

A BETTER
START

E Tīpue Rea

Impact of chronic health conditions on families across the life-course

COMPASS Seminar

27 July 2021

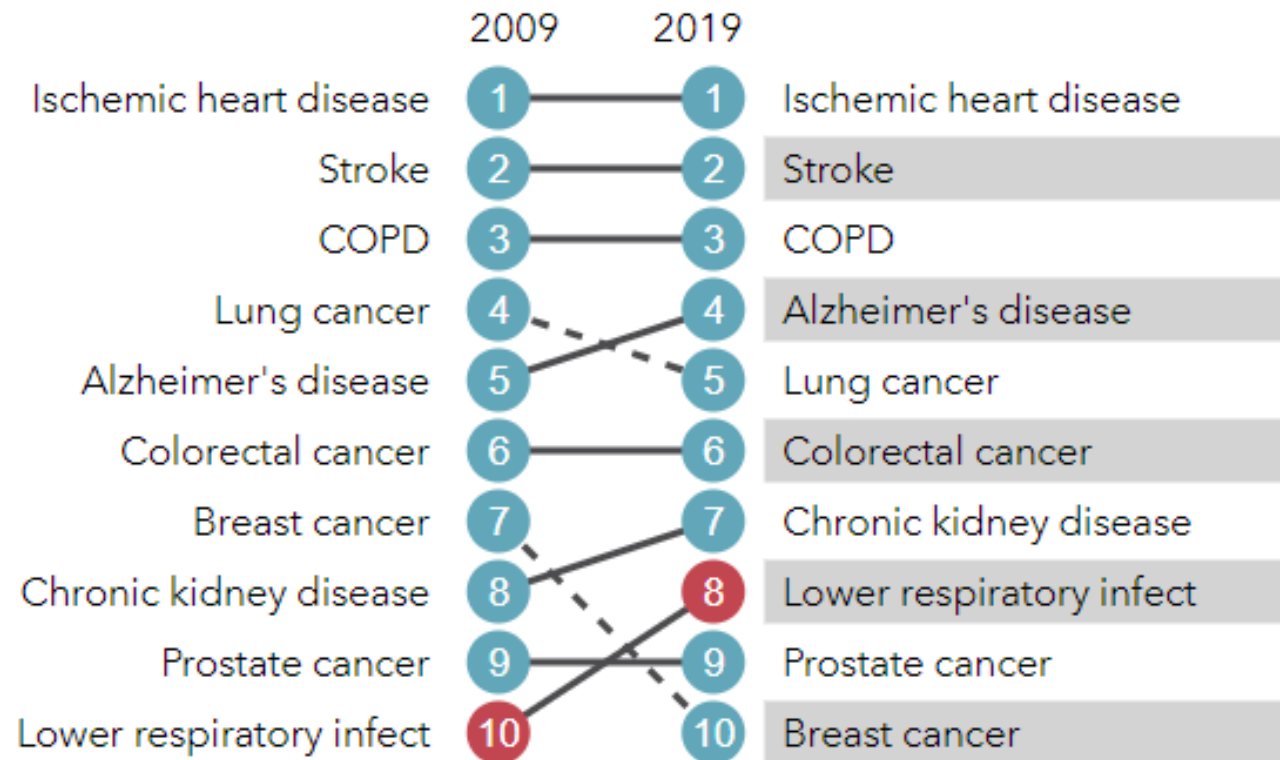
Barry Milne

Background

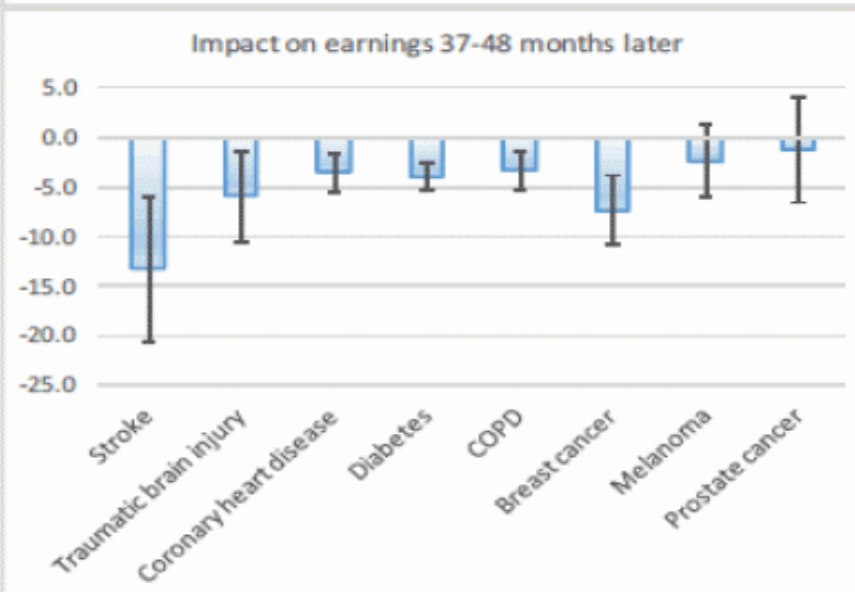
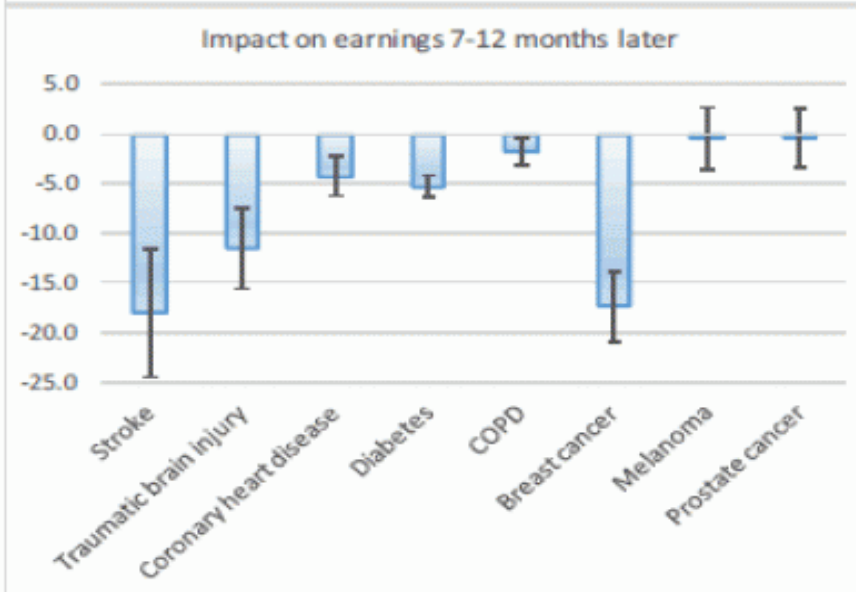
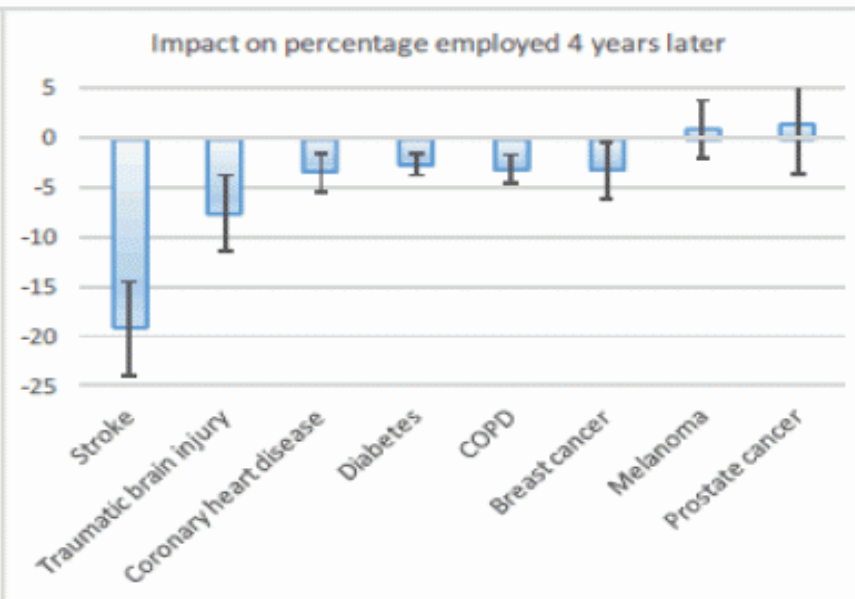
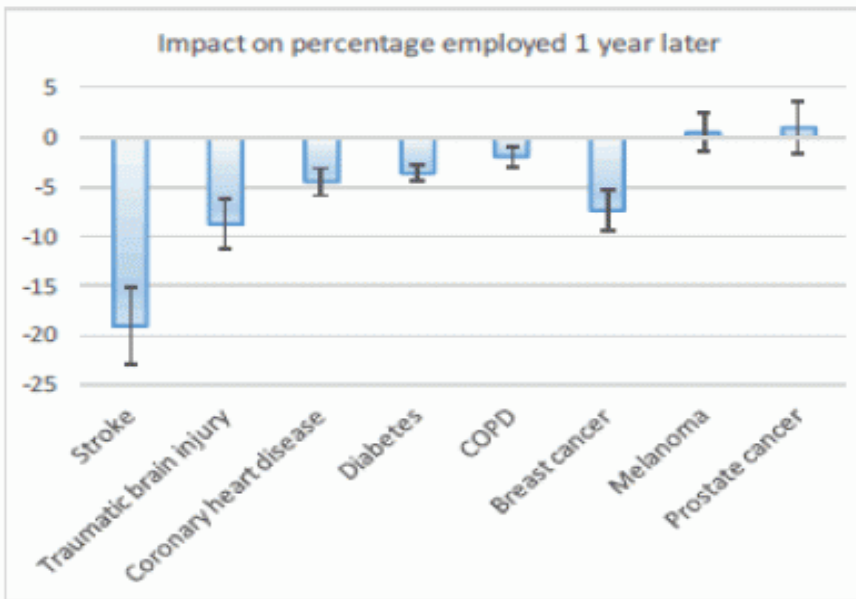
- Chronic conditions (cancer, cardiovascular disease, diabetes, mental health and obesity)
 - Leading cause of premature death and disability
 - High rates among Māori and Pacific populations
 - Impacts to the individual on functioning and quality of life well established

What causes the most deaths?

- Communicable, maternal, neonatal, and nutritional diseases
- Non-communicable diseases
- Injuries

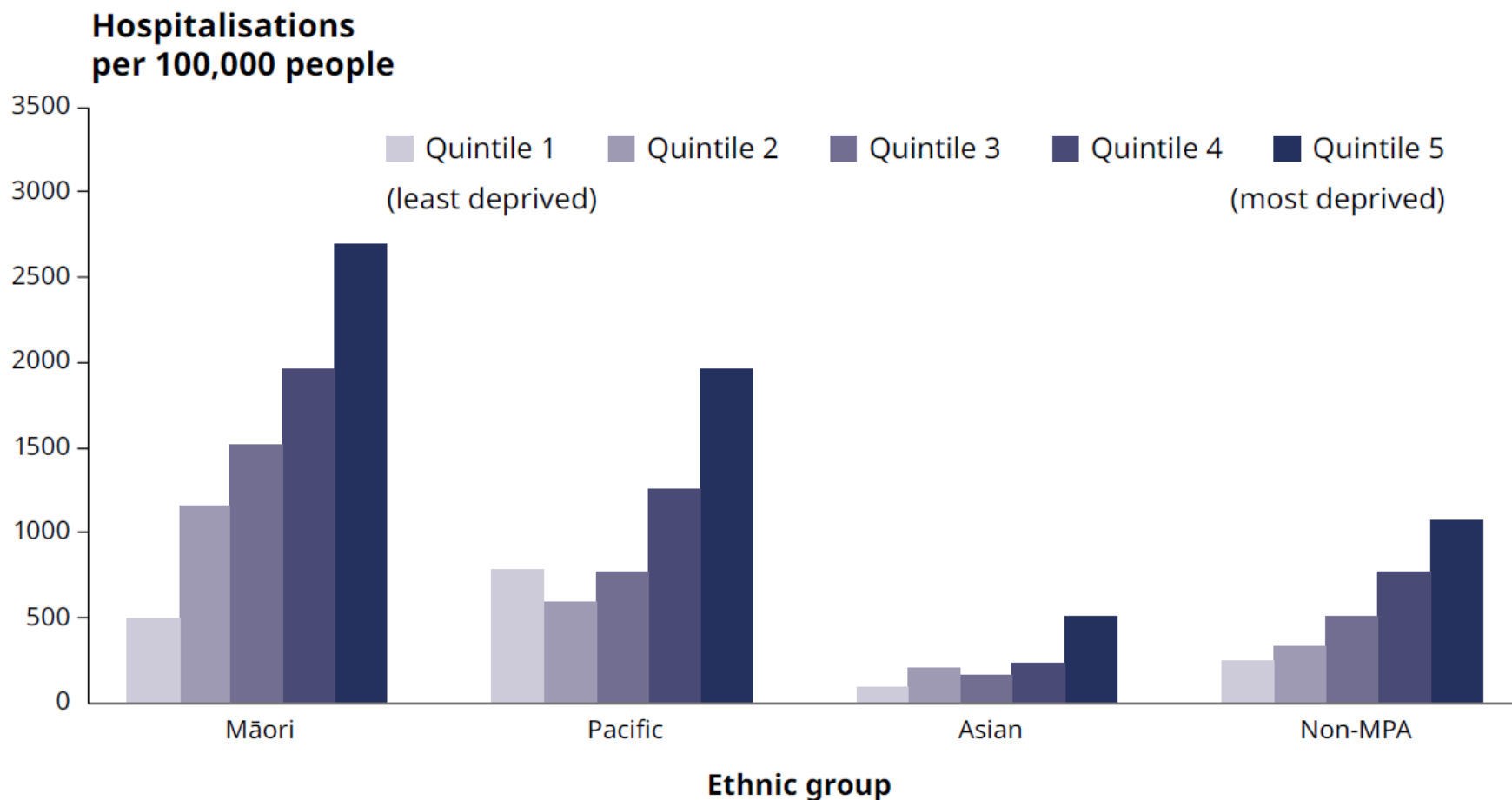


Global Burden of Disease – New Zealand
<http://www.healthdata.org/new-zealand>



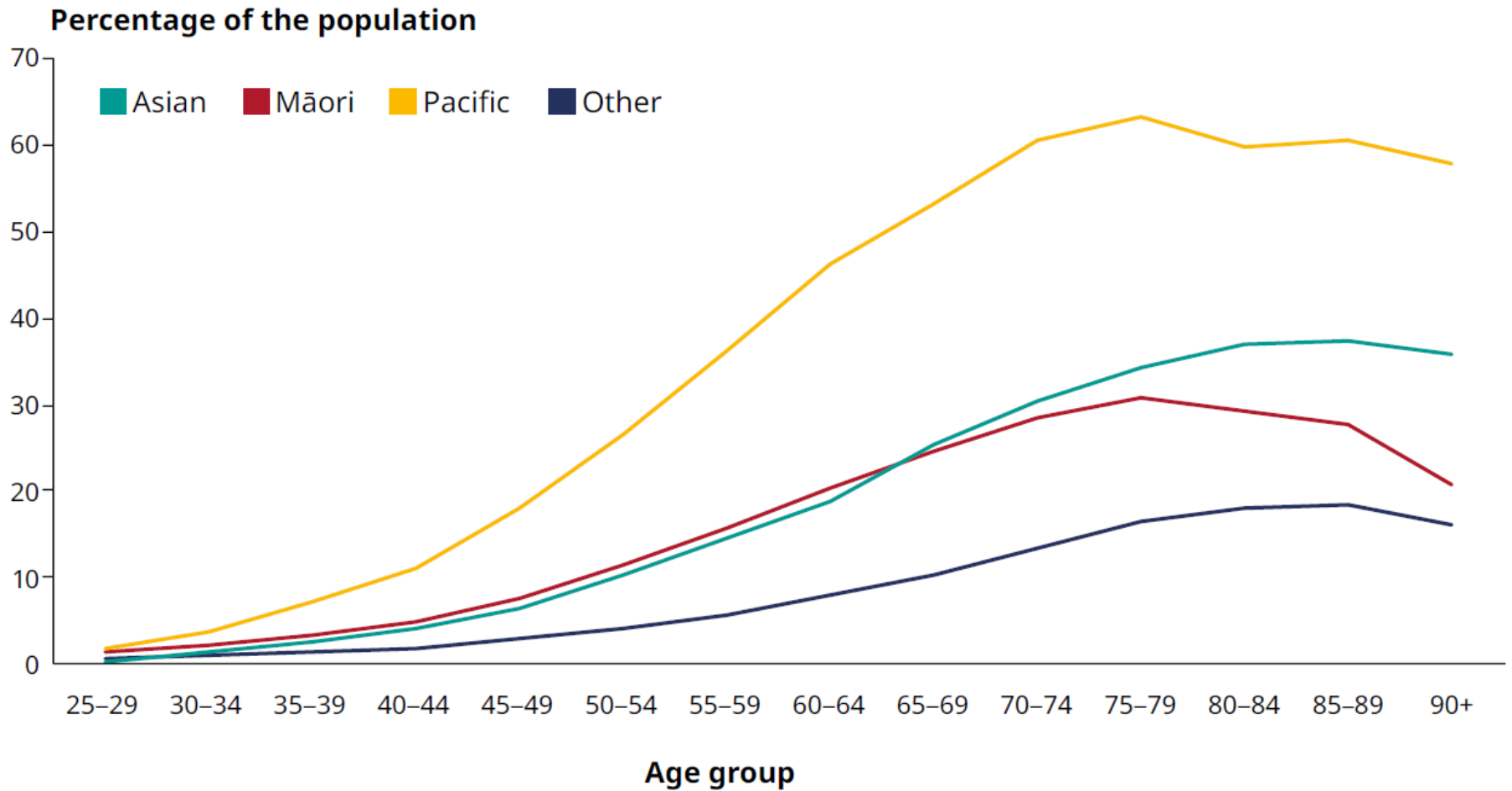
Dixon S. (2015). The Employment and Income Effects of Eight Chronic and Acute Health Conditions. Treasury Working Paper (WP 15/15)

Figure 30: Age-standardised COPD hospitalisations in adults aged 40 years and over by ethnicity and socioeconomic deprivation quintile, 2015



Ministry of Health. 2018. *Health and Independence Report 2017. The Director-General of Health's Annual Report on the State of Public Health.* Wellington: Ministry of Health.

Figure 33: Estimated percentage of New Zealand's adult population living with diabetes by ethnicity, average over 2013–2015



Ministry of Health. 2018. *Health and Independence Report 2017. The Director-General of Health's Annual Report on the State of Public Health.* Wellington: Ministry of Health.

Impact on families

- Far less known about the impacts on family
- Focus has tended to be either carers (typically older spouses) or children of depressed mothers, or parents of chronically ill children

Carers

- Carers report greater loneliness/isolation, less exercise, greater alcohol use
 - Canadian General Social survey (Ysseldyk et al., 2019)
- Older carers
 - Experience psychological distress
 - Have adverse health outcomes
 - Have lower relationship quality
 - May have work impacted
 - Schulz et al., 2020, Ann Rev Psychol
- Cancer carers
 - Have worse mental health, physical health and sleep
 - Number of studies by Kelly Shaffer and colleagues

Parental depression

- Parental depression shown to impact
 - Childhood obesity
 - Marco et al., 2020
 - Behaviour problems
 - Seay and Kohl, 2015; Harris & Santos, 2020
 - Depression
 - Weissman et al., 2006; Wickersham et al., 2020
 - Maltreatment
 - Ayers et al., 2019
- Limited evidence for physical health impacts
 - Pierce et al., 2020

Parents of ill children

- Increased
 - anxiety/depression
 - CVD/mortality (congenital abnormalities)
 - Systematic review: Cohn et al., 2020

Impact on families

- Gaps in literature
 - Impacts of parents with chronic conditions on children
 - Education, socioeconomic outcomes
 - Full range of family members
 - Full range of carers
 - Multimorbidity
 - Multiply affected families
 - Multigenerational families
 - Family-level descriptives
 - Positives and resilience

Why is this important?

New Zealand has a serious and growing type 2 diabetes problem. It is predicted that within the next 20 years, the number of people with type 2 diabetes will increase by 70-90%. Of these people, Māori, Pacific and Asian will be worst affected. Allowing this to occur will have a hugely detrimental impact on the wellbeing of our people, but also on the sustainability of our health system and economy. There is an urgent need to recognise diabetes as a Government health priority and to invest in future prevention, treatment and care.

- Estimates and projections for disease burden likely to be greatly underestimated

The Economic and Social Cost of Type 2 Diabetes

“Can also have a profound impact on the person’s family, whānau and friends” (p24)



but no data to quantify this

Why is this important?

- Greater recognition and support for the role of carers
 - Extent of caring itself likely underestimated
 - E.g., partner looking after spouse
 - Older children looking after younger children and grandparents
 - The role of young carers
 - Acceptance that caring may be rewarding as well as (instead of) being a burden

Why is this important?

- If burden is underestimated and involves impacts on family members as well as individuals... then should this be factored in when deciding treatments to fund? [...provocative...]

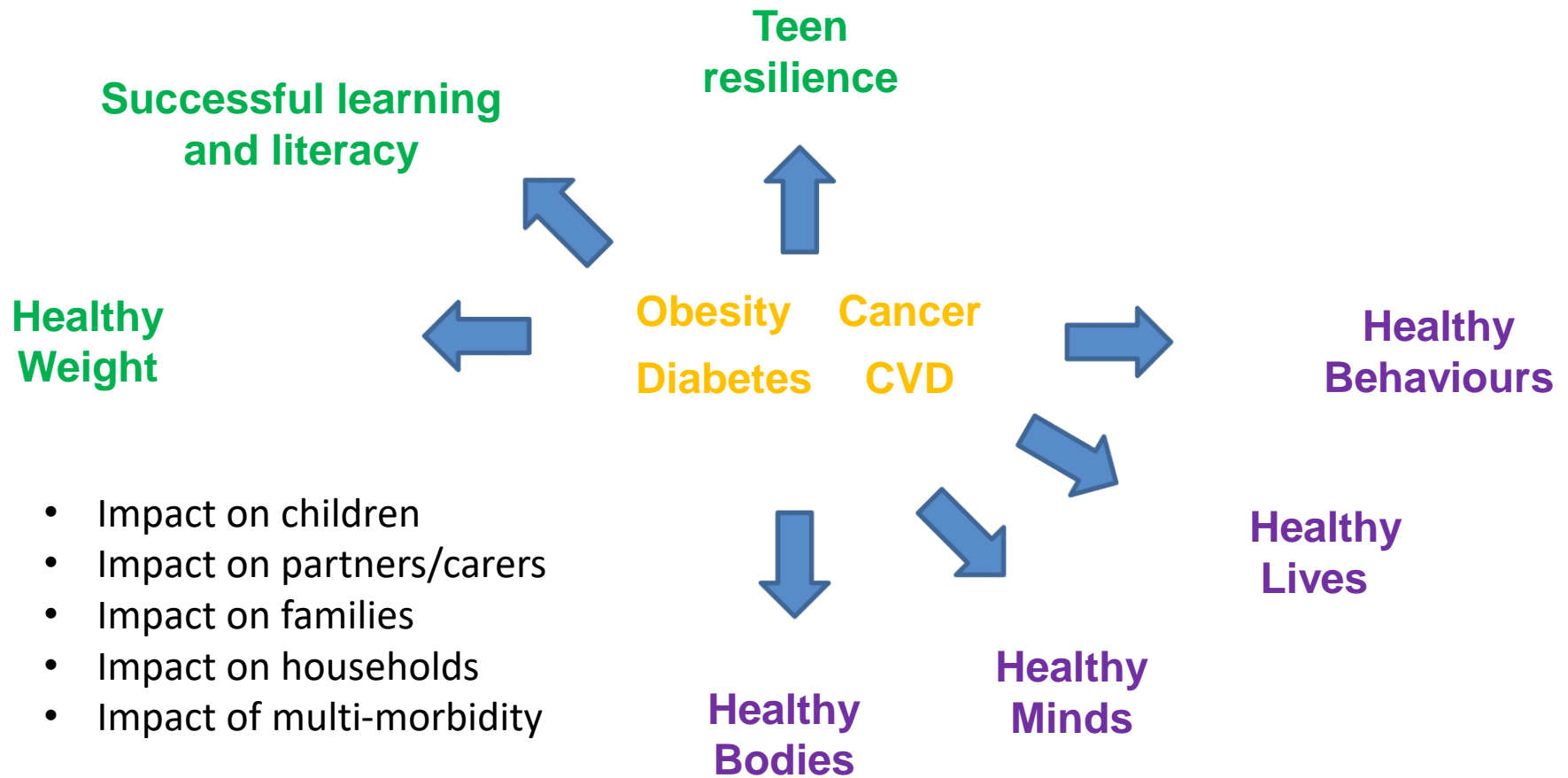
Basic idea

- Obj 1 (PI: Milne): Determine the influence of chronic disease on the wider family at different life stages, with a focus on four areas: children, households, partners and carers, and older adults.
 - Quantitative investigation using administrative data
- Obj 2 (PI: Dewes): Determine the family, household and community strengths that allow people in the Tokelauan community to thrive despite the challenges of living in families with chronic disease.
 - In depth qualitative study

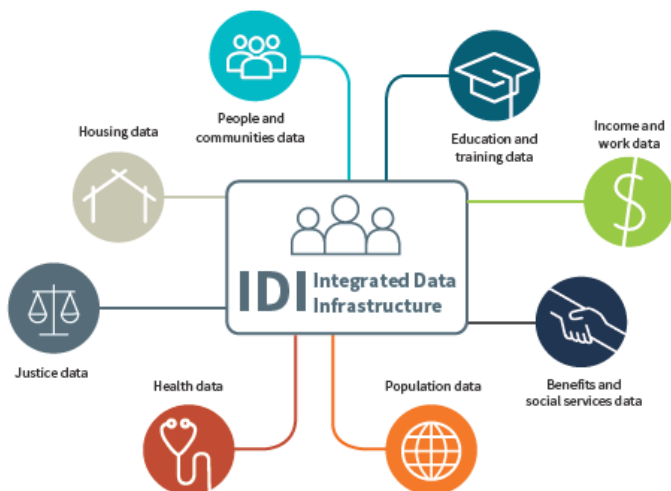
Chronic Disease on Family

- Barry Milne (PI)
- Data management
 - Lisa Underwood (COMPASS), Andrea Teng (UOW)
- Children and Families
 - Lisa Underwood
- Partners
 - Janeen Baxter, Marin O’Flaherty, Jack Lam, Yanshu Huang (UQ)
- Elders
 - Hamish Jamieson, Ulrich Bergler, Lukas Marek (UC)

Impact of chronic disease on families



Stats NZ's Integrated Data Infrastructure (IDI) is a large research database containing de-identified microdata about people and households.



The IDI contains person-centred microdata from a range of government agencies, Stats NZ surveys including the 2013 Census, and non-government organisations. For more information about data in the IDI, see www.stats.govt.nz/integrated-data/integrated-data-infrastructure

The Longitudinal Business Database (LBD) complements the IDI with microdata about businesses. For more information about data in the LBD, see www.stats.govt.nz/integrated-data/longitudinal-business-database

Benefits and social services data

- ACC injury claims – from 1994
- Benefits – from 1990
- Children's Action Plan – from 1996
- Child, Youth, and Family – from 1991
- Early Start Project – from 2016
- Family Start – from 2008
- Student loans and allowances – from 1992
- Working for Families – from 2003
- Youth services – from 2004



Education and training data

- Early childhood education participation – from 2008
- Industry training – from 2001
- Primary education – from 2007
- Programme for the International Assessment of Adult Competencies – from 2014
- Secondary education – from 2004
- Targeted training – from 2001
- Tertiary education – from 1994



Health data

- B4 School Checks – from 2011
- Cancer registrations – from 1995
- Chronic conditions – from 2007
- General medical services claims – from 2002
- Health tracker – 2006–14
- Immunisation – from 2006
- interRAI – from 2014
- Laboratory claims – from 2003
- Maternity – from 2003
- Mortality – from 1988
- National Booking Reporting System – from 2003
- National Needs Assessment and Service Coordination Information System (SOCRATES)
- National non-admitted patient collection – from 2007
- NES enrolments – from 2019
- Pharmaceuticals – from 2005
- PHO enrolments – 2003–2019
- Population cohort demographics and addresses – from 2004
- PRIMHD – from 2008
- Privately funded hospital discharges – from 2001
- Publicly funded hospital discharges – from 1988



Housing data

- Social housing – from 2000
- Tenancy – from 2000



Income and work data

- Household economic survey – from 2006
- Household labour force survey – from 2006
- NZ income survey – from 2006
- Survey of family, income, and employment – 2002–10
- Tax and income – from 1999



Justice data

- Court charges – from 1992
- New Zealand crime and victims survey – from 2018
- NIA links – from 2009
- Recorded crime: offenders – from 2009
- Recorded crime: victims – from 2014
- Sentencing and remand – from 1998



People and communities data

- Auckland City Mission – from 1996
- Disability survey – 2013
- Driver licence and motor vehicle registers
- General Social Survey – 2008–2018
- Longitudinal immigration survey of NZ – 2005–09
- Migrant Survey – from 2012
- Te Kupenga – 2013

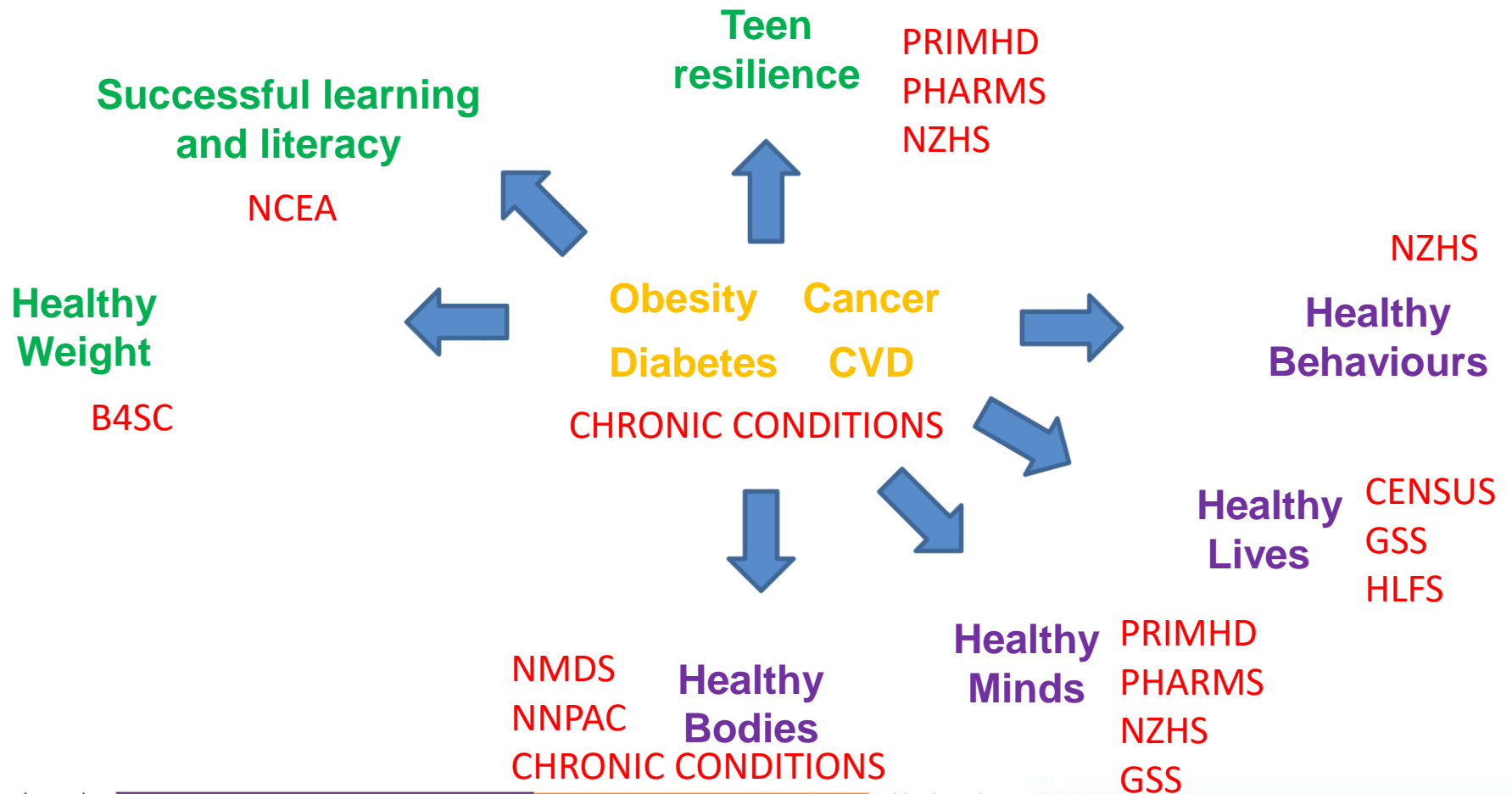


Population data

- Census – 2013, 2018
- Births, deaths, and marriages – from 1840
- Border movements – from 1997
- Civil unions – from 2005
- Departure and arrival cards – from 1997
- Visa applications – from 1997



Impact of chronic disease on families



Methods

- Define and characterise households (2013 Census)
- Define chronic conditions among household members (2013)

Ten Chronic Conditions

- Acute Myocardial Infarction
- Cancer
- Chronic Obstructive Pulmonary Disease
- Coronary Heart Disease
- Diabetes
- Gout
- Stroke
- Traumatic Brain Injury
- Dementia
- Mental Health

Basic descriptive questions

1. How many families include a family member with a chronic condition?
2. How many families include a family member with multi-morbid chronic conditions?
3. How many families include more than one family member with a chronic condition?
4. Does 1,2,3 differ by socio-economic status, ethnicity and family structure?

Substantive questions

5. How are health, education and wellbeing outcomes for children impacted by living in a family with chronic disease?
6. How are employment, income, and physical and mental health impacted over time for the partners and carers of chronic condition sufferers?
7. How is the health, mental health, and lives of the parents and elders of chronic condition sufferers impacted over time?
8. How does having a family member with a chronic conditions change families and households over time, in terms of family composition and household resources?

Analyses

- Analyses run on the whole population and stratified by major ethnic groups (European, Māori, Pacific, Asian).
- Subgroup analyses run for Tokelauan ethnic group
- Assess whether some chronic conditions have greater impact than others
- Account for functional impairment of condition
- Try to identify ‘protective’ factors
 - Disease free family members, residential stability

Example analysis

RQ: Does growing up in a family with a chronic disease sufferer impacts on educational attainment?

1. Identify families in 2013 with chronic disease sufferers with children aged 12-16.
2. Assess NCEA2 results 2013-2019 (most children aged 12-16 will have had an opportunity to attain NCEA2 by 2019).
3. Match children by age, sex, ethnicity, deprivation, region to a group of children without a chronic condition in the family.
4. Groups compared to determine whether NCEA2 attainment is more or less likely among children in families with a chronic disease sufferer.
5. If there is an association, we will investigate the impact of (i) chronic disease type and (ii) potential protective factors among children in 'chronic disease' families using a 'moderation' (interaction) approach.

Limitations

- Analysis of administrative data is good for understanding what is going on for populations, but...
 - If we find an effect (e.g., children less likely to stay in education or training), we don't know WHY it came about
 - An effect in aggregate may mask lots of different things going on for individuals
 - We can (mostly) only focus on negative outcomes; we can't uncover all the positive impacts of (e.g.) caring for a family member
- Extremely important that we augment our findings with in depth qualitative analyses

Associated Projects

- Te Kura Mai i Tawhiti
 - Develop conceptual framework and methodology for a life course wellbeing project through the delivery of whanau-based early childhood education (Taranaki)
 - Mihi Ratima, Will Edwards, Gareth Treharne, Aroaro Tamati, Ruakere Hond, Erana Hond Flavell
- E kore au e ngaro
 - Document conceptual framework for a whakapapa-centred approach to intergenerational wellbeing research, based on Ngati Tiipa (Waikato) whakapapa genealogies
 - Tahu Kukutai, Ella Newbold, Vanessa Clark, Heeni Kani

Associated Projects

- Possible implementation pathways, through whanau in Taranaki and Ngati Tiipa
- Advice on Māori data sovereignty issues
 - ‘In house team’ guidance on use of data
 - Given this study is nationwide using SNZ data, should be governed by Mana Orite agreement between SNZ and Data Iwi Leaders group

Tokelauan families study

- Tokelau population has high health needs (#1 most prevalent diabetes population in the world) but seldom the focus of research
- The Tokelau Migrant Study (Prior et al, 1974) ‘one of the most prominent examples of population context epidemiology during the “modern epidemiology” era (Pearce, 2009). Our study will enable historic comparisons.
- Population is small (n=8000), well networked, and less geographically spread than other NZ Pasifika groups

Tokelauan families study

- “Intergenerational, integrative & intellectual Pacific properties & pathways for Life (IP4Life)”
- Obj 2 (PI: Dewes): Determine the family, household and community strengths that allow people in the Tokelauan community to thrive despite the challenges of living in families with chronic disease.
- Qualitative investigation in two sites
 - Wellington (53% of Tokelauan population)
 - Auckland (24% of Tokelauan population)
 - Purposive sampling through collaborating service providers

Tokelauan families study

- Engage community leaders and family members as ‘co-researchers’ to identify solutions to addressing the impact of chronic diseases within families
- 12 community workshops, 6 focus groups, 15 family interviews
 - Facilitated by Pasifika researchers fluent in Tokelauan
 - Structure determined by ‘co-researchers’
 - Talanoa model – story telling with
 - Ofa/love, Mafana/warmth, Malie/humour, Faka’apa’apa/respect
 - Narrative and thematic analyses

Tokelauan families study

- Ofa Dewes (PI, COMPASS)
- John Fiso (Pacific Health Plus)
- Glenn Doherty (Tongan Health Society)
- Tokelauan Leaders in Auckland and Wellington
- Pasifika research interviewers



Outcomes and impacts

- Contribute to policy development around support needed for families
- Better capture the wider impact of chronic conditions, for each chronic condition
 - Can contribute to cost estimates and treatment funding decisions
- Raise awareness that what happens to individuals affects families – move away from an individual focus

THANK YOU!

QUESTIONS?