


# BMJ Open Premature mortality in early-intervention mental health services: a data linkage study protocol to examine mortality and morbidity outcomes in a cohort of help-seeking young people

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## ABSTRACT

**Introduction** Understanding the risk of premature death from suicide, accident and injury and other physical health conditions in people seeking healthcare for mental disorders is essential for delivering targeted clinical interventions and secondary prevention strategies. It is not clear whether morbidity and mortality outcomes in hospital-based adult cohorts are applicable to young people presenting to early-intervention services.

**Methods and analysis** The current data linkage project will establish the Brain and Mind Patient Research Register–Mortality and Morbidity (BPRR-M&M) database. The existing Brain and Mind Research Institute Patient Research Register (BPRR) is a cohort of 6743 young people who have accessed primary care-based early-intervention services; subsets of the BPRR contain rich longitudinal clinical, neurobiological, social and functional data. The BPRR will be linked with the routinely collected health data from emergency department (ED), hospital admission and mortality databases in New South Wales from January 2010 to November 2020. Mortality will be the primary outcome of interest, while hospital presentations will be a secondary outcome. The established BPRR-M&M database will be used to establish mortality rates and rates of ED presentations and hospital admissions. Survival analysis will determine how time to death or hospital presentation varies by identified social, demographic and clinical variables. Bayesian modelling will be used to identify predictors of these morbidity and mortality outcomes.

**Ethics and dissemination** The study has been reviewed and approved by the human research ethics committee of the Sydney Local Health District (2019/ETH00469). All data will be non-identifiable, and research findings will be disseminated through peer-reviewed journals and scientific conference presentations.

## BACKGROUND

Risk of premature death in adults accessing mental healthcare is greatly elevated relative to the general population. This increased mortality rate reflects increased rates of death

## Strengths and limitations of this study

- This study uses hospital presentations, not just premature mortality, to identify a broader range of adverse outcomes in young people accessing early-intervention services.
- A rich clinical database, tracking outcomes across a multidimensional framework, is available. This permits a more comprehensive understanding of predictors of adverse outcomes in this population.
- Such clinical data are likely to have greater validity than usual electronic health record data from hospital settings.
- The study contains longitudinal data with a duration of follow-up of up to 15 years, which will allow for a range of data-driven techniques to be used to model trajectories of illness.
- The study will be most relevant to young people accessing primary mental health and other early-intervention services, rather than population samples of young people.

from suicide, which is up to 66 times higher than the population, as well as death from all other causes, which is up to 20 times higher than the population.<sup>1 2</sup> In adult users of mental services, increased mortality rate from non-suicide causes is partially attributable to cardiometabolic disease, substance use, and accident and injury.<sup>3 4</sup> The reasons for this increased risk of non-suicide death are not clearly understood. However, a number of factors that are independently associated with suicidal behaviour, such as alcohol and substance use, poverty and social isolation, also contribute to increased mortality from other causes.<sup>5</sup>

Risk of death in young people accessing mental healthcare appears to follow a path



different from that of older populations. Although suicide is a leading cause of death in young people<sup>6</sup>, risk of death from suicide following a suicide attempt is approximately half that of adults (aged >40 years old) at 10 years.<sup>1 7</sup> Risk of death from accident and injury is also elevated,<sup>8</sup> yet it is not clear whether cohorts of young people engaged with mental health services are also at increased risk of death from other causes or whether this relationship only exists in older cohorts. Certain mediators of the relationship between suicidal behaviour and non-suicide-related premature death in adults, such as alcohol and substance use disorders, often present early in the life course,<sup>9</sup> whereas other possible mediators, such as cardiometabolic disease, may be associated with a delayed and prolonged risk of premature mortality. The causes of premature mortality in young people also differ by age category and gender. In Australia, leading causes of death in younger adolescents are motor vehicle accidents, followed by suicide and certain physical illnesses.<sup>10</sup> In older adolescents and young adults, the leading causes are suicide, then motor vehicle accidents, followed by accidental poisoning. Male gender is also associated with an increased likelihood of death from accidental causes and from assault. It is not clear whether these associations are also present in cohorts of young people accessing mental health services. However, certain neurocognitive features, such as impulsive decision-making or disinhibition, which are associated with self-harm and suicidal behaviour in young people,<sup>11</sup> may also act to increase death and morbidity outcomes from accidental causes or exposure to violence in this cohort.

The development of the early-intervention paradigm in mental health has evolved as a key approach to halting the progression of early stage, attenuated or non-specific symptoms of mental illness to full-threshold mental illness, with the associated mortality and morbidity outcomes. In Australia, the early-intervention model has led to the development of youth-specific primary mental healthcare services, known as 'headspace' services. The services delivered by these clinics across the country vary. While all provide assessment with a mental health clinician, as well as referral to general practitioners and clinical psychology services as required, some services also provide more specialised case management and psychiatric services. These clinics are typically accessed by young people with a range of mental health problems, including those with subthreshold and full-threshold mental disorders. Young people may self-refer or may be referred by family members, friends, school counselling services or via a general practitioner. The prevalence of suicidal and self-harm behaviour in young people accessing headspace services is up to 35%,<sup>12</sup> comparable to that of adult populations with full-threshold mental disorders.<sup>5</sup> Given the association between suicidal behaviour and premature death from all causes, this is of particular concern. While population studies of young people who self-harm have suggested the majority of self-harm behaviours resolve before adulthood,<sup>13</sup> it is likely that trajectories of suicidal

behaviour in clinical populations of young people diverge from those of other populations studied. Risk of premature mortality from non-suicide causes is also likely to be distinct from other populations.

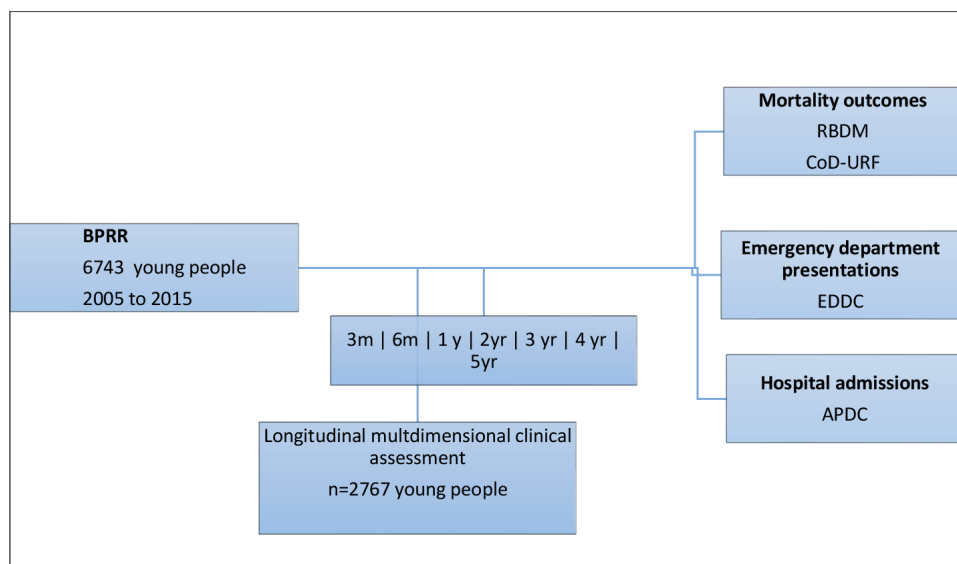
Developing predictive models of premature mortality, whether from suicide or all causes, has been limited by the relatively low base rates of the outcome of interest and thus low positive predictive value of the models.<sup>14</sup> Recent reviews have suggested prediction models may be of use in certain subpopulations where the base rate of suicide would be expected to be higher, or where secondary outcomes such as suicide attempts can be studied.<sup>15</sup> Advances in technology and data science have also increased the amount and nature of data available which has driven novel approaches to predictive modelling that may guide clinical interventions on a health system and services level.<sup>16 17</sup> As these approaches are developed, it is essential to understand whether knowledge of mortality and morbidity outcomes in hospital-based adult cohorts or broad population samples should be applied to young people engaged in primary mental healthcare services.

The proposed study will use data linkage to examine mortality and hospitalisation outcomes over a 10-year period in a cohort of 6743 young people aged 12–30 years old engaged in early-intervention mental healthcare services. A unique database (Brain and Mind Patient Research Register–Mortality and Morbidity (BPRR-M&M)) will be established by linking state-wide mortality and hospital registers to the Brain and Mind Research Institute Patient Research Register (BPRR), which contains rich longitudinal clinical, neurobiological, social and functional data (see figure 1).<sup>12 18</sup> The aims of the data linkage study were (1) to establish mortality rates from suicide and other causes in this new clinical cohort; (2) to establish rates of hospital presentations and admissions after engagement with early-intervention services; and (3) to identify predictors of these adverse outcomes, as well as trajectories of illness and service use.

## METHODS

### Data sources

The current study uses data from the BPRR, which was established by the University of Sydney (Ethics application 2012/1626) and links this database to three externally held databases held by the New South Wales (NSW) government and health services. The first external database to be linked, which contains mortality outcomes, is the NSW Registry of Births, Deaths and Marriages (RBDM) and the Australian Coordinating Registry (ACR) cause of death–unit record file (CoD-URF). The second two externally linked databases hold information on morbidity and hospital uses and include the NSW Emergency Department Data Collection (EDDC) and the NSW Admitted Patient Data Collection (APDC).



**Figure 1** The Brain and Mind Patient Research Register–Mortality and Morbidity database. APDC, Admitted Patient Data Collection; BPRR, Brain and Mind Research Institute Patient Research Register; CoD-URF, cause of death–unit record file; EDDC, Emergency Department Data Collection; RBDM, Registry of Births, Deaths and Marriages.

### Brain and mind research register database

The BPRR recruited 6743 young people aged 12–30 years old presenting to the Brain and Mind Centre’s youth mental health clinics in the Sydney suburbs of Camperdown and Campbelltown.

Inclusion criteria of the BPRR were (1) age between 12 and 30 years at first presentation and (2) attendance of at least one visit to the service. Exclusion criteria were (1) medical instability or lack of capacity to give informed consent (as determined by a psychiatrist); (2) history of neurological disease (eg, tumour, head trauma or epilepsy); (3) medical illness known to impact cognitive and brain functions (eg, cancer or electroconvulsive therapy in the last 3 months); (4) clinically evident intellectual disability; and/or (5) insufficient understanding of the English language to participate in the research protocol.

Variables held in the BPRR will be used as exposure variables (see [table 1](#)). Sociodemographic data were collected for all participants recruited to the BPRR and included age, sex, gender and whether the young person was in receipt of government benefits and/or engaged in education, employment or training on a part-time or full-time basis. Gender referred to whether the young person identified as male, female or transgender.

### Longitudinal clinical assessment

A subset of the larger BPRR cohort (n=2767) was tracked longitudinally as they accessed care in the service. Participants were included in this subset if they had at least 1 month of follow-up care with the service, that is, at least two appointments, one or more of which occurred 1 month later than their initial assessment. Follow-up clinical data were collected by a trained research assistant using a standardised proforma at the following time points: 3, 6 and 12 months and 2, 3, 4 and 5 years. If the

follow-up assessment did not take place within  $\pm 1$  month of the time points of 3 and 6 months, or  $\pm 3$  months of the yearly time points, then data were coded as missing. A ‘time last seen’ entry was used to capture final clinical information that did not align with one of the specified follow-up time points. Key clinical information about the current episode and specific illness course characteristics were collected from clinician assessment and validated rating scales. Information on engagement in education and employment as well as functioning, measured using the clinician-rated Social Occupational Functional Assessment Scale, was also collected across time points.<sup>19</sup> The characteristics of the cohort and numbers of patients with assessments at each time point have been previously described.<sup>12 18 20</sup>

Clinical variables measured included (1) mental health diagnoses (based on *Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition criteria); (2) clinical course information (hospitalisations and childhood diagnoses); (3) comorbidities (physical health diagnoses, such as autoimmune, endocrine and metabolic diagnoses); and (4) suicidal ideation and behaviours. In addition, further clinical symptoms were assessed in subsets of the wider cohort by using validated measures of common mental disorders such as depression (Hamilton Depression Rating Scale), bipolar disorder (Young Mania Rating Scale), psychosis (Brief Psychiatric Rating Scale) and substance use (WHO-ASSIST).

### Clinical assessment of suicidal ideation and behaviour

As part of standard clinical practice, the treating clinician conducted a risk assessment at baseline assessment and at each visit.<sup>21 22</sup> The risk assessment includes screening for lifetime history of suicidal ideation, suicide attempts and deliberate self-harm at the individual’s first visit and at subsequent visits, assessing whether these symptoms or

**Table 1** Multidimensional exposures of interest held in the Brain and Mind Research Institute Patient Research Register database

Brain and Mind Patient Research Register database	
Social and demographic features	
Year of birth (age)	
Gender	
Education and employment status	
Educational level attained	
Receipt of government benefits	
Social and occupational functioning (SOFAS)	
Clinical features	
Baseline	Depressive symptoms (17-Item Hamilton Depression Rating Scale)
	Psychotic symptoms (Brief Psychiatric Rating Scale)
	Mania symptoms (Young Mania Rating Scale)
	Substance use (World Health Organisation-Alcohol, Smoking and Substance Involvement Screening Test)
Longitudinally	Diagnosis ( <i>Diagnostic and Statistical Manual of Mental Disorders</i> , 5th Edition) <ul style="list-style-type: none"> <li>▶ Subthreshold or full threshold.</li> <li>▶ Primary, secondary and tertiary.</li> </ul>
	Clinical stage
	Previous hospitalisations
	Childhood onset mental illness
Suicide and self-harm	Suicidal ideation
	Suicidal plans
	Suicide attempts
	Deliberate self-harm
Physical health	Physical health diagnosis
	Body mass index

SOFAS, Social Occupational Functional Assessment Scale.

behaviours have been present between visits. Responses are recorded by clinicians in the clinical notes. Rather than use a standardised scale, clinicians may ask these questions in a way that allows them to be integrated into clinical assessment.

### Neurobiological assessment

A subset of the larger BPRR cohort also completed neurocognitive (n=1311) and neuroimaging (n=842)

**Table 2** Brain and Mind Research Institute Patient Research Register neurobiological assessment battery

Neurocognitive variables	
Premorbid IQ	Wechsler Test of Adult Reading
Premorbid IQ (If <16 years old)	Wide Range Achievement Test
Processing speed	Trail Making Test—part A
Cognitive flexibility	Trail Making Test—part B
Verbal learning	RAVLT
Verbal memory	RAVLT
Verbal fluency	Controlled Oral Word Association Test
Sustained attention	RVP task (RVP A)
Working memory	Spatial Span task
Visuospatial learning	PAL task (PAL errors)
Set shifting	IED task (IED errors)
MRI	Volumetric and diffusion tensor imaging data

IED, Intra-Extra Dimensional; MRI, Magnetic resonance imaging; PAL, Paired Associate Learning; RAVLT, Rey Auditory Verbal Learning Test; RVP, Rapid Visual Processing.

assessments (see [figure 1](#)) as part of a neurobiological study.<sup>20–23</sup> Participants were consecutively recruited from the youth clinics for those studies. Neurocognitive assessments were conducted by a research neuropsychologist, research psychologist or supervised doctoral student. The neurocognitive battery used included domains chosen based on relevance to common presenting syndromes in an early-intervention youth mental health service, particularly affective and psychotic disorders (see [table 2](#)). Measures were chosen based on sound validity and reliability, as well as overlap with the Measurement and Treatment Research to Improve Cognition in Schizophrenia initiative.<sup>24–26</sup> Premorbid intelligence (IQ) was estimated on the basis of performance on the Wechsler Test of Adult Reading<sup>27</sup> or the Wide Range Achievement Test (for participants younger than 16).<sup>28</sup> Other measures included the Trail Making Test (TMT)—part A, which measured *processing speed*, and TMT—part B,<sup>26</sup> which measured *cognitive flexibility*; the Rey Auditory Verbal Learning Test (RAVLT),<sup>26</sup> which measured *immediate memory* (sum of trials 1–5, RAVLT sum) and *delayed memory* (20 min delayed recall, RAVLT), respectively. The Controlled Oral Word Association Test was used to measure *verbal fluency*.<sup>26</sup> Participants also completed a number of subtests from the Cambridge Neuropsychological Test Automated Battery,<sup>29</sup> including Rapid Visual Processing (RVP) task (RVP A), which measured *sustained attention*; the Spatial Spantask (maximum span length), a measure of *working memory*; the Paired Associate Learning (PAL) task (PAL errors), a measure of *visuospatial learning*



and memory; and the Intra-Extra Dimensional (IED) task (IED errors), a measure of *set shifting*.

Neuroimaging was conducted using a 3-Tesla GE scanner at Southern Radiology MRI Diagnostic Services within the Brain and Mind Centre, Camperdown, NSW Australia. The images were acquired using a customised MP-RAGE 3D T1-weighted sequence to resolve anatomy at high resolution (0.9mm isotropic resolution), repetition time (TR)=7264ms; echo time (TE)=2784ms, pulse angle=15°, coronal orientation, Field-of-view (FOV)=230mm<sup>3</sup> and matrix of 256×256×196 mm. Volumetric segmentation was performed with the Free-Surfer application V.5.1 (<http://surfer.nmr.mgh.harvard.edu/>). It was also possible to create diffusion tensor imaging from the above MRI scans, which allows for analysis of white matter integrity.<sup>30</sup>

### Externally held databases for linkage

#### Mortality data

Mortality data will be extracted from the NSW RBDM and ACR CoD-URF. Primary outcome measures will include deaths from suicide, accident and injury, and physical health-related and other causes. Date of death will be extracted from the NSW RBDM. The current study's focus was to establish rates of death in this cohort and, as a secondary aim, to explore causes of death and contributing causes. Underlying cause of death and contributing causes of death will be extracted from the CoD-URF (see [table 3](#)).

Although cause of death data may not always be able to capture the complexity of contributing factors, the majority of deaths in this BPRR cohort are likely to be classified as unexpected deaths, given the young age of the cohort. Unexpected deaths, as in the case of suspected suicides, accidents or from unexpected medical or unknown causes, are required to be reported to the coroner. Investigations by the coroner may also draw on police investigation, autopsy, toxicology data or interviews with family or friends, which results in a greater reliability than certification by a medical doctor alone. Once the coroner certifies the death, information is provided to NSW RBDM, and subsequently the Australian Bureau of Statistics and CoD-URF.

The NSW RBDM and COD-URF databases contain records of all deaths in NSW, including urban, regional and remote areas. It is expected that the majority of deaths in the proposed linked database, the BPRR-M&M, will occur in the urban or major regional centres close to the Sydney metropolitan area, as this is the location of the Brain and Mind Centre clinics. However, any deaths occurring in smaller regional or remote towns in NSW will also be captured.

#### Hospital presentation and admission data

The NSW EDDC will provide information about emergency department (ED) presentations to public hospitals. The EDDC covers 184 EDs, including all those in public hospitals in the Sydney greater metropolitan area, and

**Table 3** Outcomes from mortality and hospital databases

Mortality databases	
RBDM	Date of death
CoD	Underlying CoD diagnosis code
	ICD version
	Contributing causes of death
Hospital data collections	
Emergency department data collection	Admitted patient data collection
Principal ED diagnosis	Hospital type (public/private)
Referral source	Acute hospital flag
Arrival date	Days in psychiatric unit
Arrival time	Diagnosis codes
Actual departure date	ED status
Actual departure time	Episode end date
Mode of arrival	Episode length of stay
Mode of separation	Episode start date
Triage category	Facility transferred from
	Facility transferred to
	Hours in intensive care unit
	Involuntary days in psychiatric unit
	Major diagnostic category
	Mode of separation
	Recognised public hospital flag

CoD, cause of death; ED, emergency department; ICD, International Statistical Classification of Diseases and Related Problems; RBDM, Registry of Births, Deaths and Marriages.

captures a substantial proportion of all presentations in NSW. The proportion of all NSW ED presentations covered by the EDDC is variable, however, and must be calculated per year. In NSW, over 65% of the population lives in the Sydney greater metropolitan area, and approximately 30% of the remaining population lives in other cities or regional centres where hospitals are very likely to contribute data to the EDDC. Less than 6% of the NSW population lives in rural or remote NSW.<sup>31</sup>

ED outcomes collected will include principal diagnosis, triage category, arrival date and time, departure date and time, mode of arrival and mode of separation (see [table 3](#)). Diagnosis codes in the EDDC may use Australian modification of the International Statistical Classification of Diseases and Related Problems, 10th Revision (ICD-10-AM) as well as the ICD-9-CM and Systematised Nomenclature of Medicine–Clinical Terms codes.<sup>32</sup> Clinical coding in ED is done by the clinical staff, who have a varying degree of training in use of clinical coding systems. Symptoms are often selected as diagnoses codes, which limit the reliability of diagnostic data in the EDDC. This is of limited consequence to the aims of the current study as psychiatric diagnoses only occur formally by

specialised services, over a number of visits. The current study aimed to capture broad categories of presentations related to outcomes of interest. These diagnostic codes will be grouped into a number of outcome measures by the research team following data linkage, including (1) suicide and self-harm, (2) alcohol and substance use related, (3) accident and injury, (4) physical illness related and (5) other. Two members of the research team will independently code information contained in the 'principal ED diagnosis', 'diagnosis code' and 'major diagnostic criteria' (see [table 3](#)), with any discrepancies resolved by a third team member.

The NSW APDC will be used to identify hospital admissions. Over 400 facilities across NSW contribute to the APDC, which records information on all patients admitted to NSW public and private hospitals, including psychiatric hospitals. The APDC uses ICD-10-AM to classify information on diagnosis. Outcome measures extracted from the APDC will include type of hospital, acute hospital flag, recognised public hospital flag, number of days in a psychiatric unit, number of involuntary days in a psychiatric unit, whether the patient was admitted via the ED, length of stay, hours of intensive care unit admission, major diagnostic category and mode of separation. Data extracted from these databases are summarised in [table 3](#).

### Data linkage

Data linkage will be conducted by the Centre for Health Record Linkage (CHeReL) in NSW.<sup>33</sup> The data custodians for each database release the database to CHeReL, which then carries out the data linkage. The linked data will include all records available from January 2010 to April 2020 for each dataset. To ensure the separation principle is maintained, CHeReL will receive a deidentified BPRR database and a separately held participant identification (ID) list. The BPRR database will be transferred securely to CHeReL for linkage, and only the prespecified variables (see [tables 1 and 2](#)) will be included. CHeReL then conducts the data linkage to link using personal identifiers (including full name, date of birth and sex) from records in these datasets. CHeReL uses the Choicemaker software, which provides for standardisation and parsing.<sup>34</sup> The software differs from classical probabilistic approaches to linking by using automated block algorithm and machine learning techniques for assigning weights.

After data linkage, CHeReL will remove all identifying variables, replace the previous participant IDs with new participant IDs and return the new deidentified database to the research team. At this point, it is not possible for the researcher to ascertain the individual's identity as the participant IDs in the new database are different from the original participant IDs in the BPRR database and the separately held participant ID list. The research team will not receive any list linking the two different participant IDs. In addition, researchers involved in the analysis of the new BPRR-CHeReL database will have no access to the participant ID list.

### Patient and public involvement

Consumers and carers were not directly involved in the study design. The clinical research team conducting this study is embedded within the clinical service, and this will facilitate dissemination of results to patients, carers and members of the public.

### ANALYSIS PLAN

The standardised mortality rate will be calculated using the person-time method, which is the number of deaths divided by the person-years of follow-up. Standardised mortality ratio will be calculated using the indirect methods of standardisation by age and sex groups. The group used to determine the expected number of deaths (the denominator) will be the general population of NSW in the final year of the study, available online from the Australian Bureau of Statistics.<sup>31</sup> Expected mortality rates for a cohort of people under the age of 15–30 years old would be 0.4 per 1000 (ABS 2017).<sup>6</sup> Survival analysis will be conducted to examine the relationship between the specified exposure variables and mortality outcomes. A Cox proportional hazards regression model will be used. Mortality outcomes will be analysed according to cause of death, including suicide, accident or injury, or other causes. In order to meet ethical requirements and protect privacy, outcomes where cell counts are less than five are not to be presented in publication, which may limit more detailed presentation of causes of death. Given that mortality is still likely to be a rare outcome, stratification by exposure variable may only be possible for variables such as age and gender. For the subset of the cohort who have longitudinal clinical data available (see [figure 1](#)), other exposures of interest include clinical factors, such as the presence of suicidal ideation or behaviour during care, diagnosis (or subthreshold diagnosis) of major mental disorder or substance use and neurocognitive profiles. Furthermore, missingness in datapoints prior to patients' last follow-up will be accounted for by multiple imputation to ascertain the uncertainty surrounding the modelling and will be compared with a complete case analysis to assess sensitivity. The relationship between social, clinical and neurocognitive exposures and the secondary outcomes of ED presentations and hospital admissions will be analysed using a range of statistical techniques including mixed-effects/multilevel modelling, Bayesian modelling and data-driven techniques such as hierarchical cluster analysis.

### Statistical power

The sample size of the whole cohort is 6743 young people. Based on previous studies, we anticipate 2450 individuals have had an episode of suicidal behaviour.<sup>12 35</sup> Based on median estimate of mortality rate of 2.4% at 10 years,<sup>1</sup> we anticipate 59 participants (of those who engaged in self-harm or suicidal behaviour) may now be deceased. It is difficult to estimate what percentage of the remaining cohort (4550 individuals) may be expected to be now deceased, given there are a range of risk factors that will elevate their risk above population level for this age

group. Thus, our estimate of 59 deceased participants is likely conservative.

Survival analysis will be used to calculate time to event (TTE) (either mortality from suicide or other cause). We aim to understand whether a number of commonly identified risk factors for completed suicide are significantly associated with TTE. The primary exposures of interest in the survival analysis are a number of social and clinical factors, such as gender, previous suicidal behaviour, clinical stage  $\geq 1B$ , diagnosis of major mental disorder, or alcohol or substance misuse. The number of events needed to detect a significant effect and reject the null hypothesis was calculated using Survival Package in R.<sup>36</sup> Alpha will be set to 0.05, with two-sided tests and power of 0.8. Based on the proportion of cohort with exposures of interest, we expect the number of events needed to detect an effect of these exposures as ranging from 21 (gender) to 51 (suicide attempt).

### Ethics and dissemination

Ethical approval has been obtained from the NSW Population and Health Services Research Ethics Committee (PHSREC) (2019/ETH12201). Individuals included in the current study consented to participate in the BPRR (Ethics application 2012/1626). As part of this consent, participants agreed that members of the research team access the participants medical records for clinical research for a period of 5 years. In the original consent and ethics application, it was stipulated that additional individual consent would be necessary if the participant was required to return to the clinic for additional assessments of data collection. The current study does not require any additional assessments to be conducted. No further contact with the participant is required. A waiver of consent for the current study was sought and subsequently granted by the PHSREC, on the grounds that criteria for a waiver of consent outlined in the National Statement on Ethical Conduct in Human Research (2007) were met. These criteria were (1) that the purposes of the study could not be met without temporary re-ID; (2) contacting participants for re-consent was not practicable, given the large number of participants and that the key outcome of interest was death; and (3) that there was no reason to believe participants would not have consented to the use of their routinely collected data for this study, given they had previously consented to more sensitive information being accessed, such as their individual medical record. Results of this study will be disseminated via peer-reviewed journals and at academic meetings, as well as via platforms that have wider engagement with the public, such as social media, where possible.

### IMPLICATIONS AND SIGNIFICANCE

The knowledge generated from this project will be vital for developing policy and clinical interventions in young people accessing mental healthcare. Improving understanding of risk factors for premature death and hospitalisation outcomes in this cohort is essential in designing further interventions

to prevent progression of mental illness and associated adverse outcomes in young people. While clinical services for psychosis set a precedent for the early-intervention framework, less is known about the impact of primary care-based early intervention in young people seeking care who are experiencing a broader range of mental health symptoms. Critics of early intervention have questioned the utility and cost-effectiveness of such an approach, yet there have been dramatic increases in presentations of young people with suicidality to EDs in recent years, highlighting the ongoing gap in mental health services.<sup>37</sup> Improving the knowledge of pathways to such presentations and thus better targeting clinical interventions outside of EDs is necessary to deliver high-quality care as well as reduce the burden of mental health presentations on these services.

The outcomes of this study will meaningfully add to the evidence base used to design secondary prevention strategies, particularly those targeting suicidal behaviour and physical health issues in mental health services. In recent years, there has been a growing evidence base of suicide prevention interventions, including trials of specific interventions or combinations of interventions, which have identified a range of effective clinical and population-level interventions, such as safety planning, means restriction or follow-up care.<sup>14,38</sup> In recent years, many of these interventions have been incorporated into clinical services as standard practice. Understanding how young people accessing mental healthcare may be different from adults accessing care, or population samples of young people, is important in order to understand the impact these interventions are likely to have.

The delivery of mental healthcare has also been evolving with new technologies. Online platforms, for example, may be used to triage presentations before assessment with a clinician<sup>39</sup> or to deliver common psychotherapy interventions, such as cognitive-behavioural therapy.<sup>40</sup> This transition in service delivery presents an opportunity to improve quality care and equity of access.<sup>41</sup> Understanding outcomes of existing service models via data linkage to hospital and mortality databases is essential if the potential of technology in delivering services is to be realised. The BPRR-M&M protocol presents a unique opportunity to understand key factors that predict adverse outcomes in this well-characterised cohort. For example, do young people who have been assessed by primary mental health services disengage before death or hospital presentations for suicide attempts? Are the symptom clusters associated with suicide or repeat suicide attempts in older adults the same in young people? Identifying differences will be vital to tailoring service delivery using technology to young people. The current data-linkage project will provide a framework for prospective data-linkage projects that will link data collected by novel technology-based clinical interventions that are capable of collecting patient self-report data in the community as well as in clinical systems used by professionals. Outcomes from this study may be useful in assessing the efficacy of interventions currently being implemented. These efforts will be foundational for dramatically improving the multifactorial outcomes of young people with emerging mental disorders.



## Limitations

The BPRR database was established in urban Sydney and captures presentations to two youth mental health clinics in different parts of the metropolitan area. As a result, young people living in regional or remote NSW are not likely to be captured by this study. Other groups at higher risk of premature mortality and suicidal behaviour, such as Aboriginal and Torres Strait Islander young people, may not be represented in this BPRR cohort.

Another key limitation relates to the type of data collected. The data sources used to build the BPRR-M&M are all clinical databases built with data collected from health services. Rather than measuring standardised, validated measures of exposures and outcomes, the database uses ‘real-world’ measures, and this must be discussed and considered in the publication of our findings. The subset of participants for whom more detailed clinical data are available is smaller, and thus, the study may be underpowered to detect more specific associations with our primary and secondary outcomes.

**Contributors** CM contributed to protocol design and drafting and editing of the manuscript. YJCS contributed protocol design and revisions of the manuscript. JC, FI and NH contributed to the study design, particularly analysis plan, as well as revisions of the manuscript. AN, CW and NZ contributed manuscript preparation and writing. AS provided peer review of study design as well as protocol manuscript review. EMS and IBH provided supervision and contributed to the study design, as well as manuscript preparation and revisions.

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**Competing interests** CM, YJCS, FI, JC, AN, NZ, CW, AS and NH, report no conflicts of interest. EMS is the clinical director of the St Vincent’s Youth Mental health program. She has received honoraria for educational seminars related to the clinical management of depressive disorders supported by Servier and Eli-Lilly pharmaceuticals. She has participated in a national advisory board for the antidepressant compound Pristiq, manufactured by Pfizer. She was the national coordinator of an antidepressant trial sponsored by Servier. IBH was an inaugural commissioner on Australia’s National Mental Health Commission (2012–2018). He is the codirector of Health and Policy at the Brain and Mind Centre (BMC), University of Sydney. The BMC operates an early-intervention youth services at Camperdown under contract to headspace. IBH has previously led community-based and pharmaceutical industry-supported (Wyeth, Eli Lilly, Servier, Pfizer and AstraZeneca) projects focused on the identification and better management of anxiety and depression. He was a member of the Medical Advisory Panel for Medibank Private until October 2017, a board member of Psychosis Australia Trust and a member of Veterans Mental Health Clinical Reference group. He is the chief scientific advisor to, and an equity shareholder in, Innowell. Innowell has been formed by the University of Sydney and PwC to deliver the \$30m Australian government-funded ‘Project Synergy’. Project Synergy is a 3-year program for the transformation of mental health services through the use of innovative technologies.

**Patient and public involvement** Patients and/or the public were involved in the design, conduct, reporting or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Not applicable.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data will be available upon reasonable request.

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