Journal of Mental Health

ISSN: 0963-8237 (Print) 1360-0567 (Online) Journal homepage: www.tandfonline.com/journals/ijmh20

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To cite this article: Michael Coffey, Fiona Lugg-Widger, Ben Hannigan, Viktoriya Velikova & Anthony Byrne (02 Jun 2025): Severe mental illness and last year of life: Identifying service use from a National Health Service digital dashboard in Wales, UK, Journal of Mental Health, DOI: 10.1080/09638237.2025.2512306

To link to this article: https://doi.org/10.1080/09638237.2025.2512306

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JOURNAL OF MENTAL HEALTH
https://doi.org/10.1080/09638237.2025.2512306

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Severe mental illness and last year of life: Identifying service use from a National Health Service digital dashboard in Wales, UK

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ABSTRACT

Background: Systematic reviews have identified variation and inequity in care provision for people with pre-existing severe mental illnesses who have palliative or end-of-life care needs.

Aim: To analyse service use and variation for people with severe mental illness in the last year of life in Wales.

Methods: This is an observational retrospective cohort study between 2018 – 2023 using anonymised linked routinely collected health datasets within a data dashboard.

Results: We identified n=4722 (2.3%) deaths with ICD-10 codes for severe mental illness for the period 2018-2023. As a group, people with severe mental illness die younger, are in receipt of specialist palliative care at lower rates, die more often in institutional settings rather than their own homes and comorbidity indicates more unscheduled care use in the last year of life.

Conclusions: Unscheduled care use in the last year of life is associated with comorbidity, indicating opportunities for upstream intervention to improve treatment, experience, and quality of life for people with severe mental illness. Further investigation, such as mixed methods approaches to examine experiences of those with severe mental illness in the last year of life, and the human and systems factors influencing the nature and effectiveness of unscheduled delivery, is needed.

ARTICLE HISTORY
Received 14 January 2025
Revised 24 March 2025
Accepted 3 April 2025

KEYWORDS
Mental illness; end-of-life care; dashboard systems

Introduction

People with severe mental illness (SMI) diagnoses such as schizophrenia or bipolar disorder are known to have a life expectancy some 20 years shorter than the general population (Chesney et al., 2014). For those with an additional life-limiting illness such as cancers or organ failure, there is a complex set of inequalities that lead to a mismatch between their care needs and service provision (Hannigan et al., 2022). Variation in care is attracting international research efforts to better understand care use and outcomes (Ashok et al., 2023; Svansson et al., 2024). For people with SMI diagnoses, multiple challenges exist in accessing better end-of-life care, with little research directly estimating the size of the cohort, service use, and outcomes suggesting probable significant unscheduled care use (Edwards et al., 2021). Unscheduled care use is a likely indicator of need for proactive care and preventative management of long-term conditions (Lorig et al., 1999). Healthcare systems contribute to numerous challenges for those with SMI diagnoses in negotiating access and securing coordinated care. Service use in the context of co-morbidity is likely to be higher for this group (Sadowska et al., 2023), with co-morbid cancer diagnoses leading to increased use of palliative care but less high-intensity end-of-life care (Svansson et al., 2024). Hannigan et al. (2022) did not identify any comparable UK data on incidence, prevalence, or service use for people with SMI diagnoses to inform supportive care responses although evidence from the US indicates that intervention at the intersection of physical and mental health care could address disparities in care outcomes (Shalev et al., 2020).

Routinely collected data produced in healthcare settings present an important opportunity for addressing research questions and informing planning in health services (Morrato et al., 2007). These data can address knowledge gaps, generate hypotheses (Todd et al., 2020), help in developing new tools for promoting quality and safety in healthcare (Deeny & Steventon, 2015), contribute to assessing the impact of healthcare interventions (Clarke et al., 2019), and allow evaluation of effectiveness to inform policy decisions (Morrato et al., 2007). Digital dashboards are increasingly being used as a means of data visualization in healthcare systems to communicate knowledge of utilization and prompt data-based service improvement (Schulze et al., 2023). Digital dashboards capture, analyse, and present data on how a given service is performing to allow optimisation of services

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Supplemental data for this article can be accessed online at https://doi.org/10.1080/09638237.2025.2512306.

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and enhance their performance (Helminski et al., 2022). Where these dashboards are easily accessible to clinicians, their use is associated with improved patient care and better outcomes (Dowding et al., 2015).

This paper examines data arising from a digital dashboard that collates last year of life data at a population level for the country of Wales, UK. Our research question is, 'What can a national data dashboard tell us about the use of services in the last year of life for the population of people with severe mental illness in Wales?'

The last year of life digital dashboard is provided by the Wales Value in Health Centre and Digital Health and Care Wales. Value in Health is a National Health Service (NHS) Wales programme focused on delivering value-based healthcare across healthcare delivery, centred on outcomes that matter to patients and a more data-driven system. Digital Health and Care Wales is part of NHS Wales and uses data to improve how health and care services are delivered.

Our objectives were to use the last year of life dashboard to describe this population, address the research knowledge gap of service use in the last year of life for people with SMI diagnoses in a whole population, with a specific focus on unscheduled care use in this cohort.

Methods

Study design

This is an observational retrospective cohort study using multiple routinely collected health datasets within a data dashboard. This study is reported using the RECORD reporting guidelines (available as a supplementary file) (Benchimol et al., 2015). An eligible ICD-10 cohort was produced in the last year of life dashboard, and information was aggregated to years 2018-2021 and 2022-2023. We examined data relating to deceased people for the whole of Wales and a sub-population of patients who were adults 18 years and older with SMI diagnoses.

Population

All recorded deaths for the database population (defined as everyone registered with a Welsh general practice and/or everyone identified as living in Wales at the time of death from Office of National Statistics data) in Wales for the years 2018-2023, and from these data a cohort (study population) of all deceased people 18 years and older with a record of SMI, identified as any lifetime diagnosis using ICD-10 codes for schizophrenia, schizotypal and delusional disorders F20-29, mood disorders F30-39, disorders of adult personality and behaviour F60–69 (WHO 1992). Due to the absence of primary care data available in the dashboard, diagnosis was dependent on interaction with the secondary care system. Deaths due to unnatural causes (ICD-10 codes V01-X59 & X85-Y99), e.g. accidents, were excluded as the focus was on the use of unscheduled care in the last year of life. Linkage between datasets used individual NHS numbers, and the time frame was set to 12 months prior to the patients' deaths.

Data sources

The following anonymised data sets were used to generate linked data outputs on the dashboard.

- NHS 111 calls data set – this is a National Health Service urgent call line for advice and if needed onward referral to emergency department, urgent treatment centre or pharmacy.
- General Practice (GP) out of hours data set – calls to general practice out of hours.
- Welsh Ambulance Service data set – calls and ambulances dispatched.
- Welsh Ambulance Service patient clinical record (PCR) data set - PCR data from ambulance crews (data from 2018–2021).
- Emergency department data set – emergency departments and minor injuries unit data in Wales.
- Admitted patient care data set –consultant-led admitted patient care data (elective and emergency).
- Office of National Statistics Death data set – monthly death registration data.
- Welsh Demographic Service data set – data on all patients registered with GPs in Wales.
- Cancer Network Information System Cymru (CaNISC) – collates data on specialist palliative care (SPC) for all conditions including cancer, in community and secondary care.

Permissions

Access to the dashboard created by Digital Health and Care Wales was granted in April 2024. Consent was not required as data was aggregated and anonymous. Research ethics approval was exempted on application as the project was classified as a service evaluation. Values relating to 5 or less patients were suppressed in all dashboard visualisations as a privacy protection method.

Analysis

We described the cohort of people with SMI diagnoses dying in Wales compared with a non-SMI group in the wider Welsh population, in particular:

- Demographic variables included age at death and sex.
- Underlying cause of death using ICD-10 diagnosis codes e.g., diseases of the circulatory system, neoplasms etc.
- A delineated count of care episodes, scheduled and unscheduled, in the last 12 months and last 90 days of life (A&E, Ambulance, Emergency bed days, and NHS 111 service use).
- The number of days spent in hospital (admission to discharge date) in the last 12 months of life.
- Place of death (e.g. home, care home, NHS establishment, other).
- Provision of SPC to understand patterns of use and variation.

- A Charlson Comorbidity Index (CCI) score (Charlson et al., 1987) was derived to enable an estimate of the associated impact of co-morbidities on unscheduled health care use for those with SMI diagnosis.

Patient and public involvement: patients or the public were not involved in the design, conduct or reporting of this research.

Results

Routinely collected data on the last year of life dashboard indicates 89.3% (range 74–100%) average audited clinical coding completeness across all seven Welsh University Health Boards providing acute, community and secondary healthcare for the whole population of Wales for the recent period 2022–2024 with 180k total uncoded episodes.

Demographics: The last year of life dashboard data identified 204,576 recorded deaths for the years 2018-2023 inclusive (Table 1). Of these 2.3% (n = 4722) had an ICD-10 code indicating a lifetime diagnosis of a SMI. On average people with SMI diagnoses die younger than others (SMI 37% vs non-SMI 20% in the 18–69 years group), as a cohort there are fewer individuals in receipt of SPC, they die in hospital at similar rates and have lower percentage of severe comorbidities and more ratings for mild or no comorbidities. On average, the SMI cohort uses emergency and ambulance services at similar rates as the non-SMI group, but use of emergency beds is higher.

Underlying cause of death: The top three causes of death by ICD-10 Chapter for the SMI group were diseases of the circulatory system n = 1145 (24%), diseases of the respiratory system n = 837 (17.7%), and neoplasms n = 834 (17.6%) (see Figure 1). This compares with the non-SMI group, where neoplasms n = 55,459 (27.7%), diseases of the circulatory system n = 50,624 (25.3%), and diseases of the respiratory system n = 26,496 (13.2%).

Care episodes: People with SMI had a total of 33,885 care encounters in the last year of life, with 15,650 (46%) of these contacts occurring in the last 90 days of life (Table 2). The majority of contacts for the SMI group are distributed between ambulance call outs and emergency department attendance along with admitted patient care episodes (Table 2). Primary care out of hours encounters are proportionately higher in the SMI group in the last year of life. Compared with the non-SMI group the SMI group show a higher percentage of total care encounters with unscheduled care and fewer attendances of less than one day in the last year of life. There is variance between SMI and non-SMI groups in SPC care encounters with a lower percentage for the SMI grouping (SMI n = 1932, 5.7% versus non-SMI n = 113,829, 8.5% in last year of life) (see Table 2).

Days spent in hospital: Emergency bed days are higher on average for SMI compared with the non-SMI population in the last year of life (see Table 1) and this difference remains for the last 90 days with the SMI group mean for emergency bed days higher in comparison (23 vs 19 bed days).

Table 1. Showing demographic information for last year of life in the cohort of people with SMI diagnoses versus non-SMI group.

	Non-SMI n=	%	SMI n=	%	Total	%
Deaths	199,854	97.6	4,722	2.3	204,576	100
Age groups						
<18 yrs.	942	.4	0	0	942	1
18-69 yrs.	39,851	19.9	1,742	36.9	41,593	20
70+	159,061	79.5	2,980	63.1	162,041	79
Mean yrs (median)		80.6 (81)		72.7 (75)	80.4 (81)	
Sex						
Male	99,853	49.9	2,155	45.6	102,008	49.9
Female	100,001	50	2,567	54.3	102,568	50.1
Specialist Palliative Care	66,969	33.5	1,169	25	68,133	33.3
Earliest SPC encounter in days prior to death mean (median)	94 (37)		98 (35)		94 (37)	
Dying in hospital (with SPC)	101,238 (29,185)	50.6	2,271 (611)	48.1	103,509 (29,796)	50.5
5-year Charlson comorbidity index*						
Severe	66,004	33	1,234	26	67,238	33
Moderate	45,412	22.7	1,058	22	46,570	28
Mild	50,554	25.2	1,522	32	52,072	23
None	32,788	16.4	908	19	33,696	16
Emergency department contacts in last 365 days	292,234	43.6	8,956	41.8	301,190	43.5
Ambulance call outs Last 365 days	263,682	39.3	8,794	41.1	272,476	39.4
Emergency Bed admissions last 365 days	295,811	53.4	7,813		303,624	53.8
Emergency Bed admissions last 90 days	178,594		4,195		182,789	
Emergency bed days last 365 and 90 days, mean (median)	16.5 (7) 18.9 (8)		19.9 (7) 23.4 (5.2)		16.6 (7) 19.2 (8)	

*Charlson Comorbidity Index groups by score: 0 = no CCI, 1-2 = mild, 3-4 = moderate, > = 5 = severe.

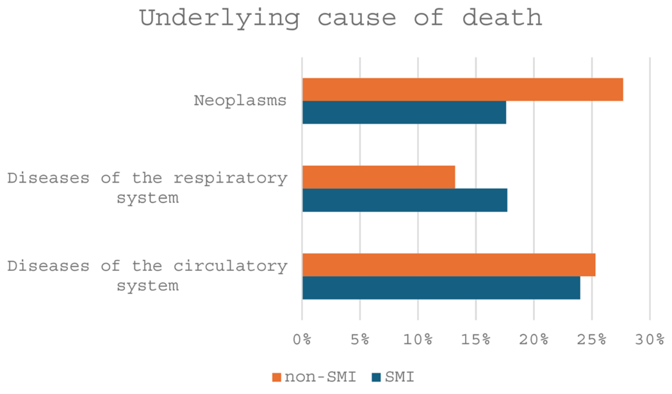

Figure 1. Showing top three underlying causes of death for SMI versus non-SMI group.

Place of death: Most people in both groups die in formal settings such as a hospital or care home (see Table 3) with the SMI group showing a higher percentage of dying in a care home and lower percentage for dying in their own home than the non-SMI group. Hospice as place of death was lower on average for the SMI group.

Specialist palliative care: The total number of patients in receipt of SPC in the SMI cohort was n = 1169 (25% of the SMI cohort) (see Table 1) and their earliest encounter with SPC was on average 98 days prior to death with a median of 35 days. Compared with non-SMI group proportionately fewer of the SMI group had SPC in the last year of life and their contacts with SPC were lower (Table 2).

In the SMI group just under half (48%, n = 2271) (see Table 3) died in hospital, of these 73% (n = 1660) had no SPC versus 26% (n = 611) who had received SPC indicating an association between SPC receipt and dying in hospital. Within the SMI cohort the total number of bed days (see Figure 2) for those with SPC was less than half (47.7%) that of those with no SPC (52,492 days vs 110,138 days).

Co-morbidities: Table 1 reports the 5-year Charlson Comorbidity Index (CCI) scores for the SMI cohort versus the non-SMI group. The CCI predicts mortality for individuals through weighting the number and severity of comorbid conditions, with higher numbers indicating greater risk of death (Charlson et al., 1987). Unscheduled service encounters in the last year of life for those with SMI and CCI scores of 5 or more (severe) are 7600 contacts for n = 1234 deaths. Those with more comorbidities have most unscheduled service encounters e.g., those with no comorbidities (n = 908) accounted for only 8% (n = 1826) of unscheduled encounters versus 35% (n = 7600) for those with most comorbidities in the last year of life.

Proportionately more contacts occur in the last 90 days of life, e.g. 41% of all unscheduled encounters for those with a CCI 'severe' score occur in the last 90 days with most encounters with ambulance and emergency departments (Table 4). Unscheduled care encounters are in the expected direction, i.e., people with higher CCI scores have the most encounters, other than those with lower CCI (scores of 1-2)

Table 2. SMI vs Non-SMI care encounters in last year of life and last 90 days of life.

Service	SMI Encounters LYOL	%	SMI Encounters Last 90 days	%	Non-SMI Encounters LYOL	%	Non-SMI Encounters Last 90 days	%
111	2,797	8.2	1,201	7.6	87,871	6.5	47,057	6.9
GPOOH	852	2.5	439	2.8	26,190	1.9	16,438	2.4
Ambulance	8,794	26	3,855	24.6	263,682	19.7	137,986	20.4
ED	8,956	26.4	3,845	24.5	292,234	21.8	146,542	21.7
APC Attendance[a]	3,107	9.1	848	5.4	271,647	20.3	69,572	10.3
APC Admission[b]	7,447	22	4,048	25.8	282,107	21	171,487	25.4
SPC[c]	1,932	5.7	1,414	9	113,829	8.5	85,836	12.7
Total	33,885	100	15,650	100	1,337,560	100	674,918	100

[a] APC Attendance:admitted patient care of less than one day.

[b] APC Admission: admitted patient care of more than one day.[c]^SPC data in the dashboard is for initial and not ongoing contacts.

Table 3. Patient numbers for SMI and Non-SMI place of death and showing with SPC.

Place of death	SMI (SPC)	%	Non-SMI (SPC)	%
Hospital	2271 (611)	48	101,244 (29,185)	50.6
Care Home	1138 (238)	24.1	33,953 (7,024)	16.9
Home	1095 (231)	23.1	56,067 (25,281)	28
Hospice	66 (59)	1.4	4,441 (3,994)	2.2
Other	152 (30)	3.2	4,149 (1,266)	2
Total	4722 (1,169)	100	199,854 (66,969)	100

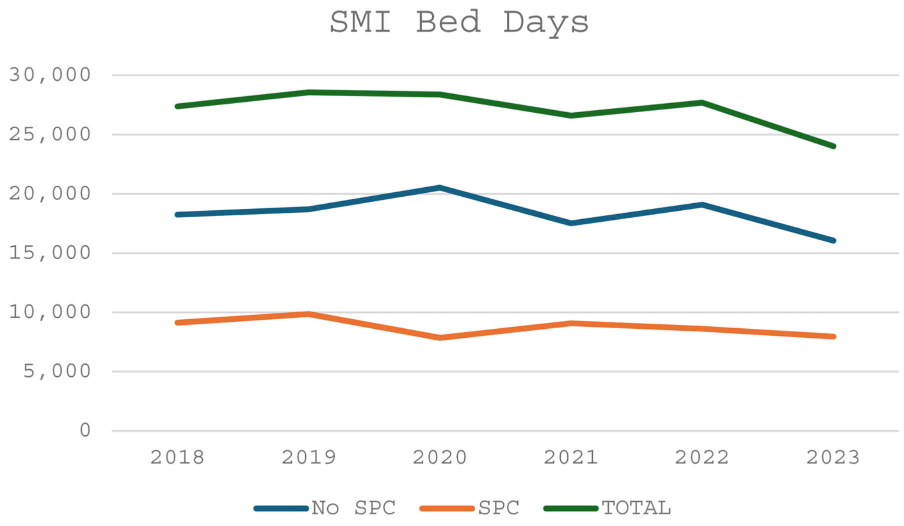

Figure 2. Showing bed day count for the SMI cohort for those with and without specialist palliative care.

Table 4. Unscheduled care encounters by CCI score in last year and last 90 days of life for the SMI cohort.

	*CCI Severe Last 365: Last 90 days N = 1,234	CCI Moderate Last 365: Last 90 days N = 1,058	CCI Mild Last 365: Last 90 days N = 1,522	CCI None Last 365: Last 90 days N = 908
+All encounters	13,536: 5,858	8,011: 3,874	9,794: 4,670	2,544: 1,248
Ambulance	3034: 1246	2,320: 1008	2744: 1,248	696: 353
ED	3151: 1298	2190: 966	2848: 1,237	767: 344
NHS 111	1086: 436	617: 282	800: 363	294: 120
GPOOH	329: 154	185: 111	269: 126	69: 48

*Charlson Comorbidity Index groups by score: 0 = no CCI, 1–2 = mild, 3–4 = moderate, >=5 = severe.

Key: ED: emergency department, NHS 111:national health service telephone support, GPOOH:general practice out of hours.

+All contacts total includes contacts such as admissions where it is not clear if these were elective or emergency.

who have the largest number of deaths and the second highest number of unscheduled care encounters.

Discussion

We explored service use in the last year of life for people with a lifetime diagnosis of SMI using a digital dashboard in Wales, UK. For the first time, we have been able to identify a whole country SMI cohort (n = 4722) over a six-year period and follow their service use in the last year of life across a number of acute services. Our results show that the SMI group die younger than the non-SMI group, have more unscheduled care episodes, die proportionately more often in a care home compared with the non-SMI group and marginally less in hospital settings, spends more time in hospital in general and are in receipt of SPC at lower rates. In the SMI cohort, those that received SPC had substantially less hospital bed days, indicating a possible effect for this care (Figure 2). Additionally, we can observe that those with comorbidities make more use of unscheduled care services (31,341 vs 2544 contacts), and that in the last 90 days of life those with comorbidities account for 92% (14,402 of 15,650 contacts) of all unscheduled contacts for this cohort (Table 4).

There is evidence across multiple conditions of greater service use, poorer outcomes, more complex clinical management and increased healthcare costs with increasing number of comorbidities (Valderas et al., 2009) and therefore value in further exploration of the role of comorbidities in exposing those with SMI to unscheduled care use in the last year of life. In a Swedish study those with psychosis and cancer were less likely to receive palliative care than those without psychosis, died on average 4 and half years younger and when SPC was provided, this led to reduced frequency of emergency care use (Bergqvist et al., 2024). Comorbidities are also implicated with an associated increased use of unscheduled care in a London cohort (Wilson et al., 2021) indicating an opportunity for interventions to access more timely care. Data from the current study indicate that intervention targeted at the SMI group with comorbidities, and whose palliative care needs are related to comorbidities other than cancer, has the potential to improve quality of life and remove variation (Carswell et al., 2022).

The experience of SMI can delay detection and treatment of physical disorders as individuals are less likely to seek treatment, verbalise pain and access timely healthcare (Goldenberg et al., 2000). Decreased engagement with medical care in comparison with the general population can be due to psychological and social issues, poor previous experiences of seeking help, healthcare professionals wrongly attributing physical symptoms to psychiatric disorders and lack of experience by mental health staff in determining how and when to refer to appropriate services (Shalev et al., 2017). In this study we have identified use of unscheduled care by people with SMI diagnoses, indicating ad hoc, chaotic and reactive engagement which could be explained by absent, reduced or missed opportunities for planned medical care. People with enduring mental health problems are approximately 50% less likely to access appropriate palliative care, including symptom control and pain relief (Shalev et al., 2017). This is despite a well-recognised outcome indicating that earlier palliative care is associated with increased survival, better quality of life, and less need for costly intervention at the end of life (Brännström & Boman, 2014; Temel et al., 2010).

Health and care systems are complex, creating challenges in the provision of services for people with SMI and for other disadvantaged groups (Hannigan & Coffey, 2011; Rutter et al., 2017). Wider social barriers exist for people with mental health problems who also have life-limiting illnesses, with implications for service organisation and provision. As a group, people with SMI are more likely to be socially isolated and to be homeless, which impacts care planning (Picot et al., 2015). Inadequate support systems are common for this group, which affects their ability to access care and navigate complex health and social care systems, likely increasing unscheduled care (Knapik & Graor, 2013).

Late presentation and reduced use of interventions such as surgery, chemotherapy, or radiotherapy for those with SMI have been noted (Irwin et al., 2014). In the current analysis, we identified that the SMI group access SPC at lower rates (Table 1) and their use of SPC appears to indicate lower use of hospital beds (Figure 2) suggesting that increased support in the last year of life can proactively better meet their needs. We also note that the cohort identified in this analysis have proportionately lower rates of cancer recorded as cause of death, which contrasts with other studies (Batty et al., 2012) and this requires further investigation. Our data suggests that the provision of SPC can lead to better outcomes, reducing unscheduled care use and the number of emergency admissions. Later involvement of these services however, makes it much more difficult to favourably impact health outcomes.

Strengths and limitations

A strength of this study is that we were able to exploit a rich source of patient-level data for a whole country and present for the first time analysis indicating variation in service use for the SMI population that experience significant inequity in care provision. There are limitations to this evaluation arising from those that apply more broadly to data from digital dashboards. For example, dashboards may direct attention towards certain data that is primarily for the purposes of service delivery and places limits on what information is collected, while important areas may be neglected such as cause and effect relationships (Deeny & Steventon, 2015). Social care and routine primary care data are not included in the dashboard to date and therefore the picture we present while important remains focused on unscheduled care with only partial access to other data. This means that diagnostic information was dependent upon contact with the secondary care system and may therefore not be complete. Those never seen in secondary care, or whose SMI were not captured on death certification, will not have been identified and hence it is possible that numbers in the cohort could be underestimated. We were also unable to determine if the SMI cohort were in receipt of continuing secondary care from mental health services. Our analysis is limited too by data availability. The dashboard does not report ethnicity data or living situation, and this reduces what we can say about the social circumstances of individuals. Dashboards are mainly visualisation tools. Our permissions did not include access to underlying data, and this therefore limits our ability to manipulate data for inferential purposes. Routinely collected data imported into a secure environment would allow more sophisticated analyses including generating a matched cohort for comparisons. We recognise too that the last year of life dashboard does not distinguish between types of hospital admissions beyond whether these were emergency of elective thus limiting our ability to further determine variation. Generalisability beyond the UK is limited to similar healthcare systems.

Conclusion

The current paper is a first step in understanding how people in Wales with SMI diagnoses interact with the health system and the variation that occurs when they do. Further research is required to address questions about the how and why of their interactions. These include mixed methodological approaches which give an depth understanding of lived experience of those with SMI in the last year of life, and the human and systems factors which determine the nature and effectiveness of unscheduled delivery for this patient cohort. Ongoing pattern generation of types of service use in the last year of life by analysing routine data at the population level will help guide more detailed multi-methods research on the leverage points available to facilitate timely referral. Continued development of datasets will allow the impact of new interventions to be assessed over time, with improved understanding of how the wider systems of care respond and adapt. There is a need too for detailed data linkage studies that include social care and nursing care data points to fully understand the effect of supportive care on unscheduled care use. Nevertheless, these data show that the SMI cohort die younger, experiences variation in care (less SPC) and make more use of unscheduled care, indicating possible opportunities for intervention to remove inequalities for this group. These data underpin the utility of population level datasets and mandates for widening the types of data available for integrated analysis with a view to iterative complex service improvements.

Authors' contribution

All authors conceived and designed the study. VV prepared the dashboard data for analysis. MC performed the analysis for this paper. All authors contributed to the interpretation of the results. MC wrote the initial draft of the manuscript, and all authors critically reviewed and approved the final version.

Disclosure statement

VV is employed by the Digital Health and Care Wales. The Centre for Trials Research at Cardiff University receives infrastructure funding from Health & Care Research Wales. The authors declare no other competing interests.

Funding

This study/research is supported by Digital Health and Care Wales (DHCW) through the provision of data. The views expressed are those of the author(s) and not necessarily those of the DHCW.

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Data availability statement

The dashboard has been developed by Digital Health and Care Wales in collaboration with the Welsh Value in Health Centre and NHS Wales Palliative Care clinicians. Use of the data and access to the dashboard is available to all NHS Wales staff and a number of Welsh Government professionals. All queries and requests for further information can be directed to the Information Services team at dhcw.info@wales.nhs.uk.

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