

## Using big data to better understand health and wellbeing

Part B: Mortality of people on the autism spectrum

#### **Final report**

Julian Trollor

Preeyaporn Srasuebkul

**Tony Florio** 

Nick Lennox

Kitty-Rose Foley

#### 30<sup>th</sup> June 2018





DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY





Australian Government Department of Industry, Innovation and Science Business Cooperative Research Centres Programme

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Julian Trollor University of NSW

Preeyaporn Srasuebkul University of NSW

Tony Florio University of NSW

Nick Lennox University of Queensland

Kitty-Rose Foley University of NSW

ISBN: 978-0-9953736-5-5

**Citation:** Trollor, J., Srasuebkul, P., Florio, T., Lennox, N., & Foley, K. -R. (2018) Using big data to understand health and wellbeing, Part B: Mortality of people on the autism spectrum. Brisbane: Cooperative Research Centre for Living with Autism.

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### Acknowledgements

The authors acknowledge the financial support of the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centre Program. Staff and non-staff in kind were provided by Autism CRC participants – UNSW Sydney and University of Queensland.

#### The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

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### 1.Project

The Autism CRC project 'Using big data to better understand health and wellbeing' has two primary overarching objectives:

- Part A : To investigate reasons for encounters, problems managed, referrals being made and medications prescribed by Australian GPs to young autistic people in comparison with those without an autism diagnosis.
- Part B: To use the existing New South Wales state-based linked administrative data infrastructure to explore the potential of an existing autism flag or identifier to examine mortality, cause of death and health outcomes for autistic Australians and compare these to the non-autistic population.

### 2. Introduction

Studies suggest that the rates of deaths for those on the autism spectrum are between two to three times as high as that of the general population in any given study period (Mouridsen, 2013). In addition to natural causes of death, intentional and unintentional injuries are a prominent cause of death for this population (Guan & Li, 2017; Schendel et al., 2016). Despite this evidence, there have been only a small number of studies exploring the topic and most have been limited to small numbers.

One study using a large dataset in California was based on data from more than 15 years ago (Pickett, Paculdo, Shavelle, & Strauss, 2006; Shavelle, Strauss, & Pickett, 2001). Two other studies based in Sweden (Hirvikoski et al., 2015) and Denmark (Schendel et al., 2016) also found higher rates of death and premature mortality for those on the spectrum, but no large-scale studies have been conducted in Australia. This study provides the most detailed, reliable and current information on mortality and cause of death for autistic individuals in Australia.

The aim of the current study was to use linked health and service datasets from NSW to describe mortality rates and cause of death for individuals on the spectrum with and without intellectual disability (ID) in comparison to the general population.



#### 3. Research design and methods

This study examined the mortality and cause of death for three different groups:

- (1) Individuals on the autism spectrum with comorbid ID (ASD with ID)
- (2) Individuals on the autism spectrum with no comorbid ID (ASD only)
- (3) Individuals from the general population in NSW (general population)

The data came from a range of services datasets (Disability Minimum Dataset, NSW Department of Education, Statewide Disability Service, NSW Public Guardian and NSW Ombudsman) and health datasets (NSW Admitted Patient Data Collection (APDC), Mental Health Ambulatory Data Collection (MH AMB) and NSW Emergency Department Data Collection (EDDC)). In the services datasets, individuals were considered to be on the spectrum if 'autism spectrum disorder' was recorded as their primary or secondary disability, and were considered to have ID where 'intellectual disability' was also recorded as a diagnosis. In health datasets, ICD10 codes (codes: F84.0, F84.1, F84.5, F84.8 and F84.9) were used to identify people on the spectrum. Overall, 35,929 individuals on the spectrum between the ages of 5 and 64 were identified from the above datasets. This included 19,823 individuals with ASD diagnosis only and 16,106 individuals with ASD with ID at January 2001 to December 2015, who were alive at 1 January 2001.

To investigate mortality and cause of death in these individuals, data was taken from the NSW Register of Births, Deaths and Marriages (RBDM) and the Cause of Death Unit Record File (COD URF). These datasets were then linked by the Centre for Health Record Linkage (CHeReL). The linked datasets covered the period of January 2001 to December 2015 inclusive. Data about deaths in the general population in NSW were obtained from HealthStats NSW and the Australian Bureau of Statistics websites. Causes of death were classified according to the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10).

Linked data with no personal identification was sent to the investigators. Examination was undertaken of mortality rates (the number of deaths per year per 1,000 people, adjusted to create comparable figures across populations of different age and size), comparative mortality figures (the mortality rate of one population in comparison to another; a figure of 1 indicates that the mortality rates are equal) and the top-ranked causes of death for each of the groups. Finally, univariate and multivariable cox proportional hazards models were used to examine factors associated with death in those on the spectrum expressed as a hazard ratio. A higher hazard ratio would indicate higher



hazard of death from the presence of the variable of interest e.g. a comorbid mental health condition. Potential factors associated with death included sex, age, source of data (health or service dataset), presence of ID, comorbid epilepsy, comorbid mental health conditions, multiple medical comorbidities (using the Charlson Comorbidity Figure; CMF), remoteness of residence and socioeconomic status. All analyses were performed using STATA statistical software (StataCorp, 2015).

This study was part of a broader data linkage investigation that was given ethical clearance by the NSW Population and Health Services Research Ethics Committee (PHSREC) (Reference: CINSW 2013/02/446). This investigation was given ethical approval under the sub-protocol title of "Comparing mortality rates in people with autism spectrum disorder to the general population in NSW" (NSW PHSREC Sub-protocol Reference: 20165/UMB0502).



## 4. Findings

There was a higher proportion of males (79.5%) than females in the ASD group overall. Rates of ID and epilepsy in the ASD cohort were 45% and 5%, respectively. Of 244 deaths for those with ASD overall, 62 deaths were recorded for those in the ASD only group and 182 were recorded for the ASD with ID group. The rates of death for those on the spectrum, as evidenced by higher adjusted death rates and CMFs, were higher compared to those from the NSW general population, especially for those with ID (Table 1). Those with 'ASD only' appeared to die at a younger age.

	Deaths n(%)	Median age at death [IQR]	Adjusted Death Rate [Cl] (per 10,000 deaths)	CMF
ASD overall (n=34,027)	244 (0.7)	35 [19.5-52]	30	2.06 [1.64-2.58]
ASD only (n=17,885)	62 (0.3)	27 [10-50]	23.5	1.61 [1.17 – 2.21]
ASD with ID (n=16,142)	182 (1.1)	35 [20-53]	32.3	2.26 [1.74 – 2.94]
NSW (N/A)	120,020	51.9 [45-58]	14.6	1

Table 1: Deaths, median age at death, adjusted death rate and comparative mortality figures for study groups

Cause of death information was available for 167 (68%) deaths in the ASD group. The leading causes of death for those with ASD and the comparison cohort by ICD-10 chapter are presented in Table 2. The top cause of death for those with ASD both overall and the subset of those without comorbid ID was 'injury and poisoning'. 'Nervous system and sense organ disorders', encompassing epilepsy, was a leading cause of death for both autistic individuals with ID and the autistic cohort overall but was not a leading cause of death in the comparison cohort.



	NSW General population	ASD all	ASD only	ASD with ID
Cause of death	Rank	Rank	Rank	Rank
Nervous system and sense organ disorders	6(2%)	2 (20%)		1 (23%)
Neoplasm (malignant)	1(53%)	3 (19%)	2 (19%)	2 (19%)
Circulatory diseases	2 (22%)		3 (8%)	
Injury and Poisoning	3(13%)	1 (23%)	1 (50%)	3 (16%)

Table 1: Deaths, median age at death, adjusted death rate and comparative mortality figures for study groups

Note. ID = Intellectual disability; ASD = Autism spectrum disorder.

After adjusting for all the terms in the model, the multivariate cox regression model found higher risk of death to be associated with older age groups (HR=3.5 - 7.87), having ID (HR=1.90), comorbid epilepsy (HR=3.00), comorbid mental health conditions (HR=3.53) and having more medical comorbidities (HR=3.20-26.02). Sex, dataset source, remoteness and socioeconomic status were not associated with higher risk of death.



#### 5. Limitations

The first cohorts of children diagnosed with ASD are only now reaching middle and older adulthood. Given the complexity and difficulties associated with obtaining a diagnosis of autism in adulthood, it is likely that a number of individuals are either not formally diagnosed or have been misdiagnosed with other conditions. The ASD group in the present study was identified by the person having 'autism spectrum disorder' documented as their first disability in service datasets or by ICD-10 codes in the health datasets. Therefore, although this was a large-scale study, it is likely that the representativeness of the sample included in these datasets was somewhat limited. This was reflected in the small number of deaths found for this group. Better identification, diagnosis and documentation of autistic adults will improve the representativeness of future research using such administrative datasets.

#### 6. Implications for research and practice

The present study has provided a preliminary exploration of an important knowledge gap in literature regarding mortality and cause of death for those on the spectrum in Australia. Injury and poisoning was a uniquely prominent cause of death for those on the spectrum. In light of studies that report elevated risk of mortality from intentional self-harm for autistic individuals as well as high rates of potentially avoidable deaths for those with intellectual disability, it is important for focused quantitative and qualitative research efforts to better understand this finding. Importantly, appropriate strategies need to be developed to address potential contributing factors and provide effective intervention to this outcome.

These findings alert the need for health promotion and management of comorbid physical and mental health conditions for those on the spectrum. Effective and adequate healthcare delivery remains a challenge for those on the spectrum, especially for adults. There have been numerous reports of inadequate and inappropriate healthcare for adults on the autism spectrum, which stem from difficulties in identification and diagnostic overshadowing of both autism and associated psychiatric comorbidities, inappropriate management of conditions, lack of professional expertise and issues with healthcare environments (Nicolaidis, Kripke, & Raymaker, 2014; Raymaker et al., 2016; Zerbo, Massolo, Qian, & Croen, 2015). Tools that improve communication in healthcare settings, alterations to healthcare environments and assistance with systems navigation will be important. These findings, alongside others, suggest that mechanisms that underlie mortality risk in



those on the spectrum may be shared with comorbid disorders (Schendel et al., 2016). The specific mechanisms via which this may occur have not yet been examined and will be important for furthering understanding of any biological vulnerabilities inherent in those on the spectrum.

#### 7.Key recommendations

- 1. Clearer documentation of ASD in health and service datasets
- 2. Targeted research identifying the specific factors contributing to injury and poisoning deaths for those on the spectrum
- 3. Better management of comorbid physical and mental health comorbidities for those on the spectrum in order to minimize risk of death
- 4. Development of strategies, programs and initiatives that reduce those causes of death due to injury and poisoning, especially for those without comorbid ID.



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