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Deaths at home during the Covid-19 pandemic and implications for patients and services

Eilís Keeble, Sarah Scobie,
Theo Georghiou, Miranda Davies

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Contents

	Summary	2
1	Introduction	6
2	Approach	11
3	Findings	19
4	Implications	42
	Information governance and ethical approval	49
	References	52

Summary

Since the start of the Covid-19 pandemic, a third more people have died at home in England, raising significant questions about whether people can access the care they need at home and the quality of that care.

While the priorities of patients and families in regard to end-of-life care are well understood – including 24/7 access to support and medication, the coordination of care and clear communication – improvements in care have been elusive. Limited data are published about the services provided to people approaching the end of life or the quality of care they receive, particularly for those who die at home.

This research sheds new light on the services that people who died at home in England used, both before and during the first year of the pandemic. It uses data covering a population of 24 million people linking GP clinical records, hospital data and death registrations. The analysis provides insights into service use in the last months of life, and how this changed after the start of the pandemic. It also looks at variation between socioeconomic and ethnic groups, and by cause of death. Our patient and public involvement group, which included people who were receiving end-of-life care as well as family members, provided an important perspective on the findings, based on their own experiences of care.

Our findings highlight the significant health needs of people approaching the end of life, as well as evidence of unmet need, both before and during the pandemic. The proportion of people recognised as having palliative care needs – a critical foundation for providing quality end-of-life care – increased slightly during the pandemic, but around 60% of people who died either before or during the pandemic did not have palliative care needs recorded in their GP record in their last year of life.

We found that, for most services, similar or greater volumes of care per person were provided during the pandemic compared with the pre-pandemic period,

but with the increased number of people dying at home, there was a shift towards more care being delivered in the community. This has significant implications for resources and capacity across community services and primary care.

Key findings across services are as follows:

- **The pandemic exacerbated socioeconomic inequalities in service use.** People from the most deprived areas who died at home used less of almost all services than people from the least deprived areas, and were prescribed fewer medications for symptom management. For general practice interactions, covering any activities leading to a change in the patient's record, not just clinical consultations, the difference grew during the pandemic, with people from the most deprived areas having almost one whole interaction less than people from the least deprived areas.
- **People from Asian ethnic backgrounds were more likely to have emergency bed days and general practice interactions before the pandemic.** While general practice interactions increased for all ethnic groups during the pandemic, the increase was largest for people from white ethnic backgrounds.
- **People who died at home were less likely to have planned hospital admissions during the pandemic,** with 4.8% having at least one admission during the pandemic compared with 5.3% pre-pandemic. People who died from circulatory diseases also had fewer outpatient appointments during the pandemic. These differences reflect reductions in planned care across the board, as the NHS focused on responding to Covid-19, but for people approaching the end of life, the reductions were not just a matter of delaying care.
- Conversely, **there was an increase in the use of Accident & Emergency (A&E) during the pandemic for people who died at home, particularly for people who died from dementia and Alzheimer's disease.** For this group, the proportion of people who had at least one A&E visit in the last month of life increased from 12% to 15% and there was also an increase in how often people went. This may reflect the greater needs of this population, some of whom may have died in institutions such as a hospital,

care home or hospice before the pandemic rather than at home. It may also reflect people developing urgent health problems that could have been avoided, because the pandemic disrupted formal and informal care.

- **Use of general practice increased during the pandemic among people who died at home.** The proportion of people with at least one general practice interaction in the last month of life rose from 64% pre-pandemic to 75% during the pandemic and the number of interactions per person also increased, from 2.5 to 3.8.
- **People who died at home during the pandemic were more likely to be prescribed at least one medication for symptom management than people who died at home before the pandemic** (38% vs 34%) and the number of medications prescribed per person increased from 1.3 to 1.5 between the pre-pandemic and pandemic periods. However, our patient and public involvement group highlighted that **patients and families were not always clear what different medications were for, and wanted more support surrounding the use of medications**, particularly when a syringe driver was needed.

Our research starts to build the evidence base for understanding services provided to people who died at home during the pandemic, and highlights the significant pressure on services in the community. But much more work needs to be done to develop measures to tell us about the quality and outcomes of end-of-life care and to understand people's experiences. Our patient and public involvement group highlighted that **an increase in the quantity of care may not reflect an increase in quality**. For example, during the pandemic, more general practice contacts were remote rather than face to face, which may have affected the quality of care people received.

Integrated care boards have a legal duty to ensure the provision of palliative care. It is critical that they consider both specialist and generalist services, and provision for people who die at home as well as in hospices, hospitals or care homes. The level of service use among people approaching the end of life demonstrates the importance of robust plans for delivering end-of-life care, across both the health and care system as a whole and individual integrated care boards. Improving access to end-of-life care at home has the potential to reduce pressure on emergency care services, but too little is currently

known at a local level about where, how and to whom end-of-life services are provided. The role of third sector organisations and social care is also poorly documented. Integrated care boards have the opportunity to address these gaps, through making better use of data at a local level, engaging with patients and communities, and bringing together service providers to improve the consistency and coordination of care.

The pandemic did not cause the challenges around care for people dying at home, but the shift towards more people dying at home has intensified the impact. As the trend continues, it is becoming increasingly essential that the delivery of care at home is tracked over time. This needs to include understanding inequalities in access to care, and further work to assess the quality of provision, to ensure services are responsive to the needs of individuals, and their families and loved ones.

1 Introduction

The Covid-19 pandemic caused widespread disruption to health and care services. One impact of the pandemic has been a shift in place of death, with a rapid and sustained increase in the number of people who die at home.

In this report we examine the end-of-life care that people who died at home in the first year of the pandemic received, starting three months into the pandemic from June 2020 and covering the nine months to February 2021. We consider how this changed from the same period before the pandemic (June 2019 to February 2020).

Our analysis covers care that general practices, community nursing teams and hospitals provided, drawing on the OpenSAFELY-TPP dataset, which covers 24 million people in England. As well as comparing care before and during the pandemic, we also examine variations in the care that different groups of people received, and indicators of the quality of care for people who died from selected causes.

Before we move on, Box 1 sets out what is meant by end-of-life and palliative care.

Box 1: What is end-of-life and palliative care?

End-of-life care is usually defined as care for people likely to die within a year. It is intended to enable people to live as well as possible until they die, and to die with dignity.⁷ For some people, and some health conditions, it can be clear well in advance that the end of life is approaching, but for others sadly they may only know months or weeks before death. Recognising when someone is likely to die can be challenging for clinicians to predict. For patients and their families, not knowing that death is approaching means it is difficult to make decisions about care and can increase distress.

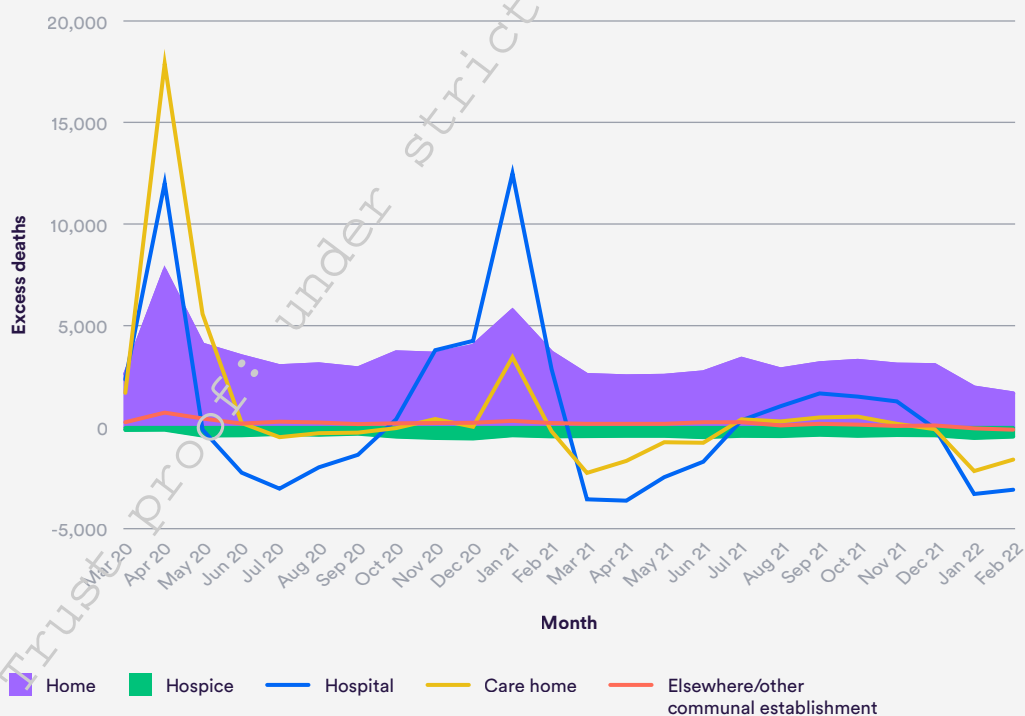
Palliative care aims to make the individual as comfortable as possible, relieve pain and other distressing symptoms, provide psychological, social and spiritual care and give support to families, carers and those close to the person.

In this report we focus on care received in the last few months of life.

Deaths at home and the impact of the pandemic on end-of-life care

The proportion of people dying at home in England was increasing before the pandemic, from 18% of deaths in 2004 to 24% in 2019.⁸ This was in line with longstanding policy ambitions for more people to die in their usual place of residence.⁹ But the pandemic rapidly accelerated this trend, with a third more people dying at home than the pre-pandemic five-year average (see Figure 1). There were 155,815 deaths at home in England in 2020, an increase from the average of 117,101.¹⁰ A consequence of this is that the number of people dying at home has already reached pre-pandemic estimates predicted for 2030.¹¹ This trend has continued. The most recent week for which we had data (to 13 January 2023), the number of people dying at home was over 30% higher than the five-year average.¹²

Figure 1: Excess deaths in the month compared with the 2015–19 average by place of death, England only



Source: Office for National Statistics.¹³

The reasons why this shift has taken place are not well understood, and are likely to have changed over the course of the pandemic.

Covid-19 itself has largely not been a direct cause of increased deaths at home, for which the leading causes are heart disease, cancers and dementia.¹⁴ Rather, the evidence suggests that deaths occurring at home for causes that would have typically been associated with deaths in another setting – a hospital, care home or hospice – are driving the increase. Pressure on health and care services may have led to fewer patients accessing hospital or other services.

Patient and family concerns about dying away from loved ones may also have been an important driver, in response to visiting restrictions in place at times across hospitals, hospices and care homes, as well as concern about the risk of Covid-19 infection.^{15,16} Admissions to care homes fell dramatically in 2020–21 compared with previous years.¹⁷

Care for people who died at home during the pandemic took place against a backdrop of widespread disruption to health and care services. In March 2020, non-Covid NHS services were reduced to protect capacity for Covid-19 patients, patients stayed away from services – both hospitals and primary care – and the number of referrals from GPs to specialist care fell.^{18,19,20} Subsequently, the NHS has struggled to deal with the combined effects of the pandemic in terms of:

- staff absence and isolation requirements
- recovering lost activity
- very high demand for urgent care²¹
- delivering the Covid-19 vaccination programme.²²

The pandemic has also impacted NHS community services, which responded by delivering more services remotely, via digital routes or the telephone.²³ Hospices also moved to providing more care remotely and in people's homes, with fewer people dying in a hospice bed during the pandemic than before it.²⁴

The combined impact of disruption to end-of-life care services and more people dying at home has raised significant questions about the level

of service provision and the quality of end-of-life care since the start of the pandemic.

Quality of end-of-life care at home

A number of previous studies have identified priorities for how to improve the care of patients approaching the end of life. These include:

- access to pain relief
- coordination of services
- 24/7 support for people at home
- good communication with and help for family and informal carers.^{25,26}

Clear communication that someone may soon die is very important.²⁷ While people are not always comfortable talking about death, finding out about a terminal diagnosis by accident, or at a late stage, can increase distress for all concerned.²⁸ Advance care planning can provide people with the opportunity to express their preferences around treatment and care towards the end of life,²⁹ and these discussions can take place over a longer period of time when care decisions are not imminent.

Surveys have found that the majority of people who express a preference would prefer to die at home,³⁰ although often people do not express a view,³¹ or change their mind as their illness progresses. For people with a terminal illness, and when the circumstance of being close to death arises, the situation is often complex, and depends on individual, family and service factors.³² There is, however, consensus that emergency hospital admission towards the end of life is often not the best outcome for patients, and there has long been a focus within national policy to encourage individual end-of-life care planning, and to enable more people to be cared for in their place of choice.³³

But even before the pandemic there were concerns about access to palliative care, whether at home or elsewhere.³⁴ People with dementia, disabled people and people who are homeless are less likely to have access to specialist care, and people dying from cancer are most likely to have access. In addition, geographic access to services³⁵ and socioeconomic factors influence the eventual place of death, with people in more deprived areas being more

likely to die in hospital.³⁶ People from minority ethnic groups may also face more barriers to receiving good, personalised care towards the end of life.³⁷ Socioeconomic inequalities widened during the pandemic, with more deprived areas having a smaller increase in the proportion of people dying at home than the least deprived areas.³⁸

While the pandemic may have accelerated a trend for more people to die at home, in line with recent policy, it is unclear whether the experience of dying at home during the pandemic has been a positive and dignified one.

In this study we used data from general practitioner (GP) and hospital records to explore the use of health services among different groups of people. We also created indicators of the quality of end-of-life care, which we were able to adapt from national guidelines covering the use of emergency hospital services, end-of-life care medication and recognition that a person needs palliative care.^{39,40}

Aims of the report

In this report we examine the following questions:

- 1 What were the characteristics of people who died at home and how did their use of care services change during the Covid-19 pandemic?
- 2 Were demographic and social factors associated with the services that people who died at home used?
- 3 How have indicators of the quality of care changed for people who died at home during the pandemic?

We then consider the implications of our findings for improving the provision of end-of-life care.

2 Approach

About OpenSAFELY

For this project we used the OpenSAFELY-TPP platform, which allowed us to analyse the individual electronic health records of people registered at GP practices in England using TPP SystemOne software. We received approval from NHS England to conduct the analysis and the UK Statistics Authority's Data Ethics Team gave ethics approval. Primary care records managed by the GP software provider, TPP, were linked through OpenSAFELY to Office for National Statistics (ONS) death registration data and hospital data (on admitted patient care, emergency care and outpatient activity) from NHS Digital's Secondary Uses Service (SUS).*

All data were linked, stored and analysed securely within the OpenSAFELY-TPP platform (<https://opensafely.org>). Data include pseudonymised data such as coded diagnoses, medications and physiological parameters. No free text data are included. Detailed pseudonymised patient data is potentially re-identifiable and therefore not shared. Using this platform meant we had no access to patient records: our analysis code was developed using dummy data before executing on the real data on a remote server. There is a public record of all the analysis that we carried out (<https://jobs.opensafely.org/nuffield-trust/deaths-at-home-during-covid-19>). Aggregated results were checked for whether they were disclosive, before being released. All analytical code is shared openly for review and re-use under an MIT open license (<https://github.com/opensafely/deaths-at-home-covid19>).

* Information on this linkage is available at: <https://docs.opensafely.org/data-sources/systemone/#externally-linked-data>.

Analysis cohorts

We used date of death from the ONS death registrations to identify two cohorts of people of any age, registered with a TPP practice on the day they died. The first cohort covered people who died before the pandemic between 1 June 2019 and 29 February 2020 and the second cohort covered people who died during the pandemic between 1 June 2020 and 28 February 2021. The March to May period was excluded so that our analyses of service use for the pandemic cohort included only activity in the pandemic period (see further below).

For each cohort we gathered descriptive information on a variety of characteristics: sex, age group, ethnic group (see Box 2 for information on how we defined these groups), Index of Multiple Deprivation (IMD) quintile, place of death and cause of death. Further details on these characteristics can be found in Appendix 1.

Box 2: Ethnic group: how was this defined?

We used the following six ONS ethnic groupings:

- Asian/Asian British
- Black/African/Caribbean/Black British
- Mixed/multiple ethnic groups
- Other ethnic group
- White
- Unknown.

The ethnic group recorded in GP data is self-reported and we used this to determine people's ethnic group. However, if this information was missing then we took a value from hospital data, where available. If ethnic group was missing from both GP and hospital data then we assigned people to the 'unknown' ethnic group.

There are known problems with the recording of ethnicity in health records, including weak agreement between hospital records, GP records and census data, and systematic biases in coding that affect minority ethnic groups more than others.^{41,42} Further, coding of ethnicity in primary care records is incomplete for more than a third of people aged over 80,⁴³ so for this group, information about ethnic group will rely more on hospital records, and thus be biased towards people who have received hospital care.

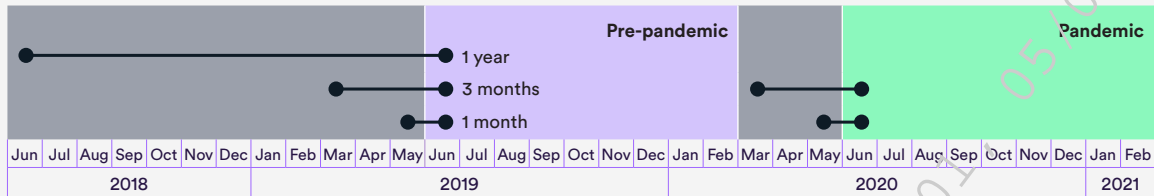
Practices that use TPP software to manage electronic health records cover around 24 million people in England, representing 43% of the population.⁴⁴ Coverage is not equally distributed across the country, with relatively low numbers of TPP practices in London, for example. However, analysis across key characteristics such as age, sex and ethnicity suggests that the data are broadly representative of the English population. The analysis cohorts represented around 40% of ONS-published deaths and this was fairly consistent across time by sex, age group, cause of death and place of death. Matching the overall representation of TPP practices across the country, the analysis cohorts had lower representation in the North West (5% of ONS-published deaths) and the highest in the East Midlands (79% of ONS-published deaths). Further details on the comparison with ONS deaths can be found in Table A1 and Figure A1 in Appendix 2.

Patients who joined a practice that used TPP software from a practice that used different software were included in the analysis cohorts (if they subsequently died during the relevant periods). For these patients, their records will likely be incomplete. We conducted a sensitivity analysis with the subset of patients who were consistently registered at TPP practices for the period our analysis covered and found no significant differences in the results.

Service-use measures

We examined service use before death using hospital and GP records. We looked at service use in the last three months of life, with a special focus on the last month of life. We also looked at service use in the last year of life for the pre-pandemic cohort. We did not replicate this for the pandemic cohort as we wanted to focus on service use during the pandemic. Looking a year before death for most of this cohort would have overlapped the pre-pandemic period (see Figure 2 for an illustration of the time periods covered). We focused on comparing the average number of events per person and the proportion of people with at least one service-use event (for example, at least one emergency admission in the month before death). Information about the statistical tests we carried out for these comparisons can be found in Appendix 3.

Figure 2: Example service-use periods for a pre-pandemic and a pandemic death



Note: Examples shown are earliest deaths in each cohort and their lookback periods before death. Deaths could occur at any point in the highlighted pre-pandemic and pandemic periods.

The hospital service-use measures were:

- Accident and Emergency (A&E) visits
- admissions (elective, including day cases, and emergency)
- bed days (following elective or emergency admissions)
- outpatient appointments and attended outpatient appointments.

General practice interactions were drawn from the primary care record and included GP consultations but could also include other types of contact (see Box 3 for further information).

Box 3: General practice interactions: what does this include?

This service-use measure covers interactions between general practice and patients. It includes consultations between health care professionals and patients but can also include changes made to the patient's record by other general practice staff such as updating patient details or receiving test results. From the OpenSAFELY-TPP data, in the majority of practices, patients had around five general practice interactions per year on average before the pandemic (see Figure A2 in Appendix 4). This is similar to figures on GP appointments that NHS Digital and the Clinical Practice Research Datalink (CPRD) have reported.^{45,46} However, there was variation across practices – in some practices, patients had as many as 60 interactions a year on average.

Differences over time in the average number of measured interactions may simply be a consequence of practices changing how they use their

electronic health records. This may be the cause of the large increase we observed in the number of interactions per patient in January and October 2020 for practices with the largest number of average interactions per patient (see Figure A2 in Appendix 4). The proportion of patients with at least one practice interaction, however, is more consistent (see Figure A3 in Appendix 4).

It is important to note that changes in care during the pandemic may also have influenced the number of interactions recorded, and we discuss this when we present our findings.

We also identified other service-use measures from the primary care record:

- palliative care
- community nursing team care
- medications prescribed for symptom management (see Box 4 for details).

A list of SNOMED codes (structured clinical vocabulary for use in electronic health records) to identify palliative care was available⁴⁷ and we developed codelists to identify community nursing team care and medications prescribed for symptom management. Our list of medications was based on a set of priority medicines for palliative and end-of-life care.⁴⁸ All the prescribed medications on our list are for subcutaneous administration and so need to be delivered by injection. These medications are anticipatory medicines – usually prescribed pre-emptively to be administered ‘if needed’ to manage pain, agitation, nausea, vomiting and other symptoms in the last days of life.⁴⁹

We also wanted to develop measures for ambulance incidents and hospice care but the data were not suitable for this purpose. Further details on all the codelists can be found in Appendix 4.

Box 4: Medications prescribed for symptom management: what does this cover?

Medication	Symptoms
Glycopyrronium	Noisy breathing, colic
Haloperidol	Delirium, nausea and vomiting
Hyoscine butylbromide	Noisy breathing, colic
Levomepromazine	Anxiety, delirium, nausea and vomiting
Midazolam	Anxiety
Morphine†	Breathlessness, pain
Oxycodone	Breathlessness, pain

Quality indicators

In order to assess whether patterns of care had changed during the pandemic, we identified four indicators of the quality of care that we could draw from the data (see Table 1). We used quality indicators covering the last three months of life so that changes during the pandemic could be identified that would not have been possible if we looked over a year before death as this would have straddled both the pandemic and the pre-pandemic periods.

Two of the measures relate to emergency admissions, for which a higher rate could indicate worse care. While an emergency admission to hospital close to the end of life can be appropriate, repeated admissions can indicate that the patient's condition is not stable, and that they have care and support needs that are not being met in the community.

The two other measures relate to whether the patient has been identified as approaching the end of life, for which a higher rate is likely to indicate

† After completing the analysis it was found that a number of morphine prescriptions were not captured by the morphine codelist and were missing from the analysis. We explored the impact of these missing prescriptions and found it did not substantially change the findings of this report. Further details on this can be found in Appendix 4.

improved care. Recognition that a patient is approaching the end of life is critical for ensuring that their palliative care needs are assessed and addressed.

Table 1: Quality indicators for end-of-life care

Indicator type	Indicator	Source
Use of emergency care – higher use may indicate that community services are not meeting patients' needs	The proportion of people with one or more emergency admissions in the last three months of life	Outcome measure for the National Institute for Health and Care Excellence (NICE) quality statement 4 (adults approaching the end of their life and their carers have access to support 24 hours a day, seven days a week) ⁵⁰
	The proportion of people with three or more emergency admissions in the last three months of life	Palliative and End of Life Care Profiles indicator from the National End of Life Care Intelligence Network ⁵¹
Recognition of end-of-life care needs	The proportion of people with palliative care recorded in their GP record in the last three months of life	Outcome measure for NICE quality statement 1 (adults who are likely to be approaching the end of their life are identified using a systematic approach) ⁵²
	The proportion of people with medications prescribed for symptom management in the last three months of life	Prescribing of medications used for managing symptoms indicates recognition, and is recommended in NICE guidelines. ⁵³

These measures do not tell us about individuals' care experiences, or whether the care they received met their specific needs, but they can be used as proxies for the quality of care that patients received, allowing us to test whether there is any evidence of a change associated with the pandemic.

Patient and public involvement

We recruited 10 patient and public involvement representatives to support the project write-up and dissemination. Representatives were selected having responded to an advertisement about the project, which was placed in email newsletters initially distributed via the Ambitions Partnership and the end-of-life care commissioning networks, and subsequently by a range of organisations including Alzheimer's Society, Macmillan Cancer Support and Hospice UK. The representatives included people personally in receipt of end-of-life care as well as family, friends and carers of people in receipt of end-of-life care. Across the group, people had experiences of care both before and during the pandemic. Several representatives had a professional role in the care of people approaching the end of life and some had developed a role supporting people approaching the end of life following recent bereavements.

The aims of the patient and public involvement were to:

- review the face validity of our findings, and the conclusions being drawn
- gain vital perspective on the reasons behind the inequalities that different groups who require end-of-life care experience
- discuss concerns relating to the use of big data in research and the safeguards in place, while also reflecting the benefits that patients and family/carers perceive.

We used input from the representatives to ensure that important context and implications of the findings from the perspective of patients and families could be drawn out. These are highlighted in pull-out boxes throughout the report. We also worked with the representatives to produce an output together, written specifically for patients in receipt of end-of-life care and their family and friends, summarising and providing wider context on aspects of the results that the representatives felt were particularly important.

The representatives were paid for their time based on guidance from the National Institute for Health and Care Research.⁵⁴

3 Findings

What were the characteristics of people who died at home and how did their use of care services change during the Covid-19 pandemic?

The shift towards more deaths occurring at home in the pandemic period is mirrored in our analysis, with just under 30% more deaths occurring at home from 1 June 2020 to 28 February 2021 when compared with the equivalent period pre-pandemic. The overall increase in deaths at home and shift in where deaths occurred were reflected across almost all subgroups of patients (see Table 2, and Tables A3 and A4 in Appendix 5). Some of the largest shifts in the proportion of people dying at home occurred for people who died from cancer (a 13 percentage-point increase) or other respiratory diseases (a nine percentage-point increase).

There were increases in the proportion of people from all deprivation quintiles dying at home but the largest increase was for people from the least deprived areas, as a previous study found.⁵⁵

By ethnic group, the largest increase in the proportion of people dying at home was for people from black ethnic backgrounds (an eight percentage-point increase). A smaller proportion of people who died both at home and across all places of death had their ethnic group recorded as unknown during the pandemic than before it which made comparisons between the two time periods difficult (see Tables A3 and A4 in Appendix 5).

Table 2: Percentage of each characteristic among people who died at home in the pre-pandemic and pandemic periods

Characteristic	Pre-pandemic (n)	Pandemic (n)
All	24.7% (36,140)	28.6%* (46,930)
Gender		
Female	21.7% (15,830)	26.2%* (21,160)
Male	27.7% (20,320)	30.8%* (25,770)
Age group		
0–9	17.9% (50)	21.1% (40)
10–19	26.9% (70)	33.3% (80)
20–29	35.1% (270)	36.1% (260)
30–39	38.3% (640)	41.5% (680)
40–49	38.3% (1,320)	41.2%* (1,640)
50–59	35.8% (2,960)	39.1%* (3,710)
60–69	33.0% (5,210)	36.8%* (6,700)
70–79	28.3% (9,330)	32.2%* (12,160)
80–89	21.6% (10,930)	25.3%* (14,240)
90+	16.6% (5,370)	20.7%* (7,390)
Ethnic group		
Asian	28.1% (940)	31.7%* (1,600)
Black	26.8% (340)	34.6%* (630)
Mixed	28.8% (150)	32.4% (220)
Other	22.1% (190)	28.0%* (300)
White	24.0% (32,730)	28.0%* (42,470)
Unknown	42.7% (1,800)	44.9%* (1,710)
Index of Multiple Deprivation (IMD) quintile		
1 (most deprived)	25.6% (7,460)	29.0%* (9,570)
2	24.2% (7,140)	27.3%* (9,110)
3	24.3% (7,640)	28.3%* (10,000)
4	25.1% (7,270)	28.9%* (9,170)
5 (least deprived)	23.9% (5,980)	29.2%* (8,200)
Unknown	27.5% (660)	29.5% (880)
Cause of death		
Cancer	31.6% (12,740)	44.3%* (17,520)
Circulatory diseases	30.3% (10,950)	36.6%* (13,180)
Covid-19	0.0% (0)	5.1% (1,410)
Dementia and Alzheimer's disease	10.5% (1,950)	16.8%* (2,770)
Flu and pneumonia	11.4% (780)	14.9%* (580)
Other respiratory diseases	22.9% (2,850)	31.5%* (2,900)
All other causes	21.4% (6,880)	26.9%* (8,560)

* Significantly different from the pre-pandemic period at the 5% level.

The total amount of services provided to people who died at home increased during the pandemic for all services, as a result of the large increase in the number of people who died at home. Before the pandemic, service use varied by place of death and the shift towards more people dying at home instead of at these other locations will have contributed to the increase in service use for home deaths as well as any differences seen in service use between the pre-pandemic and pandemic periods (see Box 5).

Box 5: Pre-pandemic service use by place of death

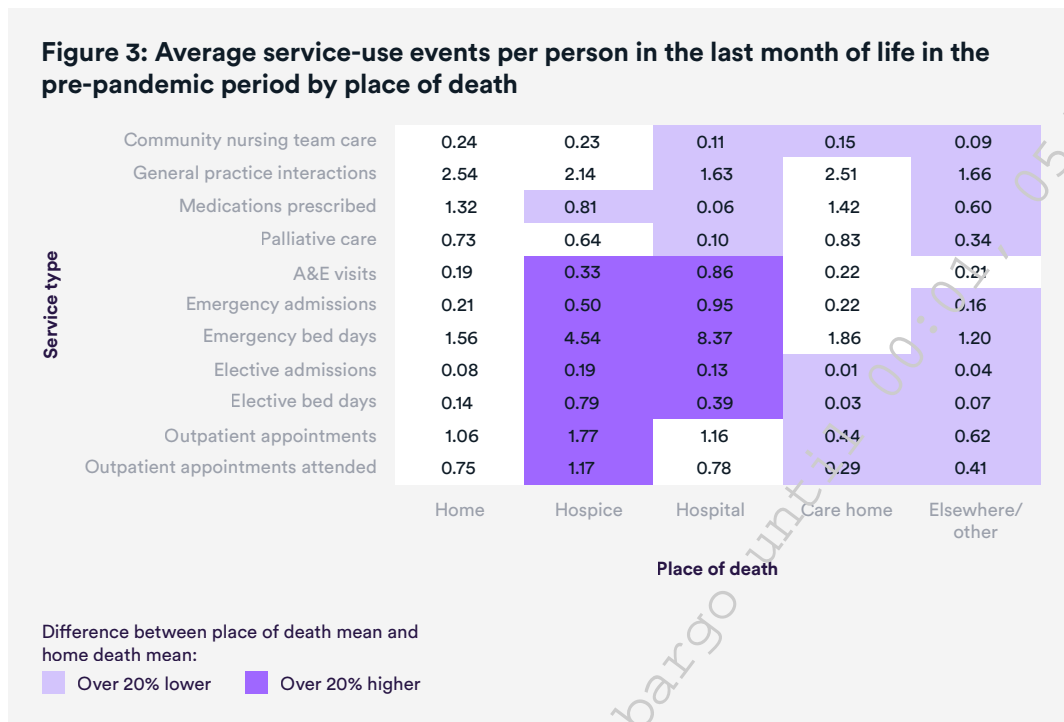
In order to interpret any changes in service use between the pre-pandemic period and the pandemic period for people who died at home, it is important to consider pre-existing variation in service use by place of death (see Figure 3).

Palliative care was least likely to be flagged in the primary care record of people who died in hospital, and these people were also least likely to be receiving primary care. Meanwhile general practice was most involved in the care of people who died at home and those who died in a care home. Community nurses were most involved in the care of people who died in a hospice or at home.

The shift towards more people dying at home instead of other locations will likely have contributed to any changes in service use seen for home deaths between the pre-pandemic and pandemic periods. For example, during the pandemic period, people who died at home rather than in hospital would likely have needed a higher level of primary and community care than the average for home deaths in the pre-pandemic period.

People who died in institutions before the pandemic may have had more complex needs than people who died at home. If these people died at home during the pandemic as part of the shift towards dying at home, they may still have needed access to institutional care, increasing the use of both elective and emergency care for people who died at home.

Further detail on service use across all locations, and how this changed during the pandemic, is included in Tables A5 and A6 in Appendix 6.



In the pandemic period, a greater proportion of people who died at home had at least one interaction with general practice in their last month of life than people who died at home in the pre-pandemic period (see Table 3). There was also an increase in the number of interactions per person. As outlined in Box 3, our measure of general practice interactions represents more than just GP consultations, and so pandemic-related initiatives such as identifying and contacting shielding patients may have increased the number of interactions without the patients themselves being aware.

Table 3: Service use coded in the GP record in the last month of life – proportion of people who died at home with at least one event and average events per person who died at home

Service type	Proportion with at least one event (n)		Average events per person	
	Pre-pandemic	Pandemic	Pre-pandemic	Pandemic
Community nursing team care	15.1% (5,460)	15.5% (7,280)	0.24	0.25
Medications prescribed for symptom management	34.2% (12,370)	37.9%* (17,780)	1.32	1.54*
General practice interactions	63.6% (22,990)	74.7%* (35,080)	2.54	3.83*
Palliative care	28.6% (10,330)	28.9% (13,580)	0.73	0.74

* Significantly different from pre-pandemic period at the 5% level.

The proportion of people who died at home with medications for symptom management that general practice prescribed in the last month of life increased in the pandemic. The average number of medications prescribed per patient also increased, suggesting that not only were more people who died at home being prescribed them, but also they were being prescribed more frequently. This increase may partly reflect changes in anticipatory prescribing during the pandemic to ensure that medications were available to patients when needed.^{56,57} Not all prescribed medications will have been used: they may not have been required, or in some cases the support required to administer them may not have been available.

People who died at home during the pandemic were as likely as people who died at home pre-pandemic to have community nursing team care and palliative care coded in their GP record in the last month of life. However, looking over the last three months of life, people who died at home during the pandemic had more palliative care coded in their GP record than those who died at home pre-pandemic, which indicates more recognition of palliative

care needs in the months further from death than pre-pandemic (see Table A6 in Appendix 6). The palliative care measure was drawn from the Quality Outcomes Framework (QOF), which was suspended during the pandemic and this may have had an impact on how often these codes were recorded in the GP record.⁵⁸ Conversely, there may have also been more awareness of the importance of these codes due to the move to identify clinically vulnerable patients.

Despite patients and the public generally staying away from hospital during the pandemic,⁵⁹ contact with hospital urgent care services was more common during the pandemic for people who died at home (see Table 4). The proportion of people with at least one A&E visit in the last month of life increased by 1.3 percentage points and the proportion with at least one emergency admission increased by 1.4 percentage points. There were also more events per person for these service types. Over the last three months of life, average emergency admissions per person during the pandemic were similar to pre-pandemic levels, which indicates that emergency admissions have shifted closer to death during the pandemic, becoming more concentrated in the last month of life (see Table A6 in Appendix 6). The increased contact with urgent care services contrasts with a fall in A&E attendances across the population; this may reflect people with more complex needs remaining at home who might previously have been cared for towards the end of life in another setting. Face-to-face contact was also still available at A&E to some extent while general practice had switched to a focus on remote consultations and therefore more people approaching the end of life who needed the reassurance of this type of contact might have sought it at A&E.

Table 4: Hospital service use in the last month of life – proportion of people who died at home with at least one event and average events per person who died at home

Service type	Proportion with at least one event (n)		Average events per person	
	Pre-pandemic	Pandemic	Pre-pandemic	Pandemic
A&E visits	16.0% (5,800)	17.3%* (8,120)	0.19	0.20*
Emergency admissions	18.4% (6,660)	19.8%* (9,270)	0.21	0.22*
Emergency bed days	18.4% (6,660)	19.8%* (9,270)	1.56	1.71*
Elective admissions	5.3% (1,910)	4.8%* (2,270)	0.08	0.08
Elective bed days	5.3% (1,910)	4.8%* (2,270)	0.14	0.14
Outpatient appointments	37.4% (13,510)	37.4% (17,550)	1.06	1.15*
Outpatient appointments attended	26.6% (9,630)	30.7%* (14,390)	0.75	0.90*

* Significantly different from the pre-pandemic period at the 5% level.

In our patient and public involvement work, people talked about the distinction between the quality versus quantity of contact with services. While more GP interactions were recorded during the pandemic than before it, this does not necessarily equate to people receiving the care they needed. Fewer contacts were face to face during the pandemic and some people found it hard to get through to their GP surgery, or experienced being passed around from person to person without their problem being resolved.

Higher use of urgent care services may reflect the challenges people experienced in trying to speak to someone about what was happening to them or their loved ones, leaving them with a feeling of no other option, despite the inherent risks of attending urgent care in a pandemic.

During the pandemic, the proportion of people who died at home with at least one elective admission in the last month of life dropped. This was even more pronounced when looking back over the last three months of life, where there were also fewer elective admissions and bed days per person (see Table A6 in Appendix 6). The reduction in elective care for the pandemic cohort likely reflects that many of these services were scaled back during the pandemic period.⁶⁰

Summary

The increase and shift to deaths at home was reflected across the characteristics we looked at, with a much greater proportion of deaths at home for people who died from cancer (a 13 percentage-point increase) or other respiratory diseases (a nine percentage-point increase) and people from black ethnic backgrounds (an eight percentage-point increase). Overall volumes of service-use events recorded for people who died at home also increased. However, some of this care will still have been delivered before the pandemic, even if people subsequently died elsewhere.

At the individual level, across most services that we looked at, people had similar levels of or more contacts during the pandemic in comparison with

the pre-pandemic period. People who died at home were more likely to have general practice interactions and medications prescribed for symptom management, and more likely to have attended outpatient appointments and A&E, than pre-pandemic. The increase in A&E visits is surprising and may be due to more people dying at home with complex conditions. Furthermore, face-to-face care was still available at A&E during the pandemic while care from general practice was often switched to remote consultations and this may have also contributed to the increase if people sought the reassurance of face-to-face contact. In contrast to the increased A&E visits, people who died at home were less likely to receive elective inpatient care. This is not surprising as elective care was scaled back early on in the pandemic, but it will be important to understand whether this meant people were not getting the care they required as they approached the end of life.

Were demographic and social factors associated with the services that people who died at home used?

In this section we examine the data in more detail and look at service use before death at home by subgroups. Our aim is to identify any differences between groups before the pandemic, and to account for how these changed during the pandemic. There are known relationships between the characteristics, which we have outlined in Tables A7 to A10 in Appendix 7, but we have not sought to adjust for these relationships in this analysis.

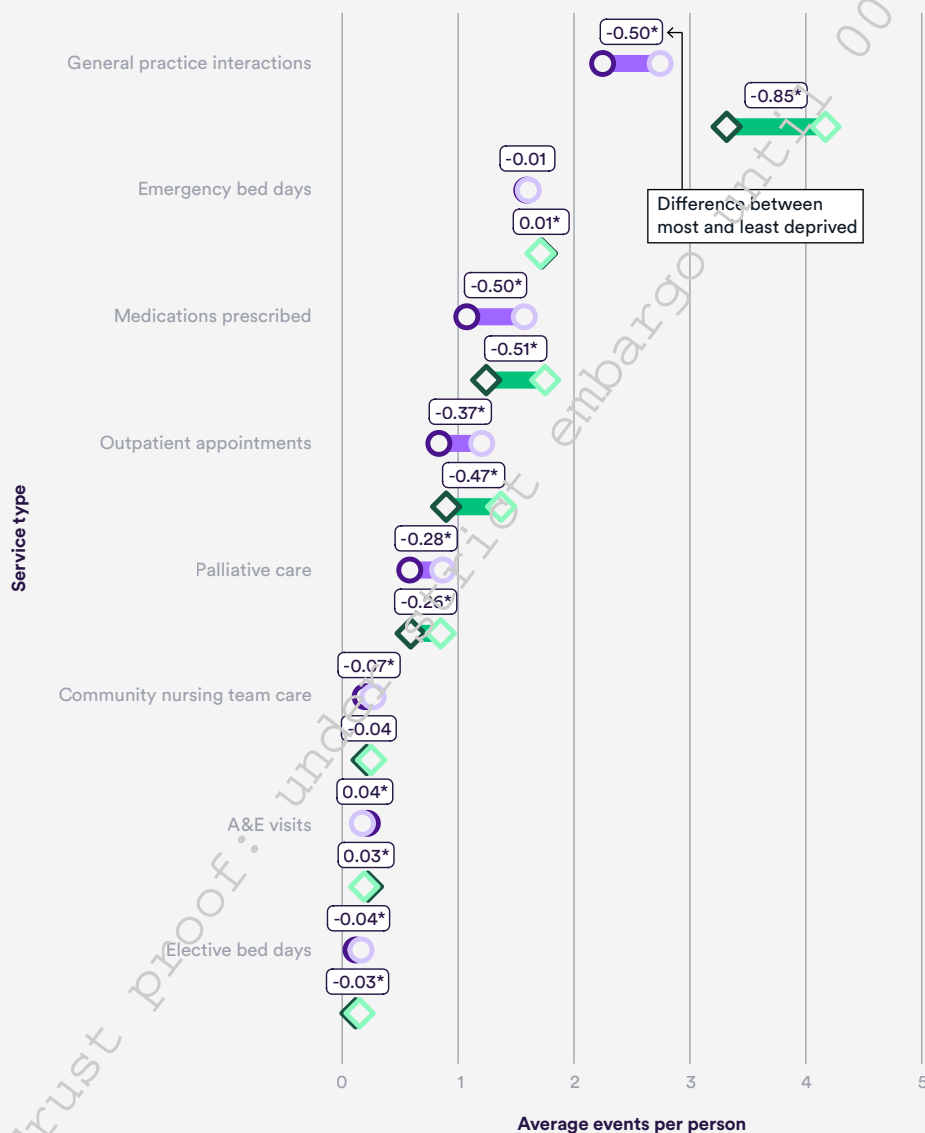
Deprivation

Differences pre-pandemic

Before the pandemic, people living in the most deprived areas had more A&E visits in the last month of life and used less of all other services (except emergency bed days where there was no difference) when compared with people from less deprived areas (see Figure 4 and Appendix 11 Table A21). People from both the most and least deprived areas were more likely to have general practice interactions in the last month of life than interactions with other service types but people from the most deprived areas had half an interaction less on average than people in the least deprived areas (see Box 3

for detail on what constitutes an interaction). People from the most deprived areas were also less likely to have medications prescribed for symptom management, with an average of only 1.1 prescriptions per person, compared with 1.6 for people from the least deprived areas.

Figure 4: Average service-use events per person in the last month of life for people from the most and least deprived areas who died at home, by pandemic period



* Difference between most and least deprived significant at the 5% level

IMD quintile:

- Most deprived pre-pandemic
- Least deprived pre-pandemic
- Most deprived pandemic
- Least deprived pandemic

Differences during the pandemic

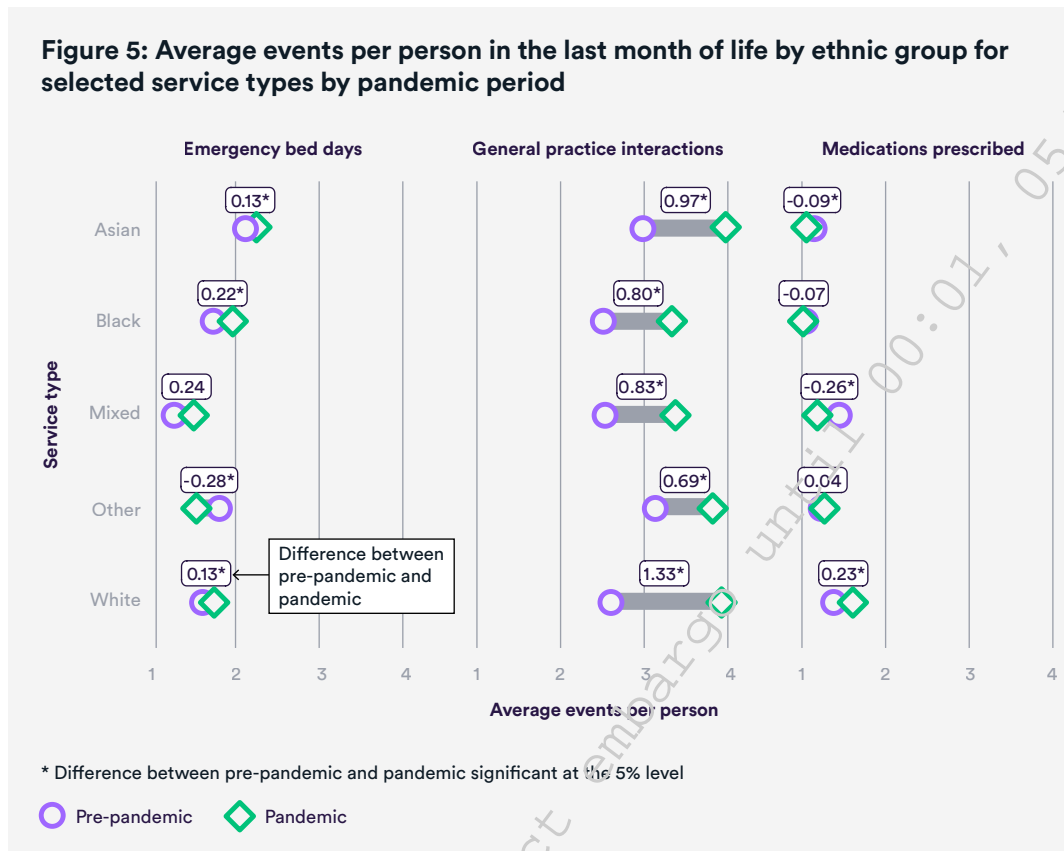
During the pandemic, general practice interactions increased for people from both the most and least deprived areas, but the largest increase was for people from the least deprived areas, which meant that the gap from the most to the least deprived was wider in the pandemic period (see Figure 4). There were larger increases in outpatient appointments for people from the least deprived areas, which meant that the gap between the most and the least deprived in this respect also grew in the pandemic. The gap between people from the most and least deprived areas for palliative care and medications prescribed for symptom management, which existed before the pandemic, remained largely unchanged during the pandemic.

In terms of why some groups (such as those living in deprived areas) may experience more challenges in accessing services, our patient and public involvement group talked about ‘dying well’ requiring people to be articulate, to have time, energy and persistence, and to have a self-belief that they deserve care.

Ethnicity

Differences pre-pandemic

There were several differences between ethnic groups in the services used before the pandemic (see Figure 5 and Appendix 11 Table A22). In the pre-pandemic period, people who died at home from Asian ethnic backgrounds had significantly more emergency bed days than all other ethnic groups, with on average 2.1 emergency bed days per person in the last month of life. People from an Asian ethnic background also had the most general practice interactions along with people from any other background, at around three interactions per person. Meanwhile people from mixed and white ethnic backgrounds had significantly more medications for symptom management prescribed in the last month of life than people from Asian and black ethnic backgrounds.



Note: People from unknown ethnic backgrounds have been excluded from this chart. They had the fewest events per person but it is difficult to draw meaning from this as people with less contact with services are less likely to have their ethnic group accurately recorded.

Differences during the pandemic

In the pandemic period, increases in activity were seen across several measures but the changes were not always consistent between ethnic groups. While people from white ethnic backgrounds who died at home had more medications for symptom management prescribed during the pandemic, people from Asian, black and mixed ethnic backgrounds had fewer prescribed medications than before the pandemic. This enhanced differences that existed before the pandemic. People from all ethnic backgrounds had an increase in the number of general practice interactions. People from white ethnic backgrounds had the largest increase, and had more interactions on average, than people from Asian and other ethnic groups.

Overall, relatively small numbers of deaths among the ethnic groups aside from the Asian and white ethnic groups meant that many differences or

changes were often not significant. In addition, the coding of ethnicity was more complete in the pandemic phase. Given known biases in ethnicity coding,⁶¹ it is likely that before the pandemic, fewer people from minority ethnic groups had ethnicity coded correctly, so shifts across the two time periods will also reflect changes in coding.

Summary

Before the pandemic, people from the most deprived areas were more likely than people from the least deprived areas to use A&E in the last month of life and less likely to use other services, or be prescribed medications for symptom management. These differences were sustained into the pandemic. With respect to general practice interactions and outpatient appointments, the gap between people from the most and least deprived areas (with higher activity for people in the least deprived areas) grew even further.

People from Asian ethnic backgrounds were more likely than most other ethnic groups to have emergency bed days and general practice interactions before the pandemic. While general practice interactions increased for all ethnic groups in the pandemic period, the increase was largest for people from white ethnic backgrounds.

We also looked at differences in service use by sex and age group. Details of this can be found in Appendix 8.

How have indicators of the quality of care changed for people who died at home during the pandemic?

Our patient and public involvement group highlighted that, as a starting point, it should be acknowledged that there were significant challenges surrounding end-of-life care well before the pandemic. People felt they had to really fight to receive the support they needed, leading to a sense of ‘endless battling’.

For patients, it was hard to both be a patient and an advocate for their own care and support, as these were effectively two roles. For family and friends involved as carers, it was hard to grieve for loved ones if things did not happen as best they could.

With the data available to us, it was not possible to determine whether people received the care they personally needed or wanted as they approached the end of life – for example, whether any advance care plans that existed had been followed. However, we were able to create four indicators to act as proxies of the quality of end-of-life care (see Table 5).

In the pandemic period, we found no material change in the proportion of people who died at home who had emergency admissions in the last three months of life, but more people had medications prescribed and palliative care coded. This suggests that more of the people who died at home in the pandemic were being identified as approaching the end of life. However, still over 60% of the people who died at home in the pandemic did not have palliative care activity recorded in the last three months of life. This may be because palliative care had already been recorded before the last three months of life, but we searched back through the full year before death, and this did not change the picture very much – almost 60% (57%) did not have palliative care coding in their record and, therefore, may not have been identified as approaching the end of life.

Table 5: Quality-of-care indicators over the last three months of life for people who died at home pre-pandemic and during the pandemic

Quality-of-care indicators (last three months of life)	Proportion with event (n)	
	Pre-pandemic (N = 36,140)	Pandemic (N = 46,930)
One or more emergency admissions to hospital	39.5% (14,280)	39.8% (18,680)
Three or more emergency admissions to hospital	4.3% (1,550)	4.1% (1,940)
One or more medications prescribed for symptom management by general practice	38.0% (13,720)	42.3%* (19,850)
One or more palliative care codes in GP record	35.8% (12,940)	36.7%* (17,220)

* Significantly different from the pre-pandemic period at the 5% level.

In our patient and public involvement work, accessing medications towards the end of life, where people needed it, and being supported to use it were felt to be a significant challenge both before and during the pandemic. For carers, pain relief was a big part of minimising their loved one's distress, but it was not always easy to get medication prescribed. There were particular issues around access to, and use of, syringe drivers in terms of the timing around when they would be offered; sometimes this was only very close to death.

There was also a degree of uncertainty around the medications prescribed when someone is approaching end of life. People were not always clear *what* the medication they were prescribed actually did, *why* it was being offered and *when* it should be given.

As recognition of whether people are approaching the end of life varies between patients depending on their health conditions, we examined change in quality-of-care measures and service use for people who died at home from one of the following seven significant causes of death:

- cancer
- circulatory diseases
- dementia and Alzheimer's disease

- Covid-19
- flu and pneumonia
- other respiratory diseases
- all other causes.

Below we set out our findings for the first three as these were the causes with either the most deaths at home (cancer and circulatory diseases) or the largest increase in the proportion of deaths occurring at home during the pandemic (dementia and Alzheimer's disease). Further details on pre-pandemic and pandemic service use in the last month of life for people who died at home from one of the seven causes of death are available in Tables A11 to A17 in Appendix 9. Information on quality-of-care indicators over the last three months of life for people who died at home from flu and pneumonia, other respiratory diseases or all other causes is given in Tables A18 to A20 in Appendix 10.

People who died from cancer

As shown in Table 2, cancer was the most common cause of death for people who died at home, both before and during the pandemic. There was a large increase (37.5%) in the number of people dying at home from cancer during the pandemic.

Out of all seven causes of death, those who died from cancer were the group most likely to use all of the services before death that we looked at (see Table 6, and Tables A11 to A17 in Appendix 9). More than 50% of this group had outpatient appointments, medications prescribed for symptom management and general practice interactions in the last month of life both pre-pandemic and during it. This is in line with previous research.⁶²

People who died at home from cancer during the pandemic had more outpatient appointments, general practice interactions and medications prescribed for symptom management on average than people who died at home from cancer pre-pandemic. Elective admissions were maintained in the pandemic for people who died at home from cancer in contrast to the overall declines for all causes, but the number of community nursing team contacts per person was lower. The larger number of cancer patients dying at home will have put considerable strain on community nursing services.⁶³

Table 6: Service use in the last month of life for selected measures for people who died at home from cancer pre-pandemic and during the pandemic

Service type	Proportion with at least one event (n)		Average events per person	
	Pre-pandemic (N = 12,740)	Pandemic (N = 17,520)	Pre-pandemic (N = 12,740)	Pandemic (N = 17,520)
A&E visits	21.0% (2,680)	21.5% (3,760)	0.24	0.25
Community nursing team care	23.9% (3,040)	22.7%* (3,980)	0.38	0.36*
Elective admissions	10.0% (1,280)	9.9% (1,730)	0.15	0.16
General practice interactions	77.6% (9,880)	89.5%* (15,680)	3.58	5.36*
Outpatient appointments	54.8% (6,980)	56.4%* (9,890)	1.79	1.96*

* Significantly different from the pre-pandemic period at the 5% level.

Across the quality-of-care indicators covering the last three months of life, people who died from cancer during the pandemic had more medications prescribed for symptom management on average but the proportion of people with palliative care coded in their GP record declined (see Table 7). Higher prescribing in the community may be expected if people approaching the end of life who died from cancer spent more time in settings other than the home before the pandemic, such as hospitals, with different prescribing systems.

Table 7: Quality-of-care indicators over the three months before death for people who died at home from cancer pre-pandemic and during the pandemic

Quality-of-care indicators (last three months of life)	Proportion with event (n)	
	Pre-pandemic (N = 12,740)	Pandemic (N = 17,520)
One or more emergency admissions to hospital	58.8% (7,490)	57.2%* (10,020)
Three or more emergency admissions to hospital	7.1% (910)	6.3% (1,190)
One or more medications prescribed for symptom management by general practice	66.3% (8,450)	68.8%* (12,060)
One or more palliative care codes in GP record	63.0% (8,030)	60.6%* (10,610)

* Significantly different from the pre-pandemic period at 5% level.

People who died from circulatory diseases

Circulatory disease was the second most common cause of death for people who died at home, both before and during the pandemic. Overall, use of services was lower for this group when compared with people who died at home from cancer. However, more than 25% had outpatient appointments and more than 50% had general practice interactions in both periods (see Table 8).

Table 8: Service use in the last month of life for selected measures for people who died at home from circulatory diseases pre-pandemic and during the pandemic

Service type	Proportion with at least one event (n)		Average events per person	
	Pre-pandemic (N = 10,950)	Pandemic (N = 13,180)	Pre-pandemic (N = 10,950)	Pandemic (N = 13,180)
A&E visits	11.8% (1,290)	12.3% (1,620)	0.14	0.14
Community nursing team care	7.8% (850)	8.5% (1,120)	0.13	0.13
Elective admissions	3.0% (330)	2.0%* (260)	0.05	0.04*
General practice interactions	52.1% (5,710)	59.3%* (7,810)	1.69	2.39*
Outpatient appointments	28.9% (3,160)	26.3%* (3,460)	0.66	0.63*

* Significantly different from the pre-pandemic period at the 5% level.

Planned hospital care (elective inpatient and outpatient care) declined for this group during the pandemic but community and primary care (including general practice interactions, medications prescribed for symptom management and palliative care coding) were more common. This is reflected over three months in the quality-of-care indicators, with more people having medications prescribed for symptom management and palliative care coded in their GP record (see Table 9). However, the proportion of people with either medications prescribed or palliative care coded in the last three months of life was much lower in both the pre- and pandemic periods compared with those who died at home from cancer.

Table 9: Quality-of-care indicators over the last three months of life for people who died at home from circulatory diseases pre-pandemic and during the pandemic

Quality-of-care indicators (last three months of life)	Proportion with event (n)	
	Pre-pandemic (N = 10,950)	Pandemic (N = 13,180)
One or more emergency admissions to hospital	24.9% (2,730)	25.0% (3,300)
Three or more emergency admissions to hospital	2.1% (230)	1.9% (250)
One or more medications prescribed for symptom management by general practice	13.2% (1,440)	16.5%* (2,180)
One or more palliative care codes in GP record	12.7% (1,390)	14.8%* (1,950)

* Significantly different from the pre-pandemic period at the 5% level.

People who died from dementia and Alzheimer's disease

A greater proportion of people who died from dementia and Alzheimer's disease during the pandemic did so at home than prior to the pandemic and, as with cancer, they also represented a greater proportion of home deaths than previously. More than 70% of people who died at home from dementia and Alzheimer's disease pre-pandemic had general practice interactions in the last month of life and this increased to almost 90% during the pandemic (see Table 10). A&E visits in the last month of life were also more common during the pandemic for this group, although the increase did not translate into more emergency admissions. There was no difference over the last three months of life in the number of A&E visits, which suggests that the visits were concentrated closer to death in the pandemic.

Table 10: Service use in the last month of life for selected measures for people who died at home from dementia and Alzheimer's disease pre-pandemic and during the pandemic

Service type	Proportion with at least one event (n)		Average events per person	
	Pre-pandemic (N = 1,950)	Pandemic (N = 2,770)	Pre-pandemic (N = 1,950)	Pandemic (N = 2,770)
A&E visits	12.3% (240)	14.8%* (410)	0.14	0.16*
Community nursing team care	20.5% (400)	22.0% (610)	0.33	0.34
Elective admissions	0.5% (10)	0.4% (10)	0.00	0.00
General practice interactions	72.3% (1,410)	88.1%* (2,440)	2.85	4.50*
Outpatient appointments	16.4% (320)	14.8% (410)	0.49	0.46

* Significantly different from the pre-pandemic period at the 5% level.

Just under 60% of the group had medications prescribed for symptom management in the last three months of life both pre-pandemic and during it (see Table 11). The proportion of people with palliative care flagged in their record in the last three months of life declined during the pandemic, although due to the increase in deaths for this group, the overall number of people with palliative care flagged increased. A smaller proportion of people who died at home from dementia and Alzheimer's disease during the pandemic had either an emergency admission or multiple emergency admissions compared with before the pandemic.

Table 11: Quality-of-care indicators over the last three months of life for people who died at home from dementia and Alzheimer's disease pre-pandemic and during the pandemic

Quality-of-care indicators (last three months of life)	Proportion with event (n)	
	Pre-pandemic (N = 1,950)	Pandemic (N = 2,770)
One or more emergency admissions to hospital	35.9% (700)	32.9%* (910)
Three or more emergency admissions to hospital	3.1% (60)	2.2%* (60)
One or more medications prescribed for symptom management by general practice	59.0% (1,150)	58.8% (1,630)
One or more palliative care codes in GP record	53.3% (1,040)	49.5%* (1,370)

* Significantly different from the pre-pandemic period at the 5% level.

Our patient and public involvement group reflected that patients with dementia and Alzheimer's disease faced specific challenges during the pandemic, which may have affected their use of health services. They received less informal care, and the loss of this support may have led to increased A&E visits and GP contacts. Informal care comes from lots of places. Less contact with family during the pandemic may have led to health deteriorating, as family play an important role as advocates when they are on hand regularly to notice and report on changing symptoms. During the pandemic, services that charities and volunteers provided were also suspended, which may have led to increased demand on other NHS services. It was also noted that people with dementia and Alzheimer's disease and their families experienced challenges getting good-quality end-of-life care before the pandemic, which would have been further exacerbated during the pandemic.

Summary

People who died from cancer used the most services both before and during the pandemic. There were increases in general practice interactions for all causes of death, with cancer and dementia and Alzheimer's disease home deaths having the largest increases. People who died at home from circulatory

diseases had fewer elective admissions and outpatient appointments during the pandemic, which could mean they did not receive all the planned care they needed (for example, diagnostic tests). People who died at home from dementia and Alzheimer's disease had more A&E visits in the month before death during the pandemic than before it, which might suggest that they were not receiving the care they needed in the community and were therefore more reliant on urgent care.

The quality indicators painted a mixed picture of care. Under 37% of people who died at home had a record of palliative care in the last three months of life. People who died from cancer and dementia and Alzheimer's disease were less likely to have palliative care coded in their record during the pandemic than before it, while people who died from circulatory diseases were more likely to have it coded. Medications for symptom management were more commonly prescribed during the pandemic for each cause of death compared with the pre-pandemic period. There was little change in emergency admissions for most causes of death between the pre-pandemic period and the pandemic period; however, people who died at home from dementia and Alzheimer's disease were less likely to be admitted as an emergency during the pandemic.

4 Implications

How did service provision change for people who died at home during the pandemic compared with pre-pandemic?

In the first year of the pandemic, there was an increase in the number of deaths and a shift in where they occurred, with more occurring at home. Our analysis supports the hypothesis that the increase was driven primarily by deaths occurring at home for causes that would have typically been associated with deaths in another setting – in a hospital, care home or hospice. While specific drivers may have changed since the start of the pandemic, the proportion of people dying at home has remained well above pre-pandemic levels, pointing to long-term changes in demand for end-of-life care services.

The number of people requiring care at home has increased, and it is likely that the level of care that each patient requires will have increased as well, reflecting the higher levels of need observed in patients who died away from home before the pandemic.

The increased volume of activity for people who died at home during the pandemic will have added to the pressure the system was already under, as community services and primary care had to adapt to provide more care to people through routes that may have been used less frequently previously. For example, we found increased general practice prescribing of medications for symptom management: for many of these medications there may well have been significant related activities, such as advance care planning, communication with relatives, interactions with community nurses or other professionals and completion of drug administration documents. This potentially represents a significant amount of additional workload for general practice and community nursing teams. There are also reports that community nurses felt ill-prepared to manage the increased volume of palliative care needs in the community, because they felt isolated and services were stretched.⁶⁴ Changes in practices around prescribing also had implications

for relatives and carers, as pre-existing arrangements to support families to administer medications were extended in some cases.⁶⁵

We found some evidence of care spread more thinly for people who died at home. There were fewer elective admissions for people who died at home during the pandemic, likely due to elective care being scaled back in the early part of the pandemic.⁶⁶ For cancer patients, levels of elective care were maintained, but people who died from circulatory diseases had fewer elective admissions and outpatient appointments during the pandemic. People who died from circulatory diseases were also less likely than people who died from other causes to have palliative care coded in their record in the three months before death, both pre-pandemic and during it, which could indicate that they were not being identified as approaching the end of their life and that their care needs were being missed. It will be important to see if this trend has been sustained following the recovery of services, particularly in light of the ongoing strain in the elective care system.

We found that a greater proportion of people who died at home during the pandemic than before it had contact with the general practice team and that interactions per person increased. People who died from cancer or dementia and Alzheimer's disease had particularly large increases in general practice interactions. General practice teams had to adapt to provide care in different ways while meeting the needs of patients with more complex needs who were dying at home, as well as supporting clinically vulnerable patients.⁶⁷ For GPs, identifying people who were close to the end of life, and wanted to remain at home, was challenging.⁶⁸ While our measure of general practice interactions includes different kinds of activities and not just consultations (see Box 3), it nevertheless paints a picture of additional pressure during the pandemic.⁶⁹ However, from a patient perspective, it is not clear from this analysis that increased interactions necessarily equated to good-quality care. As the trend for a greater proportion of people dying at home continues, it is important that the necessary care in the community is available and that care providers feel equipped and supported to deliver this care. Further consideration is also needed of the care needs of people who have limited social support; third sector organisations can play a critical role for these people.

There were increased A&E visits among people who died at home during the pandemic, in contrast to falls in A&E attendances for the population as

a whole. This increase may highlight additional unmet need. However, the types of people dying at home also changed, and they may have had greater needs that required additional hospital support. The increase in A&E visits was greatest for people who died from dementia and Alzheimer's disease and there was an especially large increase in deaths at home among this group. It would be important to explore whether the needs of these individuals were met, whether increased support was required and whether in future the needs of people with dementia and Alzheimer's disease could be met via other routes.

Inequalities

Differences in service provision emerged during the pandemic but there were also many differences between groups that pre-dated the pandemic. Before the pandemic, people who died at home in the most deprived areas had more A&E visits and less contact with the other services compared with people who died at home in less deprived areas. They were also less likely to be prescribed medications for symptom management. The difference between people from the most and least deprived areas in relation to general practice interactions and outpatient appointments grew during the pandemic.

People who live in more deprived areas have been found to rely more on A&E for access to care.⁷⁰ Reasons for this include its proximity and a lack of knowledge about how to access other services, although people from deprived areas can also face barriers to accessing services in the community due to the systemic disadvantages they experience.⁷¹ While other studies have found that access to community-based support, such as district nursing, is similar across different area deprivation levels, we found that people from more deprived areas had fewer medications prescribed for symptom management and were less likely to have palliative care coded.⁷² It will be important to explore further whether people from more deprived areas are receiving the care they need in the community or using A&E to substitute for this.

We found differences between ethnic groups before the pandemic and also changes over time. However, changes in the recording of ethnic group complicate the interpretation of differences: a higher proportion of people had an ethnic group recorded in the pandemic than before it.

Quality of care before and during the pandemic

This analysis has focused on differences between people who died before the pandemic and those who died during it, in the services they used before they died. However, multiple studies over the past 10 years have established what good end-of-life care should look like, and gaps in the care received in many cases.^{73,74} We were not able to assess the quality of care at the individual level but we were able to compare four indicators that acted as proxies for quality of care between the two time periods and by cause of death.

The quality indicators painted a mixed picture of care. We found that under 37% of patients had palliative care recorded in their GP record in the last three months of life. Feedback from our patient and public involvement group highlighted the day-to-day challenges that people approaching the end of life and their families and carers face. Despite the breadth of evidence and research on providing end-of-life care, the stumbling block seems to be delivering tangible change.

Feedback from our patient and public involvement group suggests that there are longstanding challenges with end-of-life care, which were apparent before the pandemic and, if anything, exacerbated by it. Many of the key concerns that our patient and public involvement group representatives had about end-of-life care during the pandemic were similar to those among representatives with experience of death at home before the pandemic. People were worried about access to and use of medications towards the end of life (and particularly wanted clarity as to what medications were for, as well as support to use them), the quality of contact with health services, and the distinct needs of groups who experience disadvantage, such as patients with dementia or Alzheimer's disease.

Lessons for further analysis

In this research we were able to explore changes in service use during the pandemic for people who died at home. However, the data that we used only cover around 40% of the population and deaths in the period. Our analysis cohort for the pandemic period appears to be representative across a variety of characteristics such as age, sex, cause of death and place of death; however, there was lower representation from people in some areas of England such as London and the West Midlands due to the distribution of TPP practices. This is likely to have impacted the representativeness of our analysis across ethnic groups as these regions contain some of the most ethnically diverse populations in the country. While there are no published data on ethnicity and place of death for the equivalent time period, we can see from aggregated published data covering 2019–21 that people from black ethnic backgrounds may be underrepresented in our data – 1.5% of published home deaths in 2019–21 were among people from black ethnic backgrounds compared with 0.9% in the pre-pandemic cohort and 1.3% in the pandemic cohort in our analysis.⁷⁵

In order to examine changes to care during the pandemic, we had to restrict the period before death we analysed to a maximum of three months to ensure that service use among people who died during the pandemic actually occurred in the pandemic. End of life is often a more prolonged period than three months, however, and while we were able to capture activity over a year before death among the pre-pandemic cohort, it will be important to compare this to activity during the pandemic when sufficient data are available.

Through this research we tested working with a new linked dataset, which meant that data-quality problems and the current understanding of the data limited some aspects of our work. This meant that we could not explore changes in all the services that we had planned to – for example, ambulance incidents, referrals to hospices and out-of-hours care. It would be useful to explore these but it would also be beneficial to validate some of the measures that we did use, such as general practice interactions and community nursing team care. We were able to develop some quality-of-care indicators, but we were not able to explore more specific measures of the quality of care at an individual level.

We focused on describing trends and exploring changes by individual characteristics. Many of the characteristics are interrelated and to truly explore the changes that occurred in future research it will be important to adjust for other factors in these comparisons. We were also unable to explore some characteristics, such as household composition, due to needing to narrow the scope of the project.

Finally, it was difficult to unpick the effect of Covid-19 deaths. Of home deaths, 3% were attributed to Covid-19 but it is likely that deaths attributed to other causes were also as a result of Covid-19. This may have had an impact on some of the changes in service use seen during the pandemic period for certain conditions.

What needs to happen next?

This report has used linked data, combining data on primary care, hospital care and death registrations, to shed new light on the care that people who died at home during the pandemic received. It has also provided updated estimates of the amount of care that people approaching the end of life use.

Our findings highlight the significant health needs of people approaching the end of life, as well as evidence of significant unmet need, and inequalities in access to care. While there were some changes in services used at the individual level as a result of the pandemic, the broader message from our analysis is that resource use among this group of people increased, in relation to both primary and community services, and urgent hospital care. This is likely to have resulted in significant service pressure for community services, for example, in supplying equipment and support for the provision of end-of-life medication at home.

One challenge for improving the quality of end-of-life care is the lack of data available about key aspects of care. The quality of data on community services, including core services such as community nursing, is poor. While there is a huge amount of information captured within GP clinical systems, it can be difficult to extract and use this for understanding the quality of care. And data on the services that hospices provide – specialist end-of-life services for people in their own homes, and in hospital, as well as within hospice premises

– are also incomplete, and not routinely collected or linkable to other data sources.⁷⁶ Further efforts to develop service-use and quality-of-care measures using linked datasets need to be made to address these gaps in the data. Quality measures that could be explored include divergence between people's preferred and actual place of death, and the extent of advance care planning.

The significant level of service use among people approaching the end of life demonstrates that the health and care system as a whole, and individual integrated care boards, need to have robust plans for delivering end-of-life care. However, while integrated care boards now have a statutory duty to deliver end-of-life care,⁷⁷ few areas have clear plans to do this.⁷⁸ This is likely to mean missed opportunities for improving the quality of care for individuals, for addressing inequalities in health care and for improving the effectiveness and efficiency of the system as a whole.

The use of data linking primary, community and hospital care, and ideally social care, for those approaching the end of life at integrated care board level will be essential to understanding population needs and planning the additional resources required to deliver care at home. There is considerable variation in the configuration of services at a local level –for example, the balance of NHS and voluntary services provided, and the mix of specialist palliative care services and generalist services.⁷⁹ Improved use of data to understand the needs of the population has the potential to engage partners across the health system.

Our research has highlighted growing inequalities in service use between people living in the most deprived areas and those living in the least deprived areas, alongside variations between ethnic groups. Further analysis of inequalities in end-of-life care is needed, including through engaging patients, families and carers to understand how these arise and what action is needed to address them. Integrated care boards have a responsibility to ensure they are providing equitable access to palliative and end-of-life care services, and they have the opportunity to address this by working with community and voluntary sector providers, and primary care networks.

Finally, the number and proportion of people dying at home continues to be above pre-pandemic levels. It is essential that access to care at home and the quality of that care continue to be monitored to understand the ongoing implications for individuals, and their families and loved ones.

Information governance and ethical approval

NHS England is the data controller for OpenSAFELY-TPP; TPP is the data processor; all study authors using OpenSAFELY have the approval of NHS England. This implementation of OpenSAFELY is hosted within the TPP environment which is accredited to the ISO 27001 information security standard and is NHS IG Toolkit compliant.¹

Patient data has been pseudonymised for analysis and linkage using industry standard cryptographic hashing techniques; all pseudonymised datasets transmitted for linkage onto OpenSAFELY are encrypted; access to the platform is via a virtual private network (VPN) connection, restricted to a small group of researchers; the researchers hold contracts with NHS England and only access the platform to initiate database queries and statistical models; all database activity is logged; only aggregate statistical outputs leave the platform environment following best practice for anonymisation of results such as statistical disclosure control for low cell counts.²

The OpenSAFELY research platform adheres to the obligations of the UK General Data Protection Regulation (GDPR) and the Data Protection Act 2018. In March 2020, the Secretary of State for Health and Social Care used powers under the UK Health Service (Control of Patient Information) Regulations 2002 (COPI) to require organisations to process confidential patient information for the purposes of protecting public health, providing healthcare services to the public and monitoring and managing the COVID-19 outbreak and incidents of exposure; this sets aside the requirement for patient consent.³ This was extended in July 2022 for the NHS England OpenSAFELY COVID-19 research platform.⁴ In some cases of data sharing, the common law duty of confidence is met using, for example, patient consent or support from the Health Research Authority Confidentiality Advisory Group.⁵

Taken together, these provide the legal bases to link patient datasets on the OpenSAFELY platform. GP practices, from which the primary care data are obtained, are required to share relevant health information to support the public

health response to the pandemic, and have been informed of the OpenSAFELY analytics platform.

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OpenSAFELY study authors are:

Alex J Walker (University of Oxford), Brian MacKenna (University of Oxford), Peter Inglesby (University of Oxford), Ben Goldacre (University of Oxford), Helen J Curtis (University of Oxford), Caroline E Morton (University of Oxford), Jessica Morley (University of Oxford), Amir Mehrkar (University of Oxford), Sebastian CJ Bacon (University of Oxford), George Hickman (University of Oxford), Richard Croker (University of Oxford), David Evans (University of Oxford), Tom Ward (University of Oxford), Nicholas J DeVito (University of Oxford), Louis Fisher (University of Oxford), Amelia CA Green (University of Oxford), Jon Massey (University of Oxford), Rebecca M Smith (University of Oxford), William J Hulme (University of Oxford), Simon Davy (University of Oxford), Colm D Andrews (University of Oxford), Lisa EM Hopcroft (University of Oxford), Henry Drysdale (University of Oxford), Iain Dillingham (University of Oxford), Robin Y Park (University of Oxford), Rose Higgins (University of Oxford), Christine Cunningham (University of Oxford), Milan Wiedemann (University of Oxford), Linda Nab (University of Oxford), Steven Maude (University of Oxford), Orla Macdonald (Oxford Health NHS FT), Ben FC Butler-Cole (University of Oxford), Thomas O'Dwyer (University of Oxford), Catherine L Stables (University of Oxford), Christopher Wood (University of Oxford), Victoria Speed (University of Oxford), Lucy Bridges (University of Oxford), Andrea L Schaffer (University of Oxford), Caroline E Walters (University of Oxford), Andrew D Brown (University of Oxford), Christopher T Rentsch (London School of Hygiene and Tropical Medicine), Krishnan Bhaskaran (London School of Hygiene and Tropical Medicine), Anna Schultze (London School of Hygiene and Tropical Medicine), Elizabeth J Williamson (London School of Hygiene and Tropical Medicine), Helen I McDonald (London School of Hygiene and Tropical Medicine), Laurie A Tomlinson (London School of Hygiene and Tropical Medicine), Rohini Mathur (London School of Hygiene and Tropical Medicine), Rosalind M Eggo (London School of Hygiene and Tropical Medicine), Kevin Wing (London School of Hygiene and Tropical Medicine), Angel YS Wong (London School of Hygiene and Tropical Medicine), John Tazare (London School of Hygiene and Tropical Medicine), Richard Grieve (London School of Hygiene and Tropical Medicine), Daniel J Grint

(London School of Hygiene and Tropical Medicine), Sinead Langan (London School of Hygiene and Tropical Medicine), Kathryn E Mansfield (London School of Hygiene and Tropical Medicine), Ian J Douglas (London School of Hygiene and Tropical Medicine), Stephen JW Evans (London School of Hygiene and Tropical Medicine), Liam Smeeth (London School of Hygiene and Tropical Medicine), Jemma L Walker (London School of Hygiene and Tropical Medicine), Viyaasan Mahalingasivam (London School of Hygiene and Tropical Medicine), Harriet Forbes (University of Bristol), Thomas E Cowling (London School of Hygiene and Tropical Medicine), Emily L Herrett (London School of Hygiene and Tropical Medicine), Ruth E Costello (London School of Hygiene and Tropical Medicine), Bang Zheng (London School of Hygiene and Tropical Medicine), Edward P K Parker (London School of Hygiene and Tropical Medicine), Christopher Bates (TPP), Jonathan Cockburn (TPP), John Parry (TPP), Frank Hester (TPP), Sam Harper (TPP).

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59 New Cavendish Street

London W1G 7LP

Telephone: 020 7631 8450

www.nuffieldtrust.org.uk

Email: info@nuffieldtrust.org.uk

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