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Tracking deaths of people who have experienced homelessness: a dynamic cohort study in an Australian city

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ABSTRACT

Objective Life expectancy and rates of premature death are fundamental markers of health and social equity globally, and measures on which people experiencing homelessness face enormous disparities. However, unlike for other population groups with similar disparities, concerted government action to reduce homeless mortality is rare, partly due to a lack of reliable, timely data. Contemporaneous tracking of homeless deaths is required to render such deaths less invisible and measure trends over time. Drawing on multiple data sources as recommended by the US National Health Care for the Homeless Council's seminal Homeless Mortality Data Toolkit, we routinely and contemporaneously capture, verify and report on deaths occurring among people who have experienced homelessness in the Australian city of Perth.

Design Dynamic cohort study.

Setting Perth, Western Australia, Australia, between 2016 and 2022, with deaths examined between 2020 and 2022.

Participants For this study, the cohort comprised 8753 people who experienced homelessness in Perth, with 'recruitment' into the cohort governed by engagement with one or more local homelessness services and programmes over the period.

Outcome measures Number and median age-at-death statistics.

Results There were 360 deaths over the 3-year period, which is likely an undercount. The median age at death was 50 years, >3 decades below the current Australian median age at death of 82 years. Aboriginal people accounted for 30% of the deaths.

Conclusion The ongoing poor health and premature death of people who have experienced homeless are indictments on our society. Triangulation of multiple data sources is required to identify and monitor deaths among homeless populations. Timely, verified data on homeless mortality are important for galvanising action and accountability, and targets should be set to reduce the observed three-decade life expectancy chasm.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Our cohort is novel in its size and comprehensiveness, drawing data from several large homelessness services, including the largest provider of primary care services to people experiencing homelessness in Australia.
- ⇒ We demonstrate a 'real-time' methodology, involving frequent, routine monitoring and collating of information on homeless deaths, rather than more conventional, delayed recording.
- ⇒ We present data up to end-2022, overcoming the time lag that characterises most other available data on homeless deaths.
- ⇒ Despite these advantages, our data are limited in that they exclude information for people who experienced homelessness outside of Perth or who died outside of Western Australia.
- ⇒ Information on the cause of death was unavailable.

INTRODUCTION

Life expectancy and the likelihood of premature death are fundamental markers of health and social equity globally, and metrics that are widely used to galvanise efforts to improve health outcomes for particular population groups.[1] For example, life expectancy gaps and disparities in health and mortality outcomes are routinely reported for various ethnic, socioeconomic and regional groups by governments and health institutions worldwide.[2–6] This reporting can help drive accountability, or at least awareness of health equity gaps, for example in Australia, where recognition and reporting of a substantial life expectancy gap for Aboriginal and Torres Strait Islander people has led to delineation of 'close the gap' targets and intervention funding,[7] policy reform and public monitoring of outcomes.[8]

A multitude of studies have documented the association between poor health outcomes and homelessness. Therefore, it is unsurprising that people experiencing homelessness (PEH) are at risk of premature mortality,[9] with international studies reporting multidecade life expectancy gaps between PEH and the general population.[9–11] However, publicly available data and routine reporting on homeless mortality is scarce, contributing to low visibility and less concerted action to improve life expectancy than for other groups 'left behind'.[12 13] A litany of reasons for this have been noted, prominent amongst which is the lack of routine recording of housing status at time of death.[9 12 14] However, there has been little action to address this, and routine reporting on mortality among PEH remains sparse. The only whole-of-country examples we are aware of are in the UK, where, initially driven by journalist and homelessness organisation activism and calls for public accountability,[15] national homeless mortality statistics are now reported annually for England, Wales and Scotland.[11] However, those statistics are 'experimental', with total numbers of deaths estimated using capture–recapture statistical methods.[11] More commonly, studies of homeless deaths are undertaken at more granular city or specific cohort levels (eg, deaths among homeless patients presenting to a given hospital over a period of time[16]), and their methods and data sources vary. Consequently, most available data on homeless deaths are based on the discrete findings of individual retrospective studies, rather than information collected in a comprehensive, ongoing manner.

A further limitation of available data on homeless deaths is a lack of contemporaneity, with significant time lags between experiences of homelessness, dates of death and study publication being common. Demonstrating this, out of all peer-reviewed studies of homeless mortality we are aware of, the most recent data are from 2021.[17] Contemporaneous data enhance effective, timely advocacy,[9] which is critical given PEH have dramatically reduced life expectancy and reside in environments of constantly changing, frequently severe shortages of housing.

In lieu of a 'gold-standard' approach for comprehensively measuring and reporting homeless deaths, a growing number of homelessness organisations and researchers, concerned with rising numbers of deaths, have resorted to devising and implementing their own approaches.[12 13 18] The most comprehensive of these is the 2021 Homeless Mortality Data Toolkit[18] developed by the US National Health Care for the Homeless Council (NHCHC), which describes how local authorities can track homeless deaths through gathering data from multiple different sources. However, such efforts often face governmental criticism, undermining their impact.

The context of this study is Australia, where only five peer-reviewed studies of deaths among PEH have been published.[16 19–22] These studies have examined retrospective data for discrete cohorts who were either present in a specific database (eg, a suicide registry) or who used or accessed a single homelessness or hospital service, and their data recency has been limited. Meanwhile, mirroring the predominant global situation, homelessness in Australia is increasing,[23] no routine reporting on homeless mortality exists and a severe shortage of public housing prevails,[24] with these factors combining to inhibit effective advocacy to reduce premature deaths in this vulnerable cohort.

This study aimed to overcome some of these limitations by applying the principles of the NHCHC's Toolkit[18] to contemporaneously count deaths and examine premature mortality among a large, dynamic cohort of PEH in Perth, Western Australia (WA).

METHODS

Study design and cohort

This study has a dynamic cohort design, with participants identified through engagement with one or more of these homelessness services and programmes in Perth:

- A large, specialist homelessness primary care service.
- A dedicated homeless team in a major, inner-city public hospital frequented by PEH, particularly rough sleepers.
- A homelessness programme embedded in a public mental health hospital.
- Two Housing First (HF) programmes.

Thus, all participants have a history of homelessness per their engagement with these services/programmes, with their experiences of homelessness spanning from periods of short-term, brief, insecure housing to chronic, long-term rough sleeping. Further, the cohort includes some individuals who have since been housed. Hence, for the purposes of our study, the term 'homelessness' captures all definitions under the European Typology of Homelessness and Housing Exclusion.[25]

For this study, mortality outcomes for participants entering the cohort from 2016 to 2022 are examined (n=8753). Figure 1 depicts the overlap of individuals' engagement between services. Most (93%) were patients of the homelessness primary care service, 27% were seen by the public hospital homeless team, 6% were seen by the mental health hospital-based homelessness service and 5% were participants in the HF programmes. Most patients seen by the homeless team (91%, n=2135) were known to the primary care service since the geographical catchment serviced by the hospital is also where most of the primary care, street outreach and hospital in-reach of the primary care service occurs. Further details of the services' operations are provided in online supplemental appendix.

Identification and verification of deaths

Deaths among the cohort are routinely identified, verified and cross-checked by the authors across four key data sources: hospital records, government death registry records, electronic medical and/or administrative records of the homelessness services/programmes, and death records in the Perth 'By Name List', a tool initiated in 2019 that enables homelessness organisations to collaboratively track and quantify homelessness for a given geographical area. Figure 2 summarises the process of identifying and verifying deaths.

The team prioritises cross-verification of deaths via multiple sources. This paper focuses on the period 2020–2022, the last three complete calendar years for which data were available, for reasons of data currency. For that period, 93% of deaths were verified via 2+ sources and

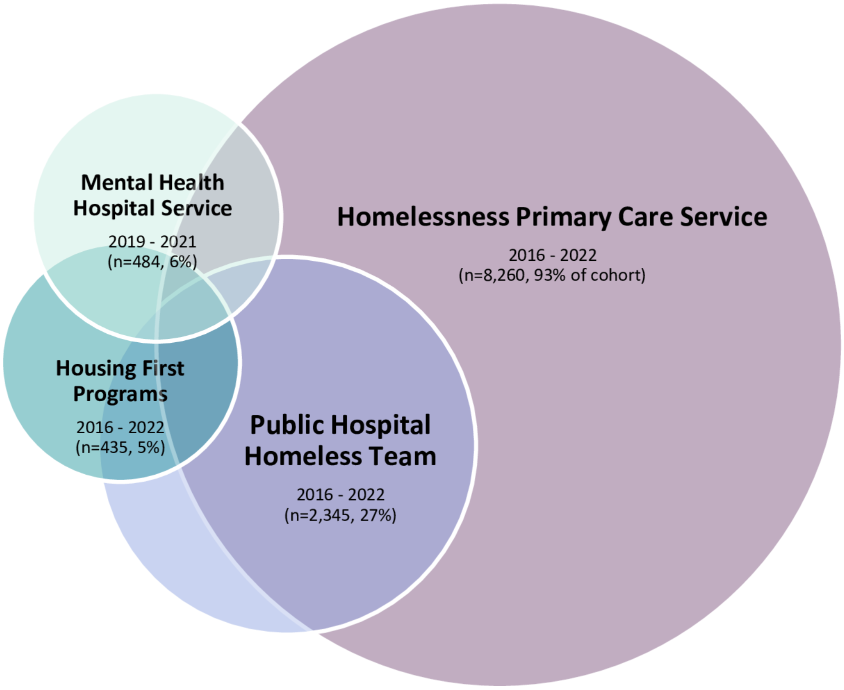

Figure 1 Representation of overlap between participating services/programmes. Service/programme sizes and degrees of overlap are only roughly drawn to scale. More precise depictions are provided in online supplemental appendix.

almost all (99%) were verified via hospital records and/or the WA Registry of Births, Deaths and Marriages, the two most reliable sources of deaths data in WA (table 1). The relatively low rate of verification of deaths via hospital records in 2022 (86%, compared with 94%–95% in 2020–2021) was due to a time delay in the recording of deaths in the hospital system.

Statistical analysis

Counts of deaths and associated summary statistics were calculated in each year and overall based on age at death, sex and Indigenous status information obtained from the cohort data sources. Indigenous status was defined as either 'Aboriginal and/or Torres Strait Islander' ('Aboriginal') or 'non-Aboriginal'.

Patient and public involvement

None.

RESULTS

Deaths among people who have experienced homelessness in Perth

Table 2 shows summary statistics for identified deaths by year. In total, 360 deaths were identified, representing 4% of the cohort (n=8753). The number was highest in 2022 (n=136), perhaps partly due to the size of the cohort increasing over time, with new patients constantly being seen by the participating services/programmes.

It is important to note that the counts of deaths in table 2 under-report the total number of deaths

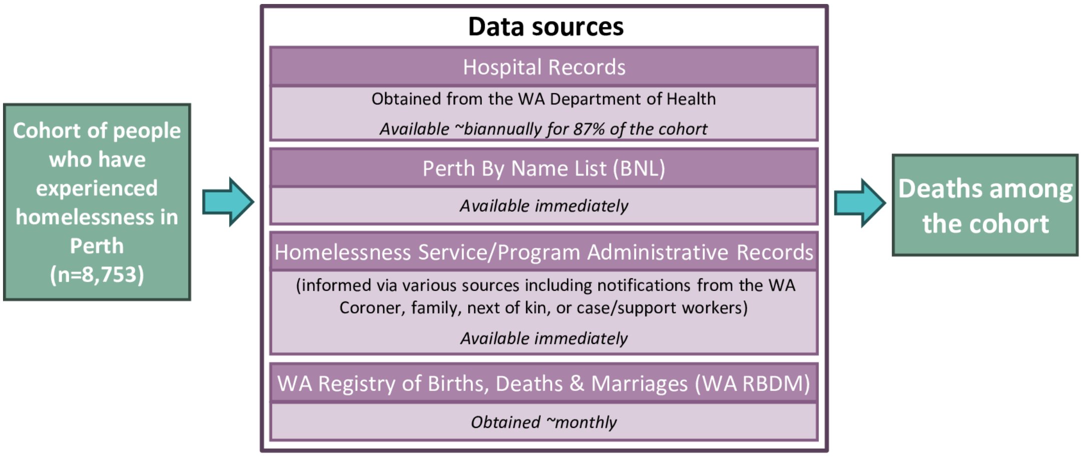

Figure 2 Identifying and verifying deaths. Further details are provided in online supplemental appendix. WA, Western Australia.

Table 1 Sources and number of sources of verification of deaths

	Year			
	2020	2021	2022	All years
Source of verification				
Hospital records	110 (94)	102 (95)	117 (86)	329 (91)
Western Australia Registry of Births, Deaths and Marriages (WA RBDM)	108 (92)	101 (94)	126 (93)	335 (93)
Hospital records and/or the WA RBDM	116 (99)	107 (100)	135 (99)	358 (99)
Homelessness services/programmes	84 (72)	73 (68)	83 (61)	240 (67)
Perth by name list	37 (32)	32 (30)	51 (38)	120 (33)
Number of sources of verification				
1	5 (4)	4 (4)	17 (12)	26 (7)
2+	112 (96)	103 (96)	119 (88)	334 (93)
Total	117	107	136	360

that have occurred among the cohort since the first individuals entered the cohort in 2016, as the deaths reported are confined to those that occurred from 2020. The database contains another 256 deaths that occurred from 2016 to 2019.

Demographic characteristics of people deceased

Over the 3-year period, the mean and median ages at death were 51 and 50 years, with the mean age at death varying only slightly over time (between 49 years in 2020 and 51 years in 2021–2022) (figure 3). Soberingly, only a few individuals (n=8) reached the current median age at death in Australia of >80 years.[6]

Males comprised almost three-quarters (73%, n=263) of recorded deaths (table 2), consistent with the over-representation of men in both the present cohort (62% male) and among PEH more generally in Australia (56%[23]) and internationally.[26 27] The annual proportion of the deceased who were male varied slightly over time between 68% in 2022 and 78% in 2021.

The proportion of the deceased who identified as Aboriginal was 30% (n=108; table 2), congruent with the proportion of Aboriginal people in the overall cohort (28%) and among PEH more generally in Australia (20%).[23] However, saliently, these figures are 6–8 times higher than the proportion of the general Australian population who identify as Aboriginal (3.5%).[28] The annual proportion of the deceased who were Aboriginal varied only marginally over time between 27% in 2020) and 32% in 2021–2022.

DISCUSSION

This study describes contemporaneous data on deaths among a large cohort of people who have recently

Table 2 Summary statistics for deaths between 2020 and 2022 of people who have experienced homelessness in Perth

	Year			
	2020	2021	2022	All years
Age (years)				
Mean	49	51	51	51
Median	49	51	51	50
Range	21–88	27–91	25–85	21–91
n (%) aged >80 years*	3 (3)	3 (3)	2 (1)	8 (2)
Sex n (%)				
Male	87 (74)	83 (78)	93 (68)	263 (73)
Female	30 (26)	24 (22)	43 (32)	97 (27)
Indigenous status n (%)				
Aboriginal	31 (27)	34 (32)	43 (32)	108 (30)
Non-Aboriginal	86 (74)	73 (68)	93 (68)	252 (70)
Total	117	107	136	360

*Approximate median age at death of the general Australian population.[6]

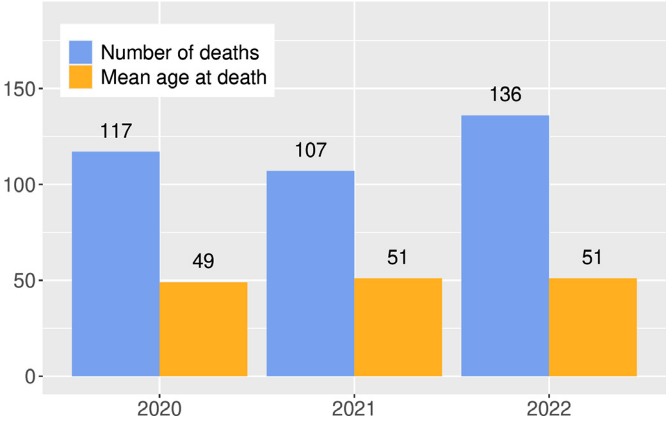

Figure 3 Number of deaths and mean age at death from 2020 to 2022.

experienced homelessness in Australia. The mean age at death of 51 years is around three decades lower than the current median age at death of the Australian population,[6] a staggering life expectancy gap to still exist in a developed, economically stable country like Australia. However, this figure mirrors similar gaps observed internationally, underscoring Robert Aldridge's reference to homelessness and deaths among PEH as a barometer of social justice.[29]

This study is novel in at least three respects:

1. Its size and comprehensiveness, due to drawing data from several large homeless health services, including the largest provider of primary care services to PEH in Australia, to form a cohort of individuals that is several times larger than those of all previously published Australian studies of homeless mortality[16 19–22] and most studies of homeless mortality internationally.[9]
2. Its 'real-time' methodology, involving frequent, routine monitoring and collating of information on deaths among a large, dynamic cohort people who have experienced homelessness, rather than more conventional, delayed reporting.
3. Its currency of data and expedience of research dissemination, with all known deaths up to end-2022 included, overcoming the time lag that characterises most published retrospective studies of homeless mortality both in Australia and internationally.[16 19–21]

The temporal recency of our data is particularly salient, with a recent systematic review of homelessness and mortality noting that timely and effective longitudinal tracking of deaths is critical to inform advocacy and policy responses.[9] Most published studies of homeless deaths 'look back' at deaths for particular cohorts over particular periods of time. By contrast, while we have confined our findings to the last three complete calendar years for which completed data were available, our methodology and database emphasise regular, routine checking and cross-verification of deaths across multiple sources of data. Through this process, and notwithstanding some limitations (see Limitations and future research), we have demonstrated that timely, city-level tracking of deaths among people who have experienced homelessness is possible.

The role of researchers and homelessness services in documenting and reporting on deaths among people who have experienced homelessness is particularly critical given the invisibility of homelessness in established data on mortality trends.[13 15] As articulated by Cooper and McCulloch in a recent paper on homelessness and mortality in Britain (Cooper and McCulloch, p6)[15]:

> The absence of homeless groups from official data on death and dying is not a new problem and to a large degree, their absence merely adds to the story of their more general invisibility from public and political discourse.

The work of services and researchers is hindered partly by the fact that housing or homelessness status is not, or at least not accurately, captured in typical mortality data sources such as government registries of deaths or coronial records. Hospital and health services often use the nomenclature of 'no fixed address' (NFA), but this has been shown to significantly under-represent the true extent of homelessness,[30] as there can be stigma and other barriers to disclosing that one is homeless,[14] records are often outdated for transient populations, and it is not uncommon to provide the address of a homeless service or relative as a postal contact. The latter phenomenon is evident in our cohort, where only about two-thirds of the deceased who had hospital data available had NFA somewhere in their hospital records.

'You can't change what you don't measure' is a saying that resonates strongly with the imperative for drawing on multiple data sources to count deaths among people who have experienced homelessness, and for timely assessment of any closing in the life expectancy chasm.[13] As powerfully articulated by Cooper and McCulloch,[15] the invisibility of homeless people in death is also linked to their invisibility in life, and to wider systemic abandonment and governmental inaction that amplifies the risks of premature death.

It is axiomatic that the longer people are homeless, the more their health deteriorates. Hence, timely data on deaths among people who have experienced homelessness has critical policy relevance for the health, homelessness and public housing sectors. Foremost, the need for rapid housing is a fundamental precursor to health. In WA, homelessness is increasing[23] in tandem with a severe shortage of affordable and social housing, with 17 000+ people on the public housing waiting list and an average wait time for housing of 116 weeks (>2 years) in 2021–2022.[31] HF,[32] recognised as global best practice, prioritises immediate access to housing as both a fundamental human right and an important precondition to addressing other issues a person might have, including health issues. Thus, advocating for more rapid housing of PEH under HF principles, combined with appropriate provision of wraparound health and support services and longitudinal monitoring of the health and well-being of individuals involved with HF initiatives, alongside provision of other initiatives suggested to support patients experiencing homelessness, such as medical respite,[33] is critical if we are to turn the tide on the life expectancy gap. Regarding HF, while previous evidence has been mixed regarding its actual effect on health,[33 34] there is a growing body of evidence that has demonstrated improved health outcomes for HF participants, in terms of both reduced hospital use and access to and engagement with health services.[35–37] This body of evidence includes a recent large US study that reported reductions in emergency, inpatient and mental health encounters, and increased pharmacy claims, for HF participants beyond regression to the mean.[34]

Suggestions for future research and tracking of deaths

The very nature of homelessness and the consequences of PEH being an often marginalised and excluded population[15] render it impossible to comprehensively identify and monitor their mortality via a single method.[10] Therefore, as stressed in the NHCHC's Toolkit,[18] it is imperative to examine as many sources of data as possible when considering both homeless mortality and the experience of homelessness generally. This has its challenges, as the ways in which services define or capture data on homelessness or housing status vary, and, at a minimum, accurate recording of name and date of birth is required for cross-checking against official death registries or hospital or health records. However, in our experience, many homelessness and health services at the coalface recognise the critical need for greater visibility of homeless mortality and are receptive to helping improve associated data capture. Robust governance and research ethics protocols are, of course, essential.

Given the multidecade life expectancy gap between PEH and the general population, concerted efforts should be made by governments to enhance capacity to link homelessness and mortality data, with such efforts dually focusing on improving consistency in homelessness definitions and the recording of individuals' housing status across services and sectors.

There is more work to be done around the causes of death among people who have experienced homelessness,[9] particularly in the light of a recent UK study finding that one in three deaths among people who had experienced homelessness were attributable to conditions that could have been prevented or treated.[10] However, caution is warranted, as the clinical or certified cause of death may not reflect the contributory influences of deep deprivation, trauma, despair and social determinants of health. Furthermore, statistics on homeless mortality are sometimes disputed by some of those in government, who argue, for example, that a person may not have been literally sleeping rough at death or that the cause of death was specifically a drug overdose or associated with a chronic disease. The implication of these criticisms is that experiences of homelessness are not part of the problem, which ignores the abundance of research demonstrating it is any (including any past) experience of homelessness that is associated with premature death (eg, see Zordan *et al*[16]).

Finally, we stress that sensitive consideration of the people behind the statistics needs to be foremost in the minds of those undertaking research around homeless mortality. We have observed first hand the emotional toll on PEH and staff in services that support this population that accompanies news of another death on the street, or someone dying of what would otherwise have been a preventable disease.

Limitations and future research

This study has several limitations. First, congruent with much of the existing literature, it examines deaths among a convenience cohort of people who have recently experienced homelessness. While the cohort is large, encompassing all patients of the main provider of primary healthcare to PEH in Perth and all patients seen by the hospital homeless team, it excludes PEH who:

a. Experienced homelessness in Perth during the period but who did not engage with one of services/ programmes.
b. Only experienced homelessness in regional WA (ie, outside Perth).

Further, the available data on deaths exclude those for individuals who:

a. Were part of the cohort but who died outside of WA (eg, in a different Australian state or territory).
b. Died but whose deaths were not (or not yet) recorded in a verifiable source.

The latter individuals were essentially lost to follow-up, though such situations are expected to be rare. Together, these factors mean it is likely we have under-reported the true number of deaths among PEH in WA for the period. Future work will investigate the possibility of broadening the cohort to include people who access additional homelessness services, particularly those outside of the inner-city domain, and obtaining national RBDM or equivalent data.

Second, it was beyond the scope of this study and the available data to examine the cause of death. Ethics approval has now been granted to obtain cause of death information (where known) for our cohort, but time lags on these data are likely given that almost two-thirds of the deaths reported in this paper were referred to the WA Coroner (data not shown).

Third, no attempt was made to estimate the homeless mortality rate, as the lack of data and reporting is the primary issue in the study of homeless mortality, which we seek to help overcome through our paper. Further, it was not feasible to define and examine a comparison group. While some studies on homeless deaths have compared mortality rates between homeless and non-homeless subcohorts, our study comprises a longitudinal, purposive sample of all patients or clients of the homelessness services/programmes, and we do not have data for any directly comparable 'non-homeless' group. Future research will examine the possibility of obtaining such data to estimate and compare mortality rates, which has been identified as an important aspect of such work.[9] In doing so, due consideration will be given to potential issues and limitations associated with the dynamic nature of our cohort, such as loss to follow-up as noted above.

CONCLUSION

Given the multidecade gap in average life expectancy that persists for people who have experienced homelessness, the timeliness of homeless mortality data and its reporting is critical if it is to aid real-time advocacy for targeted efforts and funding to reduce this chasm of inequality.

Contributors MT, SV and LW conceptualised and planned the study, liaised with the relevant agencies to obtain access to the data, interpreted the results, critically reviewed and revised the manuscript and prepared the paper for publication. MT performed the analysis, drafted the manuscript and coordinated manuscript revisions. MT and SV accessed and verified the data. All authors had full access to the data and accept responsibility for the decision to submit the paper for publication. MT is responsible for the overall content as guarantor.

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Competing interests None declared.

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 the data in this study were covered by an ethics approval obtained from the Royal Perth Hospital (RPH) HREC for a broader longitudinal study of health outcomes for people experiencing homelessness in Perth (project number RGS0000000075). A waiver of consent was granted under the study's HREC approval.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available. The data underlying the findings of this study were made available to the research team under appropriate Human Research Ethics Committee (HREC) approvals and cannot be provided to other parties by requirement of those approvals.

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