

Long-term health conditions among household families in Aotearoa New Zealand: cross-sectional analysis of integrated Census and administrative data

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ABSTRACT

AIM: Little is known about the extent to which families in Aotearoa New Zealand are affected by long-term health conditions (HCs). This study aimed to explore the rates of nine selected HCs among New Zealand family members within the same household.

METHOD: Linked population and administrative health data were obtained for families living in the same household according to the 2013 New Zealand Census (N=1,043,172). Health data (2008–2013) were used to ascertain whether people in these families (N=3,137,517) received treatment or services for nine selected HCs: cancer, chronic obstructive pulmonary disease, heart disease, diabetes, dementia, gout, stroke, traumatic brain injury (TBI), or mental health/behaviour conditions (MHBCs).

RESULTS: Over 60% of families included at least one person with a HC, and this rate was higher among multi-generation families (73.9%). The most common HCs were MHBCs (39.4% of families), diabetes (16.0%) and TBI (13.9%). At the highest level of socio-economic deprivation, 57.6% of children aged under 18 years lived with a family member who had a HC.

CONCLUSION: Three in five New Zealand household families included someone with at least one of nine selected HCs, with differences in the proportion affected according to family composition, socio-economic status and an individual's ethnicity. This suggests that there are a substantial number of people at risk of the poor outcomes associated with the experience of HCs within their family.

Non-communicable, long-term physical and mental health conditions (HCs) are increasing in prevalence globally, and are associated with high levels of impairment and multimorbidity.¹ In Aotearoa New Zealand, there are well-established inequities in the burden of HCs such as diabetes and mental health conditions, particularly with regards to health services access for Māori, Pacific peoples and those in difficult socio-economic circumstances.^{2,3} Recent national studies have reported widespread impacts of HCs on individuals and costs to society.^{4–10} The disabling impacts of HCs can be compounded by inequitable health systems and societal processes/responses; thus, it is important to understand the social environments in which HCs are experienced and how these might disadvantage or benefit outcomes.¹¹

Living with a family member who has a HC is likely to affect individuals across the life-course.¹² In addition to indirect costs, such as loss of productivity due to caregiving,¹³ there can be “intangible” costs to family quality of life, health

and wellbeing.^{14–16} A recent appraisal of 86 studies found considerable impacts of a relative's chronic HC on family members' emotional and psychological wellbeing, physical health, social, leisure and daily activities, family relationships and work.¹⁷ The one New Zealand study identified for that review found that family members supporting relatives with traumatic brain injury (TBI) experienced high levels of burden and health needs.¹⁸ Estimates from international surveys indicate that around 26% of families include a child with a health problem and a considerable proportion of children have a parent with a serious physical illness (3–4%), mental health problem (19.5%) or either of these (25–29%).^{19–23} A recent study in the United States, using the National Health Interview Survey, reported the proportion of adults who lived with a partner (7.6%), minor child (4.7%) or parent (4.8%) with major health needs.¹⁶

Aside from the studies described above, population-wide research on the overall amount or proportion of families, and family members, affected by HCs is lacking.²⁴ This has led to calls

for research with more culturally and socio-economically representative study samples on broader family types with a wider range of covariates, including family characteristics.^{22,25} Understanding the number and characteristics of families and family members affected by HCs is vital to inform policy development and research. This descriptive study was designed to explore the socio-demographic characteristics of New Zealand families affected by at least one of nine HCs: cancer, chronic obstructive pulmonary disease (COPD), coronary heart disease (CHD), diabetes, dementia, gout, stroke, TBI or mental health/behaviour conditions (MHBCs). The aim is to provide a starting point to help us understand ways that we might improve the lives and livelihoods of families affected by HCs.

Methods

Design and data sources

This study involved cross-sectional, descriptive analyses of linked administrative health and population data sourced from the New Zealand Integrated Data Infrastructure (IDI). The IDI is a national database that holds de-identified microdata about people and households from multiple government agencies and the Census.²⁶ Individuals in different datasets can be linked via the spine using unique probability-matched identifiers (IDs). The spine aims to record everyone who has ever been a resident in New Zealand. People not linked to the spine are those with no

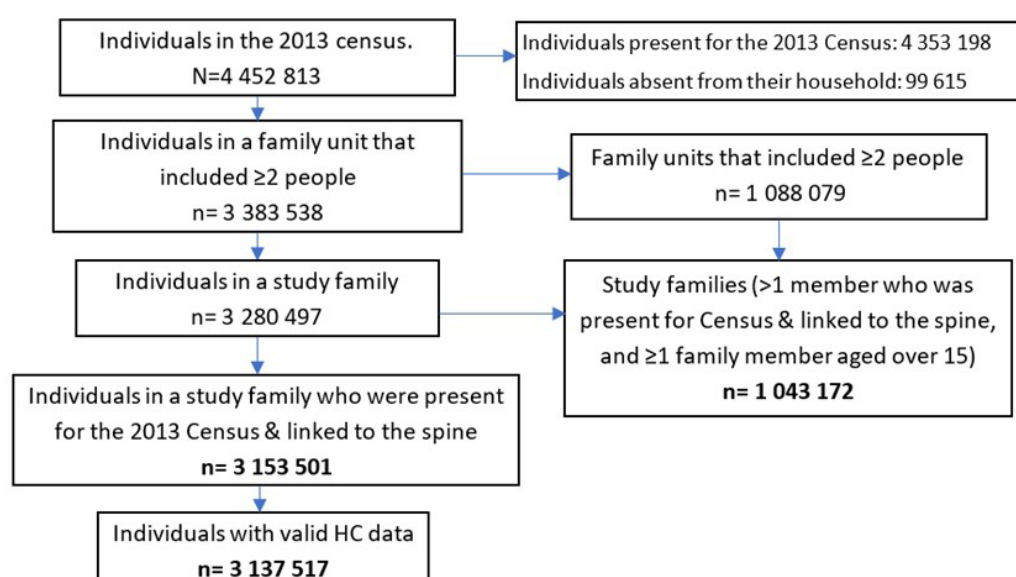
tax, visa or birth data, which are used to construct the spine. IDI data were accessed at Statistics New Zealand (Stats NZ) and The University of Auckland Data Labs by the lead author using the September 2021 IDI Refresh.

Population

The initial sample (N=4,452,813) included all individuals recorded by the New Zealand Census on 5 March 2013 (see Figure 1). Census 2013 family and extended family IDs (derived by Stats NZ from household information) for these individuals were used to construct family units, obtain family-level information and link to family members' individual data. People with the same family ID, who were not also a member of an extended family, were grouped into a family unit. People with the same extended family ID were grouped together into one family unit. Thus, a *study family* could include one or multiple family nuclei, with or without other related people.

Within the initial sample, 3,383,538 people had a family or extended family ID, resulting in the construction of 1,043,172 study families for inclusion in the study. All families were made up of two or more people, with least one family member aged 15 or over (in accordance with Stats NZ definitions).²⁷ Individuals within these families were included if they could be linked to the spine and were present in their household for the 2013 Census, since absentees' data are recorded but they are not assigned an individual ID that allows them to be linked to other datasets.

Figure 1: Study flowchart.



Measures

Socio-demographic characteristics

Individual and family socio-economic status was measured using area-level 2013 New Zealand Index of Deprivation (NZDep) data from Census, population and address datasets.²⁸ NZDep deciles were grouped into quintiles, with quintile 1 indicating people/families in the least deprived areas. Gender (as self-identified in Census 2013) was male or female, and age on 5 March 2013 was calculated in years. A child was defined as a person who was under 18 years of age. Categorisation of ethnicity (grouped total responses) was: European, Māori, Pacific peoples, Asian, Middle Eastern/Latin American/African (MELAA) and Other.²⁹ Multi-generation families were identified using the Census 2013 extended family type variable, which indicates whether extended families are one-generation, two-generation or three-or-more generation.

Health conditions

The HCs selected for this study were those that are included in the Manatū Hauora – Ministry of Health chronic condition/significant health events dataset (an IDI summary table): cancer, COPD, CHD (including myocardial infarction), diabetes, gout, stroke and TBI. With the addition of dementia and MHBCs, which were selected based on the availability of evidence-based case identification algorithms and criteria (see Appendix 1). MHBCs included attention-deficit hyperactivity disorder, anxiety disorders, autism spectrum disorder, bipolar disorder, conduct and disruptive disorders, depression, eating disorders, emotional problems, personality disorders, psychotic disorders and sleep disorders.

The following IDI datasets were searched for people who had received treatment or services for the HCs listed above: Accident Compensation Corporation (ACC) injury claims; disability needs assessment and service coordination (SOCRATES); the Cancer Registry; laboratory claims, outpatient and emergency visits (National Non-Admitted Patient Collection); pharmaceutical dispensing; public and private hospital discharges; mental health service contacts (Programme for the Integration of Mental Health Data); and the chronic condition/significant health events table. Searches were limited to records dating from 5 March 2008 up to and including 5 March 2013 (i.e., 5 years prior to identification of individuals within families). People who only had records

of COPD or gout when they were under the age of 20, or dementia under the age of 40, were excluded from these analyses (n=15,984), since there appeared to be some error in either linkage or data entry for at least one of their health records and thus it could not be determined that they did or did not have a HC (see Figure 1).

Analysis

Analyses were carried out in IDI Data Labs using SAS Enterprise Guide (version 8.3). Confidentiality rules required suppression of small numbers (<6) and random rounding of all counts to base 3, therefore some totals may not precisely add up. It was assumed that individuals with no records detected in health datasets did not have a HC, since they did not have treatment or service interactions for any of the HCs in any of the datasets searched.

Descriptive analyses were carried out at individual and family levels. Individual-level analyses included stratification by gender, age, ethnicity and NZDep quintile. Individuals were included in multiple ethnicity categories, where relevant. Individuals were divided into four groups: 1) no HC themselves or in a family member, 2) people who had a HC themselves but no other family members with a HC (HC person only), 3) no HC themselves but at least one family member with a HC (HC family only), or 4) people who had a HC and at least one family member with a HC (HC person and family). Families were stratified by composition and NZDep but not by individual-level characteristics (e.g., gender and ethnicity).

Results

Socio-demographic characteristics of the 3,137,517 individuals in families are reported in Table 1. Family composition and NZDep for the 1,043,172 study families are reported in Table 2.

Individuals living within a household family

In total, 899,949 people (28.7%) were identified as having at least one of the nine specified HCs (see Table 2; G2+G4) and an additional 1,020,987 people (32.5%) lived in a household family where other member(s) experienced a HC (G3). Thus overall, 61.2% of people (n=1,920,933) were experiencing at least one HC, either themselves or through a household family member (G2+G3+G4).

Table 2 shows a similar distribution across the four HC groups for males and females. Pacific peoples and those over 65 years old were most likely to be in a family affected by HCs, compared with other ethnicities and age groups. The proportion of people living in a family affected by any HC increased as area-level deprivation increased.

The proportion of individuals who were the only family member with a HC (G3) increased

with age, was higher for Europeans and lower for Pacific peoples and those in the highest NZDep quintile. Adults and Europeans were more likely to have a HC themselves *and* have another family member with a HC (G4) compared with children and other ethnicities, respectively.

Overall, children had a low rate of HCs themselves (11.0%, n=100,455), but more than half (53.3%; n=495,597) had a family member with a

Table 1: Percentage of individuals affected by HCs according to socio-demographic characteristics.

(% of individuals)	No HC (G1)	HC person only (G2)	HC family only (G3)	HC person and family (G4)
Total (N=3,137,517)	1,216,584 (38.8%)	397,929 (12.7%)	1,020,987 (32.5%)	502,017 (16.0%)
Female (48.6)	39.1	12.9	32.2	15.7
Male (51.4)	38.4	12.4	32.9	16.3
0 to 5 years (10.0)	47.3	3.2	45.2	4.3
6 to 17 years (19.2)	40.3	4.6	46.9	8.2
18 to 34 years (19.5)	45.4	11.7	31.1	11.9
35 to 64 years (40.2)	38.5	16.8	26.4	18.4
65 years and over (11.1)	18.0	22.2	21.1	38.7
Children (29.5)	42.7	4.1	46.3	6.9
Adults (70.5)	37.2	16.2	26.9	19.8
European (72.9)	37.7	13.7	31.5	17.1
Māori (15.4)	37.5	10.7	38.0	13.7
Pacific peoples (8.2)	32.3	8.2	45.2	14.4
Asian (12.4)	50.3	8.9	30.8	10.0
MELAA (1.2)	47.3	9.6	32.1	11.1
Other ethnicity (1.7)	38.9	13.7	30.8	16.5
NZDep Quintile 1* (22.6)	40.8	12.8	31.3	15.0
NZDep Quintile 2 (20.8)	40.6	13.0	31.1	15.4
NZDep Quintile 3 (19.7)	39.7	13.1	31.3	15.9
NZDep Quintile 4 (18.6)	37.5	12.9	32.6	17.0
NZDep Quintile 5 (18.4)	34.6	11.5	36.9	17.0

Health condition = HC; Middle Eastern/Latin American/African = MELAA; 2013 New Zealand Index of Deprivation = NZDep.

*NZDep Quintile 1 = least deprived.

HC, compared with 46.6% of adults (n=1,036,767). At the highest level of deprivation, 57.6% of children (n=119,196) had a family member with a HC (see Figure 2).

The proportion of people exposed to a HC either themselves or through a family member varied according to ethnicity and NZDep (see Figure 3). It was highest among Pacific peoples

(67.7%, n=174 393) and those in the highest NZDep quintile (65.4%, n=376 707). Figure 3 shows the interaction between ethnicity and deprivation. Relative disparities between the lowest and highest NZDep quintiles were greatest for Europeans (6.9% difference), and smallest for Māori (2.4%) and Asian peoples (3.3%).

Figure 2: Percentage of adults and children within each NZDep quintile who were living in a family in which at least one person had a HC.

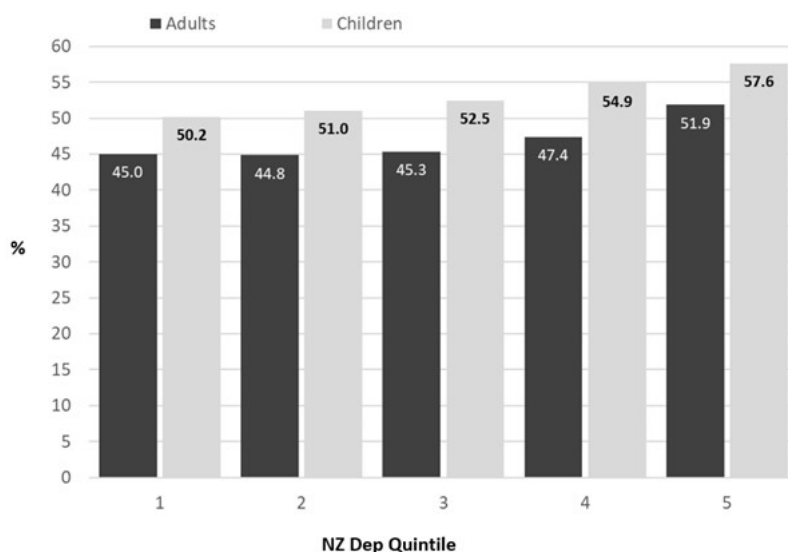
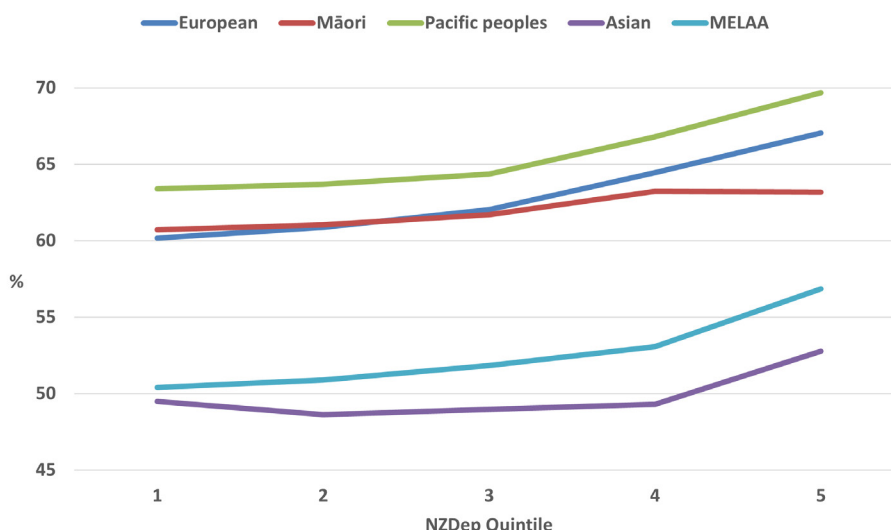


Figure 3: Percentage of people who were living in a family in which at least one person had a HC.



Health condition = HC; Middle Eastern/Latin American/African = MELAA; 2013 New Zealand Index of Deprivation = NZDep.

Table 2: Percentage of families with a HC according to family composition and area-level deprivation (NZDep).

n (% of families)	≥1 person with a HC	≥2 people with a HC	Cancer	COPD	CHD	Dementia	Diabetes	Gout	MHBCs	Stroke	TBI
Total 1,043,172 (100)	60.4	22.3	6.0	7.0	6.1	0.4	16.0	7.6	39.4	1.1	13.9
Families with ≥1 child 512,163 (49.1)	55.8	19.3	2.5	4.0	2.0	0.1	11.8	4.8	36.2	0.5	18.9
Multi-generation families 93,864 (9.0)	73.9	38.4	6.2	10.9	9.0	0.8	32.3	13.8	44.6	2.0	21.3
NZDep Quintile 1* 236,913 (22.7)	59.2	20.9	6.5	5.6	5.2	0.4	12.4	6.3	40.2	0.9	13.3
NZDep Quintile 2 221,469 (21.2)	59.2	21.1	6.2	6.2	5.7	0.4	13.9	6.5	39.6	1.0	13.2
NZDep Quintile 3 210,648 (20.2)	59.9	21.7	6.2	7.0	6.2	0.5	15.2	7.1	39.8	1.1	13.2
NZDep Quintile 4 195,366 (18.7)	61.7	23.3	5.9	8.1	6.8	0.5	17.5	8.1	40.4	1.2	14.1
NZDep Quintile 5 172,236 (16.5)	63.8	25.4	5.2	9.0	6.9	0.4	23.3	11.1	37.6	1.5	16.5

Health condition = HC; chronic obstructive pulmonary disease = COPD; coronary heart disease = CHD; traumatic brain injury = TBI; mental health/behaviour conditions = MHBCs; 2013 New Zealand Index of Deprivation = NZDep. *NZDep Quintile 1 = least deprived.

Household families experiencing health conditions

Table 2 shows the percentage of families that included at least one person with a HC (60.4%, n=629,700), two or more people with a HC (22.3%, n=232,627) and at least one person with a specific HC (0.4–39.4%). There were 397,932 families (38.1%) that included one person with a HC, 19.1% (n=199,185) had two people with a HC and 2.6% (n=27,585) had three or more people. Twenty-one families had more than seven members with a HC. Families with children had a lower rate of HCs (55.8%), while 73.9% of multi-generation families included at least one person with a HC. The proportion of families in which at least one person had a HC was highest for NZDep quintile 5 (63.8%). These patterns were similar for families that had two or more people with a HC (see Table 1).

The most common HCs within families were MHBCs (39.4%), followed by diabetes (16.0%), TBI (13.9%) and gout (7.6%). Families with children had lower rates of specific HCs compared to total population, except for TBI (18.9%). Multi-generation families had higher rates of each specific HC. The proportion of families affected by specific HCs generally increased with higher levels of deprivation, with the exception of cancer, where there was a decrease in the proportion of families affected as deprivation increased, and dementia, which was relatively uniform across groups.

Discussion

The burden and societal impact of HCs may be underestimated if research focusses on individuals rather than the whānau as a whole and does not account for outcomes of family members, especially children. Conversely, without understanding the social environments in which HCs are experienced, positive effects may be overlooked. An understanding of the extent to which HCs are experienced by New Zealand families provides an evidence base that can be built on to identify areas in which families need support, and factors that promote their success.

This nationwide study reported the rates of nine selected HCs among over 1 million New Zealand household families, and the more than 3 million individuals living in those families. In 2013, three in five household families (60.4%) had at least one person with at least one selected HC, and one in five (22.3%) had more than one person with a HC. Two in five families (39.4%) included at least one person with a MHBC; diabetes (16.0%) and TBI (13.9%) were also common in

families. Disparities in the proportion of families that experienced HCs were found across family composition and socio-economic status. Families with children had a lower rate of HCs (55.8%), while 73.9% of multi-generation families included at least one person with a HC. The latter is likely because multi-generation families were more likely to include people aged over 65 years.

Similar patterns were found for the individuals living in these families—48.6% of whom were living with a family member with a HC and 61.2% of whom either experienced a HC themselves or through a family member. There were variations across ethnic groups at each level of deprivation. Around half a million New Zealand children were living with a family member who had a HC; almost 25% of these children were living in the highest NZDep quintile (18–19% were living in each of the lower quintiles).

This was the first study to estimate the extent of a selected group of HCs among New Zealand household families and demonstrate the socio-demographic patterns associated with the presence of these HCs. These patterns align with previous New Zealand and global findings of inequity in health outcomes for these conditions, particularly for minority ethnic groups and those living in deprived areas.^{2,14} These characteristics are also likely to affect the extent to which having a family member with a HC affects health and wellbeing outcomes for individuals and the family as a whole.¹⁶ Evidence shows that caring for a family member with a HC has significant detrimental effects on wellbeing, particularly with regards to employment, financial stress and mental health.^{13,30} People living with a relative who has a HC appear to have a different socio-demographic profile compared with individuals that identify as family carers, who are more likely to be female, older European and Māori.¹³

Strengths

The main strength of the study was the use of population-wide linked data that provided a large, representative sample and high-quality individual- and family-level information.²⁶ A broad definition of family was used; people in multiple family nuclei that were living together, and other extended family members, were included in a single family unit. As such, there was a lower number of study families (n=1,043,172) compared with the Stats NZ 2013 Census count of 1,136,397 nuclear families,³¹ but an increased number of people were linked together within a family unit.

This method better represents the diversity of New Zealand family structures, particularly for Māori and Pacific peoples.³²

2013 Census data on socio-demographic characteristics, including family composition and individual-level ethnicity, has been rated as high quality.³³ Linking self-reported Census ethnicity data to health datasets improves representation for Māori and Pacific peoples, who are under-counted in health and disability data on ethnicity.³⁴ Using total response categorisation of ethnicity, rather than external prioritisation, reduces under-counts and age-related bias among non-Māori ethnic groups, particularly for those who identify with more than one ethnicity.³⁵

The HC case identification methods used in the study were more extensive than previous New Zealand research.^{4,10} For example, including ACC data and a broad range of diagnostic terms led to a high level of identification of TBI cases.⁸ That said, many people who experience a TBI do not present to secondary healthcare services or submit an ACC claim.³⁶ The high number of people with MHBCs was largely attributable to the inclusion of pharmaceutical data. This method has been shown to increase estimated rates of MHBCs, particularly for those with less severe conditions.⁴

Limitations

Family membership was not identifiable for 2.6% of households in the 2013 Census.³³ Therefore, some family members may have been missed from families in this study and some New Zealand families may not have been included. Our inclusion criteria did not include unrelated individuals who live together or sole-person households. In addition, our methods do not account for family members who live in more than one household (e.g., children in co-parenting families), related individuals who live in different households, or related people who live together but are not in a couple or parent-child relationship with another household member (e.g., adult siblings). As such, our findings cannot address potential impacts on individuals who have family members with HCs living in other households. Younger adults, Māori and Pacific peoples were under-counted in the 2013 Census, therefore our results for these groups may be less generalisable.³³

The majority of the IDI health searches used diagnostic codes to identify HCs (see Appendix 1). However, pharmaceutical, laboratory and outpatient service datasets were searched using medicine, test and health specialty codes, respectively.

IDI health searches do not identify people who only present to primary care, unless they are dispensed medication by a community pharmacy or undergo laboratory testing. As such, people with milder conditions may not have been identified by this study. Differing rates of HCs among specific groups may reflect disparities in recognition, access to health services, timeliness of diagnosis and reporting. The scope of the study was limited to nine selected HCs, and the inclusion of other conditions known to impact New Zealand families in future research may result in different findings. These conditions include, but are not limited to, asthma, arthritis, substance use, chronic kidney disease and rheumatic fever.

We used evidence-based case identification methods that have acknowledged strengths and limitations, particularly with regards to the risk of false positive case identification by inferring diagnosis from pharmaceutical data.^{5,10} The limitations of relying on administrative data for the case identification of HCs are widely recognised.⁵ Linkage across datasets within the IDI (e.g., between Census and health data) is based on probabilistic matching of individuals carried out by Stats NZ; this can result in false negative and false positive links between specific datasets and the IDI spine. False positive rates for Census 2013 and Manatū Hauora – Ministry of Health data for the September 2021 refresh were 0.9% and 0.8%, respectively.³⁷ Data management for the study mitigated for false positive matches by cross-checking dates of birth and removing individuals who appeared too young to receive a diagnosis for COPD, dementia or gout.

Conclusion

Three in five New Zealand household families included someone with at least one of the nine selected HCs included in this study, with differences in the proportion affected according to family composition, socio-economic status and an individual's ethnicity. As global populations age and multi-generational family living increases, more individuals are likely to experience HCs within their household.³⁸ Our results indicate that in New Zealand, high levels of family-based support may be needed among Pacific peoples, multi-generation families and those living in areas with a high level of deprivation. Our finding that almost one in four New Zealand families include more than one person with a HC suggests potential gains from culturally appropriate,

family-based preventative interventions that address modifiable risk factors for HCs, family-wide health screening/assessment and interventions for HCs that include the whole family.³⁹

These findings have implications for the Mahi Aroha – Carers’ Strategy Action Plan that is due to be updated in 2024. The previous plan (2019–2023) acknowledged the need for research on the needs of carers, recognising that this should include family members who do not necessarily identify

with the term “carer”.⁴⁰ Further research is needed on factors associated with the long-term impact of HCs on family members across the life-course, regardless of whether individuals are providing care for relatives with a HC. An understanding of the geographic distribution of New Zealand families affected by HCs, particularly multi-generation families, could further determine levels of need at the regional level.

COMPETING INTERESTS

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REFERENCES

1. Busija L, Tan J, Sanders KM. Associations between illness duration and health-related quality of life in specified mental and physical chronic health conditions: results from a population-based survey. *Qual Life Res.* 2017;26(10):2671-81. doi: 10.1007/s11136-017-1592-7.
2. Holder-Pearson L, Chase JG. Socio-Economic Inequity: Diabetes in New Zealand. *Front Med.* 2022;9:756223. doi: 10.3389/fmed.2022.756223.
3. Theodore R, Bowden N, Kokaua J, et al. Mental health inequities for Māori youth: a population-level study of mental health service data. *N Z Med J.* 2022;135(1567):79-90.
4. Blakely T, Siggilekow F, Irfan M, et al. Disease-related income and economic productivity loss in New Zealand: A longitudinal analysis of linked individual-level data. *PLoS Med.* 2021;18(11):e1003848. doi: 10.1371/journal.pmed.1003848.
5. Bowden N, Gibb S, Thabrew H, et al. Case identification of mental health and related problems in children and young people using the New Zealand Integrated Data Infrastructure. *BMC Med Inform Decis Mak.* 2020;20(1):42. doi: 10.1186/s12911-020-1057-8.
6. Dixon S. The Employment and Income Effects of Eight Chronic and Acute Health Conditions. New Zealand Treasury Working Paper [Internet]. Wellington (NZ): The Treasury; 2015 [cited 2023 May 18]. Available from: <https://www.treasury.govt.nz/publications/wp/employment-and-income-effects-eight-chronic-and-acute-health-conditions-wp-15-15#abstract>
7. Barnes LA, Eng A, Corbin M, et al. The Prevalence of Cardiovascular Risk Factors in Different Occupational Groups in New Zealand. *Ann Work Expo Health.* 2020;64(6):645-58. doi: 10.1093/annweh/wxaa040.
8. Horspool N, Crawford L, Rutherford L. Traumatic brain injury and the criminal justice system [Internet]. Wellington (NZ): Justice Sector; 2017 [cited 2023 May 18]. Available from: <https://www.justice.govt.nz/assets/Traumatic-Brain-Injury-paper-.pdf>
9. Walesby KE, Exeter DJ, Gibb S, et al. Prevalence and geographical variation of dementia in New Zealand from 2012 to 2015: Brief report utilising routinely collected data within the Integrated Data Infrastructure. *Australas J Ageing.* 2020;39(3):297-304. doi: 10.1111/ajag.12790.
10. Richmond-Rakerd LS, D'Souza S, Milne BJ, et al. Longitudinal Associations of Mental Disorders With Physical Diseases and Mortality Among 2.3 Million New Zealand Citizens. *JAMA Netw Open.* 2021;4(1):e2033448. doi: 10.1001/jamanetworkopen.2020.33448.
11. Goering S. Rethinking disability: the social model of disability and chronic disease. *Curr Rev Musculoskelet Med.* 2015;8(2):134-8. doi: 10.1007/

- s12178-015-9273-z.
12. Ratima M, Theodore R, Tamati A, et al. Te Kura Mai i Tawhiti: A collaborative lifecourse approach to health, wellbeing and whanau development. *MAI J*. 2019;8(1):63-76. doi: 10.20507/MAIJournal.2019.8.1.5.
 13. Grimmond D. The economic value and impacts of informal care in New Zealand [Internet]. NZ: Carers NZ and the NZ Carers Alliance; 2014 [cited 2023 May 18]. Available from: <https://carers.net.nz/wp-content/uploads/2020/11/The-economic-value-of-informal-care-in-New-Zealand-Final-copy-5.pdf>
 14. New Zealand Institute of Economic Research. The cost of long-term conditions in New Zealand [Internet]. Wellington (NZ): New Zealand Institute of Economic Research; 2022 [cited 2022 Oct 21]. Available from: health.govt.nz/system/files/documents/publications/cost_of_illness_ltcns_2_jun_-_jr.pdf
 15. Ysseldyk R, Kuran N, Powell S, Villeneuve PJ. Self-reported health impacts of caregiving by age and income among participants of the Canadian 2012 General Social Survey. *Health Promot Chronic Dis Prev Can*. 2019;39(5):169-77. doi: 10.24095/hpcdp.39.5.01.
 16. Jou J, Upchurch DM, Johnson PJ. Delay and nonreceipt of needed healthcare in U.S. adults with household family members with serious health needs. *Fam Syst Health*. 2023;41(3):320-31. doi: 10.1037/fsh0000787.
 17. Shah R, Ali FM, Finlay AY, Salek MS. Family reported outcomes, an unmet need in the management of a patient's disease: appraisal of the literature. *Health Qual Life Outcomes*. 2021;19(1):194. doi: 10.1186/s12955-021-01819-4.
 18. Migliorini C, Callaway L, Moore S, Simpson GK. Family and TBI: an investigation using the Family Outcome Measure - FOM-40. *Brain Inj*. 2019;33(3):282-90. doi: 10.1080/02699052.2018.1553307.
 19. Barkmann C, Romer G, Watson M, Schulte-Markwort M. Parental physical illness as a risk for psychosocial maladjustment in children and adolescents: epidemiological findings from a national survey in Germany. *Psychosomatics*. 2007;48(6):476-81. doi: 10.1176/appi.psy.48.6.476.
 20. Mensah FK, Kiernan KE. Parents' mental health and children's cognitive and social development: families in England in the Millenium Cohort Study. *Soc Psychiatry Psychiatr Epidemiol*. 2010;45(11):1023-35. doi: 10.1007/s00127-009-0137-y.
 21. Weaver KE, Rowland JH, Alfano CM, McNeel TS. Parental cancer and the family: a population-based estimate of the number of US cancer survivors residing with their minor children. *Cancer*. 2010;116(18):4395-401. doi: 10.1002/cncr.25368.
 22. Moffat AK, Redmond G. Is having a family member with chronic health concerns bad for young people's health? Cross-sectional evidence from a national survey of young Australians. *BMJ Open*. 2017;7(1):e013946. doi: 10.1136/bmjopen-2016-013946.
 23. Brehaut JC, Kohen DE, Garner RE, et al. Health Among Caregivers of Children With Health Problems: Findings From a Canadian Population-Based Study. *Am J Public Health*. 2009;99(7):1254-62. doi: 10.2105/AJPH.2007.129817.
 24. Maybery DJ, Reupert AE, Patrick K, et al. Prevalence of parental mental illness in Australian families. *Psychiatr Bull*. 2009;33(1):22-6. doi: 10.1192/pb.bp.107.018861.
 25. Smith J, Ali P, Birks Y, et al. Umbrella review of family-focused care interventions supporting families where a family member has a long-term condition. *J Adv Nurs*. 2020;76(8):1911-23. doi: 10.1111/jan.14367.
 26. Milne BJ, Atkinson J, Blakely T, et al. Data Resource Profile: The New Zealand Integrated Data Infrastructure (IDI). *Int J Epidemiol*. 2019;48(3):677-677e. doi: 10.1093/ije/dyz014. Erratum in: *Int J Epidemiol*. 2019 Jun 1;48(3):1027.
 27. Statistics New Zealand Tauranga Aotearoa. 2013 Census definitions and forms [Internet]. Wellington (NZ): Stats NZ; 2013 [cited 2023 May 18]. Available from: <https://www.stats.govt.nz/assets/Uploads/Retirement-of-archive-website-project-files/Methods/2013-Census-definitions-and-forms/2013-census-definitions-forms.pdf>
 28. Atkinson J, Salmond C, Crampton P. NZDep2013 Index of Deprivation [Internet]. Wellington (NZ): Department of Public Health, University of Otago; 2014 [cited 2023 May 18]. Available from: <https://www.health.govt.nz/publication/nzdep2013-index-deprivation>
 29. Statistics New Zealand Tauranga Aotearoa. Ethnicity New Zealand Standard Classification 2005 V2.1.0 [Internet]. Wellington (NZ): Stats NZ; 2021 [cited 2022 Feb 17]. Available from: http://aria.stats.govt.nz/aria/?_ga=2.23623930.1939904703.1666222931-1047940683.1649818245#ClassificationView:uri=http://stats.govt.nz/cms/ClassificationVersion/YVqOcFHSIguKkT17
 30. Carers NZ and the Carers Alliance. The State of Caring in Aotearoa [Internet]. NZ: Synergia; 2022 [cited 2023 May 18]. Available from: <https://carers.net.nz/wp-content/uploads/2022/07/State-of->

- Caring-Report-Aug2022.pdf
31. Statistics New Zealand Tatauranga Aotearoa. 2013 Census QuickStats about families and households [Internet]. Wellington (NZ): Stats NZ; 2014 [cited 2023 May 18]. Available from: <https://www.stats.govt.nz/reports/2013-census-quickstats-about-families-and-households/>
 32. Crothers C, McCormack F. Towards a statistical typology of New Zealand households and families [Internet]. Wellington (NZ): Social Policy Evaluation and Research Unit (Superu); 2006 [cited 2023 May 18]. Available from: <https://thehub.swa.govt.nz/assets/documents/BS-towards-a-statistical-typology.pdf>
 33. Statistics New Zealand Tatauranga Aotearoa. Post-enumeration survey: 2013 [Internet]. Wellington (NZ): Stats NZ; 2014 [cited 2023 May 18]. Available from: <https://www.stats.govt.nz/information-releases/post-enumeration-survey-2013/>
 34. Harris R, Paine SJ, Atkinson J, et al. We still don't count: the under-counting and under-representation of Māori in health and disability sector data. *N Z Med J*. 2022;135(1567):54-78.
 35. Boven N, Exeter D, Sporle A, Shackleton N. The implications of different ethnicity categorisation methods for understanding outcomes and developing policy in New Zealand. *Kōtuitui N Z J Soc Sci Online*. 2020;15(1):123-39. doi: 10.1080/1177083X.2019.1657912.
 36. ACC. Traumatic Brain Injury Strategy and Action Plan 2017–2021. Wellington (NZ): ACC; 2017.
 37. Statistics New Zealand Tatauranga Aotearoa. Integrated Data Infrastructure (IDI) refresh: linking report. *Statistical Methods*, September 2021 refresh [Internet]. Wellington (NZ): Stats NZ; 2021 [cited 2023 Apr 6]. Available from: <https://statsnz.contentdm.oclc.org/digital/api/collection/p20045coll4/id/542/download>
 38. Freedman VA, Agree EM, Seltzer JA, et al. The Changing Demography of Late-Life Family Caregiving: A Research Agenda to Understand Future Care Networks for An Aging U.S. Population. *Gerontologist*. 2023;64(2):gnad036. doi: 10.1093/geront/gnad036.
 39. Ho YL, Mahirah D, Ho CZ, Thumboo J. The role of the family in health promotion: a scoping review of models and mechanisms. *Health Promot Int*. 2022;37(6):daac119. doi: 10.1093/heapro/daac119.
 40. Ministry of Social Development. Mahi Aroha: Carers' Strategy Action Plan 2019–2023 [Internet]. Wellington (NZ): Ministry of Social Development; 2019 [cited 2023 May 18]. Available from: <https://www.msd.govt.nz/documents/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/carers-strategy-action-plan-2019-2023.pdf>

Appendix 1: Case identification of selected health conditions (HCs)

HC case identification algorithms were sourced from the data dictionary for the Manatū Hauora – Ministry of Health chronic condition/significant health events dataset (CC),¹ the Virtual Diabetes Register (VDR) Technical Guide,² the Social Investment Agency mental health and addiction conditions data definition (SIA),³ Bowden et al. (MHBC),⁴ ACC (TBI)⁵ and Walesby et al. (dementia).⁶ The IDI health datasets searched were: Accident Compensation Corporation (ACC) injury claims; disability needs assessment and service coordination (SOCRATES); the Cancer Registry; laboratory claims, National Non-Admitted Patient Collection (NNPAC); pharmaceutical dispensing; public and private hospital discharges (NMDS); Programme for the Integration of Mental Health Data (PRIMHD); and chronic condition/significant health events (CC).

Appendix Table 1 shows the search criteria and datasets used for each HC, and Appendix Table 2 shows a summary of the definitions for each HC.

Appendix Table 1: Search algorithm sources and IDI datasets used for HC case identification.

HC	Cancer	COPD	CHD	Dementia	Diabetes	Gout	Stroke	TBI	MHBCs
Algorithm source	CC	CC	CC	Walesby	VDR	CC	CC	ACC	SIA & Bowden
ACC claims (diagnosis codes*)	X	X	X	X	X	X	X	X	X
Cancer register (all entries)	X	-	-	-	-	-	-	-	-
Chronic conditions table (all)	X	X	X	-	X	X	X	X	-
interRAI (diagnosis codes)	X	X	X	X	X	-	X	-	X
NNPAC (health specialty and purchase unit codes)	-	-	-	-	X	-	-	-	X
NMDS (private and public) (diagnosis* and procedure codes)	X	X	X	X	X	X	X	X	X
PRIMHD (diagnosis codes*)	X	X	X	X	X	X	X	X	X
SOCRATES (diagnosis codes)	X	X	X	X	X	X	X	X	X
Pharmaceutical dispensing (medication codes)	-	X	X	X	X	X	-	-	X
Laboratory tests (test codes)	-	-	-	-	X	-	-	-	-

*International Classification of Diseases 10th Revision (ICD-10) codes were used for these datasets.

Chronic obstructive pulmonary disease = COPD; coronary heart disease = CHD; mental health and behavioural conditions = MHBCs; traumatic brain injury = TBI.

Appendix Table 2: Summary of definitions for each HC.

HC	ICD codes	Other codes
Cancer	C00–C96, D45–47	SOCRATES: 2901 (Cancer). interRAI: Cancer.
COPD	J40–J44	SOCRATES: 2501 (COPD). interRAI: Pulmonary disease. Medication: Ipratropium Bromide, Salbutamol with Ipratropium Bromide, Tiotropium Bromide, or, only if no previous diagnosis of asthma: Aminophylline, Theophylline.
CHD (and AMI)	I20–25	SOCRATES: 2404 (AMI); 2405 (CHD). interRAI: Heart disease. NMDS procedures codes: 3530400, 3530500, 3531000–2, 3849700–7, 3850000–4, 3850300–4, 3863700, 9020100–3. Medication: Two or more dispensings within 12 months: Glyceryl trinitrate, Isosorbide dinitrate, Isosorbide mononitrate, Nicorandil, or Perhexiline maleate.
Dementia	F00–F04, F051, F107, F137, F187, F197, G3	SOCRATES: 1401 (Alzheimer’s); 1405 (Vascular dementia); 1499 (Other dementia). interRAI: Alzheimer’s or dementia. Medication: Donepezil or Rivastigmine
Diabetes	E10–11, E13–14 0240–0243	SOCRATES: 2801 (Diabetes). interRAI: Diabetes mellitus. NNPAC purchase unit codes: M96, M98, M20006, M2007. Medication: Insulin or oral hypoglycaemic agent (2 or more dispensings in 24m); Laboratory tests: 4 or more Glycated haemoglobin tests in 24 months (BG=2) AND 2 or more ACR, microalbumin or early morning urine tests (BP=8).
Gout	M10	SOCRATES: 2004 (Gout). Medication: Colchicine or Allopurinol (without malignant neoplasm C81–C96)
Stroke	I60–I64	SOCRATES: 2401 (Stroke). interRAI: Stroke/CVA
TBI	See Horspool et al. (2017) ⁵	SOCRATES: 1802 (Brain injury)
MHBCs	See Bowden et al. (2020) ⁴	SOCRATES: 1201 (ADHD); 1206, 1207, 1211 (ASD); 9006 (Social Communication Disorder); 130 (Psychiatric disorders [excluding 1301 Alcohol/drug related disorders]) interRAI: anxiety, bipolar disorder, depression, schizophrenia. NNPAC (service provision codes): Y00–Y18, Y30–Y39, Y50–Y58, Y71–Y77. Two or more dispensings within 12 months of any mental health medication, see Bowden et al. (2020) for codes. ⁴

Attention-deficit hyperactivity disorder = ADHD; autism spectrum disorder = ASD; chronic obstructive pulmonary disease = COPD; coronary heart disease = CHD; acute myocardial infarction = AMI; mental health and behavioural conditions = MHBCs; traumatic brain injury = TBI.

APPENDIX REFERENCES

1. Statistics New Zealand Tatauranga Aotearoa. IDI Data Dictionary: Chronic condition/significant health event cohort [Internet]. Wellington (NZ): Stats NZ; 2015 [cited 2024 Feb 13]. Available from: <https://www.stats.govt.nz/integrated-data/integrated-data-infrastructure/data-in-the-idi/>
2. Health New Zealand – Te Whatu Ora. Virtual Diabetes Register: Technical Guide [Internet]. Wellington (NZ): Health New Zealand – Te Whatu Ora; 2024 [cited 2023 May 18]. Available from: <https://www.tewhatauora.govt.nz/publications/virtual-diabetes-register-technical-guide/>
3. Social Investment Agency. Using integrated data to understand mental health and addiction conditions [Internet]. Wellington (NZ): Social Investment Agency; 2019 [cited 2023 Mar 28]. Available from: [https://swa.govt.nz/assets/Publications/reports/Using-integrated-data-to-understand-mental-](https://swa.govt.nz/assets/Publications/reports/Using-integrated-data-to-understand-mental-health-and-addiction-conditions-1.pdf)
4. Bowden N, Gibb S, Thabrew H, et al. Case identification of mental health and related problems in children and young people using the New Zealand Integrated Data Infrastructure. *BMC Med Inf Decis Mak.* 2020;20(1):42. doi: 10.1186/s12911-020-1057-8.
5. Horspool N, Crawford L, Rutherford L. Traumatic brain injury and the criminal justice system [Internet]. Wellington (NZ): Justice Sector; 2017 [cited 2023 Mar 18]. Available from: <https://www.justice.govt.nz/assets/Traumatic-Brain-Injury-paper-.pdf>
6. Walesby KE, Exeter DJ, Gibb S, et al. Prevalence and geographical variation of dementia in New Zealand from 2012 to 2015: Brief report utilising routinely collected data within the Integrated Data Infrastructure. *Australas J Ageing.* 2020;39(3):297-304. doi: 10.1111/ajag.12790.