BMJ Open Cohort profile: The Trauma Outcomes Project, a prospective study of New Zealanders experiencing major trauma

Helen E Owen , ¹ Emma H Wyeth , ¹ Brett Maclennan, ¹ David Barson, ² Paul McBride, ³ Belinda J Gabbe, ⁴ Ian Civil, ⁵ Sarah Derrett

To cite: Owen HE, Wyeth EH, Maclennan B, *et al.* Cohort profile: The Trauma Outcomes Project, a prospective study of New Zealanders experiencing major trauma. *BMJ Open* 2023;**13**:e075480. doi:10.1136/bmjopen-2023-075480

▶ Prepublication history for this paper is available online. To view these files, please visit the journal online (http://dx.doi. org/10.1136/bmjopen-2023-075480).

Received 10 May 2023 Accepted 30 October 2023



© Author(s) (or their employer(s)) 2023. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

¹Ngāi Tahu Māori Health Research Unit, Division of Health Sciences, University of Otago, Dunedin, New Zealand ²Preventive and Social Medicine, University of Otago, Dunedin, New Zealand ³New Zealand Health Quality and Safety Commission, Wellington, New Zealand

⁴Epidemiology and Preventive Medicine, Monash University, Melbourne, Victoria, Australia ⁵New Zealand National Trauma Network, Wellington, New Zealand

Correspondence to

Professor Sarah Derrett; sarah.derrett@otago.ac.nz

ABSTRACT

Purpose Patient-reported outcome measures (PROMs) are useful for trauma registries interested in monitoring patient outcomes and trauma care quality. PROMs had not previously been collected by the New Zealand Trauma Registry (NZTR). More than 2500 New Zealanders are admitted to hospital for major trauma annually. The Trauma Outcomes Project (TOP) collected PROMs postinjury from three of New Zealand's (NZ's) major trauma regions. This cohort profile paper aims to provide a thorough description of preinjury and 6 month postinjury characteristics of the TOP cohort, including specifically for Māori (Indigenous population in Aotearoa me Te Waipounamu/ NZ).

Participants Between July 2019 and June 2020, 2533 NZ trauma patients were admitted to one of 22 hospitals nationwide for major trauma and included on the NZTR. TOP invited trauma patients (aged ≥16 years) to be interviewed from three regions; one region (Midlands) declined to participate. Interviews included questions about health-related quality of life, disability, injury recovery, healthcare access and household income adequacy.

Findings to date TOP recruited 870 participants, including 119 Maori. At 6 months postinjury, most (85%) reported that the injury still affected them, 88% reported problems with≥1 of five EQ-5D-5L dimensions (eg, 75% reported problems with pain or discomfort, 71% reported problems with usual activities and 52% reported problems with mobility). Considerable disability (World Health Organization Disability Assessment Schedule, WHODAS II, score ≥10) was reported by 45% of participants. The prevalence of disability among Māori participants was 53%; for non-Māori it was 44%. Over a quarter of participants (28%) reported trouble accessing healthcare services for their injury. Participation in paid work decreased from 63% preinjury to 45% 6 months postinjury. Future plans The 12 and 24 month postinjury data collection has recently been completed; analyses of 12 month outcomes are underway. There is potential for longer-term follow-up interviews with the existing cohort in future. TOP findings are intended to inform the National Trauma Network's quality improvement processes. TOP will identify key aspects that aid in improving postinjury outcomes for people experiencing serious injury, including importantly for Māori.

INTRODUCTION

Injury is a leading cause of disability and ill health in Aotearoa me Te Waipounamu (New Zealand; NZ). ¹² Concerningly, between

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Major trauma patients recruited to the Trauma Outcomes Project (TOP) sustained a range of injury types from various causes.
- ⇒ The data collected from this cohort included detailed postinjury quantitative and open-ended patient-reported outcome measures (PROMs) from telephone interviews, and clinical data from trauma hospital records.
- ⇒ TOP was designed as a Māori-centred study and adopted a non-deficit approach to ensure cultural safety in recruitment of Māori (Indigenous population of New Zealand) trauma patients including through Māori-led interviews.
- ⇒ High numbers of trauma patients without contact details provided, and greater loss-to-follow-up of Māori (compared with non-Māori), introduce sampling bias and likely lead to the underestimation of known health inequities for New Zealand trauma patients.

2500 and 3000 New Zealanders are admitted to hospital for major trauma annually.³ In 2020/2021, 2533 people were admitted to a trauma hospital in NZ; the largest number recorded annually since the National Trauma Network (NTN) was established.³ The NTN was established in 2012 to address the variation in the quality of trauma care in NZ, and was initially funded by the Ministry of Health. ^{4 5} After 2015, the Accident Compensation Corporation (ACC) was responsible for funding and support of NTN, with a focus on improving long-term outcomes after trauma including return to work.⁵ The NTN has a formal governance structure including regional networks for hospitals based in Northern, Midlands, Central and South Island geographical regions of NZ, and a data governance group.⁵ On 1 July 2015, the NTN implemented the New Zealand Trauma Registry (NZTR), a national collated dataset from consenting major trauma patients with an Injury Severity Score (ISS) >12 using



the Abbreviated Injury Scale 2005/2008, and who were admitted to one of 22 acute hospitals throughout the country. Often major trauma involves injuries to more than one body region. Data collection has been ongoing since the NZTR was established. The dataset is analysed by the Health Quality and Safety Commission (HQSC) to inform the NTN's annual reporting and development of appropriate quality improvement initiatives. Injury-related fatalities are decreasing over time; however, acute hospital admissions increased between 2018/2019 and 2020/2021, despite an initial decline in trauma cases between March and May 2020 during the nationwide alert level 4 COVID-19 lockdown. There was a considerable increase in the proportion of injuries caused by falls compared with pre-COVID.

Internationally, trauma registries primarily collect and collate data about survival and clinical outcomes^{8–13}; however, impacts of trauma on patients' quality of life, health and recovery can be better understood through patients' perceptions of their own health. 14 15 Trauma registries have the capacity to collect patient-reported outcome measures (PROMs) to monitor quality of trauma care, and inform changes to care delivery and policy. 15 16 Few studies explore medium-term and longterm PROMs for trauma registry patients following hospital discharge. 15 17-19 In Australia, a prospective cohort study of 8128 trauma patients on the Victoria State Trauma Registry (VSTR) followed 6517 patients to 6, 12 and 24 months postinjury. 17 18 Among patients who survived to 24 months, 23% returned to their preinjury level of disability, and the likelihood of reporting improved health was higher between 6 and 12 months compared with 12 and 24 months. The study identified a variety of preinjury (gender, age, chronic health conditions) and injury-related factors (eg, injury type, cause) associated with patients' improved functioning between 12 and 24 months. Additionally, 70% of patients who were working or studying preinjury had returned to their occupation by 24 months postinjury.¹⁷

A small feasibility study was undertaken to describe health and disability outcomes among 112 New Zealanders with an ISS>12 to 12 months postinjury.²⁰ However, to our knowledge, there is no existing research investigating postinjury PROMs overtime among trauma patients using NZTR data, despite evidence of underlying inequities in quality of, and access to, trauma care and outcomes in NZ.^{3 21 22} For example, and while not exclusive to trauma patients, the Prospective Outcomes of Injury Study (POIS; which coauthors SD and EW lead) has found that certain factors (eg, perceived threat of longer-term disability, head/neck superficial injury) were associated with an increased risk of disability at 24 months postinjury for those hospitalised.²¹ Of great concern, Māori (the Indigenous population of NZ) were at a higher risk of considerable disability compared with non-Māori after hospitalisation, which was largely explained by experiences of trouble accessing injury-related healthcare. 21 23 The NZTR have already reported examples of injury-related access difficulties experienced by trauma patients in 2020/2021, including fewer patients with traumatic brain injuries (TBIs) admitted to neuroscience centres, which may be exacerbated for Māori. Although this study does not explore opportunities for injury prevention, the NTN reported that age-standardised incidence for Māori with major trauma is 1.5 times higher than for non-Māori, and Māori men are at a significantly greater risk of injury, which influences their healthcare access and rehabilitation. Understanding outcomes for trauma patients in NZ, especially for Māori, is crucial to quantifying the burden of major trauma, evaluating quality of care provided (if accessible), reducing and ultimately eliminating inequities, and identifying areas for improvement in the trauma system.

Major trauma patients from the NZTR have participated in follow-up interviews via telephone at 6 months postinjury for the Trauma Outcomes Project (TOP). This profile paper aims to provide a thorough description of preinjury, injury-related and 6 month postinjury characteristics of the TOP cohort, including for Māori. TOP aims to estimate the prevalence of health-related quality of life (HRQoL) and disability outcomes, and describe other outcomes (eg, recovery, access to services, employment) among major trauma patients from the NZTR (including Māori) at 6, 12 and 24 months postinjury, and to identify key predictors of good (and poor) HRQoL and disability outcomes at these timepoints.

Cohort description

The NTN receives data collected by trauma hospitals about all trauma patients admitted to a trauma hospital who do not opt out of their data entering the NZTR. Between 1 July 2019 and 30 June 2020, 2533 trauma patients were placed on the NZTR across NZ's four trauma regions. With approval from the NZTR Data Governance Group, we were securely provided with the deidentified injuryrelated information for 2533 trauma patients who were aged 16+ years, had been admitted to one of NZ's four trauma regions, had survived to (at least) the time of hospital discharge and had not opted out of the NZTR. One trauma region (Midlands) declined to participate. Additionally, the HQSC sent 1547 trauma patients from three (Northern, Central, South Island) of NZ's four trauma regions information about a planned interview to collect data about trauma patients' outcomes and experiences. Of 1547 trauma patients in the three regions, 64 were not eligible for interview because: they notified the HQSC they did not wish to be interviewed (n=30), had died before interview (n=27) or, when contacted for an interview were unable to participate because of communication difficulties (n=7) (figure 1). Therefore, 1483 (96%) potential participants were assigned to one of five TOP interviewers to contact and invite to participate in an interview, 6 months postinjury.

Prior to recruitment, the HQSC posted letters of invitation on behalf of the University of Otago research team (in English and te reo Māori; the Māori language) to

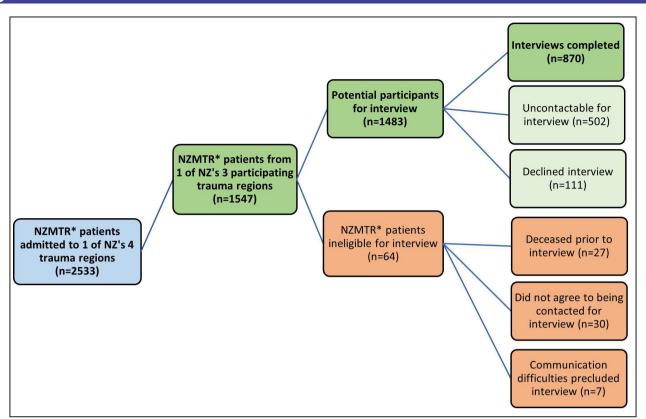


Figure 1 Trauma Outcomes Project study recruitment. *Newzealand major trauma registry.

NZTR trauma patients explaining why they were being contacted, and what the interviews would involve. The HQSC also provided comprehensive guides in English and te reo Māori for trauma patients and their family/ whānau, which included background to the NTN, the types of information collected and the purpose of quality improvement processes to better support injured people in their recovery. Trauma patients were able to opt out of an interview by contacting the NTN via email or by phoning a toll-free number. The research team had multiple contact phone numbers and emails for patients, and details for alternate contacts, where available. For those unable to still be contacted, any updated contact details were obtained from NZ's no-fault injury compensation insurer, ACC. Interviewers made up to four contact attempts via telephone, at varying times of the day across the week, to schedule an interview. If a participant remained uncontactable, the project manager sent follow-up text messages or emails. Interviewers attempted to contact trauma patients within 2 weeks of their 6 month injury 'anniversary'. If a participant was successfully contacted, the interviewer gave a short overview of the interview purpose and questions, and asked participants to verbally confirm whether they wished to take part in the study or not. If a participant was unwell, recovering from surgery or residing in a corrections facility and they still wished to take part, they gave verbal consent via telephone for their interview to be completed by a proxy (ie, a relative, carer or friend) on their behalf.

Of the 1547 trauma patients from the three trauma regions, interviewers successfully contacted 981 people including 870 (119 identifying as Māori) who completed the 6 months postinjury interview. This corresponded to a response proportion of 56% (870/1547) and a participation proportion (870/981) of 89%. The majority of interviews (n=819) were self-completed and 51 (6%) were completed by a proxy. Only 111 people declined to take part.

Data collection

Five trained interviewers, including one proficient in te reo Māori, conducted structured telephone interviews with 870 participants. The interviews were typically 10–15 min in duration and participants' responses were entered into REDCap, 24 in real time. Participants were given the opportunity to complete their interview in te reo Māori. The first phase of interviewing was completed between January 2021 and February 2022, 6 months (median) after their injury. After completion of each interview, participants were posted a thank you voucher (valued at NZ\$10), along with a list of helpful contacts for ACC, health, disability and mental well-being services, including advocacy and conflict resolution services for ACC claim disputes.

Patient-reported outcome measures (PROMs)

The 6 month telephone interview included questions about participants' current HRQoL (measured using EQ-5D-5L),²⁵ disability (measured using WHODAS

Variables	Categories
Health-related quality of life ²⁵	
EQ-5D-5L	No problems; Problems (slight/moderate/severe/extreme)
EQ-5D-VAS	0 (worst health)-100 (best health)
Disability ²⁶	
WHODAS II 12-item	No (0–9); Yes (≥10)
Injury-related*	
Injury currently affecting participant	Yes; No; Don't know
Expectations for recovery (if injury affecting)	Better soon; Better slowly; Don't know future course; Never get better
Things that have helped/not helped	(Open-ended)
Healthcare service-related	
Trouble accessing healthcare services	Yes; No; Don't know
Sociodemographics ^{27–29}	
Living arrangements	With family (immediate/extended); Alone/with non-family
Ethnicity	Multiple choices prioritised in order: Māori; Pacific (Samoan/Cook Island Māori/Tongan/Niuean); Asian (incl. Chinese/Indian); Other; NZ European
Postinjury education	No qualifications; Secondary school/University degree/Other postsecondary school qualification
Preinjury occupation status (hours/week)	Full-time (≥30); Part-time (<30)
Postinjury occupation status (paid work; hours/ week)	Yes; No. If yes: Current occupation and hours (open-ended)
Preinjury and postinjury adequacy of household income	Adequate (More than Enough/Enough); Inadequate (Just Enough/Not enough)

II), ²⁶ expectations for injury recovery, trouble accessing injury-related healthcare services and sociodemographic characteristics (ie, living arrangements, ethnicity, occupation and adequacy of household income). ^{27–29} The standardised WHODAS and EQ-5D-5L are regarded as reliable and valid measures of disability and HRQoL, respectively ^{25 26}; they have been used with injured populations internationally, ³⁰ and in NZ, ²¹ and of interest for the quality improvement processes of ACC and NTN.

Participants were asked to retrospectively report preinjury education, occupation and adequacy of household income. The interview concluded with open-ended questions about the most important factors that have helped (or not) in relation to injury recovery. Table 1 presents the information collected from interviews with TOP participants 6 months postinjury.

NZTR measures

Clinical data collected from the trauma hospitals were provided by the HQSC. With approval from the NZTR Data Governance Group, we obtained from the NZTR: age at time of injury (years), injuries sustained, International Classification of Diseases-10 injury cause (eg, fall, motor vehicle accident), injury intent (eg, unintentional), dominant injury type (eg, blunt, penetrating), activity engaged in when injury occurred, injury event description, ISS^{6 31}

and total length of hospital stay (days), including deidentified data for 613 non-participants.

Patient and public involvement

TOP participants did not participate in the study design, data collection processes or in the planning or preparation of this manuscript. After their interview, participants were provided with debriefing information including various health, well-being and advocacy services, along with a thank you voucher.

Data management and security

As per ethics approval, all data for analyses will be deidentified and securely stored (with password-protection) on University of Otago servers for 10 years after data collection. TOP findings will be deidentified and presented at the group level to protect participants' anonymity. A secure file transfer system was used to transfer information from NZTR Minimum Data Set to the University of Otago research team. All files stored and transferred were encrypted as per organisational protocols.

Findings to date

Of the 1483 trauma patients eligible for TOP, 613 did not participate because they were uncontactable (n=502) or declined (n=111). Table 2 compares known characteristics



	Participants (n=870)	Non-participants (n=613)
Characteristics	n (%)	n (%)
Sex		
Male	627 (72)	462 (75)
Female	243 (28)	151 (25)
Median age in years at injury (IQR)	56 (39-69 years)	40 (27-57 years)
Ethnicity		
Māori	119 (14)	176 (29)
Pacific	33 (4)	47 (8)
Asian	39 (5)	41 (7)
Other	6 (<1)	14 (2)
NZ/European	673 (77)	335 (55)
Dominant injury type		
Blunt	853 (98)	558 (91)
Penetrating	14 (2)	51 (8)
Other	2 (<1)	4 (<1)
Injury cause		
Fall	291 (33)	162 (26)
Motor vehicle traffic	282 (32)	209 (34)
Other land transport	112 (13)	68 (11)
Pedal cyclist, other	82 (9)	26 (4)
Struck by or against	46 (5)	57 (9)
Pedestrian, other	13 (1)	5 (<1)
Other transport	11 (1)	8 (1)
Cut/pierce	11 (1)	46 (8)
Natural/environmental	7 (<1)	3 (<1)
Other	15 (2)	29 (5)
Injury intent		
Unintentional	827 (95)	478 (78)
Intentional	38 (5)	125 (21)
Not known	4 (<1)	10 (2)
Median Injury Severity Score (ISS) (IQR)	17 (14–22)	17 (14–22)
Median length of hospital stay (IQR)	7.7 (4.1–13.2)	8.1 (4.0–15.1)

of the TOP cohort with eligible non-participants. Where multiple ethnicities are reported, ethnicity is presented using the prioritisation method and groupings (ie, Māori, Pacific, Asian, Other and NZ European), ²⁹ and is based on self-identifying ethnicity collected via telephone interviews or ethnicity recorded in the NZTR.

Of the 870 TOP participants, the median (IQR) age at the time of injury was 56 years (39-69 years), and 72% were male. Most participants sustained blunt injuries (98%; that is, non-penetrating injuries caused by force or pressure) and injuries that were unintentional (95%). TOP participants sustained a diverse range of injury types

(eg, rib fractures, TBIs, chest injuries, pelvic and hip fractures, spinal cord injuries). Falls (33%) and motor vehicle traffic crashes (32%) were the most commonly occurring injury causes.

Compared with the TOP cohort, non-participants were younger, median (IQR) age at the time of injury was 40 years (27-57 years). The median length of hospital stay (IQR) was 7.7 days (4.1-13.2 days) for participants and 8.1 days (4.0-15.1 days) for non-participants. The groups were similar in relation to gender and ISS. The median (IQR) ISS was 17 (14-22) for both groups. The proportions of Māori and Pacific trauma patients were

Table 3	Preinjury, injury-related and postinjury
characte	ristics of the TOP cohort collected during the
interview	s (n=870)

interviews (n=870)	
Characteristics	n (%)
Preinjury	
Adequacy of household income	
Adequate	626 (72)
Inadequate	231 (27)
Working for pay	
Yes	546 (63)
No	324 (37)
Injury-related	
Trouble accessing healthcare services (past 6 months)	
Yes	245 (28)
No	623 (72)
Expectations for recovery	
Already recovered	131 (15)
Expect to recover soon/slowly	451 (52)
Unsure	209 (24)
Expect to never recover	77 (9)
Six months postinjury	
Education	
Less than secondary school	125 (14)
Secondary school or higher	741 (85)
Living arrangements	
Alone/with non-family	244 (28)
With family	626 (72)
Adequacy of household income	
Adequate	477 (55)
Inadequate	378 (44)
Working for pay	
Yes	391 (45)
No	479 (55)
HRQoL (EQ-5D-5L; any problems)	
Mobility	454 (52)
Self-care	302 (35)
Usual activities	618 (71)
Pain or discomfort	652 (75)
Anxiety or depression	384 (44)
Any problems with one or more EQ-5D items	767 (88)
Disability (WHODAS II; any difficulty)	
Standing for long periods	494 (57)
Household responsibilities	499 (57)
Learning new tasks	275 (32)
Community activities	365 (42)
Emotionally affected by health problems	563 (65)
	Continued

Table 3 Continued	
Characteristics	n (%)
Concentrating more than 10 min	322 (37)
Walking a long distance	449 (52)
Washing whole body	315 (36)
Getting dressed	338 (39)
Dealing with unknown people	257 (30)
Maintaining a friendship	182 (21)
Day to day work	561 (65)
Any issues with one or more WHODAS items	762 (88)
WHODAS>10	378 (45)

%s may not add to 100 due to rounding or missing/'don't know' responses. Total WHODAS scores could not be calculated for 34 participants because they had missing responses to two or more items. Less than 1% had data missing for one EQ-5D dimension (n=8). No participants were missing responses to all five EQ-5D-5L items or all 12 WHODAS II items. There were no missing data for preinjury employment, nor employment or living arrangements at 6 months postinjury. One percent of participants had missing data for preinjury adequacy of household income (n=13) and <1% for education (n=4). Less than 2% of participants had missing data for adequacy of household income postinjury (n=15); <1% for trouble accessing healthcare (n=1) and injury recovery (n=1). HRQoL, health-related quality of life; TOP, Trauma Outcomes Project.

higher among non-participants than in the TOP cohort. Compared with the TOP cohort, the prevalence of penetrating injuries was higher among non-participants, as were intentional injuries (ie, those that were caused by others or self-inflicted).

Ethnicity was self-identifying for TOP participants and NZTR recorded for non-participants. Injury intent is recorded as unknown if the patient's account is not consistent with the objective trauma assessment. Percentages may not add to 100 due to rounding or missing values. There were no missing data for gender, age, ethnicity and dominant injury type among TOP participants and non-participants. Data were missing for <1% of non-participants for injury cause and injury severity (both n=5), and 1% for LOS in hospital (n=7). Less than 2% of TOP participants had missing data for LOS in hospital (n=13); <1% for ISS (n=8) and one participant was missing injury intent data.

Table 3 presents preinjury, injury-related, and postinjury characteristics reported by TOP participants 6 months postinjury, including EQ-5D-5L, WHODAS and paid work. As shown in table 3, most TOP participants (85%) reported still being affected by their injury at the time of interview; however, 52% expected to recover soon or slowly, and 9% felt that they would never recover. The majority (72%) did not experience trouble accessing injury-related healthcare services. Prior to injury, 63% of participants were in paid employment and 72% reported that they had adequate household income. However, 6 months after injury, only 45% were in paid employment



Preinjury, injury-related and 6 month postinjury characteristics of Māori and non-Māori Trauma Outcomes Project participants (n=870)

Variable	Māori (n=119) n (%)	Non- Māori (n=751) n (%)
Sociodemographic		
Sex		
Male	93 (78)	534 (71)
Female	26 (22)	217 (29)
Median age in years at injury (IQR)	41.0 (25– 58)	57.0 (42–71)
Preinjury		
Adequacy of household income		
Adequate	74 (63)	552 (74)
Inadequate	43 (37)	188 (25)
Working for pay		
Yes	75 (63)	471 (63)
No	44 (37)	280 (37)
Injury-related		
Injury intent		
Unintentional	105 (88)	722 (96)
Intentional	13 (11)	25 (3)
Not known	0 (0)	4 (<1)
Median Injury Severity Score (ISS) (IQR)	17 (16–22)	17 (14–21)
Median length of hospital stay (IQR)	9.0 (4.9– 18.1)	7.4 (4.1– 12.9)
Trouble accessing healthcare services (past 6 months)		
Yes	31 (26)	214 (29)
No	88 (74)	535 (71)
Expectations for recovery		
Already recovered	20 (17)	111 (15)
Expect to recover soon/slowly	52 (44)	399 (53)
Unsure	37 (31)	172 (23)
Expect to never recover	9 (8)	68 (9)
Six months postinjury		
Education		
Less than secondary school	26 (22)	99 (13)
Secondary school or higher	92 (78)	649 (87)
Living arrangements		
Alone/with non-family	33 (28)	211 (28)
With family	86 (72)	540 (72)
Adequacy of household income		
Adequate	45 (38)	432 (59)
Inadequate	73 (62)	305 (41)
Working for pay		

Continued

<i>V</i> ariable	Māori (n=119) n (%)	Non- Māori (n=751) n (%)
Yes	39 (33)	352 (47)
No	80 (67)	399 (53)
EQ-5D-5L (any problems)		
Mobility	68 (57)	386 (51)
Self-care	43 (36)	259 (34)
Usual activities	79 (66)	539 (72)
Pain or discomfort	92 (77)	560 (75)
Anxiety or depression	68 (57)	316 (42)
Any problems with one or more EQ-5D items	107 (90)	660 (88)
Median EQ-5D VAS score (IQR)	70 (50–85)	75 (60–85
WHODAS II (any difficulty)		
Standing long periods	75 (64)	419 (56)
Household responsibilities	70 (59)	429 (58)
Learning new tasks	53 (45)	222 (30)
Community activities	57 (50)	308 (44)
Emotionally affected by health problems	83 (70)	480 (64)
Concentrating more than 10 min	58 (49)	264 (35)
Walking a long distance	70 (59)	379 (51)
Washing whole body	42 (35)	273 (36)
Getting dressed	47 (40)	291 (39)
Dealing with unknown people	58 (50)	199 (27)
Maintaining a friendship	33 (28)	149 (20)
Day to day work	75 (65)	486 (69)
WHODAS≥10	62 (53)	316 (44)

responses.

and only just over half (55%) reported having an adequate household income.

As shown in table 3, a high proportion of participants reported experiencing any problems (eg, slight, moderate, severe or extreme/unable) across the five EQ-5D-5L dimensions (ie, mobility, self-care, usual activities, pain/discomfort, anxiety/depression), ranging between 35% reporting problems with self care and 75% reporting problems with pain or discomfort. Only 12% of participants reported no problems with any of the five EQ-5D-5L dimensions. The median (IQR) EQ-5D VAS score, recording participants' self-rated overall health, was 75 (55-85) on a 0 (worst) to 100 (best) scale.

Proportions reporting some level of disability (ie, mild, moderate, severe or extreme) according to the 12 items of WHODAS II ranged between 21% reporting difficulties maintaining a friendship and 65% being emotionally

affected by their health problems, and having difficulties with their day-to-day work. Only 102 (12%) reported no difficulties with any of the 12 WHODAS II items, and 378 (45%) of participants were experiencing considerable disability (WHODAS≥10).

Table 4 compares preinjury, injury-related and postinjury characteristics of Māori with non-Māori TOP participants. Higher proportions of injuries were sustained by men than women among Māori and non-Māori participants. Compared non-Māori participants, Māori participants were younger at the time of injury and, concerningly, a greater proportion sustained intentional injuries (ie, self-inflicted or caused by others). Higher proportions of non-Māori participants had (at minimum) a secondary school education qualification and reported adequate household income preinjury. Over a third of Māori participants (37%) reported that their preinjury household income was inadequate. The difference in income inadequacy between Māori and non-Māori was greater postinjury; 62% of Māori reported inadequate household income 6 months postinjury compared with 41% of non-Māori. Although there were no differences in preinjury employment, a smaller proportion of Māori were in paid employment 6 months postinjury compared with non-Māori. Similar proportions of Māori and non-Māori reported problems on most EQ-5D-5L dimensions; however, a higher proportion of Māori reported problems with anxiety or depression compared with non-Māori.

More than half (53%) of Māori were experiencing disability (WHODAS≥10) 6 months postinjury compared with 44% of non-Māori. Compared with non-Māori, higher proportions of Māori reported difficulties with three WHODAS II items: learning new tasks, concentrating for longer than 10 min and dealing with unknown people 6 months after injury. The median ISS was similar for non-Māori and Māori; however, the IQR for ISS was higher for Māori. Expectations for recovery only marginally differed between groups; for instance, Māori participants were more likely to report being unsure about the future course of their injury. Similar proportions of Māori and non-Māori reported trouble accessing injury-related healthcare services.

Strengths and limitations

TOP is a prospective cohort study that collects and describes a wide range of PROMs and other important health, social and well-being information at multiple timepoints for NZ trauma registry patients, across three trauma regions, including specifically for Māori. TOP has collected both quantitative and open-ended preinjury, injury-related, health service-related and postinjury data, with a relatively short retrospective recall for preinjury factors at the 6 month interview. This is the first time such outcomes have been collected from a large sample of NZTR patients. It is hoped that this study will inform the routine collection of such data in the future. An earlier feasibility study explored PROMs at 6 and 12 months postinjury among a similar cohort of injured New

Zealanders with an (ISS)> 12^{20} ; however, that cohort was limited to ≤ 100 injured New Zealanders at each interview timepoint, and only recruited patients admitted to an Auckland-based hospital.

Interviews were deliberately restricted to <15 min duration to reduce the burden on participants. TOP collected data from the same standardised measures at all timepoints except for preinjury sociodemographic questions, which were only asked at 6 months postinjury, and financial security over the next 10 years, which was only asked at 24 months postinjury. Missing data was minimal for most variables at 6 months postinjury. Apart from postinjury WHODAS II and adequacy of household income, less than 1% of participants were missing responses to all other variables. TOP adopted flexible criteria for inclusion in follow-up interviews. All eligible participants who were uncontactable 6 months postinjury remained eligible for follow-up 12 months postinjury. Participants were only required to have completed one interview at either 6 or 12 months postinjury to be eligible for the final follow-up. Finally, TOP was designed as a Maori-centred study that adopted a non-deficit approach, especially with a Māori coprincipal investigator (EW) and through Māori-led interviews, the availability of te reo Māori translated interviews, and inclusion of questions focussing on systemic barriers to treatment and rehabilitation for injury, rather than referring to Māori as a vulnerable group. TOP is the first study to explore inequities in injury recovery, healthcare service access, and health and disability outcomes between Māori and non-Māori major trauma patients.

Limitations of TOP relate to the generalisability of findings to the wider NZ trauma population. The majority of the 986 patients for whom we had no contact information were trauma patients admitted to hospitals in the Midlands region in NZ and included about one-third of all Māori trauma patients. Māori and Pacific people also comprised larger proportions of all eligible nonparticipants on the NZTR than in our TOP cohort. Given Māori are under-represented in the TOP cohort, our findings are likely to underestimate known health inequities for injured Māori, such as trouble accessing healthcare,²¹ and the prevalence of considerable postinjury disability for Māori.²³ Second, people with lived experience of major trauma and the trauma system in NZ were not involved in codesigning TOP. Although this was not an expectation of the study funders, adopting a codesign approach in future follow-ups could enhance the wider relevance of the cohort study.

Future plans

Plans for data collection and analyses were developed by the University of Otago leads (SD and EW) in collaboration with the NTN team. Data collection was completed in August 2023 for 24 month follow-ups. The next stage of quantitative data analysis is to explore potential socio-demographic and injury-related predictors of HRQoL and disability, including specifically for Māori. We also plan to analyse outcomes collected at 12 and 24 months

postinjury. Now that data has been collected to 24 months postinjury for this cohort, TOP will explore incidence of disability, health and HROoL over time, and investigate expectations of recovery and employment overtime. TOP will also qualitatively analyse factors that have helped or hindered injury recovery at each timepoint. In addition to academic dissemination channels (eg, peer-reviewed journals, conference proceedings), study findings will be presented to community groups, and key outcomes will be publicly available in annual reports by NTN. There is potential for longer-term follow-up interviews with the existing cohort in future.

Future analyses will explore associations between recovery and postinjury employment and will measure the rate of returning to work at 6, 12 and 24 months postinjury. At 6 months postinjury, the proportion of TOP participants in paid employment had decreased from preinjury levels and may be explained by slower recovery. However, findings from the VSTR prospective cohort study are encouraging ¹⁷; the likelihood of trauma patients returning to work or study was 14% higher between 6 and 12 months postinjury and increased by a further 8% to 24 months postinjury. It is important that trauma patients receive additional and appropriate support with their transition back into the workforce when ready. Early intervention could include adaptations to the injured individual's role and workplace environment, 32 33 early engagement with employers and provision of social and emotional support in the workplace.³⁴

TOP findings reveal that inequities are evident between Māori and non-Māori for certain outcomes collected. Most concerning, the prevalence of disability (WHODAS≥10) for Māori trauma patients at 6 months postinjury was higher than for non-Māori, and is consistent with the greater disability burden found for hospitalised Māori at 24 months postinjury.²¹ Māori TOP participants also sustained injuries of greater severity, were more likely to sustain intentional injuries and were hospitalised for longer after injury compared with non-Māori participants; these associations will be further investigated, including their impacts over time. Future research is required to explore the involvement of whanau, friends and community in the patient's trauma rehabilitation, as these factors positively impact post-injury health outcomes for Māori. 35 36

This study has the potential to influence systemic changes to trauma care in future, including the provision of healthcare information and treatment, and especially for Māori trauma patients. 37 38 Over a quarter of participants experienced difficulties accessing injury-related healthcare services, and concerningly, 45% of participants were experiencing disability at 6 months postinjury. This is consistent with hospitalised POIS participants' reports of difficulty accessing healthcare services (despite contact with a health provider to register with ACC), which increased the risk of disability at 24 months postinjury.²¹ This may reflect the participants' early stages of recovery but also highlights difficulties trauma patients experience

accessing appropriate and timely healthcare services. The NTN intends to improve access to trauma care through its continued focus on the transition of patients between acute services, rehabilitation providers and ACC.³⁹ Identifying characteristics of injuries, health outcomes among NZ trauma patients and inequities experienced by Māori will inform quality improvement processes in the NZ trauma system, improve the completeness of patient information on the NZTR and, more importantly, improve the consistency in the quality of trauma care delivered to patients, leading to better outcomes for this injured population.

Collaboration

TOP is led by SD and EW at the University of Otago. Their research team was contracted by NTN to undertake this project. Protecting the identities of TOP participants and eligible non-participants is imperative, particularly in the context of injury events and intention. Publicly sharing data would threaten the identities of TOP participants given the detailed quantitative and qualitative data collected, including personal and sociodemographic characteristics; therefore, sharing outside of the University of Otago research team is not possible.

Twitter Emma H Wyeth @ehwyeth

Acknowledgements The authors would like to thank the TOP participants for sharing their injury experiences, and the team of highly skilled interviewers for their accuracy, empathy and care. We are grateful to the Australian Government's National Health and Medical Research Council for supporting BG's contribution to this paper.

Contributors SD and EHW are principal investigators of TOP and collaborated directly with HQSC and NZTR. SD is guarantor for the work and conduct of the study. HEO prepared the first draft of the manuscript, collated the descriptive data and is the TOP project manager. BM led the data analyses, and DB was responsible for data management and helped collate descriptive data. All authors, including PM, BG and IC, contributed to manuscript editing and writing of the final draft.

Funding Our research team was contracted by HQSC, on behalf of the NTN and the Accident Compensation Corporation (ACC), to interview injured New Zealanders who were admitted to one of three NZ Trauma regions (grant number NA). PROMs were collected at 6, 12 and 24 months after patients' injuries to inform NZTR's quality improvement programmes.

Competing interests SD is a member of the EuroQol Group which is responsible for the development of the EQ-5D-5L instrument used in this study. Other authors have no competing interests to declare.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by Ethics approval was obtained from the University of Otago Human Ethics Committee (Health) (H20-115) to analyse the data collected for research purposes. The Health Quality and Safety Commission (HQSC) was granted approval by the NZTR Data Governance Group to analyse the data for quality improvement purposes. Potential participants were required to provide verbal consent to either a self-completed or proxy interview via telephone once they were successfully contacted by an interviewer. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data may be obtained from a third party and are not publicly available. From September 2024, all outcomes data will be held by the New Zealand Trauma Registry; applications to access data from September 2024 can be made to help@majortrauma.nz.



Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/.

ORCID iDs

Helen E Owen http://orcid.org/0000-0003-4333-3641 Emma H Wyeth http://orcid.org/0000-0002-6869-5190 Sarah Derrett http://orcid.org/0000-0003-2867-0498

REFERENCES

- 1 Statistics New Zealand. He hauā Māori Findings from the 2013 Disability Survey. Wellington: Statistics New Zealand, 2015.
- 2 Ministry of Health. Briefing to the incoming Minister. Part A: The New Zealand Health and Disability System. Wellington, NZ: Ministry of Health. 2020.
- 3 New Zealand Trauma Registry & National Trauma Network. Annual Report 2020/21. Wellington, New Zealand: National Trauma Network, 2021.
- 4 Flabouris A, Civil IDS, Balogh ZJ, et al. The New Zealand trauma system verification. J Trauma Acute Care Surg 2020;89:585–96.
- 5 National Trauma Network. Our history, our mission, our people, Available: https://www.majortrauma.nz/about-us/our-history
- 6 Isles S, Christey G, Civil I, et al. The New Zealand major trauma Registry: the foundation for a data-driven approach in a contemporary trauma system. NZ Med J 2017;130:19–27.
- 7 Statistics New Zealand. Serious injury outcome indicators: 2000-2020 Wellington: statistics New Zealand. 2021. Available: https:// www.stats.govt.nz/information-releases/serious-injury-outcomeindicators-2000-2020
- 8 Cameron PA, Finch CF, Gabbe BJ, et al. Developing Australia's first statewide trauma Registry: what are the lessons ANZ J Surg 2004;74:424–8.
- 9 Huber S, Biberthaler P, Delhey P, et al. Predictors of poor outcomes after significant chest trauma in multiply injured patients: a retrospective analysis from the German trauma Registry (trauma register DGU®). Scand J Trauma Resusc Emerg Med 2014;22.
- 10 Moore L, Turgeon AF, Lauzier F, et al. Evolution of patient outcomes over 14 years in a mature, inclusive Canadian trauma system. World J Surg 2015;39:1397–405.
- 11 Lesko MM, Jenks T, Perel P, et al. Models of mortality probability in severe traumatic brain injury: results of the Modelling by the UK trauma Registry. J Neurotrauma 2013;30:2021–30.
- 12 Lai CY, Maegele M, Yeung JHH, et al. Major trauma care in Hong Kong and Germany: a trauma Registry data benchmark study. Eur J Trauma Emerg Surg 2021;47:1581–90.
- 13 Driessen MLS, Sturms LM, Bloemers FW, et al. The Dutch nationwide trauma Registry: the value of capturing all acute trauma admissions. *Injury* 2020;51:2553–9.
- 14 Turner GM, Slade A, Retzer A, et al. An introduction to patient-reported outcome measures (Proms) in trauma. J Trauma Acute Care Surg 2019;86:314–20.
- 15 van der Vliet QMJ, Bhashyam AR, Hietbrink F, et al. Routine incorporation of longer-term patient-reported outcomes into a Dutch trauma Registry. Qual Life Res 2019;28:2731–9.
- 16 Gabbe BJ, Williamson OD, Cameron PA, et al. Choosing outcome assessment instruments for trauma registries. Acad Emerg Med 2005;12:751–8.
- 17 Gabbe BJ, Simpson PM, Harrison JE, et al. Return to work and functional outcomes after major trauma: who recovers, when, and how well *Ann Surg* 2016;263:623–32.

- 18 Gabbe BJ, Sutherland AM, Hart MJ, et al. Population-based capture of long-term functional and quality of life outcomes after major trauma: the experiences of the Victorian state trauma Registry. J Trauma 2010;69:532–6;
- 19 Sleat GKJ, Ardolino AM, Willett KM. Outcome measures in major trauma care: a review of current international trauma Registry practice. *Emerg Med J* 2011;28:1008–12.
- 20 Czuba KJ, Kersten P, Anstiss D, et al. Incidence and outcomes of major trauma in New Zealand: findings from a feasibility study of New Zealand's first national trauma Registry. NZMJ 2019;132:26–40.
- 21 Derrett S, Wilson S, Samaranayaka A, et al. Prevalence and predictors of disability 24-months after injury for hospitalised and non-hospitalised participants: results from a longitudinal cohort study in New Zealand. PLoS One 2013;8:e80194.
- 22 Wyeth EH, Derrett S, Hokowhitu B, et al. Indigenous injury outcomes: life satisfaction among injured Maori in New Zealand three months after injury. Health Qual Life Outcomes 2013;11:120.
- Wyeth EH, Samaranayaka A, Lambert M, et al. Understanding longer-term disability outcomes for Māori and non-Māori after Hospitalisation for injury: results from a longitudinal cohort study. Public Health 2019;176:118–27.
- 24 Research electronic data capture. Project: Redcap. n.d. Available: https://www.project-redcap.org
- 25 EuroQol Research Foundation. EQ-5D-5L user guide 2019. 2019. Available: https://euroqol.org/publications/user-guides
- 26 Üstün T, Kostanjsek N, Chatterji S, et al. Measuring Health and Disability: Manual for WHO Disability Assessment Schedule (WHODAS 2.0). Malta: WHO Press, 2010.
- 27 Statistics New Zealand. Household Economic Survey 2006-07. Wellington, New Zealand: Statistics New Zealand, 2007.
- 28 Statistics New Zealand. New Zealand Census of Population and Dwellings - Individual Form. Wellington: Statistics New Zealand, 2006
- 29 Ministry of Health. HISO 10001:2017 Ethnicity Data Protocols. Wellington, New Zealand: Ministry of Health, 2017.
- 30 Schweininger S, Forbes D, Creamer M, et al. The temporal relationship between mental health and disability after injury. *Depress Anxiety* 2015;32:64–71.
- 31 Lopes M, Whitaker IY. Measuring trauma severity using the 1998 and 2005 revisions of the abbreviated injury scale. Rev Esc Enferm USP 2014;48:641–8.
- 32 Lilley R, Davie G, Ameratunga S, *et al.* Factors predicting work status 3 months after injury: results from the prospective outcomes of injury study. *BMJ Open* 2012;2:e000400.
- 33 Hay-Smith EJC, Dickson B, Nunnerley J, et al. The final piece of the puzzle to fit in": an interpretative phenomenological analysis of the return to employment in New Zealand after spinal cord injury. Disabil Rehabil 2013;35:1436–46.
- 34 Nunnerley J, Dunn J, McPherson K, et al. Return to work for severely injured survivors of the Christchurch earthquake: influences in the first 2 years. *Disabil Rehabil* 2016;38:987–93.
- 35 Wilson B-J, Bright FAS, Cummins C, et al. The Wairua first brings you together': Māori experiences of meaningful connection in Neurorehabilitation. Brain Impairment 2022;23:9–23.
- 36 Elder H. Te Waka Kuaka and te Waka Oranga. working with Whānau to improve outcomes. ANZ J of Family Therapy 2017;38:27–42. 10.1002/anzf.1206 Available: https://onlinelibrary.wiley.com/toc/14678438/38/1
- 37 Reid J, Cormack D, Crowe M. The significance of relational continuity of care for Māori patient engagement with predominantly Non-Māori doctors: findings from a qualitative study. Aust N Z J Public Health 2016;40:120–5.
- 38 Bourke JA, Owen HE, Derrett S, et al. Disrupted mana and systemic abdication: Māori qualitative experiences Accessing Healthcare in the 12 years post-injury. BMC Health Serv Res 2023;23:130.
- 39 National Trauma Network. National Trauma Network Strategic Plan 2023-2027. Wellington, New Zealand, 2022.