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NHMRC Centre of Research Excellence in Suicide Prevention

Care After a Suicide Attempt

A report prepared for the National Mental Health Commission by

The NHMRC Centre of Research Excellence in Suicide Prevention,

Black Dog Institute, the University of New South Wales, in partnership with

The University of Melbourne, Lifeline, and the Australian National University

CONTENTS

EXECUTIVE SUMMARY 2
ACKNOWLEDGEMENTS 6
1. INTRODUCTION 7
1.1. BACKGROUND 7
1.2. AIMS 7
2. PROJECT METHODOLOGY 9
2.1. DEFINITIONS 9
2.2. INVESTIGATORS 9
2.3. ADVISORY PANEL 9
3. WHAT WE KNOW ABOUT SUICIDE AND PREVENTING REPEATED SUICIDE ATTEMPTS 10
3.1. SUICIDE RATES 10
3.2. SUICIDE ATTEMPTS 13
3.3. RE-ATTEMPTS AND FAILURE OF CONTINUITY OF CARE 13
3.4. PEOPLE'S EXPERIENCE OF HEALTH SERVICES AFTER A SUICIDE ATTEMPT 14
3.5. A SYSTEMATIC REVIEW OF THE LITERATURE: WHAT WORKS TO PREVENT FURTHER SUICIDE ATTEMPTS? 16
4. FINDINGS FROM CAASA PARTICIPANTS: WHAT CARE ARE PEOPLE RECEIVING IN AUSTRALIA? 22
4.1. RESULTS FROM THE SEMI-STRUCTURED INTERVIEWS 22
4.2. RESULTS FROM THE ONLINE SURVEYS 39
4.3. DATA LINKAGE STUDY: MENTAL HEALTH CARE RECEIVED BY PEOPLE ADMITTED TO HOSPITAL FOR DELIBERATE SELF-HARM IN NSW 60
4.4. WHAT DATA ARE AVAILABLE TO EVALUATE HEALTH SERVICE STRATEGIES AND PROGRAMS? 70
5. KEY FINDINGS AND PRIORITIES 72
6. REFERENCES 78
APPENDIX A: PROJECT METHODOLOGY 85
APPENDIX B: ADVISORY PANEL MEMBERS 91
APPENDIX C: SUICIDE RATES 92
APPENDIX D: STUDY CHARACTERISTICS AND OUTCOMES 95
APPENDIX E: SURVEY CODING FOR SPECIFIC ITEMS 1
APPENDIX F: DATASET DESCRIPTIONS 2

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EXECUTIVE SUMMARY

Improving the care received by people after a suicide attempt is important for reducing suicide attempts and suicide deaths in Australia, not least because a suicide attempt is one of the strongest predictors of future suicide attempts. As such, this period represents a critical time for high quality care. To better understand how health services can improve the quality of care people receive following a suicide attempt, a clearer picture of peoples' current experience is needed. To date, no systematic examination of people's health service experiences after a suicide attempt has been undertaken in Australia. The stigma which continues to underpin mental illness and suicide within society infiltrates our ways of research where it is too often presumed that people are not capable or unwilling to talk. Consequently, the perspective of people with lived experience of suicidality has not been properly considered. This project aims to investigate the response of health services to people who have had a suicide attempt. More specifically, it aims to provide a better understanding of what support people currently receive, how helpful or otherwise these services are, and the barriers to improvement.

Previous research has identified that the period immediately after discharge from psychiatric inpatient care represents a very high risk of death by suicide. Failure to provide outpatient follow-up care after suicide attempts is associated with increased risk of re-attempt and death by suicide. A review of suicide deaths in Western Australia (WA) found that one-third of men and over half of women who died by suicide had previously been hospitalised for self-inflicted injuries. There is evidence that implementing the following policies reduces suicide deaths: assertive follow-up in the week after discharge from inpatient care, assertive outreach for non-compliant patients, and 24-hour crisis teams. As such, the care that people receive after a suicide attempt must form a critical part of the national suicide prevention strategy. This is particularly important at a time when suicide rates have increased (from 2011 to 2012: ABS Causes of Death, 2012). Yet people's experience of health services after a suicide attempt is at best, mixed. Clinical staff may harbour negative attitudes, anger, or irritation towards patients who have had a suicide attempt. Importantly, the attitude towards patients by clinical staff following a suicide or self-harm episode can strongly impact the individual and influence their future help-seeking behaviour. Many health professionals are committed to providing good care to those experiencing mental illness and suicidality. Nevertheless, they work within a health system which is under stress and where staff are increasingly stretched in their efforts to meet the expectations of the system and their patients.

Recent research indicates that the most effective strategies are multi-level, multi-component, systems-based approaches. It is when a range of elements operates in conjunction with one another in a systematic way that suicide risk in the population is lowered and suicide prevention outcomes are maximised. Such systems approaches, for which there is current or emerging evidence, are described in this report. Chain of care models are likely to be part of a larger system aimed at preventing suicide *and* preventing reattempts. Intensive case management in the Australian context also has evidence for its effectiveness, as do brief contact strategies where they are preceded by good clinical care. The most promising psychosocial interventions for preventing re-attempts in adults are cognitive behavioural therapy and problem solving therapy. Evidence-based strategies and models are available and yet, appear not to be systematically and thoroughly implemented. Doing so requires a coordinated, systems-based approach which ensures that patients are not lost within the health care system. Improved routine data collections are needed to monitor improvements and to ensure that health systems are accountable to achieving these improvements.

We used five primary methods to achieve the study's aims: a systematic review of the literature regarding what works to reduce the risk of a re-attempt; online surveys with people who have had a suicide attempt and with caregivers; interviews with people who have had a suicide attempt and with caregivers; a data linkage study examining mental health care use following hospital admission for a suicide attempt; and a

review of currently available data. These methods identified a number of barriers. We were only able to use admitted patient data as the primary episode of treatment for the data linkage study since data on suicide attempts is not systematically collected in emergency departments. This misses out any patients who present to emergency but are not admitted. It was also not possible to conduct this study at a national level because the datasets are not available in every jurisdiction. Further, we found it difficult to recruit large numbers of participants for the online surveys, despite an intensive recruitment effort over several months. A third barrier was lack of accessible information on what data are collected that could inform policy and procedures regarding care after a suicide attempt. Findings from the online surveys, interviews, data linkage study, and review of currently available data are presented below.

- Our findings from both the **online surveys** and **interviews** consistently revealed low levels of satisfaction with health care services after a suicide attempt. Satisfaction with emergency department care is particularly low, which is concerning given that this is a first point of contact for many people, and because lower satisfaction with emergency services and emergency department care was associated with unwillingness to disclose future suicidal ideation to a health care professional. Dissatisfaction increases at discharge: discharge planning and its communication, or lack thereof, to patients and caregivers, continues to be a major hurdle to effective ongoing care.
- The problems identified in the **online surveys** included poor staff attitudes towards the patient, inadequate staff knowledge about suicide, being discharged too rapidly, not being followed up after discharge from hospital, and not having their emotional distress attended to.
- **Semi-structured interviews** with people who have had an attempt and with caregivers identified some key themes regarding people's needs within the health system: many felt that their complex problems did not 'fit' the mental health system; empathic clinical staff are important; those who found good help felt that they were 'lucky'; there is a need for advocacy within the healthcare system so that all patients can find good care; and consistent care with the same person or team is important.
- **The data linkage study** carried out using New South Wales data found that 63% of patients admitted for a suicide attempt received any kind of mental health treatment in the public health system (inpatient or outpatient). Ten per cent of patients admitted for a suicide attempt are treated in specialist psychiatric services during their hospital stay. Some of these patients are likely to return to the care of an already established mental health team but are not tracked systematically by the hospital once they have been discharged. Fifty-nine per cent of those who receive outpatient treatment receive only one session of 30 minutes or less, and half of those outpatient sessions are with a nurse.
- The **review of currently available data** found that there is currently no way to capture a substantial proportion of suicide attempts. Systematic collection of these data in emergency departments would allow hospitals to examine the number of suicide attempts presenting, how many people re-present, who goes on to be admitted, and who receives outpatient care. Better data needs to be available to improve our understanding what happens to patients once they are discharged from the hospital system. Further, without routinely collected data on suicide attempts, the many community and health service efforts to reduce suicide behaviours cannot be properly evaluated. Currently available data do not adequately inform and evaluate public policy and health systems procedures or ensure that patients receive quality, ongoing care.

These findings, taken together, indicate a number of reform priorities outlined below.

The Human Side of Responses to Suicide Attempts

Treatment at the time of presenting to hospital needs to address psychological distress as well as physical injury. Support for individuals who have made a suicide attempt and their families must be enhanced,

with particular attention directed to the emotional, social and psychiatric needs of the person concerned. Care needs to be tailored to the needs of the person.

Research participants, including caregivers, consistently expressed a desire to be involved in treatment planning following a suicide attempt. Patients require timely access to advice and support if their treatment plan needs to be adjusted (see recommendation 6). A reduction in care is associated with increased risk of death by suicide. Survey results show that as time passes, levels of satisfaction with care provided decrease, indicating that many people desire ongoing support that is unfortunately, not forthcoming.

A systems approach to improving aftercare

An integrated approach to improving care after a suicide attempt is required, including data driven improvements, organisational leadership, systems changes that allow patients to be followed-up assertively, and staff training/attitudinal change.

Combined clinical and non-clinical models of care

There is an urgent need to identify ways of delivering treatments that are more effective than the presently offered stand-alone psychological and psychopharmacologic therapies. A collaborative model of aftercare that includes family/friends/caregivers is needed, i.e. a matching up of personal supports with the treatment program. A family and community-oriented approach to care can support the person to build a greater sense of belonging as well as providing support for caregivers. Better results in both adherence to treatment and clinical outcomes appears possible, as well as enhanced alleviation of the personal distress and trauma associated with a suicide attempt. Within this model, accountability for service delivery and follow-up must be clear.

Post-discharge plans and primary health care

Nationally consistent practice standards should be developed to support the assertive follow-up of all patients discharged from hospital following a suicide attempt. Patients and caregivers should be encouraged to be involved in treatment planning prior to discharge and with their general practitioner. Continuity of care strategies need to target individuals that are at high risk both for suicide and for non-adherence to the recommended treatment plan.

Coordinated support to utilise available services

Coordinated care needs to be facilitated, perhaps with the benefit of an individual who can help people to navigate the health system. Previous work in Australia on quality health care as it relates to consumer information should be used as the basis for the design of a 'suicide attempt quality in care guide'. In other crisis situations (e.g. bushfires), affected individuals are provided with a caseworker to assist them in accessing services and resources. In these instances, it was not the therapy that was reported as being beneficial, but rather this assistance to navigate systems and services.

Use of technology and e-Mental health strategies

e-Mental health programs and other online services for suicide prevention should be integrated into the referral systems of hospital clinical staff and general practitioners. There is ample potential to better incorporate technology-based services and treatments, in the knowledge that social isolation, stigma and service access barriers may contribute to under-utilisation of the health services by individuals who have attempted suicide. The experience of e-Mental Health Services in Australia is that they are clinically effective and attract consumers who may not otherwise utilise or adhere to face-to-face treatment programs. Furthermore, caregivers may find online or mobile application information and support of greater benefit than printed materials or conventional face-to-face interactions.

Data and monitoring of service performance

A coordinated approach to health care should be informed by data collection and monitoring so that early identification of lapses in adherence to treatment, or changes in clinical assessments, occurs. Evaluation of the effectiveness of post-acute release services would also be significantly better informed through the collection and analysis of this data.

Improved data collection systems are needed to quantify and track suicide attempts and suicide deaths. Without this routinely collected data, the many community and health service efforts to reduce suicide behaviours cannot be evaluated. Current gaps include national data on the number of people who present to emergency departments following a suicide attempt or an episode of deliberate self-harm; what treatments they receive; the proportion of this population who are re-presenting following a previous attempt; and national data on what care patients receive after they have been discharged from hospital. A mix of aggregated, publicly available data and application-only unit level de-identified data is required, taking into account issues of privacy and security.

Providing support for caregivers and recognising their role

Caregivers consistently expressed a need for help in managing their own mental health and distress. The role of family and friends in providing ongoing support for those who live with chronic mental illness and suicidality is critical and requires greater support.

This report and its findings represent the culmination of several pieces of work. All data sources point to a need for substantial reform in the way the health system and health professionals respond to people following a suicide attempt. Despite health system policies regarding follow up of people after hospital discharge, in many instances this contact is not made. Strong leadership is required in setting the agenda and ensuring that existing and new policies and procedures are adhered to. Ongoing education and systems improvements are needed to support the implementation of improved care at this critical time in people's lives.

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1. INTRODUCTION

1.1. BACKGROUND

A history of suicide attempt is a risk factor for completed suicide [1, 2] and other premature mortality [3]. Within nine years of a suicide attempt, three to twelve per cent of individuals will have died by suicide [2]. Given these statistics, intervention following a suicide attempt is an important element to preventing suicide. With limited or no help-seeking prior to many suicide attempts [4], contact immediately after an attempt represents an opportunity to provide much needed treatment and support to the individual as well as support to the family and caregivers. Yet, services provided to individuals and their family or caregivers following a suicide attempt are inconsistent, are often not based on current evidence, and evaluated poorly by patients [4]. This is perhaps understandable given inconsistent findings from randomised controlled trials of psychological and pharmacological therapies [5] with regard to suicide prevention, and the difficulties in translating research into practice. There is evidence that following up patients (both brief and intensive follow-up) after a suicide attempt can reduce the likelihood of a further attempt, notably if this is combined with a treatment program [6-11]. Other studies have found no effect of follow-up – generally those where the follow-up is not coordinated with treatment [12-14]. As such, research is investigating improving compliance with outpatient treatment and a more intensive case management approach [15], especially using collaborative models of care. There is also evidence that the way in which services and their delivery are structured can influence suicide rates [16, 17].

There is a strong incentive for interventions to be delivered within the immediate aftermath of a suicide attempt in order to engage with the individual and lessen their chances of following this trajectory. Yet some research suggests that clinical staff often harbour negative attitudes, anger, or irritation towards patients who self-harm [18]. Relatedly, the attitude towards, and treatment of, patients by clinical staff following a suicide or self-harm episode can strongly impact the individual and influence their future help-seeking behaviour [19]. The role that caregivers play in identifying warning signs, encouraging help-seeking and supporting ongoing wellbeing is recognised as vital. Understanding the patient and caregiver experience as thoroughly as possible, therefore, is an invaluable pursuit for developing an intervention that is effective in preventing repeat attempts.

Although there is much anecdotal evidence regarding people's experience of Australian health services following a suicide attempt, to date there has not been a comprehensive study of their experiences combined with a review of what works to reduce the risk of re-attempts. The following report lays out evidence regarding the importance of providing effective treatment and support following a suicide attempt. This evidence is strongly supported by the voices of those who have lived experience of suicide. We thank those people who participated in our research for their courage and input.

The Care After a Suicide Attempt (CAASA) study was commissioned by the National Mental Health Commission to achieve the following aims:

1.2. AIMS

1. To identify national and international service delivery models for care after a suicide attempt; to identify evidence-based components of these models (i.e. the evidence for the effectiveness of the components). With respect to service models, identify best models for both the person concerned and for their families or caregivers;
2. To identify national and international trends in suicide attempts, and best practice in looking after people who have made a suicide attempt (and their supporters);
3. To identify the health service experiences of individuals and their supporters following a suicide attempt, and to establish whether these services met the needs of these people and their caregivers;

4. To identify currently available Australian data that will assist in ascertaining the number and characteristics of people who have made a suicide attempt and the types of health services they use. An assessment of the quality and limitations of the data in determining these characteristics and service usage patterns will be included.

2. PROJECT METHODOLOGY

The methodology is described in detail in Appendix A. The key components of the project were:

1. A literature review of national and international trends in suicide attempts; evidence regarding what works to reduce repeat attempts; models of service delivery, and international best practice for intervening after a suicide attempt.
2. Online surveys (1) for people who have had a suicide attempt, and (2) for caregivers of those who have had a suicide attempt. These surveys and the semi-structured interviews had specific exclusion criteria and safety protocols to ensure the wellbeing of potential participants (Appendix A).
3. Semi-structured interviews with people who have had a suicide attempt, and with caregivers of those who have had a suicide attempt.
4. A data linkage study examining the health service utilisation of NSW patients admitted to hospital following a suicide attempt.
5. A review of currently available data regarding treatment following a suicide attempt.
6. A study with Indigenous Australians in the Hunter New England area. This component of the project has been delayed because of the time taken to gain ethics approval and will be reported on separately.

2.1. DEFINITIONS

Suicide definitions are contentious. Part of this difficulty stems from differences in intent and making inferences about this. Intent ranges from self-harm to reduce intolerable distress through to severe intent to die. For the purposes of this report, we have included research on self-harm where at least some of the participants expressed intent to die, but excluded research on non-suicidal self-injury (see Box 1 for definitions).

2.2. INVESTIGATORS

The project investigators are Dr Fiona Shand, Professor Helen Christensen, Professor Jane Pirkis, Dr Philip Batterham, Dr Matthew Spittal, Ms Hannah Buckley, Mr Alan Woodward, Mr Joseph Tighe and Dr Kathryn McKay.

2.3. ADVISORY PANEL

The CAASA project advisory panel members are listed in Appendix B.

3. WHAT WE KNOW ABOUT SUICIDE AND PREVENTING REPEATED SUICIDE ATTEMPTS

The section below provides, firstly, an overview of suicide and suicide attempts in Australia and internationally. We then review what is known about the impact of failure of continuity of care on the risk for re-attempts. Finally, a systematic review of the literature with respect to preventing re-attempts is provided.

3.1. SUICIDE RATES

Trends in suicide rates, attempts, and methods from national and international databases are presented below. Current international suicide rates are estimated to be 16.7 per 100,000. However this statistic does not communicate the large variability across countries [20].

The most recently available Australian data (2012) shows an increase in the absolute number of deaths by suicide, from 2,132 in 2009 to 2,535 in 2012. This translates to more than 11 suicide deaths per 100,000 people [21]. In the decade to 2011, the suicide deaths in Australia had stabilised or fallen slightly, with rates in 2002 at 11.8 per 100 000 falling to 10 per 100 000 in 2011 [22]. Trend analysis in Australia is to be qualified by the data quality issues in pre-2007 data, which have been addressed in data from 2007 onwards by the Australian Bureau of Statistics.

The decreases observed to 2011 were largely present among males between the ages 15 and 44, although this decline has not occurred among certain groups of males (rural, Aboriginal and Torres Strait Islander men) [23]. Minor increases (between 0.1 and 1.7 per 100,000) in suicide rates were found in males aged 55-64 and 75-84 and females aged 15-24 and 65-74. The largest subpopulation increase in suicide rates was observed in females aged 15 to 24. These increases were overshadowed by the large reductions (between 4.7 and 10.7 per 100,000) in young to middle-aged males. A rolling average annual rate is shown in Appendix C.

Although problems with the data make it difficult to be definitive about trends, the suicide rate of Indigenous Australians was recorded as roughly twice as high as non-Indigenous Australians between the years 2007 and 2011 [22]. The most recent data shows tat suicide rates of 15-24 year old Indigenous Australians are five times as high as non-Indigenous Australians of the same age. Suicide rates among 25-34 years olds are more than three times as high for Indigenous Australians. Overall, suicide rates among Indigenous Australians decreased very slightly between the years 2001 and 2010 (23.8 to 22.3 per 100,000), however this reduction has not been as large nor as reliable as the reduction for non-Indigenous Australians [24].

Compared with some developed nations (US, Canada, England and Wales), Australia's suicide rate has dropped more rapidly since 1998 (Figure 1). Higher rates are commonly found in Northern and Eastern European countries, such as Lithuania. Rates among males vary to a greater extent and are generally 3 to 7.5 times higher than female suicide rates [20]. Overall, the international statistics suggest there has been a slight but significant increase in suicide rates between the years 1950-2004 [25]; however, the inconsistencies within and between countries suggests poor generalizability of this data worldwide. Suicide rates within Australia appear to have risen more substantially than the international increase over periods within 1950 and 2004 [25-27]. These increases, particularly within Australia, were due primarily to increasing suicide rates in males between the ages 15-34 [25].

Recent declines in suicide rates have also been observed in the European Union (13.2 in 2002 to 11.8 in 2010), Japan (23.8 in 2002 to 22.9 in 2011), and New Zealand (11.6 in 2002 to 10.6 in 2011) while rates in Canada (11.5 in 2002 to 11.1 in 2009) and the United Kingdom (6.9 in 2002 to 6.7 in 2010) have remained stable. In contrast, a rise in suicide rates has been observed in the United States (10.4 in 2000 to 12.1 in 2010) and India (10.5 in 2002 to 11.2 in 2012) [28-30].

BOX 1: TERMS FOR NON-FATAL SELF-INFLICTED HARM[1]

Attempted suicide
Used widely (especially in North America) for episodes where there was at least some suicidal intent, or sometimes without reference to intent. Repetitive bodily harm may be excluded.

Deliberate self-harm
Used in UK for all episodes survived, regardless of intent.

North American usage refers to episodes of bodily harm without suicidal intent, especially if repetitive. Usually excludes overdoses and methods of high lethality.

Parasuicide
Episodes survived, with or without suicidal intent (especially in Europe) or episodes without intent. Repetitive bodily harm may be excluded.

Self-poisoning or self-injury
Self-harm by these methods regardless of suicidal intent.

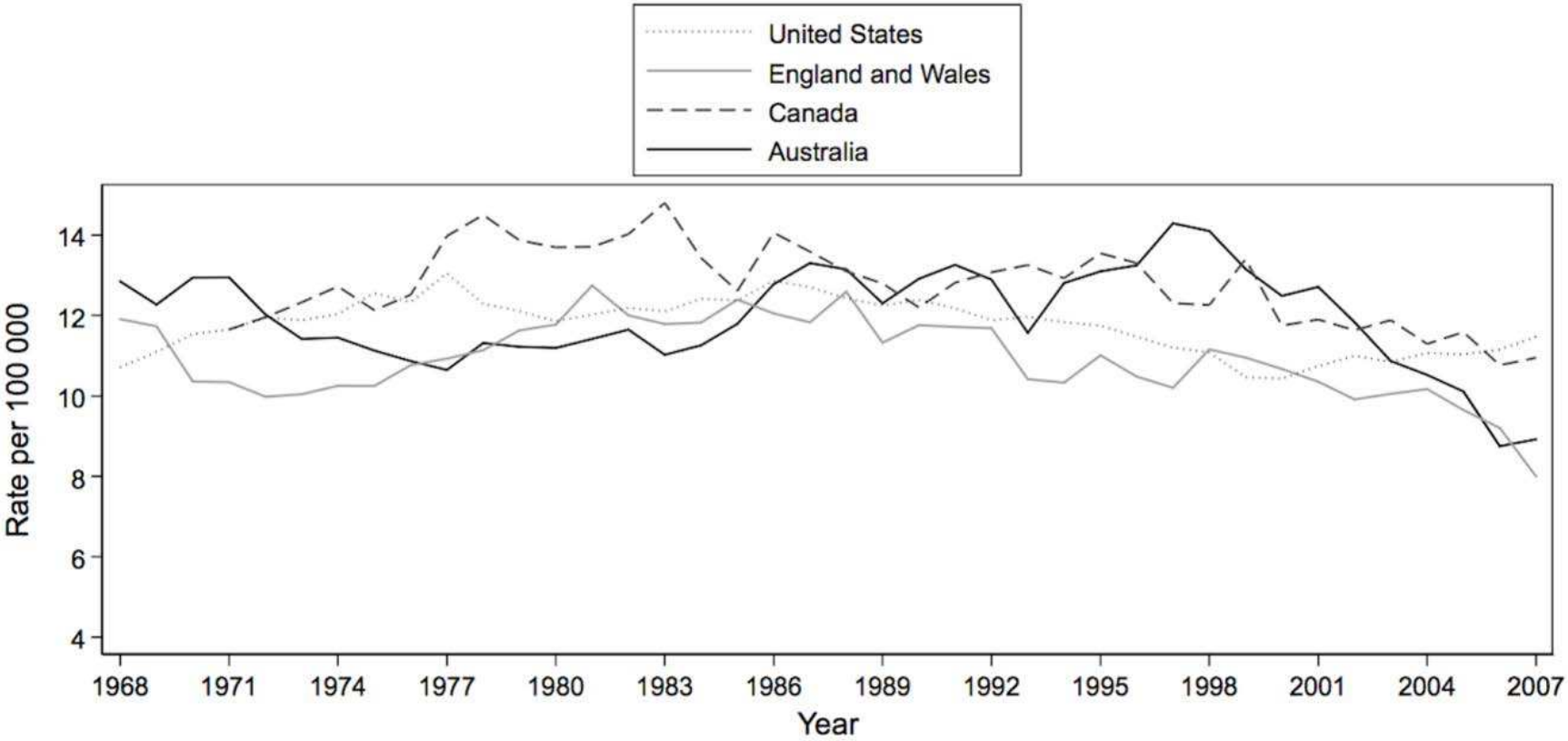
Self-mutilation
Serious bodily mutilation without suicidal intent. Repetitive superficial bodily harm without suicidal intent (synonymous with North American term deliberate self-harm). Also known as self-injurious behaviour, self-wounding.

Sometimes the term is used to describe both the above meanings and also stereotypical self-harm in intellectually disabled people.

Self-directed violence
Behaviour that is self-directed and deliberately results in injury or the potential for injury to oneself. This does not include behaviours such as parachuting, gambling, substance abuse, tobacco use or other risk-taking activities, such as excessive speeding in motor vehicles. These are complex behaviours some of which are risk factors for self-directed violence, but are defined as behaviour that while likely to be life-threatening, is not recognized by the individual as behaviour intended to destroy or injure the self. Self-directed violence is categorised as suicidal or non-suicidal.

[1] Adapted from Skegg K (2005). Self-harm. *Lancet*; 366: 1471–83.

Figure 1: Death by suicide per 100,000 [31]



3.2. SUICIDE ATTEMPTS

Suicide rates tell only part of the story, with data on suicide attempts contributing to our understanding of suicidality and the need for intervention in order to prevent further attempts. Mixed patterns have been found across the globe in relation to trends in suicide attempts. A sharp rise in suicide attempts was observed in the 1960's and 1970's in Australia, the United States of America and the United Kingdom [32, 33]. Between 1989 and 1992 the overall rates of suicide attempts fell across Europe as a whole, though not in any uniform or linear manner [32]. Both sexes between 35 and 44, females aged 45-54 years and males aged 15-24 years all experienced large drops in suicide attempts while rates among males and females over 55 years increased. Most countries held rates between 3% and 5% overall, 2% and 3% in males and 3% and 7% in females, with this gender difference significant in over half of the countries assessed. Those divorced or separated also demonstrated higher suicide rates than married or never married individuals, with the rate between two and seven times as high. Data collected by the World Health Organisation from 21 countries at one time-point between 2001 and 2007 found that the 12-month prevalence of suicide attempts was 0.3% in developed countries and 0.4% in developing countries [34].

Findings from the 1997 Australian National Survey of Mental Health and Wellbeing (NSMHWB) suggest that the 12-month prevalence of suicide attempts in Australia was 0.4% for females and 0.3% for males, with an overall prevalence of 0.3% [35]. The 2007 NSMHWB results indicate a rise in the overall number of suicide attempts, up to 0.4% of Australians between 16 and 85 years of age [36]. This overall rise reflects the rise in female suicide attempts, which increased to 0.5% while rates in males remained stable at 0.3%. The increase found in this Australian data reflects the change seen in American data. This most recent figure suggests suicide attempts in Australia are higher than other developed countries [34].

3.3. RE-ATTEMPTS AND FAILURE OF CONTINUITY OF CARE

The period immediately after discharge from psychiatric inpatient care is particularly dangerous, with a UK study identifying that 47% of suicide deaths occurred within the month after discharge, and 43% of those occurring before their first follow-up appointment [37]. A missed appointment was a risk factor for death by suicide, making assertive follow-up an essential component to care after a suicide attempt. Further, a reduction in professional care is strongly associated with suicide [38].

In Western Australia, the Stokes Review identified that over one-third of Western Australian men who died by suicide between 1986 and 2005 had been admitted to a psychiatric hospital or a public hospital for psychiatric treatment at some point in their lifetime [39]. Fifteen per cent of these men completed suicide on the day of discharge from their last admission. Similarly, one-fifth of women completed suicide on the day of discharge, and a third within a month of discharge. Around one-third of men and over half of women who completed suicide had also been hospitalised previously for self-inflicted injuries. The proportion of men who died by suicide with a previous history of hospitalisation for self-inflicted injury has increased in recent years, particularly among those aged 30-34 years. People admitted to hospital in Western Australia for self-injury were 20 times more likely than the general population to eventually die by suicide [39].

Failure to provide outpatient follow-up care after suicide attempts is associated with increased risk of re-attempt and death by suicide [40]. The service organisation and delivery factors associated with suicide are: unplanned discharge, key personnel on leave or leaving, short admissions (under seven days), admitted under a new consultant, time when not in contact with services in the period following discharge from hospital, and having a key worker on holiday or about to leave the service at the time of the incident [41-43].

Finally, there is evidence that implementing the following policies reduces suicide deaths: assertive follow-up in the week after discharge from inpatient care, assertive outreach for non-compliant patients, and 24-

hour crisis teams [44]. Taken together, these research findings point to the need for intensified efforts to improve the care and support that people receive following a suicide attempt.

3.4. PEOPLE'S EXPERIENCE OF HEALTH SERVICES AFTER A SUICIDE ATTEMPT

Patients report both positive and negative aspects of hospitalisation following an episode of self-harm or attempted suicide. Although little of this research was conducted in Australia, we report here on the experience of patients elsewhere.

Psychiatric inpatients in Sweden expressed a distinct relief at hospitalisation, since it removed the responsibility of having to look after themselves [45]. Moreover, a sense of care was emphasised by many participants, who felt that the setting was one of acceptance and security. One patient felt that the staff represented the hope that she could not possibly muster herself at that time. When it was expressed towards them, patients appreciated the sensitivity of staff to the fragility of their moods, as well as the confidence that they could be trusted. Unsurprisingly, of vital importance was having someone to talk to and to understand his or her situation, and staff often provided this opportunity. Repeatedly, however, negative experiences were voiced. Patients were ashamed at their hospitalisation, and often perceived personnel as being indifferent, uncaring, or as exhibiting a lack of respect, for example in behaving like guardians rather than nurses [45]. In some circumstances, patients described feeling burdensome, and as though exposed and neglected when staff failed to show empathy, or conveyed the sense that there were other, more serious situations requiring attention.

In an older ethnographic study [46] that sought to compare and contrast the nurses' views with the patient views about constant observation for suicidal individuals in a psychiatric hospital, it was also found that patients harboured many negative feelings about staff actions, such as being coerced and feeling degraded. There were stark inconsistencies between staff and patient perceptions of the nature of the observation, for example, sitting outside with patients was described as therapeutic and supportive by staff, and yet as controlling by patients. The authors conclude there are lessons to be learned for staff treatment in terms of how to empower the patient rather than reinforce hopelessness through controlling actions.

Interviews with a small sample of people who had self-harmed revealed that the purpose of psychosocial assessment was often not clear, nor taken as an opportunity for patients to voice their needs. From their findings, it appears that the psychosocial assessment might be most effective when it adequately meets the patient's needs, legitimises their need for help, and takes into account the social as well as the psychological dimensions to their struggle. In the positive instances, psychosocial assessment was able to promote help-seeking, and engender within patients, hope for the future and change. Psychosocial assessment can be a vital tool for self-harm management, for engaging patients in treatment and improving their rates of aftercare [47].

In their investigations into the psychiatric consultation process with people who had attempted suicide, researchers in the Netherlands drew attention to the group of patients for whom the suicide attempt was not a first time [48]. It was found in particular that for those demonstrating recurrent suicidal behaviour, or who were former inpatients, the psychiatric consultation was not considered sufficient or effective. Furthermore, one third of the whole sample reported that the reason and circumstances of their suicide attempt was ignored, and a large proportion rated the consultation overall as being negative. The authors recommend that a greater emphasis be placed on training consultants to effectively manage people who had had a suicide attempt in particular.

A systematic review of attitudes towards clinical services among those who self-harm identified various aspects of services that require improvement [49]. Several recurring themes were evident. Participants reported negative experiences of care as a result of staff demonstrating poor communication about

treatment, a lack of knowledge or understanding about self-harm, a disregard for the patient's mental health problems, or lack of empathy. Similarly, Camgan (1994) noted that each of their six respondents (who had attempted suicide through self-poisoning) experienced communication difficulties with hospital or nursing staff, and pointed to the need for a more detailed and personal psychosocial assessment that extends beyond physical care [50].

People who have recently had a suicide or self-harm attempt have collectively provided, in these and other studies, a clearer picture of their wants and needs from health services in the immediate aftermath of an episode. Cooper and colleagues (2011) specifically explored the needs of both service users and clinical staff for contact-based interventions (such as letters, telephone calls, or crisis cards) after hospitalisation for self-harm [51]. Service users emphasised the importance of support and encouragement immediately after discharge, and described how this could be better implemented. Early and proactive intervention, for example, was highlighted, as well as the importance of authenticity in the service, i.e. a sincere attempt to help the patient and not merely a generic attempt at contact. It was commonly endorsed that contact-based interventions be delivered by mental health specialists, with a phone call voted the best means initially, with follow-up letters to suffice after this. A more recent study with recently discharged service users highlighted the need to better prepare people for discharge from hospital, with those who felt ill-prepared to leave hospital more likely to re-experience suicidal urges [52]. The re-emergence of pre-existing stressors as a trigger for suicidal thoughts and urges suggests that discharge planning needs to address gaps in coping skills and problem-solving skills.

Research has thus gone some way to exploring the experiences of people who have attempted suicide with health services. Much of the work cited, however, has investigated these questions following a self-harm episode [47, 49, 51], and less has been conducted following suicide attempts specifically. In this realm, there remains much to be learned and improved.

Nevertheless, several themes emerge from the existing research on peoples' health service experiences after a suicide attempt, including:

- Psychosocial assessment might be most effective when it adequately meets the patient's needs, legitimises their need for help, and takes into account the social as well as the psychological needs. A properly conducted psychosocial assessment may promote help-seeking, engage patients in treatment, improve rates of aftercare and engender hope for the future and change.
- For those demonstrating recurrent suicidal behaviour, the psychiatric consultation was not considered sufficient or effective, with many patients reporting that the underlying reason and circumstance of their suicide attempt was ignored. A greater emphasis should be placed on training consultants to effectively manage people who have had a suicide attempt.
- Some patients, particularly where they are treated with respect and kindness, report being relieved to be hospitalised. Nevertheless patients can also experience shame about being hospitalised and often perceive health staff as being indifferent, uncaring, or as exhibiting a lack of respect.
- There is a need to better prepare people for discharge after a suicide attempt and provide ongoing support post-discharge. Contact made after discharge needs to be sincere and purposeful rather than just a routine check-in.

3.5. A SYSTEMATIC REVIEW OF THE LITERATURE: WHAT WORKS TO PREVENT FURTHER SUICIDE ATTEMPTS?

The systematic review below describes clinical trials of brief, psychosocial, and drug treatments. There is little to guide clinicians in deciding who should receive what, although there are some clues. For instance, a more lethal method used in a suicide attempt is associated with increased risk of death by suicide in a subsequent attempt [53]. We have restricted this review to interventions that were aimed at reducing the risk of *reattempts*: at least 51% of participants in the study needed to have had a recent suicide attempt. All of the studies described below are randomised controlled trials. The methodology for the systematic review is described in Appendix A. Each of the studies reviewed is described in more detail in Appendix D.

BRIEF PSYCHOSOCIAL INTERVENTIONS

There were 16 studies evaluating the effectiveness of brief interventions in reducing deliberate self-harm or suicide attempts. Six studies reported significant reductions in reattempts or completions while 10 found no significant effects for the interventions.

Of the effective interventions, three employed postcards/letters that aimed to express care about how the receiver is doing as well as invite them to respond (without obligation) if they wanted to [54-56]. While considered a 'brief' intervention, contact was periodically continued over a span of one year (for postcard studies) and five years (for letter study), which is likely to have an impact on the efficacy of the interventions.

It is of note that the effective postcard studies were both targeted at individuals who had self-poisoned [54, 55]. Two other studies investigated the use of postcards in individuals who deliberately self-harmed using other methods (which may/may not include self-poisoning) but found no significant reductions in suicide attempts [57{Chen, 2013 #247]. Furthermore, the effectiveness of the postcard interventions was seen only in females but not males. This may suggest that the efficacy of postcard/letter interventions is specific to females who self-poison. It is also unclear how much treatment the control group received in the Beautrais study.

Providing a brief information session and regular contact (via telephone or home visits) soon after discharge from hospital may be of benefit in reducing reattempts and/or deaths by suicide. One intervention resulted in no significant reductions in number of reattempts [58] but was able to lower the number of deaths by suicide compared to TAU [59]. One study examined the impact of a single information session on deliberate self-harm and noted that it may be beneficial for those with prior self-harm episodes yet harmful for those with no prior history of self-harm [60].

Other outcomes have yet to be examined, for instance, time to reattempt or rehospitalisation, and the impact of establishing a therapeutic relationship in the early phases of treatment: it may be that those brief interventions showing an effect have been built upon good early therapy, such as that provided preceding the Postcards from the Edge study [54].

PSYCHOLOGICAL INTERVENTIONS FOR ADULTS

Sixteen studies examined psychosocial interventions for the prevention of reattempts or repeated self-harm in adults. Four of those were for self-harm in patients diagnosed with borderline personality disorder, three of which used dialectical behaviour therapy (DBT) and one, cognitive behavioural therapy (CBT). Each of these interventions had an effect on reducing repeated self-harm or suicide attempts. Seven studies used cognitive behavioural therapy or cognitive therapy. Three were effective in reducing suicide attempts or suicidal ideation, whilst four were not. Three of the studies showing no effect were either brief, had an active control condition, or a very small sample size. This suggests that in more robust

studies, CBT is effective. Finally, two studies of problem solving therapy (PST) showed an effect on reducing suicide attempts.

In sum, CBT and PST both appear to have an effect on reducing reattempts, while DBT reduces repeated self-harm in patients with a diagnosis of borderline personality disorder.

ADOLESCENT INTERVENTIONS

Thirteen studies investigated interventions for suicidality in adolescents. Five studies yielded positive outcomes while eight studies did not report significant differences between interventions and controls.

CBT appears to be effective, with two studies finding significant reductions in suicidal ideation, suicide attempts, and secondary outcomes such as hospitalisation, depression, and substance use, in the intervention group [61, 62].

Parent-focused interventions show promise. One study successfully reduced suicidal behaviours in adolescents after providing psychoeducation to parents to improve family functioning [63]. Conversely, family-based approaches appear to be inconsistent. A brief parent-child intervention provided in the emergency department showed no benefit in reducing suicidality while a year-long psychodynamic family therapy effectively reduced self-harm and depression in adolescents [64]. The duration and type of therapy may be important variables in determining efficacy.

Developmental group psychotherapy, an integrated therapy approach involving techniques from CBT, DBT, and group psychotherapy, reduced repeated episodes of deliberate self-harm in one study [65] but these results could not be replicated in a later study [66]. Further investigation is warranted to ascertain the efficacy of this approach.

HOSPITALISATION

Two studies [67, 68] assessed the efficacy of hospitalisation on repeated suicide attempts and found no significant differences in outcome between intervention and TAU/discharge. Hospitalisation with or without brief problem-solving crisis treatment did not significantly reduce reattempts compared to control.

However, an intervention involving partial hospitalization, wherein patients resided at home and participated in psychotherapy and treatment five times per week for over a year (mean 1.25 years), resulted in significant reductions in suicide attempts and self-harm compared to standard psychiatric treatment for individuals with borderline personality disorder [69]. These benefits were maintained at 18 and 36 months [70]. The intervention group continued to report significantly fewer reattempts 5 years after cessation of treatment [71].

Evidence to support the benefits of hospitalisation after deliberate self-harm is inconsistent. No significant differences in repetition rate at one and 16 week follow-up were observed between low-risk individuals who were hospitalised (for a median of 17 hours) and those who were discharged after presentation for self-harm [72]. Similarly, an intensive psychosocial intervention including a one to four day hospitalisation period followed up by problem-solving therapy did not result in reduced repetition at 12 month follow-up [73]. On the contrary, a randomised trial of two 10-day inpatient interventions (behaviour therapy and insight-oriented therapy) showed significant improvements in suicide attempts and ideation up to 2 years post-treatment [74]. However, the intervention was not compared to an outpatient group; therefore, it is not possible to draw conclusions about the efficacy of hospitalisation specifically. Partial hospitalisation accompanied by psychological intervention is superior to treatment as usual for individuals with borderline personality disorder, but again the hospital-based intervention was

not compared with a similar outpatient intervention [71]. It is possible that hospitalisation alone is not related to fewer re-attempts.

INTENSIVE INTERVENTIONS

Intensive interventions were assessed in two studies [71, 75]. The intensive follow-up did not result in reductions in repeat attempts compared to treatment as usual, while mentalisation-based intensive treatment study showed a larger proportion of participants without severe suicidal behaviours in the intervention group compared to a structured clinical management group [71].

HOME-BASED INTERVENTIONS

One study investigated the efficacy of psychodynamic interpersonal therapy delivered in patients' homes after presentation to the emergency department for deliberate self-poisoning [76]. Suicidal ideation was significantly reduced in the intervention group compared to treatment as usual, and intervention group participants were less likely to report repeated self-harm attempts at 6-month follow-up.

CASE MANAGEMENT

The efficacy of case management in reducing suicidality was examined in two studies [77];[78]. Clarke and colleagues did not find significant improvements in readmission to the emergency department for deliberate self-harm in the intervention group compared to treatment as usual; however, intensive case management in an Australian setting was able to significantly reduce depressive symptoms (at 6 month follow-up) and suicidal ideation (at 12 months) [78].

MEDICATIONS

Three meta-analyses have found that antidepressants do not reduce suicide attempts or suicide when used to treat mood and other psychiatric disorders [79-81], while one more recent review of observational studies found that antidepressants reduced suicidality in older patients but increased it amongst adolescents [82]. Nevertheless, higher rates of antidepressant prescribing correlate with reduced rates of suicide in a number of countries [83, 84], including Australia [85]. Regions or groups with the highest SSRI prescription rates have the lowest rates of suicide in some countries [86], but not all [87, 88]. Those countries which had the greatest increase in SSRI prescribing have also seen the most marked decline in suicide rates [89].

Three studies investigated the utility of medications/supplements in reducing suicidality. The medications included: n-3 essential fatty acid supplement [90], lithium adjunct therapy [91], and SSRI paroxetine [92]. Nevertheless, antidepressants have also been implicated in triggering suicidality in the early phases of treatment of depression, particularly in adolescents [93].

The n-3 essential fatty acid supplement resulted in improved depression scores compared to placebo; however, improvements in suicidal ideation were not statistically significant. Similarly, lithium adjunct therapy did not significantly reduce repeated attempts or completed suicides compared to placebo. SSRI paroxetine was successful in lowering the number of repeat attempts; however, the effects were observed only in participants with fewer than five previous attempts and who did not have a diagnosis of major depression.

Finally, although lacking randomised controlled trials, ketamine shows some promise in treating suicidality, particularly in the presence of depression [94 , 95].

SYSTEMS APPROACHES TO PREVENTING RE-ATTEMPTS

While a range of suicide prevention interventions have been shown to be somewhat effective, more recently the evidence is demonstrating that stand-alone strategies are insufficient. The *most* effective

strategies are multi-level, multi-component, systems-based approaches. For example, interventions such as means restriction, crisis lines, dual diagnosis policies and follow-up after self-harm show promising results [44]; however it is when a range of elements operate in conjunction with one another in a systematic way that suicide risk in the population is lowered and suicide prevention outcomes are maximised. Such systems approaches, for which there is current or emerging evidence, are described below. Continuity of care models are likely to be part of a larger system aimed at preventing suicide *and* preventing reattempts. Only two fully developed 'continuity of care' models were identified in the literature. These are described first:

CONTINUITY OF CARE APPROACHES FOLLOWING A SUICIDE ATTEMPT

Baerum and Norwegian Models: these approaches seek to improve the quality and continuity of care following a suicide attempt, thereby reducing the risk of repeat attempts. They have been shown to be effective in maintaining long-term care through the implementation of a systematic 'chain of care' that links general hospitals and community aftercare services for patients who are discharged following a suicide attempt.

The Norwegian approach has three main components:

1. Close monitoring of suicide attempt related hospital admissions.
2. Systematic psychosocial and suicide risk assessment of people who have had a suicide attempt (in hospital).
3. Structured collaboration between hospitals and aftercare providers to ensure patients receive adequate follow-up treatment ("rapid and active aftercare").

Specific recommendations (seen as indicators of quality of care) require emergency departments to have:

- Monitoring systems for suicide attempt-related admissions which provide data on the number of patients treated after a suicide attempt in previous years.
- Dedicated team/coordinator responsible for care and follow-up of people who have had a suicide attempt.
- Written guidelines including a quality assurance system.
- Training of staff in management and care of people who have had a suicide attempt within the last three years.
- Systematic supervision of staff working with people who have had a suicide attempt.
- Structured collaboration with aftercare providers.
- Routine suicide risk assessments of people who have had a suicide attempt.
- Specific procedure for patients who have not been assessed for suicide risk.
- Specific guidelines for follow-up care of people who have had a suicide attempt after discharge.
- Referrals of at least 90% of people who have had a suicide attempt for follow-up care after discharge.
- Information about available help resources to be provided to people who have had a suicide attempt after discharge.
- Contact with aftercare provider no later than first workday after discharge.

In Baerum (Norway) and Copenhagen (Denmark), a continuity of care model has been trialled to reduce the risk of subsequent attempts/suicides. Upon presentation to the emergency department, patients receive acute life-saving treatment and medical monitoring. The hospital-based suicide prevention team (SPT) is notified and employed to provide crisis intervention, and assessment of psychosocial functioning and suicide risk. Based on the results, appropriate measures are taken with the patients' consent (e.g.,

referral to inpatient/outpatient care). Patients who are not referred to inpatient care are referred to the community SPT, which includes public health nurses and a psychologist. The nurse will contact the patient shortly after discharge to motivate treatment attendance within an acceptable time post-discharge and adherence once the psychological treatment has begun. Most contact will be via telephone. Within the Baerum model, a nurse also assists the person to navigate the health system: where to go, who to see, and what might be the best course of treatment for their particular circumstance. Nurses act as a support and motivator, making contact with the person for up to a year after discharge.

Although a naturalistic study of the initial Norwegian model did not show a benefit, more rigorous research models (a quasi-experimental study and a follow-up randomised controlled trial in Denmark) found that coordinated, integrated and assertive follow-up is an effective approach when engaging with and treating those who have attempted suicide. The randomised controlled trial (n = 133) indicated a significant difference in repeat attempts between the control (21.9%) and intervention (8.7%) groups [96]. The number of repetitive suicidal acts was also lower in the intervention group (8 vs. 22).

This program used a model called OPAC (Outreach, Problem solving, Adherence, Continuity):

- Outreach: active outreach, rapid response, initiating and maintaining individually tailored contact
- Problem solving: solution-focused counselling
- Adherence: act as motivator and supporter for adherence to psychiatric therapy and other forms of treatment otherwise offered
- Continuity: contact with the same nurse throughout the programme, as far as possible [96]

In a quasi-experimental study (comparing a period prior to the intervention in 2002 to the intervention period in 2004), there was a significant reduction in the rates of repeated attempts from 34% to 14% at the one year follow-up.

OTHER SYSTEMS APPROACHES TO MENTAL HEALTH AND SUICIDE PREVENTION

The systems described below are aimed more broadly at improving mental health care and preventing suicide, not specifically at preventing reattempts.

The United States Air Force Program: this programme appears highly effective within a closed community. Within this community there is a universal approach using 11 core strategies, with a focus on stigma reduction, early identification and early intervention. These 11 strategies have strict protocols and are supported by top-down accountability at every level of their implementation within the Force [97, 98].

The Nuremburg, German and European Alliance against Depression: a strong multi-dimensional programme with a focus on depression awareness and suicide prevention through improving depression and suicide literacy and increasing access to care. It also requires significant involvement and support from policy-makers and healthcare providers. Evidence now suggests that the programme reduces suicide [99-101].

The Zero Suicide (Perfect Depression Care initiative): a systems-driven approach seeking to improve healthcare and achieve zero suicides within a health service setting. This initiative is a comprehensive, multiple intervention. It features an all-systems, manualised approach that seeks to eliminate suicide by improving quality and safety in depression care delivery through focussing on safety, effectiveness, patient-centeredness, timelines, efficiency, and equity [102, 103].

SUMMARY

There is evidence for a systems-based approach to suicide prevention, including care after a suicide attempt, where continuity of care is vital in reducing high rates of death by suicide in the period after

discharge from hospital. Hospitals that have implemented a chain of care program attain significantly higher levels on quality of care indicators. Training of staff in care after a suicide attempt and having written guidelines for care after suicide attempt both predict higher quality care. Given the comprehensive changes required, the systems approach requires strong and ongoing commitment from policy makers and organisational leaders.

The following section lays out the findings from our online surveys, semi-structured interviews, data linkage study and review of currently available data. These data collection methods provide a comprehensive picture of the experience of health care services after a suicide attempt in Australia. More specifically, they help to identify the extent to which service users have experienced the systematic approaches outlined above, and where gaps or deficits exist in service delivery.

4. FINDINGS FROM CAASA PARTICIPANTS: WHAT CARE ARE PEOPLE RECEIVING IN AUSTRALIA?

In this section, we use three different approaches to examine the question of what kind of care people are receiving after a suicide attempt. First, we conducted semi-structured interviews with people who have had a suicide attempt, and with those who care for someone who has had a suicide attempt. Caregivers were included in the research because of the vital role they can play in identifying suicidality in loved ones, in assisting them to get treatment, removing access to means, and in supporting their loved one's ongoing recovery. Yet as the results below highlight, they often feel excluded by health systems. As early as the 1960s the role that family and friends play has been recognised in the literature [104]. As our results below show, this does not appear to have translated into Australia's system of care following a suicide attempt. Second, we use data collected directly from people who have had a suicide attempt, and caregivers, via online surveys to describe their health service experiences. Finally, we describe a study which linked three datasets to examine what treatment patients receive following admission to hospital for deliberate self-harm.

4.1. RESULTS FROM THE SEMI-STRUCTURED INTERVIEWS

Semi-structured research interviews serve as a valuable addition to the quantitative component of the current study by allowing a deeper insight into the personal experiences of individuals who have had a suicide attempt and those who care for them. This method of inquiry allows respondents to direct the conversation and perhaps highlight points of interest not yet considered by the researchers, as well as to provide a more in-depth and rich explanation of the patient experience in healthcare settings.

> ... I try so hard to – to be the best person I can and – and to strive, um, to do the best things I can, um, and yet that can be exhausting and – and ultimately just can't cope with living anymore and having to – to face the battle of living but, um – so I guess in a sense I just grabbed life and said okay, you know, we're going to do this but we're doing it on my terms. (Felicity)

.....

Altogether, 32 interviews were conducted with 20 from people who had attempted suicide in the past and 12 from people who provided care for people who continued to be suicidal. Of these 12 caregiver interviews, two caregivers' daughters and one caregiver's son had died by suicide. Each interview was initially coded with a number (simply referring to chronology) and a letter (C – caregiver; A – person who had a suicide attempt); they were later given a pseudonym.

These interviews were semi-structured in nature. While their focus remained on the care and support structures available and appropriate during a suicidal crisis and its aftermath, the stories of the people who had attempted suicide and caregivers themselves also came through in terms of how they had survived situations of extreme trauma, including the three individuals bereaved by the suicide of their child. For this reason, the analytical foundation of this part of the project was grounded in Tamas' 'dirty text' approach where articulated stories of trauma "reach for the redemptive possibilities of thought" (2011, 431). This does not undermine the trauma of these stories; rather, it acknowledges the strength of the narrators as they continue to survive the trauma and work towards a place of healing, even though this is often not a linear process. Tamas argues that silencing trauma is dangerous: "Trauma is rendered unspeakable because it is too dirty and dangerous, a filthy stray ghost dog scavenging on the margins, unfit to let into or house of words" (2011, 444). While it can be difficult speaking about trauma, it can be the only way to exorcise those ghosts, begin a journey of healing, and support others. As Honor said at the end of her interview: "...you know, for me to talk about [my experience] is healing, but also provides, um, people who are in that black hole, um, some hope that they can - can come out of it".

Further, a 'dirty text' approach also allows stories to live with the storytellers – stories are not static events, rather they change with the telling depending upon time, place, and audience. For example, with a suicide attempt, the story may change when told: on an anniversary compared to another day; at the emergency department compared to their home; to a mental health nurse on admission compared to a researcher. This does not make one story 'less true' than another. Instead, Tamas writes this approach "takes a messier view of memory, assuming that our sources of knowing and remembrance operate both within and against social construction and convention" (2011, 447-448). This "suits the post-traumatic condition because I don't need to definitely know anything; my task is not 'emancipate the authentic story of the narrator –none exists – but rather to expose as much as [it] can of the relations that influence the construction of the story that is told"' (Presser, 2005, 2067 cited in Tamas, 2011, 448).

This is particularly important given the previous absence within suicide research of the voices of those who have attempted suicide. Some participants acknowledged that their memories were hazy around some events, particularly initial admission, as they were either emotionally raw or unconscious from the attempt itself. Further, even when people were able to look on their learnings from the attempt as positive, even protective, the time leading up to the attempt itself was described as traumatic in varying ways by all. Here, the stories shared by every participant are analysed as important illustrations of pathways to survival and healing, where the care and support received (both appropriate and inappropriate) are acknowledged as influencing the ways in which stories are told. The narratives of both people who had had a suicide attempt and caregivers are analysed in this way.

The speaking of trauma as redemptive and healing is also demonstrated in the reasons why people participated in the study. Many of the participants hoped that, by sharing their stories, they would be able to help someone else in a similar situation so they would not have to struggle in the same way. This altruism speaks to similar findings in suicide bereavement research when participants were asked why they agreed to become involved (see Dyregrov et al., 2010-2011).

Both the person who had a suicide attempt and caregiver transcripts were coded using a frame based around the broad themes that emerged during initial familiarisation with the transcripts. While the person who had had a suicide attempt and caregiver frames are similar, they do have some differing individual codes. Responses were firstly coded for theme, and then more finely for narrative – the ways in which language was used and the story told as a whole and continuing experience. In this way, each story could be explored and experiences compared across participants.

The broad codes for both people who had had a suicide attempt and caregivers included:

- Basic demographics: ID, pseudonym, gender (and age if stated), state and place, how many suicide attempts over how long a period of time, whether medical or psychiatric help was received after the attempt, whether they were currently seeing a (mental) health professional, and mental illness (if present and stated)
    - People who had had a suicide attempt: whether they cared for anyone
    - Caregivers: who they were caring for and whether the person was still alive
- Previous suicide attempt
- Getting to hospital
- Hospital experience – physical
- Hospital experience – psychiatric
- How did they feel when they survived? (person who had had a suicide attempt only)
- Anything that makes them feel vulnerable (person who had had a suicide attempt only)
- Caregiver's role/non-hospital care (caregiver only)
- Professional support

- Support of family and friends
- How did they find help?
- What helped? What was appropriate?
- What did not help? What was not appropriate?
- What could have helped?
- Stigma around mental illness and suicide
- Advice for others (person who had had a suicide attempt only)
- Advice for other caregivers (caregivers only)
- Impact of attempts
- Self-care (people who had had a suicide attempt only)
- Who takes care of the caregiver? (caregivers only)
- Laughter (after interview questions started)
- Last thought
- Impact of interview

People who had attempted suicide and the people who cared for suicidal loved ones (here, the term 'loved ones' is appropriate as all were talked about as such), provided different perspectives around their connected experiences. All had interacted with myriad physical and mental health facilities and organisations, and all lived with the different impacts of mental illness and the suicide attempt itself. However, knowledge around the treatment received and the support provided differed at times between persons who had had a suicide attempt and caregivers, and at times between different attempts. Further, these experiences also appeared to differ between hospitals, and could be dependent on specific staff. Audrey, whose daughter had recently died by suicide, spoke around the lack of communication from the hospital:

> I know she died. And that she wasn't treated well. That's the only thing I know.

Several important themes and issues emerged from the analysis:

BOX 2: KEY THEMES EMERGING FROM SEMI-STRUCTURED INTERVIEWS

1. What happens if a person does not 'fit' the (mental) health system? This was found to be an issue for those people with complex presentations and comorbidities.
2. The small kindnesses and little things that helped – the human side of our response to suicidality.
3. The need for advocacy within the healthcare system to assist people to find quality care.
4. Many expressed that they felt 'lucky' to find help.
5. The importance of consistent care and staff and its relationship to quality of care.
6. Day-to-day living with someone who remains suicidal (caregivers) is hard.
7. Even with strong coping strategies, surviving day-to-day is still hard.
8. Stigma around mental illness and suicide remains a problem within our health systems.

1. What happens if a person does not 'fit' the (mental) health system?

All but one of the participants sought some form of help from the medical system; the majority of whom received some sort of care from a mental health facility or professional. However, while participants' satisfaction with their care varied, not all people were able to access appropriate care for their specific needs. This was expressed in a general way by Felix and Claire who believed the system catered for people with severe mental illnesses; however, people who were deemed to have 'less severe' mental illnesses, like he did, could not always access hospitalisation after an attempt and were discharged before they felt emotionally ready. Felix writes that hospitalisation would "have been something I would have found some solace in. Would have taken me away from the environment that was causing my stresses". Felix had attempted suicide during an argument with his ex-partner and upon discharge had to return to the home they still shared – "it was a little bit distressing for me but, you know... I had nowhere else to go". He thought the current mental health system needed to encompass a "greater diversity" of needs.

However, two groups appeared to especially vulnerable in terms of simply having no appropriate care to access regardless of their help-seeking behaviours. First, women with eating disorders had great difficulty in accessing appropriate care after their eating disorders; this included Tora and Val who had attempted suicide, and Isabel, Charlotte, and Audrey who cared for their daughters, one of whom had died. It must be noted here that this does not discount men's experiences of eating disorders, rather only women spoke these traumas in this study. Isabel did not have any concerns about the treatment received by her daughter; however, she was unusual in her satisfaction with treatment (see further below) and often used language around 'luck' when speaking about her experiences. The other four all encountered significant stumbling blocks with treatment because of their co-morbidity. Charlotte spoke about the proactive role she had taken in seeking help for her daughter only to find "they wouldn't treat her because she had too many co-morbidities and because she was bulimic as well and she was chronic – they said 'no, we only help acute people' so they wouldn't treat her either". Val gave several examples of hospitalisation which lacked the "holistic integrated care" she needed. While acknowledging the life-threatening nature of both her anorexia and suicidality, Val also argued that one could not be treated without the other although no facility catered to this need:

> And the thing is I need more help for my depression, but I need the eating disorder to be managed while I'm getting help for the depression. But I can't get the depression help because I have an eating disorder. And when I do try to get help for the depression, if they ignore the eating disorder then that gets worse, and then I get too unwell to participate in the depression treatment.... But when you go into the depression unit they don't do any of that stuff and they don't support you to help manage the disorder. So I can't get the treatment I need for depression because they're not managing the eating disorder. But if I go into ED treatment, they're not looking at the depression at all; and I need more help for the depression and the suicidality.

In this way, Val felt vulnerable in the facilities meant to be supporting her because she continually felt at risk of dying, if not from anorexia-related complications than from suicide.

Second, children also had significant difficulty in accessing appropriate care; here, children were classified as those 15 years of age and younger. These were stories predominantly told by caregivers as the suicidal person was not old enough to be included in the study as a participant themselves. These many obstacles were demonstrated by Emma, whose daughter had eventually died by suicide. Emma's daughter experienced different but significant difficulties due to her age – a high-achieving student, she struggled to access her school work during her hospitalisation. While acknowledging the stress her daughter placed on herself, Emma explained that the mental health facility did not help her daughter cope with this stress either:

> ...when she first went into the hospital we said, "We need to get her homework, her classwork from school, 'cause she's already anxious about her schoolwork. Is it possible to take information from the school that I can bring it into her?" And they said, "Oh no. It's all right. We run classes here at the hospital for students." Well, the classes were aimed I think at Grade three; certainly wasn't the classwork that she was doing. She was terribly anxious about trying to keep up. So that when she got out of hospital she could get back into the school things once she got into school. So all of these delays just kept adding to the stress-level...

This girl, described as "the most brilliant, intelligent person that I have probably every known", lost the ability to speak to the professionals trying to treat her, which further hindered any treatment:

> ...as soon as somebody from any sort of medical situation tried to speak to her, she just couldn't talk. She'd explain it as getting this freezing in the throat, and she would try to talk but nothing would come out. So she could talk to me perfectly fine – before she got in there she could talk perfectly fine. We thought after we got out, we would sit and practice what she was going to say when she got in to see anybody. Like when we went back to see a psychologist or anything afterwards. But as soon as she'd walk in the room, it was like shut down. It was the most dreadful thing to watch.

While Emma managed to access care deemed to be appropriate to her daughter's age, it was neither appropriate to her experiences nor was the care consistently or reliably available. Emma found that treatment, when received, was not tailored to her daughter's inability to speak:

> ...I went into a number of the interviews with her because of this communication problem. But she also went to a few on her own. And at one stage there was nothing changing there. And I went into one of these interviews and I said, "You're not doing anything different. Every week that she comes in here you have the same conversation with her. She needs something to work with, something to grasp hold of. Something to give her some hope, you know." And the girl that was her case manager said to me, "Yes. But I have to get to know her first. And because she doesn't talk, I can't do the next step without her talking." And I said, "But she's not going to talk. You've got – you already know this about this person. You need to try something different, you know." "Oh well, we can't. It's not part of our process."

In this way, all responsibility for care and support was placed on the shoulders of a young, vulnerable girl. As she experienced forgotten and rearranged appointments with this agency, and her mother chased up the care promised by this agency as best she could, she lost all hope:

> To be truthful, I think our experience [at the agency] was the most unhelpful thing that happened to her. Because she lost belief that anyone could help her.[...] I repeat the story without any belief that anyone is actually going to, you know, do anything. It's just all another lot of paperwork filling. So they were the things she said to me, nobody actually cares.

Jane, whose 14-year-old daughter had attempted suicide, had a different experience in that she was unable to initially find any help, despite her best efforts. Jane received no follow-up support upon initial discharge from hospital, even though she was meant to be weaning her daughter off anti-depressants, which can be a dangerous time for already-vulnerable people. Jane was further stymied when she tried to find her daughter further mental health support: "...even my GP hasn't been helpful. He tried one psychiatrist that said, "Oh, he wouldn't touch her because she's 14," and it was - that was the end of the matter". Even at the time of the interview, with new professionals in place, Jane did not yet feel hopeful that her daughter was receiving appropriate care: "...I don't think it's enough just to go in there and ask her how she's feeling and have a chit-chat to her for about an hour and then say, 'I'll see you in two weeks'." Jane felt that the health system did not provide enough information during her daughter's hospitalisation: "...I still, to this day, don't know what they actually did to my daughter other than put a

drip on her [...]Or how serious her condition was". Nor did Jane feel that the follow-up care provided was adequate given the age of her daughter and her family situation. Here, she had found people with lived experience provided more practical support: "And the scary thing is the people that are giving me advice on where to go are people that have had to go through the system themselves because of their own problems".

Most worrying within these narratives of not-fitting-in with the (mental) health system was the vulnerability of continuing suicidality and, as with Charlotte's and Emma's daughters, eventual death. Jane still did not feel her daughter was receiving appropriate or effective care. Felix was experiencing "psychological shutdowns" he found extremely distressing and had only begun to talk to a psychologist about. Val struggled to balance her care needs between two serious mental health issues.

1. The need for advocacy within the healthcare system

The immediate aftermath of a suicide attempt – where the person is initially taken to hospital for care – was described by both people who'd had a suicide attempt and caregivers as one of confusion, fear, and uncertainty; although, it must be noted that some people who attempted suicide were unconscious during this time. The journey from the emergency department to a psychiatric unit was one described as "really daunting" (Hope), where neither family members nor the person who had attempted knew what to expect, particularly with the first attempt. Consequently, if care at these different psychiatric units was not perceived to be effective or appropriate, caregivers found themselves taking on the role of advocate for their loved one: "... if I'm not going to be proactive for my daughter then nobody else is going to be" (Jane).

In this way, the health system was not seen to simply be helpful in and of itself; help had to be proactively sought, even if the situation was frightening. One mother spoke about a "mini-riot" that occurred the night her daughter needed to be admitted: "...in the interview process while we were there obviously we could hear what was going on. Um, it was very frightening, um, for her and for us. But, um, we had to stand our ground because she needed help and we needed help" (Sophie).

The need for a caregiver to be a proactive advocate was even more apparent when trying to ensure follow-up care once their loved one was discharged. One mother, whose daughter eventually died by suicide, spoke about the difficulty in simply accessing the first appointment from the service promised as part of the discharge plan:

> So about two and a half weeks after she'd been released by the hospital, I rang them and said, 'My daughter is in a really bad state. I need someone to see her right now'. We can't keep getting put off from these appointments. We need support; we need some help. (Emma)

In this instance, a (very brief) appointment was kept but it did not ensure a positive or helpful experience.

Other caregivers also talked about the increased difficulty in accessing help from (mental) health professionals when they were around. There was a perception that if a child, particularly, had an active caregiver then the caregiver would be able to take full responsibility for keeping them safe. This perception appeared to be grounded in a belief that a parent would do all necessary to keep their 'loved one' from dying by suicide. However, while true, it also ignored the real life situations of many families where: more than one child needed to be cared for; jobs were not always flexible enough to allow time off during crisis situations; the caregiver was also the sole breadwinner as was the case in single-parent households; and, that the caregiver was themselves well enough to continually take on the full responsibility of care (discussed later). Even though she had "five other kids at home", Jane felt hospital staff manifested "a guilt trip on me, 'if you don't stay, we've got problems' [...] As far as the hospital was concerned it was my problem to sit with her 24 hours". Indeed, after her experience, and watching others struggle to access appropriate care, Jane wondered: "How many people are actually dying because they're

lost in a system that either doesn't work or, quite frankly, I think is not actually in place". Jane was a vital advocate for her daughter as they navigated a health system in which she did not fit.

However, while caregivers sometimes saw themselves as being the only person concerned for the welfare of their loved one, this could also be construed as interference within the health sphere. Mothers particularly talked about health professionals presuming that they would be interfering rather than helpful; in this way, the motives of their advocacy was questioned. Emma gave an example of an appointment with one psychiatrist where she had accompanied her daughter to be a support as she wasn't able to speak. The psychiatrist initially presumed this to be an act of control:

> Then he realised that as the time went on that I wasn't an interfering mother. And that actually maybe I had been there all along trying to help my daughter survive this. So by the time we got to the end of the appointment, he was actually much more closer to me.

It was clear in this situation that health care professionals need to talk to the caregiver to gauge their perceptions of how the suicidal person is faring, particularly when that person is not in a state to talk for themselves.

The importance of advocacy was also echoed in the narratives of those who had attempted suicide. The psychache which had made them vulnerable to suicide in the first place did not simply dissipate after the attempt. In the immediate aftermath of their survival, they were experiencing severe emotional pain as well as processing their feelings around survival itself. Some spoke about having advocates including family (Evie) and bosses (Val). Participants often did not see themselves as capable of advocating for themselves during this time simply because they did not yet see their value: "I just think, umm, that when you – that when you're in that position, when you don't want to be around anymore, you're not in a position to advocate for your own care. You know? [Laughs]" (Evie)

Others talked about their inability to actively seek help, or follow-up on the services promised, as they grappled with the raw emotions following their attempt (not all were happy to have survived). After her attempt, Grace felt like:

> I was like floating around in a bit of a mess. And I didn't, like, doing anything was hard. You know, like getting up in the morning and getting ready to do anything was hard. And it was easier just to hide from the world.

She did not feel able to search for, and attend, support that existed. This view was reiterated by Hope who felt a weight in having to be proactive in accessing support services:

> ...I guess my thought process was – was very jumbled and unclear and – and I'd had to, I suppose, take the steps and such to – to get back into some sort of routine and – and the fact that all of the things were at my instigation, I probably found a little hard. Like, there was no – it was kind of like I was responsible for having to organise everything.

Further, when a suicide attempt happened in part because of a person's isolation, the lack of active support extended after discharge only seemed to serve to heighten these feelings of loneliness: "in relation to my suicide attempt I felt very alone, as in help after the hospital. Virtually nil help was available or was offered to me as such at that period of time" (Ed). In part due to this sense of loneliness, Ed still felt vulnerable to suicidality.

Indeed, familiarity with the health system was not necessarily an advantage in accessing appropriate care and support after a suicide attempt. Despite working within the health field, Evie did not feel able to either access the type of care she needed or advocate effectively by herself to gain this care. This was not only detrimental to her wellbeing but made her concerned for others with no experience in the health system:

> I know more of, like, how I should be treated. Umm, what – what my – what my rights are as – as a patient [...] and if I can't get – if I can't get the level of care that – that I need, then I don't really see what hope there is for people who don't know, like, how they should be treated.

Fear for others less able to search for help and support, and information, themselves was also reiterated by Naomi:

> I've had to educate myself a lot on depression, I've read a lot of your research and stuff at the Black Dog Institute and that has really helped but it's a shame that people have to self-help. You know, so and I'm – and I'm quite educated, so I worry about the people who aren't, you know, and who don't know how to look up these things and so forth.

These comments indicated a need for support systems and (mental) health services to be more proactive in following-up people discharged from hospital after a suicide attempt – or even at the point where a suicidal person initially seeks help at a general practitioner. The responsibility for accessing care cannot be placed on the person who has attempted, or their caregiver, as neither may be emotionally able to deal with that kind of advocacy after discharge, when vulnerability to suicide has been shown to be highest.

2. Lucky to find help

As both caregivers and people who'd had a suicide attempt spoke about the need to proactively seek effective and appropriate care, language around 'luck' (lucky/chance/fluke) tended to centre on experiences of finding help that suited the person who had attempted suicide after discharge. The language of luck was more predominant among caregivers where it was easier to find help when you were already entrenched in the system, often after several suicide attempts; it was 'lucky' to find help when you were not yet entrenched. Here, follow-up care was not guaranteed post-discharge and people had to find their own professional support: "...it was only through sheer fluke that we stumbled across him. Like, it was just someone, he's a bulk bill doctor and we – we were just desperate..." (Anna).

Luck, and lack thereof, was particularly pertinent in the experiences of caregivers of suicidal children (the youngest being 11 years old). As described above, these vulnerable children did not seem to fit anywhere as the support for their age group was not suited to their complex needs and they were sometimes deemed too young for other formal community mental health care. In one case, an education-based program suited the needs of a teenage girl: "...by pure chance we found out about this alternative school and, um, we never looked back after that" (Sophie).

In another, 'bad luck' left a young girl without care. After her suicide, her mother sought answers from the organisation meant to handle the post-discharge support:

> ...they were asking all these questions. 'But didn't you get peer support? Didn't you get this happening?' I said, 'No. None of those things happened to me.' So I think those things are supposed to happen really early on in the process. But they've all been missed for us. Maybe it was just – it was just bad luck, really I think. 'Cause as I said, it wasn't that it wasn't part of their process. We just had never been given it – and no one ever checked to see if we had received those services. And so they were quite upset when I went to that afterwards interview, that – that we had not received any of these things. (Emma)

Yet, the most positive experience of the health system overall was told by a mother whose 14-year-old daughter had attempted suicide five times within a six-month period. She recognised though that her experience was not always achieved by her peers:

> My experience of the healthcare system has been amazing. I really, really cannot fault it. And I know I am incredibly lucky in that regard. Because it just – and it is totally – I have spoken to

> people whose child has made attempts, and they have gone, 'We don't even have a psychiatrist.' So, really? (Isabel)

Further, Isabel also admitted that she would not know how to find appropriate help had her daughter simply felt suicidal rather than made an attempt. In this case, the attempt was perceived to be serious enough to garner follow-up care: "It is really tricky, because I think it was luck of the draw that we were, um, snapped up when we were. Um, I don't know. Do you know, I wouldn't know how to access it?" (Isabel).

People who had attempted suicide talked about luck in terms of the type of care they were able to access. This was articulated in two ways. The first was whether the person was able to access the private health system, which was deemed better than the public system:

> I've been really lucky to, umm, be able to afford to get private health cover and to go and – go and access, umm, programmes in Perth, umm, that a lot of people, sort of, can't afford. And also been lucky to – like I was saying before to know my – know where I stand and know how I should be treated and, umm, have people just, sort of, try and, umm, help me to advocate for better treatment for myself. (Evie)

Second, as also demonstrated by Evie, Gaby, and Felix, luck was articulated in whether a person was able to access care that was appropriate to their needs, both emotional and financial: "I've been really lucky. I actually have two psychologists now...through the university I can get access to psychology services" (Grace). She felt particularly lucky that one was a clinical psychologist as his skills suited her needs. In more regional areas, others, like Kay, felt lucky they had access to any support at all.

3. The importance of consistent care

In general, once accessed, the type of care that was considered most helpful and appropriate was consistent, where the person who attempted suicide and their caregiver saw the same person/people each time. While acknowledged that this was not always possible in the emergency department, having to retell one's story of suicidality to a different health professionals at each consultation was emotionally painful for both parties. Emma talked about retelling her daughter's story as another hurdle to overcome in seeking care. It was a tiring and apparently useless process:

> ...when you walk into the psychiatrist appointment when you first have it at the hospital, you get asked your whole story. So you tell the whole story. And then the next day the psych that's actually on the ward interviews you, and you go through the whole story. [...] And you go, 'Haven't you got all this information already?' 'Oh on record, yes, but we have to ask the questions now.' By the time you get through repeating that story five or six times you go, 'You know what? I know nobody is listening to me'. (Emma)

The need to retell the story often appeared to be the result of poor record sharing between physical and mental health facilities, and even between professionals at the same facility:

> There needs to be a system where if the GP is responsible for managing your mental health plan, the people that have been looking after you in hospital pass all the crap over about you. So that all of your records are in one place. And it's not up to you to go chasing the universe to get stuff transferred back and forth. (Grace)

This lack of basic information sharing, and the negative impact this had on the people having to retell the story, appeared to reaffirm the idea that seeking appropriate care and support within the healthcare system was neither an intuitive nor easily-accessible process. Indeed, at times, it particularly hindered the help-seeking process in children by frustrating them to the point of tantrum:

> ...she was so sick and tired of rehashing her story that she put on this manic act where the psychiatrist was ready to call the police and take her to Bentley adolescent. And I said, 'No, you don't need to do this. She's putting this on because she's so sick and tired of the process that she has to go through. All we want is the script, you know.' She, you know – but it was just – it was just – it was ridiculous. (Sophie)

These feelings were also reiterated by Zara, who at 24 years of age identified as being suicidal since the age of eight. Her struggle to access consistent mental health support meant more than having to retell her story but knowing that the story would be received in a supportive manner. Zara gave examples of inconsistent caring that she and others she knew had experienced:

> ... having to re-tell their story over and over and over again, um, because it's just not something that they need and then to have one person that might be really kind to them and the next time you get this absolute bitch on the other end of the phone saying that you're not sick enough for them to call you [...] I was getting two different people as well and so I told them that as well. I said, "Look, can you – just one person call me," because it seems to be that that's the kind of thing that mental health seems to do, like, just one file and it's just chucked around [...] it's not cool.

When considered in terms of how difficult some people found it to access care in the first place, it is concerning to think that support may not be consistently offered by services. There is an implication here that mental health professionals need adequate and intensive training, mentorship, and support to ensure they are able to provide the care and support needed by people who have attempted suicide.

4. Day-to-day living with someone who remains suicidal

Caregivers not only had to be an advocate for their loved one but they often also provided practical day-to-day care as well. Caregivers took their loved one to different physical and mental health appointments, they scoured the internet and community sources for different support strategies, and they often balanced this with their own employment and family commitments. Yet, their loved one's survival was not up to them. When talking about caring for her mother who had attempted suicide several times, Caroline said: "... it's...very much swimming in a black pool and – with a little spark of light coming along every now and again". Caroline's mother lived her family and she looked after her everyday needs, including her mother's medication. Despite all her care and precautions, Caroline knew her mother remained suicidal:

> Um, which means we live in this constant fear, where if I go out for the day, even though she has no access to any medication, but if I go out and I know she's not doing very well, I come home with this feeling of dread, going, what are we going to find [laughter].

This fear was echoed by Louisa, the sister of a man who had struggled with mental illness and suicidality for many years. However, Louisa had begun to come to terms with the fact that her brother may die – and that his death wouldn't be her fault:

> ... like my brother has been ill for 18 years, so since I was, like, 10, um, but I think you learn to realise that you can't predict or prevent it and you know unfortunately it quite likely that at some point he will do that and it's awful and it makes me feel sick in my tummy but, um, I can't take responsibility for him living or dying. If – if he wants to make that decision at some point, then it's going to happen. There nothing I can do about it. In the meantime, I will try my best to support him.

While several of the caregivers spoke about their own struggles with mental health and wellbeing, particularly in the time since their loved one had become suicidal, Sophie specifically talked about her own suicidal ideation:

> I've been close, um, you know, to wanting to take my own life..... I call Dad and just say to him, you know, just to talk, to let me cry, just to let me talk. Once I do that I feel myself literally, I've left that darkness that's been there with me for a little bit. And, you know, then that will happen every couple of weeks or so. I don't think I would ever follow it through. But there's always – the thought is there.

However, Sophie's only support appeared to be her father; she didn't seem to share these feelings with anyone else: "I put out to a lot of people that I'm okay. You know, I tell everyone I'm fine. I'm fine. Although, you know, I'm not [laughter]".

Little support seemed to be formally available for caregivers who spoke about the need for more information about how to most effectively support their loved ones, as well as other family members and themselves. As Audrey grieved for her daughter, she said: "...it's not just the person with the mental illness, it's everyone who is left afterwards, and it's horrible it is, it's just horrible [crying]".

5. Even with strong coping strategies, surviving day-to-day is still hard

Surviving a suicide attempt did not necessarily mean the end of vulnerability nor did survival extinguish any of the myriad factors which fed a person's psychache. Continuing survival, and finding a way to live life that was more than mere survival, was often a complex process. People who had attempted suicide spoke about the difficulties of not acting upon their suicidal ideation, especially as life did not seem to get any easier the longer they survived: "... the older I get the harder it gets; it gets harder every year, ah, because it's like this is all I've got to look forward to, you know" (Clem).

Having accessed appropriate support, either medical or social, some women talked about learning how to live well after their suicide attempt, while still acknowledging that this was not always a straight-forward process. Bree's family was important to her continuing survival: "knowing that I have family who care for me and love me, and everything, I can't – I – I don't feel comfortable anymore about – about committing suicide again... I don't think I want to put them through that". Felicity also talked about navigating the reactions of her family as she tried to find a way to live well:

> I've tried twice and it's not worked. So, as a result I'd better find a way of living.... So in addition to having to deal with the fact that I was still alive I was also having to deal with a huge amount of guilt, um, about what I'd done, um, to my family and friends. Um, so it was a very head thing to do, a very, you know, thought out thing that I actually have to find a way of – of living that – that's authentic for me, um, ah, which wasn't the easiest thing to do, um, but it – it certainly has meant that I've changed my life and the way that I react to things significantly.

Similarly, Honor had found mindfulness (as part of a therapeutic toolbox) to be protective against suicidal thoughts. However, she also realised this would be a lifelong process. Honor wouldn't necessarily stop having suicidal thoughts altogether:

> And so once you get really used to using them, then if you do get, you know, bailed up by a black thought or whatever, then you don't need to feel scared that you're going to commit suicide. [...] But you can actually look at what caused it, and you can look at, um, what feeling you're experiencing at that time, is there a trigger? Um, you know, the - it's really endless [laughs].

Other participants struggled more with finding effective coping strategies, particularly against strong suicidal thoughts or during vulnerable times: "... I self-medicate with wine and Seroquel, which is not ideal, but at least it doesn't – at least it gives me some buffering. So that I can just forget about it for a while, and shut my mind down" (Grace). While Grace had other coping strategies, including exercise, these were not necessarily effective "in the beginning" of suicidal ideation; these were strategies that, while effective, took time. Time was not always available to people when severe suicidal thoughts could appear almost unexpectedly:

> ... I know in the last couple of months my thoughts have been so – so much more active about, like, it – it has to be the end. Like, no more of this – this, kind of, like, pussy footing around. Like, it is going to be the end.... Like, I mean, I can safely say that I am totally fine today and I have no thoughts even of it. But it is like, I don't know, it can change [...] because I know how powerful they get. (Tora)

During Tora's long struggle to survive and live well with an eating disorder, she needed to be constantly aware of her thoughts, and what they meant in a particular time and space; Tora needed to be able to work through severe suicidality at any given moment simply because these thoughts were not always triggered by something tangible.

In this way, the idea that any one therapy or medication alone could necessarily 'fix' someone's suicidality was not only inaccurate but also offensive to participants:

> ...you need to have health professionals that understand that this stuff just doesn't go away in five minutes. And you know, eating pills isn't going to just fix it. And everything will just be all right. And that they can – they will deal with it for as long as it takes for you to get over it. (Grace)

In this way, participants talked about needing to find the right type of support for them – and this may differ from the right type of support for another person or, indeed, the right type of support for the previous attempt. Felix considered living well after his suicide attempt, and finding the right support, as a "personal journey". Other participants, including Gaby and Beth, had negative experiences with some health professionals; Gaby had now found someone who suited her while Beth was thinking about seeing her general practitioner for a new referral. However, this took time, and it took an understanding general practitioner who was willing to formulate a mental health plan that allowed them to try another psychologist when the first was not appropriate.

Further, Alisa talked about her inability to afford specialist treatment after using up all her sessions under the Better Access program. She was uncertain about what do in terms of future psychological treatment, and had previously relied on the kindness of her service provider to see her on the day of her attempt without worry about payment. Charlotte also talked about the cost of her daughter's dialectical behaviour therapy (DBT) sessions and admitted she wouldn't have been able to afford them without private health insurance. She argued that one way to improve the care and support offered to people who had attempted suicide would be to democratise access to all sorts of care for as long as needed:

> Um, well, for a start not charge as much because normal people can't afford to be paying $180 an hour to see a psychologist and - and mental illness isn't fixed after 10 visits [laughs], you know. And that's all you get on the mental health plan and then after that who's got that, sort of, money to continue paying it.

After her son's suicide, Lucy talked about the lack of support offered to her as a bereaved parent. She had been unable to afford the psychologist visits once her mental health plan had run out.

6. Stigma around mental illness and suicide

Linked to the myth of a 'quick fix', participants spoke of the continuing lack of understanding and stigma around mental illness and suicidality. The psychache they endured everyday was invisible and, as such, was not taken as seriously as physical pain: "...the general public don't, sort of, you know, they think, oh, it's a terrible thing, and it's a selfish thing, and they don't have any comprehension of what's going on with the person and the amount of pain" (Clem). Similarly, Sophie argued that "there's not a lot of understanding behind why people attempt suicide, and – and the real stigma out there that it's just attention seeking". It should be noted here that participants were not asked directly about stigma; rather, those who talked about it gave examples of either internal or external stigma (or both) as reasons why the

care they had received was inappropriate or unhelpful, or why they had struggled to tell their story and seek help in the first place.

Stigma was perceived to still attach to mental illness. When a mental illness was diagnosed, people talked about a sense of fault within themselves, that there was something wrong with them. Emma spoke in great detail about her deceased daughter – an intelligent, caring young girl whose anxiety made her stop speaking, and who found solace in pet therapy. She conceptualised her daughter's experience of mental illness comparing it to a physical one:

> ...with mental health, you're already criticising yourself, and blaming yourself. Because I don't have cancer that I can point to. So therefore, 'It must be my fault. It's happening to my brain. I'm doing this to myself'. So when you have anything that actually confirms that belief, you just make the situation 10 times worse... But to her she felt she was responsible for her own mental problems. She must be to blame because, you know, what could you pinpoint it on? [...] Therefore she's thinking, 'oh I don't really have an illness; I'm making it up – all up in my mind'. (Emma)

Participants, both those who had attempted suicide and caregivers, also spoke the stigma attached to suicide attempt and death. Ed felt "embarrassed about the whole thing" after seeking help for his suicide attempt. Gaby was "embarrassed" to talk to her general practitioner about her experience and to seek further help. Audrey called herself "a bad person" for not having been able to save her daughter's life.

Further, the stigma attached to mental illness and suicide – these feelings of embarrassment, blame, and lack – stopped people from seeking help when they needed it most. Louisa believed stigma was the only reason her brother would neither actively seek help nor adhere to the support offered. Trudie lied in the emergency department about how her injuries were caused simply because she did not want to talk about how she was feeling or admit to what she had done. For this reason, she had received very little follow-up care after her attempt. While seeing a psychologist for other reasons, Trudie had not spoken about the attempt until approximately six months later even though she acknowledged the psychologist was "extremely helpful".

Indeed, Trudie's story highlighted how difficult identifying and helping someone who is suicidal can be, even if they are already embedded into a support system. In contrast, Beth had not sought medical help at all after her attempt, and asked for little help from her friends, as her "personal pride" got in the way and she did not want to be a "bother". Beth's isolation from almost any support – and the ease in which this occurred as she simply woke up after an overdose and went about her day without telling anyone what had happened – highlighted the opposite problem to that faced by people like Trudie. How can support be targeted to people who simply remove themselves from the system? The question must also be asked as well of those people who fall in-between – people who have been suicidal in the past, are not suicidal now, but are vulnerable to becoming suicidal in the future. Along with Claire, Felix, and Evie, Naomi argued that the current (mental) health system only really caters for people who are acutely suicidal and who have attempted suicide. They do not take care of people who are struggling to live well every day after their attempt and are looking for supports that empower and enable them, rather than solely pathologise them and medicalise the support offered. Naomi argued:

> ...the thing is that I worry about the people who don't, you know – I just wonder how many people, if somebody had got to them earlier and we didn't make it such a big hoo ha about being a mental health patient and how many people could be saved because I know that right now, I mean, I'm not suicidal at the moment but, you know, I've got an awful lot of pressure on myself to get better and, you know, I just feel like the whole system disables people like myself when it should be enabling.

Indeed, in her search, Naomi had found cartoons depicting mental illness to be "extremely helpful.... because you can actually put your illness into that dog and you can see it for what it is"; she was able to think about her situation outside of her own experiences and see how other techniques might work.

Lucy found that one of the few places she did not experience stigma after her son's suicide was in the support group. Here, she was around people who had been through similar experiences and with whom she could talk freely about her grief. When talking about the way other people, including her colleagues, had treated her, Lucy said: "we all deal with it in our own way and that's okay, but, um, people don't need to be looked at if they've weird or strange or [...] put in the too hard box".

Yet, even when help was sought, stigma was found among people who were meant to provide the care and support. Nurses and doctors within the emergency department and mental health units were a particular example, in part because people felt vulnerable within these environments after surviving their attempt. Stigma in these situations was reported by both people who had had a suicide attempt and caregivers. When her daughter was admitted to the emergency department after an overdose, Anna said "one of the nurses was really quite, um, aggressive. She – she believed that [my daughter] was taking up valuable bed space and was a waste of time". A similar experience was also shared by Jane whose daughter had attempted suicide several times. When describing the attitudes between the attending doctors and nurses at different attempts, Jane said: "...before when she threatened to commit suicide the doctor that treated her cuts and stuff, because she self-harms, was very judgemental... some of the nurses in, um, the emergency department were actually quite rude and abrupt". In contrast, the doctor at the most recent attempt had not been judgemental. These experiences were also shared by Charlotte and Audrey. The ways in which these stories of stigma were told demonstrated the distress these caregivers felt as they watched someone they loved, who had tried to take their own life, being treated in a way that did not indicate care for their wellbeing.

This distress was also felt by Amity and Naomi, who both talked about experiences of judgemental doctors and nurses:

> ...actually there was a doctor who came in with their – with his, um – I think they were interns or something like that. Um, and they came in and he basically told me off for trying to kill myself and said that was a very stupid thing to do and not to do it again. (Amity)

> ...in emergency for example, um, the nurses would hardly speak to me, I was told by one nurse, 'Well, that was a stupid thing to do, wasn't it'? Um, there was very little care or empathy shown [...] I was left to my own devices, nobody really checked on me, um, and I noticed there was a clear difference because I was with other patients that had other medical conditions, um, and I just found the whole thing quite discriminatory. I was definitely treated differently. (Naomi)

While these negative experiences did not greatly hinder Naomi's help-seeking as she considered herself quite proactive, Amity's belief that she would be able to find help was dented, especially as she did not find her psychologist's advice useful. Amity considered that the healthcare system "wasn't helpful and possibly even made my recovery even slower".

This feeling was also shared by Andrew. While his attempt had occurred 20 years previously, his experiences within a mental health facility obviously continued to impact upon him. After escaping from a locked ward, Andrew attempted suicide and, after several hours, walked back to the hospital:

> And when I walked in they put me in a room by myself. No one comforted me or really asked me – no one had asked me what I'd done or where I've been. They put me in a room by myself until a doctor arrived and he gave me stitches and then they bandaged me up, all the time only the doctor was really with me. There was one other guy who was sort of hovering around, but no one sort of questioned where I've been or offered me a drink or something to eat, because I was

> clearly thirsty I think. Um, I lost a lot of blood. And, um, then they threw me in the lock up ward. [...] Like a prison.

After this experience, Andrew initially "didn't think there would be anyone out there that would take the time to listen or – or care or have any other way of treating me other than the way I was being treated". He had only recently accessed new support with a general practitioner and psychiatrist who were effective and caring. Yet, even after his experiences and especially since he had found appropriate support, Andrew could see some positives in the treatment he received. He believed individuals were more at fault in some ways than the system itself:

> In relation to the suicide attempt I think that they were good but there were certain people there that were quite nasty. You know what I mean? Um, and I think they would be nasty if I had a heart attack too. Um, so it's just that particular person.

Another point raised by both people who attempted suicide and caregivers was the stigma around some mental illnesses. Since a recent re-diagnosis, Andrew believed: "it's more acceptable to have bipolar than schizophrenia in society". Audrey felt her daughter's diagnosis of borderline personality disorder (BPD) made her suicide attempts more likely to be labelled as non-serious and attention-seeking. However, more than this, some participants felt that there remained a very narrow view around the types of mental illnesses that were connected to suicidality and that were effectively treated. Kay spoke about her difficulties in accessing appropriate care because she was not acting like a 'depressed person' – the seriousness of her suicidality was not acknowledged until she had made the attempt.

Further, and as discussed earlier, Audrey also believed that people with comorbidities were falling in the gaps and not receiving the help they needed. While stigma may be increasingly dismantled with regards to depression and anxiety, and their links to suicide, Audrey did not believe this to be the case with all mental illness:

> I find it upsetting that there is a promotion of help for people who have depression – which I think is absolutely wonderful – but there is no promotion of actually people who have an associated mental illness. I don't think that helps those people with the mental illness at all. I think that needs to be recognised, that there is a lot of people out there with a mental illness apart from depression who are not being treated as well.

Audrey believed her daughter was not alone in her lack of appropriate treatment – that these gaps continue to put others at risk.

7. The small kindnesses and little things that helped

However, while experiences of stigma and instances of inappropriate support were not uncommon, participants also mentioned what they had found helpful and appropriate. Many of the participants who had attempted suicide mentioned the helpful general practitioners, psychiatrists, psychologists, and other health professionals they had found. This included Tora, Andrew, and Gaby. Others mentioned the support of family and friends, including Amity, Hope, and Naomi. These were often talked about in terms of their over-arching support.

However, others also mentioned things that may seem small but, at the time, made all the difference to them as they tried to navigate a daunting environment in a raw emotional state following their suicide attempt. Sophie's daughter reacted more positively to the introduction of pets within the hospital as part of her therapy than interacting with any person: "...maybe that's because she didn't have to speak to the pets.... To be able – I guess have affection, and all the other things that go with having animals around". Clem talked about having her own room at the hospital when she "really needed that peace and quiet, and tranquillity, and no-one around me". While Alisa did not find her hospitalisation as peaceful, one social worker made her recovery more positive:

> It was just, you know, like people went out of their way to do little things, like, um, you know, it might be like the social worker - apart from coffee, whatever, the social worker went and got me some fresh clothes because I didn't have any, like, I only had the clothes that I was wearing at the time, but then, I obviously like I didn't have anyone to, not by choice, didn't have anyone to come visit, so, um, so I was wearing the same clothes like four days in a row, or apart from like hospital gowns that were all too big anyway, so it was just, um, yeah, it was more like people going out of their way whereas the actual system really, really sucks [laughs].

It is these small kindnesses that helped people who had attempted suicide feel cared for within the health system. Andrew argued that the system should always be like this where its role is to "treat you like you're a human and not an animal, or a number in the system". He had only found this in recent years.

These kindnesses were also found outside the hospital system. Honor did not find her hospitalisation positive and, upon discharge, still felt vulnerable. She called her general practitioner one morning and he cancelled all his appointments to spend time with her and arranged for different referrals. He made follow-up appointments with her as well until she felt better again.

The stories shared within this project, by both people who have attempted suicide and the people who care for their suicidal loved ones, are vital in understanding how people survive the trauma and vulnerability that suicidality brings. Further, the stories shared also illustrate the importance that such research continues to involve the people at its very heart – people who have attempted suicide and people who care for them. At the conclusion of each interview, each participant was asked how they felt. While some felt a little emotional given the story told, all were pleased to have been able to participate and happy at the opportunity to tell their story:

> I really wanted to add - add something to the situation and - and I thought, well, I want to be able to do this. (Claire)
>
> I appreciate being given the opportunity. I think that's one of the key things that's missing, is actually getting feedback from people who attempted suicide, you know. (Felicity)
>
> ...I will be okay. Yeah. I – you know, I'm okay when I feel like I can do something. And what was so frustrating about watching my daughter so unwell, was not being able to do anything. [...] So if I know I can do something as a result of what's happened, then that's good for me. (Sophie)
>
> In fact, it's good to talk about it and tell somebody about your treatment because nobody asks [...] so it's really nice to have somebody who will listen and, you know, you can tell them what you think. So no, I'm fine but I do appreciate that, it's very kind. (Naomi)

Indeed, Naomi's point is incredibly important in developing future research plans. The stigma which continues to underpin mental illness and suicide within society infiltrates our ways of research where it is too often presumed that people are not capable or unwilling to talk. These interviews demonstrate the whole-hearted and courageous way in which people are willing to share their stories to someone willing to listen with an open mind and without agenda, and as a way to help others who may be experiencing a similar situation. For that, the writers of this report acknowledge the participants for their generosity in sharing their experiences.

The current narrative around suicide is one very much based in prevention, intervention, and bereavement. While inclusive of all of these, the participants' stories here also reflect the liminal space of survival in-between days of suicidal ideation and acts and days without. Hearing the stories of these spaces, and understanding what keeps someone alive during the days of suicidal ideation, will allow for more holistic practices that incorporate a person beyond their mental illness and acknowledge the journey that healing will take, rather than simply looking for quick fixes. A whole-of-life approach must be taken

in order to support a person to live well after a suicide attempt and to better support people who undertake caring roles.

In the next section, results from the online surveys describe peoples' experience of health services following a suicide attempt from a more quantitative perspective. The surveys complement the semi-structured interviews through the use of data analytic strategies which examine the frequency of certain experiences and the relationship between variables.

4.2. RESULTS FROM THE ONLINE SURVEYS

The online surveys were conducted to collect views about the health system from those who had had a suicide attempt and their caregivers. We asked questions about peoples' experiences and about the kind of changes they would like to see in order to improve the ways in which the health system responds to individuals and their caregivers following a suicide attempt. We sought information from those who did not attend a health service about the reasons for not doing so.

For the final report, we are able to report on data from 112 individuals who have had a suicide attempt and 81 people who care for someone who had a suicide attempt. Our inclusion criteria were:

- Had a suicide attempt between one and 18 months prior or cared for someone who had a suicide attempt during this time period
- Resident of Australia
- Aged 18 or over

Participants were recruited via social media, through Google ads, and through websites of the Black Dog Institute and consumer and caregiver organisations. The online survey took approximately 20 minutes to complete. Participants provided ratings of their mood state before and after the survey. Those who completed the survey were invited to contact us to take part in an interview for the semi-structured component of the study.

Pre and post-survey distress

At the beginning and end of the surveys, participants were asked 'how (sad/irritable/agitated/anxious) are you feeling right now?' There were two reasons for doing so. First, it provided participants the opportunity to reflect on how they were feeling and to engage with Lifeline if their feelings were overwhelming. Second, very little research is conducted online with people who have had lived experience of suicide. As such, we wanted to collect some data to determine the impact of this type of research on participants. There were no significant differences between the pre and post-survey scores (Table 1).

Table 1: Pre and post-survey emotional ratings

Emotion	People who had attempted suicide		Caregivers	
	Pre-survey score	Post-survey score	Pre-survey score	Post-survey score
Sad	5.5	5.6	4.2	4.5
Irritable	4.8	4.5	3.2	2.6
Agitated	4.7	4.7	2.9	2.6
Anxious	5.5	5.5	3.6	3.4

RESULTS FOR PEOPLE WHO HAD A SUICIDE ATTEMPT

Participant characteristics

Those who had a suicide attempt had a median age of 31 years (range 18-59 years). The majority of participants were female, in paid employment, not in a live-in relationship, and identified as heterosexual (80%). An overwhelming majority had a current or lifetime psychiatric diagnosis (as categorised by World Health Organisation's International Statistical Classification of Diseases and Related Health Problems version 10 (ICD-10)[105]; see Appendix E), the most common being a mood disorder (Table 2).

Table 2: Characteristics of those who have had a suicide attempt, online survey

Characteristics	Percentage n=112
Demographics	
Female	80
Married/defacto	37
Employed	57
Indigneous status	2
Education	
Completed year 12	27
Completed trade or diploma	30
Completed university degree or higher	34
Living situation	
Alone	13
Family	67
Friends/flatmates	5
Other	2
*Psychiatric diagnoses (current or lifetime)**	
Any psychiatric diagnosis	95
Mood disorder (incl Bipolar disorder)	80
Anxiety disorder (excl PTSD)	57
Personality disorder	18
Any psychotic disorder (incl. psychosis)	2
Eating disorder	12
Substance use disorder	5
PTSD	22

*Variables were not mutually exclusive; could select more than one category

Characteristics of suicide attempts

The mean number of lifetime suicide attempts and hospital attendances following an attempt was three. One quarter of the sample had five or more lifetime attempts (Table 3). The most common method used in the most recent attempt was self-poisoning (overdose) followed by cutting. Just over half required medical treatment following the most recent attempt and the vast majority were in contact with a treatment service in the week following the attempt. More than half had a psychiatric evaluation in the week following and a similar proportion completed prescribed treatment.

Table 3: Characteristics of suicide attempts

Lifetime suicide attempts	Percentage n=110
1	26
2	22
3	14
4	15
≥5	25
Hospital attendances following SA	
0	18
1	31
2	20
3	13
4	7
5	2
≥6	9
Timeframe of recent attempt	
Within last 3 months	14
Within last 6 months	21
Within last 12 months	24
Within last 18 months	42
Method*	
Poisoning	60
Motor vehicle exhaust	5
Hanging	6
Firearms	0
Jumping	3
Cutting/piercing	20
Drowning	1
Other methods	5
Medical treatment required	54
Contacted treatment service(s) post-attempt *	96
Psychiatric consultation within a week of attempt	57
Completed full course of recommended treatment	61

*Variables were not mutually exclusive; could select more than one category

Adequacy of help and barriers to help-seeking

Less than half (47%) of the participants felt that the help they were offered immediately after their most recent suicide attempt was adequate. After discharge, 41% felt the help they were offered was adequate; and at six months, 45% rated the help as adequate. Of those who saw a mental health professional after their attempt (59%), three-quarters rated their experience as somewhat or very helpful. About 10% thought it was a little or not helpful, with 15% unsure. When asked why they did not receive enough help in the six months following discharge, concern about poor health service staff attitude was most

commonly selected (19%), followed by being afraid what others would think (15%), not being able to afford services (13%), thinking no one could help (11%), asking but not receiving help (10%), not knowing where to get help (8%) and preferring to manage it themselves (7%).

Help-seeking behaviour

More than half (57%) of the participants did not tell a health professional about their suicidal ideation prior to their attempt, primarily because they did not want to be stopped, they felt ashamed, felt that no one could help them, or did not want to be admitted to inpatient psychiatric care. Close to half (44%) reported that they would not tell a health professional in the future.

Eleven participants did not seek any treatment following their most recent suicide attempt. The main reasons centred around treatment being unwanted or pointless (Table 4). Of those who did not seek help, the factors that would increase the likelihood of help-seeking were essentially relational: seven of the respondents endorsed 'assurance services would provide caring, respectful treatment' or 'better relationship with mental health professional'.

Table 4: Reasons for not seeking help

Reasons for not seeking help post-attempt	N = 11
Severity level of outcome did not warrant treatment	3
Self-treatment	6
Treatment was unwanted	7
Treatment perceived to not be required	2
Negative previous experiences of treatment services	4
Fear of involuntary hospital admission	3
Depression too extreme	3
Help-seeking seemed pointless	7
No motivation to seek help	4
Hopelessness in future	4
Lack of knowledge of treatment services available	1

First, second and third points of contact

First point of contact was typically ambulance/police or emergency department, followed by a non-health professional (e.g. family, friend) (Table 5). Most did not have contact with a second or third health service. The second point of contact was most commonly a psychiatrist followed by emergency department or a psychologist/mental health worker. The most frequent outcome of the first contact with a health service was being taken to the emergency department, followed by admission to a psychiatric ward (Table 6).

Table 5: First, second and third points of contact with the health system

Type of service – initial point of contact	First contact (%) n=95	Second contact (%) n=33	Third contact (%) n=15
Ambulance/police	24	6	7
Accident and Emergency department	20	12	0
Family/friend/neighbour/stranger	17	3	0
Telephone helpline / crisis service	10	3	7
Suicide prevention crisis team	4	6	7
General Practitioner	4	9	13
Psychologist	3	12	20
Counsellor	2	0	7
Mental health/social worker	2	12	7
Psychiatrist	1	27	20
General hospital medical department	1	9	13

Table 6: Outcome of first and second contacts with health service

Outcome	First contact % n=112	Second contact %
Taken to Accident and Emergency Department (AED)	25	11
Admission to psychiatric ward	17	15
Advised to see General Practitioner	8	4
Triage assessment; subsequently discharged	6	7
Psychiatric follow-up arranged by AED staff	6	4
Prescribed medication	5	11
Referral to psychologist	5	12
Letter for health professional by AED staff	5	3
Helpline/crisis team/friend contacted police/ambulance	5	-
Treatment of physical injury; subsequently discharged	4	2
Admission to general medical ward	4	4
Discharged without assessment or follow-up	3	2
Discharged and referred to follow-up	3	5
Self-discharged before full treatment completion	2	1

*not mutually exclusive; could select multiple options

Satisfaction and quality of services obtained

Participants were asked to rate different aspects of the services they had encountered including the service quality and staff attitudes (Table 7). Participants reported they were most satisfied with the services, attitudes and knowledge displayed by General Practitioners and telephone helplines. Participants were least satisfied with the services and quality of care provided by accident and emergency departments and crisis teams. Participants also rated the attitudes and knowledge of these two groups least favourably.

Free text entries from the online surveys express some of this dissatisfaction:

> … A suicide attempt usually suggests an underlying cause. There was no attempt by health personnel to work out what was actually wrong or to solve it. Many assumptions were made about me because of my age, gender, family's higher SES and my own qualifications, which led to a superficial assessment and swift discharge with no follow-up care other than what I decided to arrange myself. If this experience were to happen to someone I care about, I would be horrified.

> …Not enough follow-up after getting out of hospital. I put that down to lack of funding from the government.

> …Resources were lacking and swift action was avoided for financial reasons (I do not have private health insurance).

> …All my experiences have been very traumatic after the attempt. I am now afraid to tell anyone I would like to know why I suddenly feel suicidal…I would like people to treat me with the same respect as a patient having a heart attack.

Table 7: Satisfaction with and quality of services

Service (N)	N	Satisfaction with services[a]	Quality of services[b]	Staff attitudes[c]	Staff knowledge[d]
GP	17	1.71	1.83	1.56	1.50
Telephone helpline or crisis service	14	2.21	2.14	1.79	1.86
Psychologist	18	2.50	2.17	2.06	1.56
Ambulance / police	28-32	2.53	2.29	2.32	2.28
Psychiatrist	30	2.67	2.20	1.93	1.60
Mental health/social worker	13	2.69	2.00	2.23	1.92
General hospital medical department	7	2.86	2.57	3.00	2.71
Family / friend / neighbour	14-20	2.95	2.90	2.29	2.79
Suicide prevention / crisis team	15	3.07	2.73	2.33	1.93
Accident and Emergency Department	39-41	3.17	3.23	2.97	2.98

[a] 1 (Extremely satisfied) - 5 (Not at all)

[b] 1 (Extremely well) - 5 (Not at all)

[c] 1 (Excellent) - 5 (Very poor)

d 1 (Very knowledgeable) - 5 (Not knowledgeable)

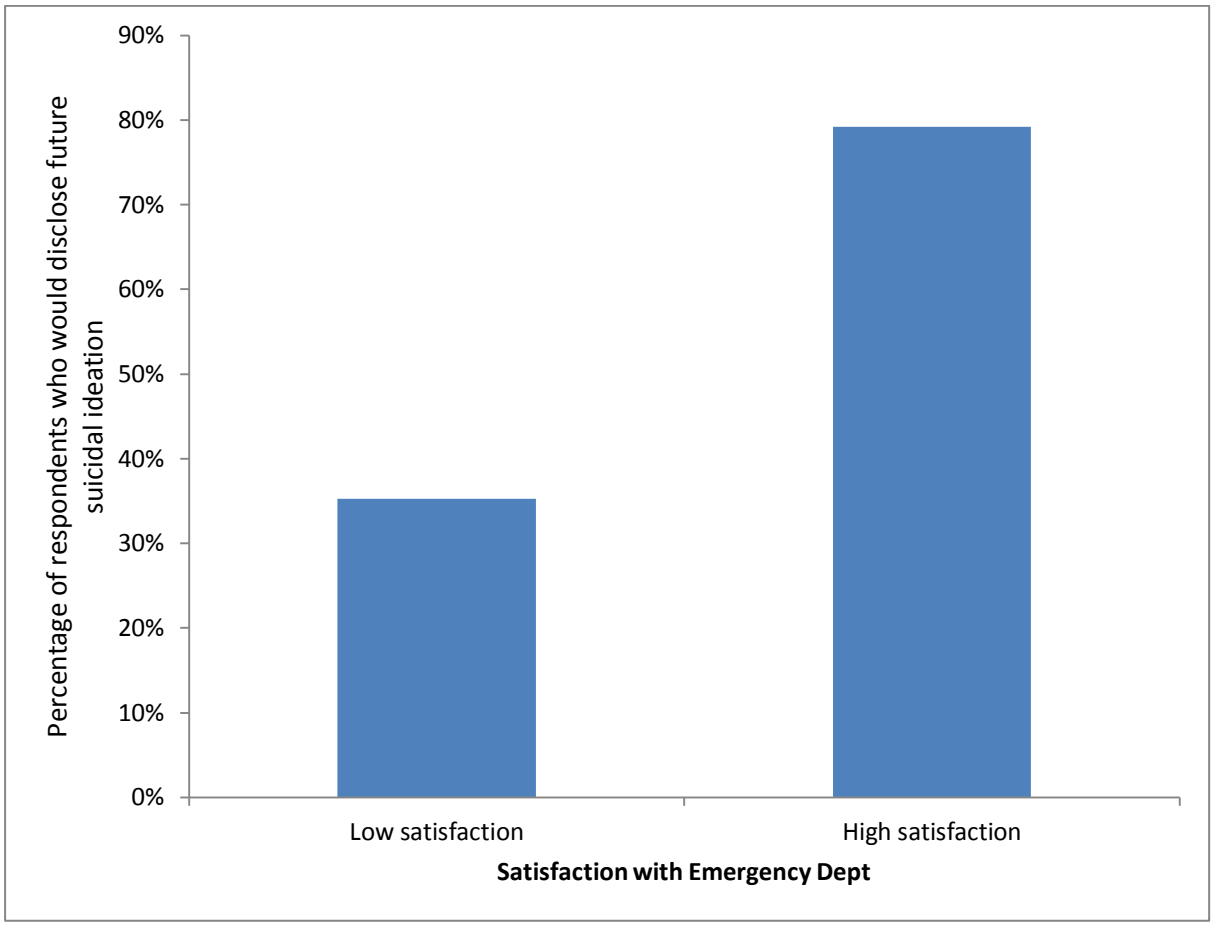
Predictors of satisfaction

Predictors of satisfaction with the three services reported as being most commonly used following a suicide attempt (Accident and Emergency Department, Ambulance/Police, and Psychiatrists) were

examined. Several predictors were tested including gender, marital status, education, employment, diagnosis, number of attempts, time of last attempt, method: pills/cutting, previous disclosure of ideation, future disclosure of ideation, and age.

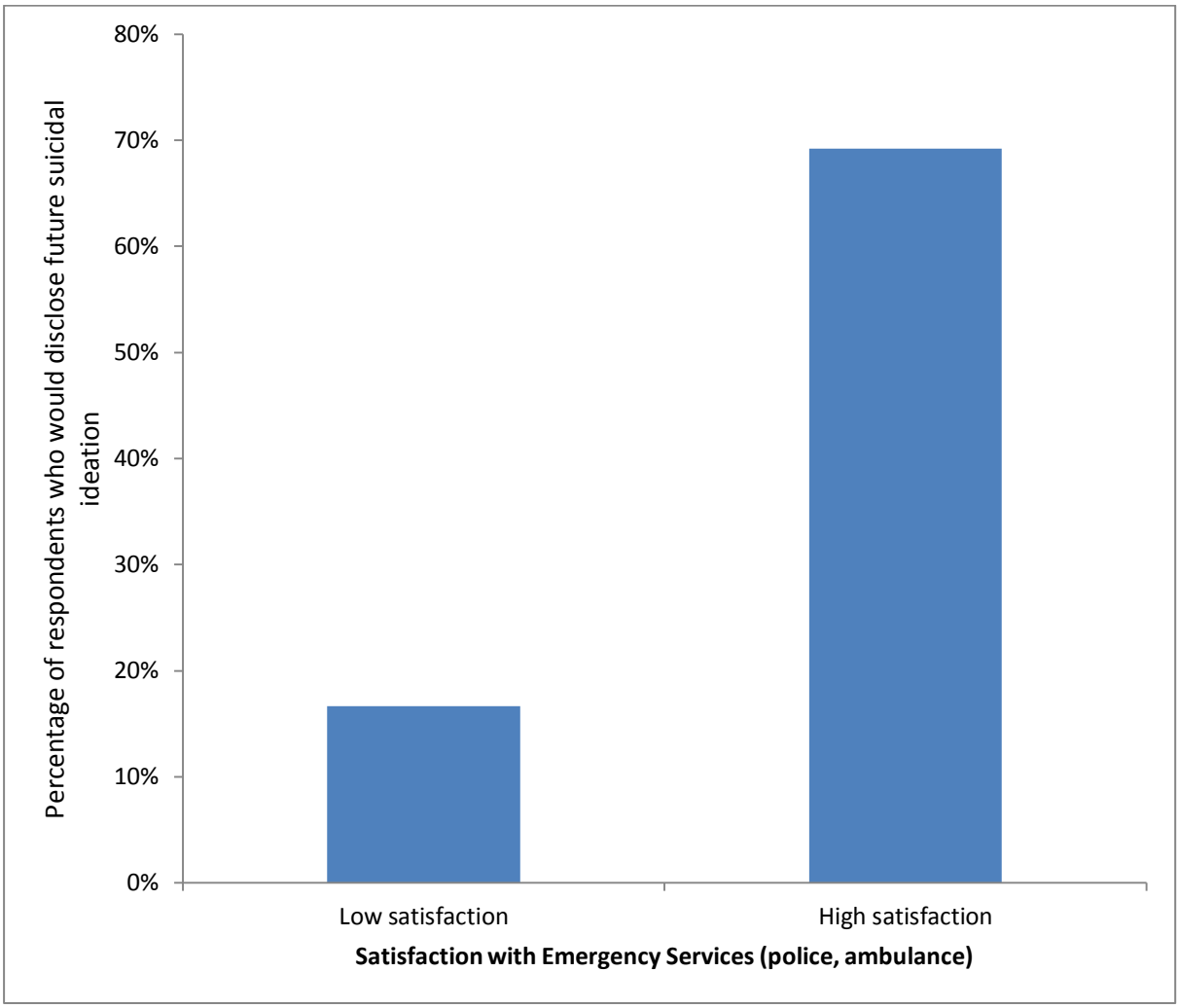
Similar rates of satisfaction for Emergency Department (ED) services were found across all variables; however, a poor ED experience has a strong association with lower inclinations to disclose future suicidality (Figure 2).

Figure 2: Association between ED experience and likelihood of disclosure of future suicidality



Similarly, rates of satisfaction for emergency services (ES) such as Ambulance and Police were found to be similar across the board. However, poor experiences with ES have a strong association with lower inclinations to disclose future suicidality (Figure 3).

Figure 3: Association between emergency services experience and likelihood of disclosure of future suicidality



Predictors of service use

Predictors of service use for the three services that were reported as being most commonly used (Accident and Emergency Department, Ambulance/Police, and Psychiatrists) were analysed. Several predictors as per above were tested.

Employment status was associated with service use, so that those identifying themselves as a student, retired, engaged in home duties or working in volunteer positions were more likely to utilise the emergency department (Figure 4) and emergency services (Figure 5) more frequently than others in alternative forms of employment.

Figure 4: Emergency department use by employment status

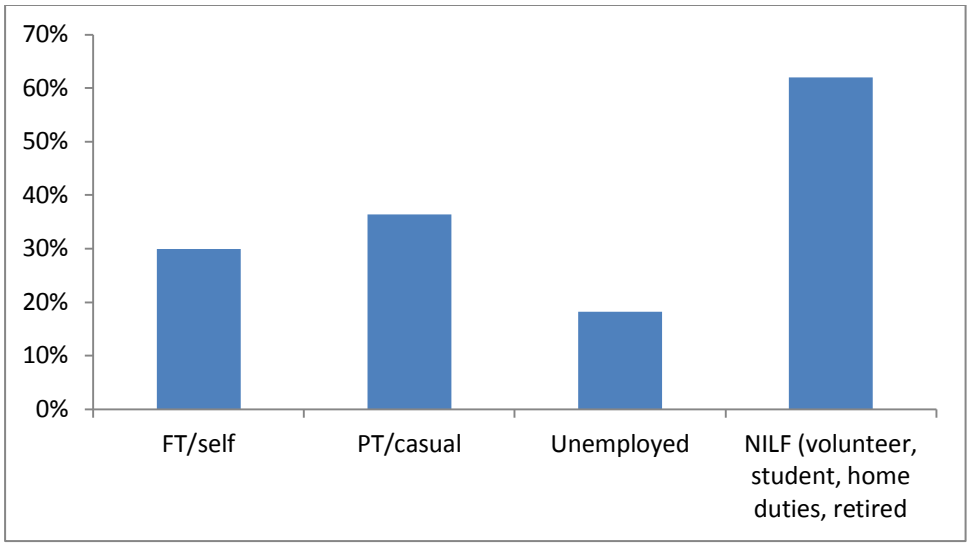
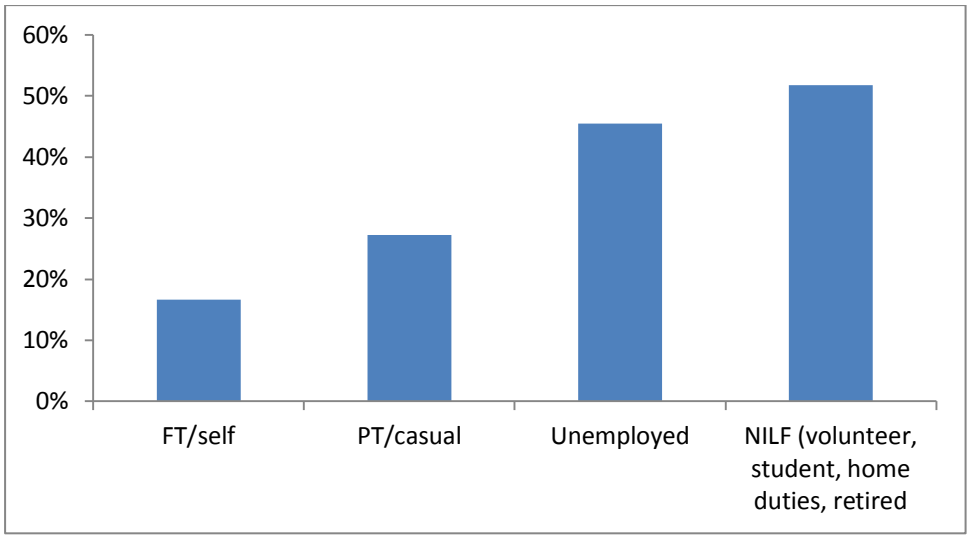


Figure 5: Emergency services use by employment status



Higher use of psychiatric services was associated with higher education status and prior disclosure of suicidal ideation. Those indicating they had completed a degree or higher education (Figure 6) as well as those reporting they had previously disclosed suicidal ideation (Figure 7) were more likely to utilise psychiatric services.

Figure 6: Association between educational attainment and use of psychiatric services

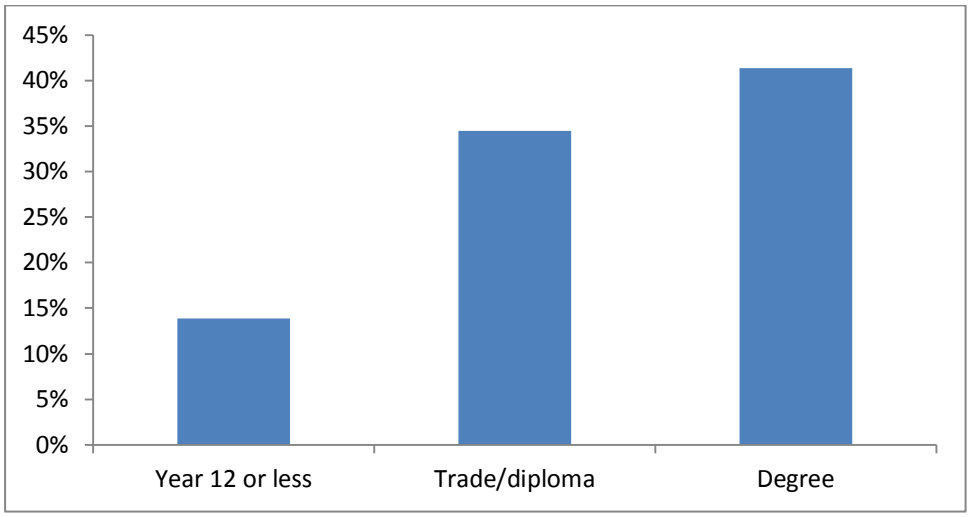
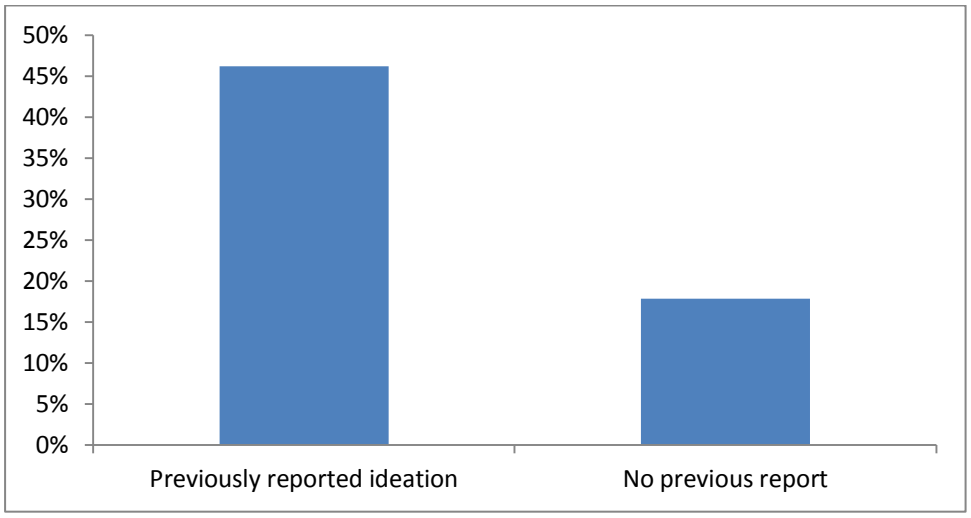


Figure 7: Association between previous disclosure of suicidality and use of psychiatric services



Reasons for low levels of satisfaction at first point of contact

Regardless of the type of service, the reasons given for low levels of satisfaction were predominantly centred around poor staff attitudes to the patient, inadequate staff knowledge about suicide, being discharged too rapidly, not being followed up after discharge from hospital, and not having their emotional distress attended to.

Involvement in treatment

More than half of the respondents said that they had been involved in decision making regarding their treatment needs, with three quarters of those respondents saying that this was a little, somewhat or very helpful (Table 8). Three-quarters reported that they would have preferred to be involved in such decision making, leaving a substantial minority who did not want to be involved.

Table 8: Patient involvement in treatment

Patient involvement in treatment	Percentage n=74
Involved in decision-making regarding treatment needs	59
Helpfulness of such involvement in decision making post-attempt:	
Very helpful	36
Somewhat helpful	36
A little helpful	2
Not helpful	6
Unsure	21
Preferred to have been involved in decision-making	71
Perceived helpfulness of having been involved in decision making regarding treatment , if not involved:	
Very helpful	54
Somewhat helpful	5
A little helpful	0
Not helpful	5
Unsure	35

Provision of information about treatment options

Participants were asked if they had been given information about treatment and the adequacy of this information. Around two-thirds reported being given this information, and of those who had not, the majority would have liked to receive it (Table 9).

Table 9: Information provision regarding treatment options

Information provision regarding treatment options	Percentage n=73
Provided with information on treatment options	69
Adequacy of information provided regarding treatment options:	
Given enough information	35
Given some information but would have liked more	34
Given no information but would have liked some	25
Given no information and didn't want any	7
Desire for additional information on following treatment options*:	
Local self-help groups	22
Community mental health services	20
Leaflets on self-harm and suicide	15
Psychiatric services	12
Contact information in case of emergency	11
Psychologist services	11
Online crisis services	11
Telephone helplines	9
Culturally appropriate treatment options	5
Other	4

*respondents could select more than one option

Suicide prevention strategies

The most frequently endorsed method of informing those at risk of suicide about treatment options was mental health professionals, followed by General Practitioners, family and friends, websites and social media, and online crisis support services (Table 10). Suicide prevention strategies perceived to be effective are shown in Table 11, with stigma reduction and General Practitioner training most commonly nominated, followed by improved follow-up care after a suicide attempt.

Table 10: Methods to inform those at-risk of suicide of available services and options for help

Source	n	%
General Practitioner	47	39
Mental health professionals	50	38
Family and friends	46	37
Websites (Lifeline)	43	35
Social media	43	35
Online crisis support services	41	33
Hospitals	36	28
Telephone helplines	35	28
Online treatment programs	32	24
Online chat rooms	23	20

Table 11: suicide prevention strategies perceived to be effective

Suicide prevention strategy	n	%
Reduction in stigma around help-seeking	60	49
Training for general practitioners on detection of suicide risk	59	46
Improved access to mental health professionals	56	43
Improved follow-up care for individuals who have attempted suicide	55	43
Education of general public on detection of suicide risk	52	42
Access to online treatment programs	38	33
More information about online help services	27	22
More information about telephone helplines	23	18
Restriction of firearm licensing	16	14
Media reporting guidelines	18	14
Restriction of medication supply	17	12

RESULTS FOR CAREGIVERS

Caregivers had a median age of 41 years; almost all were female, half were married or in a de-facto relationship, three-quarters were living with family and two-thirds were in paid employment (Table 12). Around one-third were supporting a son or daughter who had had a suicide attempt and one-quarter were supporting a partner/spouse. The remainder were supporting a parent (26%), sibling (11%), friend (8%), ex-partner (3%) or other relative (3%) (Table 13). Forty-two per cent of caregivers were caring for someone who had made one attempt, with a substantial proportion (19%) having made five or more attempts. Three-quarters were caring for someone who had sought treatment following a suicide attempt, and more than half had accompanied the person to treatment.

Table 12: Demographic characteristics of caregivers

Characteristics	**Percentage n=81**
Median age in years (range)	41 (18-84)
Female	94
Married/defacto	54
Employed	68
Indigenous status	6
Living situation	
Alone	8
Family	83
Friends/flatmates	6
Other	0

Table 13: characteristics of suicide attempt (caregivers' loved ones)

Variable	Percentage
Current relationship to loved one	
Partner/spouse	21
Ex-partner	3
Parent	26
Sibling	11
Son/daughter	29
Other relative	3
Friend	8
Number of previous attempts (loved one)	
1	42
2	18
3	12
4	6
≥5	19
Unsure	3
Timeframe of most recent attempt	
Last month	17
Last 3 month	10
Last 6 months	14
Last 12 months	21
Last 18 months	22
Unsure	17
Treatment was sought by loved one	77
Treatment was provided to loved one (if sought)	85
Caregiver accompanied loved one to treatment setting	58

Information provision

We asked caregivers if they had received sufficient information on the nature of their loved one's condition, treatment options, the likely effects of treatment, and updates on treatment actions. The majority of caregivers reported they received insufficient information and would have liked more information on all topics (Table 14).

Table 14: Sufficiency of information provided to caregivers post-attempt

Nature of information provided post-attempt to caregiver	Sufficient %	Insufficient %	Insufficient & additional information desired %
Nature of injury/condition	41	12	47
Different treatment options available	24	17	60
Likely effects of treatment	26	21	53
Updates on treatment actions, status, waiting times	36	21	43

Involvement in post-discharge planning

Just under half of the respondents reported being involved in decision making post-discharge (Table 15). A similar proportion said they were not involved but would have liked to have been. Half said that their views were not considered by a mental health professional when the future risk of self-harm was being considered. More than half reported that there was no information provided to them post-discharge and that they would have liked to receive such information. Around half reported that they would have liked information on how to best support their loved one and action to take in the event of another attempt. Around 40% said they would have liked information on caregiver support services, suicide warning signs and where to go for help. The resources developed by Beyondblue for caregivers, *Guiding their Way Back* (www.beyondblue.org.au/thewayback) may be one option.

Table 15: Post-discharge planning

Post-discharge planning	Percentage
Involvement in decision making regarding post-discharge needs	
Involved	41
Not involved	11
Not involved; but would have liked to be	48
Caregiver views accounted for by mental health professional in consideration of degree of future risk of self-harm by person	
Yes, very much accounted for	10
Yes, somewhat accounted for	39
Not accounted for, but would have liked to have had views considered	41
Not accounted for	10
Provision of information at discharge	
Discharge care plan provided	
Yes	18
No	23
No, but would have liked to have received one	59
Brochures or reference material on self-harm/suicide provided	
Yes	18
No	23
No, but would have liked to have received some	59
Other types of information that would have been helpful to have received at discharge*	
How to best support person	47

Action to take in event of another attempt	45
Caregiver support services	41
Suicide warning signs	36
Where to go for help	35
Websites	23
Telephone helplines	25
Nothing	2
Other	6

*respondents were able to select more than one variable

Respondents' views regarding the provision of information at different time-points post-attempt show that as time passes, caregivers want to continue to receive information (Table 16). This may be a reflection of the disengagement over time by the health service from caregivers, particularly post-discharge. The two most commonly identified barriers to obtaining adequate information were time-poor staff and negative staff attitudes which made it difficult to approach them (Table 17).

Table 16: Adequacy of information provided across different time points

	Time point						
Nature of information %	Initial notification of attempt	Waiting in AED/ treatment facility	During treatment of persons' physical wounds	During psychiatric assessment of person	During period of hospitalisation	At discharge	After discharge
Too much	0	0	2	0	0	0	0
Enough	33	21	24	14	17	14	8
Some information but desired more	3	15	6	24	20	15	11
A little bit	14	8	14	12	17	9	9
Not enough	20	29	21	39	30	49	61
Unsure/NA	29	27	33	11	17	14	12

^ 1 (too much information) – 6 (Unsure)

Table 17: Barriers to obtaining adequate information

Barriers	Endorsement %
Staff too time-poor	25
Negative staff attitudes made it difficult to approach them	27
Inadequate staff knowledge of self-harm and suicide	17
No information available at treatment facility	16
Lacking knowledge of where to obtain information	19
Other	8
NA	2

Satisfaction with services

Participants were asked to rate their satisfaction with different aspects of health services post-attempt. In keeping with the desire for more information over time identified in Table 16, dissatisfaction rose quite dramatically post-discharge. This may also indicate problems with continuity of care (Table 18). The two time points during the hospitalisation period that created the most dissatisfaction were the waiting period in Accident / Emergency Department and the psychiatric assessment.

Table 18: Degree of satisfaction with health services at different time points (N=54)

Time point	Extremely satisfied %	Very satisfied %	Moderately satisfied %	Moderately dissatisfied %	Very dissatisfied %	Extremely dissatisfied %
Initial notification of attempt	11	17	21	6	11	9
Waiting in AED*/ treatment facility	3	21	18	9	11	18
During treatment of persons' physical wounds	5	12	29	8	2	11
During psychiatric assessment of person	5	5	27	21	8	26
During hospitalisation	5	6	21	24	8	21
At discharge	3	2	18	21	11	33
Immediately after discharge	5	5	14	17	9	41
1 month after discharge	3	5	14	8	11	37
3 months after discharge	3	8	8	3	9	41
6 months after discharge	3	5	3	8	7	32
12 months after discharge	5	2	5	8	3	27

*AED: Accident and Emergency Department

Barriers and enablers to obtaining adequate information and treatment

The key barriers to obtaining more information about suicide were a perceived lack of staff time and negative staff attitudes which made it difficult to approach them (around one-quarter of participants endorsed these items). Other barriers were that staff did not have much knowledge about suicide and that there was no printed information available to caregivers. Barriers to obtaining help and treatment were, in order of frequency of endorsement, long waiting times to access services, negative experiences with services in the past, negative staff attitudes, high service costs, shame and embarrassment, and lack of services close to home.

Conversely, getting help to manage their own distress, knowing where to go for help, having a chance to talk to someone about what to expect, and knowing about suicide risks and warning signs were perceived as being most useful in helping caregivers to care for the person who attempted to take their own life.

Confidence in getting help and services likely to be used to get help

Just over half of the survey respondents said that they would be extremely or very confident in accessing help for their loved one in future. Less than one-fifth said they would be somewhat confident, while one-third said they would be only a little confident or not confident. The service respondents are most likely

to access in the future is the ambulance or police service, followed by a mental health professional of a telephone helpline (Table 19). The supports nominated to increase confidence in getting help were, in order, having access to a support group, having the contact details for 24-hour telephone support lines or knowing how to contact the community mental health team, and knowing how to contact a good psychiatrist (Table 20).

A large majority (87%) thought that training for caregivers in suicide risk, warning signs and safety would be extremely or very helpful.

Table 19: Where would you most likely go for help?

Where you would go for help	Endorsement %
Ambulance/police	32
Mental health professional	26
Telephone helpline or crisis service	22
Accident and emergency department	21
General Practitioner	18
Suicide prevention/crisis team	17
Family/friend/neighbour	12
Online crisis service	9
Websites such as Suicide Call Back Service	7
I'd speak to someone who has been in a similar situation	3
Social media	1
Online chat rooms	1

Table 20: What might increase your confidence in your ability to help the person?

What would increase confidence to help*	Endorsement %
A caregiver or support group	28
Having the contact details for 24hour telephone support lines	27
Knowing how to contact the community mental health team	27
Knowing how to find a good psychiatrist	22
A better relationship with my GP	10
Easily able to find the information online	10
Organisations such as SANE Australia	10
Nothing	8

*could select more than on variable

Sources of information and strategies perceived as helpful

Participants would like those at risk of suicide to receive information via General Practitioners, family and friends, mental health professionals, the internet, online crisis support services, hospitals and telephone helplines, in that order (Table 21).

Table 21: Methods to inform those at-risk of suicide of available services

Methods*	Endorsement %
General Practitioner	40
Family and friends	39
Mental health professionals	38
Internet	37
Online crisis support services	28
Hospitals	25
Telephone helplines	22
Other – workplaces/schools/tertiary institutions	4
Other – nothing can help	1
Other – mainstream media	1
Other – social media	4

*could select more than on variable

Respondents were asked to identify the suicide prevention strategies they thought would be most helpful. The most commonly endorsed strategy was improved follow-up care for individuals who have attempted suicide and access to mental health professionals (evidence shows that both of these strategies reduce deaths by suicide), followed by raising awareness of suicide amongst the general population, education in schools about suicide, and improved access to free or discounted services (Table 22). Interestingly, one of the other evidence-based strategies for suicide prevention – restricting access to means – was not strongly endorsed by caregivers.

Table 22: Suicide prevention strategies perceived as helpful

Suicide prevention strategy*	Endorsement %
Improved follow-up care for individuals who have attempted suicide	53
Improved access to mental health professionals	51
Education and awareness raising of suicide in general public	50
Improved access to free or discounted services	46
Education in schools about suicide	45
Reduction in stigma around help-seeking	44
Training for General Practitioners on detection of suicide risk	32
Access to online treatment programs	28
More information about telephone helplines	21
Restriction of medication supply	14
Media reporting guidelines	11
Restriction of firearm licensing	6

*could select more than on variable

Key findings from the online surveys

Both surveys point to low levels of satisfaction with health services following a suicide attempt. For caregivers, satisfaction decreased during and after discharge, indicating poor continuity of care and low levels of caregiver involvement beyond the hospital environment.

Key drivers of dissatisfaction were poor staff attitudes and lack of knowledge about suicide, inadequate aftercare, rapid discharge, and emotional distress not being addressed.

A negative experience with health services decreased the likelihood of disclosing future suicidality.

Both groups wanted to be involved in decisions about treatment.

Respondents who were unemployed were more likely to use emergency services and emergency departments, whereas respondents with a higher level of education were more likely to use psychiatric services.

Unemployment may be a marker for more complex mental health presentations, which is concerning given that unemployment did not increase the likelihood of receiving psychiatric care.

For caregivers, having access to a support group, having the contact details for 24-hour telephone support lines or the community mental health team, and knowing how to contact a good psychiatrist were strategies they believed would increase their confidence in caring for the person who had a suicide attempt.

The following section describes findings from a data linkage study. The key advantage of a data linkage approach is that it is possible to examine outcomes for a whole population, while the semi-structured interviews and online surveys provide a level of detail not possible using data linkage. Thus, each approach adds to and complements the other.

4.3. DATA LINKAGE STUDY: MENTAL HEALTH CARE RECEIVED BY PEOPLE ADMITTED TO HOSPITAL FOR DELIBERATE SELF-HARM IN NSW

Internationally, relatively little is known about health care contacts following attempted suicide. United States of America data suggests that the majority of those who present at emergency departments for deliberate self-harm are discharged to the community without referrals for follow-up care or have poor compliance with referrals for outpatient care [106]. In Australia, little is known about the treatment of people admitted to hospital for deliberate self-harm or about their follow-up treatment in the community. We therefore investigated this using routinely collected hospital admission and discharge data and mental health ambulatory data from NSW.

In this study, we used admission to hospital for deliberate self-harm as an entry point into the study. Using routinely collected data, we followed those admitted to hospital for deliberate self-harm to identify whether they were treated as a psychiatric inpatient. Following discharge from hospital, we then followed them to identify whether they received specialist mental health outpatient care within 30 days of discharge. The major advantage of this approach is that we were able to access routinely collected statewide data of all hospital admissions for deliberate self-harm and match this to statewide data about mental health outpatient care for those same individuals. However, the challenge this approach brings is that by defining the population of interest as only those admitted to hospital, other population groups are excluded, in particular those who present at an emergency department for deliberate self-harm but are discharged without being given a hospital bed [107]. The results we present here should be interpreted in this light, noting that there is no available data to determine how many emergency department presentations lead to hospital admission or not, nor how this varies by hospital location, severity of injury or other clinical characteristics [108]. Nonetheless, using hospital admission data as a starting point provides a valuable viewpoint into the care of those who are treated for deliberate self-harm.

We focus on several questions, specifically:

1. What proportion of those admitted to hospital for deliberate self-harm are treated as inpatients in a psychiatric ward?
2. What proportion of those admitted to hospital for deliberate self-harm go on to use mental health outpatient services within 30 days of discharge?
3. What are the types of mental health outpatient services that they use (if any)?

METHOD

The Centre for Health Record Linkage assembled the data for this study using information from the NSW Admitted Patient Data Collection, the NSW Mental Health Ambulatory Data Collection and the NSW Register of Births, Deaths and Marriages. An overview of each of these datasets is given in Box 3.

We used data from the NSW Admitted Patient Data Collection as the starting point of our study. We identified everyone in the state admitted to hospital for deliberate self-harm. From this dataset, we extracted information on patient characteristics (such as their age, sex, method of self-harm) as well as characteristics about their treatment (e.g., whether or not they were treated in a designated psychiatric ward). From the NSW Mental Health Ambulatory Data Collection we then identified any mental health outpatient contacts the patients may have had following their discharge from hospital. We distinguished between those contacts that began within 30 days of discharge from hospital, from those that occurred (if at all) after 30 days of discharge. At this stage, we also extracted information on the type of care the patient received and who provided this care. Finally, we used the NSW Register of Births, Deaths and Marriages to exclude from the analysis anyone who died within 30 days of discharge, ensuring that our results were not distorted by including those who may have died in hospital, or shortly after discharge from hospital.

Because data from all these datasets only overlaps between January 2005 and December 2011, we focus only on these years for our analysis.

BOX 3: DATA SOURCES

New South Wales Admitted Patient Data Collection

- Records all admissions and discharges from all public and private hospitals in New South Wales.
- Contains information on diagnosis, psychiatric stay as an inpatient, causes of injury, etc.
- Data available from July 2000 to June 2012.

New South Wales Mental Health Ambulatory Data Collection

- Records contacts and activities of mental health outpatient care. Contacts refer to an instance of mental health outpatient care; activities refer to the interventions or administrative work undertaken during a contact.
- Contains information on date of each contact, type of health provider, number of activities within the contact.
- Data available from January 2005 to December 2011.

New South Wales Register of Births, Deaths and Marriages

- Records fact of death and date of death.
- Data available from July 2000 to June 2013.

All datasets use an encrypted, project-specific identification (ID) number – this allows individuals be tracked across datasets but prevents individuals being identified (there are no names or other identifying information contained in the research datasets).

RESULTS

There were 43,207 individuals admitted to hospital for deliberate self-harm in New South Wales. These individuals had at total of 67,035 inpatient admissions for deliberate self-harm. The majority were female (56.8%) and at their first admission, aged between 15 and 40 years (63.2%) and single (67.4%) (Table 23). Most had only a single admission for self-harm (75.4%). The most common psychiatric diagnoses were depression (42.8%); substance misuse disorder (33.2%) and anxiety disorder (29.3%).

In the following analysis, we focus on the admissions as the unit of analysis (as opposed to individuals), because we are interested in what happens following each admission to hospital for deliberate self-harm.

Sixty-three percent of the 67,035 admissions (42,716 cases) resulted in the patient either being treated as a psychiatric patient or receiving mental health outpatient care within 30 days of discharge from hospital. We explore each of these outcomes in more detail below.

Table 23: Characteristics of the 43,207 individuals admitted to hospital for deliberate self-harm, NSW 2005-2011

Characteristic	n	%
Age at baseline		
15-19	7,121	16.5
20-29	10,620	24.6
30-39	9,529	22.1
40-49	7,890	18.3
50-59	4,361	10.1
60-69	1,815	4.2
70-79	1,042	2.4
80 and over	829	1.9
Female	23,549	56.8
Relationship status at baseline		
Partnered	11,843	27.4
Single	29,117	67.4
Unknown	2,247	5.2
Total number of DSH episodes		
1	32,576	75.4
2	6,514	15.1
3	1,925	4.5
4	842	2.0
5	410	1.0
6 or more	940	2.2
Substance misuse disorder*	14,340	33.2
Schizophrenia and related psychoses*	3,001	7.0
Mania*	2,506	5.8
Depression*	18,503	42.8
Anxiety disorder*	12,640	29.3
Eating disorder*	545	1.3
Personality disorder*	5,939	13.8
Died (any cause)	1,526	3.5

* Variable refers to whether the event ever occurred during the study period

Admission as a psychiatric inpatient

In the 67,035 inpatient admissions for deliberate self-harm, 6,579 (9.8%) resulted in the patient being treated as a psychiatric patient (that is, in a designated psychiatric ward for at least one day). Patients were treated in a psychiatric ward between 5.6% and 29.2% of all cases, depending on a range of factors shown in Table 24, namely: gender, source of referral, number of prior admissions for self-harm, method of self-harm and psychiatric diagnosis.†

† Our interpretation is based on contingency table analysis. Throughout this study we note differences only where there is moderate ($p < 0.05$) or strong evidence ($p < 0.01$) of a difference between groups.

Table 24: Probability of inpatient psychiatric care by patient characteristics

Characteristic	Percent	95% Confidence Interval
Age		
15-19 (n = 10,342)	9.9	9.3 to 10.5
20-29 (n = 16,445)	10.3	9.8 to 10.8
30-39 (n = 15,568)	10.2	9.8 to 10.7
40-49 (n = 13,156)	9.8	9.3 to 10.3
50-59 (n = 6,554)	8.7	8.0 to 9.4
60-69 (n = 2,573)	8.5	7.5 to 9.7
70-79 (n = 1,342)	8.9	7.5 to 10.6
80 and over (n = 1,055)	7.1	5.7 to 8.8
Sex		
Male (n = 26,888)	9.7	9.3 to 10.0
Females (n = 40,142)	9.9	9.9 to 10.2
Relationship status		
Partnered (n = 16,806)	9.2	8.7 to 9.6
Single (n = 47,165)	10.1	9.8 to 10.4
Unknown (n = 2,998)	9.2	8.2 to 10.2
Referred from emergency department		
No (n = 12,901)	24.4	23.7 to 25.2
Yes (n= 54,134)	6.3	6.1 to 6.5
Number of previous episodes		
0 (n = 43,189)	7.7	7.5 to 8.0
1 (n = 10,631)	14.0	13.4 to 14.7
2 (n = 4,117)	13.0	12.0 to 14.1
3 (n = 2,192)	12.5	11.2 to 14.0
4 (n = 1,350)	15.2	13.4 to 17.2
5 or more (n = 5,547)	13.4	12.5 to 14.3
Method		
Poisoning (n = 49,189)	5.6	5.4 to 5.8
Cutting (n = 12,327)	21.3	20.6 to 22.0
Other (n = 5,519)	21.9	20.8 to 23.0
Substance misuse disorder		
No (n = 46,827)	8.8	8.6 to 9.1
Yes (n = 20,208)	12.1	11.7 to 12.6
Schizophrenia and related psychoses		
No (n = 62,548)	9.1	8.9 to 9.3
Yes (n = 4,487)	20.0	18.8 to 21.2
Mania		
No (n = 63,519)	9.5	9.3 to 9.7
Yes (n = 3,516)	15.8	14.6 to 17.0
Depression		
No (n = 42,913)	8.8	8.6 to 9.1
Yes (n = 24,122)	11.6	11.2 to 12.0
Anxiety disorder		
No (n = 51,711)	7.8	7.5 to 8.0
Yes (n = 15,324)	16.7	16.1 to 17.3
Eating disorder		
No (n = 66,221)	9.6	9.4 to 9.8
Yes (n = 814)	29.2	26.2 to 32.5
Personality disorder		
No (n = 55,588)	7.7	7.4 to 7.9
Yes (n = 11,447)	20.3	19.6 to 21.0

For men, the probability of being treated as a psychiatric patient was 9.7%; for women it was 9.9%. For patients referred to hospital for admission from an emergency department (the majority of patients), the probability of being treated as a psychiatric patient was 6.3%. For patients referred to hospital from other channels, the probability was 24.4%.

The number of prior admissions for deliberate self-harm was associated with increased probability of being treated as a psychiatric patient. For a person with no prior admissions for self-harm, the probability of being treated as a psychiatric patient was 7.7%. For those with one or more prior admissions, the probability was greater. For instance, for a person with one prior admission, the probability was 14.0%; for a person with two prior admissions it was 13.0%; and for a person with five or more prior admissions it was 13.4%.

The probability of being admitted as a psychiatric patient was lowest when the method of self-harm was poisoning (5.6% of admissions). It is noteworthy that this is the most common method of self-harm resulting in admission to hospital (78% of all admissions). The probability of being admitted as a psychiatric patient was higher for all other methods – for cutting, the probability was 21.3% and this was similar to the probability for all other methods (21.3%). These findings may reflect that patients admitted to hospital for poisoning are admitted primarily to monitor and treat the effects of the poisoning (rather than for psychiatric reasons).

Finally, the presence of a number of psychiatric diagnosis predicted treatment as a psychiatric inpatient. The strongest associations were for patients with schizophrenia. The probability of being treated as a psychiatric inpatient was 20.0% for patients with a diagnosis of schizophrenia compared to 9.1% for patients without schizophrenia. Similarly, for people with an anxiety disorder, the probability of being treated as a psychiatric inpatient was 16.7% (compared to 7.8% without a diagnosed anxiety disorder). Finally, for patients with a personality disorder, the probability of being treated as a psychiatric inpatient was 20.3% (compared to 7.7% for patients without a personality disorder). In general, a diagnosis of any disorder listed in Table 2 was associated with increased chances of being treated as a psychiatric inpatient.

Of the variables listed in Table 24, only age and relationship status were unrelated to the probability of being treated as a psychiatric inpatient. That is, only small differences were observed among the age and relationship groups.

Treatment as a mental health outpatient within 30 days of discharge

Of the 67,035 admissions to hospital for deliberate self-harm, there were 40,213 cases (60.6%) where there was contact with mental health outpatient services within 30 days of discharge. This varied from 44.8% to 76.0% of all cases, depending on the characteristics listed in Table 25.

The probability of being treated as an outpatient within 30 days of discharge declined with age. For those aged 15-19, the probability of receiving mental health outpatient care within 30 days of discharge was 65.5%. All other age groups had lower probabilities of being treated as a mental health outpatient within 30 days of discharge (range 61.7% to 44.8%). Women had a higher probability than men of being treated as an outpatient (62.7% vs. 57.4%, respectively). For those who had partners, the probability of receiving outpatient care was 57.6%; those who were single were more likely to receive mental health outpatient care (62.3%) but when this information was unknown, they were less likely to receive outpatient care within 30 days (50.1%). It is unclear why unknown relationship status is associated with a lower probability of receiving outpatient care.

Table 25: Probability of mental health outpatient care within 30 days of discharge by patient characteristics

Characteristic	Percent	95% CI
Age		
15-19 (n = 10,342)	65.5	64.6 to 66.4
20-29 (n = 16,445)	59.1	58.3 to 59.8
30-39 (n = 15,568)	61.7	60.9 to 62.4
40-49 (n = 13,156)	60.8	60.0 to 61.6
50-59 (n = 6,554)	58.0	56.8 to 59.2
60-69 (n = 2,573)	58.3	56.3 to 60.2
70-79 (n = 1,342)	53.7	50.9 to 56.4
80 and over (n = 1,055)	44.8	41.7 to 48.0
Sex		
Male (n = 26,888)	57.4	56.8 to 58.0
Females (n = 40,142)	62.6	62.2 to 63.1
Relationship status		
Partnered (n = 16,806)	57.6	56.8 to 58.3
Single (n = 47,165)	62.2	61.8 to 62.7
Unknown (n = 2,998)	50.8	49.1 to 52.6
Referred from emergency department		
No (n = 12,901)	62.7	61.9 to 63.5
Yes (n= 54,134)	60.1	59.6 to 60.5
Number of previous episodes		
0 (n = 43,189)	56.5	56.0 to 56.9
1 (n = 10,631)	63.2	62.3 to 64.2
2 (n = 4,117)	68.4	67.0 to 69.8
3 (n = 2,192)	69.3	67.3 to 71.2
4 (n = 1,350)	70.9	68.4 to 73.3
5 or more (n = 5,547)	75.4	74.3 to 76.6
Method		
Poisoning (n = 49,189)	60.9	60.4 to 61.3
Cutting (n = 12,327)	60.6	59.7 to 61.5
Other (n = 5,519)	57.7	56.4 to 59.0
Substance misuse disorder		
No (n = 46,827)	62.2	61.7 to 62.6
Yes (n = 20,208)	56.9	56.2 to 57.6
Schizophrenia and related psychoses		
No (n = 62,548)	59.5	59.1 to 59.8
Yes (n = 4,487)	76.0	74.8 to 77.3
Mania		
No (n = 63,519)	60.3	59.9 to 60.6
Yes (n = 3,516)	66.0	64.4 to 67.5
Depression		
No (n = 42,913)	58.9	58.4 to 59.3
Yes (n = 24,122)	63.6	63.0 to 64.2
Anxiety disorder		
No (n = 51,711)	60.2	59.7 to 60.6
Yes (n = 15,324)	61.9	61.1 to 62.6
Eating disorder		
No (n = 66,221)	60.6	60.2 to 60.9
Yes (n = 814)	60.9	57.5 to 64.2

Personality disorder		
No (n = 55,588)	58.7	58.3 to 59.1
Yes (n = 11,447)	69.4	68.5 to 70.2
Inpatient psychiatric care		
No (n = 60,456)	60.4	60.0 to 60.8
Yes (n = 6,579)	62.2	61.0 to 63.4

Patients referred to hospital from the emergency department had lower probability of being treated as an outpatient within 30 days than patients referred from other parts of the health system (60.2% vs. 62.7%, respectively).

The number of prior admissions to hospital for deliberate self-harm had a strong and positive association with mental health outpatient care. For those with no prior admissions, the probability of receiving outpatient care within 30 days was 56.5%; for a person with one prior admission, the probability was 63.2%. These probabilities increased as the number of prior episodes increased, such that for those with five or more prior admissions, the probability of being treated as an outpatient was 75.4%.

The probability of being treated as a mental health outpatient varied by method of self-harm. The probability of receiving outpatient care within 30 days of discharge was about the same for people who used the two most common methods – poisoning and cutting (60.9% and 60.6%, respectively). The probability of receiving outpatient care was lower for those who used other methods (57.7%).

All mental health diagnoses except an eating disorder were associated with outpatient care within 30 days. A diagnosis of substance misuse disorder (in comparison to those without this diagnosis) was associated with lower probability of being treated as a mental health outpatient within 30 days of discharge (56.9% vs. 62.2%, respectively). This may be because those with substance misuse problems are instead being treated by other alcohol and drug specialists in the community or because of low rates of help-seeking among this group (4). For all other diagnoses, the opposite was true – a diagnosis was associated with increased chance of receiving outpatient care within 30 days. The strongest relationship was for those with a diagnoses of schizophrenia (76.0% compared to 59.5% for those without this diagnosis), followed by a diagnosis for a personality disorder (69.4% vs. 58.7% without this diagnosis).

Finally, patients treated as a psychiatric inpatient prior to discharge had a slightly higher probability of receiving outpatient care within 30 days than those who were treated as a general patient (62.2% vs. 60.4%).

Type of care received as a mental health outpatient

Among those who received mental health outpatient care within 30 days of discharge, the majority of patients (59.0%) had only a single outpatient activity (Table 26) — typically less than 30 minutes in duration (59.8% of contacts); although 16.9% of contacts were between 30 minutes and one hour. The patient was present for 51.0% of all outpatient activities, not present for 34.2%, and unknown for 14.8% of all activities. (When this patient is not present, the provider is nonetheless doing work on their behalf.) Patients were largely treated by a single practitioner (96.2% of all contacts) — nurses (49.1%), doctors (2.7%) allied health practitioners (psychologists, social workers, occupational therapists) (19.1%) and 'other' providers (9.9%). This information was unknown for 19.2% of all contacts.

Table 26: Characteristics of outpatient mental health care among those who receive care within 30 days of discharge

Characteristic	N	Percent
Total number of contacts		
1	23,714	59.0
2	7,146	17.8
3	3,715	9.2
4	2,288	5.7
5-10	2,951	7.3
11 or more	399	1.0
Contact duration		
0-15 minutes	14,012	34.8
16-30 minutes	10,051	25.0
31-60 minutes	6,777	16.9
61-90 minutes	1,620	4.0
91-180 minutes	1,552	3.9
181 minutes or more	438	1.1
Unknown	5,763	14.3
Client present		
No	13,755	34.2
Yes	20,509	51.0
Unknown	5,949	14.8
Number of different providers		
1	38,697	96.2
2	1,078	2.7
3 or more	438	1.1
Provider type		
Nurse	19,757	49.1
Doctor	1,075	2.7
Allied health practitioner	7,681	19.1
Other	3,979	9.9
Unknown	7,721	19.2

SUMMARY

This study of people admitted to hospital for deliberate self-harm suggests that only around 10% of all admissions are treated in specialist psychiatric services during their stay in hospital. However, there is some variation in this – for people who had used poisoning as a method of self-harm, the probability of being treated as a psychiatric patient was around 6%, but for all other methods, it was around 21%. Poisoning is by far the most common method of self-harm in Australia [109], and in this data, comprise nearly 80% of all admissions. These findings suggest that patients admitted to hospital for treatment of poisoning are admitted for medical observation, rather than for treatment of underlying mental health issues. If so, these findings echo the results of a United Kingdom study which demonstrated wide variation in the chances of an individual receiving a specialist psychosocial assessment while in the emergency department [110]. (Although one important difference with our findings was that the United Kingdom study found that it was those who used cutting, not poisoning, who were least likely to receive specialist assessment.)

Focusing on mental health outpatient care within 30 days of discharge from hospital, the majority of people admitted to hospital for deliberate self-harm appear to receive outpatient care. The type of care they typically receive is a single session of treatment, usually less than 30 minutes in duration and delivered by a nurse. It is unclear to what extent this level of care is adequate to treat any underlying psychiatric disorders that may contribute to self-harming behaviour. It is also likely that a proportion of these patients are referred back to their current mental health team (for instance, a General Practitioner, psychiatrist and/or psychologist in private practice). Nevertheless, this data is not captured in any systematic way and it is likely that the hospital loses track of these patients once they are discharged.

Our study has several limitations. First, because we cannot track referrals to outpatient services, we rely on the occurrence of a new mental health outpatient activity within 30 days as evidence of a referral. While we focus only on new contacts after discharge, some of these contacts will be unrelated to the hospital admission for self-harm; although the extent to which this occurs is unknown.

Second, and relatedly, we are unable to ascertain the number of people offered referrals to mental health services but who did not attend an appointment within 30 days. Based on previous research, we would expect that some groups (e.g., those with a diagnosis of substance use disorder) are less likely to attend outpatient appointments because of these groups are known to have poor help-seeking behaviour [111].

Third, our analysis is based on data from one state health system only (New South Wales). While there are many similarities between NSW and the other states (for instance, guidelines on the treatment of deliberate self-harm [112]) there are important differences too. These findings may not therefore generalize to other settings, especially in relation to the precise percentages reported here.

Finally, the starting point for our study was admission to hospital for deliberate self-harm. Ideally we would have used emergency department presentations as a starting point, since these are greater in number than admissions for deliberate self-harm. However, reliable data on emergency department presentations for deliberate self-harm is unavailable in Australia (external cause of injury codes are not recorded in any state or territory). Therefore, our findings relate only to those admitted to hospital for deliberate self-harm, not those who present to an emergency department or whose injuries mean they do not present to hospital at all. In spite of these limitations, we believe this study gives a useful overview of mental health treatment for people who are treated for deliberate self-harm.

Key findings

Sixty-three per cent of patients admitted for deliberate self-harm receive any kind of mental health treatment in the public health system (inpatient or outpatient).

Ten per cent of patients admitted for deliberate self-harm are treated in specialist psychiatric services during their hospital stay.

Only six per cent of those admitted for self-poisoning are treated by specialist psychiatric services.

Sixty-one per cent receive outpatient treatment in the 30 days after hospital discharge. Some of these patients are likely to return to the care of an already established mental health team but are not tracked systematically by the hospital once they have been discharged.

Fifty-nine cent of those who receive outpatient treatment receive one session of 30 minutes or less.

Forty-nine per cent of those outpatient sessions are with a nurse.

The limitations of the data linkage study stem primarily from limitations of currently available data relating to health services provided following a suicide attempt. The final component of this study, presented next, reviews the currently available data and identifies gaps in the data.

4.4. WHAT DATA ARE AVAILABLE TO EVALUATE HEALTH SERVICE STRATEGIES AND PROGRAMS?

We reviewed currently available data that might inform policy and practice relating to preventing suicide re-attempts in Australia, with a view to identifying gaps in program delivery and outcomes, and in policy domains. In order to do this, it is useful to consider the purpose of having such data available and to determine whether currently available data meets these needs. Details of the datasets identified are shown in Appendix F, with national datasets described first, followed by jurisdiction-specific datasets.

WHY DO WE NEED DATA?

- To ensure continuity of care by allowing tracking of patients through the health system
- To evaluate programs, community interventions, strategies and service quality
- To identify service requirements
- To evaluate jurisdictional and national policies
- To answer specific research questions

HOW WELL DO EXISTING DATASETS MEET THESE NEEDS?

There may be internally available data that allows health services to evaluate how well they are performing concerning continuity of care and other indicators of quality care after a suicide attempt, although we were not able to identify where this was the case. The successful models (for example, Zero Suicides) make this data publicly available. There is very little qualitative or quantitative data on what happens to patients post-attempt and post-discharge.

The data linkage study found that there is currently no way to capture a substantial proportion of suicide attempts because these cases are not systematically captured in the emergency department. Emergency department data does not record external cause of injury, e.g. accidental shooting. If these data were collected, it would allow us to examine the number of suicide attempts presenting, how many people re-present, who goes on to be admitted, and who receives outpatient care. At the moment, it is not possible to follow the trajectory of those who present to an emergency department after a suicide attempt. The National Health Partnership Agreement specifies the types of information each jurisdiction is required to collect and would need to be modified for such data to be collected.

An additional gap is in knowing what happens to patients once they are discharged from the hospital system. There is very little data captured on the psychological follow-up care provided. A system with multiple points of linked, sequential data collection is required, so that no matter what the person's entry point, certain standardised data are collected and shared amongst health services.

Without routinely collected data on suicide attempts, the many community and health service efforts to reduce suicide behaviours cannot be properly evaluated. Further, health services and their initiatives to reduce re-attempts cannot be properly evaluated, and service quality cannot be measured. There is also a case for better public access to aggregate data in order to hold governments and health services accountable for reaching targets to reduce suicide and suicide attempts.

CASE STUDY: A PILOT NATIONAL SURVEILLANCE SYSTEM OF SUICIDE ATTEMPTS FROM AMBULANCE ATTENDANCES

This pilot was established in 2013 at Turning Point Victoria to establish procedures to ensure that data is collected, transferred, coded and reported accurately. The pilot study established procedures to collect, code, and report the data from the five Eastern Seaboard jurisdictions by June 2013. The project is now modifying systems in order to be able to code and report data from the three remaining jurisdictions. The data is coded and analysed and Turning Point reports to the Ambulance Services in each jurisdiction. The project is now able to provide quarterly snapshots to the Federal Government three months after the end of the quarter. Although it is not real time data, compared with other datasets this represents timely reporting.

The variables the project can report against include:

- Number of suicide attempts attended
- Number of call-outs involving suicidal ideation
- Method of suicide attempt
- Number of call-outs involving deliberate self-injury
- Number of attendances involving threats of deliberate self-injury
- Mental health symptoms observed at attendances
- Number of attendances with police co-attendance
- Treatment provided
- Outcome of each attendance (e.g. hospitalisation)
- Other services patient is linked in with (e.g. community mental health)
- Whether the crisis/acute care team was involved
- History of mental illness
- History of deliberate self-harm
- Alcohol and other drug information
- Life events/stressors reported by the patient (e.g. family problems, chronic pain, physical illnesses, prevalence of self-harm in their social network, Indigenous status)
- Number of paramedics in attendance
- Time taken for the attendance to occur
- Time and date stamp
- Geographic location

The data allows for geospatial mapping of suicide attempt patterns or clusters. The data have already been linked with emergency department and hospital records and there is potential for it to be linked to other datasets, for example, alcohol and other drug treatment, ambulatory mental health data, and mortality data.

However, the dataset does not capture suicide attempts where the ambulance service is not called. It is likely to under-report suicide attempts where intent is unclear; however, it may be a more accurate reflection of intent given the incidence of people altering their retelling of the events once they are at the hospital and facing the possibility of admission to a psychiatric unit. Paramedics are usually first at the scene and can collect initial evidence of intent (suicide notes, early statements from the patient, information from family and friends) that may not be available to other health services. The number of deaths by suicide is likely to be under-reported by this dataset, compared with other data sources such as the National Coronial Information System.

5. KEY FINDINGS AND PRIORITIES

This report and its findings represent the culmination of several pieces of work. As far as we know, it represents the only comprehensive investigation of people's experience of health services after a suicide attempt in Australia to date. The combination of rich qualitative information from the interviews, the quantitative survey data and the comprehensive nature of the data linkage study provides a strong evidence base for the findings outlined below.

All three data sources indicate that many people are not receiving adequate support after a suicide attempt. The data linkage study found that a substantial proportion of patients in New South Wales who have had a suicide attempt do not have contact with the public health system once they've been discharged from hospital. Where contact is made, in more than half of the cases it is a single contact. Our review of the literature indicates that this is likely to be inadequate.

Of equal importance to these systems issues is the human side of our response to suicide attempts. Attending to the person's emotional needs is essential if we are to have an impact on the risk of re-attempt. Frontline health staff can positively influence the likelihood that the person will reveal future suicidality, and perhaps the likelihood that the person will engage fully with treatment. From the surveys and interviews, it is clear that participants have a relatively poor view of the human side of the services they received following a suicide attempt, with more than half saying that the help they were offered was inadequate. Perception of negative staff attitudes towards those who have had a suicide attempt is a substantial barrier to receiving good quality care, and a poor experience with health services was associated with reduced likelihood of disclosing future suicidality. A lack of involvement in treatment planning was also viewed as problematic. Rapid discharge from hospital, no post-discharge care, and lack of attention to emotional distress were cited as reasons for low satisfaction with health services.

The majority of caregivers who participated in the research would like greater involvement in post-discharge treatment planning for their loved one. At a minimum, they would like to be made aware of the discharge plan. We are mindful that this raises issues regarding confidentiality. Nevertheless, this issue is worth further consideration given the potentially valuable role caregivers can play in the recovery process. One of the key themes emerging from the semi-structured interviews was the need for advocacy within the health system. If caregivers are excluded from communications, this makes it difficult for them to adopt this critical role. Navigating the health system was viewed as particularly challenging, even for those who have worked within it. As both caregivers and people who had had a suicide attempt spoke about the need to proactively seek effective care, language around 'luck' tended to centre on experiences of finding follow-up care that suited the person who had attempted suicide after discharge. The type of care that was considered most effective was consistent care, where the person who attempted suicide and their caregiver saw the same person/people each time. This 'chain of care' approach has empirical evidence to support its utility.

Little support seems to be available for caregivers to assist them to effectively support their loved ones, as well as other family members and themselves, following a suicidal crisis. Caregivers not only had to be an advocate for their loved one but they often also provided practical day-to-day care, took their loved one to different physical and mental health appointments, scoured the internet and community sources for different support strategies, and often balanced this with their own employment and family commitments.

At a systems level, our work suggests that currently available data do not adequately inform and evaluate public policy and health systems procedures or ensure that patients receive quality, ongoing care. There are models in other countries (for example, Zero Suicides) where publicly available data are used to

inform a quality assurance approach to reducing suicides within health systems A similar approach to aggregate, publicly available data would improve the quality of care received following a suicide attempt.

As with any study, this one has some limitations. We were not able to identify any 'chain of care' models being used or evaluated in Australia. Whilst we believe that such models are a reform priority, it will be important to evaluate their effectiveness within the Australian context. The online surveys and the interviews did not use a representative sample. The inclusion of the data linkage study goes some way to address this limitation. Nevertheless, it is possible that our sampling frame contains some bias. Recruitment for the online survey was particularly slow and we were not able to recruit the number of participants we had anticipated. Research on the topic of suicide is difficult. Despite this, some clear and consistent findings emerged regarding how health services are viewed and where in the chain of care the deficits are most problematic. Gaps in currently available data meant that the data linkage study could only be conducted with admitted patients and not with patients who presented to the emergency department without being admitted.

Our response to suicide attempts needs to change. Of particular importance is ensuring that our health services respond to the needs of the whole person, not just their physical injuries; strong leadership to reform practices at a systems level; and providing continuity of care to the individual rather than responding to each suicidal crisis as it arises.

WHAT IS NEEDED?

1. The Human Side of Responses to Suicide Attempts

Treatment at the time of presenting to hospital needs to address psychological distress as well as physical injury. Support for individuals who have made a suicide attempt and their families must be enhanced, with particular attention directed to the emotional, social and psychiatric needs of the person concerned.

Many participants in this project describe the hospital experience following a suicide attempt as overwhelming and distressing. The most frequently nominated reason for perceived poor treatment by health services was that the person's emotional distress was not attended to (15.3%). The research finding reinforces the importance of a mix of clinical and non-clinical responses being offered to people who have made a suicide attempt. How people are treated as human beings, not just as patients, must be a priority. Our analyses identified that a poor experience with health services after a suicide attempt reduces the likelihood of disclosing future suicidality.

We recommend:

- Training and quality assurance measures to be implemented yearly to improve attitude and behaviour of all staff in contact with those making an attempt. This change in attitude and behaviour needs to be driven by a systems approach to improving aftercare (see point 2 below).
- A dedicated staff member should be allocated to provide psychosocial support at the time of emergency department admission to assist the individual to navigate their way through the health system and to ensure continuity of care.
- Routine provision of information on suicide crisis support services, especially after hours services and those operated by non-government organisations, that are available to provide emotional support at a time of crisis. The need to have access to 24-hour services was clearly indicated in the online surveys. Many of these crisis support services operate after hours and may be convenient for people to access when they are needed.

Care needs to be tailored to the needs of the person.

Research participants, including caregivers, consistently expressed a desire to be involved in treatment planning following a suicide attempt. Patients require timely access to advice and support if their treatment plan needs to be adjusted (see recommendation 6). A reduction in care is associated with increased risk of death by suicide. Survey results show that as time passes, levels of satisfaction with care provided decrease, indicating that many people desire ongoing support that is unfortunately, not forthcoming.

We recommend:

- Improvements in treatment planning that address the patient's immediate, medium and long-term needs. Patients need access to advice and support if their treatment plan needs to be adjusted (see recommendation 6).
- That patients be proactively followed up at regular intervals following discharge, more frequently in the first weeks.

2. A systems approach to improving aftercare

An integrated approach to care after a suicide attempt is required, including data driven improvements, systems changes that allow patients to be followed-up assertively, and staff training/attitudinal change.

Organisations where the leaders have a strong focus on reducing suicides have demonstrated the effectiveness of a systems approach (for example Zero Suicides, US Military).

We recommend:

- That the number of suicide repetitions and suicide deaths are published as a function of hospital or health service organisation.
- The Key Performance Indicators of senior managers include responsibility for training of junior staff; accountability for the implementation of suicide management guidelines; and oversight of accurate reporting and data analysis.
- A key facet must be the use of existing quality in care techniques to ensure integrated management and practice improvement occurs on a continual basis, with routine monitoring of performance. National protocols on practice and quality in care for suicide attempt responses by hospital and health services would be valuable inputs to defining more precisely what is meant by 'quality in care' and for the establishment of benchmarks across state/territory and private hospital and health services.

3. Combined clinical and non-clinical models of care

There is an urgent need to identify ways of delivering treatments that are more effective than the presently available cognitive-psychological and psychopharmacologic therapies offered as stand-alone solutions.

Whilst specific stand-alone treatments have demonstrated effectiveness in some trials, they are likely to be insufficient where people have complex comorbidities and social circumstances. The research evidence appears to support modes of care that combine clinical and medical treatments with personal supports and psychosocial development – better results in both adherence to treatment and clinical outcomes appears possible, as well as enhanced alleviation of the personal distress and trauma associated with a suicide attempt. This model of care should be adopted Australia-wide.

We recommend:

- Outreach interventions such as telephone reminders of appointments coupled with encouragement to seek treatment, and home visits where appointments are missed.

- Providing a "crisis card" with emergency phone numbers and safety measures to caregivers.
- Motivational counselling and case management to achieve improved adherence to recommended treatment.
- Letters of support after a suicide attempt to provide a means of motivation for all patients subsequent to a suicide attempt and even for patients that refuse follow-up.

The potential to develop or extend the national helplines in Australia to facilitate follow-up of suicidal persons after medical or health service treatment should be explored. Notably, the national crisis line in the USA, the National Suicide Prevention Lifeline, has recently completed trials with hospitals, state health authorities and researchers at Columbia University to examine the effectiveness of collaborative care models involving a mix of clinical services and crisis line/chat support services. The emerging research findings from these trials should be examined for application to the Australian context.

Nationally consistent practice standards should be developed to support the assertive follow-up of all patients discharged from hospital following a suicide attempt.

Those who have had a suicide attempt are at high risk of further attempts and suicide. Our data linkage study in New South Wales shows that around 63% of patients received psychiatric or outpatient mental health care after being admitted to hospital following a suicide attempt. For most, this treatment involved one session of less than thirty minutes. Many suicides occur in the week after discharge from hospital, and a missed appointment after discharge is a risk factor for suicide. As such, greater efforts must be made to engage patients in timely post-discharge treatment.

We recommend:

- All patients are proactively followed up by a hospital/mental health outpatient service within 24-hours after discharge from hospital, again at seven days, and then at monthly intervals to determine whether treatment/case management has been sought or organised, and whether it has been delivered.
- All treating General Practitioners and mental health professionals are notified of a suicide attempt, and engaged in aftercare of their patients.

4. Post-discharge plans and primary health care

Patients and caregivers should be encouraged to be involved in treatment planning prior to discharge and with their general practitioner. The Primary Health Organisations throughout Australia could be funded specifically to develop and implement the protocols and program guides to support post-discharge planning around suicide attempts, in a similar way to the involvement of Divisions of General Practice in aged care post-discharge protocols. Being discharged from an emergency department or from an inpatient unit after a serious suicide attempt is very serious. Many individuals struggle daily with how difficult it is to stay alive and how easy it would be to die from suicide. Regardless of the particular attributes of any one individual, post-attempt discharge is a sufficient reason to justify follow-up within a few days and sometimes within a few hours of discharge. Long waits for a first outpatient appointment can be deadly. Continuity of care has never been formally implemented in Australian hospitals and other health services. Continuity of care strategies need to target individuals that are at high risk both for suicide and for non-adherence to the recommended treatment plan.

We recommend:

- That post-discharge plans be provided to patients who have attempted suicide as a routine practice, and should be based on psychosocial assessments as well as medical and treatment requirements.
- The design, testing, and implementation of integrated networks of care that ensure follow-up (assertive if needed) and evidence-based treatment of high suicide risk.

5. Coordinated support to utilise available services

Coordinated care needs to be facilitated, perhaps with the benefit of an individual who can help people to navigate the health system. A consistent theme emerging from the semi-structured interviews is that receiving good care after a suicide attempt appears to be a matter of luck. Post-discharge was also identified as a problematic time in the surveys and data linkage study. Health information for consumers and access to 'advocates' or assistants who can provide information on the range of health and community services available, and the expectations consumers should have surrounding these services, should be offered as a routine response to a suicide attempt. Previous work in Australia on quality health care as it relates to consumer information should be used as the basis for the design of a 'suicide attempt quality in care guide'. In other crisis situations (e.g. bushfires), affected individuals are provided with a caseworker to assist them in accessing services and resources. In these instances, it was not the therapy that was reported as being beneficial, but rather this assistance to navigate systems and services.

A collaborative model of aftercare that includes family/friends/caregivers is needed, i.e. a matching up of personal supports with the treatment program. A family and community-oriented approach to care can support the person to build a greater sense of belonging as well as providing support for caregivers. Within this model, accountability for service delivery and follow-up must be clear.

We recommend:

- A liaison or caseworker for people who have had a suicide attempt be based at major hospital emergency departments to take responsibility for coordinating care. This includes negotiating permission from the patient to involve caregivers in ongoing care and facilitating re-engagement with the community.

6. Use of technology and e-Mental health services

e-Mental health programs and other online services for suicide prevention should be integrated into the referral systems of hospital clinical staff and general practitioners.

The current health system and service response to persons who have attempted suicide is steeped in the traditions of face-to-face delivery of service upon presentation at health facilities. While this should remain a key part of the national response to suicide attempts and for suicide prevention, there is potential to better incorporate technology-based services and treatments, in the knowledge that social isolation, stigma and service access barriers may contribute to under-utilisation of the health services by individuals who have attempted suicide. The experience of e-Mental health services in Australia is that they are clinically effective and attract consumers who may not otherwise utilise or adhere to face-to-face treatment programs. Furthermore, caregivers may find online or mobile application information and support of greater benefit than printed materials or conventional face-to-face interactions.

We recommend the development of:

- e-mental health guides for case workers and mental health staff
- A collaborative care/case management tool for carers and families
- A 'tracking alert tool" for GPs and clinical managers

7. Data and monitoring of service performance

An integrated approach to aftercare is required, including data driven improvements, systems changes that allow patients to be followed up assertively, and staff training/attitudinal change.

In order to improve assertive outreach after hospital discharge, coordinated systems of care are required so that patients can be tracked across different aspects of a service, and followed up if an appointment is missed. This approach to health care should be informed by data collection and monitoring so that early

identification of lapses in adherence to treatment, or changes in clinical assessments, occurs. Evaluation of the effectiveness of post-acute release services would also be significantly better informed through the collection and analysis of this data.

Improve data collection systems to quantify and track suicide attempts and suicide deaths. Without this routinely collected data, the many community and health service efforts to reduce suicide behaviours cannot be evaluated. Current gaps include national data on the number of people who present to emergency departments following a suicide attempt or an episode of deliberate self-harm; what treatments they receive; the proportion of this population who are re-presenting following a previous attempt; and national data on what care patients receive after they have been discharged from hospital. This could include the development of a national surveillance system along the lines of the ambulance system being developed at Turning Point Victoria. A mix of aggregated, publicly available data and application-only unit level de-identified data is required, taking into account issues of privacy and security.

We recommend:

- The improvement of routinely collected data, including national data on the number of people who present to the emergency department following a suicide attempt or an episode of deliberate self-harm; what treatments they receive; the proportion of this population who are re-presenting following a previous attempt; and national data on what care patients receive after they have been discharged from hospital. This could be achieved in part by setting up sentinel sites across Australia for collection of emergency department data on suicide attempts/deliberate self-harm.

8. Providing care for caregivers

Caregivers consistently expressed a need for help in managing their own mental health and distress. The role of family and friends in providing ongoing support for those who live with chronic mental illness and suicidality is critical and requires greater support.

We recommend:

- That case workers/liaison officers provide caregivers with information about caring for someone with suicidality (such as the Beyondblue resources[113]) as well as referrals to local services and support groups.

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APPENDIX A: Project Methodology

LITERATURE REVIEWS

The Centre for Research Excellence in Suicide Prevention has an existing database of suicide prevention trials which has been supplemented with searches of electronic databases for this study. For a review of current international evidence, the review will include only RCTs and high quality longitudinal studies. To understand Indigenous interventions and current health practice, the review will be broadened to include longitudinal, cross-sectional and pre-post designs. Following the database searches, reference lists of key articles were hand-searched to identify other relevant literature. A grey literature search has been conducted to supplement the peer-reviewed literature. The literature search encompasses four areas:

1. National and international trends in suicide attempts.
2. Evidence regarding what works to reduce repeat attempts and completed suicides.
3. Models of service delivery for intervention following a suicide attempt.
4. International best practice for intervention following a suicide attempt.

Where data is available, it was extracted and presented in tables for the final report. This process allows for critical consideration of the evidence regarding intervention following a suicide attempt.

Methodology for the systematic review

Title A systematic review of the evidence for interventions designed to reduce suicidal behaviour and death for individuals who have attempted suicide.

Question Which interventions have shown to be effective for preventing further suicidal behaviour (suicidal ideation, suicide attempt, deliberate self-harm) in those who have already made a suicide attempt?

Introduction

Rationale Individuals with a history of attempted suicide are at higher risk of death by suicide than those without an attempt. Little is known about the interventions that aim to reduce repeat attempts, or whether these are effective in achieving this. The aim of this review is to examine the current literature base to determine what works to reduce repeat attempts and completed suicides.

Objectives The objectives are to:

1. Examine what interventions are used to reduce repeated suicide attempts for individuals who have made an attempt to take their own life
2. Examine which interventions are most effective in helping to reduce repeated attempts.

Methods

Eligibility Criteria All peer-reviewed published RCTs which examine the impact of an intervention to reduce suicidal behaviour (including suicidal ideation, suicide attempt and deliberate self-harm) for those that have had at least one prior suicide attempt within 12 months prior to study entry. RCTs should include a control condition (e.g. wait list or alternative interventions) with participants randomly allocated to conditions; English language publications; articles published from 1980 onwards. There was no restriction on participant age ranges. If studies have a mix of individuals who have suicidal ideation and those that have a

	prior attempt, at least 51% of the sample must have had a prior attempt to be included.
Information Sources	Databases to be searched: Medline, PsychInfo, Ovid, Embase, Cochrane Library; Science Direct; Web of Science
Search	keywords: (OR) suicide, suicidal behavio*, self-harm, self harm, self-poisoning, poisoning, self-injur*, suicide attempt*, attempted suicide, self-mutilation, self-inflicted wounds, cutting, overdose keywords: (AND) randomised controlled trial, randomized controlled trial, RCT Limits: human, English, peer-reviewed
Study Selection	Implementation or evaluation of interventions following a suicide attempt as a key component of the study; objective measures of primary outcomes (suicidal ideation, suicide attempt or deliberate self-harm) and/or the use of reliable and validated measures; include studies that manage deliberate self-harm and suicidal risk where intent was not specified; include studies comparing medications without a psychosocial intervention; exclude studies of non-suicidal self-injury.
Data Collection Process	Obtaining listings of all published articles (titles and abstracts) which fulfil initial selection criteria; developing a table to document results of the different studies; consensus meetings with team members to confirm inclusion/exclusion criteria and screening results; collection of full text papers for final inclusion and coding of study characteristics in table (see below).
Data Items	Extract information on all included trials regarding their description of suicide prevention interventions, measures of attempts/suicidal behaviour/ideation and secondary outcomes, numbers/characteristics of subjects, inclusion/exclusion criteria, description of control interventions (if any).
Risk of Bias in Individual Studies	Consensus between team members used to assess the adequacy of randomisation and validity and accuracy of outcome measures using the Cochrane Risk Bias tool.
Summary Measures	Document the primary suicidal behaviour outcome measure(s) for each study and the effect size (if possible); document any secondary outcome measures including mental health.
Synthesis of Results	Results of studies to be presented in a table.
Risk of Bias Across Studies	Note replication studies that aim to re-affirm previous findings and which may report data in a biased way (selective reporting within studies).
Additional Analyses	Note whether studies re-analysed their results with subgroups to further explain their findings.

Results

Study Selection	Report numbers of studies screened, assessed for eligibility and included in this review; give reasons for excluding studies.
Study Characteristics	For each study provide characteristics for which data was extracted, numbers of subjects, follow-up period and reference.

Risk of Bias within Studies	Note several studies being reported from one large dataset by an individual research group.

Discussion

Summary of Evidence

Limitations	Response rate may be low, although likely to be similar to other studies and falling between 20-60%; length of follow-up may be short or inadequate to demonstrate reductions in repeat attempts.

Funding

Funding Sources	National Mental Health Commission

ONLINE SURVEYS

The quantitative data collection component involved two purpose-designed online surveys; one targeting those individuals who have attempted suicide; another targeting the support people/caregivers of those who have attempted suicide. The survey of those who have attempted suicide, Survey A, collected: basic demographic details; data on any current diagnoses of mental disorders and previous suicide attempts; information on most recent suicide attempt; data on pathways to, sources of, and duration of help and support following the most recent suicide attempt; data on experiences of services and supports, including risk assessment, referrals, staff attitudes and follow-up; and information on what was most helpful following the suicide attempt. We surveyed participants' perceptions of what they believe to be the best suicide prevention strategies, and how they believe people at risk might best be reached. Screening of participants for suicidality and recent suicide attempt (i.e. less than one month ago) will also be undertaken to both verify eligibility and, if appropriate, provide support and referral information.

The survey of caregivers, Survey B, collected: basic demographic details; data on the most recent suicide attempt of the person to whom they provide support; data regarding the level of information they were provided at key points, such as during care and at discharge; information on the extent to which they were consulted following the most recent suicide attempt of the person they support; and views that they might have of potential improvements to the current services.

Participants and recruitment

The participants for this project were community-dwelling adults aged over 18 years who have (a) recently attempted suicide or (b) support and/or care for someone who has recently attempted suicide.

Recruitment occurred through a range of networks, including through advertisement of the survey through websites such as Centre for Research Excellence and Suicide Prevention (CRESP), Black Dog Institute, other CRESP member websites, suicide-related websites, relevant professional, consumer and caregiver sites and other media (such as Google and Adwords).

Eligibility criteria

Eligibility to participate in the project was determined via an online screening process. For Survey A, participants were required to:

- Be 18 years of age or older.
- Have reliable internet access.
- Be located in Australia.
- Have made a suicide attempt in the last 18 months but not in the past month[2].
- Be willing to make contact with Lifeline.

To be eligible for Survey B, participants were required to:

- Be 18 years of age or older.
- Have reliable internet access.
- Be located in Australia.
- Care for or support someone who has attempted suicide in the past 18 months but not in the past month.
- Be willing to make contact with Lifeline.

[2] the aim was to capture individuals with recent experience, but who are not currently experiencing a suicidal crisis, and who will not be traumatised by reporting their experience

Safety of participants

As Survey A was conducted with individuals who have been at risk for suicide, screening was undertaken to both verify eligibility and ensure the safety of participants. All participants, including those whose responses to screening suggest they are feeling suicidal or have attempted suicide within the past four weeks, were offered support from Lifeline. The service acted as a dedicated care provider to our participants and participants were reminded they could contact the service at any time. Those who were experiencing suicidal ideation but were not at immediate risk had the option of being contacted by a clinical psychologist within 48 hours. Participants in Survey B were also screened for suicidality and supported as per the protocol for Survey A. Details of the supports available to them, such as Lifeline and other caregiver organisations, were provided upon completion of the survey.

SEMI-STRUCTURED INTERVIEWS

Following completion of the online survey, participants were invited to take part in a telephone interview. In addition, the telephone interviews were advertised in the same locations as the online survey. Twenty people who had had an attempt and 12 supporters/caregivers were interviewed and saturation was reached. The purpose of the semi-structured interviews was to provide a more nuanced, in-depth understanding of peoples' experiences and needs following a suicide attempt. Interviews were taped and transcribed. Thematic analysis was used to draw conclusions from the content of all interviews. The interviews focused on the barriers individuals face when accessing health services and their views as to the types of services that best met their needs.

Interviews were conducted by a clinical psychologist experienced in working with those at risk of mental health problems including depression and anxiety and who has experience in conducting research interviews with people who have had a suicide attempt. Interview participants were reimbursed with a $30 voucher for out-of-pocket expenses.

DATA LINKAGE STUDY

Hospital admission data and mental health ambulatory data are available at the individual level in New South Wales. Linkage keys between all the major health datasets (Admitted Patients Data Collection, Emergency Department Data Collection, Mental Health Ambulatory Data, Central Cancer Registry) have been developed so that it is possible to identify individuals who have multiple contacts with health services.

We used this data to identify a cohort of individuals admitted to hospital for deliberate self-harm and to track any subsequent contacts they had with inpatient psychiatric services and mental health outpatient services. This design enabled us to examine the types of services used by those making medically serious suicide attempts at the population level. No research has previously examined this.

The methodology for the data linkage study is described in more detail in the main body of the report.

REVIEW OF CURRENTLY AVAILABLE DATA

The aim of this component was to review existing datasets to identify gaps in the data, and to ascertain their ability to indicate the number and characteristics of people accessing specific types of health services following suicide attempts. Thus, the review will provide an overview of the gaps, scope, quality, and accessibility of routinely collected data. The research team has good knowledge of the existing datasets resulting from their experience in data linkage research in suicide. To supplement this knowledge, the review included:

- Identifying and reviewing existing data dictionaries.
- Consulting with our advisory panel and sector representatives regarding other routinely collected datasets.
- Identifying and describing known datasets, e.g. the National Hospital Morbidity Database (NHMD); Admitted Patients Data Collection, Emergency Department Data Collection, Mental Health

Ambulatory Data; Ambulance data; National Minimum Datasets; Bettering the Evaluation and Care of Health (BEACH) data, Medicare data; and regular and irregular community surveys.

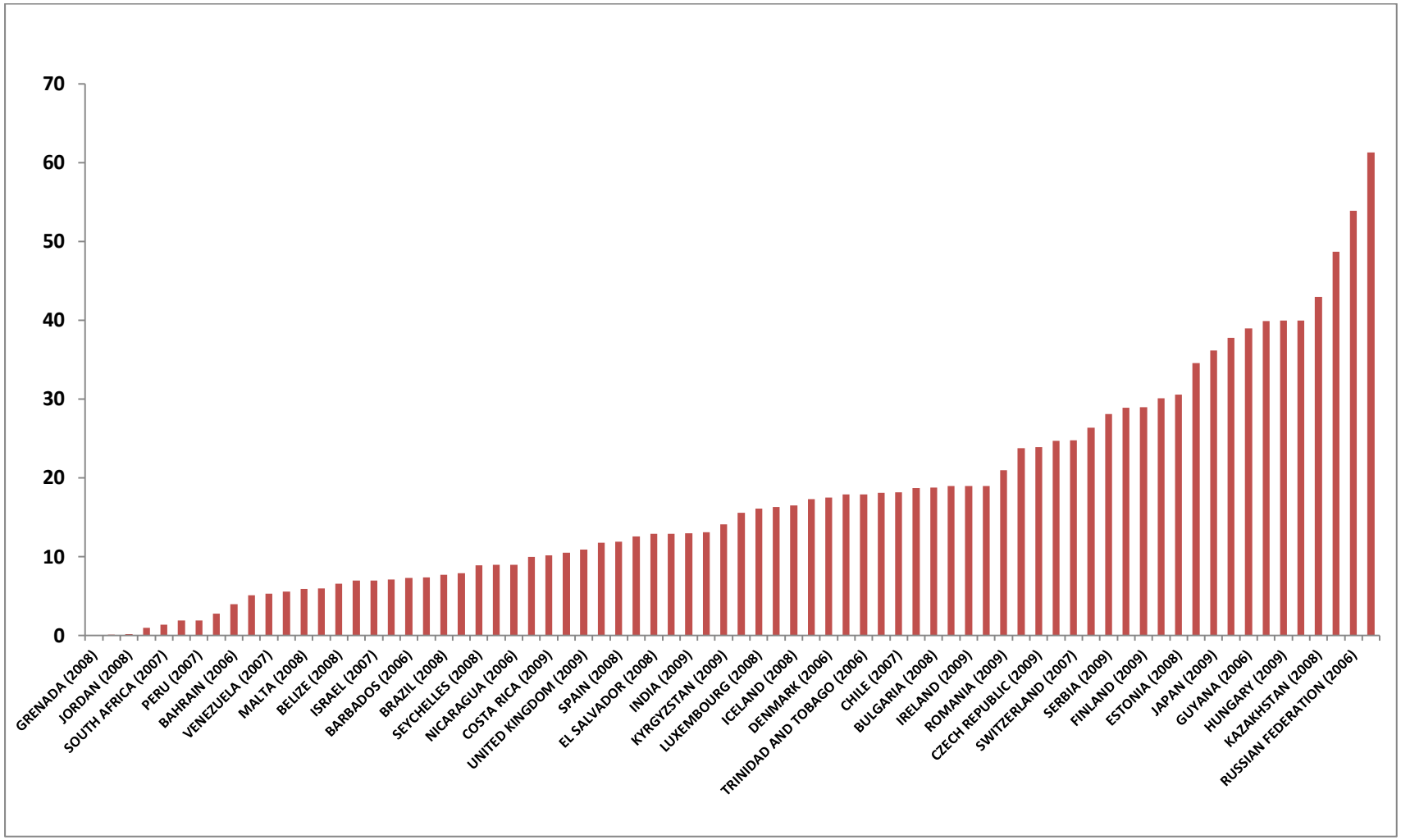
- Comparing jurisdictional datasets.
- Critiquing datasets for accessibility, cost, useability, consistency, and quality.
- With the assistance of our advisory panel and sector representatives, identifying the gaps in routinely collected data.

APPENDIX B: ADVISORY PANEL MEMBERS

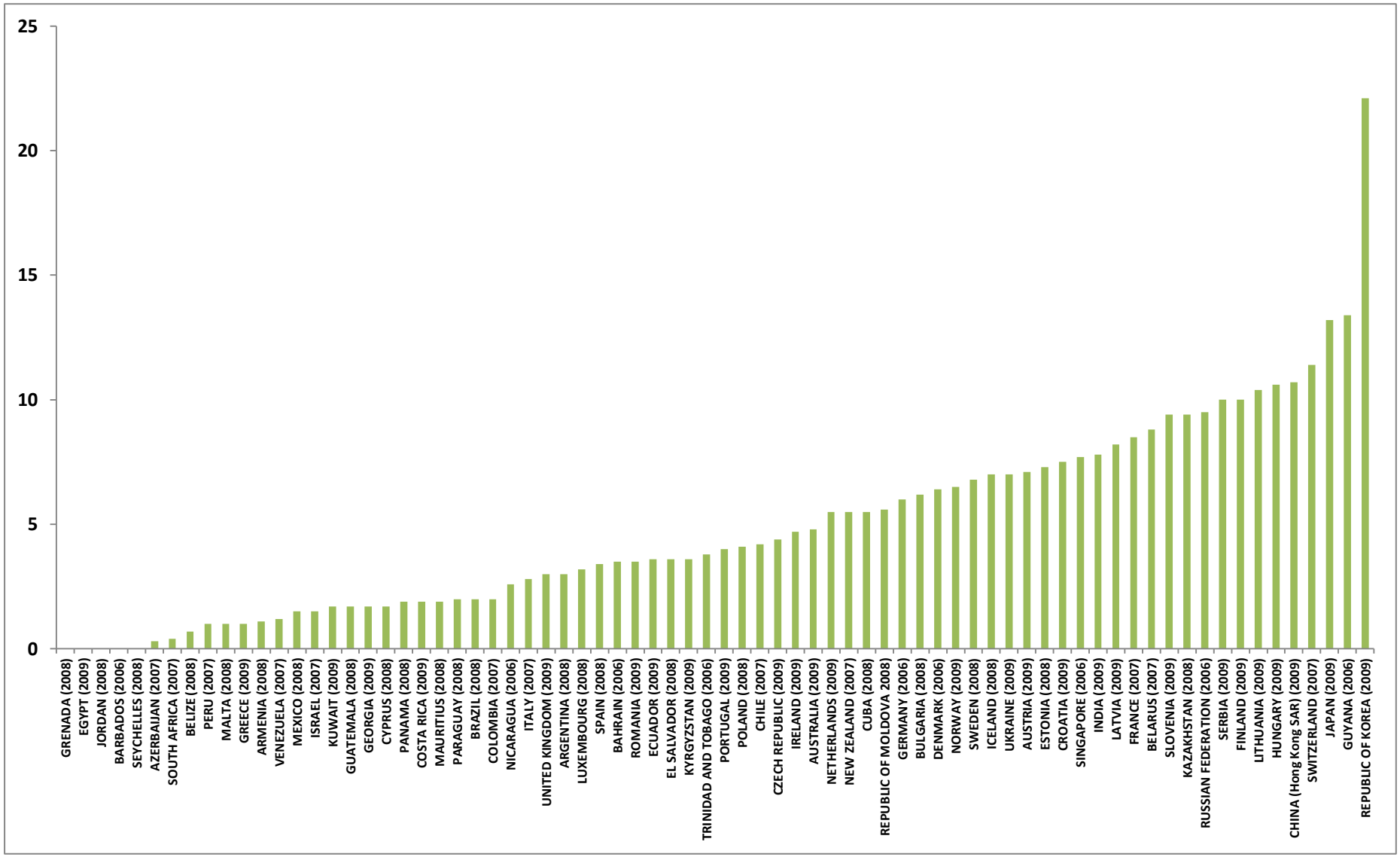
Name	Institute	Expertise
Michelle Banfield	NA	Consumer representative
Margaret Springgay	NA	Carer representative
Prof Annette Beautrais	University of Canterbury, NZ	Suicide Prevention expert
Prof Ad Kerkhof	VU, The Netherlands	Suicide Prevention expert
Prof Eric Caine	University of Rochester Medical Centre, US	Suicide Prevention expert
Todd Heard	University of Newcastle	ATSI representative
Dr Vered Gordon	Black Dog Institute	General Practice
Prof Greg Carter	University of Newcastle	Emergency Department
Prof Luke Larkin	University of Auckland, NZ	Emergency Department
Susan Beaton	BeyondBlue	Suicide prevention advisor
Barry Taylor	National LGBTI Health Alliance	LGBTI
Kevin McLaughlin	Ambulance NSW	Ambulance

APPENDIX C: SUICIDE RATES

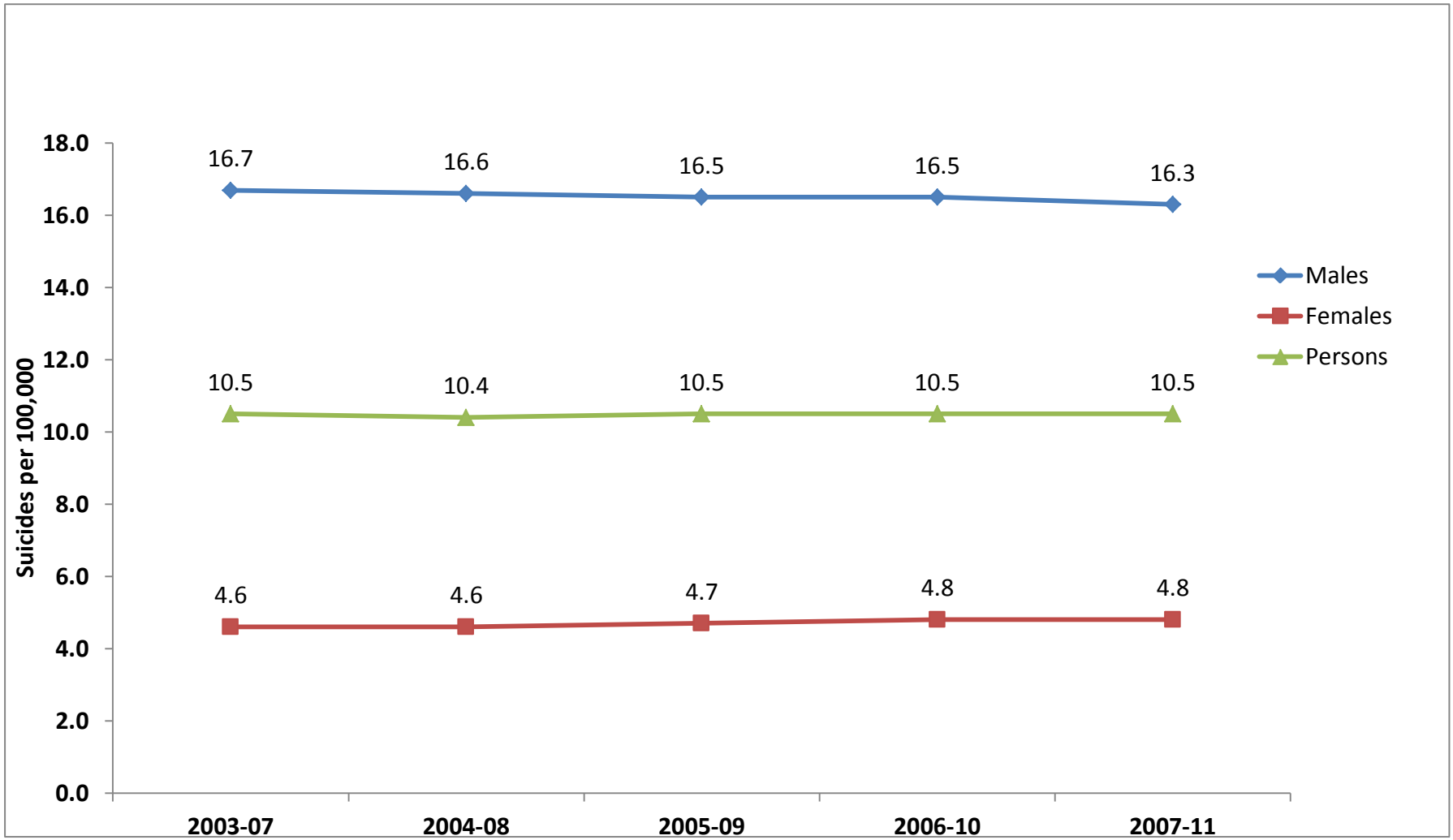
Suicide rates for selected countries, males



Suicide rates for selected countries, females



Average Australian annual age-standardised suicide rates (per 100,000 population) by five year period, 2003-07 to 2007-11



APPENDIX D: STUDY CHARACTERISTICS AND OUTCOMES

Studies with adolescents

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? yes/no)*
Alavi, A., Sharifi, B., Ghanizadeh, A., & Dehbozorgi, G. 2013 Iran	Intervention *Age:* M = 16.1, SD = 1.6 Control *Age:* M = 16, SD = 1.2 10% males Diagnosed with mild to moderate major depressive disorder Recruited from hospital setting *Inclusion criteria:* SA in the past 3 months	12 sessions (once a week) of CBT vs wait list condition	N = 30 *Intervention:* N = 15 *Control:* N = 15	3 months	*Primary outcome measure;* Suicidal ideation (SI), hopelessness, and depression *Results:* Reduction in suicide ideation (SI), hopelessness, and depression in the intervention group.	No
Byford et al (1999) [114] UK[3]	*Age*: M = 14.5, SD = 1.1 10% male Recruited via referral to child mental health teams *Inclusion criteria:*	*Intervention* Home-based social work plus routine care *Control:* Routine care (+ cost-effectiveness analysis)	N = 162 *Intervention:* N = 85 *Control:* N = 77	6 months	*Primary outcome measure:* Suicidal ideation, hopelessness, and family functioning *Results:* No significant differences between	Yes

[3] Details of the RCT in Harrington et al., 1998

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? yes/no)*
	• Deliberate self-poisoning • 16 years and younger •				groups in SI, hopelessness, family functioning[4] or costs, parents in intervention group more satisfied with treatment	
Asarnow et al., 2011 [115, 116] US	*Age:* M = 14.7, SD = 2.0 (10-18 years) 31% male Recruited from ED *Inclusion:* Presenting for SA, SI or both	Family Intervention for Suicide Prevention (FISP)[5] vs usual ED care enhanced by staff training	N = 181 *Intervention* N = 89 *Control* N = 92 21 (13+8) = lost to follow-up	2 months	*Primary outcome measure:* Linkage to outpatient mental health treatment *Results:* • Increase in linkage to outpatient MH treatment in intervention group • No differences regarding SA or other clinical or functioning outcomes	Yes
Cotgrove et al., 1995[117] UK	*Age:* M = 14.9 years 15% male Recruited at hospital setting (child & adolescent department/clinic) *Inclusion criteria:* • Admitted after a SA • 16 years or younger •	Standard management plus a token/green card allowing readmission to hospital on demand vs standard management	N = 105 *Intervention:* N = 47 *Control:* N = 58	12 months	*Primary outcome measure:* Use of green card and repeated suicide attempt *Results:* No differences in repeated SA (lower SA repetition in intervention group 6% vs 12%)	No
Esposito-Smythers	*Age:* M=15.7, SD=1.2	Integrated CBT protocol for	N=40	18 months	*Primary outcome measure:*	Yes

[4] In a sub-group of children without major depression, SI was significantly lower in the intervention group at the six-month follow-up.
[5] Enhanced mental health intervention involving a family-based CBT session designed to increase motivation for follow-up treatment and safety, supplemented by care linkage telephone contacts after emergency department discharge.

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? yes/no)*

et al., 2011 [118]
 	
US
	(13-17 years)
	
	32% male
	
	Recruited from psychiatric inpatient unit
	
	Inclusion criteria:
	• SA in past 3 months or reported clinically significant SI during past month
	• Alcohol or cannabis use disorder
	• Living in the home with a parent or guardian willing to participate
		co-occurring alcohol and other drug use disorders and suicidality vs enhanced TAU	*Intervention*: N=20
			
			Control:
			N=20
			
			3 (2+1) = lost to follow-up
					Alcohol or other drug use disorder outcomes (days of alcohol use, heavy alcohol use, marijuana use, and alcohol and marijuana problems), lower suicidal ideation and general impairment, at 3, 6, 12, and 18 months postenrollment
					
					Results
					• In intervention group:
					  ○ Fewer heavy drinking days and days of marijuana use
					  ○ Less global impairment
					  ○ Fewer SA
					  ○ Fewer inpatient psychiatric hospitalisations, ED visits, and arrests
					• Equivalent reductions in SI in both groups	

Green et al., 2011 [119] UK	*Age:* 12-17 years 11% male Recruited from child and adolescent MH services teams	Developmental group therapy intervention[6] and routine care vs routine care (+ cost-effectiveness analysis)	N = 366 *Intervention* N = 183 *Control* N = 183	12 months	*Primary outcome measure:* Frequency of episodes of self-harm over a defined period (12 months before baseline, 6 months before 6 month assessment, 6 months before end point)	Yes

[6] A manual-based treatment specifically designed for self-harming adolescents. The programme integrated techniques from a number of other therapies, including CBT, DBT, and group psychotherapy.

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? yes/no)*
	Inclusion criteria: 2+ past episodes of self-harm within past 12 months		7 (4+3) = lost to follow-up		*Results*: No differences between groups in frequency of self-harm, secondary outcomes[7] or cost effectiveness	
Hazell et al., 2009 [120] Australia	*Age:* M=14.5, SD=1.1 (12-16 years) 10% male; Recruited from child and adolescent MH service *Inclusion criteria:* At least 2 episodes of self-harm in the past year, one of which occurred in the past 3 months	Group intervention[8] vs routine care	N = 72 *Intervention:* N = 35 *Control*: N=37 4 (1+3) = lost to follow-up	12 months	*Primary outcome measure:* Repetition of self-harm *Results:* • More adolescents in intervention group self-harmed • Few differences on secondary outcome measures[9]	Yes
King et al., 2006 [121] US	*Age:* M=15.3, SD=1.5 (12–17 years) 32% male *Inclusion criteria:*	Youth-Nominated Support Team-Version 1 (YST–1)[10] plus TAU vs TAU	N=298 *Intervention:* N = 151 *Control*:	6 months	*Primary outcome measure:* Suicidal ideation and suicide attempts *Results:* No main effects for intervention on SA or SI, internalizing symptoms, or related functional impairment[11]	Yes

[7] Severity of subsequent self-harm, mood disorder, SI, global functioning, total costs of health, social care, education, criminal justice sector services, family related costs and productivity losses.
[8] Intervention informed by principles of CBT, social skills training, interpersonal and group psychotherapy.
[9] … other than a trend for greater improvement over time on global symptom ratings among the experimental group compared with the control group
[10] A social network intervention: psycho-education for support persons whom youths nominate from within and outside their family and facilitation of the supportive weekly contact of these support persons with the suicidal adolescent.

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? yes/no)*
	• SA or significant SI/intent during the past month • Score of 20 or 30 on the Self-Harm subscale of the Child and Adolescent Functional Assessment Scale (CAFAS) • At least one completed baseline measure; psychiatric hospital setting		N = 138 53 (38+15) = lost to follow-up			
King et al., 2009 [122] US	*Age:* M=15.6, SD=1.3 (13–17 years) % male not reported Recruited in psychiatric hospital setting *Inclusion criteria:* Significant SI or SA within the past 4 weeks	Youth-Nominated Support Team-Version 2 (YST–2)[12] plus TAU vs TAU	N=448 *Intervention*: N = 223 *Control*: N = 225 Retention 75% at 6 weeks, 76% at 3 months, 70% at 6 months, and 77% at 12 months	12 months	*Primary outcome measures:* Suicidal ideation • More rapid decreases in SI for participants with multiple SA during the initial 6 weeks after hospitalisation • For those with one suicide attempt, it was associated with greater decline in functional impairment at 3 and 12 months • No effects on SA and SI	Yes

[11] However, relative to girls in the TAU-only condition, those in TAU+YST-I improved more on mood-related functional impairment in intent-to-treat analyses. There was also a suggestion that girls in TAU+YST-I showed- greater decreases in suicidal ideation, although these effects were only evident in actually treated rather than intent-to treat analyses.
[12] The intervention provides psycho-education and ongoing consultation for the parent-approved adult support persons that have been nominated by the adolescent, providing them with information about the adolescent's emotional and behavioural problems or disorders, treatment plan and rationale for recommended treatments, signs of increased suicide risk, and availability of professional resources. The support persons maintain regular supportive contact with the adolescents for 3 months following hospitalisation.

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? yes/no)*
Ougrin et al., 2011 [123] UK	*Age:* M = 15.6, SD = 1.3 (12–18 years) 20% male Recruited from child and adolescent MH services *Inclusion criteria:* • Not currently engaged with psychiatric services • Self-harm and referral for psychosocial assessment	Therapeutic Assessment[13] vs assessment as usual	N = 70 *Intervention* N = 35 *Control* N = 35 5 (2+3) = lost to follow-up	3 months	*Primary outcome measure* Participant's attendance at the individual outpatient treatment sessions *Results:* • Improvement in engagement (attending first follow-up appointment and four or more treatment sessions) in intervention group • No differences in general psychopathology and function	Yes
Pineda & Dadds, 2013 [63] Australia	*Age:* M = 15.2, SD = 1.2 (12-17 years) 25% male Recruited from ED and community MH service setting *Inclusion criteria:* • At least 1 episode of suicidal behaviour (includes SA, SI, suicidal intent, or deliberate self-inflicted injurious behaviour) within the last	Resourceful Adolescent Parent Program (RAP-P)[14] plus routine care vs routine care	N = 48 (adolescents and their parents) *Intervention* N = 24 *Control* N = 24 8 (2+6) = lost to follow-up	6 months	*Primary outcome measure:* Suicide/self-harm risk and psychiatric impairment *Results:* High recruitment and retention, greater improvement in family functioning, reductions in adolescents' suicidal behaviour (largely mediated by changes in family functioning) and psychiatric disability in intervention group	Yes

[13] A manualised procedure including a basic psychosocial assessment and a 30 min therapeutic intervention.
[14] An interactive psycho-education program for parents of adolescents implemented over four 2-hour sessions (held once a week or once every 2 weeks).

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? yes/no)*
	2 months • Residing with at least 1 parent • Primary DSM-IV diagnosis including any of the following: major depression, PTSD, or anxiety disorder					
Rossouw & Fonagy, 2012 [64] UK	*Age:* M = 14.7, SD = 1.2 (12-17 years) 15% male Recruited from community MH services or acute hospital emergency rooms *Inclusion criteria:* • At least one episode of confirmed self-harm within the past month • Self-harm primary reason for referral • Self-harm confirmed as intentional	Mentalization-based treatment for adolescents (MBT-A) vs TAU	N = 80 *Intervention* N = 40 *Control* N = 40 43 (20+23) = lost to follow-up	12 months	*Primary outcome measure:* Self-harm in the previous 3 months *Results:* Greater decrease in self-harm, depression, and borderline features in intervention group	Yes
Wood et al. 2001 [124]	*Age:* M=14.2, SD=1.6	Developmental group psychotherapy[15] and routine care vs routine care	N = 63 *Intervention*:	7 months	*Primary outcome measure:* Depression and suicidal behaviour *Results:*	Yes

[15] It brings together techniques from a variety of other therapies, including the problem-solving and cognitive-behavioural interventions, DBT and psychodynamic group psychotherapy.

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? yes/no)*

UK	(12-16 years)
	
	22% male
	
	Inclusion criteria:
	
	• Referral to child and adolescent MH service following an incident of deliberate self-harm
	• At least one other occasion of deliberate self-harm during the previous year
			N = 32
			
			Control:
			N = 31
			
			21 (9+12) = lost to follow-up
					• Intervention group:
					  ○ Reduction in repeated deliberate self-harm on two or more further occasions
					  ○ Lower likelihood of using routine care
					  ○ Better school attendance
					  ○ Lower rate of behavioural disorder in intervention group
					• No differences in depression or global outcome	

Brief interventions

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? (yes/no)*
Beautrais et al., 2010 [125] New Zealand	Intervention *Age*: M = 38.8 years 29.6 % male 75% self-poison Control *Age*: M = 33.9 years 37.7% males 78.2% self-poison Self-harm by: poisoning, cutting, hanging, vehicle exhaust carbon monoxide poison, purposeful MVA, other Recruited via admittance to psychiatric emergency department (ED) of one hospital in New Zealand (August 2006-April 2007) *Inclusion criteria:* • 16 years or older • Admitted for a self-harm episode or a suicide attempt	Postcard intervention vs TAU *Intervention:* • Post card intervention • Received TAU as well • Sent 6 postcards in the mail in the 12 months following admittance to ED • Posted at 2 and 6 weeks, and 3, 6, 9, and 12 months • All postcards had the same message written on them *TAU:* • Crisis assessment referral to inpatient community-based health services	N = 327 randomised *Intervention:* N = 153 *TAU:* N = 153 All participants were followed-up and analysed	Follow-up at 12 months	3 primary outcome measures: 1) re-admittance to psychiatric ED at 12 months 2) re-admittance to normal ED at 12 months 3) re-admittance to either type of ED (total re-visits) at 12 months *Results:* • Significant reduction in the number of psych ED re-visits, ED re-visits and total re-visits for the intervention group After adjusting for the fact the intervention group had fewer prior admittances to any ED for self-harm or suicide attempts, all results no longer significant	Yes
Bennewith et al., 2002 [60] UK	Intervention *Age*: M = 32.3 years 39.7% male Self-poisoning = 90.1%	Single consultation session vs usual care *Intervention:*	N = 1932 randomised *Intervention*	12 month follow-up	*Primary outcome*: Reoccurrence of deliberate self-harm episodes within the 12 months after the index episode	No

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? (yes/no)*
	Control *Age*: M = 32.8 years (16-95 years) 42.7% male Self-poisoning = 89.3% *Recruitment:* • Potential participants collected from register of cases for deliberate self-harm • Database info collected on weekly basis from hospital accidents and ED departments from around the UK • 49 practices for each group were used for recruitment *Inclusion criteria:* • At least 16yrs of age • Drug OD, unless intentional, and self-harm due to psychosis were excluded •	• Letter of invitation extended by their GP for a session on deliberate self-harm • The treatment was developed for this trial *Control:* • Offered usual care which meant no special services were offered to participants	N = 964 *Control* N = 968 *Lost to follow-up not included in paper*		*Results:* • No difference between groups in the proportion of participants that repeated self-harm at 12 months • Above results still NS if gender and method of attempt accounted for • **Odds ratio found a significant effect that the intervention was beneficial for those with prior self-harm episodes** • Odds ratio found a significant effect that the intervention was harmful to those that had no prior self-harm episodes	
Bertolote et al., 2010 [58] Brazil India Sri Lanka	*Age across countries:* Median = 23 years China • Intervention - M = 35/34 years (M/F)	Brief Intervention and Contact (BIC) vs TAU *Intervention:* (A 1 hour info session (individually conducted) that was close to the time of	N = 1867 total randomised *Intervention:* N Randomised = 922	18 months follow-up	*Primary outcome measure:* Repeated suicide attempts Prior study (Fleischmann et al., 2008) looked at whether this intervention reduced deaths from suicide	No

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? (yes/no)*
Iran China	29% male • Control - M = 28/30 years (M/F) 33% male <u>Brazil</u> • Intervention - M = 29/30 years 29% male • Control - M = 34/29 years 39% male <u>India</u> • Intervention - M age = 25/22 years 48% male • Control - M age = 25/22 years 49% male <u>Sri Lanka</u> • Intervention - M age = 24/ 21 years 40% male • Control - M age = 22/22 years 44% <u>Iran</u> • Intervention - M age = 21/22 years 36% male • Control -	hospital discharge • Visits or phone calls at 1, 2, 4, 7, and 11 weeks and 4, 6, 12, and 18 months • Visits and phone calls consisted of asking the participants how they felt and if they needed more support *Control:* TAU • Acute management of somatic symptoms in hospital • No psychiatric or psychological consultation • Referred on to outpatient mental health services	N received intervention = 922 Lost to follow-up = 50 Analysed = 863 *Control:* Randomised = 945 Received TAU = 945 Lost to follow-up = 118 Analysed = 800		Results: • More TAU dropped out of study than the BIC group (across countries) • Gender differences found in different countries o i.e. more females than males re-attempted in Brazil o More males than females reattempted in Iran • Differences in whether there was a rise or drop in reattempts overall across country o i.e. Brazil increased in reattempts and China decreased • **There were no significant differences between intervention and control groups in number of reattempts**	

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? (yes/no)*
	M age = 22/22 years 39% male Recruited from EDs in 5 countries Admitted to ED for suicide attempt					

Carter et al., 2013 [54]
 	
Australia
	Age: 24-44 years (median = 33 years)
	
	32% male
	
	Self-poison only
	
	Recruited when presented to EDs or admitted to a regional toxicology unit between April 1998 to December 2001
	
	Inclusion criteria:
	16 years and older
		Postcard intervention vs TAU
		
		Intervention:
		• Sent 8 postcards at 1, 2, 3, 4, 6, 8, 10 and 12 months after discharge
		• Also received TAU
		
		Control:
		• TAU
			N = 772 randomised
			
			Intervention:
			• N randomised = 378
			• 12 months follow-up = 378
			• (only 3023 consented to take part in the study)
			• 24mths follow-up = 378
			• 60mths follow-up = 378
			
			Control:
			• N randomised = 394
			• 12mths follow-up = 394
			• 24mths follow-up = 394
			• 60mths follow-
				5 year follow-up	*Primary outcome measures:*
					1) General hospital admissions for repetition of self-poisoning
					2) Psychiatric admissions but for any reason
					
					Results:
					• At 5 years, ns difference between the two groups in one or more repeat self-poisonings
					• **Significant reduction in the event rate of revisits due to self-poisoning between groups – intervention had lower rates at 5 years**
					  ○ Further analysis showed that this was true for females but not males
					  ○ Significant reduction in the intervention group but only those with a prior history of self-poison – n.s. result for those without prior history
					
					• Significant lower rates of any psychiatric admission for
						Yes

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? (yes/no)*
			up = 394		intervention group over control group – no difference for gender or prior history • N.s. difference between the two group in deaths at 5 years or completed suicides	
Cedereke et al., 2002 [126] Sweden	<u>Intervention</u> *Age:* M = 40 years 34% male <u>Control</u> *Age:* M = 42 years 34% male *Inclusion criteria:* • Treated for suicide attempt in one hospital in Sweden • Admitted to the hospital between Feb 1995 and April 1997	Phone intervention vs TAU All participants assessed in hospital then referred to further treatment and told they would be contacted in one month after attempt At one month, all came back in for a face-to-face interview – Told they MIGHT receive phone call *Intervention:* • Called at 4 and 8 months • Interview that gave advice and encouraged continued or renewed treatment • 20-45 minutes • Called at end point of 12 months • TAU Control: • TAU • Were not contacted until 12	216 randomly assigned *Intervention:* N = 107 *TAU:* N = 109 Intervention follow-up = 89 (18 lost) Control follow-up = 89 (20 lost) Analysed: Intervention = 86 Control = 89	12 month follow-up	*Primary outcome measures:* does a phone intervention impact treatment outcome? *Results:* • N.s. difference between the groups in the frequency of repeated suicide attempts *OR* the amount of people that repeated attempts during the 12 months • **Both groups were more likely to have reattempted if they had follow-up treatment** • Significant reduction for those in the control group of their psychological symptoms compared to the intervention group • Both groups significantly improved their global function and suicidal ideation scores over time but there was no difference between the groups	No

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? (yes/no)*
		month follow-up				
Chen et al., 2013 [127] Taiwan	Intervention: *Age:* M = 39.8 years 34.9% male Controls: *Age:* M = 40 years 29.1% male Recruited July to Dec 2011 *Inclusion criteria:* Attempted suicide in the previous month	Postcard intervention and case management vs case management (CM) *Control:* • Completed at least 6 CM sessions within 3 months • CM sessions included things like psychological support and coping strategies and participants given a brief crisis intervention if needed *Intervention:* • Completed 6 CM sessions within 3 months • Sent crisis postcard at the end of 6 CM sessions • Coping strategies and contacts were listed on the card • Small enough to fit in wallet so they could keep it on them • Tailored to individual based on the CM sessions	N = 761 randomised[16] *Intervention:* N = 373 • N = 17 excluded for not completing CM sessions • N = 250 read postcard • N = 106 did not read postcard • N=356 included in final analysis *Control:* N = 388 • N = 25 lost to follow-up • N = 363 analysed	6 month follow-up	*Primary outcome measure:* Suicide attempts during 6 month follow-up *Results:* • Found that there was no difference between groups in reducing suicide attempts in 6 months	Yes
Crawford et al.,	Control	Referral for brief intervention	N = 103 total	Follow-ups	*Primary outcome measures:*	Yes

[16] Randomised via their individual identification number given by the government at birth. Those with an odd no. at the end were in the intervention group and those with an even no. at the end were placed in the control group

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? (yes/no)*
2010 [128] UK	*Age*: M = 36.6 years 73% female 35% OD as self-harm method <u>Intervention</u> *Age*: M = 37.8 years 26% male 39% OD as self-harm method Recruited from EDs between Nov 2005 and Jan 2008 *Inclusion criteria:* • 18 years and older • Reported to the ED for deliberate self-harm • Also had to be misusing alcohol and were not seeking treatment for it	vs leaflet *Intervention:* • Given referral to an appointment with an Alcohol nurse in the ED • 30 minute assessment and discussion about drinking habits • Referred to other services if need be • Leaflet given on alcohol and health *Control:* • Given a leaflet on alcohol and health	randomised *Intervention*: N = 51 included N = 24 who received treatment 17 lost to follow-up N=51 assessed *Control*: N = 52 included N = 54 assessed 11 = lost to follow-up	at 3 and 6 months	1) Number of time deliberate self-harm was repeated 2) Level of alcohol consumption 3) Current general mental health – measured by the GHQ *Results:* • N.s. number of reductions in the repetition of deliberate self-harm	
Evans et al., 2005 [129] UK	Admitted to hospital for self-harm Recruited between 1994 and July 1996 *Participant demographics, inclusion criteria, etc. not included in paper*	Crisis card intervention vs TAU *Intervention:* • Given a card that offered 24hr crisis telephone consults with a psychiatrist • Offered for 6 months after the interview *Control:* • TAU	N = 827 randomised *Intervention:* N = 417 *Control:* N = 410 *Lost to follow-up etc. not included in paper*	6 and 12 month follow-ups	*Primary outcome measures:* If self-harm was repeated within 6 months and 12 months *Results:* • N.s. difference in the number of reattempts between groups at 12 months • N.s. difference between groups in the time between index attempt and repeat episode	No

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? (yes/no)*
		• Varied • Some referred to on to community services, some admitted to psychiatric care				
Fleischmann, et al., 2008 [59] Brazil, Sri Lanka, India, Iran & China	Median age across countries = 23 years Recruited from EDs in 5 countries Admitted to ED for suicide attempt	Brief Intervention and contact (BIC) vs TAU	N = 1867 total randomised	18 months follow-up	*Primary outcome measure:* Deaths from suicides at the 18 month follow-up *Results:* • All 5 countries were analysed together • Significantly fewer overall deaths in the BIC treatment group than the TAU group at follow-up o Not suicide specific • **Significantly fewer deaths from suicide in the BIC intervention group than the TAU group at follow-up**	No
Hassanian-Moghadda et al., 2011 [55] Iran	*Age:* M = 24.1 years 33.6% males Recruited from a toxicology hospital from March to June 2006 *Inclusion criteria:* • 12 years and older • Purposeful self-poisoning	*Postcard intervention vs TAU* *Intervention:* • Based on postcards from the edge study • Sent a 4-page greeting card 8 times: 1, 2, 3, 4, 6, 8, 10 and 12 months after hospital discharge • Also received TAU *Control/TAU:* • Hospital care for self-poisoning	N = 2300 randomised *Intervention:* • N = 1150 • N = 1043 at 12 month follow-up • 107 lost to follow-up *Control:* • N = 1150 • 1070 at 12	12 month follow-up	*Primary outcome measures:* 1) Suicidal ideation 2) suicide attempts 3) self-cutting/ mutilation *Measured by asking participants direct questions – i.e. "have you ever…?"* *Results:* • Significant reductions in suicidal ideation for both males and females in the intervention group • Significant reduction in suicide attempts and # of suicide attempts	No

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? (yes/no)*
		• Not many services outside hospital for follow-up options in Iran	month follow-up • 80 lost to follow-up		per person for the intervention group females but not males • N.s. reduction in self-cutting episodes both overall and per person •	
Hassanzedah et al., 2010 [130] Iran	Intervention *Age*: M = 24 years 12.3% male Control *Age*: M = 25 years 12.8% male Age range: 12-78 years Recruited from 5 EDs in Iran from July 2002 to April 2003 *Inclusion criteria:* Attempted suicide and presented to EDs	Brief-intervention and contact vs TAU All participants • Intake interview • Questionnaires *Intervention:* • BIC and TAU • 1 hour psychosocial educational information session • Phone calls or visits at 1, 2, 4, 7, and 11 weeks and 4 and 6 months *Control:* • TAU • TAU = regular ED treatment for suicide attempt	N = 632 randomly assigned *BIC:* N = 321 *TAU:* N = 311 *Lost to follow-up, etc. not included in paper*	6 month follow-up	*Primary outcome measures:* Suicide re-attempts *Results:* • N.s. difference between the two groups for the number of participants reattempted suicide at 6 months • Significantly fewer reattempts in TAU group compared to BIC at 6 months • Significantly more participants in the BIC group wanting help/support at the end of the 6 months	No
Kapur, et al., 2013 [131] UK	Recruited from November 2010 to May 2011 *Inclusion criteria:* • 18 years and older • Those who presented to the ED for self-harm or poisoning regardless of	Information leaflet, telephone calls and letters vs TAU *Intervention:* • Two phone call within the first two weeks after hospital discharge • Leaflet about services they	N = 66 randomised *Intervention:* • N = 33 • 0 = lost to follow-up	12 month follow-up	*Primary outcome measures:* 1) Proportion of patients that reattempted self-harmed that resulted in hospitalisation in 12 months 2) Number of repeat self-harm episodes *Results:*	Yes

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? (yes/no)*
	whether intentional or not *Participants demographics not included in paper*	could contact • Sent letters at 1, 2, 4, 6, 8 and 12 months • Included TAU *Control: TAU* • Hospital assessment • Referrals to community services	• Analysed = 32 *Control:* • N = 33 • 2= lost to follow-up • Analysed = 32		• Intervention group was significantly more likely to have individually repeated self-harm than TAU at 12 months • The intervention group had significantly more repeated episodes of self-harm than TAU at 12 months **Above results were no longer significant once adjusted for demographics and differences in method of harm between the two groups**	
Marasinghe et al., 2012 [132] Sri Lanka	*Age:* (15-74 years) Group 1 M = 30/34 years (M/F) Group 2 M = 29/31 years (M/F) 50% males in both groups Recruited participants from a hospital in Sri Lanka *Inclusion:* • Participants were admitted to hospital for self-harm • Showed suicidal intent at interview	*Mobile phone psychotherapy* *Intervention:* Face to face interview: • 1 to 2 hours mental health assessment • 3-4 hours of treatment including meditation, problem solving, ways to increase social support Brief mobile treatment: • Phone calls at day 2 and 4, 1, 2, 4, 6, 12, 18 and 24 months post discharge • 10-15 minutes each call • Assess suicidality and mood • Had access to 5 minute audio messages anytime • Weekly SMS reminders up to 26 weeks	Randomised N = 68 *Group 1*: N = 34 *Group 2*: N = 34 *Lost to follow-up etc. not included in the paper*	12 month follow-up	*Primary outcome measure:* Suicide attempts reduced due to intervention above usual care *Results:* • Significant interaction between the two groups at 6 months compared to baseline on ratings of suicidal ideation where group 1 had lower ratings than group 2 ○ This was n.s. at 12 months though – both groups declined at 12 months and showed no group difference • The above results were also found for depression and the amount of perceived social support • **Ns reduction in actual self-harm between groups at any time point**	Yes

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? (yes/no)*
		Group 1 • Immediate brief mobile treatment • Received treatment right away • Also administered usual care Group 2 • Delayed brief mobile treatment • Received the intervention but 6 months after the first group				
Motto et al., 2001 [56] US	*Age (across 3 groups):* M = 33.9 years 44% male Recruited from 9 psychiatric units between 1969 and 1974 *Inclusion criteria:* Either in a depressive or suicidal state or regarded to be at suicidal risk	Contact vs. no contact (both without treatment) All participants interviewed for 2-4 hours for a psychosocial evaluation If not in treatment at the 30 days, then randomly assigned to either the contact group or control group *Intervention/ Contact group:* • Sent letters 24 times over a period of 5 years • Letters were personalised and different each time, written by the person who interviewed them initially and touched on response letters	Treatment N = 1939 Contact intervention: N = 389 No-contact/ control: N = 454 *Lost to follow-up etc. not included in paper*	Follow-up = 5 years and 15 years	• **The contact group had significantly lower percentage of completed suicides in the first two years than the no-contact groups** • The graph indicated this was the case for the contact vs treatment group although significance testing was not shown • There was no significant differences between the contact group and no-contact group at any other year, although a trend towards significance was noted that diminished as the year passed	No

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? (yes/no)*
		researchers may have received back from participant • Asked how they were going and told they could respond if they wished to No contact (control) group: • Interviewed at 30 days				
Vaiva et al., 2006 [133] France	<u>Intervention group 1</u> *Age:* M = 38 years 22% males <u>Intervention group 2</u> *Age:* M = 35 years 28% males <u>Control group</u> *Age:* M = 35 years 29% male Aged 18-65 years across groups Recruited from 13 emergency departments in France over 6 months *Inclusion criteria:* • Attempted suicide by drug overdose (had to be deliberate OD) • Addicts and those with psychosis were excluded	Contact vs no-contact/ TAU *Intervention groups:* • Contacted by phone by a psychiatrist • Went over treatment suggested by the ED • New treatment suggested if not working • Psychotherapy over the phone *Intervention group 1:* • Contacted 1 month after suicide attempt *Intervention group2:* • Contacted 3 months after suicide attempt *Control group:* • TAU • Usually a referral to their GP	N = 605 randomised *Intervention group1:* • N = 107 • 107 completed the intervention • 107 followed up at 13 months *Intervention group 2:* • N = 146 • 97 completed the intervention • 95 followed up at 13 months *Control:* • N = 312 • 280 followed-up at 13 months	13 month follow-up	*Primary outcome measure:* 1) Proportion of participants who reattempted suicide 2) Number of completed suicides 3) Losses to follow-up at 18 months *Results:* • N.s. difference in the proportion of adverse effects between all three groups • **Significantly fewer participants reattempted at follow-up in the 1 month group compared to the control group at 6 months** • Ns difference in reattempted suicide between 3 month group and the control group	Yes

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment and control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*	*Intention to treat? (yes/no)*
Vijaykumar et al., 2011 [134] India	BIC group *Age*: M = 26.6 years 49% male TAU *Age:* M = 25.8 years 46% male Recruited from ED between Jan 2002 and Jan 2004 *Inclusion:* • 12 years and older • Admitted to the ED for attempted suicide	Brief intervention and contact vs. TAU *Intervention:* • Brief-intervention and contact (BIC) • 1hr info individual session close to the time of discharge • Sessions covered info about distress, coping strategies and gave info on who to contact if need support • 9 home visits at 1, 2, 4, 7, and 11 weeks and 4, 6, 12 and 18mths after discharge *TAU* • Control group • Acute somatic treatment in hospital before discharged • No psychological or psychiatric treatment in hospital • Contacted at 6 and 18 months for suicidal assessment	N = 680 randomly assigned *Intervention = 320* • 304 analysed • 16 lost to follow-up • 302 in the study at 18mths *TAU = 360* • 324 analysed • 32 lost to follow-up • 320 in the study at 18 months	Follow-up period = 18 months	*Primary outcome measure:* The number of attempted suicides and the number of completed suicides *Results:* • **The number of attempted suicides were significantly lower in the BIC group compared to the TAU group at 18 months** • **The number of completed suicides were significantly lower in the BIC group than the TAU group at 18 months** • There was no differences between the groups in terms of socio-demographic info, prior suicide attempts, clinical ratings of suicide, at baseline between the two groups	No

Psychosocial interventions for adults

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment Vs control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*
Brown et al., 2005 USA [135]	Adults presenting to ED who had attempted suicide	10 sessions of cognitive therapy Vs enhanced usual care	120 (35)	18 months	Suicide attempt: 24% of intervention group and 42% of control group had 1 or more attempts (50% less likely for IG); time to re-attempt longer for IG; Depression lower for IG. Suicide ideation N.s. difference
Davidson et al., 2010 [136] United Kingdom	Diagnosis of BPD; 71% had 1 or more suicidal acts in previous 12 months	30 sessions of CBT Vs TAU	105 (30)	6 years	Number of suicide attempts: fewer in the IG at 12 months and 2 years; difference was not significant at 6 years.
Evans et al., 1999 [137] United Kingdom	Reported to either of two hospital mental health units for deliberate self-harm; had a prior deliberate self-harm episode; had a flamboyant personality disturbance; aged 16-50 years; alcohol/ drug dependence or schizophrenia excluded	2 to 6 sessions of MACT (manual assisted CBT) vs TAU	34(2)	6 months	Primary outcome measure: time to the next deliberate self-harm episode Results: N.s. reduction over time in suicide attempts for MACT groups; Significant reduction in self-rated depression symptoms in MACT group
Gratz et al., 2006 [138] USA	Women aged 18 to 60 years with diagnosis of BPD; recruited from private practices; history of prior self-harm; at least one episode of deliberate self-harm in the last 6 months;	14 weeks of group based emotion regulation intervention (acceptance and behavioural based group therapy) + TAU vs TAU	22 (0)	15 weeks (1 week after last interventio n session)	Main primary outcome measures: • Emotion dysregulation • Emotional avoidance • Self-harm frequency Results: N.s. difference over time in TAU group for all outcome measures; Significant reduction over time in intervention group in all three

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment Vs control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*
					outcomes measures
Hatcher et al., 2011 [139] New Zealand	Adults (16 and over) presenting to hospital with self-harm	PST + usual care (up to 9 sessions in a 3 month period) Vs usual care alone	1094 (158)	12 months	Repeat episode of self-harm. Intervention no more effective than control, except for those with a more extensive history of self-harm
Kaslow et al., 2010 [140] USA	African American women; experience of intimate partner violence and a suicide attempt both within the last year; hospital emergency departments and hospital clinics	7 to 10 sessions of Nia intervention (manualised, culturally informed psychosocial educational group intervention) vs TAU	208 (74)	12 months	Primary outcome measure: reduction in psychological symptoms and suicidal ideation Results: Nia group had significantly greater reductions in depressive symptoms over time and at 12 month follow-up than TAU; Nia intervention ns reduced suicidal ideation and PTSD symptoms
Linehan et al., 2006 [141] USA	Women with recent suicide attempt or self-harm	1 year of DBT Vs 1 year non-behavioural treatment by experts	111 (10)	24 months	Suicidal behaviours, emergency services use, and general psychological functioning. DBT group had fewer suicidal behaviours, better treatment maintenance, fewer psychiatric hospitalisations and fewer ED visits
Linehan et al., 1991 [142] USA	BPD diagnosis, 1 self-harm incident in past 8 weeks and 2 in the past 5 years, aged 18-45 yrs.	12 months of DBT Vs 12 months of TAU	53 (19)	12 months	% with self-harm incidents, suicide attempt, suicidal ideation, depression, hopelessness, reasons for living, maintenance in treatment, psychiatric inpatient days. DBT group had fewer self-harm incidents (1.5 Vs 9), better treatment maintenance and fewer inpatient days during the 12-month

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment Vs control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*
					treatment period than the TAU group. No other differences.
Priebe et al., 2012 [143] United Kingdom	Age 16 or over, at least 1 PD diagnosis, at least 5 days of self-harm in previous year. Recruited through a number of health services in London	12 months of DBT Vs 12 months of TAU	80 (70)	12 months	No of days of self-harm, quality of life, BPD symptoms. Treatment group had fewer days of self-harm compared to TAU group. No difference on other outcomes.
Raj et al., 2001 [144] Bangalore	Included if 1st or 2nd suicide attempt, aged 16-50, and had anxiety or depression. 58% female	10 sessions of CBT Vs TAU. 40% of the intervention group received 1-5 additional booster sessions. TAU received monthly letters to tell them they could seek treatment.	40 ()	3 months	Suicidal ideation, hopelessness, anxiety, depression, problem solving, impulsivity, dysfunctional attitudes. Experimental group improved more than control group on all outcomes except impulsivity. There was 1 suicide attempt in the control group.
Rudd et al., 1996 [145] USA	Referred through outpatient and inpatient mental health services and ED at a military medical centre for suicide attempt or ideation. Mean age 22 yrs, 82 male. 51% had at least 1 suicide attempt	Problem solving and adaptive coping skills training (group) Vs TAU. Intervention was hospital day stay for 9 hrs/day for 2 weeks	302 (231 at 12 months)	12 months	Suicidal ideation, life stress, hopelessness, depression, problem solving. No significant differences between groups on any outcomes.
Salkovskis et al., 1990 [146] United Kingdom	Presented to hospital following suicide attempt Aged 18-65 yrs	5 sessions of cognitive behavioural problem solving (inpatient and/or at home) Vs TAU	20 (not noted)	12 months	No of repeat attempts, suicidal ideation, depression, hopelessness, no of problems. All outcomes except suicidal ideation improved for intervention group at each time point compared with control group.
Slee et al., 2008 [147]	Recent DSH episode >90% female. Aged 15-35	12 CBT sessions + TAU Vs TAU only	90 (9)	9 months	Number of DSH episodes, depression, anxiety, self-esteem, suicidal cognitions

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment Vs control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*
Netherlands	yrs. (mean ~25 yrs.)				and problem-solving ability – all outcomes significantly better for the CBT group
Tyrer et al., 2003 [148] United Kingdom	>1 episode of DSH	POPMACT– brief cognitive therapy (booklet + up to 7 sessions) Vs TAU	480 (78)	12 months	No. of parasuicide events, time to next episode, proportion in each group with a parasuicide event. No differences on any outcomes.
Wei et al., 2013 [149] China	Suicide attempt presentation at ED	10 cognitive therapy sessions Vs 12 telephone calls (psychological supports Vs no treatment	239 (67)	12 months	Repeat attempts, ideation, depression, QoL no significant difference on any measures *83% refused cognitive therapy, very high dropout rates*
Stewart et al., 2009 [150] Australia	Suicide attempt presentation at ED	Cognitive behaviour therapy Vs problem solving Vs TAU	32 completed the study. Unclear how many were randomised.	Immediatel y post-treatment for CBT and PST, 2 months after randomisat -ion for TAU	Re-attempts – no difference between groups Hopelessness – no difference between groups Client satisfaction – higher for CBT and PST than for TAU Problem solving – no differences Suicidal ideation – PST superior to TAU

Intensive interventions, hospitalisation and medications

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment Vs control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*
Bateman and Fonagy, 1999 [69] United Kingdom	Control: 33.3±6.60 (n=19) Int: 30.3±5.86 (n=19) 42% male Borderline personality disorder Recruited from referrals to psychiatric unit. Inclusion criteria not explicit: 16-65, referred to service, borderline personality disorder.	Psychoanalytically-oriented partial hospitalisation VS standard outpatient psychiatric care Intervention: individual + group psychotherapy, expressive therapy, community meeting, case meeting, medication review Control: regular psychiatric review, as-required in-patient admission, outpatient+ community follow-up	44 randomised 0 lost to follow-up 6 excluded from analysis (n=3 control crossed over to hospitalised intervention following SA; n=3 intervention dropped out) 38 analysed	18 months	Primary outcomes not explicit: incidence of SA and self-harm (separately) Significant reduction in SA and self-harm.
Bateman and Fonagy, 2001 [70] United Kingdom	As above NB: demographics for larger group not re-stated.	As above - NB: those randomised to intervention previously were offered follow-up intervention.	44 randomised 0 lost to follow-up 3 excluded from analysis (n=3 control crossed-over) 41 analysed	18 month results above recalculated 36 month follow-up reported	Significant reduction in SA and self-harm at both 18 and 36 months.
Bateman and Fonagy, 2008 United Kingdom	As above	As above (no further intervention after initial 36 months)	As above	8 years from randomisat-ion (5 years after	Number of SA Significantly fewer SA in intervention group

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment Vs control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*
				previous follow-up intervent-ion)	
van der Sande et al., 1997 [67] Netherlands	Control: 36.8±14.6 (n=134) Int: 35.8±15.6 (n=140) 34% male No diagnosis Recruited from ED Aged 15+, attending for SA.	Brief in-patient crisis treatment VS TAU Intervention: 1-4 days admission to unit for SAers with problem solving therapy; contact with unit if required post-discharge	274 randomised & analysed	12 months	Occurrence of repeat SA No statistically significant difference (fewer repeat attempts in the intervention group)
Waterhouse and Platt, 1990 [68] United Kingdom	Int (admission): 33.7±13.4 (n=38) Control: 26.8±10.9 (n=39) 38% male No diagnosis Recruited from ED Aged 16+, attending for SA by self-poisoning, no immediate medical or psychiatric needs Inclusion.	Hospital admission VS discharge home Neither arm received additional treatment/counselling	77 randomised 52 analysed	16 weeks	Not explicit: Psychiatric Status Schedule (PSS) NB: no baseline measure of PSS. Results reported for those who completed PSS at 1 and 16 weeks. No significant difference between groups at 1 or 16 weeks. Both groups show sig. reduction in 'depression and anxiety', 'social isolation' and 'total score' from 1 to 16 weeks. Control group shows sig reduction in 'daily routine impairment'. Both groups show n.s reduction in 'suicide ideation'; 'somatic concerns' mixed.
Morthorst et al.,	Control: 31±12 (n=120)	8-20 assertive outreach	243 randomised &	1 year	Repeat SA within 1 year.

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment Vs control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*
2012 [151] Denmark	Int: 31±14 (n=123) 24% male No diagnosis Recruited after admission for a SA to ED, ICU, paediatric units & psychiatric emergency rooms. Six regional hospitals around Copenhagen. Aged 12+, SA in past 14 days. Self-injury included if not habitual.	consultations VS TAU Intervention: case management with crisis intervention; problem-solving assertive outreach through motivational support; active assistance to/from appointments. TAU: includes psychiatric assessment + referrals + 6-8 CAMS therapy sessions.	analysed		No statistically significant difference (slightly more repeat attempts in the intervention group).
van Heeringen et al., 1995 [152] Belgium	Control: 33.8 (n=258) Int: 34.0 (n=258) SDs not reported 43% male No diagnosis Recruited from ED Aged 15+, attending for SA	Home visits by community nurse if non-compliant VS TAU Compliant = attended out-patient appointment after discharge	516 randomised 125 lost to follow-up 391 analysed	1 year	Repeated SA No statistically significant difference. Reduced repetition in intervention group (nearly significant).
Hallahan et al., 2007 [90] Ireland	Placebo: 30.7 (n=27) Active: 30.5 (n=22) SDs not reported 35% male	n-3 essential fatty acid supplement VS placebo	49 randomised & analysed	12 weeks	Not explicit. Significant improvement in Back Depression Inventory and Hamilton Rating Scale for Depression

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment Vs control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*
	No diagnosis Recruited from ED Aged 16-64, attending for self-harm, lifetime history of 1+ previous episode				No significant improvement in Overt Aggression Scale, although larger occurrence of no suicide ideation in intervention arm. Other scales included
Lauterbach et al., 2008 [91] Germany	Control: 39.3±13.0 (n=83) Int: 39.6±3.9 (n=84) 43% male Depressive spectrum disorder Recruited in ED after admission for SA. Five hospitals around Germany. Aged 18+, SA in past 3 months.	Lithium adjust therapy VS placebo	167 randomised & analysed	12 months	Repeat SA/completed suicide within 12 months No statistically significant difference (fewer repeat attempts in the lithium group)
Verkes et al., 1998 [92] The Netherlands	SSRI: 34.1±11.6 (n=46) Placebo: 37.1±13.0 (n=45) 41% male No diagnosis Recruited from ED after admission for SA. Aged 18+, 1+ previous SA including index attempt	SSRI paroxetine VS placebo	91 randomised 91 analysed	52 weeks	Time to first reoccurrence of SA Fewer repeat SA attempts in the paroxetine group – but not statistically significant. When adjusted for number of previous attempts, becomes highly significant. (NB primary result does not relate to stated primary outcome)

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment Vs control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*
Allard et al., 1992 [75] Canada	Int: 46% aged 30+ (n=76) Control: 51% aged 30+ (n=74) NB: mean/SDs not given 45% male No diagnosis Recruited from ED following SA SA within 1 week	Intensive intervention VS TAU Intensive: explicit treatment plan, schedule of visits, 1+ home visits, appointment reminders,	150 randomised 24 lost to follow-up 126 analysed	24 months	Repeat attempt within 24 months Higher proportion of intensive intervention group have a repeat attempt after 2 years (not significant)
Bateman and Fonargy, 2009 [71] United Kingdom	Int: 31.3± 7.6 (n=71) Control: 30.9± 7.9 (n=63) 20% male Borderline personality disorder Recruited from specialist personality disorder service Aged 18-64, SA or life-threatening self-harm within 5 months, borderline personality disorder	Mentalisation-based treatment (MBT) VS structured clinical management (SCM) Both groups received equivalent doses of clinical supervision, including crisis contacts, crisis plans, pharmacotherapy, psychiatric review, written info about treatment	134 randomised 134 analysed	18 months	Proportion of each group without severe parasuicidal behaviour (SA, life-threatening self-harm, hospital admission) Larger proportion of intervention group without severe suicidal behaviour.
Guthrie et al., 2001 [76] United Kingdom	Age not stated 45% male	4 sessions of psychodynamic interpersonal therapy VS TAU	119 randomised 24 lost to follow-up at 6 months	6 months	Suicide ideation (Beck scale for suicide ideation) Significant improvement in BSSI in

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment Vs control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*
	No diagnosis Recruited from ED Aged 18-65, presented with deliberate self-poisoning		95 analysed at 6 months		intervention group at 6 months
Clarke et al., 2002 [77] United Kingdom	Mean age: 33yo Int: 32 (n=220) Con: 34 (n=247) SDs not stated 44% male No diagnosis Recruited in ED following admission for DSH. 2 EDs in UK. Aged 16+ (excluding 16-19 in FT secondary education)	Case management VS TAU	526 randomised 59 excluded (not eligible n=33; refused n=17; other reasons n=9) 467 entered study 467 analysed	12 months	Proportion readmitted to ED for DSH within 12 months Slightly lower readmission in intervention group (NS)
De Leo and Heller, 2007 [78] Australia	Int: 34.0 (n=30) Con: 37.0 (n=30) SDs not stated 100% male Admission for severe suicide ideation or SA. Local psychiatric ward. Aged 18+, male, current	Intensive case management VS TAU	60 randomised 38 dropped out 22 analysed	12 months	Not explicit, included Beck's Depression Inventory II, Beck's Hopelessness Scale, Scale of Suicide Ideation, WHO QOL scale, Reasons for Living - Brief ANOVA analysis: significant improvement for BDI, SSI in intervention group

Study authors, country and year	*Participant details, recruitment setting, inclusion criteria*	*Treatment Vs control condition*	*Number randomised (no. lost to follow-up or excluded)*	*Follow-up period*	*Primary outcome and results*
	admission for severe SI or SA.				
Hvid et al., 2011 [153] Denmark	Intervention (male): 46±19.8 (n=20) Intervention (female): 33±17.1 (n=49) Control (male): 46±10.8 (n=18) Control (female): 34±18.1 (n=46) 29% male No diagnosis Recruited from ED Aged 12+, daily ED admission records assessed for SA or DSH	Baerum Model outreach programme VS TAU	133 randomised 8 dropped-out, but still monitored 133 analysed	1 year	Repeat SA or completed suicide Fewer repeat events in the intervention arm

APPENDIX E: SURVEY CODING FOR SPECIFIC ITEMS

Coding of suicide method

Method used in the most recent suicide attempt was coded into eight categories, based on the World Health Organisation's International Statistical Classification of Diseases and Related Health Problems version 10 (ICD-10). This is an internationally recognised classification method for means of suicide attempt, employed overseas and within Australia. Notably, the Australian Institute of Health and Welfare utilises the ICD-10 to classify national registered deaths each year.

ICD codes X60-X84 in the first external cause of injury field indicate suicide. Our coding of suicide method follows the ICD coding categories as follows: poisoning (X60-X66, X68, X69), motor vehicle exhaust (X67), hanging (X70), drowning (X71), firearms (X72-X74), cutting/piercing (X78, X79), jumping (X80), and all other methods (X75-X77, X81-X84). Participants could select as many methods as applicable for their case.

Method*
Poisoning
Motor vehicle exhaust
Hanging
Firearms
Jumping
Cutting/piercing
Drowning
Other methods

Coding of psychiatric diagnoses

Psychiatric diagnoses were coded into six categories, based upon the World Health Organisation's International Statistical Classification of Diseases and Related Health Problems version 10 (ICD-10) codes for psychiatric conditions. Our categories were as follows (ICD-10 codes and subsumed diagnoses): mood disorders (F32-F39; including depression, bipolar), anxiety disorders (F40-F49; including GAD, social phobia, OCD), eating disorders (F50; including AN, BN, EDNOS); personality disorders (F51-F59), schizophrenic disorders (including psychosis, schizoaffective disorder), and all other diagnoses [including substance misuse disorders (F20-F29), PTSD, ADHD, adjustment disorders]. Participants were able to select as many diagnostic categories as required, as the variables were not mutually exclusive.

Psychiatric diagnoses (current or lifetime)*
Any psychiatric diagnosis (lifetime)
Mood disorder
Anxiety disorder
Personality disorder
Schizophrenic disorder (incl. psychosis)
Eating disorder
Other (incl. PTSD)

APPENDIX F: DATASET DESCRIPTIONS

Table of Contents

National Minimum Data Sets

ADMITTED PATIENTS NMDS 4
ADMITTED PATIENTS MENTAL HEALTH NMDS 5
INSTITUTIONAL MENTAL HEALTH CARE NMDS 6
ALCOHOL AND OTHER DRUG TREATMENT NMDS 7
COMMUNITY MENTAL HEALTH NMDS 8
NON-ADMITTED PATIENT EMERGENCY DEPARTMENT NMDS 9
OUTPATIENT CARE NMDS 10

National Data Sets

ATAPS NMDS 11
RELEVANT ABS STATISTICS 13
BEACH DATA 15
MBS AND PBS DATA (COMMONWEALTH DATA) 16
PRIVATE HOSPITAL DATA BUREAU COLLECTION 18
AUSTRALIAN LONGITUDINAL STUDY ON WOMAN'S HEALTH 19

NSW Data Sets

AMBULATORY MENTAL HEALTH DATA NSW 21
ADMITTED PATIENT CARE NSW 22
EMERGENCY DEPARTMENT DATA COLLECTION NSW 23
THE 45 AND UP STUDY PROJECT 25
THE HUNTER COMMUNITY STUDY NSW 26

WA Data Sets

MENTAL HEALTH INFORMATION SYSTEM WA 28
EMERGENCY DEPARTMENT DATA COLLECTION WA 29
HOSPITAL MORBIDITY DATA WA 31
DEATHS REGISTRATION WA 31

SA Data Sets

SOUTH AUSTRALIA MONITORING AND SURVEILLANCE SYSTEM 33

EMERGENCY DEPARTMENT DATA SA 34
INPATIENT HOSPITAL SEPARATIONS SA 35
SA DEATHS REGISTRY 36
ACT Data Sets
ADMITTED PATIENT CARE ACT 38
EMERGENCY DEPARTMENT DATA COLLECTION ACT 39
VIC Data Sets
VIC EMERGENCY DEPARTMENT MINIMUM DATASET 41
ADMITTED EPISODES DATA VIC 42
VICTORIAN INTEGRATED NON-ADMITTED HEALTH 43
TAS Data Sets
PUBLIC HOSPITAL ADMITTED PATIENT COLLECTION TAS 45
TASMANIAN PUBLIC HOSPITAL ED PRESENTATIONS 46
NT Data Sets
NT ADMITTED PATIENTS 47
NT DHCS HOSPITAL MORBIDITY DATA 48
NT DEATHS REGISTRY 49
QLD Data Sets
QLD EMERGENCY DEPARTMENT INFORMATION SYSTEM 51
QLD HOSPITAL ADMITTED PATIENT DATA 52
QLD CONSUMER INTEGRATED MENTAL HEALTH APPLICATION 53
QLD GENERAL DEATHS REGISTRY 54

National Minimum Data Sets

Admitted Patients NMDS

Main Data Attributes

Level of information:	Information is recorded per separation not per individual. Aggregate information is available through annual reports.
Location breakdown:	Postcode
Data available from:	1st July 1997
Jurisdiction available:	All jurisdictions
Jurisdiction differences:	None, information collected is standardized across jurisdictions as part of the National Minimum data sets standards.
How data is collected:	Data are collected at each hospital from patient administrative and clinical record systems. Hospitals forward data to the relevant state or territory health authority on a regular basis (e.g. monthly). State and territory health authorities provide the data to the Australian Institute of Health and Welfare for national collation, on an annual basis. Data is collated annually typically at the end of the financial year.
Brief summary of data:	The scope is episodes of care for admitted patients in all public and private acute and psychiatric hospitals, freestanding day hospital facilities and alcohol and drug treatment centres in Australia. Hospitals operated by the Australian Defence Force, corrections authorities and Australia's offshore territories may be included. Hospitals specialising in dental, ophthalmic aids and other specialised acute medical or surgical care are included.
Variables of interest:	Demographics such as age, date of birth, sex, postcode of residence Indigenous status, country of birth, marital status Area of service, health area of hospital, Source of referral to hospital Date and time of admission, separation, length of stay in hospital, Primary diagnosis, additional diagnosis, External code of injury or poisoning (defined using ICD 10-AM codes) If admitted to psychiatry ward, days in designated psychiatry ward, If transferred from hospital, transferred to hospital.

Data access and linkage

Where data is held:	Australian Institute of Health and Welfare
Is there a data dictionary?	National Health Data Dictionary
Data custodian:	Each jurisdiction has its own data custodian
Who can get access:	The general public can access aggregate data available on the AIHW website. It is advised to go to each jurisdiction when applying for individual data.
Is linkage possible:	Advisable to apply for data linkage through each jurisdiction. This data set does not contain a Statistical Linkage Key or identifiers for linkage.
Jurisdiction differences:	Yes, access to the information vary within each jurisdiction

How to get access:	There is easy access to 'Australian hospital statistics' publications on the AIHW website. These are published annually with the latest covering 2012-2013. Data is also available as part of a 'data cube' on the AIHW website. This is aggregate data only and information is limited although diagnostic information using ICD codes is available. The latest information that is available is 2011/2012
Cost:	There is no cost for the aggregate data available on the website

Admitted Patients Mental Health NMDS

Main Data Attributes

Level of information:	Individual data is available. Aggregate information is available through annual reports
Location breakdown:	Postcode
Data available from:	1st July 2010
Jurisdiction available:	NSW, possibly QLD and WA
Jurisdiction differences:	None in terms of what information is collected, as it is standardised across jurisdictions as part of the National Minimum data sets standards. However, the number of days in home care data was collected from all states and territories except Western Australia. This data started being collected at a later date.
How data is collected:	Data are collected at each hospital from patient administrative and clinical record systems. Hospitals forward data to the relevant state or territory health authority on a regular basis (e.g. monthly). State and territory health authorities provide the data to the Australian Institute of Health and Welfare for national collation, on an annual basis. Data is collated annually at the end of the financial year.
Brief summary of data:	The scope of this minimum data set is restricted to admitted patients receiving care in psychiatric hospitals or in designated psychiatric units in acute hospitals. The scope does not currently include patients who may be receiving treatment for psychiatric conditions in acute hospitals who are not in psychiatric units.
Variables of interest:	Demographics such as age, date of birth, sex, postcode of residence Indigenous status, country of birth, marital status Area of service, health area of hospital, Source of referral to hospital Date and time of admission, separation, length of stay in hospital, Primary diagnosis, additional diagnosis, External code of injury or poisoning (defined using ICD 10-AM codes) Admitted to psychiatry ward, days in designated psychiatry ward, Transferred from hospital, transferred to hospital

Data access and linkage

Where data is held:	Data is available through the Australian Institute of Health and Welfare (AIHW) however the data is not stored there. Data is stored within each jurisdictions department of health.
Is there a data dictionary?	National Health Data Dictionary
Data custodian:	Each jurisdiction has its own data custodian.

Who can get access:	The general public can access aggregate, available on the AIHW website. It is advised to go to each jurisdiction when applying for individual data.
Is linkage possible:	Advisable to apply for data linkage through each jurisdiction. This data set does not contain a Statistical Linkage Key or identifiers for linkage.
Jurisdiction differences:	Yes, access to the information vary within each jurisdiction
How to get access:	there is easy access to 'Australian hospital statistics' publications on the AIHW website. These are published annually with the latest covering 2012-2013. Data is also available as part of a 'data cube' on the AIHW website. This is aggregate data only and information is limited although diagnostic information using ICD codes is available. The latest information that is available is 2011/2012
Cost:	There is no cost for the aggregate data available on the website

Institutional Mental Health Care NMDS

Main Data Attributes

Level of information:	Individual data may be available and aggregate information is available through annual reports
Location breakdown:	Area of residence
Data available from:	1997
Jurisdiction available:	unclear
Jurisdiction differences:	None in terms of what information is collected as it is standardised across jurisdictions as part of the National Minimum data sets standards.
How data is collected:	Data are collected at each hospital from patient administrative and clinical record systems. Hospitals forward data to the relevant state or territory health authority on a regular basis (e.g. monthly). State and territory health authorities provide the data to the Australian Institute of Health and Welfare for national collation, on an annual basis. Data is collated annually, at the end of each financial year.
Brief summary of data:	The National Minimum Data Set (NMDS)—institutional mental health care represents an agreement between States and Territories to collect and report information on patients in hospital who receive specialised psychiatric care. This includes patients who receive treatment and/or care in psychiatric hospitals or in specialised psychiatric units of public acute hospitals (also referred to as designated units). The NMDS—institutional mental health care is in effect a sub-set of the broader NMDS—institutional health care which covers all patients in all hospitals. The care received is thus referred to as 'specialised'.
Variables of interest:	Demographics such as age, date of birth, sex, postcode of residence Indigenous status, country of birth, marital status Area of service, health area of hospital, source of referral to hospital date and time of admission, separation, length of stay in hospital, primary diagnosis, additional diagnosis, External code of injury or poisoning (defined using ICD 10-AM codes) If admitted to psychiatry ward, days in designated psychiatry ward, If transferred from hospital, transferred to hospital

Data access and linkage

Where data is held:	Data is available through the Australian Institute of Health and Welfare (AIHW) however the data is not stored there. Data is stored within each jurisdiction department of health
Is there a data dictionary?	National Health Data Dictionary
Data custodian:	Each jurisdiction has its own data custodian
Who can get access:	The general public can access aggregate, available on the AIHW website. It is advised to go to each jurisdiction when applying for individual data.
Is linkage possible:	Advisable to apply for data linkage through each jurisdiction. This data set does not contain a Statistical Linkage Key or identifiers for linkage.
Jurisdiction differences:	Yes, access to the information vary within each jurisdiction
How to get access:	there is easy access to 'Australian hospital statistics' publications on the AIHW website. These are published annually with the latest covering 2012-2013. Data is also available as part of a 'data cube' on the AIHW website. This is aggregate data only and information is limited although diagnostic information using ICD codes is available. The latest information that is available is 2011/2012
Cost:	There is no cost for the aggregate data available on the website

Alcohol and other drug treatment NMDS

Main Data Attributes

Level of information:	Individual may be available and aggregate information is available through annual reports
Location breakdown:	Postcode
Data available from:	1st July 2010
Jurisdiction available:	Possibly NSW
Jurisdiction differences:	None in terms of what information is collected as it is standardised across jurisdictions as part of the National Minimum data sets standards.
How data is collected:	Publicly funded government and non-government agencies providing alcohol and/or drug treatment services record information. These include community based ambulatory services and outpatient services All states and territory health authorities provide the data to the Australian institute of Health and Welfare for national collation on an annually basis; generally at the end of the financial year 30th June.
Brief summary of data:	The Alcohol and other drug treatment services national minimum data set (NMDS) is nationally mandated for collection and reporting. The following services are currently not included in the coverage: • services based in prisons and other correctional institutions; • agencies that provide primarily accommodation or overnight stays such as 'sobering-up shelters' and 'half-way houses'; • agencies that provide services concerned primarily with health promotion; • needle and syringe programs; • agencies whose sole function is to provide prescribing and/or dosing of methadone; and • acute care and psychiatric hospitals, or alcohol and drug treatment units that report to the Admitted patient care NMDS and do not provide treatment to non-admitted patients.

	Clients who are on a methadone maintenance program may be included in the collection where they also receive other types of treatment.
Variables of interest:	Demographics such as age, date of birth, sex, postcode of residence Indigenous status, country of birth, marital status Area of service, health area of hospital, Source of referral to hospital Date and time of admission, separation, length of stay in hospital, Primary diagnosis, additional diagnosis, External code of injury or poisoning (defined using ICD 10-AM codes) Admitted to psychiatry ward, days in designated psychiatry ward, Transferred from hospital, transferred to hospital

Data access and linkage

Where data is held:	Data is available through the Australian Institute of Health and Welfare (AIHW) however the data is not stored there. Data is stored within each jurisdiction department of health
Is there a data dictionary?	National Health Data Dictionary
Data custodian:	Each jurisdiction has its own data custodian
Who can get access:	The general public can access aggregate, available on the AIHW website. It is advised to go to each jurisdiction when applying for individual data.
Is linkage possible:	Advisable to apply for data linkage through each jurisdiction. This data set does not contain a Statistical Linkage Key or identifiers for linkage.
Jurisdiction differences:	Yes, access to the information vary within each jurisdiction
How to get access:	There is easy access to 'Australian hospital statistics' publications on the AIHW website. These are published annually with the latest covering 2012-2013. Data is also available as part of a 'data cube' on the AIHW website. This is aggregate data only and information is limited although diagnostic information using ICD codes is available. The latest information that is available is 2011/2012
Cost:	There is no cost for the aggregate data available on the website

Community Mental Health NMDS

Main Data Attributes

Level of information:	Individual may be available and aggregate information is available through annual reports
Location breakdown:	Postcode
Data available from:	1st July 2000
Jurisdiction available:	possibly QLD, WA and VIC
Jurisdiction differences:	None in terms of what information is collected, as it is standardised across jurisdictions as part of the National Minimum data sets standards.
How data is collected:	All states and territory health authorities provide the data to the Australian Institute of Health and Welfare (AIHW) for national collation on an annually basis; generally at the end of the financial year 30th June.
Brief summary of data:	The Community mental health care national minimum data set includes data about service contacts provided by specialised mental health services for patients/clients, other than those admitted to psychiatric hospitals or

	designated psychiatric units in acute care hospitals and those resident in 24-hour staffed specialised residential mental health services.
Variables of interest:	Demographics such as age, date of birth, sex, postcode of residence Indigenous status, country of birth, marital status Area of service, health area of hospital, Source of referral to hospital Date and time of admission, separation, length of stay in hospital, Primary diagnosis, additional diagnosis, External code of injury or poisoning (defined using ICD 10-AM codes) Admitted to psychiatry ward, days in designated psychiatry ward, Transferred from hospital, transferred to hospital

Data access and linkage

Where data is held:	Data is available through the Australian Institute of Health and Welfare (AIHW) however the data is not stored there. Data is stored within each jurisdiction department of health
Is there a data dictionary?	National Health Data Dictionary
Data custodian:	Each jurisdiction has its own data custodian
Who can get access:	The general public can access aggregate, available on the Australian Institute of Health and Welfare website. It is advised to go to each jurisdiction when applying for individual data.
Is linkage possible:	Advisable to apply for data linkage through each jurisdiction. This data set does contain a Statistical Linkage Key or identifiers for linkage.
Jurisdiction differences:	Yes, access to the information vary within each jurisdiction
How to get access:	there is easy access to 'Australian hospital statistics' publications on the AIHW website. These are published annually with the latest covering 2012-2013. Data is also available as part of a 'data cube' on the AIHW website. This is aggregate data only and information is limited although diagnostic information using ICD codes is available. The latest information that is available is 2011/2012
Cost:	There is no cost for the aggregate data available on the website

Non-Admitted Patient Emergency Department NMDS

Main Data Attributes

Level of information:	Recorded in terms of episodes not individuals. Aggregate information is available through annual reports.
Location breakdown:	Postcode
Data available from:	1st July 2010
Jurisdiction available:	all jurisdictions
Jurisdiction differences:	None in terms of what information is collected as it is standardised across jurisdictions as part of the National Minimum data sets standards.
How data is collected:	Administrative and clinical staff such as nurses record information regarding each presentation at an emergency department in public hospitals. All states and territory health authorities provide the data to the Australian Institute of Health and Welfare for national collation on an annually basis; generally at the end of the financial year 30th June.
Brief summary of data:	The scope of this NMDS is non-admitted patients registered for care in emergency departments in selected public hospitals that are classified as either

Peer Group A or B in the Australian Institute of Health and Welfare's Australian Hospital Statistics publication from the preceding financial year. The care provided to non-admitted patients who are treated in the emergency department prior to being admitted is included in this NMDS. Care provided to patients who are being treated in an emergency department site as an admitted patient (e.g. in an observation unit, short-stay unit, 'emergency department ward' or awaiting a bed in an admitted patient ward of the hospital) are excluded from the emergency department care NMDS since the recording of the care provided to these patients is part of the scope of the Admitted patient care NMDS.

Variables of interest: Demographics such as age, date of birth, sex, postcode of residence
Indigenous status, country of birth, marital status
Area of service, health area of hospital, Source of referral to hospital
Date and time of admission, separation, length of stay in hospital,
Primary diagnosis, additional diagnosis, External code of injury or poisoning (defined using ICD 10-AM codes)
Admitted to psychiatry ward, days in designated psychiatry ward,
Transferred from hospital, transferred to hospital

Data access and linkage

Where data is held: Data is available through the Australian Institute of Health and Welfare (AIHW) however the data is not stored there. Data is stored within each jurisdictional department of health

Is there a data dictionary? National Health Data Dictionary

Data custodian: Each jurisdiction has its own data custodian

Who can get access: The general public can access aggregate, available on the AIHW website. It is advised to go to each jurisdiction when applying for individual data.

Is linkage possible: Advisable to apply for data linkage through each jurisdiction. This data set does not contain a Statistical Linkage Key or identifiers for linkage.

Jurisdiction differences: Yes, access to the information vary within each jurisdiction

How to get access: there is easy access to 'Australian hospital statistics' publications on the AIHW website. These are published annually with the latest covering 2012-2013. Data is also available as part of a 'data cube' on the AIHW website. This is aggregate data only and information is limited although diagnostic information using ICD codes is available. The latest information that is available is 2011/2012

Cost: There is no cost for the aggregate data available on the website

Outpatient Care NMDS

Main Data Attributes

Level of information: Individual, Aggregate information is available through annual reports

Location breakdown: Postcode

Data available from: 01/07/2007

Jurisdiction available: information not available

How data is collected: Based on information patient records which document patient attendances and care provided

	All states and territory health authorities provide the data to the Department of Ageing and Australian Institute of Health and Welfare for national collation on an annually basis by the 31st of December each calendar year for the previous financial year. Data is collected and collated generally at the end of the financial year 30th June.
Brief summary of data:	The scope is for services provided to non-admitted, non-emergency department patients registered for care by specialist outpatient clinics of public hospitals that are classified as either principal referral and specialist women's and children's hospitals and large hospitals. Hospitals use the term 'clinic' to describe various arrangements under which they deliver specialist outpatient services to non-admitted nonemergency department patients. Outpatient clinic services should be interpreted as encompassing services provided through specific organisational units staffed to administer and provide a certain range of outpatient care
Variables of interest:	information not available

Data access and linkage

Where data is held:	Data is available through the Australian Institute of Health and Welfare (AIHW) however the data is not stored there. Data is stored within each jurisdiction department of health
Is there a data dictionary?	National Health Data Dictionary
Data custodian:	Each jurisdiction has its own data custodian
Who can get access:	The general public can access aggregate, available on the AIHW website. It is advised to go to each jurisdiction when applying for individual data.
Is linkage possible:	Advisable to apply for data linkage through each jurisdiction. This data set does contain a Statistical Linkage Key and is therefore possible to link data at the individual level
Jurisdiction differences:	Yes, access to the information vary within each jurisdiction
How to get access:	there is easy access to 'Australian hospital statistics' publications on the AIHW website. These are published annually with the latest covering 2012-2013. Data is also available as part of a 'data cube' on the AIHW website. This is aggregate data only and information is limited although diagnostic information using ICD codes is available. The latest information that is available is 2011/2012
Cost:	There is no cost for the aggregate data available on the website

ATAPS NMDS

Main Data Attributes

Level of information:	aggregate only
Location breakdown:	postcode
Data available from	2003, only a ten-year report is available
Jurisdiction available:	national
Jurisdiction differences:	non stated
How data is collected:	The database is a web-based system allowing multiple users and regular reporting at a national level. The database is password-protected, so that only authorised personnel are able to access it. Authorisation is decided by personnel from a given Medicare Local.

Brief summary of data:	The minimum dataset was developed to gather common, basic information from all Medicare Locals implementing Access To Allied Psychological Services (ATAPS), and therefore acts as an important evaluation tool. The minimum dataset is designed to capture de-identified, consumer-level information. The minimum dataset is invaluable in collecting information that provides a picture of the level of uptake of the projects (by GPs and other referrers, mental health professionals and consumers);a description of the socio-demographic and clinical characteristics of consumers; an overview of the services consumers are receiving; pre- and post-treatment consumer outcomes on standardised outcome measures. Socio-demographic and clinical information are collected by the GP or referrer, and treatment information is collected by the mental health professional at each session. Importantly, the minimum dataset also captures consumer-level outcome data, which are collected by either/both the GP and mental health professional.
Variables of interest:	Demographics such as age, gender, Indigenous status, education GP data: referrer code (unique code to de-identify the individual referrer), referral date, if the person has received mental health care before, ICD primary care diagnostic categories, if the person is in an ATAPS program (general ATAPS, suicide prevention, perinatal depression. Homelessness etc.) Mental health care provider data: Type of session, if the patient did not attend, session duration. This is recorded for each session with the mental health care provider

Data access and linkage

Where data is held:	Medicare local/Department of Health
Is there a data dictionary?	No
Data custodian:	Information unclear, possibly the Department of Health
Is linkage possible:	No
Who can get access:	Advised that individual level information is not publically available. Aggregate level information is available to registered ATAPS providers. The University of Melbourne's Centre for Health Policy, Programs and Economics has been commissioned to provide evaluation support to Medicare Local. A 10-year evaluation report is available with aggregate information 10 year-consolidated report (PDF).
How to get access:	Access to aggregate data needs to be approved by a Medicare local officer and is only available to ATAPS providers
Cost:	NA

National Data Sets

Relevant ABS statistics

Main Data Sets

Suicides in Australia

Level of information:	Aggregate.
Location breakdown:	Broken down by State level and then if rural, urban. Defined by statistical Local Area of residence
Data available from:	2001-2010 only
Jurisdiction available:	All
Jurisdiction differences:	None at least with aggregate data. Can get aggregate information on suicide per state
How data is collected:	Information below;
Brief summary of data:	ABS data on suicide deaths are sourced from the state and territory Registrars of Births, Deaths and Marriages and supplemented by information from the National Coroners Information System (NCIS). The management of death registration systems is the responsibility of the eight individual state and territory Registrars. As part of the registration process, information about the cause of death is supplied by the medical practitioner certifying the death, or by a coroner. Other information about the deceased is supplied by a relative or other person acquainted with the deceased or by an official of the institution where the death occurred.
Variables of interest:	Age, gender, state, cause of death

Australian Health Survey

Level of information:	Aggregate and possible individual level
Location breakdown:	Broken down by State level and then if rural, urban defined by statistical Local Area of residence
Data available from:	2011-2013 with the next release covering 2013-2014
Jurisdiction available:	All
Jurisdiction differences:	None at least with aggregate data.
How data is collected:	Information not available
Brief summary of data:	The 2011-13 Australian Health Survey (AHS) is the largest and most comprehensive health survey ever conducted in Australia. The survey was designed to collect a range of information from Australians about health related issues, including health status, risk factors, socioeconomic circumstances, health-related actions and use of medical services. In 2011-13, the AHS collected new information on nutrition and physical activity. It also included the first national biomedical information collection. Australians' health service usage, such as consultations with health professionals and use of medical facilities; health-related actions, including medication use, self-management of long-term health conditions and days away from work or study/school due to ill-health; breastfeeding information for children aged 0-3 years; numbers of people with

hypertension, calculated from data on measured blood pressure and hypertension medication; and information about Australians' private health insurance membership.

Variables of interest: Demographics such as age, gender, country of birth, employment and education status.
Health services utilisation including visit to health professional, inpatient stay, outpatient visit.
Mental health; K10, if they have been diagnosed and current medications.

Mental Health of Young People 2007

Level of information: Aggregate data is easily available. Individual data may be available but can only be discussed if an information consultancy is organised and a fee is paid.

Location breakdown: None
Data available from: 2007
Jurisdiction available: All
Jurisdiction differences: None at least with aggregate data.
How data is collected: Information not available
Brief summary of data: This article provides a brief overview of the mental health of young people aged 16-24 years in Australia. It includes information on the prevalence of mental disorders* for people in this age group, as well as their socioeconomic characteristics, level of impairment and the health service usage of young people with mental illness. Data are sourced from the 2007 National Survey of Mental Health and Wellbeing (SMHWB
Variables of interest: Limited information. Available variables include whether diagnosed with a mental health disorder (broad categories i.e. affective disorder) and whether help was sought

National Survey of Mental Health and Wellbeing

Level of information: Individual (de-identified) may be available, Aggregate information is available through annual reports
Location breakdown: Postcode
Data available from: Once of survey, conducted from August to December 2007.
Jurisdiction available: All states and territories
Jurisdiction differences: None in terms of what information is collected however, response rates vary between the jurisdictions.
How data is collected: Households were randomly selected and sent an invitation to participate. Trained Australian Bureau of Statistics interviewers interviewed one person from each household.
Brief summary of data: The survey was conduct by the Australian Bureau of Statistics. (ABS)The survey collected information from approximately 8,800 Australians aged 16-85 years. The survey provides information on the prevalence of selected lifetime and 12-month mental disorders, by the major disorder groups: Anxiety disorder, affective disorder and substance abuse disorders. The survey also provides information on the level of impairment, health services used for mental health problems, physical conditions, social networks and caregiving as well as demographic and socio-economic characteristics.
Variables of interest: Demographics such as age, date of birth, sex, postcode of residence country of birth, marital status, education, income, Socio-Economic indexes for area,

sexual orientation, homelessness, incarceration, service in the Australian Defence Forces
Mental health diagnostics for Anxiety, Affective and substance use disorders.
Physical health such as chronic conditions and disability, K10, Delighted-Terrible Scale, Self-assessed health rating, psychosis screener, suicidal behaviour including thoughts and behaviours over the lifetime and 12 months prior to interview.
Health services utilisation; consultations with health professionals (lifetime and 12 months prior to interview), hospital admissions and self-management strategies. What types of assistance was received i.e. medication, counselling, whether the need for assistance was met and if not why

Data access and linkage

Where data is held:	Australian Bureau of Statistics
Data custodian:	Australian Bureau of Statistics
Who can get access:	The general public can access aggregate, available on the ABS website. For further access need to apply for an Information consultancy.
Is linkage possible:	Information not available
Jurisdiction differences:	Yes, access to the information vary within each jurisdiction
How to get access:	Through the ABS, aggregate data is available on the ABS website
Cost:	There is no cost for the aggregate data available on the website. If more information is required, a cost is charged at a 'cost-recovery' rate. Minimum cost for consultancy is $475. The average cost for consultancy is $1200

BEACH data

Main Data Attributes

Level of information:	Aggregate (encounters) and individual level
Location breakdown:	Postcode
Data available from:	1st April 1998
Jurisdiction available:	All
Jurisdiction differences:	None specified
How data is collected:	Each individual in a random sample of recognised GPs records details of 100 consecutive GP–patient encounters of all types (including indirect consultations which resulted in clinical action) on structured paper encounter forms. In a full-data collection year 1,000 GPs will participate and this will provide details of approximately 100,000 encounters. GPs are recruited several weeks ahead throughout the year and constitute a rolling ever-changing sample. As each of the random samples is received, GPs are approached in their randomised order by letter at a rate of approximately 50 per week. The letter outlines the study aims and method with particular reference to the time and work each doctor will need to contribute. The GPs are also informed about the benefits they will receive in return for their participation. A copy of the approach letter is attached as Appendix 3. Approximately 10 days after the approach letter is posted a trained research assistant contacts each GP by telephone, inviting their participation in the study and answering any questions. Where the GP agrees to take part in *BEACH* a date to begin recording is agreed by telephone. The GP is then allocated an individual GP identification number and their details are entered into the GP database as a participant. Data is available three months after collection
Brief summary of data:	*BEACH* is a collaborative study between the Australian Institute of Health

	and Welfare and the University of Sydney. The aims of BEACH are: To provide a reliable and valid data-collection process for general practice which is responsive to the ever changing needs of information users. To establish an ongoing database of GP–patient encounter information. To assess patient risk factors and health states and the relationship these factors have with health service activity.
Variables of interest:	Demographics; age, gender, NESB status, Indigenous status GP demographics; age, gender years in practice, location or practice (rurality), country of graduation Using ICPC-2 codes; Reasons for encounter (up to three); problems managed at the consultation (up to four) (these problems are only generally categorised so that the labels only go as far as 'depression' or 'anxiety; there does not appear to be a label for 'self-harm' or 'suicidal ideation') Management of each problem i.e. medication, therapeutic procedures counselling, referrals to specialists, allied health professionals and admissions.

Data access and linkage

Where data is held:	The University of Sydney
Data custodian:	Contact is Associate Professor Helena Britt (02) 9845 8150.
Who can get access:	The general public to aggregate data, researchers may have access to individual data, however would need to contact custodian to discuss
Is linkage possible:	Not likely, there are no patient ID's to use for linking data
How to get access:	Public annual reports are available on the website http://sydney.edu.au/medicine/fmrc/beach/ To purchase a report based upon individual request, the custodian above needs to be contacted directly.
Cost:	Pricing is as follows **WAMTC** (Weighted average monthly treatment cost) dosage data: single class $24,200. **Other subjects:** $24,200 for analysis of one year of BEACH data (incl. 1 day of senior analyst time) *Plus* $2,420 for each additional day of analysis required for the request $1,210 for each additional data year accessed $ 4,840 (two additional analyst days @ $2,420 each) $ 2,420 (two additional BEACH years @ $1,210 each) Note: Prices may be different for Academics, Students and not for profit organisations

MBS and PBS data (Commonwealth Data)

Main Data Attributes

Level of information:	Aggregate and possible individual data
Location breakdown:	Postal Area
Data available from:	For MBS data; July 1993. For PBS data January 1992
Jurisdiction available:	All
Jurisdiction differences:	None
How data is collected:	TBA

Brief summary of data:

PBS Statistics

These statistics include data from both the Pharmaceutical Benefits Scheme (PBS) and the Repatriation Pharmaceutical Benefits Scheme (RPBS). The statistics are based on the items and groups in the Pharmaceutical Benefits Schedule

MBS STATISTICS

Statistics available from this website are based on the items and groups in the Medicare Benefits Schedule (MBS). These statistics can be broken down by patient gender and age group. Services and Benefits can be reported as count, percentage or per capita statistics. Individual MBS item statistics can be displayed as charts.

Variables of interest:

MBS: date of processing/referral/service, hospital indicator, MBS item number, item category/description, provider speciality.
PBS: PBS item code/description, patient category, date of prescribing/supply.

Data access and linkage

Where data is held:

Available through a data integration services such as through the Australian Bureau of statistics (ABS), Population Health Research Network (PHRN), Australian Institute of Health and Welfare (AIHW) and Medicare local statistics

Data custodian:

Head of the Department of Health

Who can get access:

General public can access certain aggregate data, researchers may get access to de-identified individual data with consent

Is linkage possible:

Linkage from Commonwealth to State data is possible but restricted. Application for linking Commonwealth data to State data needs to be through an accredited Commonwealth Integrating Authority.

How to get access:

Access to aggregate level data can be found on the Medicare local statistics website. For linked data and individual data the process is as follows;

- The researcher makes contact with DISC, for example through contact directly through the AIHW Data Linkage or DISC units. DISC will then undertake preliminary project discussions.
- A Data Integration Services Application form (DISA) is completed by the researcher with assistance from DISC to ensure sufficient quantity and quality of information is collected. The intent of the DISA is to:

• document the project for DISC use, including developing budget estimates and quotes;
• collect information to allow drafting (and completion where appropriate) of other documentation, e.g. Ethos application (the AIHW on line ethics application), Dept. of Health Departmental Ethics Committee (DEC) application; and
• serve as the researcher's formal application for DISC services

- During preliminary discussions with data user and development of the DISA, DISC will assess feasibility and refine the project. This will also involve a preliminary project risk assessment.

- The project will then go to Ethics Committees (ECs), Data Custodians and other approving bodies for approval. Projects involving Commonwealth data will also be registered with the NSS, there will also be a review of the risk assessment by a delegate of the Cross Portfolio Data Integration Oversight Board (though the project can ahead at this point). DISC can assist with your preparations for these approvals, which will require an application to AIHW Ethics Committee
- Once approved, applications for data provision can be made. For example, in the case of the Department of Health (Health) this will be

achieved by producing a dataset specification in conjunction with the data user to be an attachment to the Health issued Public Interest Certificate (PIC). The PIC serves two purposes:

- Once all (including data custodian and other, e.g. EC) approvals have been received data integration operations and access to integrated data can proceed.

Cost: The cost is estimated based upon the research project. AIHW provides data integration services on a cost recovery basis. These costs will vary depending on the size and complexity of your project. Typical costs vary between $20k-$50k, though routine data linkages can be lower and very complex projects can be higher. There may also be data extraction fees levied by the Department of Human Services (DHS). High risk projects involving Commonwealth data require secure data access mechanisms to be used, which could incur additional costs. The Secure Unified Research Environment (SURE) managed by the Sax Institute offers a secure research environment that can be employed for accessing integrated data for high-risk projects,

Private Hospital Data Bureau collection

Main Data Attributes

Level of information: Individual information is only available internally. Aggregate data is available to the public.

Location breakdown: Postcode

Data available from: 1997-1998

Jurisdiction available: Seemingly available at a national level. Not clear if available through each jurisdiction

Jurisdiction differences: Information not available

How data is collected: The private hospital will provide a monthly data submission to the Department of Health and Ageing within 6 weeks after the end of a hospital separation month for each episode. For example, a data file for all separations that occurred during the month of July must be submitted to the Department by mid-September.

Brief summary of data: The PHDB data collection contains de-identified information on all private hospital separations, including patient demographics, hospital episode, clinical information (ICD-10-AM) and hospital charges for all patients in private hospitals.

Variables of interest: Demographics such as gender, DOB,
Admission and separation date, diagnosis related group, discharge intention on admission (including discharge to psychiatric care, etc.)
Principle and additional diagnosis (ICD code)

Data access and linkage

Where data is held: Department of health and aging

Is there a data dictionary? Possibly hospital morbidity

Data custodian: Information not available

Who can get access? General public can access aggregate data

Is linkage possible? No

How to get access:	Through annual reports. Last report is 2012-2013. Link is as follows http://www.health.gov.au/internet/main/publishing.nsf/Content/health-casemix-data-collections-publications-PHDBAnnualReports
Cost:	NA

Australian Longitudinal study on Woman's Health

Main Data Attributes

Level of information:	Individual
Location breakdown:	Postcode
Data available from:	1996-2016
Jurisdiction available:	All
Jurisdiction differences:	None
How data is collected:	In April 1996, women in three age groups - 18-23 years (born 1973-78), 45-50 years (born 1946-51), and 70-75 years (born 1921-26) were selected from the Medicare database, which contains the name and address details of all Australian citizens and permanent residents. These women were sent an invitation to participate in the Australian Longitudinal Study on Women's Health (ALSWH), and more than 40,000 responded and agreed to participate in the project for 20 years
Brief summary of data:	**The Australian Longitudinal Study on Women's Health** (ALSWH) is a longitudinal survey of over 40,000 women in three cohorts who were aged 18-23, 45-50 and 70-75 when surveys began in 1996. In 2012/13 more than 10,000 young women aged 18-23 were recruited to form a new cohort. ALSWH assesses women's physical and mental health, as well as psychosocial aspects of health (such as socio-demographic and lifestyle factors) and their use of health services. Since its inception, ALSWH has provided invaluable data about the health of women across the lifespan, and informed federal and state government policies across a wide range of issues. The study is funded by the Australian Government Department of Health and is scheduled to continue until at least 2016.
Variables of interest:	Demographics such as age, Indigenous status, country of birth, employment status, marital status. Health related variables such as; mental health, anxiety and depression scales, medications, social support, life is not worth living/self-harm.

Data access and linkage

Where data is held:	The University of Queensland and the University of Newcastle
Data custodian:	Information not available
Who can get access:	Researchers with approval.
Is linkage possible:	With approval it is possible to link de-identified data from the survey to MBS and PBS data. Process of application is detailed below - Visit www.alswh.org.au and read appropriate documents - Contact an ALSWH Steering Committee member from the list on the website to discuss proposed project - Submit and Expression of interest (EoI) to sph-wha@sph.uq.edu.au

- Formal search for overlap carried out by project staff
- If overlap found - applicant invited to submit a revised EoI
- EoI circulated to Publications, Substudies and Analysis Committee (PSA) for review and comment – as per the schedule of reviews
- PSA Coordinator to respond to applicant, and adjustments to be made are reported

Cost: Information not available

NSW Data Sets

Ambulatory Mental Health data NSW

Main Data Attributes

Level of information:	Individual
Location breakdown:	Postcode of residence
Data available from:	2001 onwards. Data may be missing before 2005/2006. Last data available is Dec 2011
Jurisdiction available:	Only seems to be available in NSW
How data is collected:	Activities performed by the clinician are recorded within a contact record. Data is recorded and extracted on a weekly basis from the Area Health Information Exchange. A further extraction from Area to State occurs once data has been de-identified. This data is then added to the Community Client Mental Health Care NMDS by December following to end of each financial year
Brief summary of data:	Ambulatory mental health care is dedicated to the assessment, treatment, rehabilitation or care of non-admitted patients. It may include mental health day programs, psychiatric outpatients and outreach services (e.g., home visits). Also included is care provided by hospital based consultation-liaison services to admitted patients in non-psychiatric and hospital emergency settings; same–day admitted non–procedural (e.g. not ECT) care; care provided by community workers to admitted patients and clients in staffed community residential settings and mental health promotion and prevention services
Variables of interest:	Demographics such as age, date of birth, sex, postcode of residence Indigenous status, country of birth, marital status Service details; Individual Provider Identifier (the person responsible for provided the service), mental health provider role, mental health provider type, mental health service referred from and referred to, referred to further care type, source of referral type, method of communication of care i.e. face to face or phone, Principle service code includes codes for early intervention, acute, emergency etc. and service delivery location type such as inpatient health care setting, outpatient setting etc. Mental health details; mental health additional diagnosis, mental health diagnosis group includes a code for suicide ideation (not an ICD code)

Data access and linkage

Where data is held:	Ministry of health, available through the Centre for Health record Linkage (CheRel)
Data custodian:	Director Mental Health and Drug and Alcohol Office NSW Ministry of Health
Is linkage possible:	Yes, linkage is possible through CheRel
Who can get access:	Researchers with approval
How to get access:	Process of application is detailed below - Contact the Research Project Manager (02 9391 9924) to discuss study where a cost estimate will be provided. - Complete the Application for Data form where an outline is provided including the data sets of interest, variables and linkage required.

- CHeReL forwards the application onto the data custodians for them to make suggestions and identify potential problems. This process takes 2-3 weeks
- If required the application is amended based on custodians input
- All studies using linked data must obtain ethics approval from NSW Population and Health Services Research Committee through a National Ethics Application form and Research Protocol
- CHeRel will provide researcher with a technical feasibility letter and a written quote whereby all documents will be sent to data custodians to sign off on.

Cost: To be advised upon application, the cost varies depending upon

- Number of individuals in the study
- Number of data sets from which information is requested
- Whether the study involves linking a data set which is not part of the Master Linkage Key (MLK).
- An example: the Linkage and extraction records from two MLK datasets for 50/00 individuals would cost approximately $5000.

Admitted Patient Care NSW

Main Data Attributes

Level of information: Recorded per separations or episodes of care, not on an individual basis

Location breakdown: Postcode

Data available from: July 2000. Data is updated quarterly with the last available Dec 2013

Jurisdiction available: NSW

How data is collected: Public hospitals record data In terms of episodes of care (EOC). An episode of care ends with the patient ending a period of stay in hospital or by becoming a different 'type' of patient within the same period of stay. For private hospitals the record represents a complete hospital stay. These records are counted based on the date of separation from hospital.

Brief summary of data: The NSW Admitted Patient Data Collection (APDC) records all inpatient separations (discharges, transfers and deaths) from all public, private, psychiatric and repatriation hospitals in NSW, as well as public multi-purpose services, private day procedure centres and public nursing homes. In order to identify acute hospital use in the Admitted Patient Data Collection, it is strongly recommended that applications for data include the "Peer group" and the "Acute hospital flag" variables. Patient separations from developmental disability institutions and private nursing homes are not included. While the APDC includes data relating to NSW residents hospitalised interstate, names and addresses are not included on these records and therefore cannot be included in record linkage studies.

Variables of interest: Demographics such as age, date of birth, sex, postcode of residence
Indigenous status, country of birth, marital status
Major Diagnosis category (not ICD code) includes codes for a mental health diseases and disorder, substance use, injury, poisoning and toxic effects of drugs)
Area of service, days in designated Psychiatric unit if applicable,

Diagnosis codes (ICD10-AM), Emergency status (for public hospitals only), mode of separation, episode stay and length of stay, episode start date, end date, length of stay, episode of care type, Facility identifier, hospital transferred from and to, source of referral

Data access and linkage

Where data is held: Access through Centre for Health record Linkage (CheRel) and records kept within the Ministry of health

Data custodian: Dr Zoran Bolevich
Director
Health System Information and Performance Reporting
NSW Ministry of Health

Is linkage possible: Yes through CHeReL however there are no patient names prior to July 2000. As names are one of the principal variables used to link records between and within data sets, linkage studies should use data from July 2000 onwards. Names are not available for admissions to private hospitals. This information can be linked on demographic details however should be interpreted with caution.

Who can get access: Researchers with approval

How to get access: Process of application is detailed below

- Contact the Research Project Manager (02 9391 9924) to discuss study where a cost estimate will be provided.
- Complete the Application for Data form where an outline is provided including the data sets of interest, variables and linkage required.
- CHeReL forwards the application onto the data custodians for them to make suggestions and identify potential problems. This process takes 2-3 weeks
- If required the application is amended based on custodians input
- All studies using linked data must obtain ethics approval from NSW Population and Health Services Research Committee through a National Ethics Application form and Research Protocol
- CHeRel will provide researcher with a technical feasibility letter and a written quote whereby all documents will be sent to data custodians to sign off on.

Cost: To be advised upon application, the cost varies depending upon

- Number of individuals in the study
- Number of data sets from which information is requested
- Whether the study involves linking a data set which is not part of the Master Linkage Key (MLK).
- An example: the Linkage and extraction records from two MLK datasets for 50/00 individuals would cost approximately $5000.

Emergency Department Data Collection NSW

Main Data Attributes

Level of information: Presentations at Emergency departments

Location breakdown: Postcode

Data available from:	Commenced in 1994 but was only organised into formal data collection from 1996. The number of participating ED's has intermittently increased over time from 46 EDs in 1996 to around 90 in 2010. Data is updated quarterly, last available Dec 2013
Jurisdiction available:	NSW
How data is collected:	Administrative and clinical staff such as nurses record information regarding each presentation at an emergency department in public hospitals. Data is collected and sent to the Department of Health.
Brief summary of data:	The Emergency Department Data Collection is an administrative data collection that contains de-identified, demographic, administrative and clinical data detailing presentations to Emergency Departments (ED) at public metropolitan hospitals in New South Wales. The EDDC is based on the "Non-admitted Patient Emergency Department Care" National Minimum Data Set (NMDS). Diagnosis coding is not by trained clinical information managers but by medical, nursing or clerical personnel. There are different coding systems used including ICD-9/10 or SNOMED CT. Data may be subject to the availability of GP services. There are a few limitations to this data set outlined in the data dictionary http://www.cherel.org.au/data-dictionaries#section2 that should be looked at before considering using the data for research.
Variables of interest:	Demographics such as age, date of birth, sex, postcode of residence Indigenous status (except Western Sydney), country of birth, marital status Diagnosis based upon systems SNOMED CT or ICD 9, ICD 10 Health area of Facility, arrival date and time, mode of arrival. Ambulance etc., reason for visit i.e. emergency presentation, outpatient clinic, etc. referral source, mode of separation. Status of person at separation i.e. if they were admitted to another ward, referred to service, departed hospital or admitted.

Data access and linkage

Where data is held:	Ministry of Health
Data custodian:	Dr Zoran Bolevich Director Health System Information and Performance Reporting NSW Ministry of Health
Who can get access:	Researchers with approval
How to get access:	Process of application is detailed below - Contact the Research Project Manager (02 9391 9924) to discuss study where a cost estimate will be provided. - Complete the Application for Data form where an outline is provided including the data sets of interest, variables and linkage required. - CHeReL forwards the application onto the data custodians for them to make suggestions and identify potential problems. This process takes 2-3 weeks - If required the application is amended based on custodians input - All studies using linked data must obtain ethics approval from NSW Population and Health Services Research Committee through a National Ethics Application form and Research Protocol - CHeRel will provide researcher with a technical feasibility letter and a written quote whereby all documents will be sent to data custodians to sign off on.
Cost:	To be advised upon application, the cost varies depending upon

- Number of individuals in the study
- Number of data sets from which information is requested
- Whether the study involves linking a data set which is not part of the Master Linkage Key (MLK).
- An example: the Linkage and extraction records from two MLK datasets for 50/00 individuals would cost approximately $5000.

The 45 and Up Study

Main Data Attributes

Level of information:	Individual/ aggregate
Location breakdown:	Postcode
Data available from:	2006 for baseline data and 2012 for follow-up data
Jurisdiction available:	NSW only
How data is collected:	This prospective study has recruited more than 250,000 men and women from the NSW general population. Potential participants were randomly sampled from the Department of Human Services (formerly Medicare Australia) database and mailed a Study questionnaire and information leaflet. There is oversampling of individuals from rural areas and of those aged 80 and over. Participants joined the Study by completing the questionnaire and providing signed consent for follow-up and linkage to a range of health databases. Recruitment commenced in February 2006, when more than 36,000 participants joined the Study. The remainder of the cohort was recruited over the period 2007-09, with the full cohort reached by December 2009. Linkage to health data sets began in 2008. The response rate to the study is about 18%, similar to other studies requiring extensive consent for data linkage. The first follow-up of participants began in 2012, with 40,000 questionnaires mailed out. A further 86,000 questionnaires were mailed in late 2013 and the remainder of the cohort will be resurveyed over the next couple of years.
Brief summary of data:	More than 250,000 people — one in 10 NSW men and women aged over 45 — are participating in our 45 and Up Study, the largest ongoing study of healthy ageing in the Southern Hemisphere. By following such a large group of people over the long term, a world-class research resource is developing, that can be used to boost our understanding of how Australians are ageing. This will answer important health and quality-of-life questions and help manage and prevent illness through improved knowledge of conditions such as cancer, heart disease, depression, obesity and diabetes
Variables of interest:	Demographic data such as age, postcode, education, ethnicity and type of housing; lifestyle and habits including physical activity, smoking and alcohol consumption; current medications; history of disease; surgical procedures; functional capacity (MOS-PF) and psychological distress (Kessler-10); social support (Duke sub-scale) and employment status, paid and unpaid work and income, treatment for depression anxiety in the last month. Can also be linked to MBS data: provider, provider speciality MBS item number, item category and description and PBS data; item description, PBS item code, patient category, date of prescription and date of supply.

Data access and linkage

Where data is held:	Sax Institute
Data custodian:	Information unknown
Who can get access:	Researchers with approval
Is linkage possible:	With approval it is possible to link de-identified data from the survey to MBS and PBS data. Can also link to data sets that are part of the Master Linkage Key at CHeRel including: NSW admitted patients, emergency data, deaths registration, mental health ambulatory data and ACT admitted patients, emergency department collection, emergency department information system. It also possible to link data to collections that are not part of the Master Linkage Key such as the national death index, NSW community mental health collection and the possibility of other data sets.
How to get access:	An application form and Questionnaire variable form are submitted to the SAX institute (https://www.saxinstitute.org.au/our-work/45-up-study/for-researchers/#application-forms).
Cost:	To access 45 and Up Study baseline questionnaire data, a data licence is required. The fee is based on the number of users, length of time of data access and questionnaire source. For one user the cost of a licence for one year is $7,500, for 2 years 14,250 and for 3 years $21,000. This cost increases as the number of users increase. Follow-up data is an additional 50% of the baseline data cost. Additional charges will apply where the main database is being linked with external databases. The fee to link CHeReL master linkage key (MLK) data collections is $3,460 + GST per occasion. This fee covers an unlimited number of MLK data collections being linked in one occasion and is often a "one-off" unless additional or revised data collections are requested through the CHeReL. This cost is separate from those charged by CHeReL and a separate quote must be obtained from CHeReL for their linkage costs. The fee for Medicare Benefits Schedule (MBS) or Pharmaceutical Benefits Scheme (PBS) data is $2,750 + GST per data collection, i.e. $5,500 + GST for both. This charge is per an occasion of new supply of data.

The Hunter Community Study NSW

Main Data Attributes

Level of information:	Individual
Location breakdown:	Postcode
Data available from:	2004- 2008
Jurisdiction available:	NSW only
How data is collected:	Detail as follows;
Brief summary of data:	The Hunter Community Study (HCS) is a population-based prospective cohort study established to assess factors important in the health, wellbeing, and social functioning of older Australians. The cohort consists of participants aged 55 to 85 years randomly selected from the Hunter Region of the Australian electoral roll. Health data in the form of clinic assessments, surveys and blood samples have already been collected at baseline and participants have consented to have

their data linked to health and other registers (Medicare, PBS, DVA, RBDM, NSW Cancer Register, Hunter Area Heart and Stroke Register and Area Health Service Medical Records). The HCS database contains 3253 study participants who have completed questionnaires and/or clinical assessment between 2004 and 2008. The HCS is a collaborative study between the University of Newcastle's School of Medicine and Public Health and the Hunter New England Area Health Service.

Variables of interest: *Survey information:* demographic, socioeconomic, education, nutrition, depression, anxiety, medical and surgical history, quality of life, cognition, medication, employment, social support, tobacco and alcohol use, and spirituality.

Data access and linkage

Where data is held: University of Newcastle's School of Medicine and Public Health and the Hunter New England Area Health Service.

Data custodian: Mrs Rosanne Peel
University of Newcastle
0438648081/Roseanne.peel@newcastle.edu.au

Who can get access: Researchers with approval

Is linkage possible: Yes through CHeRel this dataset can be linked to MBS and PBS data.
Can also link to datasets that are part of the Master Linkage Key at CHeRel including: NSW admitted patients, emergency data, deaths registration, mental health ambulatory data and ACT admitted patients, emergency department collection, emergency department information system. It also possible to link data to collections that are not part of the Master Linkage Key such as the national death index, NSW community mental health collection and the possibility of other datasets.

How to get access: Process of application is detailed below

- Contact the Research Project Manager (02 9391 9924) to discuss study where a cost estimate will be provided.
- Complete the Application for Data form where an outline is provided including the datasets of interest, variables and linkage required.
- CHeReL forwards the application onto the data custodians for them to make suggestions and identify potential problems. This process takes 2-3 weeks
- If required the application is amended based on custodians input
- All studies using linked data must obtain ethics approval from NSW Population and Health Services Research Committee through a National Ethics Application form and Research Protocol
- CHeRel will provide researcher with a technical feasibility letter and a written quote whereby all documents will be sent to data custodians to sign off on.

Cost: To be advised upon application, the cost varies depending upon

- Number of individuals in the study
- Number of datasets from which information is requested
- Whether the study involves linking a data set which is not part of the Master Linkage Key (MLK).
- An example: the Linkage and extraction records from two MLK datasets for 50/00 individuals would cost approximately $5000

WA Data sets

Mental Health Information System WA

Main Data Attributes

Level of information:	Individual
Location breakdown:	Postcode
Data available from:	1966 for ambulatory data (MHAD) and 2005 for National Outcome Casemix Collection data (MHNOCC)
Jurisdiction available:	WA
Jurisdiction differences:	Only available in WA
How data is collected:	Data is linked monthly and recorded on a patient based system where every patient is allocated a unique number. Psychiatric episodes can be inpatient (public and private) and outpatient (public only). Inpatient data is sourced from: Community Accommodation Support Program Hostels Community Residential Facilities; and Acute general hospitals Outpatient data is sourced from: Designated Psychiatric Inpatient Units, Psychiatric Clinics, Triage Services, Community mental health centres, Psychiatric Day centres, Outreach programs; and Rehabilitation programs.
Brief summary of data:	The Mental Health Information System collects data about people who use public mental health services in Western Australia. It is a patient based information system in which each patient is allocated a unique number. Data for each person contains demographic information and clinical information from outpatient clinics and hospital visits. The collection of mental health information is authorised by Hospitals and Health Services Act 1927. Based upon the MHAD and MHNOCC data
Variables of interest:	A**mbulatory data**; Demographics such as gender, age, Indigenous status, country of birth, marital status, employment and education status. Primary diagnosis (ICD code), venue of contact, health professional type, outcome of contact (including treatment, referred to another service etc. only available on completed episodes) **NOCC data**: Gender, age, inpatient or outpatient setting, SDQ, CGAS, LSP-16, K-10, primary diagnosis (unclear if it is ICD or not)

Data access and linkage

Where data is held:	Department of Health with access through Western Australia Data Linkage Branch
Data custodian:	Jo Denooyer
Who can get access:	Researchers with approval
Jurisdiction differences:	This specific collection is only available in WA, but based on ambulatory data.
How to get access:	Apply for linked and unlinked data through Western Australia Data Linkage Branch. The process is as follows: - Draft application is sent to the Data linkage Branch (DLB) for data custodians to review and provide feedback via DLN. - The final application is sent back to DLB Project Officer for review - Researcher sends application to Human Research Ethics Committee

The following items are sent with the application

- Signed Application for Data
- Data services Form
- Variables Lists
- Research Protocol
- Feasibility letter
- Any other supporting documentations and Declarations of Confidentiality

Once this is approved, contact the DLB Project Manager Alexandra Godfrey regarding status of request

Cost: Charges usually apply for linkage, geocoding or extraction requests that fall outside core activities. Funds derived from these charges assist in supporting staff and equipment used for the on-going development of the linkage system. The charges depend on the size and complexity of the linkage or extraction tasks involved. For extractions, the cost depends on the number of datasets, number of years and number of individuals in the data extract. A quote form can be submitted.

Emergency Department Data Collection WA

Main Data Attributes

Level of information: Individual

Location breakdown: Postcode

Data available from: 2000/2001

Jurisdiction available: WA

How data is collected: Data is linked on a weekly basis, with catch-up linkages every 6 months. Data is collected from emergency department activity in WA's public hospitals as well as ED activity in private hospitals

Include 4 systems: Emergency Department Information System (EDIS) - used by all EDs in metropolitan public hospitals and the Joondalup Health Campus Health Care and Related Information System (HCARe) - used by all rural public hospital (except Bunbury Regional Hospital)

The Open Patient Administration System (TOPAS) - used by Bunbury Regional Hospital

The Electronic Patient Administration System (ePAS) - used by Peel Health Campus

Brief summary of data: The EDDC contains data on emergency department activity in Western Australia's public hospitals, as well emergency department activity from private hospitals under contract with the WA Government. In addition to data specifically related to episodes of care in emergency departments (e.g. triage category, presentation date and time), the collection also includes demographic data (e.g. name, date of birth) and data required under the Australian Health Care Agreement (e.g. whether an interpreter service was required).

Variables of interest: Age, gender, Indigenous status, country of birth, marital status, employment status, socioeconomic status

Presenting complaint and diagnosis on discharge (not coded just text field). Standard Emergency Record information; establishment type, triage code, disposal code (episode and status), departure destination, type of visit to ED, referral source, principal diagnosis, symptom, major diagnostic category.

Data access and linkage

Where data is held:	Department of Health with access through Western Australia Data Linkage Branch
Data custodian:	Jennifer Atthowe
Who can get access:	Researchers with approval
Jurisdiction differences:	This specific collection is only available in WA, but based on ambulatory data
How to get access:	Apply for linked and unlinked data through Western Australia Data Linkage Branch. The process is as follows - Draft application is sent to the Data linkage Branch (DLB) for data custodians to review and provide feedback via DLN. - The final application is sent back to DLB Project Officer for review - Researcher sends application to Human Research Ethics Committee The following items are sent with the application - Signed Application for Data - Data services Form - Variables Lists - Research Protocol - Feasibility letter - Any other supporting documentations and Declarations of Confidentiality Once this is approved, contact the DLB Project Manager Alexandra Godfrey regarding status of request
Cost:	Charges usually apply for linkage, geocoding or extraction requests that fall outside core activities. Funds derived from these charges assist in supporting staff and equipment used for the on-going development of the linkage system. The charges depend on the size and complexity of the linkage or extraction tasks involved. For extractions, the cost depends on the number of datasets, number of years and number of individuals in the data extract. A quote form can be submitted.

Hospital Morbidity Data WA

Main Data Attributes

Level of information:	Individual
Location breakdown:	Postcode
Data available from:	Inpatient records dated back to 1970, hospital survey data since 1993
Jurisdiction available:	WA
How data is collected:	Data is linked monthly and collected from all public and private hospitals in WA.
Brief summary of data:	Information not available
Variables of interest:	Information not available

Data access and linkage

Where data is held:	Department of Health with access through Western Australia Data Linkage Branch
Data custodian:	Paul Steven
Who can get access:	Researchers with approval
Jurisdiction differences:	This specific collection is only available in WA
How to get access:	Apply for linked and unlinked data through Western Australia Data Linkage Branch. The process is as follows - Draft application is sent to the Data linkage Branch (DLB) for data custodians to review and provide feedback via DLN. - The final application is sent back to DLB Project Officer for review - Researcher sends application to Human Research Ethics Committee The following items are sent with the application - Signed Application for Data - Data services Form - Variables Lists - Research Protocol - Feasibility letter - Any other supporting documentations and Declarations of Confidentiality Once this is approved, contact the DLB Project Manager Alexandra Godfrey regarding status of request
Cost:	Charges usually apply for linkage, geocoding or extraction requests that fall outside core activities. Funds derived from these charges assist in supporting staff and equipment used for the on-going development of the linkage system. The charges depend on the size and complexity of the linkage or extraction tasks involved. For extractions, the cost depends on the number of datasets, number of years and number of individuals in the data extract. A quote form can be submitted.

Deaths Registration WA

Main Data Attributes

Level of information:	Individual
Location breakdown:	Postcode

Data available from:	1969
Jurisdiction available:	WA
Jurisdiction differences:	The Western Australian Deaths Registry is administered under the Births, Deaths and Marriages Registration Act 1998 by the WA
How data is collected:	Information not available
Brief summary of data:	The Death Registration Statements contains the details prescribed by Regulation, including but not limited to: demographic details such as name at birth, Aboriginal/Torres Strait Islander status, sex, occupation, date and place of birth; age at death; date of death; place of death; cause of death (ICD-9); marital status; details of parents; details of children; Coroner details; and funeral director details.
Variables of interest:	As above

Data access and linkage

Where data is held:	The West Australian Deaths Registry
Data custodian:	Information not available
Who can get access:	Researchers with Approval
How to get access:	Apply for linked and unlinked data through Western Australia Data Linkage Branch. The process is as follows - Draft application is sent to the Data linkage Branch (DLB) for data custodians to review and provide feedback via DLN. - The final application is sent back to DLB Project Officer for review - Researcher sends application to Human Research Ethics Committee The following items are sent with the application - Signed Application for Data - Data services Form - Variables Lists - Research Protocol - Feasibility letter - Any other supporting documentations and Declarations of Confidentiality Once this is approved, contact the DLB Project Manager Alexandra Godfrey regarding status of request
Cost:	Charges usually apply for linkage, geocoding or extraction requests that fall outside core activities. Funds derived from these charges assist in supporting staff and equipment used for the on-going development of the linkage system. The charges depend on the size and complexity of the linkage or extraction tasks involved. For extractions, the cost depends on the number of datasets, number of years and number of individuals in the data extract. A quote form can be submitted

SA Data sets

South Australia Monitoring and Surveillance System

Main Data Attributes

Level of information:	Individual
Location breakdown:	Area of residence
Data available from:	2002 with data collected (and available) monthly
Jurisdiction available:	SA only
Jurisdiction differences:	SA only
How data is collected:	Each month since July 2002, a sample of South Australians is randomly selected from the Electronic Whites Pages (EWP). Introductory letters are sent to each household selected to inform them of the upcoming telephone survey, inviting the person who had the last birthday in the household to participate in a telephone interview. In the case of a child under 16 years of age being the person with the last birthday, the interview is conducted by proxy (i.e. a parent or guardian). Professional interviewers, using Computer Assisted Telephone Interview (CATI) technology, conduct the survey. Approximately 600 respondents participate in each SAMSS survey.
Brief summary of data:	The South Australian Monitoring and Surveillance System (SAMSS) is owned by SA Health and is an epidemiological chronic disease and risk factor monitoring system, provided by Population Research & Outcome Studies (PROS) within the Discipline of Medicine, University of Adelaide. SAMSS aims to detect and facilitate understanding of trends in the prevalence of chronic conditions, risk and protective factors, and other determinants of health. These data monitor departmental, state and national priority areas and are linked to key indicators.
Variables of interest:	Demographics; age, gender, employment, country of birth, area of residence divided into categories; remote, rural, metro, ***Use of health care services in last four weeks;*** GP, ED, clinic, psychologist, psychiatrist ***Health;*** treated for mental health problem, suicide ideation, current mental condition.

Data access and linkage

Where data is held:	SA Health, available through the University of Adelaide
Data custodian:	Population research and outcome studies, University of Adelaide
Who can get access:	Researchers
Jurisdiction differences:	SA only
How to get access:	A request of information from SAMSS will need to be approved by the Service Advisory Committee (SAC) in SA Health by submitting a 'Request for Analysis of SA Health Data Form'.
Cost:	Information not available

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Emergency Department Data SA

Main Data Attributes

Level of information:	Individual
Location breakdown:	Postcode
Data available from:	July 2003 onwards. All metropolitan ED submit data monthly. Identified data is available 30th November each year for the previous year
Jurisdiction available:	SA
Jurisdiction differences:	Information collected from SA hospitals and based on the "Non-admitted Patient Emergency Department Care" national minimum Data set
How data is collected:	Data is collected from Hospital Administration Software Solutions-Emergency Department (HASS-ED) systems for all metropolitan hospitals except Flinders Medical Centre (FMC) and Modbury Hospital (MPH). FMC and MPH do not use HASS-ED and their data is collected from their own local systems. Data is submitted monthly via an encrypted .xml file which is loaded and validated in a holding area prior to its inclusion in the EDDC. Each month after data is loaded, processed and cleaned it is transferred to the Central Data Warehouse/Health Information Portal (CDW/HIP).
Brief summary of data:	The SA Emergency Department Data Collection (EDDC) contains de-identified, demographic, administrative and clinical data detailing presentations to Emergency Departments (ED) at public metropolitan hospitals in South Australia. Information in the EDDC is required under the National Health Care and National Health Information Agreements (NHCA & NHIA). The scope of this data collection currently covers the Emergency Departments of all the major metropolitan public hospitals. Diagnosis codes from 2007/2008 are in ICD 10-AM. Prior to that diagnosis codes may vary
Variables of interest:	Demographics such as gender, country of birth, Indigenous status, age. Diagnosis is available however a full list of data variables is only available on request

Data access and linkage

Where data is held:	SA department of health data accessed through SA NT Data Link
Data custodian:	Mr Paul Basso Director Information Management SA Health
Who can get access:	Researchers with approval
Linkage?	EDDC does not contain name and address information and so for the purposes of linkage these elements are added for metropolitan hospitals through linkage to Open Architecture Clinical Information Systems (OACIS). Although the quality of this linkage is improving over time, it's not 100% meaning that for the period 2003/2004 to 2007/2008 inclusive some records in EDDC did not have matching names in OACIS.
How to get access:	For unlinked data, need to apply directly to data custodians. For linked data can use the SA NT data link application process as follows - A Statistical Linkage Application Form and submit to SA NT data link - A member of SA NT DataLink Client Services review application and facilitates meeting with Researchers, Data Custodians and Data providers - Data custodians provide conditions and possible 'in principle' approval - If 'in principle' the request is approved, researchers then apply for ethics approval.

- Once ethics is approved, the completed SA NT Datalink application form with this approval needs to be submitted to the Data Custodians.
- Once final approval from all data custodians is obtained, SA NT Datalink creates and extracts project specific linkage keys using data records from the Master Linkage File
- Data Custodians will use these keys to extract to approved research variables removing all identifiers and provide the file to the researchers.

Cost: The SA NT DataLink Steering Committee approved **'Access and Pricing Policy'** describes the principles SA NT DataLink uses to determine the cost of a research project to a researcher or their organisation, which may then be used to inform a grant application. The estimated cost or quotation (based on the principle of partial cost recovery) is based on the provision of the following services and project requirements:

- engagement of client services staff to assist researchers with the project application process, and agreements with Data Custodians;
- maintenance of the Master Linkage File (used to generate project linkage across multiple datasets);
- production of project specific linkage keys, required for each Statistical Linkage Project.
- the number of datasets and the anticipated cohort size;

Inpatient Hospital Separations SA

Main Data Attributes

Level of information: Recorded as separations, not individuals

Location breakdown: Postcode

Data available from: Data available for linkage is from 2003 and reported monthly. Identified data for linkage is provided on the 30th of Nov of each year the proceeding financial year

Jurisdiction available: SA

How data is collected: ISAAC collects morbidity data on admitted patients from all recognised public and private hospitals in South Australia, under the authority of the Health Care Act 2007.

Data are recorded by hospital staff in the course of hospital business. Hospitals submit data to the collection in a variety of formats (paper, disc, email) and it is processed into the collection by SA Health Information Assembly unit.

Records are updated at the time of separation, e.g. discharge, transfer or death.

Brief summary of data: ISAAC is an admitted patient morbidity data collection with information on all admitted patient activity in public and private hospitals in South Australia. All admitted patient separations (discharges, transfers and deaths) form every SA public acute hospital, public psychiatric hospital, private acute hospital, private psychiatric hospital and private day surgery is collected.

Variables of interest: Demographics such as gender, country of birth, Indigenous status, age. Diagnosis is available however a full list of data variables is only available on request

Data access and linkage

Where data is held:	SA department of health data accessed through SA NT Data Link
Data custodian:	Mr Paul Basso
Who can get access:	Researcher with approval
Linkage?	Yes although, separations from private hospitals are not available for data linkage.
How to get access:	For unlinked data, need to apply directly to data custodians. For linked data can use the SA NT data link application process as follows - A Statistical Linkage Application Form and submit to SA NT data link - A member of SA NT DataLink Client Services review application and facilitates meeting with Researchers, Data Custodians and Data providers - Data custodians provide conditions and possible 'in principle' approval - If 'in principle' the request is approved, researchers then apply for ethics approval. - Once ethics is approved, the completed SA NT Datalink application form with this approval needs to be submitted to the Data Custodians. - Once final approval from all data custodians is obtained, SA NT Datalink creates and extracts project specific linkage keys using data records from the Master Linkage File - Data Custodians will use these keys to extract to approved research variables removing all identifiers and provide the file to the researchers.
Cost:	The SA NT DataLink Steering Committee approved **'Access and Pricing Policy'** describes the principles SA NT DataLink uses to determine the cost of a research project to a researcher or their organisation, which may then be used to inform a grant application. The estimated cost or quotation (based on the principle of partial cost recovery) is based on the provision of the following services and project requirements: - engagement of client services staff to assist researchers with the project application process, and agreements with Data Custodians; - maintenance of the Master Linkage File (used to generate project linkage across multiple datasets); - production of project specific linkage keys, required for each Statistical Linkage Project. - the number of datasets and the anticipated cohort size;

SA Deaths registry

Main Data Attributes

Level of information:	Individual
Location breakdown:	Information not available without submitting an application
Data available from:	1990 onwards
Jurisdiction available:	SA
How data is collected:	The registration of a death requires a death registration statement and either a medical report or coroner's report. Registration details are entered electronically by Births, Deaths and Marriages staff
Brief summary of data:	The Death Registration Statements contains the details prescribed by Regulation, including but not limited to: demographic details such as name at

birth, Aboriginal/Torres Strait Islander status, sex, occupation, date and place of birth; age at death; date of death; place of death; cause of death; marital status; details of parents; details of children; Coroner details; and funeral director details

Variables of interest: As above

Data access and linkage

Where data is held: The South Australian Deaths Registry

Data custodian: SA Registrar of Births, Deaths and Marriages
Ms Lyn Guerin

Who can get access: Researchers with approval

Linkage? Yes

How to get access: For unlinked data, need to apply directly to data custodians. For linked data can use the SA NT data link application process as follows

- A Statistical Linkage Application Form and submit to SA NT data link
- A member of SA NT DataLink Client Services review application and facilitates meeting with Researchers, Data Custodians and Data providers
- Data custodians provide conditions and possible 'in principle' approval
- If 'in principle' the request is approved, researchers then apply for ethics approval.
- Once ethics is approved, the completed SA NT Datalink application form with this approval needs to be submitted to the Data Custodians.
- Once final approval from all data custodians is obtained, SA NT Datalink creates and extracts project specific linkage keys using data records from the Master Linkage File
- Data Custodians will use these keys to extract to approved research variables removing all identifiers and provide the file to the researchers.

Cost: The SA NT DataLink Steering Committee approved **'Access and Pricing Policy'** describes the principles SA NT DataLink uses to determine the cost of a research project to a researcher or their organisation, which may then be used to inform a grant application. The estimated cost or quotation (based on the principle of partial cost recovery) is based on the provision of the following services and project requirements:

- engagement of client services staff to assist researchers with the project application process, and agreements with Data Custodians;
- maintenance of the Master Linkage File (used to generate project linkage across multiple datasets);
- production of project specific linkage keys, required for each Statistical Linkage Project.
- the number of datasets and the anticipated cohort size;

ACT Data sets

Admitted Patient care ACT

Main Data Attributes

Level of information:	Episode
Location breakdown:	Postcode
Data available from:	July 2004 onwards. Data is available each financial year. Last records available June 2013
Jurisdiction available:	ACT
How data is collected:	Episodes of care are recorded from all public and private hospitals in ACT
Brief summary of data:	The ACT Admitted Patient Care (APC) data records all inpatient separations (discharges, transfers and deaths) from all public and private hospitals in ACT. Public hospital APC data are recorded in terms of episodes of care (EOC). An episode of care ends with the patient ending a period of stay in hospital (e.g. by discharge, transfer or death) or by becoming a different "type" of patient within the same period of stay. The categories of types of care are listed under the variable "Service Category". For private hospitals, each APC record represents a complete hospital stay. APC data are based on the date of separation (discharge) from hospital.
Variables of interest:	Demographics such as age, date of birth, sex, postcode of residence Indigenous status, country of birth, marital status Area of service, health area of hospital, Source of referral to hospital Date and time of admission, separation, length of stay in hospital, Primary diagnosis, additional diagnosis, External code of injury or poisoning (defined using ICD 10-AM codes) Admitted to psychiatry ward, days in designated psychiatry ward, Transferred from hospital, transferred to hospital

Data access and linkage

Where data is held:	ACT Ministry of Health
Custodian:	Julie Searle
Who can get access:	Researchers with approval
Linkage?:	Data is available from July 2004. Currently only data from one ACT public hospital has been added to the Master Linkage Key. Data for the remaining public hospital and ACT private hospitals will be added as it becomes available.
How to get access:	Process of application is detailed below - Contact the Research Project Manager (02 9391 9924) to discuss study where a cost estimate will be provided. - Complete the Application for Data form where an outline is provided including the data sets of interest, variables and linkage required. - CHeReL forwards the application onto the data custodians for them to make suggestions and identify potential problems. This process takes 2-3 weeks

- If required the application is amended based on custodians input
- All studies using linked data must obtain ethics through a National Ethics Application form and Research Protocol
- CHeRel will provide researcher with a technical feasibility letter and a written quote whereby all documents will be sent to data custodians to sign off on.

Cost: To be advised upon application, the cost varies depending upon

- Number of individuals in the study
- Number of data sets from which information is requested
- Whether the study involves linking a data set which is not part of the Master Linkage Key (MLK).
- An example: the Linkage and extraction records from two MLK datasets for 50/00 individuals would cost approximately $5000.

Emergency Department Data collection ACT

Main Data Attributes

Level of information: Episode

Location breakdown: Postcode

Data available from: commenced 2000 but is only available through the Master Linkage Key from 2005. Data is available each financial year. Last records available June 2013

Jurisdiction available: ACT

How data is collected: Each presentation to an emergency department is recorded as an episode of care (EOC).

Brief summary of data: The ACT Admitted Patient Care (APC) data records all inpatient separations (discharges, transfers and deaths) from all public and private hospitals in ACT. Currently, data from Canberra Hospital are included in the Master Linkage Key

Variables of interest: Demographics such as age, date of birth, sex, postcode of residence
Indigenous status, country of birth, marital status
Area of service, health area of hospital, Source of referral to hospital
Date and time of admission, separation, referral source, type of visit
Primary diagnosis, (defined using ICD 10-AM codes),

Data access and linkage

Where data is held: ACT Ministry of Health

Custodian: Contact details are found via email HealthInfo@act.gov.au

Who can get access: Researchers with approval

Linkage?: Currently only data from one ACT public hospital has been added to the Master Linkage Key. Data for the remaining public hospital will be added when it becomes available. The EDDC has substantial limitations. These limitations must be considered when planning a study using ED data, and in particular, when interpreting and presenting the data

How to get access: Process of application is detailed below

- Contact the Research Project Manager (02 9391 9924) to discuss study where a cost estimate will be provided.
- Complete the Application for Data form where an outline is provided including the data sets of interest, variables and linkage required.

- CHeReL forwards the application onto the data custodians for them to make suggestions and identify potential problems. This process takes 2-3 weeks
- If required the application is amended based on custodians input
- All studies using linked data must obtain ethics through a National Ethics Application form and Research Protocol
- CHeRel will provide researcher with a technical feasibility letter and a written quote whereby all documents will be sent to data custodians to sign off on.

Cost: To be advised upon application, the cost varies depending upon

- Number of individuals in the study
- Number of data sets from which information is requested
- Whether the study involves linking a data set which is not part of the Master Linkage Key (MLK).
- An example: the Linkage and extraction records from two MLK datasets for 50/00 individuals would cost approximately $5000.

VIC Data sets

VIC Emergency Department Minimum Dataset

Main Data Attributes

Level of information:	Episode of care
Location breakdown:	Statistical local area of residence
Data available from:	From July 2000
Jurisdiction available:	VIC
How data is collected:	Data is collected through administrative staff from all public hospital emergency departments in VIC. Collection processes are based on standard definitions that comply with the Emergency Department Care National Minimum Data Set (NMDS).
Brief summary of data:	This data set collects information on emergency presentations at Victorian public hospitals that receive the non-admitted emergency services grant, and other hospitals as designated by the Department of Health
Variables of interest:	Demographic data such as gender, age, marital status Care type, admission type, month or separation, length of stay, patient type, admission source i.e. transfer or referral, transfer destination ICD-10-AM diagnosis

Data access and linkage

Where data is held:	Victorian data linkage, Department of Health
Data custodian:	Contact through department of Health
Who can get access:	Researchers with approval
Jurisdiction differences:	Not much information available from the Department of Health for Victorian data. It has been advised by the Australian Institute of Health and Welfare that it is difficult to get access to Victorian data especially ED data.
How to get access:	The process involves; - SUMBIT application For Data Form to Victorian Data Linkages and list of requested variables table and justification. HREC application. Application for Data linkage form found here http://docs.health.vic.gov.au/docs/doc/VDL-Data-Request-Form - Research Services and Data Integration team meets to review application and may request more information from researcher - Researcher gains Human Research Ethics Committee approval and provides application and approval letter - A data application is sent to the Department of Health Data Custodians by Department of Health. Data Custodians may request changes to the application - The researcher is informed of what variables have been approved - Researcher then completes the Department of Health Conditions of Release form - Data is released
Cost:	Based on a 'cost-recovery' system. No quotes available without an application.

Admitted Episodes Data VIC

Main Data Attributes

Level of information:	Recorded in episodes of care not as individual
Location breakdown:	Postcode
Data available from:	from 1979 but early data is limited. Information is transmitted monthly. Information is compiled and available every financial year
Jurisdiction available:	VIC
How data is collected:	All hospitals including public, private and denominational hospitals, rehabilitations centres, acute psychiatric units in public hospitals. These data items are processed via the PRS/2 interface and data validation system. It is then compiled into the Victorian Admitted Episodes Dataset (VAED) by the Department of Health. Information is required monthly.
Brief summary of data:	The Victorian Admitted Episodes Dataset (VAED) comprises demographic, clinical and administrative details for every admitted episode of care occurring in Victorian hospitals, rehabilitation centres, extended care facilities and day procedure centres. From 1 July 2012, the dataset includes posthumous organ procurement and off-site restorative care episodes, which are not admitted but are reportable to the VAED. Specific Criterion for Admission codes allow for the reporting of these episodes
Variables of interest:	Demographics such as age, date of birth, sex, postcode of residence Indigenous status, country of birth, marital status Area of service, health area of hospital, Source of referral to hospital Date and time of admission, separation, length of stay in hospital, Primary diagnosis, additional diagnosis, External code of injury or poisoning (defined using ICD 10-AM codes) Admitted to psychiatry ward, days in designated psychiatry ward, Transferred from hospital, transferred to hospital

Data access and linkage

Where data is held:	Victorian data linkage, Department of Health
Data custodian:	Contactable through department of Health
Who can get access:	Researchers with approval
Jurisdiction differences:	Not much information available from the Department of Health for Victorian data. It has been advised by the Australian Institute of Health and Welfare that it is difficult to get access to Victorian data especially ED data.
How to get access:	The process involves; - Submit application For Data Form to Victorian Data Linkages and list of requested variables table and justification. HREC application. Application for Data linkage form found here http://docs.health.vic.gov.au/docs/doc/VDL-Data-Request-Form - Research Services and Data Integration team meets to review application and may request more information from researcher

- Researcher gains Human Research Ethics Committee approval and provides application and approval letter
- A data application is sent to the Department of Health Data Custodians by Department of Health. Data Custodians may request changes to the application
- The researcher is informed of what variables have been approved
- Researcher then completes the Department of Health Conditions of Release form
- Data is released

Cost: Based on a 'cost-recovery' system. No quotes available without an application.

Victorian Integrated Non-Admitted Health

Main Data Attributes

Level of information: Individual
Location breakdown: Postcode
Data available from: Information unclear, last available data is from July 2001.
Jurisdiction available: VIC
How data is collected: All public hospitals providing non-admitted services in scope for VINAH need to report a minimum data set of patient-level data related to their activities. At the department, these demographic, administrative and clinical data are compiled into the Victorian Integrated Non-admitted Health Minimum Dataset (VINAH MDS). Victorian hospitals transmit data to the VINAH
Brief summary of data: The Victorian Integrated Non-Admitted Health (VINAH) data collection comprises data for Sub Acute Ambulatory Care Services, Hospital Admission Risk Program, Post-acute Care, Family Choice Program, Victorian HIV Service, Victorian Respiratory Support Service, Community Palliative Care, Transition Care Program, Residential In-reach and from 1 July 2011, Specialist Outpatients clinics. The VINAH data collection integrates patient-level data across many government-funded programs which in turn benefits health services, as they are now supported to collect one set of data elements rather than managing multiple collections across many program streams
Variables of interest: Demographics such as gender, country of birth, age. Referral from and referral to i.e. service type, episode information such as start date, episode location, care plan agreement date, proposed treatment plan completion, episode health condition (not ICD coded, only a general code for mental health, no code for suicidal behaviour).

Data access and linkage

Where data is held: Victorian data linkage, Department of Health
Data custodian: Contactable through department of Health
Who can get access: Researchers with approval
Jurisdiction differences: Not much information available from the Department of Health for Victorian data. It has been advised by the Australian Institute of Health and Welfare that it is difficult to get access to Victorian data especially ED data.
How to get access: The process involves;

- SUMBIT application For Data Form to Victorian Data Linkages and list of requested variables table and justification. HREC application. Application for Data linkage form found here http://docs.health.vic.gov.au/docs/doc/VDL-Data-Request-Form
- Research Services and Data Integration team meets to review application and may request more information from researcher
- Researcher gains Human Research Ethics Committee approval and provides application and approval letter
- A data application is sent to the Department of Health Data Custodians by Department of Health. Data Custodians may request changes to the application
- The researcher is informed of what variables have been approved
- Researcher then completes the Department of Health Conditions of Release form
- Data is released

Cost: Based on a 'cost-recovery' system. Quotes are only available with an application.

TAS Data Sets

Public Hospital Admitted Patient Collection TAS

Main Data Attributes

Level of information:	Information not available
Location breakdown:	Information not available
Data available from:	Information not available
Jurisdiction available:	TAS
Jurisdiction differences:	Limited information is available for TAS. The only seemingly available data set is the Disability Services National Minimum data set
How data is collected:	The collection includes all admitted patient separations from each of the four major public hospitals in Tasmania. Data are recorded by hospital staff in the course of hospital business. Hospitals submit data to the collection in a variety of formats data held centrally in a data warehouse. Records are updated at points of care, at care changes and at the time of separation.
Brief summary of data:	The dataset is an admitted patient morbidity data collection designed to provide the Department of Health and Human Services (DHHS) Tasmania with the information resources necessary to effectively deliver integrated patient care and to assist with the organisation, evaluation and planning of public health services in Tasmania. Each person admitted to a public hospital in Tasmania is assigned a unique 9-digit patient identifier. The collection includes all admitted patient separations from each public hospital in Tasmania.
Variables of interest:	Demographics such as age, date of birth, sex, postcode of residence Indigenous status, country of birth, marital status Area of service, health area of hospital, Source of referral to hospital Date and time of admission, separation, length of stay in hospital, Primary diagnosis, additional diagnosis, External code of injury or poisoning (defined using ICD 10-AM codes) Admitted to psychiatry ward, days in designated psychiatry ward, Transferred from hospital, transferred to hospital

Data access and linkage

Where data is held:	Tasmanian Data Linkage Unit; Department of Health and Human Services and the Menzies Research Institute Tasmania Brian Stokes
Data custodian:	Information not available
Who can get access:	Made contact to enquiry about access.
Is linkage possible?	It seems that the linkage unit is under development
How to get access:	Information not available
Cost:	Information not available

Tasmanian Public Hospital ED presentations

Main Data Attributes

Level of information:	Information not available
Location breakdown:	Information not available
Data available from:	Information not available
Jurisdiction available:	TAS
Jurisdiction differences:	limited information is available for TAS
How data is collected:	Information not available
Brief summary of data:	Emergency Department (ED) presentations at public hospitals in Tasmania are captured in an administrative data collection and contain demographic, administrative and clinical data specific to each presentation. Each person presenting to an ED is assigned a unique 9-digit patient identifier.
Variables of interest:	Information not available

Data access and linkage

Where data is held:	Tasmanian Data Linkage Unit; Department of Health and Human Services and the Menzies Research Institute Tasmania Brian Stokes
Data custodian:	Information not available
Who can get access:	Made contact to enquiry about access.
Is linkage possible?	It seems that the linkage unit is under development
How to get access:	Information not available
Cost:	Information not available

NOTE: This year the TAS deaths registry and community and residential mental health data sets will be available and added to the Master Linkage file

NT Data Sets

NT Admitted Patients

Main Data Attributes

Level of information:	Information is recorded per separation not per individual
Location breakdown:	Postcode
Data available from:	Information not available
Jurisdiction available:	NT
Jurisdiction differences:	None, information collected is standardised across jurisdictions as part of the National Minimum data sets standards.
How data is collected:	Data are collected at each hospital from patient administrative and clinical record systems. Hospitals forward data to the relevant state or territory health authority on a regular basis (e.g. monthly). State and territory health authorities provide the data to the Australian Institute of Health and Welfare for national collation, on an annual basis. Data is collated annually, end of financial year.
Brief summary of data:	The scope is episodes of care for admitted patients in all public and private acute and psychiatric hospitals, freestanding day hospital facilities and alcohol and drug treatment centres in Australia. Hospitals operated by the Australian Defence Force, corrections authorities and in Australia's offshore territories may also be included. Hospitals specialising in dental, ophthalmic aids and other specialised acute medical or surgical care are included.
Variables of interest:	Demographics such as age, date of birth, sex, postcode of residence Indigenous status, country of birth, marital status Area of service, health area of hospital, Source of referral to hospital Date and time of admission, separation, length of stay in hospital, Primary diagnosis, additional diagnosis, External code of injury or poisoning (defined using ICD 10-AM codes) Admitted to psychiatry ward, days in designated psychiatry ward, Transferred from hospital, transferred to hospital

Data access and linkage

Where data is held:	NT Department of Health
Data custodian:	Information not available
Who can get access:	Researchers with approval
Is linkage possible:	There is a linkage unit for NT data however currently only available for the NT deaths registry
How to get access:	To access unlinked data the application needs to go straight to the data custodian. For linked data, can go through SA/NT data link. NT is currently developing its Master linkage file which at present there is only the Admitted activity data set (hospital data) with Emergency data being negotiated for next.
Cost:	unknown

NT DHCS Hospital Morbidity Data

Main Data Attributes

Level of information:	Possibly individual, definitely aggregate
Location breakdown:	District
Data available from:	1976 onwards
Jurisdiction available:	NT
Jurisdiction differences:	NT data is not easily accessible
How data is collected:	Information not available
Brief summary of data:	information regarding the data is not readily available however there are reports on hospital statistics available through the NT Department of health digital library website: http://digitallibrary.health.nt.gov.au The data is available in reports that generally date back to 2008. Information after that does not seem to be readily available.
Variables of interest:	Information not available

Data access and linkage

Where data is held:	NT Department of Health
Data custodian:	Information not available
Who can get access:	Access may not be available yet for individual data for researchers. Aggregate data is available to the public in annual reports from the NT Department of Health
Is linkage possible:	There is a linkage unit for NT data however currently only available for the NT Deaths Registry
How to get access:	For unlinked data, need to apply directly to data custodians. For linked data can use the SA NT data link application process as follows; - A Statistical Linkage Application Form and submit to SA NT data link - A member of SA NT DataLink Client Services review application and facilitates meeting with Researchers, Data Custodians and Data providers - Data custodians provide conditions and possible 'in principle approval - If 'in principle" the request is approved, researchers then apply for ethics approval. - Once ethics is approved, the completed SA NT Datalink application form with this approval needs to be submitted to the Data Custodians. - Once final approval from all data custodians is obtained, SA NT Datalink creates and extracts project specific linkage keys using data records from the Master Linkage File - Data Custodians will use these keys to extract to approve research variables removing all identifiers and provide the file to the researchers. ***Note:*** NT is currently developing its Master linkage file which at present there is only the Admitted activity data set (hospital data) with Emergency data being negotiated for next.
Cost:	**T**he SA NT DataLink Steering Committee approved **'Access and Pricing Policy'** describes the principles SA NT DataLink uses to determine the cost of a research project to a researcher or their organisation, which may then be used to inform a grant application. The estimated cost or quotation (based on the principle of partial cost recovery) is based on the provision of the following services and project requirements:

- engagement of client services staff to assist researchers with the project application process, and agreements with Data Custodians;
- maintenance of the Master Linkage File (used to generate project linkage across multiple datasets);
- production of project specific linkage keys, required for each Statistical Linkage Project.
- the number of datasets and the anticipated cohort size.

NT deaths Registry

Main Data Attributes

Level of information:	Individual (assumed, information not available)
Location breakdown:	Information not available
Data available from:	1870 onwards
Jurisdiction available:	NT
How data is collected:	Registered by BDM staff from a death registration statement, burial certificate, and either a medical or coroner's report.
Brief summary of data:	The Register includes any person who has died in the Northern Territory. Deaths in utero that occur after 20 weeks gestation or at greater than 400 grams are recorded in the BDM Births Register. BDM do not have a separate stillbirths register as they do in South Australia. The stillbirth is not recorded in the Deaths Register. Where there is sign of life at birth, but the neonate subsequently dies, the birth is recorded in the Births Register and the death is recorded in the Deaths Register. The Death Registration Statements contains the details prescribed by Regulation, including but not limited to: demographic details such as name at birth, Aboriginal/Torres Strait Islander status, sex, occupation, date and place of birth; age at death; date of death; place of death; cause of death; marital status; details of parents; details of children; Coroner details; and funeral director details.
Variables of interest:	Information not available

Data access and linkage

Where data is held:	The Office of Births, Deaths and Marriages of the NT department
Data custodian:	Senior Deputy Registrar-General for Births, deaths and Marriage
Who can get access:	Researchers with approval
Is linkage possible:	There is a linkage unit for NT data however currently only available for the NT deaths registry. Linkage is possible through a number of variables including DOB, gender, parents address, surname occupation etc.
How to get access:	For unlinked data, need to apply directly to data custodians. For linked data can use the SA NT data link application process as follows; - A Statistical Linkage Application Form and submit to SA NT data link - A member of SA NT DataLink Client Services review application and facilitates meeting with Researchers, Data Custodians and Data providers - Data custodians provide conditions and possible 'in principle approval - If 'in principle" the request is approved, researchers then apply for ethics approval.

- Once ethics is approved, the completed SA NT Datalink application form with this approval needs to be submitted to the Data Custodians.
- Once final approval from all data custodians is obtained, SA NT Datalink creates and extracts project specific linkage keys using data records from the Master Linkage File
- Data Custodians will use these keys to extract to approve research variables removing all identifiers and provide the file to the researchers.

Note: NT is currently developing its Master linkage file which at present there is only the Admitted activity data set (hospital data) with Emergency data being negotiated for next.

Cost:

The SA NT DataLink Steering Committee approved **'Access and Pricing Policy'** describes the principles SA NT DataLink uses to determine the cost of a research project to a researcher or their organisation, which may then be used to inform a grant application. The estimated cost or quotation (based on the principle of partial cost recovery) is based on the provision of the following services and project requirements:

- engagement of client services staff to assist researchers with the project application process, and agreements with Data Custodians;
- maintenance of the Master Linkage File (used to generate project linkage across multiple datasets);
- production of project specific linkage keys, required for each Statistical Linkage Project.
- the number of datasets and the anticipated cohort size;

QLD Data Sets

QLD Emergency Department Information System

Main Data Attributes

Level of information:	Recorded in terms of episodes rather than individual
Location breakdown:	Hospital postcode
Data available from:	1st July 2008. Data is collected in real time.
Jurisdiction available:	QLD
Jurisdiction differences:	QLD only data set
How data is collected:	Administration staff from Emergency departments at most public hospitals in QLD. Data is based on the non-admitted patient emergency department care NMDS
Brief summary of data:	The Queensland Emergency Department Information System (EDIS) is an administrative data collection that contains demographic, administrative and clinical data detailing presentations to Emergency Departments (ED) at most public hospitals in Queensland. The EDIS is based on the "Non-admitted Patient Emergency Department Care" National Minimum Data Set (NMDS). The EDIS is administered by the Queensland Department of Health. Information in the EDIS is required under the National Health Care and National Health Information Agreements (NHCA & NHIA). The scope of this data collection currently covers the Emergency Departments of most Qld public hospitals. The purpose of the collection is to enable comparisons of performance with respect to access to services, quality clinical outcomes and patient management. The collection aims to show patterns in presentations to assist in the planning of services and improvement of care and outcomes for the Queensland public
Variables of interest:	Information not available

Data access and linkage

Where data is held:	Department of health Queensland
Data custodian:	Executive Director Clinical Access and Redesign Unit Phone: 07 3131 6920
Who can get access:	Researchers with approval
Is linkage available?	Yes through Research Linkage Group Queensland department of Health. There is also a Master Linkage File containing permanently linked references to certain data sets including the Admitted Patients Data collection and Registrar General Deaths
How to get access:	Applications to access data are directed to Queensland Department of health and are as follow: - Researcher contacts data custodians to discuss data - Ethics approval is obtained from a Human Research Ethics Committee - Researchers submit a completed PHA application to Data Custodians - The custodians reviews the application and consults researcher if applicable before forwarding approval - Researcher forwards all relevant applications and approvals to QH office of Health and Medical Research (HMR) - HMR collaborate with researchers to prepare final application for approval from Director-General

- The Director General makes a decision on research application
- HMR informs researchers of Director General decision and associated conditions of approval
- Researchers provide copy of Director General approval to Research linkage group for data request to proceed.

Cost: Information not available

QLD Hospital Admitted Patient Data

Main Data Attributes

Level of information: Possibly recorded in hospital separations rather than individual

Location breakdown: Postcode

Data available from: 1st July 1995 for public and 1st July 2007 for private hospitals. Data is available approx. 3 months prior to current date however completeness of data may vary by facility

Jurisdiction available: QLD

How data is collected: Information is collected for all admitted patient separations from recognised public hospitals and licensed private hospitals and day surgery units. Data is collected on a monthly basis, and finalised on a financial year basis

Brief summary of data: QHAPDC contains data on all patients separated (an inclusive term meaning discharged, died, transferred or statistically separated) from any hospital permitted to admit patients, including public psychiatric hospitals. In Queensland, ICD-10-AM codes have been used to define principal and other diagnoses since 1 July 1999. Prior to this, diagnoses were coded using ICD-9-CM.

Variables of interest: Demographics such as gender, date of birth, marital status, occupation, Indigenous status

Hospital admission and separation date, hospital type (public vs private).

Principal and other diagnosis (using ICD codes) as well as any external cause of injury codes.

Data access and linkage

Where data is held: Department of Health Queensland

Data custodian: Statistical Output & Library Services Unit Phone: 07 3234 1875

Who can get access: Researchers with approval

Is linkage available? Yes through Research Linkage Group Queensland department of Health. There is also a Master Linkage File containing permanently linked references to certain data sets including the Admitted Patients Data collection and Registrar General Deaths

How to get access: Applications to access data are directed to Queensland Department of health and are as follow:

- Researcher contacts data custodians to discuss data
- Ethics approval is obtained from a Human Research Ethics Committee
- Researchers submit a completed PHA application to Data Custodians
- The custodians reviews the application and consults researcher if applicable before forwarding approval
- Researcher forwards all relevant applications and approvals to QH office of Health and Medical Research (HMR)
- HMR collaborate with researchers to prepare final application for approval from Director-General

- The Director General makes a decision on research application
- HMR informs researchers of Director General decision and associated conditions of approval
- Researcher provides copy of Director General approval to Research linkage group for data request to proceed.

Cost: Information not available

QLD Consumer Integrated Mental Health Application

Main Data Attributes

Level of information: Individual
Location breakdown: Postcode
Data available from: 2008
Jurisdiction available: QLD
Jurisdiction differences: QLD only data set
How data is collected: Information not available
Brief summary of data: Queensland Health set up CIMHA to be used as a single statewide database, allowing clinicians and researchers access to relevant mental health information from one system.
This system replaced, integrated and enhanced three large older and unintegrated mental health information systems used by mental health services across Queensland. Queensland health regularly publishes reports on mental health and can be found on the following webpage:
http://www.health.qld.gov.au/mentalhealth/pub/qld_pub.asp

Variables of interest: Demographics such as gender, date of birth, Indigenous status, country of birth, marital status, education and employment status
Primary diagnosis, diagnosis description (unclear how these are coded), episode start and end date, service type. Referral to and referral from information

Data access and linkage

Where data is held: Department of Health Queensland
Data custodian: Executive Director Phone: 07 3328 9509
Who can get access: Researchers with approval. Aggregate data is available on the Queensland Department of Health website
Is linkage available? Yes through Research Linkage Group Queensland department of Health. There is also a Master Linkage File containing permanently linked references to certain data sets including the Admitted Patients Data collection and Registrar General Deaths
How to get access: Applications to access data are directed to Queensland Department of health and are as follow:

- Researcher contacts data custodians to discuss data
- Ethics approval is obtained from a Human Research Ethics Committee
- Researchers submit a completed PHA application to Data Custodians
- The custodians reviews the application and consults researcher if applicable before forwarding approval
- Researcher forwards all relevant applications and approvals to QH office of Health and Medical Research (HMR)
- HMR collaborate with researchers to prepare final application for approval from Director-General

- The Director General makes a decision on research application
- HMR informs researchers of Director General decision and associated conditions of approval
- Researcher provides copy of Director General approval to Research linkage group for data request to proceed.

Cost: Information not available

QLD General Deaths Registry

Main Data Attributes

Level of information: Information not available
Location breakdown: Information not available
Data available from: 1st July 1996. Data is updated weekly
Jurisdiction available: QLD
How data is collected: Data is collected form the death registration application form which is provided by a funeral director and completed by spouse, partner or relative of deceased or supplied by the certified medical practitioner or result from coronial investigation
Brief summary of data: The Deaths Registry is administered under the Births, Deaths and Marriages Registration Act 2003 and the Births, Deaths and Marriages Registration Regulation
Variables of interest: Information not available

Data access and linkage

Where data is held: Queensland Department of Health
Data custodian: Information not available
Who can get access: Researchers with approval
Is linkage available? Yes through Research Linkage Group Queensland Department of Health. There is also a Master Linkage File containing permanently linked references to certain data sets including the Admitted Patients Data collection and Registrar General Deaths
How to get access: Applications to access data are directed to Queensland Department of Health and are as follow:

- Researcher contacts data custodians to discuss data
- Ethics approval is obtained from a Human Research Ethics Committee
- Researchers submit a completed PHA application to Data Custodians
- The custodians reviews the application and consults researcher if applicable before forwarding approval
- Researcher forwards all relevant applications and approvals to QH office of Health and Medical Research (HMR)
- HMR collaborate with researchers to prepare final application for approval from Director-General
- The Director General makes a decision on research application
- HMR informs researchers of Director General decision and associated conditions of approval
- Researcher provides copy of Director General approval to Research linkage group for data request to proceed.

Cost: Information not available