Aotearoa Self-harm Hospital Study:

Multi-site sentinel surveillance of self-harm in New Zealand

A. Project summary

New Zealand has a persistently high rate of suicide and one of the highest rates of youth suicide in the world. In addition, around 10 children (10-14 years) die by suicide in New Zealand each year, with Māori females particularly vulnerable[1,2]. Despite high public interest little progress has been made in reducing suicide[3], partly due to lack of good quality data to inform interventions. Evidence suggests that those who attend hospital following an act of self-harm (SH) are fifty times more likely to die by suicide, so are an important way to inform suicide prevention activities[4]. Hospital presentation for SH is one of strongest predictors of death by suicide, so a comprehensive understanding of this high-risk population is essential for suicide prevention[5]. Self-harm is defined as any form of intentional self-poisoning or self-injury regardless of motivation or the degree of intention to die[6]. Current data reporting practices in NZ undercount hospital presentations of SH by 50 – 60%[7].

This study, will establish surveillance systems of hospital presenting self-harm cases or cases of suicidal ideation at four large hospitals, Dunedin (for cases of all ages) and Middlemore, Christchurch and Southland (for cases under 15 years) in addition to a monthly national survey of paediatricians (through the NZ Paediatric Surveillance Unit) about presentations for SH. This study will adopt the WHO practice guidelines for sentinel surveillance of suicide attempts and SH[8]. All consecutive cases of intentional SH or suicidal ideation in those under 15 years, presenting to Middlemore, Christchurch and Southland hospitals and patients of all ages presenting to Dunedin Hospital, will be identified by study staff by checking both electronic and manual records against WHO definitions of "caseness". The study will provide robust information about the rates of SH, risk factors associated with SH and the types of services or interventions that those presenting to hospital with self-harm receive and are likely to need, identifying methods of SH amenable to means restriction and check for the emergence of novel methods of SH.

B. Rationale

NZ has one of the highest rates of suicide in the developed world, particularly among the young[1,2]. Premature deaths by suicide are particularly tragic for two reasons; first they occur early in the life course, resulting in significant DALYs[9] and economic costs of around $2.2 billion[10]. Secondly,

suicide is preventable. Despite increasing public interest in prevention, almost no progress has been made in reducing the persistently high suicide rate in NZ[3].

Evidence suggests that those who attend hospital following an act of self-harm (SH) are fifty times more likely to die by suicide compared with the general population. One in four will re- present with a further episode within six months[4]. Hospital presentation for SH is the strongest predictor of suicide, so a comprehensive understanding of this high-risk population, and their treatment needs is essential for suicide prevention[5].

Current data reporting practices undercount SH presentations in New Zealand by 50 – 60%[7]. The Ministry of Health have previously reported on hospital presentations for SH[11] derived from the National Minimum Data Set. These data suggested rising rates of SH[11], however, they are misleading due to incomplete recognition of cases and definitions[12]. For example, patients in hospital for < three hours[11] are excluded; but are at high risk of death by suicide particularly those who harm themselves repeatedly, and young men who are intoxicated[13,14]. Children and adolescents who self-harm are at high risk of suicide but due to the relatively low base-rate of this phenomena little is known about their treatment needs[15].

This project will establish sentinel surveillance sites for self-harm, an important approach to suicide prevention, as it provides robust information about the rates of SH, risk factors associated with SH and the types of services or interventions that those presenting to hospital with self-harm or suicidal ideation are likely to need. The WHO have published guidelines on best practice for sentinel surveillance of SH [8] which will form the basis of the methodology of this study. The study methods are comparable with those used by Australasian colleagues and in established SH surveillance programs in the UK and Ireland. This will allow robust trans- Tasman and international comparisons.

Several small, short term studies of Emergency Department (ED) presentations of SH have demonstrated that surveillance can be achieved[16,7,17,18]. However, these studies are relatively old, focused on a single hospital, specific sub-group of patients or single method of presentation. Therefore, this study will establish surveillance systems of hospital presenting cases of SH or suicidal ideation at Middlemore, Dunedin, Christchurch and Southland Hospitals. Such systems allow evaluation of suicide prevention initiatives; in the UK similar data were used to identify the role of paracetamol and co-proxamol in overdose fatalities. Researchers campaigned for regulatory changes and 500 suicides were prevented 2005-2010[19]. Surveillance data will also evidence to inform resource allocation and early detection of emerging methods of SH[8]. For example, a novel method suicide attempt using helium balloons was noticed via similar systems overseas and led to the

introduction of retail controls on helium, thereby preventing deaths.

Currently, the lack of surveillance data has made it difficult to establish whether or not multi- level suicide prevention interventions shown to be effective overseas (anti-stigma, depression treatment, gatekeeper training), can actually work in NZ[20]. Thus, d**eveloping a "real time" warning system for unexpected increases in self-harm** presentations is a new and innovative area of work which would allow hospitals to identify local spikes in presentations and rapidly respond with appropriate services[21].

Suicide rates in NZ have remained stubbornly high in part because prevention activities have been developed in a low data environment. This study will provide robust and detailed epidemiological data on who self-harms and which interventions are most likely to reduce suicide deaths both for children and adults throughout NZ.

C. Aims and objectives

The primary objectives of this study are:

1. To establish multi-centre sentinel surveillance of SH patients at four large public hospitals, Middlemore, Christchurch and Southland Hospitals (for under 15 years) and Dunedin Hospital (for all age groups), as per the recommended WHO practice guidelines on sentinel surveillance for self-harm
2. To establish and test robust data collection methods as per the recommended WHO practice guidelines on sentinel surveillance for self-harm
3. Identify the epidemiology of current presentations for SH or suicidal ideation in terms of age, gender, ethnicity, methods of SH, alcohol misuse, prior history of SH, intention to die, exposure to suicide, mental health assessments and discharge outcome
4. Identify patterns of repetition of non-fatal SH
5. Undertake surveillance of self-harm among children and adolescents under 15 years of age via the NZ Paediatric Surveillance Unit (NZPSU)

The secondary objectives of this study are:

1. To identify potential gaps in self-harm services

2. To identify systemic levers for suicide prevention
3. To identify predictors of repetition of self-harm
4. To identify patterns of repetition of non-fatal SH

D. Study methodology

Study Design: This cross-sectional observational study will adopt the WHO practice guidelines for sentinel surveillance of suicide attempts and SH[8]. The sentinel surveillance sites will be set up at the emergency departments of Middlemore, Dunedin, Christchurch and Southland Hospitals. Middlemore, is one of the largest public hospitals in New Zealand and has been selected to ensure good geographical spread and serves a large, young, and ethnically diverse population which suffer undue burden of suicide deaths[2]. The hospital receives 110,000 ED presentations per annum, of which 4,000 are SH and around 800 episodes in paediatric population. Similarly, Dunedin Hospital is one of the largest public health hospitals in South Island serving a population of 289,000 with 36,000 ED presentations and 1,800 SH episodes per annum. Christchurch hospital has 100,000 ED presentations, and Southland around 30,000 presentations per annum. Thus, the four study sites will represent diverse sociodemographic communities in New Zealand.

The study will also use the current New Zealand Paediatric Surveillance Unit to receive surveillance data for pediatric population groups via registered Pediatricians on a monthly basis. This approach will allow national coverage and a good sampling of smaller and regional hospitals where younger patients tend to be admitted to paediatric units due to difficulty in accessing mental health services.

Sampling: All consecutive cases of intentional SH or suicidal ideation in those under 15 years, presenting to Middlemore, Christchurch and Southland hospital ED's and all consecutive cases of intentional SH or suicidal ideation presenting to Dunedin Hospital ED during the study period will be identified by checking both electronic and manual records against the definition of case-ascertainment as defined by the study protocol.

The study will gather data that is documented as a part of the routine clinical assessment and will include the following - day and time of SH, age, gender, ethnicity, method/s of SH including medicines used in overdose, alcohol/substance misuse, prior history of SH, intention to die, exposure to self-harm/suicide, exposure to adverse child events, chronic illness, mental health assessments and discharge outcomes.

Eligible participants: The study population includes people who present with self-harm or suicidal

ideation, where **self-harm** is defined as intentional self-injury or self-poisoning, irrespective of type of motivation or degree of suicidal intent. **Self-poisoning** is defined as the intentional ingestion of more than the prescribed or recommended dose of any drug (e.g. analgesics, antidepressants), and includes poisoning with non-ingestible substances (e.g. household bleach), overdoses of 'recreational drugs', and severe alcohol intoxication where clinical staff consider such cases to be acts of self-harm. **Self-injury** is defined as any injury that has been deliberately self-inflicted (e.g. self-cutting, jumping from a height, hanging, burns, gunshot, strangulation).

Inclusion criteria:

- Self-injury or self-poisoning must be intentional and not accidental
- Individuals who make a suicide plan or have suicidal thoughts but have not acted on these thoughts or plans
- All individuals under 15 years of age presenting SH at emergency department of Middlemore, Christchurch and Southland Hospital's or presenting to paediatricians registered with New Zealand Paediatric Surveillance Unit would be eligible. There are no age-specific criteria for those presenting with SH at emergency department of Dunedin Hospital.

Exclusion criteria:

- Accidental overdose of alcohol in an individual who drinks alcohol to excess requiring hospital treatment, but without any intention to self-harm, and who does not combine alcohol with other methods of self-harm.
- Accidental overdose of illicit drugs in an individual who takes illicit drugs on a regular basis but without any intention to self-harm.
- Accidental overdose of prescription or over-the-counter medications by incorrectly following a prescribed dosage, or addition

E. Study outcomes:

The primary outcomes of the study are listed as below:

1. Outcome related to hospital presentations:

- Annual number of acts of hospital-presenting self-harm
- Trends in frequently used methods of self-harm
- "New" or emerging methods of self-harm
- Frequently used drugs in overdose related SH
- Variations (seasonal/demographic/temporal) in self-harm presentations
- Variations (seasonal/demographic/temporal) in suicidal ideation presentations
- Trends in referrals to specialist services
- Average time taken between time of self-harm and time of ED presentation

2. Incidence rates:

- Annual rates of self-harm per 100,000 population
- Annual rates of self-harm in paediatric population (<15 years)
- Annual rates of self-harm in young people (15-24 years)
- Annual rates of self-harm in adult population (25+ years)
- Annual rates of suicidal ideation
- Variation by gender, age and ethnicity
- Variation by geographical region

3. The secondary outcomes of the study will be:

- Potential gaps in self-harm services
- Systemic levers for suicide prevention
- Predictors of repetition of self-harm

F. Study procedures

Using the inclusion and exclusion criteria, eligible participants will be identified through the routine clinical assessment of patients who present with symptoms of self-harm or suicidal ideation in the emergency department of the four hospitals or the paediatric outpatient clinics in regional hospitals of New Zealand.

All patients who arrive at the emergency department undergo a routine clinical assessment by the ED staff; if the assessment outcome is self-harm or suicidal ideation (using the inclusion and exclusion criteria defined above), then the following information will be extracted from the routine patient records - day and time of presentation, age, gender, ethnicity, method/s of SH including medicines used in overdose, alcohol misuse, prior history of SH, intention to die, exposure to self-harm/suicide, exposure to adverse child events, chronic physical conditions, mental health assessments and discharge outcomes. Since the data collected for this study is a part of the routine clinical assessment and participants do not have to undergo any additional procedure, participant consent is not required. However, information about the ongoing surveillance will be available in the hospital via leaflets/flyers.

As this is a cross-sectional observational study, no follow-up assessments will be conducted. The study PI, in consultation with the hospital management will conduct a standardised training session to orientate the clinical ED staff to the study. For the paediatricians registered with the NZPSU, a short online video about significance of self-harm surveillance will be shared with them when they are notified of this new condition which is being added to the national paediatric surveillance system which has been running for many years as required by the WHO[22].

G. Data – collection, entry and analysis

Data entry: At the four hospital sites, the study team will review the patient's paper and electronic record to extract data using a standardised data extraction tool.

For data collection via NZPSU, the NZPSU team will notify the study team regularly on the reported cases of paediatric self-harm as notified by Registered Paediatricians. The study team will then share the link to the data collection tool (built in REDCap - a secure web application for managing online surveys) with the respective paediatricians to complete the surveillance- related information retrospectively.

A unique participant code will be allocated by the study team to each participant. Once cases have been selected, all identifying name, home address and date of birth variables will be stored separately and de-identified data will be used for aggregated statistical analysis and publication. During the project, the de-identified analysis dataset will be stored on the research team's password protected computers in locked offices. Only the core study team will have access to the complete database in REDCap.

Data cleaning: Data cleaning will be done at the time of data entry in REDCap at each study site by the study research staff. Any missing values or variables will be checked against records to ensure that all possible information is included. This may require the study team to revisit some case files to collect any missing information. A preliminary statistical analysis will be conducted after every 100 cases (for the initial period of 6 months) to ensure that necessary data has been captured correctly.

Data audit: At each hospital site and cases received through NZPSU, information for 10% participants registered every month will be cross-checked with the preliminary clinical assessment form to see if it matches the case-ascertainment definition. Cases will be selected using the random number generator in Stata. Any discrepancies in case ascertainment will be documented and reported to the study PI for resolution.

Data quality & reliability: Regular quality-control meetings and processes will ensure the production of high-quality reliable data and allow for concordant decision-making and coding across the dataset. Both inter- and intra-rater agreement for coding will be assessed. A random sample of 20 files that have been identified will be independently reviewed for determination of self-harm relatedness by two independent reviewers at the beginning and the end of the review process. Intra-rater (within reviewer) reliability will also be determined by comparing the determination of self-harm-relatedness between the beginning and end of the review process. The reasons behind any inconsistencies between reviewers in determining self-harm- relatedness will be examined further and if necessary, cases will be re-coded.

Data analysis: The annual incidence rate per 100,000 population will be calculated for the total population, for males and female separately, for subgroups by age and sex, based on the number of persons who presented to hospital following SH in each calendar year. Crude and age-standardized SH rates will be calculated using the 2013 population and WHO World standard population. A 95% confidence interval will be calculated to establish whether the two rates differ in statistical significance. An analysis of repeat events will be conducted using conditional risk set analysis and Cox hazard proportional models will be used to identify independent and multivariable predictors of

repetition of self-harm.

H. Ethics and safety

Informed consent: This is a cross-sectional observational study; the data collected for the study will be extracted from routine clinical data and will not involve any direct patient contact.

The study procedures do not require participants to undertake any activity nor does it affect care and treatment services they will receive. Further, only de-identified data will be used to report the study findings. Therefore, study participation does not require informed consent from the participants. This study is similar to a number of surveillance studies which are routinely conducted in hospital settings[23]. Self-harm is being added to the NZPSU surveillance system which has been running for many years as required by the WHO[22] and has previously reported on sensitive topics such as fetal alcohol syndrome[24] and perinatal HIV exposure. The New Zealand Paediatric Surveillance Unit has previously been granted approval by the Southern Health and Disability Ethics Committee to collect patient's NHI number as part of surveillance data for topics including HIV transmission.

Participant confidentiality: Potential cases presenting to the paediatricians registered with the NZPSU and presenting to the emergency department of Middlemore, Christchurch, Dunedin and Southland hospitals will be identified using clinical record data. The study will capture personal information as this is essential for Case ascertainment. Once cases have been selected, all identifying name, home address and date of birth variables will be partitioned off so they will not be available in the analysis data set. A de-identified (name, address, NHI and DoB removed) set of data will be produced for aggregated statistical analysis and publication.

Data storage / protection: All data will subject to the University of Otago data security policy. All individual level data will be treated as sensitive data. A de-identified dataset (with names, home addresses and dates of birth removed and securely stored separately by the University of Otago data manager) will be created for analysis and stored on password protected computers during the analysis phase of this project. Data will be transferred between University ofOtago researchers employed on this project via a secure server. All University of Otago computers are in offices that are locked when the occupant is not present and have password protected logins and screensavers.

Upon completion of this project, electronic format data will be stored by the University of Otago in an encrypted form on password protected computers within a separate locked office. During the project a separate de-identified analysis dataset will be stored in research team's password protected

computers in locked offices. All hard copies of data will be stored in locked cabinets within locked offices. Original data of published material is securely stored by the study team for 10 years consistent with University of Otago Data Archiving policy to allow for future scrutiny. The archived analytical dataset will not contain identifying data (name, home addresses or dates of birth).

Data ownership: The research data will be solely owned by the University of Otago and the de-identified data will be stored as per the University of Otago data storage policy.

I. Project management

The project team has a proven record of successfully implementing, completing and disseminating research on suicide prevention. Two of the team (Fortune and Hetrick) have participated in similar sentinel surveillance studies overseas, providing expertise and insights that come from successfully implementing sentinel surveillance. A third member has completed similar work with adults and was the principal investigator on the Canterbury Suicide Project (Mulder). The team also possess a wealth of research experience with large health datasets (McDonald), as well as statistical and data management expertise (Sharma). The investigators have extensive linkages with national and international suicide prevention research and clinical networks undertaking similar surveillance programmes who are fully supportive of this study.

Dr Sarah Fortune, Senior Lecturer – Psychological Medicine (University of Otago), Registered Clinical Psychologist and study principal investigator, will undertake project leadership (liaison with international experts on sentinel surveillance and suicide prevention, seek relevant ethical approvals, conduct trainings for the ED staff) and coordination between the different study sites and NZPSU. She will lead data analysis, write-up and dissemination of results through annual reports, peer-reviewed articles and presentations for the hospital staff. She will provide clinical supervision to the team.

Dr Sarah Hetrick, Associate Professor in Youth Mental Health (University of Auckland), Registered Clinical Psychologist is a co-Principal Investigator on this study and will specifically lead the study site at Middlemore hospital – routinely meet with hospital staff, oversee data collection and be available for any onsite trouble-shooting. She will also closely collaborate with Sarah Fortune on data analysis and development of dissemination products such as annual reports and peer-reviewed articles.

Dr Gabrielle McDonald, Senior Research Fellow (University of Otago), will head the data management team to supervise data collection, cleaning and coding of the data and ensure data quality

assurance across the study sites. She will also oversee building of the database, webforms (in compliance with WHO guidance manual) and conduct data analysis.

Dr Vartika Sharma, Assistant Research Fellow (University of Otago), will closely work with the team to establish the surveillance sites– coordinate with the hospital staff and participate in regular meetings with the ED staff, collect electronic and physical patient data, monitor data quality, coordinate with other sites for data compilation and assist in data cleaning and data analysis.

Professor Roger Mulder (FRANZCP, PhD, Registered Psychiatrist) has experience in conducting clinical trials and using large data sets for meta-analyses and other health research. He was a principal investigator on the Canterbury Suicide Project and has published widely in the area of suicide and risk assessment. He is Editor of Personality and Mental Health and Associate Editor of the Australian and New Zealand Journal of Psychiatry and the New Zealand Medical Journal. Mulder will provide expertise in data analysis, write-up and dissemination.

Dr Fortune and Dr McDonald are based in University of Otago, Dunedin, Professor Mulder in Christchurch while Dr Hetrick and Dr Sharma are based in Auckland. The research team are arranging contracts for all the study team members to access hospital records and systems.

To monitor the progress of the study, the study team has extended invitations to experts in sentinel surveillance, emergency medicine, paediatricians and mental health experts to become members of the **Project Advisory Committee (PAC)** and the **Project Steering Committee (PSC)**. The PAC will ensure compliance with international standards and best practices by international experts in sentinel surveillance of SH – A/Prof. Jo Robinson and Dr Katrina Witt, University of Melbourne, Prof. Ella Arensman - National SH Registry of Ireland, Prof. Keith Hawton - University of Oxford, Prof. Greg Carter - University of Newcastle, Prof. Allan House, Denise Kingi ‘Ulu’ave – Le Va (community-based organisation for Pacific suicide prevention), Taimi Allan – lived experience advocate.

Additionally, the PSC will oversee the overall implementation and progress of the study by experts in emergency medicine and mental health (Dr. Christopher Lash and Dr. Eunicia Tan, Middlemore Hospital, Dr Sierra Beck - Dunedin Hospital, A/Prof. Ben Wheeler - University of Otago, Madonna Dasler – Middlemore Hospital, Dr Adrienne Adams and Dr Song Chen - Middlemore Hospital).

J. Timetable

Activity	Timeline
Project development, alignment with international surveillance systems	October - November 2019
Ethics approval – HDEC and locality approval	December, 2019 – January 2020
Commence data collection	February 2020
Data analysis (ongoing)	February 2020 onwards
Report/disseminate results	Ongoing to December 2022

K. Resources

This study is supported by two funding agencies – Cure Kids which provides support for the sentinel surveillance site at Middlemore, Christchurch and Southland Hospital and data collection via New Zealand Paediatric Surveillance Units, and the James Hume Bequest Fund which supports the site at Dunedin Hospital. The Hugo Charitable Trust is partially supporting the time of Dr. Fortune. The grants support the salary of the study staff who will be involved in setting up the study sites including data management (data entry, cleaning and compilation). The University of Otago and University of Auckland provide in-kind support to the study by funding the time of the study PIs – Sarah Fortune and Sarah Hetrick - and Professor Kate Scott.

L. Research Outputs

This study will provide robust and detailed epidemiological data on who engages self-harms and which interventions are most likely to reduce suicide deaths across the entire country. Research impact will be achieved through provision of up-to-date, detailed and robust epidemiological data which will establish local trends in SH, particularly spikes in non-fatal presentations proximal to suicide deaths to inform local prevention and postvention activities. Additionally, the study data will also give an opportunity to map local changes in prevalence and SH methods to the local service needs. The study will also provide valuable inputs to identify systemic levers for prevention and support workforce development. The study will also provide valuable inputs to inform current emergency department interventions and treatment programmes related to self-harm. The study outcomes will be disseminated through annual reports for policy-makers, quarterly presentations for hospital staff, peer review papers and presentations in conferences locally and internationally to disseminate study outcomes.

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