

Social impacts and costs of schizophrenia: a national cohort study using New Zealand linked administrative data

Sheree Gibb, Naomi Brewer, Nicholas Bowden

ABSTRACT

AIM: To identify a national population of individuals living with schizophrenia in New Zealand, and to examine health, social support, justice, economic outcomes and estimated government costs compared to a matched comparison group.

METHODS: Data were sourced from the Integrated Data Infrastructure. Individuals with a schizophrenia diagnosis in public hospital discharge or specialist secondary mental health service data, aged 18 to 64 and living in New Zealand were included in the schizophrenia population. Propensity score matching was used to select a comparison group of individuals without schizophrenia from the New Zealand resident population and compare outcomes and costs.

RESULTS: In 2015 there were 18,096 people living with schizophrenia in New Zealand, a prevalence of 6.7 per 1,000 people. Compared to the matched comparison population, individuals with schizophrenia had higher hospitalisation rates for mental (OR=52.80) and physical (OR=1.18) health conditions. They were more likely to receive social welfare benefits (OR=17.64), less likely to be employed (OR=0.11) and had lower income (\$26,226 lower). Per-person government costs were higher for the schizophrenia group across all domains, particularly health (\$14,847 higher) and social support (\$11,823 higher).

CONCLUSION: Schizophrenia is associated with a range of adverse health, social and economic outcomes and considerably higher government costs compared to the general population.

Schizophrenia is a chronic and disruptive illness and has been ranked one of the top 25 causes of disability globally.¹ The illness typically presents in the early adult years and has a chronic course, usually requiring lifelong treatment and monitoring.^{2–6}

Estimates of schizophrenia prevalence vary worldwide, with a recent meta-analysis finding a median lifetime prevalence of 0.48% (interquartile range 0.34–0.85%)⁷ and another finding a median lifetime prevalence of 0.40% (interquartile range 0.30–0.66%).⁸ Despite the relatively low prevalence, the health, social, economic and personal costs associated with schizophrenia are substantial. Individuals with schizophrenia are at increased risk for premature death, both from suicide and from physical

health conditions.^{9–11} The early adult onset and chronic course of schizophrenia has a considerable impact on economic and social outcomes including employment, income, housing and contact with the justice system.^{12,13} For example, in an international review, employment rates among adults with schizophrenia ranged from 11.9% to 39.0%,¹⁴ and a recent study found that the cumulative earnings among working age individuals with schizophrenia was equivalent to only 14% of those without schizophrenia.¹⁵

These adverse outcomes for individuals living with schizophrenia are associated with a range of direct and indirect financial costs. A recent systematic review of international studies found annual costs for the schizophrenia population ranged

from US\$94 million to US\$102 billion (2013 dollars), and the economic burden of schizophrenia was estimated to range from 0.02% to 1.65% of gross domestic product.¹⁶ In the United States, estimated excess direct healthcare costs attributed to schizophrenia in 2013 were US\$37.7 billion while indirect costs totaled US\$117 billion.¹⁷ Similarly, in England, societal costs of schizophrenia were estimated at £6.7 billion in 2004/05, including direct government costs of £2 billion.¹³ In Australia, costs of psychosis to society have been estimated at AU\$4.91 billion annually (as of 2010), of which AU\$3.52 billion were borne by the Australian government.¹⁸

There is limited New Zealand epidemiological research on schizophrenia. Studies using administrative data on health service use have suggested a 12-month incidence of 0.5 per 1,000 for Māori and 0.3 per 1,000 for non-Māori,¹⁹ and a 12-month prevalence of 1.0 per 1,000 for Māori and 0.3 per 1,000 for non-Māori.²⁰ Other studies have examined various clinical aspects of schizophrenia illness and treatment.^{21–23} However, there has been little research on the social and economic outcomes and associated government costs for people living with schizophrenia in New Zealand.

Previously, the investigation of the life outcomes of schizophrenia at a national level has been limited by the lack of available social and economic measures in administrative health service data. The recent development of New Zealand's Integrated Data Infrastructure (IDI) now provides an opportunity to quantify the health, social support, justice sector and economic outcomes for individuals with schizophrenia in New Zealand.²⁴ The IDI also contains a range of cost information that can potentially be used to estimate government costs, although methods for using these costs are underdeveloped.

The aims of this paper are to use linked data from the IDI to:

1. identify a national population of individuals living with schizophrenia in New Zealand in 2015
2. examine the health, social support, justice sector and economic outcomes for individuals with schizophrenia, and to contrast those with a

comparison group who do not have schizophrenia

3. construct broad estimates of government costs for individuals with and without schizophrenia across a range of sectors.

Methods

Data source: the Integrated Data Infrastructure

Data were sourced from Stats NZ's IDI. The IDI is a large database containing linked individual-level microdata about people and households in New Zealand.²⁴ Data come from a range of government and non-government administrative and survey data sources including health, tax, welfare and justice. All data are probabilistically linked and de-identified; only approved researchers can access data in a secure environment; and all outputs must be aggregated, confidentialised and checked by Stats NZ before release.

For more information about IDI, see <https://www.stats.govt.nz/integrated-data/integrated-data-infrastructure>.

Participant population

The base population used for this study was the IDI estimated resident population of New Zealand (IDI-ERP) for 31 December 2015, created using established methods for identifying a resident population within the IDI.^{25,26} This population aims to capture all individuals who were alive and living in New Zealand as at 31 December 2015. All individuals in the schizophrenia and comparison populations were drawn from this population.

Individuals were included in the schizophrenia population if they had a diagnosis of schizophrenia, defined as:

1. having a public hospital discharge in the National Minimum Dataset (NMDS) between the dates of 1 January 1988 (date the dataset begins) and 31 December 2015 with a primary or secondary diagnosis code for schizophrenia using International Classification of Disease (ICD)-9 or ICD-10 (see Appendix Figure 1 for list of codes), or
2. having a record in the Programme for the Integration of Mental Health

Data (PRIMHD) diagnosis dataset for secondary mental healthcare between the dates 1 July 2008 (date the dataset begins) and 31 December 2015 with a diagnosis code for schizophrenia using Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV, ICD-9 or ICD-10 (see Appendix Figure 1 for list of codes).

For comparison, a cohort of individuals without schizophrenia was identified. The absence of a diagnosis code for schizophrenia in either NMDS or PRIMHD over the same time periods defined this group. This cohort was matched to the schizophrenia population on age, sex and ethnicity (see the subsection *Analytical sample* for further details).

The schizophrenia and comparison populations were further restricted to individuals aged 18 to 64 as at 31 December 2015 to capture the typical working age population, because many of the outcome measures are only relevant for working age individuals, and because mental health care for ages 65 and over is not well recorded in PRIMHD.²⁷

Outcome measures

Unless otherwise stated all outcomes were estimated for the 2015 calendar year.

Health

Public hospital admissions

NMDS data were used to identify admissions to a public hospital.

Inpatient psychiatric admission

PRIMHD data were used to identify admissions to an inpatient psychiatric facility.

Emergency department visits

National Non-Admitted Patient Collection (NNPAC) data were used to identify attendance at an emergency department.

Accident Compensation Corporation support

Accident Compensation Corporation (ACC) data were used to identify individuals who had received ACC support through either income compensation or having their medical expenses paid for by ACC.

Social support

Social welfare benefit received

The Ministry of Social Development (MSD) Benefit Dynamics Dataset was used

to identify individuals who received one of the Tier 1 working age benefits (Jobseeker Support, Supported Living Payment and Sole Parent Support).

Social housing

Kāinga Ora data were used to identify individuals who were an applicant on a social housing tenancy agreement.

Socioeconomic deprivation: the New Zealand Index of Deprivation 2013

Address notification data were used to identify each individual's meshblock of residence and the corresponding New Zealand Index of Deprivation 2013 (NZDep2013) score. NZDep2013 measures socioeconomic deprivation based on the meshblock (small area geography comprising approximately 100 households) in which individuals live.²⁸ It is available for everyone who has an address recorded in the IDI (over 99% of the sample). Deprivation scores were collapsed into deciles, with 1 representing the least deprived and 10 the most deprived.

Justice sector

Police proceedings

New Zealand Police data were used to identify individuals who had police proceedings initiated against them (including warrants, arrests and charges, but excluding infringement notices).

Conviction

Ministry of Justice data were used to identify individuals who were convicted of a crime.

Imprisonment

Department of Corrections data were used to identify individuals who were incarcerated.

Economic

Income

Inland Revenue (IR) data were used to calculate the total taxable income from: wages and salaries; withholding payments; government benefits (including Jobseeker Support, Supported Living Payment, Sole Parent Support and New Zealand Superannuation); student allowance; paid parental leave; pensions (superannuation); claimants compensation; and declared self-employment income.

Income estimates do not include investment income, cash income or income earned overseas, as these sources of income are not reliably recorded in IR records.

Employment

IR data were used to identify employed individuals, defined as all those who received income from wages, salaries or self-employment.

Costs

All costs were calculated for the 2015 calendar year in New Zealand dollars. Unless otherwise stated, costs were drawn from the Social Investment Analytical Layer (SIAL) (<https://swa.govt.nz/what-we-do/analytics/social-investment-analytical-tool/>) produced by the Social Investment Agency, which calculates individual-level government service costs within the IDI.

Health

Health costs included government costs for: hospital admissions; emergency department (ED) attendances; outpatient visits; community pharmaceuticals; laboratory tests; general medical subsidies; specialty mental health services; and ACC. They did not include primary healthcare, private healthcare or patient co-payments. Hospital admission costs were calculated by multiplying the case mix cost weight by the purchase unit cost for the relevant year, with no further adjustment. Outpatient and ED costs were calculated from purchase unit costs in the NNPA dataset. The general medical subsidy and the government subsidies for laboratory tests and community pharmaceuticals were obtained directly from the community laboratory or pharmaceutical table.

Mental health costs were calculated using purchase unit costs obtained from the Social Investment Agency, which were applied to events in the PRIMHD dataset. These included all publicly funded secondary mental health consultations and treatments, including both inpatient and outpatient general, forensic and addiction services. It included pharmaceuticals given in inpatient settings but excluded private treatment, community dispensed pharmaceuticals (which are included under the pharmaceuticals cost category above) and mental health treatment given in primary care.

ACC costs were calculated by summing payments made for medical expenses (from ACC records) and compensation for income loss (from IR records). All medical expenses costs were allocated to the year in which the accident occurred. Compensation was allocated to the year in which the compensation was paid.

Social support

Benefit costs were calculated by summing the Tier 1 (as previously defined) benefit payments from the IR tables (which record actual amount paid) and Tier 2 (payments and allowances such as housing supplements and child disability allowances) entitlements from MSD Benefit Dynamics Dataset tables (which record entitlement: actual amount paid is not available for Tier 2 benefits).

Social housing costs included total government rent subsidies for social housing, calculated from the Kāinga Ora tables in the IDI. The total social housing cost was allocated to the person who was the main applicant on the social housing application. Therefore, individuals living in social housing where they were not the main applicant on the application (eg, if they were the partner of the main applicant) will not have social housing costs recorded.

Justice sector

Justice costs were taken directly from the Ministry of Justice and Department of Corrections data collections in the IDI. Costs included government costs for charges, court proceedings, imprisonment and other sentences. Where a sentence lasted more than a year, only the current year of costs was included.

Total government costs

This was calculated as the sum of all health, social support and justice sector costs.

Demographics

Age (18–24, 25–34, 35–44, 45–54, 55–64 years), sex (male/female) and ethnicity were sourced from the personal detail table in the IDI. Ethnicity was recorded in total response format (so an individual can identify with more than one ethnic group) and, for this study, restricted to Level 1 groupings (European, Māori, Pacific, Asian). The Middle Eastern, Latin American and African

(MELAA) and Other ethnic categorisations had small counts and were therefore not used in this study.

Procedure

Data were accessed from the September 2017 refresh of the IDI. Data were extracted using SAS version 7.1²⁹ and analysed using R version 3.6.1³⁰ and Stata/MP version 15.³¹ Random rounding to base 3 was applied to all counts, in adherence to Stats NZ confidentiality requirements.

Statistical analysis

Calculation of prevalence

Schizophrenia prevalence was calculated as the proportion of the New Zealand IDI-ERP of 18 to 64 year olds for 2015 who had a schizophrenia diagnosis identified any time until 31 December 2015. Prevalence was calculated overall and by sex, age and ethnicity. Odds ratios (ORs) were generated using logistic regressions for each sociodemographic sub-group. ORs for ethnicity were adjusted for age and sex to take account of differences in population structure between ethnic groups.

Analytical sample

The analytical sample for the outcomes analysis contained a schizophrenia group defined as all those in the New Zealand IDI-ERP of 18 to 64 year olds for 2015 with a schizophrenia diagnosis for at least two years on or prior to 31 December 2013, and who had complete data on the matching variables of age, sex and ethnicity. We restricted the sample to individuals with at least a two-year history of schizophrenia in order to exclude impacts that are related to the period of initial diagnosis. To examine whether a longer delay from diagnosis to outcomes might be required, a sensitivity analysis was run on an alternative schizophrenia population whose diagnosis was recorded on or prior to 31 December 2010 (indicating they had been living with schizophrenia for at least five years). Results were not substantively different to those from the main analysis (see Appendix Tables 1–6), so we opted to use the two-year restriction as it retains a larger sample size.

For comparison, a matched sample without schizophrenia was also generated from the IDI-ERP of 18 to 64 year olds for 2015. Propensity score matching methods were used to select the comparison group of

individuals without schizophrenia. Nearest neighbour one-to-one matching was undertaken using the MatchIt package version 3.0.2 in R. Matches were drawn without replacement from the IDI-ERP for 2015. Matching variables were age at the end of 2015, sex and ethnicity. These variables were selected because they were available for almost all individuals and rarely change over time. Individuals who had ever been diagnosed with schizophrenia or who had missing data on any of the matching variables were not eligible to be selected as matches.

We also conducted two sensitivity analyses with variations to this matching method in which each individual with schizophrenia was matched to five and ten controls respectively. Results were not substantively different to the single matching, so we elected to stay with single matching for the analysis (see Appendix Tables 1–6).

Comparisons of outcomes and costs

To compare outcomes between the schizophrenia and comparison groups we fitted linear (for continuous outcomes) or logistic (for dichotomous outcomes) regression models in which the outcome was modelled as a function of schizophrenia population membership. Estimated odds ratios (for dichotomous outcomes) and beta coefficients (for continuous outcomes) were drawn from these models.

Ethics approval

This study was approved by the University of Otago Human Research Ethics Committee (Reference: H17/062). The study was reviewed as a 'Minimal Risk Health Research – Audit and Audit related studies' proposal. Access to IDI data was approved by Stats NZ.

Results

Schizophrenia population size and prevalence

A total of 18,096 individuals aged 18 to 64 had a schizophrenia diagnosis recorded on or prior to 31 December 2015. This is equivalent to a prevalence of 6.7 per 1,000 people, or 0.67%.

Table 1 shows the number and corresponding prevalence of individuals with schizophrenia in New Zealand by age, sex and ethnicity. Schizophrenia prevalence

was significantly lower among females compared to males (OR 0.52) and higher in Māori and Pacific ethnic groups compared to non-Māori and non-Pacific (ORs 3.36 and 1.70 respectively). Prevalence was highest in the middle adult years (35 to 54) and lowest in the youngest (18 to 24).

Description of the population for outcomes analysis

After excluding from the schizophrenia population all individuals whose diagnoses were only recorded in the last two years or who had missing data on any of the matching variables (see section *Methods*), 15,639 individuals with schizophrenia remained. A pool of 2,691,342 individuals without a schizophrenia diagnosis existed from which to select the matched cohort.

Table 2 displays the demographic characteristics of the analytical sample (N=31,278) after one-to-one matching. Note that the one-to-one matching resulted in the schizo-

phrenia and non-schizophrenia sub-groups being identical on the demographic measures, so for the purposes of presenting the analytical sample, the groups have been combined. The majority (63.8%) of the analytical sample were male. Approximately two thirds (65.4%) identified as European, one third (35.4%) as Māori, 11.2% as Pacific and 5.6% as Asian. The majority were in the middle age groups (35–54 years); only 3.9% were aged 18–24; 18.9% were aged 25–34, and 19.7% were in the oldest age group (55–64 years).

Health and social outcomes

Table 3 shows a range of outcomes for the schizophrenia population and the matched comparison group for 2015. Individuals in the schizophrenia group were significantly more likely than the comparison group to have a general hospital admission (OR 1.18), a psychiatric inpatient admission (OR 52.80) or an emergency department attendance (OR 2.35). Individuals with schizophrenia

Table 1: Prevalence of schizophrenia in New Zealand as at 31 December 2015 by age, sex and ethnicity.^a

	Number with schizophrenia	Prevalence (per 1,000)	OR ^b (95% CI)
Overall	18,096	6.7	
Sex			
Male (reference group)	11,577	8.9	-
Female	6,519	4.7	0.52 (0.51, 0.54)
Ethnicity^c			
European	11,730	6.3	0.77 (0.74, 0.79)
Māori	6,624	16.7	3.36 (3.26, 3.47)
Pacific	2,106	10.9	1.70 (1.62, 1.78)
Asian	1,065	3.0	0.39 (0.36, 0.41)
Age group			
18–24	1,068	2.5	0.38 (0.35, 0.41)
25–34 (reference group)	3,582	6.5	-
35–44	4,854	8.9	1.37 (1.31, 1.43)
45–54	5,169	8.2	1.26 (1.21, 1.32)
55–64	3,423	6.3	0.96 (0.92, 1.01)

^a Sub-group values may not sum to totals due to Stats NZ rounding requirements.

^b Ethnic comparisons are adjusted for age and sex.

^c Reference groups for ethnic comparisons are non-European, non-Māori, non-Pacific and non-Asian respectively.

were significantly more likely to be receiving a social welfare benefit (OR 17.64) and living in social housing (OR 3.39). Justice system interactions were also significantly more common among the group with schizophrenia; they were around twice as likely to have police proceedings initiated against them (OR 2.15), receive a conviction (OR 1.78) and receive a prison sentence (OR 2.49) than individuals in the comparison group. Finally, individuals with schizophrenia were significantly less likely to be employed than the matched comparison group (OR 0.11), and while their odds of receiving any income were higher than the control group (OR 2.40), their average annual income was less than half that of those without schizophrenia. People with schizophrenia were also significantly more likely to live in areas of higher socioeconomic deprivation (mean NZDep2013 score 7.4 compared to 5.9).

Government costs

Table 4 displays the estimated government costs for health, social support and the

justice sector for those with and without schizophrenia. Costs were significantly higher for the schizophrenia group than in the matched comparison group across each of these domains. The largest difference was in health costs, where the average per-person cost for the schizophrenia group was nearly seven times higher than for the control group. Social support costs were five times higher among the schizophrenia group and justice sector costs nearly two times higher.

Discussion

This paper identified a national cohort of working age individuals living with schizophrenia in New Zealand, examined a range of health and social outcomes for those individuals and estimated associated government costs using information available from linked administrative data in the IDI.

The schizophrenia population included 18,096 individuals corresponding to a preva-

Table 2: Demographic characteristics of the analytical sample as at 31 December 2015 by age, sex and ethnicity.*

	N	%
Overall	31,278	
Sex		
Male	19,959	63.8
Female	11,322	36.2
Ethnicity		
European	20,445	65.4
Māori	11,403	36.5
Pacific	3,504	11.2
Asian	1,743	5.6
Age group		
18–24	1,209	3.9
25–34	5,901	18.9
35–44	8,646	27.6
45–54	9,363	29.9
55–64	6,162	19.7

* Sub-group values may not sum to totals due to Stats NZ rounding requirements.

Table 3: Health, social support, justice sector and economic outcomes for schizophrenia and matched comparison populations.^a

	Schizophrenia population (N=15,639)	Matched non-schizophrenia population (N=15,639)	OR / difference in means (95% CI)
Health			
Non-mental health inpatient stay (%)	13.0	11.2	1.18 (1.10, 1.26)
Mental health inpatient stay (%)	12.2	0.3	52.80 (38.72, 72.01)
Emergency department visit (%)	6.7	3.0	2.35 (2.10, 2.62)
ACC compensation (%)	16.3	29.8	0.46 (0.43, 0.48)
Social support			
Any social welfare benefit (%)	78.8	17.4	17.64 (16.68, 18.67)
Social housing (%)	13.2	4.3	3.39 (3.09, 3.71)
Justice sector			
Police proceedings against (%)	9.4	4.6	2.15 (1.96, 2.36)
Conviction (%)	4.7	2.7	1.78 (1.58, 2.01)
Prison sentence (%)	2.3	0.9	2.49 (2.05, 3.03)
Economic			
Employed (%)	27.6	78.2	0.11 (0.10, 0.11)
Any income (%)	91.0	80.7	2.40 (2.24, 2.57)
Mean income (\$)	17,865	44,092	-26,226 (-27,067, -25,384)
Mean NZDep13 (decile)	7.4	5.9	1.53 (1.47, 1.59)

^a Sub-group values may not sum to totals due to Stats NZ rounding requirements.

Table 4: Government health, social support and justice sector costs (in New Zealand dollars) for schizophrenia and matched comparison populations.^a

	Schizophrenia population (N=15,639)	Matched non-schizophrenia population (N=15,639)	Cost difference (95% CI)
Health (\$)	17,333	2,486	14,847 (14,340, 15,354)
Social support (\$)	14,667	2,845	11,823 (11,649, 11,997)
Justice sector (\$)	795	431	363 (267, 459)
Total government (\$)	32,795	5,762	27,033 (26,467, 27,599)

^a Costs may not sum to totals due to Stats NZ rounding requirements.

lence of 6.7 per 1,000 people in the working age (18 to 64) population. This estimate is in line with previous international estimates of the prevalence of schizophrenia,^{7,8} but it is slightly higher than previous New Zealand estimates, a difference that may be accounted for by the previous estimates having used smaller time windows³² or more limited data sources.¹⁹ The higher prevalence for Māori reported in this study is consistent with previous New Zealand studies that used administrative data and found schizophrenia incidence and prevalence rates around two to three times higher for Māori than for non-Māori.^{19,32} Higher rates among Māori could reflect higher rates of schizophrenia. But these rates could also reflect that Māori are more likely than non-Māori to be given a schizophrenia diagnosis when they have psychosis symptoms.³³ Our finding that the prevalence of schizophrenia is higher among males than females adds to the existing literature where conclusions about sex difference in prevalence are inconclusive.^{8,34} Prevalence rates are highest among the 35–54 age group. The lower rate for the 55–64-year-old cohort is likely because our available data do not enable us to look back far enough to the peak (early adult) diagnosis ages for that group. In contrast, for the younger cohorts, in particular those aged 18 to 24, it is probable that a schizophrenia diagnosis has yet to be formalised for many.

Compared with matched controls, people living with schizophrenia had more ED visits and more inpatient hospital admissions for both mental and physical health reasons. The high rates of mental health service use are unsurprising given the substantial mental health burden of living with schizophrenia, and increased ED and hospital use has been reported previously.^{35,36} There is evidence that people living with schizophrenia have poorer physical health and higher rates of co-occurring medical conditions,^{11,37,38} and this, along with ED visits directly related to schizophrenia, may account for the high levels of ED and hospital use. Our finding of lower ACC use among the schizophrenia population is likely due to lower employment rates in the schizophrenia group and therefore reduced eligibility for income compensation.

Our finding that people with schizo-

phrenia have higher rates of interactions with the criminal justice system than the general population aligns with existing literature.^{39–42} However, our finding that approximately one in ten working-age individuals with schizophrenia have criminal justice system involvement is at the lower end of existing estimates.^{41,42} Methodological differences likely explain some of this variation. However, it is also possible that some of this difference is due to the time period covered: the risk of offending may be highest in the pre-diagnosis period,⁴³ which our study did not include.

Our estimated employment rate among the schizophrenia group of 27.6% is consistent with findings from a recent international review where employment rates ranged from 11.9% to 39.0%.¹⁴ Our finding of low incomes among the schizophrenia population, in particular relative to the non-schizophrenia group, is also consistent with existing literature.^{15,44} This is likely explained by low employment rates and the high proportion of individuals receiving social welfare benefits that provide a low income. International evidence has demonstrated that employment among individuals with schizophrenia can decrease the reliance on mental health services.^{45,46} Given the substantial use of healthcare associated with schizophrenia, this suggests that targeting resources towards providing stable and meaningful employment for those with schizophrenia may be cost saving. This is an area of research that could be explored further.

This is the first study to provide information about the government costs for a New Zealand schizophrenia cohort, which totalled \$32,795 per person and were more than five times higher than for individuals without schizophrenia, consistent with overseas studies.^{13,17,47,48} The largest areas of costs, both in absolute terms and relative to the non-schizophrenia population, were health (\$17,333 per person, seven times higher) and social support (\$14,667 per person, five times higher).

Our reported costs for the schizophrenia population are lower than those in a 2010 Australian study that reported total government costs of AUD\$55,403 per person. That study employed a prevalence-based, bottom-up approach utilising

survey data and unit costs from government and non-government organisation (NGO) sources.¹⁸ Furthermore, the Australian study included some large costs that were not available for inclusion in our study, such as primary healthcare and tax foregone. The low employment rates and high use of healthcare among our schizophrenia population suggest that costs related to primary care and tax foregone would be high and, if included, would bring our estimates closer to those of the Australian study.

The cost estimates in this paper were drawn directly from recorded costs in the IDI without additional refinements, and therefore may contain some level of error. In addition there are government costs that were not able to be captured from the IDI, such as the costs of primary and private healthcare, which may have led to an underestimation of the true government cost of schizophrenia. However, as the same costing methods were applied to the schizophrenia and comparison groups, the relative differences in costs between the two groups are likely to be more reliable.

Social sector cost data have not been widely used for research and there is little information available about the best way to use these costs. One exception is the health sector, where complex methods do exist for refining health costs.⁴⁹ It may be useful to develop similar protocols for using costs from other sectors, such as justice or social support. Incorporating these refinements would improve the accuracy of the cost estimates in future work that uses cost data from the IDI.

Schizophrenia has many costs that cannot be captured from existing administrative data. Examples include caregiver costs, time and productivity loss and intangible costs related to pain and suffering. Detailed survey data, such as those used in the Australian psychosis costing study,¹⁸ may be required to quantify those costs that are not collected in administrative data.

The use of linked administrative data from the IDI confers a number of advantages. Whole-of-population data meant we were able to identify a national cohort living with schizophrenia in New Zealand. In addition, individuals were removed from the analysis if they died or moved overseas after their schizophrenia diagnosis, leaving a more

relevant population for measuring outcomes and costs. Linked health and non-health data enabled us to consider outcomes and government costs across a range of areas including health, social support, justice and the labour market. Finally, we were able to select a comparison group of individuals without schizophrenia, who were also living in New Zealand, and match these to the schizophrenia population on age, sex and ethnicity. From this we are able to understand how outcomes and costs for those with schizophrenia compare to an equivalent subset of the general population without schizophrenia.

The use of administrative data also has some limitations. The identification of schizophrenia diagnoses relied on records of hospital admissions and specialist secondary mental health service use. Although we expect that most individuals with diagnosed schizophrenia will have been treated by specialist mental health services at some point, we will have missed a number of individuals who were being managed solely in primary care, by NGOs or by family and whānau. A New Zealand study indicated as many as 30% of those with psychosis do not seek medical help at all.⁵⁰ In addition, our method of identification relies on the accuracy of diagnosis attribution as well as the quality of clinical coding. The extent to which these result in incorrect identifications or missed identifications remains unknown.

Although the comparison group in this study was matched to the schizophrenia population on age, sex and ethnicity, it is possible that the comparison population differs from the schizophrenia population in other ways that may be related to the measured outcomes, such as deprivation or family background. Due to the restricted time series of many datasets in the IDI, for most people these potential matching variables were not available prior to the onset of schizophrenia. Future studies may be able to match more comprehensively as the time series of data in the IDI continues to lengthen.

Schizophrenia is one of the most prospectively consistent psychosis diagnoses over time.^{51,52} However, we acknowledge that for a small proportion of our schizophrenia cohort there may be a recovery or a change

in diagnosis over time. Further research could explore the extent to which different diagnostic trajectories are associated with different health, social and economic outcomes.

The use of administrative data in New Zealand for research purposes is legal, and the use of IDI data is highly regulated. Nonetheless, there are ethical concerns, including concerns around social licence and especially in relation to the IDI, which now links data at the individual level across a range of domains. As discussed by Bowden et al, further consultation around these concerns is necessary, in particular given that comparisons across ethnic groups may disadvantage Māori and Pasifika.^{53,54}

Administrative data are a useful tool for providing a whole-population perspective on the impact of mental health conditions. This is especially true when multiple data sources are combined in resources such as the IDI, which allow us to consider impacts across different domains. Further methodological development, especially around costing, would improve the usefulness of this resource for researchers.

Disclaimer

These results are not official statistics. They have been created for research purposes from the Integrated Data Infrastructure (IDI) which is carefully managed by Stats NZ. For more information about the IDI please visit <https://www.stats.govt.nz/integrated-data/>.

Appendix

Appendix Figure 1: diagnosis codes used to define schizophrenia

- Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) codes of 295.1 to 295.9, excluding 295.7, or
- International Classification of Diseases, Tenth Edition, Australian Modification (ICD-10-AM) codes of F20.0 to F20.9, or
- International Classification of Diseases, Ninth Edition, (ICD-9) diagnosis codes of 295.0 to 295.9, excluding 295.7.

Appendix Table 1: Health, social support, justice sector and economic outcomes for schizophrenia and matched comparison populations for (five-year schizophrenia diagnosis).^a

	Schizophrenia population (N=12,045)	Matched non-schizophrenia population (N=12,045)	OR / difference in means (95% CI)
Health			
Non-mental health inpatient stay (%)	13.0	10.6	1.25 (1.16, 1.36)
Mental health inpatient stay (%)	11.5	0.2	67.69 (44.79, 102.29)
Emergency department visit (%)	6.7	2.7	2.56 (2.25, 2.92)
ACC compensation (%)	16.8	29.5	0.48 (0.45, 0.51)
Social support			
Any social welfare benefit (%)	78.0	17.4	16.83 (15.79, 17.94)
Social housing (%)	13.2	4.3	3.35 (3.02, 3.71)
Justice sector			
Police proceedings against (%)	8.6	4.2	2.15 (1.92, 2.39)
Conviction (%)	4.1	2.8	1.45 (1.26, 1.67)
Prison sentence (%)	1.9	0.9	2.04 (1.62, 2.56)
Economic			
Employed (%)	27.5	78.0	0.11 (0.10, 0.11)
Any income (%)	91.0	80.4	2.45 (2.27, 2.65)
Mean income (\$)	18,175	43,754	-25,575 (-26,477 -24,673)
Mean NZDep13 (decile)	7.4	5.8	1.58 (1.51, 1.65)

^a Sub-group values may not sum to totals due to Stats NZ rounding requirements.

Appendix Table 2: Government health, social support and justice sector costs (in New Zealand dollars) for schizophrenia and matched comparison populations (five-year schizophrenia diagnosis).^a

	Schizophrenia population (N=12,045)	Matched non-schizophrenia population (N=12,045)	Cost difference (95% CI)
Health (\$)	16,695	2,619	14,070(13,491, 14,649)
Social support (\$)	14,760	2,907	11,850 (11,649, 12,054)
Justice sector (\$)	642	414	228 (129, 324)
Total government (\$)	32,096	5,942	26,150 (25,505, 26,795)

^a Costs may not sum to totals due to Stats NZ rounding requirements.

Appendix Table 3: Health, social support, justice sector and economic outcomes for schizophrenia and matched comparison populations (five matched controls for every schizophrenia case).^a

	Schizophrenia population (N=15,639)	Matched non-schizophrenia population (N=78,195)	OR / difference in means (95% CI)
Health			
Non-mental health inpatient stay (%)	13.0	10.7	1.24 (1.18, 1.31)
Mental health inpatient stay (%)	12.2	0.2	56.12 (48.35, 65.15)
Emergency department visit (%)	6.7	2.9	2.45 (2.27, 2.64)
ACC compensation (%)	16.3	29.7	0.46 (0.44, 0.48)
Social support			
Any social welfare benefit (%)	78.8	17.5	17.58 (16.85, 18.34)
Social housing (%)	13.2	4.3	3.37 (3.18, 3.57)
Justice sector			
Police proceedings against (%)	9.4	4.5	2.19 (2.05, 2.33)
Conviction (%)	4.7	2.6	1.82 (1.67, 1.99)
Prison sentence (%)	2.3	0.9	2.56 (2.26, 2.91)
Economic			
Employed (%)	27.6	78.2	0.11 (0.10, 0.11)
Any income (%)	90.9	80.5	2.43 (2.3, 2.57)
Mean income (\$)	17,865	44,092	-26,226 (-27,067, -25,384)
Mean NZDep13 (decile)	7.4	5.8	1.57 (1.52, 1.62)

^a Sub-group values may not sum to totals due to Stats NZ rounding requirements.

Appendix Table 4: Government health, social support and justice sector costs (in New Zealand dollars) for schizophrenia and matched comparison populations (five matched controls for every schizophrenia case).^a

	Schizophrenia population (N=15,639)	Matched non-schizophrenia population (N=78,195)	Cost difference (95% CI)
Health (\$)	17,331	2,535	14,802 (14,535, 15,072)
Social support (\$)	14,667	2,868	11,796 (11,673, 11,916)
Justice sector (\$)	795	411	387 (321, 453)
Total government (\$)	32,798	5,815	26,983 (26,668, 27,300)

^a Costs may not sum to totals due to Stats NZ rounding requirements

Appendix Table 5: Health, social support, justice sector and economic outcomes for schizophrenia and matched comparison populations (10 matched controls for every schizophrenia case).^a

	Schizophrenia population (N=15,639)	Matched non-schizophrenia population (N=156,390)	OR / difference in means (95% CI)
Health			
Non-mental health inpatient stay (%)	13.0	11.2	1.18 (1.10, 1.26)
Mental health inpatient stay (%)	12.2	0.3	52.80 (38.72, 72.01)
Emergency department visit (%)	6.7	3.0	2.35 (2.10, 2.62)
ACC compensation (%)	16.3	29.7	0.46 (0.44, 0.48)
Social support			
Any social welfare benefit (%)	78.8	17.4	17.64 (16.68, 18.67)
Social housing (%)	13.2	4.3	3.39 (3.09, 3.71)
Justice sector			
Police proceedings against (%)	9.4	4.6	2.15 (1.96, 2.36)
Conviction (%)	4.7	2.7	1.78 (1.58, 2.01)
Prison sentence (%)	2.3	0.9	2.49 (2.05, 3.03)
Economic			
Employed (%)	27.6	78.2	0.11 (0.10, 0.11)
Any income (%)	91.0	80.7	2.4 (2.24, 2.57)
Mean income (\$)	17,865	44,092	-26,226 (-27,067, -25,384)
Mean NZDep13 (decile)	7.4	5.9	1.53 (1.47, 1.59)

^a Sub-group values may not sum to totals due to Stats NZ rounding requirements.

Appendix Table 6: Government health, social support and justice sector costs (in New Zealand Dollars) for schizophrenia and matched comparison populations (10 matched controls for every schizophrenia case)^a

	Schizophrenia population (N=15,639)	Matched non-schizophrenia population (N=15,639)	Cost difference (95% CI)
Health (\$)	17,333	2,486	14,862 (14,649, 15,075)
Social support (\$)	14,667	2,845	11,769 (11,655, 11,889)
Justice sector (\$)	798	435	363 (300, 423)
Total government (\$)	32,795	5,762	26,983 (26,668, 27,300)

^a Costs may not sum to totals due to Stats NZ rounding requirements.

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Author information:

Sheree Gibb: Department of Public Health, University of Otago, Wellington, New Zealand.
Naomi Brewer: Department of Public Health, University of Otago, Wellington, New Zealand;
Centre for Public Health Research, College of Health,
Massey University, Wellington, New Zealand.
Nicholas Bowden: Department of Women's and Children's Health,
University of Otago, Dunedin, New Zealand.

Corresponding author:

Sheree Gibb: Department of Public Health, University of Otago, Wellington,
New Zealand, PO Box 7343, Wellington South, Wellington, New Zealand 6242
sheree.gibb@otago.ac.nz

URL:

www.nzma.org.nz/journal-articles/antipsychotic-and-sedative-medication-use-in-long-term-care-facilities-providing-dementia-care

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