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## Deaths at home during COVID-19 in Scotland: Demographics, multimorbidity, and palliative care needs in population data

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### Abstract

#### Introduction

Deaths at home increased by a third in Scotland during the pandemic period, yet little is known about the population who died at home. Policy towards supporting this increased number will benefit from understanding differences in the socio-demographic composition and clinical needs of those dying at home following the pandemic.

#### Objectives

To describe the population who died at home in Scotland during the first year of the Covid-19 pandemic and compare them to the population of decedents five years prior, in terms of demographic and clinical characteristics and estimated palliative care needs. Demographic characteristics included age, sex assigned at birth, marital status, the area-based Scottish Index of Multiple Deprivation (SIMD) and the Scottish urban-rural indicator.

#### Methods

Retrospective cohort study of death registrations for Scottish decedents between March 2015 and March 2021, with the 12-month period from 2020-03-23 defined as the pandemic period. Death registrations were linked to 10 years of inpatient admissions to identify comorbid conditions and compute the Elixhauser Comorbidity Index (EI). Palliative care needs were estimated from underlying and contributory causes of death using ICD-10 codes. Number of distinct medications dispensed in the final 12 months of life was computed from prescribing records. A binary logistic regression model was used to estimate the association between individual characteristics, the pandemic period, and death at home, and their average marginal effects (AME).

#### Results

During the pandemic, home decedents were on average 1.03 years older, more likely to be male and married, their Elixhauser Morbidity increased by 0.39, and they received 0.25 more medication types. The EI of home decedents increased past that of care home decedents. The adjusted effect of the pandemic on probability of death at home was AME = 5.9% (95%CI 5.5%,6.3%).

#### Conclusions

In addition to increasing by a third, home decedents were as ill as before the pandemic or more, and were somewhat more similar to hospital and care home decedents than before the pandemic. Policy support is needed for enabling care at home for complex needs and increased support for carers.

#### Keywords

palliative care; end of life; place of death; care at home; multimorbidity; administrative data

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## Introduction

Deaths at home increased by a third in Scotland with the start of the Covid-19 pandemic and now represent a third of all deaths, up from about 25% before the pandemic [1]. Given that care needs increase closer to death [2], this change represents considerable increased demands on community care services [3].

Deaths at home increased in the rest of the United Kingdom [4, 5], as well as internationally: 23 of 29 countries (including the UK) saw increased deaths at home, with Scotland and Northern Ireland increasing the highest above 10-year projections [6].

Increased deaths at home have important implications for healthcare systems, given the major role played by end-of-life (EOL) care. Scottish censuses of all inpatients between 2010 and 2015 found between 20% and a third were in their final 12 months of life [7–9]. People at EOL are high users of secondary care, accounting for a high proportion of healthcare costs [2, 10]. Multimorbidity increases with age and is highly prevalent in Scotland, with more than 80% of those aged 85 or over having at least two or more chronic conditions [11], increasing the likelihood and intensity of palliative care required [12], as well as increasing vulnerability to drug toxicity due to e.g. polypharmacy [13]. Pre-pandemic projections have underestimated the current levels of deaths at home [1, 14] and with an estimated 74–90% of deaths in Scotland indicating palliative care needs (Finucane et al. 2021), the number of people dying at home with high levels of care needs have likely increased. Understanding death at home trends is essential to resource allocation and planning palliative care [15, 16]. Given the death at home increases internationally [6] and the pre-pandemic warnings of increasing demand for services [3], this is a pressing issue not limited to Scotland.

To address the increase of people dying at home we need to ascertain how the population changed during the pandemic. A population who are older, have higher multimorbidity, lower access to unpaid care, and geographical difficulties accessing care, will require a higher intensity of support and resources. This paper compares the socio-demographic composition of the population who died at home prior to Covid-19 to those dying in the first year of the pandemic, by answering the following questions (also available in an online protocol at <https://osf.io/6q8pb>): 1) Were the demographic and clinical characteristics of people who died at home during the pandemic different to those who died prior to the pandemic? 2) Were people who died at home during the pandemic more likely to have had palliative care needs?

## Method

Table 1 outlines the data sources used. A pandemic group of individuals who died aged 18 or older in Scotland during the first 12 months of the pandemic, starting from the first lockdown on 23<sup>rd</sup> March 2020, were compared to a pre-pandemic group who died in the five years prior. The first year of the pandemic and the five years prior were chosen pragmatically due to the ready availability of the data in

the PHS Covid-19 holding [18]. Death records from National Records Scotland (NRS, [19] were linked to General Acute Inpatient hospital discharges (SMR01, [20]) and community prescriptions in the PIS dataset [21], using the Community Health Index (CHI, [22]), the unique patient identifier used in health data in Scotland.

Death records included a single underlying and up to ten contributory causes of death coded using ICD-10. Place of death was coded as hospital, home or other non-institutional setting, care home, or 'other'. 'Other' comprised select institutional settings such as prisons and certain clinics providing palliative care and were therefore merged with care homes to form a 'care home and other' category. Home & other non-institutional settings included locations such as roads and public spaces, though up to 80% of such records indicated home settings so the entire category was coded as 'home'. Hospices were not reported separately and were coded partly as 'hospital' and partly as 'care home' in the data [14, 23]. The postcode recorded at death registration was used to derive the 2016 8-category measure of urban-rural location, based on population and accessibility, ranging from "Large urban" areas to "Remote rural" areas [24]. Postcodes were also used to derive the 2020 version of the Scottish Index of Multiple Deprivation (SIMD), which assigns small geographic areas ("data zones" in Scotland) a composite ranking according to seven domains: income, employment, education, health, access to services, crime and housing [25]. As a measure of multimorbidity (and a proxy measure of general health), we used the Elixhauser comorbidity index (EI) which weights each of 31 comorbid conditions to yield a composite score and is associated with hospital admissions and mortality (20). We computed the index from conditions recorded in inpatient general hospital records 10 years before death. Palliative care needs were estimated from underlying and contributory causes of death using a list of conditions compiled by Murtagh et al. in their upper mid-range estimate [17]. These were compiled prior to the Covid-19 pandemic so we reported two estimates: including and excluding deaths involving Covid-19. As another proxy measure of general health but using primary care data, we computed the number of distinct types of medications received in Community Prescribing data (PIS), by counting unique BNF sections (see Supplementary File for details) among items dispensed in each individual's final 12 months of life; a similar measure was used previously to measure polypharmacy [13, 26].

The demographics, clinical characteristics, and palliative care need estimates of the cohort were described using frequency tables and central tendency measures, and entered as covariates in a logistic regression model alongside a binary variable denoting the time period (pandemic/pre-pandemic), with death at home as outcome (the alternative being 'institutional death', combining hospital, care home, and other places of death). We computed Average Marginal Effects (AME) to estimate the effect of each covariate on the probability of dying at home [27]. R 4.4.0 was used for analysis, utilising 'tidyverse', 'lubridate', and 'marginaleffects' packages [27–29]. Results were reported according to the "Reporting of Studies conducted using Observational Routinely-collected Health Data" (RECORD) statement [30].

Table 1: Data sources

| Data source                                                       | Description                                                                                                                                                                    | Variables                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|-------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Death registrations (NRS)                                         | Central register of all deaths in Scotland; extracted all deaths between 23 <sup>rd</sup> March 2015 and 22 <sup>nd</sup> March 2022 for individuals who died aged 18+.        | <ul style="list-style-type: none"> <li>• Cause of death (ICD-10): underlying &amp; contributory; used to estimate palliative care needs using the Murtagh et al. upper-mid criteria [17]</li> <li>• Place of death (home &amp; other non-institution, hospital, care home, other)</li> <li>• Sex assigned at birth,</li> <li>• Age at death</li> <li>• Marital status (single; married or in a civil partnership; divorced or separated; widowed),</li> <li>• Ethnicity,</li> <li>• Postcode-derived geographical variables (Scottish Index of Multiple Deprivation - SIMD, and urban-rural location).</li> </ul> |
| Central patient register (CHI)                                    | Central register of all patients registered with a general practice in Scotland.                                                                                               | <ul style="list-style-type: none"> <li>• Community Health Index (CHI) provides link between personal identifiers (name, date of birth, address) in death records and health data. CHI was used for linkage between all datasets.</li> </ul>                                                                                                                                                                                                                                                                                                                                                                       |
| Scottish Morbidity Record 01 (SMR01): general hospital discharges | Register of all admissions to & discharges from a general hospital whether as inpatient or day case; covers all specialties except neonatal, maternity, and mental health care | <ul style="list-style-type: none"> <li>• Diagnosis codes (ICD-10) in discharge records were used to identify comorbidities according to the Elixhauser Comorbidity Index in the 10 years prior to death.</li> <li>• Diagnosis codes were also used to estimate palliative care needs using the Murtagh et al. upper-mid criteria [17]</li> </ul>                                                                                                                                                                                                                                                                  |
| Prescribing Information System (PIS)                              | Covers all National Health Service (NHS) prescriptions prescribed, dispensed and reimbursed within the community setting.                                                      | <ul style="list-style-type: none"> <li>• British National Formulary (BNF) codes were used to derive unique medication types (using BNF sections), used as a proxy measure of general health using primary care data</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                    |

<sup>1</sup>Abbreviations: EOL: End of life; SIMD: Scottish Index of Multiple Deprivation; NRS: National Records Scotland; PHS: Public Health Scotland; CHI: Community Health Index; SMR: Scottish Morbidity Record; PIS: Prescribing Information System; BNF: British National Formulary; EI: Elixhauser Index; AME: Average Marginal Effect.

## Results

A total of 351,145 individuals died in the study period, ranging 55,592-59,789 in 2015-16 to 2019-20, to 65,375 in 2020-21 (see Supplementary Tables 1a-b for details). A total of 8,756 (13.4%) pandemic deaths involved Covid, of which 5,177 (59.1%, or 18.4% of hospital deaths) were in hospital, 489 (5.6% or 2.3% of deaths at home) were at home, and 3,090 (35.3% or 19.9% of care home deaths) were in care homes. There were an additional 5,578 deaths at home in 2020-21 over 2019-20, or an increase of 34.6%. Figure 1 (and Supplementary Table 1b) summarises changes in demographics between the pre-pandemic and pandemic periods, for home decedents and those who died in an institution (hospital or care home).

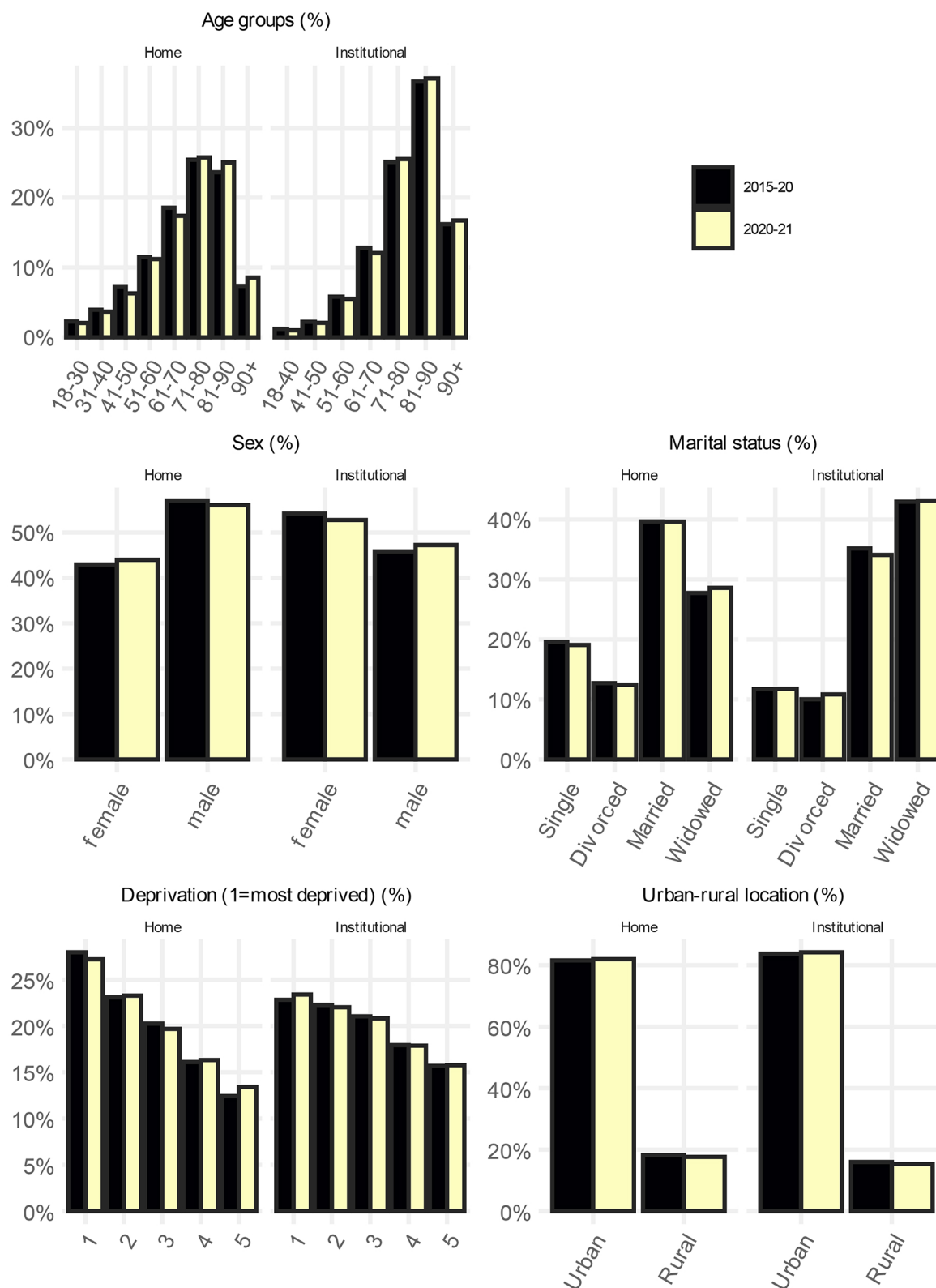
## Demographics

During the first year of the pandemic, the age at death for people who died at home increased from 70.28 to 71.31 years; for people who died in care homes it increased from 83.30 to 84.20; in contrast, in hospital it remained similar to 76.64 at 76.47. The proportion of decedents aged 71-80 increased in all places of death, while the proportion of those aged 81 or above increased in home and care home settings whilst decreasing in hospital (see Supplementary Table 1a).

The proportion of female decedents in deaths at home increased from 43.0% to 44.0%. In care homes, female deaths decreased from 63.2% to 62.0%, and in hospital they decreased from 49.8% to 47.6% during the pandemic.

Most decedents were married or widowed – married individuals being the majority in home and hospital deaths, and the proportion of widowed decedents increasing from home to

Figure 1: Demographic changes between the pre-pandemic and pandemic periods in home and institution deaths



hospital to care homes, where they were the majority. Deaths at home saw modest decreases in the proportions of single (19.6% to 19.1%), divorced (12.7% to 12.5%) and married decedents (39.7% to 39.6%) and an increase in widowed decedents (27.7% to 28.6%). Hospital deaths exhibited the opposite pattern with modest increases in single (11.9% to 12.1%), divorced (10.9% to 11.7%), and married decedents (39.8% to 39.9%), and a decrease in widowed decedents

(37.4% to 36.1%), while care homes deaths exhibited increases in divorced (8.3% to 9.2%) and widowed decedents (54.5% to 55.8%), and decreases in single (11.4% to 11.2%) and married decedents (25.6% to 23.6%).

Non-white ethnic groups were recorded rarely, with Asian being the most common group; all other groups were merged into Black and Minority Ethnicity (BME) to avoid disclosing small numbers. The proportion of white decedents saw modest

decreases from 96.9% to 96.7% at home, from 98.4% to 98.0% in hospital, and from 97.8% to 97.2% in care homes. The rate of missingness was consistently higher in home and care home deaths than in hospital. In every year, there were more records with missing ethnicity (a combination of 'Not known', 'Refused to respond', and missing values) than there were non-white records combined. The number of people of Asian ethnicity who died at home more than doubled between 2019-20,  $N = 75$  (0.5%) and 2020-21,  $N = 159$  (0.7%).

Deaths at home had the most unequal deprivation distribution throughout the study period, with most deaths in the most deprived quintile, but saw a small shift towards greater equality between deprivation quintiles during the pandemic. The proportion decreased for the most deprived (27.9% to 27.2%) and middle quintiles (20.3% to 19.7%) while increasing in quintiles 2 (23.1% to 23.3%), 4 (16.1% to 16.3%) and 5 (least deprived; 12.4% to 13.4%). The deprivation gradient increased in hospital deaths, with an increase in the proportion of the most deprived quintile (24.4% to 25.3%), and decreases across quintiles 2 (23.8% to 23.5%), 3 (20.7% to 20.1%), 4 (16.7% to 16.6%), and 5 (14.1% to 14.0%). Care homes had the most even distribution across deprivation quintiles before and during the pandemic, with (non-significant at  $\alpha = 0.05$ ) decreases in the most deprived quintile (19.5% to 19.3%) as well as quintile 4 (20.5% to 20.2%), and increases in quintiles 2 (19.2% to 19.3%) and 3 (21.7% to 20.0%), while quintile 5 remained constant at 19.0%.

The distribution of deaths across urban-rural locations can be characterised as small shifts from rural to urban locations: deaths at home shifted from 81.5% to 81.9% urban, hospital from 83.2% to 83.7% urban, and care home from 84.8%

to 85.1% urban. The degree of missingness also increased modestly during the pandemic across all places of death.

## Palliative care need estimates

An estimated  $N = 18,628$  (85.8% of all deaths at home, see Table 2) people with palliative care needs died at home during the pandemic, up 35.8 percentage points in absolute terms from 2019-20, similar in proportion to the 2015-20 average of 85.5%. Conversely, the proportion of decedents in hospital with palliative care needs decreased from 94.0% to 91.9%, and in care homes from 97.2% to 94.3%. Put differently, the share of deaths at home amongst decedents with estimated care needs increased from 24.8% to 31.5% while decreasing in hospital from 50.1% to 43.7%, and in care homes from 25.1% to 24.8%. The conditions used to define palliative care needs were defined before the Covid-19 pandemic [17] so we also computed estimated palliative care needs only amongst those where Covid was not mentioned on a death certificate (as either an underlying or contributory cause of death). When Covid-involved deaths were excluded, the proportion of deaths at home with palliative care needs was 86.0% in 2020-21, or 93.0% in hospital, or 96.0% in care homes. In other words, there was a trend of modest increase in deaths at home with

Table 2: Estimated palliative care needs, EI, and number of distinct medicines, by cohort & place of death

|                                                           | Place of death | 2015-20         | 2020-21                        | 2020-21, excl. Covid           |
|-----------------------------------------------------------|----------------|-----------------|--------------------------------|--------------------------------|
| Individuals with estimated palliative care needs, $N$ (%) | Home           | 65,605 (85.5%)  | 18,628 (85.8%) <sup>x</sup>    | 18,113 (86.0%) <sup>x</sup>    |
|                                                           | Hospital       | 132,351 (94.0%) | 25,852 (91.9%) <sup>***x</sup> | 20,610 (93.0%) <sup>***x</sup> |
|                                                           | CH             | 66,370 (97.2%)  | 14,672 (94.3%) <sup>***x</sup> | 11,749 (96.0%) <sup>***x</sup> |
|                                                           | All            | 264,326 (92.5%) | 59,152 (90.4%) <sup>***x</sup> | 50,472 (91.0%) <sup>***x</sup> |
| EI, Mean (SD)                                             | Home           | 8.64 (9.07)     | 9.03 (9.17) <sup>***y</sup>    |                                |
|                                                           | Hospital       | 11.95 (8.56)    | 11.33 (8.55) <sup>***y</sup>   |                                |
|                                                           | CH             | 9.30 (8.35)     | 8.54 (8.15) <sup>***y</sup>    |                                |
|                                                           | All            | 10.42 (8.54)    | 9.90 (8.87) <sup>***y</sup>    |                                |
| Number of distinct medicines, Mean (SD)                   | Home           | 12.23 (6.11)    | 12.48 (6.07) <sup>***y</sup>   |                                |
|                                                           | Hospital       | 11.42 (5.05)    | 10.95 (5.03) <sup>***y</sup>   |                                |
|                                                           | CH             | 13.24 (4.68)    | 12.89 (4.57) <sup>***y</sup>   |                                |
|                                                           | All            | 12.07 (5.32)    | 11.92 (5.36) <sup>***y</sup>   |                                |

CH: Care home & other; EI: Elixhauser index; <sup>x</sup>Fisher's exact test with simulated p-values using  $10^4$  replicates (differences in distribution within each place of death were tested against 2015-20); <sup>y</sup>Welch's 2-sample t-test; \* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$ ; number of distinct medicines was computed only for individuals with one or more dispensed items in their final 12 months of life. The 2020-21 excl. Covid-19 column was computed to estimate palliative care needs when deaths involving Covid-19 were excluded from 2020-21 data. Sources used: death registrations (palliative care needs); hospital discharges (SMR01; palliative care needs & Elixhauser index); community prescribing (PIS; number of distinct medicines).

palliative care needs concomitant with a decrease in hospital and care homes, both including or excluding deaths involving Covid-19.

## Multimorbidity & number of distinct medications

Pre-pandemic, home decedents had the lowest multimorbidity measured by EI, followed by care home and hospital decedents. Comorbidity rates are reported in Supplementary Table 2, with the most frequent comorbidities in deaths at home during the pandemic being solid tumour without metastasis, 35.8%, hypertension (uncomplicated), 28.2%, chronic pulmonary disease, 22.6%, cardiac arrhythmias, 20.7%, and metastatic cancer, 19.5%. In deaths at home mean EI increased from 8.64 to 9.03. In contrast, hospital EI decreased from 11.95 to 11.33 and in care homes from 9.30 to 8.54, below death at home EI. A pattern of somewhat increased rates in deaths at home and decreased rates in hospital and care homes was observed for comorbid solid tumour without metastasis (home: +1.3%, hospital: -3.9%, CH: -7.3%) and metastatic cancer (home: +0.9%, hospital: -4.0%, CH: -4.5%).

Hospital decedents received the fewest distinct medications on average, followed by home, and care home decedents. The mean number of distinct medications in deaths at home increased modestly from 12.23 to 12.48, while decreasing in hospital (11.42 to 10.95), and care home deaths (13.24 to 12.89).

## Regression model & average marginal effects

After removing missing values ( $N = 527$ ),  $N = 350,618$  individuals' data were entered into a logistic regression model with death at home as outcome, with un-/adjusted odds ratios (OR/aOR) and average marginal effects (AME) reported in Table 3. There was little collinearity between covariates, with the highest variance inflation factor (VIF) for marital status at 1.62. The effect of the pandemic on probability of death at home was estimated at  $aOR = 1.37$  (95%CI 1.34,1.40), or an AME of 5.9% (95%CI 5.5%,6.3%). All covariates were significantly associated with death at home. The pandemic effect estimate was similar in magnitude to the effect of sex (males having an average of 5.3% (95%CI 5.0%,5.6%) higher probability of death at home, or living rurally,  $AME = 5.0\%$  (95%CI 4.6%,5.4%). A 10-year age increase was associated with a 6.8% reduction in probability of death at home (95%CI -6.9%,-6.6%). Married individuals had a 2.1% (95%CI, 1.6%,2.5%) increased probability of dying at home relative to single individuals, while the relative increase was 1.5% (95%CI, 0.9%,2.1%) for those divorced; widowed status was not significantly different from single. Estimated palliative care need was the strongest association with death at home, reducing the probability of death at home by  $AME = 9.9\%$  (95%CI, -10.5%,-9.3%). Decreasing deprivation was associated with lower probability of death at home, with effects relative to the most deprived quintile ranging from 0.9% for quintile 2 to 2.3% for quintile 5. Multimorbidity and number of distinct medications had opposite effects on probability of death at home: a 5-point increase in EI was associated with 3.2% reduction (95%CI -3.3%,-3.1%), while

a 5-item increase in number of distinct medications was associated with a 4.3% increase (95%CI 4.2%,4.4%).

## Discussion & conclusions

There was a large increase (34.6%) in the number of people who died at home, while their demographic characteristics, palliative care needs, multimorbidity, and medication receipt, saw modest shifts in the direction of smaller differences between decedents at home and in hospital or care homes. This is consistent with some of the population with higher needs (due to old age, multimorbidity, palliative care needs) shifting from institutional to death at home.

The number of people with palliative care needs increased during the pandemic: across places of death, our estimate of 59,152 (90.5% of all decedents) people with palliative care needs in the first year of the pandemic was comparable to a pre-pandemic projection of 59,000 deaths expected in 2034–2035 [12]. An additional 4,190 people with estimated palliative care needs died at home in 2020–21 over 2019–20 (4,395 excluding deaths involving Covid) and whether they were able to receive appropriate care is unknown. According to the logistic regression model, estimated palliative care needs were associated with an average 10% reduction in the probability of dying at home, demonstrating the importance of ensuring palliative care, and support in the desired place of care, is available.

Average age in deaths at home increased by 1.03 years, due to the increase in decedents aged 81 or over (an additional 2,532, or 53% more, died during the pandemic, relative to the 5-year average prior); age also increased by 1.10 years in care homes, and decreased by 0.15 years in hospital. In other words, deaths in the oldest age groups shifted somewhat from hospital to community settings.

The severity of multimorbidity increased for people who died at home by 0.39 points on the EI, while decreasing for those who died in hospital (-0.62) and in care homes (-0.76). Multimorbidity in deaths at home overtook that of care homes during the pandemic, and rates of comorbid cancer increased in deaths at home while decreasing in hospital and care home deaths. The number of distinct medications dispensed in the final 12 months of life also increased in home decedents (0.25 medication types), while decreasing in hospital (-0.47) and care homes (-0.35).

The small shift towards more female home decedents and towards a greater number of widowed, and fewer single and divorced decedents prompts questions of access to unpaid care. The greater proportion of males dying at home has been described elsewhere as enabled by the care provided by the female partners, who are more likely to outlive their male partners, as well as facing a greater burden of care generally in Western countries [31]. An increase in female home decedents could indicate greater availability of unpaid care but potentially also greater unmet need for unpaid care. Data on receipt and provision of unpaid care are required to interpret these demographic changes conclusively.

Ethnicity was poorly recorded: the proportion of missing records exceeded the proportion of non-white records every year. Deaths at home of Asian people more than doubled

Table 3: Odds of dying at home by study period (pandemic/pre-pandemic), age, sex, marital status, urban-rural location, deprivation, palliative care needs, multimorbidity, and number of distinct medicines, estimated by logistic regression

| Variable                                                           | Level                 | OR       | OR 95% CI   | aOR     | AOR 95% CI  | AME      | AME 95% CI   |
|--------------------------------------------------------------------|-----------------------|----------|-------------|---------|-------------|----------|--------------|
| (Intercept)                                                        |                       |          |             | 6.51*** | 6.20,6.83   |          |              |
| Study period<br>(reference = Pre-pandemic)                         | Pandemic              | 1.35***  | 1.33,1.38   | 1.37*** | 1.34,1.40   | 5.9%***  | 5.5%,6.3%    |
| Age                                                                | 10 years              | 0.676*** | 0.672,0.679 | 0.69*** | 0.684,0.693 | −6.8%*** | −6.9%,−6.6%  |
| Sex<br>(reference = Female)                                        | Male                  | 1.54***  | 1.52,1.56   | 1.34*** | 1.32,1.36   | 5.3%***  | 5.0%,5.6%    |
| Marital status<br>(reference = Single)                             | Divorced <sup>a</sup> | 0.749*** | 0.729,0.771 | 1.09*** | 1.05,1.12   | 1.5%***  | 0.9%,2.1%    |
|                                                                    | Married <sup>b</sup>  | 0.682*** | 0.668,0.697 | 1.12*** | 1.09,1.15   | 2.1%***  | 1.6%,2.5%    |
|                                                                    | Widowed               | 0.391*** | 0.382,0.400 | 1.01    | 0.982,1.04  | 0.2%     | −0.3%,0.7%   |
| Urban–rural<br>location(reference = Urban)                         | Rural                 | 1.17***  | 1.15,1.19   | 1.31*** | 1.28,1.34   | 5.0%***  | 4.6%,5.4%    |
| Deprivation: SIMD<br>quintile<br>(reference = 1, most<br>deprived) | 2                     | 0.858*** | 0.840,0.877 | 0.95*** | 0.931,0.974 | −0.9%*** | −1.3%,−0.5%  |
|                                                                    | 3                     | 0.790*** | 0.773,0.808 | 0.89*** | 0.866,0.909 | −2.2%*** | −2.6%,−1.7%  |
|                                                                    | 4                     | 0.743*** | 0.726,0.760 | 0.87*** | 0.843,0.888 | −2.6%*** | −3.1%,−2.2%  |
|                                                                    | 5                     | 0.664*** | 0.648,0.681 | 0.88*** | 0.857,0.904 | −2.3%*** | −2.8%,−1.8%  |
| Palliative care<br>needs estimated<br>(reference = No)             | Yes                   | 0.332*** | 0.324,0.340 | 0.61*** | 0.589,0.624 | −9.9%*** | −10.5%,−9.3% |
| Multimorbidity:<br>Elixhauser index                                | 5 points              | 0.862*** | 0.858,0.866 | 0.84*** | 0.833,0.841 | −3.2%*** | −3.3%, −3.1% |
| Number of distinct<br>medicines                                    | 5 items               | 1.011*** | 1.00,1.02   | 1.27*** | 1.26,1.28   | 4.3%***  | 4.2%,4.4%    |

OR: (unadjusted) odds ratio; aOR: adjusted odds ratio; AME: average marginal effect computed from fully adjusted model;

<sup>a</sup>includes dissolved and annulled marriage or civil partnership; <sup>b</sup>includes civil partnership; \*p < 0.05; \*\*p < 0.01; \*\*\*p < 0.001. Total sample size: N = 350,618.

during the pandemic, though it is unclear whether this represents a true trend or a consequence of poor data quality [32].

Deaths at home exhibited a more pronounced pre-pandemic deprivation gradient than hospital or care home deaths, but that gradient lessened during the pandemic. This may indicate the greater availability of home care in areas with lower deprivation, but it may also reflect the higher health needs and multimorbidity in more deprived areas, requiring hospital care and resulting in hospital deaths. Most deaths occurred in urban areas, though deaths at home represented a higher proportion of rural deaths than hospital and care home deaths, and the balance shifted somewhat towards more urban deaths during the pandemic.

Home decedents had a distinct profile from decedents in institutional settings in terms of demographics, multimorbidity and medicine receipt: they were younger on average, predominantly male, married, somewhat more likely to have lived in a high deprivation area, and slightly more likely to have lived rurally; they also had the lowest multimorbidity, palliative care needs, and moderate medication receipt, and had the highest rates of comorbid cancer. With the pandemic, small shifts occurred in demographics, bringing home decedents a little closer to the profile of hospital and care home

decedents, even ranking higher than care home residents on multimorbidity, for example.

## Strengths & Limitations

Increased numbers of people dying at home during the pandemic have been found in several countries [6], and in Scotland this increase is ongoing [1]. To our knowledge, there have not been any studies comparing the populations of those dying at home before and since the increase. This paper has taken the first steps to addressing that gap.

NRS death registrations allowed us to create a population sample with near complete coverage of demographic & clinical data, minimising sampling bias, and avoiding recall bias characteristic of survey studies. PHS enabled rapid access to pandemic-relevant datasets, making a study of this scope much more feasible than previously [18].

Multimorbidity was derived from historic hospitalisations which were elsewhere found to underestimate the prevalence and overestimate the severity of conditions [33]; this may bias the estimate upwards, but it likely affects the entire population since we used a 10-year period to derive comorbid conditions. If a different data source (e.g. primary care data) were available that captured a wider range of comorbid

conditions we might observe a different pattern in average severity. Notwithstanding the possibility of upward bias, deaths at home had a distinct profile such as having the highest rates of comorbid cancer, with rates of cancer increasing in deaths at home whilst decreasing elsewhere during the pandemic. In the absence of primary care data on diagnoses we were able to derive a simple measure of the number of distinct medications received in the final year of life, which showed a similar pattern of pandemic change to multimorbidity: increased number of medications in deaths at home with decreases in hospital and care homes. This lends further support to the argument that people dying at home were more ill than previously and received a wider range of medications in community settings. Hospital decedents having lower medication receipt than home decedents may be explained by hospital prescriptions being recorded in a separate dataset, Hospital Electronic Prescribing and Medicines Administration (HEPMA) [34], and therefore utilising community prescribing less. HEPMA was unavailable for linkage at the time of this study. Including hospital prescriptions would give us a more precise estimate of medication receipt or polypharmacy. The measure of distinct medications was intended to approximate the range of medications received by an individual as a proxy measure of general health and did not account for nuances such as severity of the conditions for which medications were prescribed, dosage, or short- vs long-term prescribing; more precise estimates of polypharmacy were previously used to investigate interactions between medications [13, 26].

Palliative care need was strongly associated with institutional death despite a high rate of needs across places of death. Palliative care needs were derived (partly) from causes of death [17], which makes them a poor choice for predictive modelling. This was not an issue for this paper due to the focus being on describing differences between pre-pandemic and pandemic populations of decedents, but there is room for improvement in measuring palliative care needs using more detailed data collected prior to death, such as General Practice records, for example. Data on service utilisation from specialist palliative care units could supplement the present analysis.

A further direction of research would be to investigate people's movements in the last year of life, which aren't captured by death registration data. During lockdown, people may have moved to access care, for example to receive unpaid care from a relative. The central patient register tracks changes in residence when these are recorded with primary care providers, but we don't know what proportion of such movements are recorded. Consequently, the postcode-derived measures such as deprivation and urban-rural location may not reflect the decedent's usual residence but instead that of the destination. If people were more likely to move to access care during the pandemic, this would confound the findings of a more equitable distribution of deprivation quintiles and the small changes in urban-rural location. The rate of movement at EOL for this cohort, and its implications for the present findings, is unknown and warrants further study.

## Further directions for research

Data on occupation, income, and household composition were not included in the datasets investigated and are important factors in the availability of paid and unpaid care. A potential

avenue for investigating these would be by linking data to the Scottish census which took place in 2022. Lockdown measures such as furlough payments and the move to remote working may have enabled individuals to provide more unpaid care during the first year of the pandemic, so furlough data could also be linked to household data from the census to estimate whether co-habiting with a furlough recipient enabled deaths at home. Moreover, data on receipt of social care may also be available for linkage, though the quality varies across health boards/local authorities, and so a nationwide comparison may not be feasible [35]. Data on unpaid care are not routinely collected outside of the census, which only asks respondents whether they provide care, rather than receive it [36]. Similarly, data on the quality of home care during the pandemic would be helpful to understand the shift to deaths at home [37].

There is also the outstanding question to what extent deaths at home during the pandemic represented realised preferences versus displacement from healthcare facilities [37]. To this end we will need to investigate the patterns of health service use to understand whether those changed alongside the demographic and clinical characteristics, as well as palliative care needs. However, without a record of preference for place of death administrative data can only approximate the answer.

Finally, this study only covered population changes during the first year of the Covid-19 pandemic, and it is unknown whether the trends identified, aside from the increased number of deaths at home, persist to the current day. Policy in Scotland has since emphasised the need to address what matters most to people at EOL, including preferences for place of care, e.g., care at home, and ensuring hospital admissions are as short as possible [38]; European Union policy additionally recognised increasing deaths at home, requiring additional funding and development of palliative care services [39].

## Conclusions

There are two main messages of policy relevance: firstly, the absolute number of home decedents has increased dramatically, including those with palliative care needs and/or a cancer diagnosis; secondly, the differences between decedents at home and those in hospital and care homes have shrunk somewhat, with people dying at home being as ill as previously on average, or more. This means policy needs to tackle both the increased number of people requiring care at home, and ensure that their needs are addressed, by resourcing community care as well as supporting unpaid carers. The profile of people dying at home saw small shifts to higher age, multimorbidity, and medication receipt, while changes to the distributions of sex, marital status and deprivation point towards potential changes in the availability of unpaid care, though further study is needed to explore this.

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## Statement on conflicts of interest

None declared.

## Ethics statement

The study was approved by Edinburgh Napier University's School of Health and Social Care's ethics committee (study number SHSC2719211).

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## Data availability statement

The data used in the study are not publicly available for privacy reasons and can be accessed by application to Public Health Scotland & National Records Scotland, via the Public Benefit & Privacy Panel.

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Supplementary appendices

Supplementary Appendix 1: contains details of the measure of distinct medications, a frequency table of demographic characteristics by cohort and place of death, and a frequency table of comorbid conditions by cohort and place of death.

Number of distinct medications

Only items in BNF chapters 1 to 15 were included in the count as they comprise “active substances” (the other chapters contain “preparations used in diagnosis”, “dressings”, and “appliances”). BNF chapters correspond roughly to organ systems, so the next level of granularity (“BNF section”) was used to approximate a count of distinct types of medications. The total number of distinct BNF sections in the data was 110.

Supplementary Table 1a: Demographic characteristics of the cohort by place of death (home, hospital, care home)

|                       | Place of death          |                |                | Home               |                 |                | Hospital           |                         |                        | CH                 |                           |                           | Total              |         |         |
|-----------------------|-------------------------|----------------|----------------|--------------------|-----------------|----------------|--------------------|-------------------------|------------------------|--------------------|---------------------------|---------------------------|--------------------|---------|---------|
|                       | Levels                  | 2015-20        | 2020-21        | p                  | 2015-20         | 2020-21        | p                  | 2015-20                 | 2020-21                | p                  | 2015-20                   | 2020-21                   | p                  | 2015-20 | 2020-21 |
| Place of death, N (%) |                         | 76,770 (26.9%) | 21,705 (33.2%) |                    | 140,722 (49.2%) | 28,111 (43.0%) |                    | 68,278 (23.9%)          | 15,559 (23.8%)         |                    | 285,770 (100.0%)          | 65,375 (100.0%)           |                    |         |         |
|                       | Age, Mean (SD)          | 70.28 (16.48)  | 71.31 (16.34)  | .036 <sup>y</sup>  | 76.64 (12.97)   | 76.47 (12.82)  | <.001 <sup>y</sup> | 83.3 (11.23)            | 84.2 (10.30)           | <.001 <sup>y</sup> | 76.52 (13.63)             | 76.60 (13.58)             | .222 <sup>y</sup>  |         |         |
| Age group, N (%)      | 18-30                   | 1,733 (2.3%)   | 446 (2.1%)     | <.001 <sup>x</sup> | 776 (0.6%)      | 134 (0.5%)     | <.001 <sup>x</sup> | 285 <sup>a</sup> (0.4%) | 48 <sup>a</sup> (0.3%) | <.001 <sup>x</sup> | 7,289 <sup>a</sup> (2.6%) | 1,683 <sup>a</sup> (2.6%) | .007 <sup>x</sup>  |         |         |
|                       | 31-40                   | 3,030 (3.9%)   | 800 (3.7%)     |                    | 1,465 (1.0%)    | 255 (0.9%)     |                    | 807 (1.2%)              | 124 (0.8%)             |                    | 20,249 (3.6%)             | 2,270 (3.5%)              |                    |         |         |
|                       | 41-50                   | 5,612 (7.3%)   | 1,365 (6.3%)   |                    | 3,830 (2.7%)    | 781 (2.8%)     |                    | 2,250 (3.3%)            | 355 (2.3%)             |                    | 20,990 (7.3%)             | 4,840 (7.4%)              |                    |         |         |
|                       | 51-60                   | 8,831 (11.5%)  | 2,432 (11.2%)  |                    | 9,909 (7.0%)    | 2,053 (7.3%)   |                    | 5,105 (7.5%)            | 922 (5.9%)             |                    | 41,038 (14.4%)            | 9,048 (13.8%)             |                    |         |         |
|                       | 61-70                   | 14,244 (18.6%) | 3,778 (17.4%)  |                    | 21,689 (15.4%)  | 4,348 (15.5%)  |                    | 12,789 (18.7%)          | 2,925 (18.8%)          |                    | 72,008 (25.2%)            | 16,742 (25.6%)            |                    |         |         |
|                       | 71-80                   | 19,526 (25.4%) | 5,593 (25.8%)  |                    | 39,693 (28.2%)  | 8,224 (29.3%)  |                    | 28,392 (41.6%)          | 6,821 (43.8%)          |                    | 94,699 (33.1%)            | 21,624 (33.1%)            |                    |         |         |
|                       | 81-90                   | 18,145 (23.6%) | 5,433 (25.0%)  |                    | 48,162 (34.2%)  | 9,370 (33.3%)  |                    | 18,650 (27.3%)          | 4,364 (28.0%)          |                    | 39,497 (13.8%)            | 9,168 (14.0%)             |                    |         |         |
|                       | 90+                     | 5,649 (7.4%)   | 1,858 (8.6%)   |                    | 15,198 (10.8%)  | 2,946 (10.5%)  |                    | 43,129 (63.2%)          | 9,649 (62.0%)          | .006 <sup>x</sup>  | 146,176 (51.2%)           | 32,587 (49.8%)            | <.001 <sup>x</sup> |         |         |
|                       | female                  | 32,980 (43.0%) | 9,547 (44.0%)  | <.001 <sup>x</sup> | 70,067 (49.8%)  | 13,391 (47.6%) | .009 <sup>x</sup>  | 25,149 (36.8%)          | 5,910 (38.0%)          |                    | 139,594 (48.8%)           | 32,788 (50.2%)            |                    |         |         |
| Marital status, N (%) | male                    | 43,790 (57.0%) | 12,158 (56.0%) |                    | 70,655 (50.2%)  | 14,720 (52.4%) |                    | 7,805 (11.4%)           | 1,740 (11.2%)          | <.001 <sup>x</sup> | 39,527 (13.8%)            | 9,282 (14.2%)             | <.001 <sup>x</sup> |         |         |
|                       | Single                  | 15,046 (19.6%) | 4,141 (19.1%)  | <.001 <sup>x</sup> | 16,676 (11.9%)  | 3,401 (12.1%)  | .060 <sup>x</sup>  | 5,646 (8.3%)            | 1,447 (9.3%)           |                    | 30,703 (10.7%)            | 7,434 (11.4%)             |                    |         |         |
|                       | Divorced <sup>y,b</sup> | 9,759 (12.7%)  | 2,704 (12.5%)  |                    | 15,298 (10.9%)  | 3,283 (11.7%)  |                    | 17,478 (25.6%)          | 3,667 (23.6%)          |                    | 103,938 (36.4%)           | 23,488 (35.9%)            |                    |         |         |
|                       | Married <sup>c</sup>    | 30,450 (39.7%) | 8,603 (39.6%)  |                    | 56,010 (39.8%)  | 11,218 (39.9%) |                    | 37,225 (54.5%)          | 8,681 (55.8%)          |                    | 111,082 (38.9%)           | 25,049 (38.3%)            |                    |         |         |
|                       | Widowed                 | 21,295 (27.7%) | 6,206 (28.6%)  |                    | 52,562 (37.4%)  | 10,162 (36.1%) |                    | 124 (0.2%)              | 24 (0.2%)              |                    | 520 (0.2%)                | 122 (0.2%)                |                    |         |         |
| Ethnicity, N (%)      | Missing                 | 220 (0.3%)     | 51 (0.2%)      |                    | 176 (0.1%)      | 47 (0.2%)      |                    | 170 (0.2%)              | 37 (0.2%)              | <.001 <sup>x</sup> | 1,510 (0.5%)              | 464 (0.7%)                | <.001 <sup>x</sup> |         |         |
|                       | Asian                   | 366 (0.5%)     | 159 (0.7%)     | <.001 <sup>x</sup> | 974 (0.7%)      | 268 (1.0%)     |                    | 66,778 (97.8%)          | 15,130 (97.2%)         |                    | 279,661 (97.9%)           | 63,657 (97.4%)            |                    |         |         |
|                       | White                   | 74,375 (96.9%) | 20,984 (96.7%) |                    | 138,508 (98.4%) | 27,543 (98.0%) |                    | 98 (0.1%)               | 17 (0.1%)              |                    | 526 (0.2%)                | 143 (0.2%)                |                    |         |         |
|                       | BME                     | 148 (0.2%)     | 50 (0.2%)      |                    | 280 (0.2%)      | 76 (0.3%)      |                    | 1,232 (1.8%)            | 375 (2.4%)             |                    | 4,073 (1.4%)              | 1,111 (1.7%)              |                    |         |         |
|                       | Missing                 | 1,881 (2.5%)   | 512 (2.4%)     |                    | 960 (0.7%)      | 224 (0.8%)     |                    |                         |                        |                    |                           |                           |                    |         |         |

Continued



Supplementary Table 1a: Continued

| Place of death                                      |         | Home           |                |                     | Hospital        |                |                    | CH             |                |                    | Total           |                |                    |
|-----------------------------------------------------|---------|----------------|----------------|---------------------|-----------------|----------------|--------------------|----------------|----------------|--------------------|-----------------|----------------|--------------------|
|                                                     |         | 2015-20        | 2020-21        | p                   | 2015-20         | 2020-21        | p                  | 2015-20        | 2020-21        | p                  | 2015-20         | 2020-21        | p                  |
| Deprivation (SIMD quintile), N (%) (=most deprived) | 1       | 21,460 (27.9%) | 5,900 (27.2%)  | <.001 <sup>x</sup>  | 34,390 (24.4%)  | 7,200 (25.6%)  | <.001 <sup>x</sup> | 13,300 (19.5%) | 3,010 (19.3%)  | .456 <sup>x</sup>  | 69,150 (24.2%)  | 16,110 (24.6%) | <.001 <sup>x</sup> |
|                                                     | 2       | 17,720 (23.1%) | 5,050 (23.3%)  |                     | 33,450 (23.8%)  | 6,600 (23.5%)  |                    | 13,080 (19.2%) | 3,010 (19.3%)  |                    | 64,250 (22.5%)  | 14,660 (22.4%) |                    |
|                                                     | 3       | 15,550 (20.3%) | 4,270 (19.7%)  |                     | 29,120 (20.7%)  | 5,660 (20.1%)  |                    | 14,850 (21.7%) | 3,430 (22.0%)  |                    | 59,520 (20.8%)  | 13,360 (20.4%) |                    |
|                                                     | 4       | 12,360 (16.1%) | 3,540 (16.3%)  |                     | 23,490 (16.7%)  | 4,660 (16.6%)  |                    | 13,980 (20.5%) | 3,140 (20.2%)  |                    | 49,830 (17.4%)  | 11,340 (17.4%) |                    |
|                                                     | 5       | 9,540 (12.4%)  | 2,910 (13.4%)  |                     | 19,790 (14.1%)  | 3,920 (14.0%)  |                    | 12,990 (19.0%) | 2,960 (19.0%)  |                    | 42,320 (14.8%)  | 9,790 (15.0%)  |                    |
| Urban-rural location, N (%)                         | Missing | 150 (0.2%)     | 30 (0.1%)      |                     | 500 (0.4%)      | 60 (0.2%)      |                    | 80 (0.1%)      | 10 (0.1%)      |                    | 730 (0.3%)      | 100 (0.2%)     |                    |
|                                                     | Urban   | 62,605 (81.5%) | 17,787 (81.9%) | .003 <sup>y,x</sup> | 117,036 (83.2%) | 23,533 (83.7%) | <.001 <sup>x</sup> | 57,927 (84.8%) | 13,233 (85.1%) | <.001 <sup>x</sup> | 237,568 (83.1%) | 54,553 (83.4%) | <.001 <sup>x</sup> |
|                                                     | Rural   | 13,998 (18.2%) | 3,827 (17.6%)  |                     | 23,158 (16.5%)  | 4,446 (15.8%)  |                    | 10,242 (15.0%) | 2,245 (14.4%)  |                    | 47,398 (16.6%)  | 10,518 (16.1%) |                    |
| Missing                                             |         | 167 (0.2%)     | 91 (0.4%)      |                     | 528 (0.4%)      | 132 (0.5%)     |                    | 109 (0.2%)     | 81 (0.5%)      |                    | 804 (0.3%)      | 304 (0.5%)     |                    |

CH: Care home & other; <sup>a</sup>the 18-30 and 31-40 categories in Care homes and the Total column, were combined due to small numbers; <sup>b</sup>includes dissolved and annulled marriage or civil partnership; <sup>x</sup>Fisher's exact test with simulated p-values using 10<sup>4</sup> replicates (differences in distribution within each place of death between years were tested for each covariate; for place of death, the distribution across places and years was tested); <sup>y</sup>Welch's 2-sample t-test. Deprivation was measured using the Scottish Index of Multiple Deprivation (SIMD). Numbers for deprivation were rounded to nearest 10 due to small numbers missing – the totals may therefore add to slightly more than the total sample size.



Supplementary Table 1b: Demographic characteristics of the cohort by combined place of death (home vs institutional)

| N (%)<br>Variable                                  | Place of death<br>Levels | Institutional   |                |                | Home           |                |                |
|----------------------------------------------------|--------------------------|-----------------|----------------|----------------|----------------|----------------|----------------|
|                                                    |                          | 2015-20         | 2020-21        | p <sup>x</sup> | 2015-20        | 2020-21        | p <sup>x</sup> |
| Age group                                          | 18–30                    | a               | a              | <0.001         | 1,733 (2.3%)   | 446 (2.1%)     | <0.001         |
|                                                    | 31–40                    | 2,526 (1.2%)    | 437 (1.0%)     |                | 3,030 (3.9%)   | 800 (3.7%)     |                |
|                                                    | 41–50                    | 4,637 (2.2%)    | 905 (2.1%)     |                | 5,612 (7.3%)   | 1,365 (6.3%)   |                |
|                                                    | 51–60                    | 12,159 (5.8%)   | 2,408 (5.5%)   |                | 8,831 (11.5%)  | 2,432 (11.2%)  |                |
|                                                    | 61–70                    | 26,794 (12.8%)  | 5,270 (12.1%)  |                | 14,244 (18.6%) | 3,778 (17.4%)  |                |
|                                                    | 71–80                    | 52,482 (25.1%)  | 11,149 (25.5%) |                | 19,526 (25.4%) | 5,593 (25.8%)  |                |
|                                                    | 81–90                    | 76,554 (36.6%)  | 16,191 (37.1%) |                | 18,145 (23.6%) | 5,433 (25.0%)  |                |
|                                                    | 90+                      | 33,848 (16.2%)  | 7,310 (16.7%)  |                | 5,649 (7.4%)   | 1,858 (8.6%)   |                |
| Sex                                                | female                   | 113,196 (54.2%) | 23,040 (52.8%) | 0.007          | 32,980 (43.0%) | 9,547 (44.0%)  | <0.001         |
|                                                    | male                     | 95,804 (45.8%)  | 20,630 (47.2%) |                | 43,790 (57.0%) | 12,158 (56.0%) |                |
| Marital status                                     | Single                   | 24,481 (11.7%)  | 5,141 (11.8%)  | 0.062          | 15,046 (19.6%) | 4,141 (19.1%)  | <0.001         |
|                                                    | Divorced <sup>b</sup>    | 20,944 (10.0%)  | 4,730 (10.8%)  |                | 9,759 (12.7%)  | 2,704 (12.5%)  |                |
|                                                    | Married <sup>c</sup>     | 73,488 (35.2%)  | 14,885 (34.1%) |                | 30,450 (39.7%) | 8,603 (39.6%)  |                |
|                                                    | Widowed                  | 89,787 (43.0%)  | 18,843 (43.1%) |                | 21,295 (27.7%) | 6,206 (28.6%)  |                |
|                                                    | Missing                  | 300 (0.1%)      | 71 (0.2%)      |                | 220 (0.3%)     | 51 (0.2%)      |                |
| Ethnicity                                          | Asian                    | 1,144 (0.5%)    | 305 (0.7%)     | <0.001         | 366 (0.5%)     | 159 (0.7%)     | <0.001         |
|                                                    | White                    | 205,286 (98.2%) | 42,673 (97.7%) |                | 74,375 (96.9%) | 20,984 (96.7%) |                |
|                                                    | BME                      | 378 (0.2%)      | 93 (0.2%)      |                | 148 (0.2%)     | 50 (0.2%)      |                |
|                                                    | Missing                  | 2,192 (1.0%)    | 599 (1.4%)     |                | 1,881 (2.5%)   | 512 (2.4%)     |                |
| Deprivation (SIMD<br>quintile)(1=most<br>deprived) | 1                        | 47,690 (22.8%)  | 10,210 (23.4%) | <0.001         | 21,460 (27.9%) | 5,900 (27.2%)  | <0.001         |
|                                                    | 2                        | 46,530 (22.3%)  | 9,610 (22.0%)  |                | 17,720 (23.1%) | 5,050 (23.3%)  |                |
|                                                    | 3                        | 43,970 (21.0%)  | 9,090 (20.8%)  |                | 15,550 (20.3%) | 4,270 (19.7%)  |                |
|                                                    | 4                        | 37,470 (17.9%)  | 7,800 (17.9%)  |                | 12,360 (16.1%) | 3,540 (16.3%)  |                |
|                                                    | 5                        | 32,780 (15.7%)  | 6,880 (15.8%)  |                | 9,540 (12.4%)  | 2,910 (13.4%)  |                |
|                                                    | Missing                  | 580 (0.3%)      | 70 (0.2%)      |                | 150 (0.2%)     | 30 (0.1%)      |                |
| Urban-rural location                               | Urban                    | 174,963 (83.7%) | 36,766 (84.2%) | <0.001         | 62,605 (81.5%) | 17,787 (81.9%) | <0.001         |
|                                                    | Rural                    | 33,400 (16.0%)  | 6,691 (15.3%)  |                | 13,998 (18.2%) | 3,827 (17.6%)  |                |
|                                                    | Missing                  | 637 (0.3%)      | 213 (0.5%)     |                | 167 (0.2%)     | 91 (0.4%)      |                |

'Institutional' place of death combines Hospital, Care home, & Other places of death;<sup>a</sup>the 18-30 and 31-40 categories in Care homes and the Total column, were combined due to small numbers; <sup>b</sup>includes dissolved and annulled marriage or civil partnership; <sup>c</sup>includes civil partnership; <sup>x</sup>Fisher's exact test with simulated p-values using 10<sup>4</sup> replicates (differences in distribution within each place of death between years were tested for each covariate; for place of death, the distribution across places and years was tested). Deprivation was measured using the Scottish Index of Multiple Deprivation (SIMD). Numbers for deprivation were rounded to nearest 10 due to small numbers missing – the totals may therefore add to slightly more than the total sample size.



Supplementary Table 2: Frequency of comorbid conditions included in the Elixhauser index

| Comorbid condition                              | Home                   |                         | Hospital               |                         | CH                     |                       | All                    |                         |
|-------------------------------------------------|------------------------|-------------------------|------------------------|-------------------------|------------------------|-----------------------|------------------------|-------------------------|
|                                                 | 2015-20                | 2020-21                 | 2015-20                | 2020-21                 | 2015-20                | 2020-21               | 2015-20                | 2020-21                 |
| AIDS/HIV <sup>a</sup>                           | 90 (0.1%)              | 20 (0.1%)               | 110 (0.1%)             | 30 (0.1%)               | 50 (0.1%)              | 10 (0.1%)             | 230 (0.1%)             | 60 (0.1%)               |
| Alcohol abuse                                   | 9,281 (12.1%)          | 2,471 (11.4%)**         | 12,674 (9.0%)          | 2,557 (9.1%)            | 3,447 (5.0%)           | 820 (5.3%)            | 25,402 (8.9%)          | 5,848 (8.9%)            |
| Blood loss anaemia                              | 128 (0.2%)             | 40 (0.2%)               | 407 (0.3%)             | 63 (0.2%)               | 151 (0.2%)             | 26 (0.2%)             | 686 (0.2%)             | 129 (0.2%)*             |
| Cardiac arrhythmias                             | <b>14,955 (19.5%)</b>  | <b>4,498 (20.7%)***</b> | <b>46,284 (32.9%)</b>  | <b>9,114 (32.4%)</b>    | <b>18,685 (27.4%)</b>  | <b>4,295 (27.6%)</b>  | <b>79,924 (28.0%)</b>  | <b>17,907 (27.4%)**</b> |
| Chronic pulmonary disease                       | <b>17,256 (22.5%)</b>  | <b>4,908 (22.6%)</b>    | <b>40,856 (29.0%)</b>  | <b>7,833 (27.9%)***</b> | <b>12,155 (17.8%)</b>  | <b>2,765 (17.8%)</b>  | <b>70,267 (24.6%)</b>  | <b>15,506 (23.7%)*</b>  |
| Coagulopathy                                    | 1,175 (1.5%)           | 332 (1.5%)              | 3,513 (2.5%)           | 660 (2.3%)              | 940 (1.4%)             | 175 (1.1%)*           | 5,628 (2.0%)           | 1,167 (1.8%)*           |
| Congestive heart failure                        | 8,321 (10.8%)          | 2,372 (10.9%)           | 29,793 (21.2%)         | 5,551 (19.7%)*          | 8,054 (11.8%)          | 1,806 (11.6%)         | 46,168 (16.2%)         | 9,729 (14.9%)*          |
| Deficiency anaemia                              | 5,076 (6.6%)           | 1,528 (7.0%)*           | 13,862 (9.9%)          | 2,700 (9.6%)            | 6,127 (9.0%)           | 1,296 (8.3%)*         | 25,065 (8.8%)          | 5,524 (8.4%)*           |
| Depression                                      | 4,113 (5.4%)           | 1,032 (4.8%)*           | 6,279 (4.5%)           | 1,246 (4.4%)            | 3,772 (5.5%)           | 856 (5.5%)            | 14,164 (5.0%)          | 3,134 (4.8%)*           |
| Diabetes mellitus, complicated                  | 1,649 (2.1%)           | 490 (2.3%)              | 4,878 (3.5%)           | 1,133 (4.0%)*           | 1,278 (1.9%)           | 308 (2.0%)            | 7,805 (2.7%)           | 1,931 (3.0%)*           |
| Diabetes mellitus, uncomplicated                | 10,979 (14.3%)         | 3,298 (15.2%)*          | 29,681 (21.1%)         | 6,352 (22.6%)*          | 10,541 (15.4%)         | 2,555 (16.4%)*        | 51,201 (17.9%)         | 12,205 (18.7%)*         |
| Drug abuse                                      | 3,499 (4.6%)           | 1,119 (5.2%)*           | 1,639 (1.2%)           | 370 (1.3%)*             | 244 (0.4%)             | 59 (0.4%)             | 5,382 (1.9%)           | 1,548 (2.4%)*           |
| Fluid & electrolyte disorders                   | 9,559 (12.5%)          | 3,127 (14.4%)*          | 26,686 (19.0%)         | 5,781 (20.6%)*          | 11,773 (17.2%)         | 2,884 (18.5%)*        | 48,018 (16.8%)         | 11,792 (18.0%)*         |
| Hypertension, complicated                       | 1,023 (1.3%)           | 188 (0.9%)*             | 3,395 (2.4%)           | 408 (1.5%)*             | 1,419 (2.1%)           | 202 (1.3%)*           | 5,837 (2.0%)           | 798 (1.2%)*             |
| Hypertension, uncomplicated                     | <b>21,807 (28.4%)</b>  | <b>6,116 (28.2%)</b>    | <b>59,844 (42.5%)</b>  | <b>11,761 (41.8%)*</b>  | <b>27,012 (39.6%)</b>  | <b>6,269 (40.3%)*</b> | <b>108,663 (38.0%)</b> | <b>24,146 (36.9%)*</b>  |
| Hypothyroidism                                  | 3,095 (4.0%)           | 862 (4.0%)              | 8,508 (6.0%)           | 1,502 (5.3%)*           | 4,996 (7.3%)           | 1,123 (7.2%)          | 16,599 (5.8%)          | 3,487 (5.3%)*           |
| Liver disease                                   | 4,447 (5.8%)           | 1,395 (6.4%)*           | 10,990 (7.8%)          | 2,348 (8.4%)*           | 1,855 (2.7%)           | 432 (2.8%)            | 17,292 (6.1%)          | 4,175 (6.4%)*           |
| Lymphoma                                        | 1,356 (1.8%)           | 396 (1.8%)              | 3,674 (2.6%)           | 708 (2.5%)              | 1,066 (1.6%)           | 194 (1.2%)*           | 6,096 (2.1%)           | 1,298 (2.0%)*           |
| Metastatic cancer                               | <b>14,265 (18.6%)</b>  | <b>4,223 (19.5%)*</b>   | 25,851 (18.4%)         | 4,326 (15.4%)*          | 10,746 (15.7%)         | 1,742 (11.2%)*        | 50,862 (17.8%)         | 10,291 (15.7%)*         |
| Obesity                                         | 2,036 (2.7%)           | 564 (2.6%)              | 4,990 (3.5%)           | 1,266 (4.5%)*           | 908 (1.3%)             | 213 (1.4%)            | 7,934 (2.8%)           | 2,043 (3.1%)*           |
| Other neurological disorders                    | 7,049 (9.2%)           | 1,991 (9.2%)            | 16,579 (11.8%)         | 3,244 (11.5%)           | 9,544 (14.0%)          | 2,272 (14.6%)*        | 33,172 (11.6%)         | 7,507 (11.5%)*          |
| Paralysis                                       | 1,244 (1.6%)           | 328 (1.5%)              | 3,352 (2.4%)           | 647 (2.3%)              | 1,703 (2.5%)           | 366 (2.4%)            | 6,299 (2.2%)           | 1,341 (2.1%)*           |
| Peptic ulcer disease                            | 1,523 (2.0%)           | 382 (1.8%)*             | 3,730 (2.7%)           | 683 (2.4%)*             | 1,270 (1.9%)           | 235 (1.5%)*           | 6,523 (2.3%)           | 1,300 (2.0%)*           |
| Peripheral vascular disorders                   | 5,953 (7.8%)           | 1,628 (7.5%)            | 19,002 (13.5%)         | 3,778 (13.4%)           | 5,022 (7.4%)           | 1,040 (6.7%)*         | 29,977 (10.5%)         | 6,446 (9.9%)*           |
| Psychoses                                       | 1,427 (1.9%)           | 381 (1.8%)              | 1,861 (1.3%)           | 423 (1.5%)*             | 1,192 (1.7%)           | 331 (2.1%)*           | 4,480 (1.6%)           | 1,135 (1.7%)*           |
| Pulmonary circulation disorders                 | 4,529 (5.9%)           | 1,313 (6.0%)            | 12,522 (8.9%)          | 2,630 (9.4%)*           | 3,500 (5.1%)           | 728 (4.7%)*           | 20,551 (7.2%)          | 4,671 (7.1%)*           |
| Renal failure                                   | 9,369 (12.2%)          | 2,744 (12.6%)*          | <b>32,997 (23.4%)</b>  | <b>6,492 (23.1%)*</b>   | <b>13,208 (19.3%)*</b> | <b>3,217 (20.7%)*</b> | <b>55,574 (19.4%)*</b> | <b>12,453 (19.0%)*</b>  |
| Rheumatoid arthritis/collagen vascular diseases | 2,182 (2.8%)           | 685 (3.2%)*             | 6,402 (4.5%)           | 1,182 (4.2%)*           | 2,437 (3.6%)           | 519 (3.3%)            | 11,021 (3.9%)          | 2,386 (3.6%)*           |
| Solid tumour without metastasis                 | <b>26,479 (34.5%)*</b> | <b>7,777 (35.8%)*</b>   | <b>44,980 (32.0%)*</b> | <b>7,896 (28.1%)*</b>   | <b>20,934 (30.7%)*</b> | <b>3,579 (23.0%)*</b> | <b>92,393 (32.3%)*</b> | <b>19,252 (29.4%)*</b>  |
| Valvular disease                                | 5,006 (6.5%)           | 1,556 (7.2%)*           | 16,339 (11.6%)         | 3,199 (11.4%)*          | 5,204 (7.6%)           | 1,192 (7.7%)*         | 26,549 (9.3%)*         | 5,947 (9.1%)*           |
| Weight loss                                     | 3,552 (4.6%)           | 1,048 (4.8%)*           | 8,287 (5.9%)           | 1,594 (5.7%)*           | 3,196 (4.7%)*          | 688 (4.4%)*           | 15,035 (5.3%)*         | 3,330 (5.1%)*           |

CH: Care home & 'other' places of death. <sup>a</sup>Numbers for AIDS/HIV were rounded to nearest 10 to avoid disclosing small numbers. The 5 most frequent comorbidities in each place of death are shown in bold. p-values reported in 2020-21 column for proportion test between rates in 2015-20 and 2020-21 for each condition, within each place of death; \* p<.05; \*\* p<.01; \*\*\* p<.001.

