.a) How do you rate the hours that your clinic is open for appointments?

Very poor ☐_1 Poor ☐_2 Fair ☐_3 Good ☐_4 Very good ☐_5 Excellent ☐_6

b) What additional hours would you like the clinic to be open?

(Please tick all that apply)

Early morning ☐_1 Lunch times ☐_1 Evenings ☐_1 Weekends ☐_1 None, I am satisfied ☐_1

G4 Thinking of the times when you want to see a particular GP:

(Please tick only one box)

a) How quickly do you usually get to see that GP?

Same day ☐_1 Next working day ☐_2 Within 2 working days ☐_3 Within 3 working days ☐_4 Within 4 working days ☐_5 5 or more working days ☐_6 Does not apply ☐_7

b) How do you rate this?

Very poor ☐_1 Poor ☐_2 Fair ☐_3 Good ☐_4 Very good ☐_5 Excellent ☐_6 Does not apply ☐_7

g5 Thinking of the times when you are willing to see any GP:
(Please tick only one box)

a) How quickly do you usually get seen?

Same day	Next working day	Within 2 working days	Within 3 working days	Within 4 working days	5 or more working days	Does not apply
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆	☐ ₇

b) How do you rate this?

Very poor	Poor	Fair	Good	Very good	Excellent	Does not apply
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆	☐ ₇

g6 If you need to see a GP urgently, can you normally get seen on the same day?

Yes ☐ ₁

No ☐ ₀

Don't know / never needed to ☐ ₂

g7a) How long do you usually have to wait at the clinic for your consultations to begin? (Please tick only one box)

5 minutes or less ☐ ₁

6 to 10 minutes ☐ ₂

11 to 20 minutes ☐ ₃

21 to 30 minutes ☐ ₄

More than 30 minutes ☐ ₅

b) How do you rate this?

Very poor	Poor	Fair	Good	Very good	Excellent
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆

g8 Thinking about the times you have phoned the clinic, how do you rate the following:

a) Ability to get through to the clinic on the phone?

Very poor	Poor	Fair	Good	Very good	Excellent	Don't know/never tried
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆	☐ ₇

b) Ability to speak to a GP on the phone when you have a question or need medical advice?

Very poor	Poor	Fair	Good	Very good	Excellent	Don't know/never tried
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆	☐ ₇

The next questions ask about your 'usual GP'. If you don't have a 'usual GP', answer about the one GP at your clinic who you know best.

g9 a) In general, how often do you see your usual GP?

Always	Almost always	A lot of the time	Some of the time	Almost never	Never
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆

b) How do you rate this?

Very poor	Poor	Fair	Good	Very good	Excellent
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆

g10 Thinking about when you consult your usual GP, how do you rate the following:

a) How thoroughly the

GP asks about your symptoms and how you are feeling?

Very poor	Poor	Fair	Good	Very good	Excellent	Does not apply
☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆	☐ ₇

	Very poor	Poor	Fair	Good	Very good	Excellent	Does not apply
b) How well the GP listens to what you have to say?	1	2	3	4	5	6	7
c) How well the GP puts you at ease during your physical examination?	1	2	3	4	5	6	7
d) How much the GP involves you in decisions about your care?	1	2	3	4	5	6	7
e) How well the GP explains your problems or any treatment that you need?	1	2	3	4	5	6	7
f) The amount of time your GP spends with you?	1	2	3	4	5	6	7
g) The GPs patience with your questions or worries?	1	2	3	4	5	6	7
h) The GPs caring and concern for you?	1	2	3	4	5	6	7
G11 Have you seen a nurse from your usual GP clinic in the past 12 months? Yes 1 (Go to question G12) No 0 (Go to question G13)							

G12 Thinking about the nurse(s) you have seen, how do you rate the following:

a) How well they **listen** to what you say?

Very poor	Poor	Fair	Good	Very good	Excellent
1	2	3	4	5	6

b) The **quality** of care they provide?

1	2	3	4	5	6
------------------------	------------------------	------------------------	------------------------	------------------------	------------------------

c) How well they **explain** your health problems or any treatment that you need?

1	2	3	4	5	6
------------------------	------------------------	------------------------	------------------------	------------------------	------------------------

G13 All things considered, how satisfied are you with your clinic? *(Please tick only one box)*

Completely satisfied	Very satisfied	Fairly satisfied	Neutral	Fairly dissatisfied	Very dissatisfied	Completely dissatisfied
1	2	3	4	5	6	7

H Your relationships

In this section we ask about your relationships because they are an important part of your life that may influence your health. We ask you about your experiences in adult intimate relationships. By adult intimate relationship we mean husband/wife, partner or boy/girl friend for longer than 1 month.

H1 Have you ever been in an adult intimate relationship?

(Since you were 16 years of age)

Yes ☐_1

No ☐_0 (If NO, go to Section I)

H2a) Have you been in an adult intimate relationship in the past 12 months?

Yes ☐_1

No ☐_0

b) Are you currently in an intimate relationship?

Yes ☐_1

No ☐_0 (If NO, go to question H4)

H3 Are you currently afraid of your partner?

Yes ☐_1

No ☐_0

H4 Have you ever been afraid of any partner?

Yes ☐_1

No ☐_0

H5 We would like to know if you experienced any of the actions listed below and how often it happened during the past twelve months. If you were not with a partner in the past twelve months, could you please answer for the last partner that you had.

Please tick the appropriate box, which matches the frequency, over a twelve month period, that it happened to you. (Please tick one box on each line)

Actions	How often it happened					
My Partner:	Never	Only once	Several times	Once/month	Once/week	Daily
Told me that I wasn't good enough	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Kept me from medical care	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Followed me	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Tried to turn my family, friends and children against me	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Locked me in the bedroom	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Slapped me	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Raped me	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Told me that I was ugly	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Tried to keep me from seeing or talking to my family	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Threw me	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Hung around outside my house	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Blamed me for causing their violent behaviour	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6
Harassed me over the telephone	☐ _1	☐ _2	☐ _3	☐ _4	☐ _5	☐ _6

Actions

My Partner:

How often it happened

Never Only once Several times Once/month Once/week Daily

Shook me	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Tried to rape me	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Harassed me at work	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Pushed, grabbed or shoved me	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Used a knife or gun or other weapon	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Became upset if dinner/housework wasn't done when they thought it should be	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Told me that I was crazy	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Told me that no one would ever want me	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Took my wallet and left me stranded	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Hit or tried to hit me with something	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Did not want me to socialise with my female friends	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Put foreign objects in my vagina/anus	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Refused to let me work outside the home	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Kicked me, bit me or hit me with a fist	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Tried to convince my friends, family or children that I was crazy	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Told me that I was stupid	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
Beat me up	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

I About your community participation and social support

This section asks about various community activities that you may have participated in during the past 3 months.

12 During the past 3 months, how often have you done any of the following activities? (Please tick one box on each line)

Once a week or more A few times a month Monthly Rarely Never

Visited family/ family visit	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Visited friends/ friends visit	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Visited neighbours/had neighbours visit	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Attended church or a religious group	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Gone to a social club	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Used the Internet for social communication	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Gone to a café or restaurant	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Gone to a club, pub or bar	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Gone to the cinema or theatre	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Gone to watch a sports event	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Gone to a party or dance	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Played sport	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Had social contact through children's sport	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Gone to the gym or exercise class	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Self-help or support groups	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Singing, acting or played music in a group	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Been involved in a hobby group	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
Gone to a class	☐ 1	☐ 2	☐ 3	☐ 4	☐ 0
I have not done any of the above activities	☐ 1				

12 In the past 12 months, have you been involved in the following community or group activities?

(Please tick either 'Yes' or 'No' for each statement)

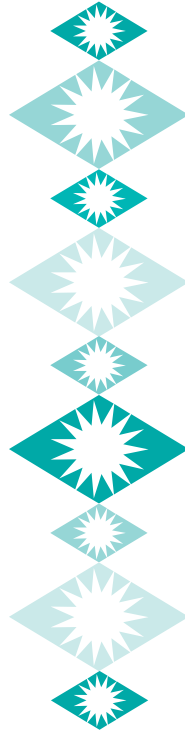
	Yes	No
School-related group	☐ _1	☐ _0
Service club (e.g. Lions, CWA)	☐ _1	☐ _0
Ethnic group (e.g. Croatian, Italian club)	☐ _1	☐ _0
Volunteer organisation or group	☐ _1	☐ _0

13a) Do you have any household pets?

Yes	No
☐ _1	☐ _0 (If NO, go to page 44)

b) If Yes, how attached are you to your pet/s? (Please tick one box)

Extremely attached	Moderately attached	A little attached	Not attached at all
☐ _1	☐ _2	☐ _3	☐ _0



Next are some questions about the support that is available to you.

The following questions ask about people in your environment who provide you with help or support. Each question has two parts.

For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the persons' initials and their relationship to you (see example). Do not list more than one person next to each of the numbers beneath the question.

Example

Who do you know whom you can trust with information that could get you into trouble?

No one	1) T.N. (brother)	4) T.N. (father)	7)
	2) L.M. (friend)	5) L.M. (employer)	8)
	3) R.S. (friend)	6)	9)

If you have had no support for a question, circle the words "No one", but still rate your level of satisfaction. Do not list more than nine persons per question.

For the second part, tick how satisfied you are with the overall support you have.

Example

How satisfied?

Very dissatisfied	Fairly dissatisfied	A little dissatisfied	A little satisfied	Fairly satisfied	Very satisfied
☐ _1	☐ _2	☐ _3	☐ _4	☒ _5	☐ _6

Please answer all the questions as best you can.

14a) Whom can you really count on to be dependable when you need help?

No one 1) 4) 7)
2) 8)
3) 6) 9)

b) How satisfied?

Very dissatisfied Fairly dissatisfied A little dissatisfied Fairly satisfied Very satisfied
☐_1 ☐_2 ☐_3 ☐_4 ☐_5 ☐_6

15a) Who can you really count on to help you feel more relaxed when you are under pressure or tense?

No one 1) 4) 7)
2) 8)
3) 6) 9)

b) How satisfied?

Very dissatisfied Fairly dissatisfied A little dissatisfied Fairly satisfied Very satisfied
☐_1 ☐_2 ☐_3 ☐_4 ☐_5 ☐_6

16a) Who accepts you totally, including both your worst and best points?

No one 1) 4) 7)
2) 8)
3) 6) 9)

b) How satisfied?

Very dissatisfied Fairly dissatisfied A little dissatisfied Fairly satisfied Very satisfied
☐_1 ☐_2 ☐_3 ☐_4 ☐_5 ☐_6

17a) Who can you really count on to care about you, regardless of what is happening to you?

No one 1) 4) 7)
2) 8)
3) 6) 9)

b) How satisfied?

Very dissatisfied Fairly dissatisfied A little dissatisfied Fairly satisfied Very satisfied
☐_1 ☐_2 ☐_3 ☐_4 ☐_5 ☐_6

18a) Who can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

No one 1) 4) 7)
2) 8)
3) 6) 9)

b) How satisfied?

Very dissatisfied Fairly dissatisfied A little dissatisfied Fairly satisfied Very satisfied
☐_1 ☐_2 ☐_3 ☐_4 ☐_5 ☐_6

19a) Who can you count on to console you when you are very upset?

No one 1) 4) 7)
2) 8)
3) 6) 9)

b) How satisfied?

Very dissatisfied Fairly dissatisfied A little dissatisfied Fairly satisfied Very satisfied
☐_1 ☐_2 ☐_3 ☐_4 ☐_5 ☐_6

Your experiences

J1 During the past 3 months, how would you describe your emotional health?

(Please write your response in the space below)

[illegible]

J2 During the past 3 months, what has been the thing that has helped you most of all with depression, stress or worries? (Please write your response in the space below)

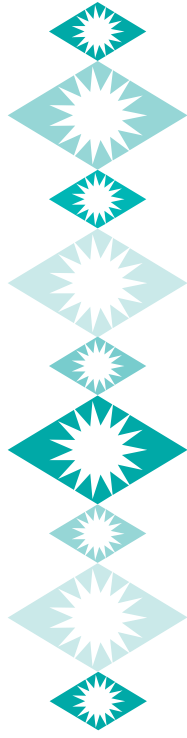
worries? (Please write your response in the space below)

[illegible]

47

Comments

This image shows a full page of a document template designed to look like lined paper. It features a series of evenly spaced, vertical blue lines running from the top to the bottom of the page. The background is a light cream or off-white color. There are no margins, text, or other markings present on the page.



Thank you very much for the time and effort you have taken in completing this survey.

Please use the reply paid envelope to send it back to us. If no envelope was enclosed with your survey or you have mislaid it, please call a member of the **diamond** team on **(03) 8344 9719** and we will send you another one.

Or use our REPLY PAID return address (no stamp is required):

diamond Project
Department of General Practice
University of Melbourne
REPLY PAID 65443
200 Berkeley Street
Carlton VIC 3053

If you wish to talk to someone about any of the issues raised in this survey we have provided a card with phone numbers to call to access information. You can also contact the **diamond** project team on **(03) 8344 9719**.

Many thanks,

The **diamond** team

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- The Centre for Epidemiologic Studies - Depression (CES-D) scale, Radloff LS.
- The WHOQOL GROUP (1998), Development of the World Health Organisation WHOQOL-BREF Quality of Life Assessment. Psychological Medicine, 28, 551-558.
- The SF-12® Health Survey, © 1994, 2000 QualityMetric Incorporated - all rights reserved SF-12® is a registered trademark of the Medical Outcomes Trust (MOT).
- Life Experiences Scale (LES): Sarason IG, Johnson JH, Siegel JM. (1978) Assessing the Impact of Life Changes: Development of the Life Experiences Survey. Journal of Consulting and Clinical Psychology, 46(5), 932-946
- Life Events Questionnaire (LEQ): Norbeck JS (1984) Modification of Life Event Questionnaires for Use with Female Respondents. Research in Nursing and Health, 7(1), 61-71.
- FAST - Hodgson RJ, John B, Abbasi T, Hodgson RC, Waller S, Thom B, Newcombe RG (2003). Fast screening for alcohol misuse. Addictive Behaviours, 28, 1453-1463.
- The Centre for Epidemiologic Studies - Depression (CES-D) scale, Radloff LS
- The PRIME MD PHQ developed by Drs RL Spitzer, JBW Williams, K Kroenke and colleagues. PRIME MD® is a trademark of Pfizer Inc. Copyright© 1999 Pfizer Inc.
- Composite Abuse Scale (1999) Hegarty K.
- Baum et al. (2000). Epidemiology of participation: An Australian community study, JI Epidemiol Community Health, 54; p414-423
- Sarason, IG, Sarason BR, Shearin EN and Pierce GR (1987). A brief measure of social support: Practical and theoretical implications. Journal of Social and Personal Relationships, 4, 497-510.

