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Better End of Life 2022

Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers

Research Report

> *"You are guaranteed a better death if you die between 9am and 5pm Monday to Friday, so I've asked my mum if this would be possible… just because you would have access to the people you need."*
>
> **Better End of Life workshop participant (informal carer)**

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Executive summary

Key research findings

We found that out-of-hours emergency department attendance increases in frequency as death approaches, and is more common among people living in the most socioeconomically deprived areas; that although all areas have access to telephone lines for general NHS services out-of-hours (e.g. NHS 111 in England and Wales), not all areas have a designated telephone line for out-of-hours palliative care support; that access to medicines out-of-hours can be complicated and time consuming; that there are gaps between what is theoretically in place and what is actually experienced by patients and informal carers; that equipment is hard to access; that care packages are often delayed or unavailable; and that much out-of-hours care relies on stretched community nursing services.

For those living at home with advanced illness, deterioration in health can happen at any time of the day or night. Severe symptoms, sudden changes, or new problems may occur unexpectedly. Individuals and their informal carers – whether family or friends – may need to cope with all manner of crises and changes, large or small.

At all times, people with advanced illness and their informal carers need integrated, seamless, and high-quality care that is accessible, effective, competent, safe, and supportive. Care also needs to be rapidly and reliably available; this is particularly crucial in the out-of-hours period. The out-of-hours period covers the time outside of Monday to Friday, 9am to 5pm. This out-of-hours period accounts for over 75% of the time in every week.

For people living with advanced illness, care during the out-of-hours period is provided by a number of different health and care professionals; both those who provide general health and care (such as general practitioners, and district nurses or community nursing teams) and those who specialise in palliative and end of life care. This report considers both general and specialist care, and how they work together.

In this report, we deliver **new and timely evidence on out-of-hours care**, derived from (1) UK data on out-of-hours emergency department attendance among people who are in the last year of life, (2) interviews with health professionals about out-of-hours services across the UK, and (3) a patient and public involvement (PPI) workshop (see 'The people's perspectives' for more information). We address major questions about out-of-hours care in the community for people approaching the end of their lives, and their informal carers:

- We know that when care in the community **is not available**, potentially avoidable emergency department attendances (and subsequent hospital admissions) may occur. We therefore asked: **what are the patterns of emergency department attendance out-of-hours across the UK among people in their last year of life, including any socio-economic inequalities?**
- We know that when care in the community **is available**, provision may vary and gaps in care may exist. **We therefore asked: what are the patterns in the provision of out-of-hours care for people living with advanced illnesses across the UK, and where are the gaps?**

Our research uncovered considerable variation and gaps in out-of-hours care across the UK. Our patient, carer and public partners in this research project provide illuminating insights into why these gaps matter, and what these findings mean. Throughout the report, we also highlight approaches or innovations that have been adopted to address these issues.

Our research highlights that in the UK, we are not currently delivering high quality out-of-hours care at home for all who need it, despite some examples of excellent practice. We need to plan for the known future increase in palliative care needs, and address current challenges, so that the right community-based care is available at the right time, for everyone who needs it. This is imperative, not only for the individuals concerned and the people caring for them, but also to reduce strain on emergency departments and acute hospital beds, which often become the default place for care when support and care at home are not rapidly and reliably available.

As one of those interviewed said: "Out-of-hours care is a good barometer for in-hours care. Proactive planning will never be able to manage everything, but a robust and accessible out-of-hours service should be a marker of good quality service provision."

Recommendations

Effective, responsive, and timely out-of-hours care improves the wellbeing of patients and families, and helps prevent emergency hospital admissions. Despite this, we found considerable gaps between the out-of-hours care available in theory and that delivered in practice. To address this, we recommend:

1. Out-of-hours palliative and end of life care is currently inadequate and fragmented, and must be better valued, prioritised and strengthened. Services must be developed and provided equitably, irrespective of diagnosis, socio-demographic characteristics (e.g. age, ethnicity) and geographical area.

2. Service development and planning must be actively informed by the voices of patients and informal carers; collaboration with patients and informal carers should be used to drive improvements in out-of-hours care, shape service development and help identify potential solutions for gaps in care.

3. Integrated Care Systems, Health Boards and NHS Trusts, Integration Joint Boards and NHS Health Boards, and Health and Social Care (HSC) Trusts across the UK need to strategically develop, enable and support greater integration and coordination of out-of-hours services.

4. District nurses and community nursing teams play an extensive role in providing hands-on out-of-hours care, but huge pressures on this workforce limit the care they can provide; improved workforce planning, provision, and support for community providers of out-of-hours palliative and end of life care is essential.

5. A designated telephone line for people with palliative and end of life care needs and their informal carers should be available 24/7, in every part of the UK.

6. Availability and use of shared care records should be audited regularly to overcome the challenges identified in using, sharing and implementing these records across the UK. Such records should be based on timely conversations about needs, wishes and preferences for care at the end of life, and include the availability of anticipatory medicines (if appropriate).

7. The questionnaire provided in this report can be used by those with commissioning responsibilities to understand and address gaps in out-of-hours service provision and identify priorities for improvement.

8. Research into out-of-hours care is essential for future service development and needs continued funding.

Contents

What do we already know?

Palliative care refers to physical, psychological, social, and spiritual support for people with advanced life-threatening illness, that focuses on relief of persistent symptoms, optimising quality of life, and support for informal carers (whether family or friends)[1]. Palliative and end of life care is provided in every setting, including hospital and home, by a range of professionals including GPs, district nurses and community nursing teams, care professionals and specialists in palliative care. Although preferences vary among individuals and across different types of illness, many people wish to be cared for and die at home, provided that they and their informal carers can access appropriate care and support there[2, 3].

The number of people who need palliative and end of life care is increasing, across all four nations of the United Kingdom (UK)[4-6]. Without a corresponding increase in palliative and end of life care at home, then by default, hospital admissions and hospital deaths will increase[4, 7]. Community palliative and end of life services are already under severe pressure, following the sustained increase in deaths at home during the COVID-19 pandemic[8, 9]. Access to, and availability of, good quality palliative and end of life care at home varies widely by geographical location[10, 11].

Care provided 'out-of-hours' is a key part of home-based care and has been identified as a priority for research by patients, family and other caregivers, and policymakers[12]. Safety issues in out-of-hours care have also been identified, including difficulties with timely access to care[13]. In the UK, most home-based health and care is provided between 9am and 5pm, Monday to Friday. But over three-quarters of each week (evenings, weekends, and bank holidays) occurs outside of these hours, when help may not be as readily available.

Out-of-hours palliative and end of life care is provided by a number of different health and care professionals[13]. These include primary and community care providers (such as general practitioners and district nurses or community nursing teams) and providers who specialise in palliative and end of life care[14-16].

Contact with services during the out-of-hours period is frequent for those with palliative and end of life care needs, with just under a third of patients contacting services in the last few days of life and many needing out-of-hours support during the last 12 months of life[17, 18]. Out-of-hours, there is a higher risk that professionals may be unfamiliar with the patient's medical history, because they have not seen the person before or because they do not have access to their clinical records[13].

This evidence emphasises important challenges, including how to ensure integrated, seamless, and continuous care which is high quality (i.e., accessible, effective, competent, safe, and supportive of patients and their informal carers at all times), yet also rapidly and reliably available.

What is the current UK context?

Health and social care systems in the UK are facing a time of unprecedented pressure, as they struggle to recover from the COVID-19 pandemic[19-21]. Inequalities in healthcare have been starkly exacerbated by the pandemic[22-24], and most services are currently undergoing a major 're-set'. There is a growing drive across the UK for integrated and comprehensive palliative and end of life care to be accessible and available at home twenty-four hours a day, seven days a week, to all who need it[25-30]. In England, there is a new requirement within the Health and Care Act (2022) for specialist palliative care services to be provided in all settings. There has been a call for transformation of community-based provision in palliative and end of life care in Wales[31]. In Scotland, there are new partnership working initiatives, such as the Highland Hospice's End of Life Care Together project[32]. And in Northern Ireland, a recent report highlights the need for increased awareness around access to end of life care and support[33].

Across the UK, health and care services are organised differently. All parts of England are – from July 2022 – served by an Integrated Care System (ICS), bringing together health and social care partners, with the aim of improving the coordination of services, and replacing the previous system of Clinical Commissioning Groups (CCGs). In Wales, NHS services are delivered through seven Health Boards and three NHS Trusts. Regional Partnership Boards have been introduced to bring together Health Boards, local authorities and third sector providers to promote models of integrated health and social care. A recent review of specialist palliative care services[34] outlines the progress made since the 2008 recommendations from the Palliative Care Planning Review, commissioned by Welsh Assembly Government (i.e. the 'Sugar Report'). In Wales, as elsewhere, there has been a major increase in demand for, and provision of, palliative care for those with non-cancer illnesses and workforce challenges remain a major obstacle[34]. In Scotland, community health services and social care have been integrated since 2016, but care coordination remains challenging[35] and the transition towards the National Care Service for Scotland is yet to be navigated. Northern Ireland has had integrated health and social care since 1973, with five fully integrated Health and Social Care Trusts in operation which encompass primary, secondary and community care[36]. However, as throughout the UK, constraints on workforce availability and skills are persistent and increasing.

Across the UK, much palliative and end of life care at home is provided by primary and community services, that is, general practitioners, and district nurses and community nursing teams, with support from allied health and social care practitioners. Specialist palliative care services add to the provision of palliative and end of life care, usually seeing people with more complex needs, and working collaboratively with primary and community services to help deliver palliative and end of life care. The 2019 EAPC Atlas of Palliative Care in Europe estimated that there are around 860 specialist palliative and end of life care services for adults in the UK (including home palliative care teams, inpatient hospices, and hospital palliative care support teams)[37].

What research did we undertake?

In order to better understand out-of-hours care for people with advanced illness and their informal carers, and make recommendations to improve out-of-hours care, we undertook:

1. Analysis of data on out-of-hours emergency department attendances during the last year of life for people who died in 2020 in England, Wales, Scotland and Northern Ireland.

2. Interviews with health care professionals with commissioning or leadership responsibilities for, or detailed knowledge about, out-of-hours palliative and end of life care, from across the UK.

Part 1: Out-of-hours emergency department attendance across the UK

Our approach

For those with advanced illness, deteriorations are not always predictable. Severe symptoms, sudden changes, new problems, and therefore the need for extra care and support, may occur or increase at any time; this often occurs out-of-hours. Without access to community services, this can lead to potentially avoidable emergency hospital admissions; hospitals being the one setting where care is readily available 24/7[38].

To explore patterns in out-of-hours emergency hospital use, we used mortality data linked to hospital episodes data to report the rate of emergency department attendance in the last 12 months of life. We used data on all deaths in England, Wales, Scotland and Northern Ireland in 2020, and data on emergency department visits in 2019 and 2020 (to ensure a whole 'year before death' could be examined). For the purposes of this analysis, the out-of-hours period was defined more conservatively as after 6pm and before 8am, weekends and bank holidays. We were interested in understanding how rates of emergency department attendance change during the last 12 months of life, and whether there are differences by area-based level of deprivation or by geographical area. For further details of methods, see Appendix.

What we found

We examined data on 570,416 people who died in England, 17,375 people who died in Northern Ireland, 37,166 people who died in Wales and 64,088 people who died in Scotland. We identified 1,132,033 (England), 41,936 (Northern Ireland), 56,039 (Wales) and 138,457 (Scotland) emergency department attendances (both in-hours and out-of-hours) that occurred during the last 12 months of life. We found that patterns of emergency department attendance in the last year of life are similar across the UK (Figure 1). Rates of emergency department attendance are relatively low and stable for most of the final year of life, but increase rapidly during the final three months of life, with out-of-hours visits increasing more than in-hours visits, especially in the last month of life (Figure 1).

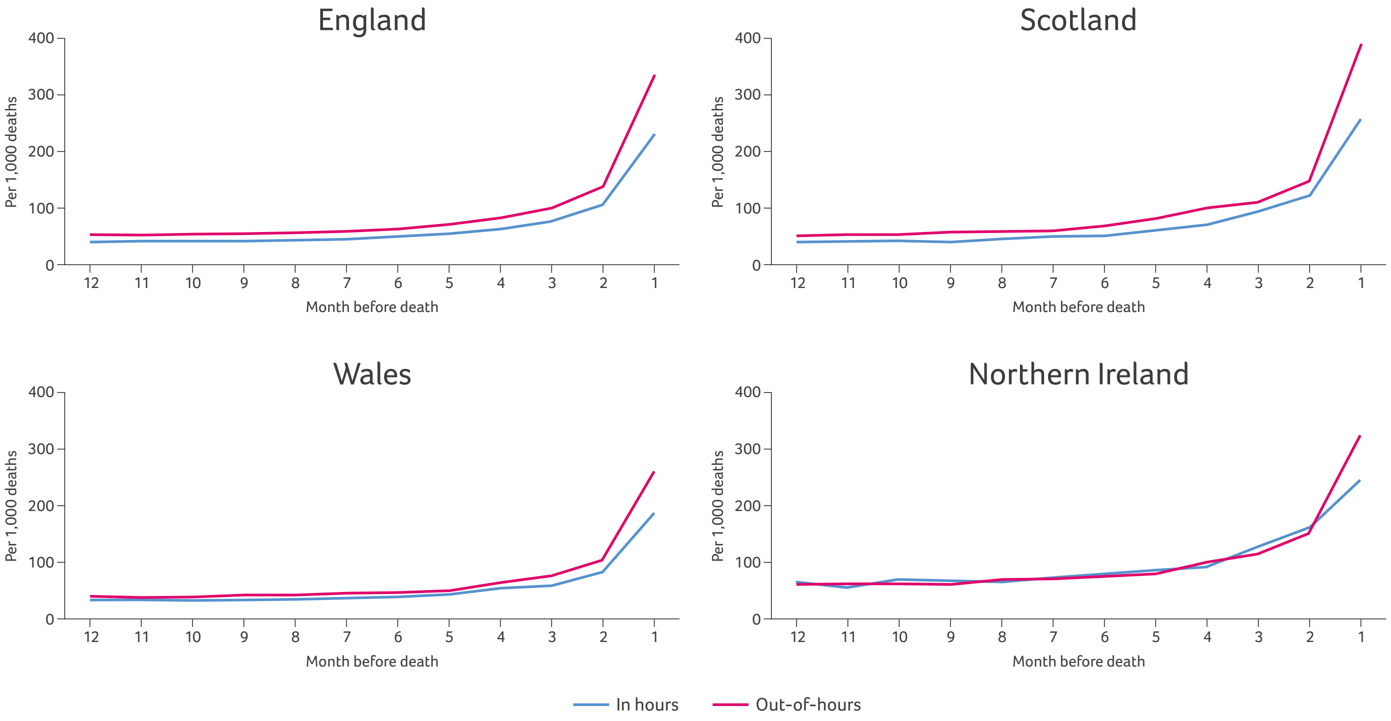


Figure 1: Rate per 1,000 deaths in 2020 of in-hours and out-of-hours Emergency Department attendance in the last 12 months of life, in England, Scotland, Wales and Northern Ireland

Socioeconomic inequalities in palliative and end of life care are well described[39]. We wanted to know if there are socioeconomic differences in out-of-hours emergency department attendance in the last year of life. We found that, for people who died in 2020, out-of-hours emergency department attendance during the last year of life was higher among people living in the more deprived areas compared to people living in the less deprived areas (Figure 2). This social gradient was present across the UK, and for both women and men; it was most consistent in England, and steepest in Scotland. We found a very high rate of emergency department attendance among men aged under 65 living in deprived areas in Scotland, which requires further exploration. In Northern Ireland, and for men in Wales, the pattern was less clear.

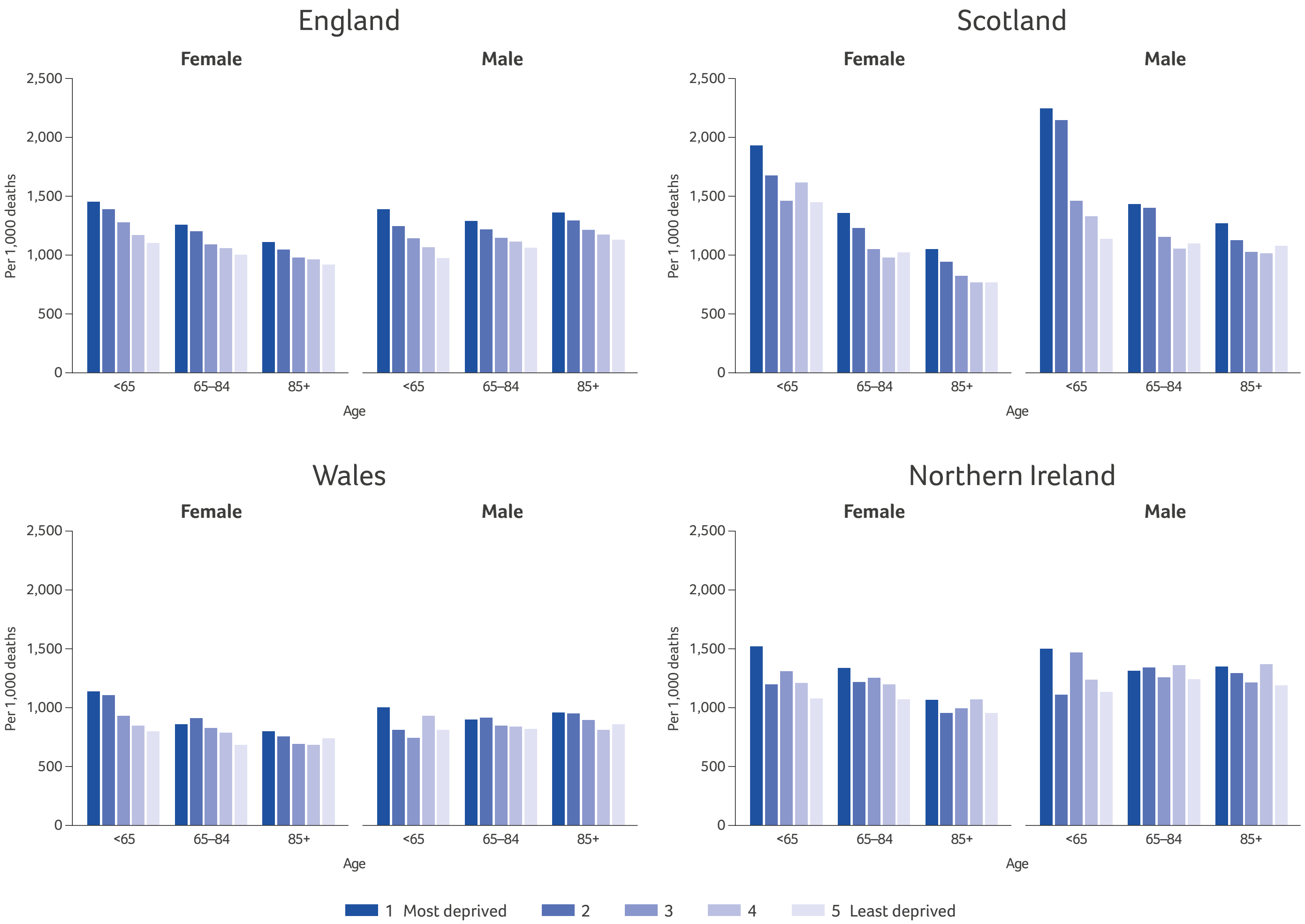
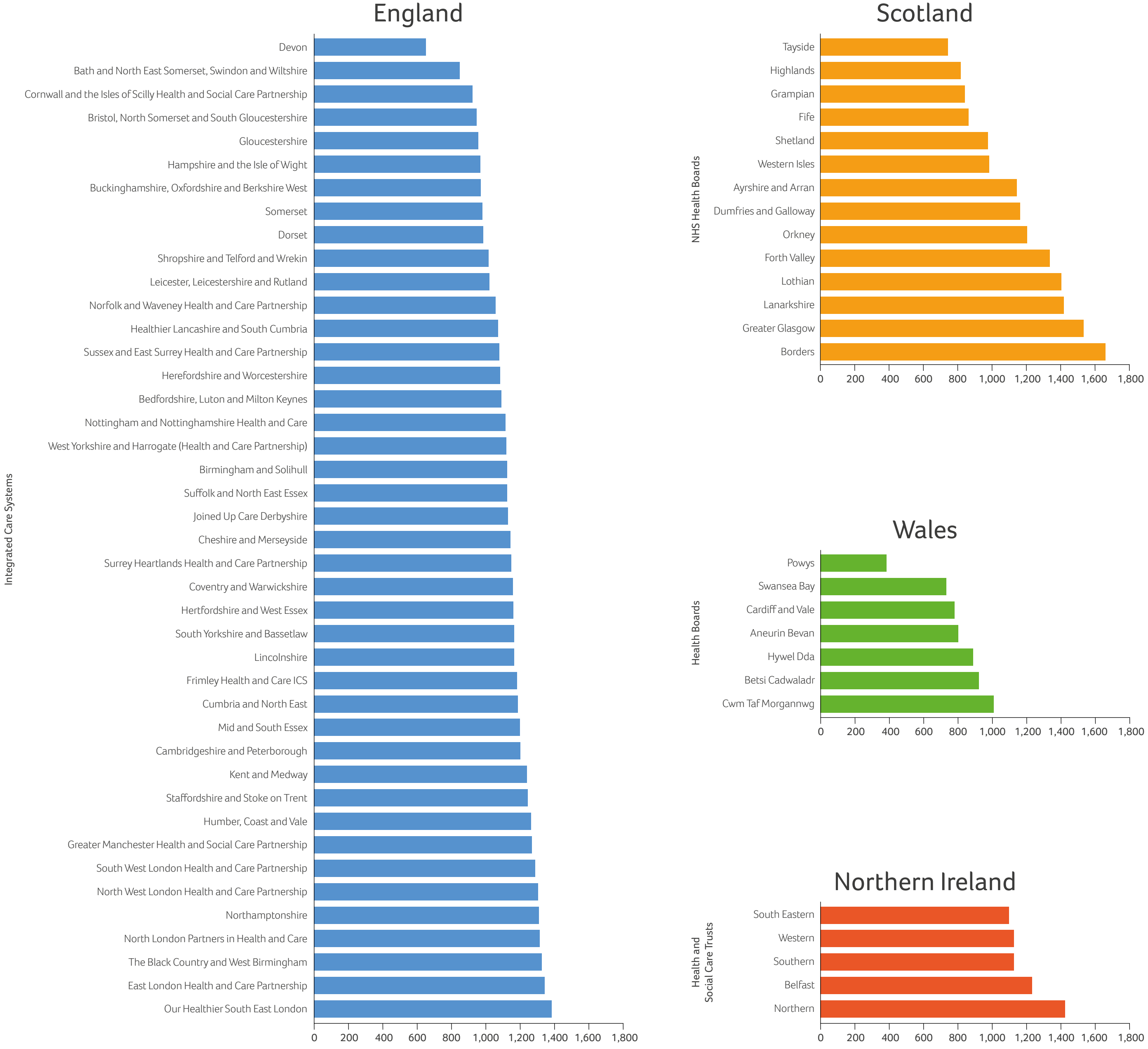


Figure 2: Rate per 1,000 deaths in 2020 of out-of-hours Emergency Department attendance for people in the last 12 months of life, by age, sex and deprivation quintile

Last, we were interested in exploring variation in emergency department attendance by geographical area. We found that rates of emergency department attendance in the last year of life vary widely across the UK (Figure 3). In England, the rates of emergency department attendance were highest in urban areas; for example, the five London Integrated Care System geographies were all in the top ten areas by rates of emergency department attendance. There was similar variation across Northern Ireland, Scotland and Wales. The lowest rate of emergency department attendance was found in Powys in Wales, which may reflect that people in Powys use acute hospital services in England which are not captured in the data.

Figure 3: Rate per 1,000 deaths in 2020 of out-of-hours Emergency Department (ED) attendance for people in the last 12 months of life, by geographical area



* All x-axes show age and sex standardised rate of out-of-hours ED visits in the last 12 months of life, per 1,000 deaths, shown by country and by health geography

Part 2: Provision of out-of-hours care across the UK

Our approach

To understand what palliative and end of life care is provided out-of-hours at home, we undertook interviews with professionals from across the UK with commissioning or leadership responsibilities for, or detailed knowledge about, out-of-hours palliative and end of life care in their local area. The interviews were not intended to provide full information on out-of-hours care in each area (which is beyond the scope of this project), but to provide high-level insights into what is provided and to identify where variations or gaps might exist.

The interviews were conducted between 21st December 2021 and 1st June 2022. We approached potential participants through a range of different networks across the UK. We purposively sampled to ensure England, Wales, Scotland and Northern Ireland were represented, and to include as many areas within each nation as possible.

We asked about aspects of out-of-hours care that had previously been identified as important by patients, families and friends, public representatives, and professionals in a Marie Curie funded Delphi study conducted by the Cicely Saunders Institute, King's College London[40]. These were:

- provision of telephone advice to patients and families/friends at night and weekends
- access to and administration of palliative medicines at night and weekends
- crisis management at night and weekends
- care in the last few days of life, including care during the day and through the night
- continuity of care and support for health and care professionals at night and weekends.

In telephone or video interviews, we used a combination of structured closed questions (with answers: yes, partial, no, unknown, and not applicable where relevant) and open questions, based on these topics (full details of interview questionnaire in Appendix). 'Partial' refers to a service or provision that is available but where respondents report provision being limited, such as by geography (partially covering the area under discussion), time (a service partially available during out-of-hours), or other factors (for example, unfilled posts or reduced workforce). The interviews were recorded and transcribed. We used respondent checking to improve accuracy and check detail.

Closed questions are reported using numbers and percentages. Open questions are analysed thematically, with illustrative quotes provided in this report. Although the majority of those interviewed reported on a single area, a few reported on more than one area (up to five). For clarity and to ensure the report is as useful as possible, we report throughout by area, rather than by respondent. For a few areas, we had data from more than one respondent. Where this occurred, we amalgamated respondent reports and – for the very infrequent episodes of divergence after respondent checking – opted for the more conservative response (i.e., a 'partial' answer rather than 'yes'). Formal ethical approval was received from Hull York Medical School Ethics Committee (reference 21/22 7) on 19th November 2021.

Who did we interview?

We completed 71 structured interviews in total, relating to 60 different areas across the UK (25 of 42 ICSs and 45 of 106 CCG areas) in England, 4 of 7 Health Boards in Wales, 6 of 14 NHS Health Boards in Scotland, and all 5 Health and Social Care Trusts in Northern Ireland, see Figure 4). Based on mid-2020 population estimates, the population size for these areas varies; from an average of 658,296 people (minimum 114,496, maximum 2,111,469) in England[41]; 549,250 people (minimum 390,949 to maximum 703,361) in Wales[42]; 311,297 people (minimum 22,400 to maximum 585,550) in Scotland[43]; and 379,102 people (minimum 303,207 to maximum 480,194) in Northern Ireland[44].

Of those interviewed, 27 were strategic/clinical leads or managers of service(s), 21 were commissioners of services, 36 were senior clinicians within services, and 3 had a specific service development role (16 had more than one role). Their average years of experience was 19.3 years (range 3 – 40 years). All had responsibility for provision, leading, commissioning, developing, or providing strategic oversight of out-of-hours services.

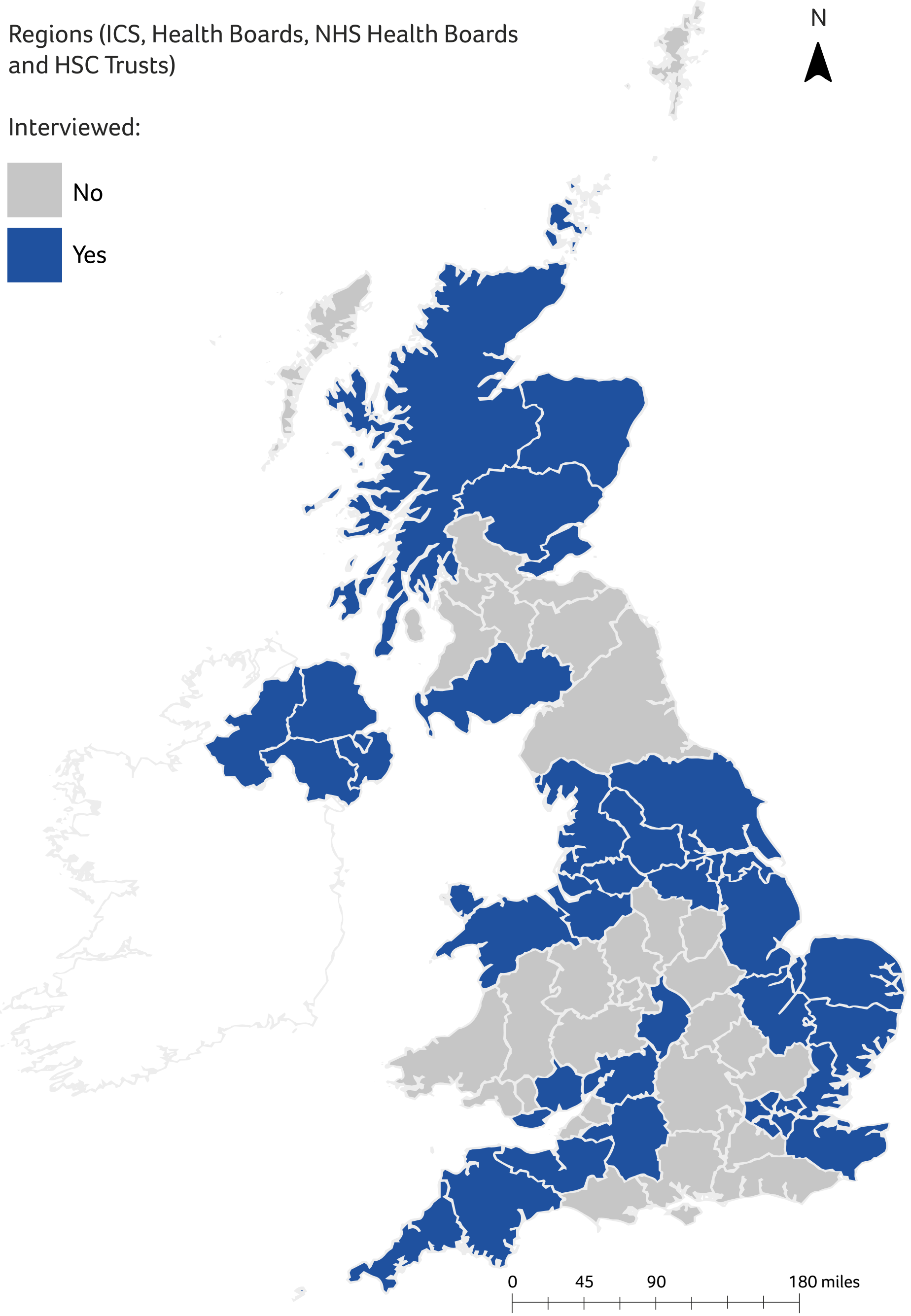


Figure 4: Map illustrating the 60 areas included within the interviews

Based on discussion with our Public and Patient Involvement (PPI) group, and the previous Delphi survey[40], we report our findings according to the following topics:

- How do patients and their informal carers (whether family or friends) get help out-of-hours?
- Who sees the patient out-of-hours, especially if they need a medicine prescribed or administered?
- Can patients and informal carers access care and equipment out-of-hours?
- Can patients and informal carers access specialist palliative care out-of-hours, if needed?
- Do services work together out-of-hours?

How do patients and their informal carers get help out-of-hours?

For everyone across the UK, a phone number is available that should enable contact with local NHS services, such as general practitioners and district nurses out-of-hours. This includes the NHS 111 service for England and Wales, NHS 24 for Scotland, and the GP out-of-hours service for Northern Ireland. However, for people with palliative and end of life care needs, the National Institute for Health and Care Excellence recommends that a designated telephone line should be available 24/7[25, 45, 46]. We therefore asked whether there was a designated telephone line for patients with palliative and end of life care needs and their informal carers, available out-of-hours. In 27% of the 60 areas surveyed, a designated phone line was not available, while in a further 42% of areas this was available but covered only part of the out-of-hours period (such as evenings or weekend daytime) or was limited in other ways (available for only part of the area or constrained by workforce challenges) (Figure 5). Where a designated phone line was available, the telephone responder was usually clinically trained, and the responder had some access to clinical information about the person concerned.

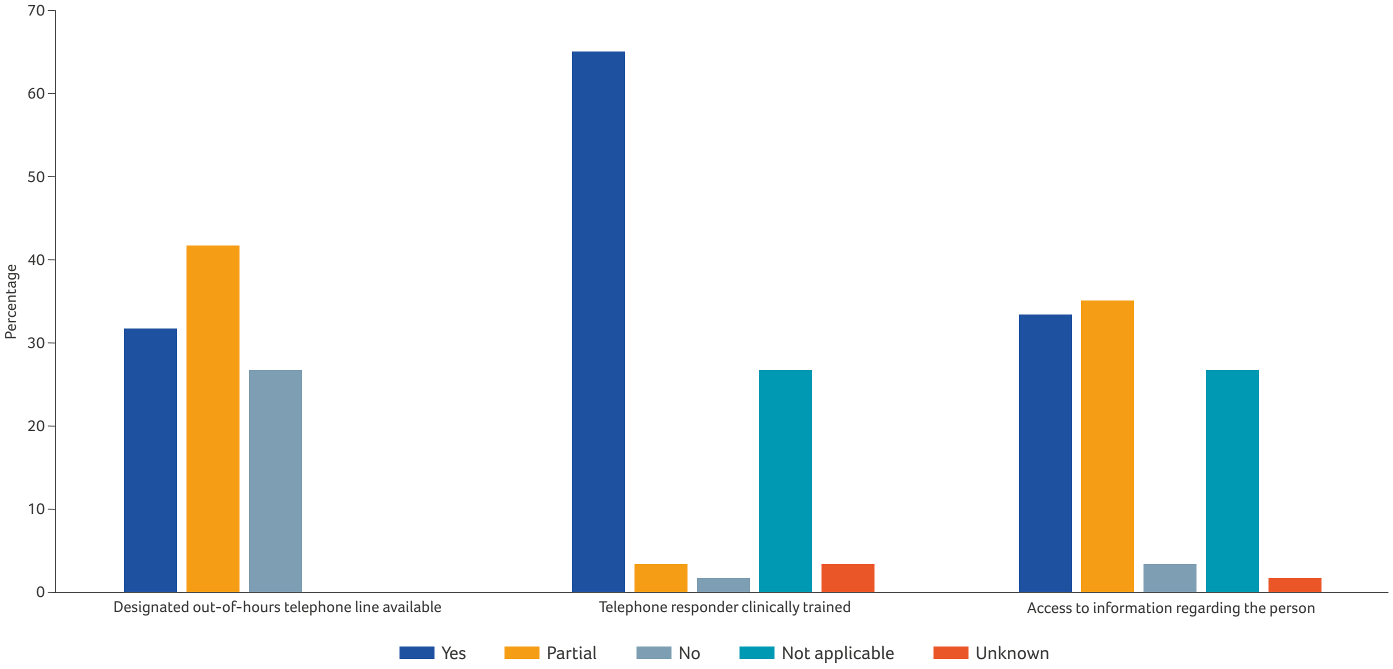


Figure 5: Provision of out-of-hours designated telephone services, in the 60 UK areas surveyed

For out-of-hours care and support, a designated phone line is considered crucial – as one interviewee said: “When there isn’t a single point of access, it is overwhelming knowing who to call and when”. A further respondent felt the designated phone service to be “one of the most valuable services” they offered. Those who replied ‘no’ to this question reported reliance on GP out-of-hours services. However, this more general service was often complicated for patients and informal carers to use to negotiate the right help; prolonged telephone waiting or processing times were often reported.

Examples of innovation

In Fife, Scotland, since the introduction of the Palliative Care Support Line and the redeployment of staff and resources from the hospice units into the community, they have seen a dramatic increase in the proportion of people dying at home. There has also been a decrease in the demand for a hospice-based care as there is now additional support in the community.

In Cheshire and Merseyside, England, there are dedicated telephone lines available to patients and families with palliative and end of life care needs across the ICS, operating 24 hours a day. This is a new service that was implemented in 2021 and has now been picked up by the CCG in terms of funding. Patients and families/friends can access any kind of support as it is a triage system. The team may be able to send people out if needed (e.g., district nurses or clinical nurse specialists) or they can provide advice over the phone.

In some areas, a designated telephone line was only available to patients already known to palliative care services, and this was problematic. One respondent highlighted that “For palliative and end of life care advice out-of-hours you need to have been referred to the service, otherwise you will not be able to access this advice. […] The difficulty [arises] if you are not actively on the [palliative care] team’s books.” Early recognition of palliative care needs, and consequent referral to specialist palliative care services, is required to access this service, but it does not always occur. This is a theme which recurred throughout the interviews.

For those who do provide a designated telephone line, the quality of help provided may depend on access to existing health records, especially when patients live alone or have no family or friends to support or advocate. Health records are especially important for recording a person’s needs, wishes and preferences for their own care at the end of life. There have been substantial advances in improving access to shared health records over recent years; about two thirds of areas reported partial or complete access to clinical information about the person needing help. This was either through access to the GP record, a summary record, or an electronic palliative care coordination record. However, several of those interviewed reported on-going challenges with implementing shared electronic records or systems; and quite frequently, access to the shared record required – again – that the patient was already referred to specialist palliative care services.

Who sees the patient if they need a medicine to be prescribed or administered out-of-hours?

We asked about visits to prescribe or administer medicines out-of-hours and found a complicated picture. In all areas, patients can – technically – get a prescriber visit out-of-hours, if needed. This is either an out-of-hours GP or nurse prescriber, via the NHS 111 service or equivalent. However, the interview comments show that, while this is universally available in theory in all of the areas surveyed, delivery of this service is often challenging in practice. Interviewees spoke of long waiting times of several hours for visits to review, prescribe or administer medicines, according to workforce, capacity, rurality, and models of care. Ensuring that visits are provided when needed was reported as very challenging in more rural areas, such that it is just not practically possible at times. Difficulties especially occur where there is a large geographical coverage by a single out-of-hours service; there may simply not be enough staff, or travel time for visits may not be feasible when busy.

We found that there is almost always a pharmacy open at weekends and bank holidays that can dispense palliative medicines, although it was less common for pharmacies to be open through the night (Figure 6). Home delivery of medication – while available sometimes at weekends in cities (but less so rural areas) – was generally not available at night. The biggest challenges with pharmacy and medicines access were reported in rural or remote areas, where families or friends often have to travel considerable distances to collect any new prescription.

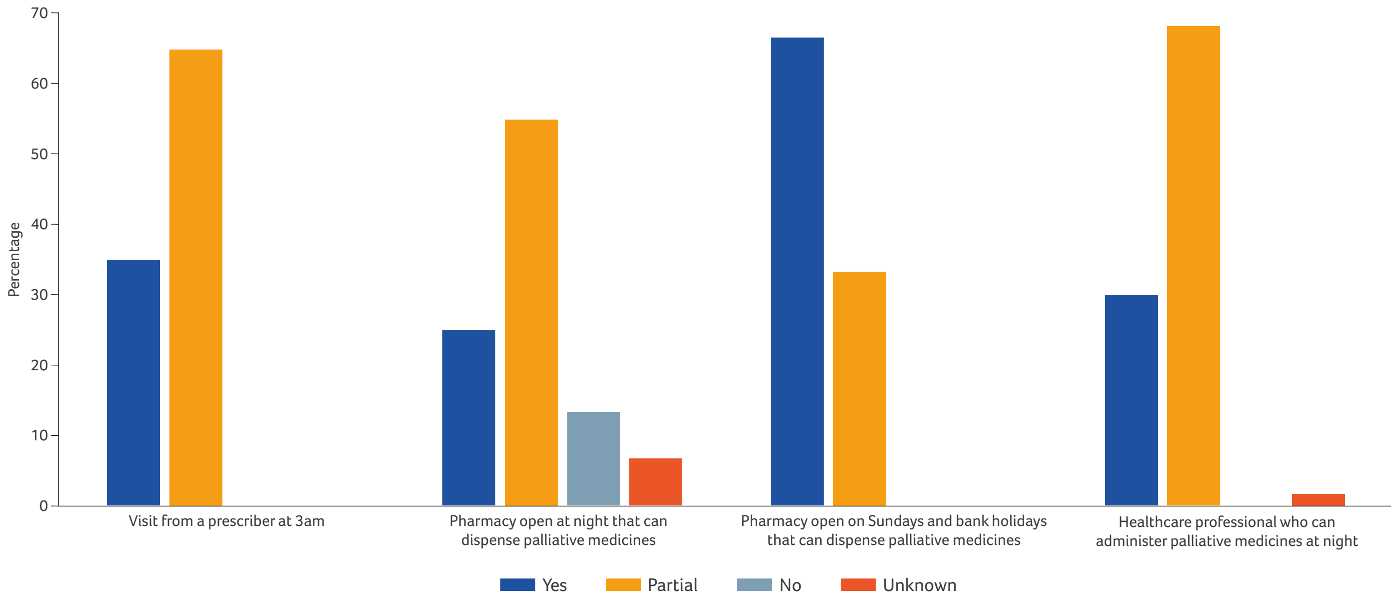


Figure 6: Responses about out-of-hours prescribing and administering of medicines, in the 60 UK areas surveyed

Many respondents also made detailed reference to the importance of anticipatory prescribing – that is, planning ahead to ensure appropriate medicines are already prescribed, collected, and in the house, well in advance of any possible need. Anticipatory prescribing was also reported as being highly dependent on the early recognition of palliative care needs. This is another example of how early recognition of palliative and end of life care needs and comprehensive advance care planning conversations are critically important for the effective delivery of out-of-hours care.

One respondent reported "The only pharmacy available is open until 11pm but they may not stock the medications needed, that is why it is necessary to pre-empt what is needed". They went on to report that "when the people are known to the [palliative care] service, this scenario [needing a new prescription at night] is uncommon, [so it is] unlikely that they would need to attend a pharmacy at that time of night. It is more when people are not known to the service, which seems to have happened more during COVID." Another explained: "[We] have noticed that during the pandemic, people at end of life are being identified much later, which has a knock-on effect with other factors like [anticipatory medicines and] being referred to the district nurses".

There is almost always – at least in principle – a healthcare professional who can visit the patient's home at night to administer palliative medicines (e.g., injectable medicines for symptom control) if needed. However, in many areas, this was reported as available in theory but that there were many difficulties in delivering this in practice. Many of those interviewed reported a heavy reliance on district nurses to administer medicines, and that this was often problematic because district nursing services are extremely stretched or cover a large geographical area. One respondent reported that "district nurses attend to administer medicines. Response times will depend on their workload; but they do prioritise people at the end of life. However, there is [often] skeleton staff on and if they are already out seeing patients, then they can't respond until they have finished with that patient. It is hard to put a time on it".

Administration of medicines in a crisis was only infrequently reported as being undertaken by palliative care specialist nurses. Where palliative care clinical nurse specialists are available to administer medicines, there were comments about the limited availability of staff or the challenges of a large geographical area to cover.

Example of innovation

In London, England, a GP co-operative has developed a protocol for collection of palliative medicines from the out-of-hours pharmacy at the local hospital and delivery of these to the patient's home for administration. This aims for action within a two-hour window. This has helped alleviate the pressures on family or friends having to leave the home to obtain medication, and improves staff safety and security.

Can patients and informal carers access care and equipment out-of-hours?

Almost all areas provided a service to address practical nursing problems, such as blocked catheters, for at least some or part of the night (Figure 7). This was also available at weekends. Practical nursing tasks were almost always the remit of the district nurses or community nursing teams, although occasionally, additional rapid response services have been set up to deliver practical nursing tasks when required. Throughout all areas, this reliance on district nurses or community nursing teams for out-of-hours palliative and end of life care was evident. But again, large gaps were reported between what was technically available, and delivery ‘on the ground’.

We also asked whether there was a service available – in addition to routinely-available district nurses and community nursing teams – to help with care in the last days of life i.e., to provide professional carer(s) who can stay in the home for several hours at a time during the last days of life. Over 90% of areas reported that this type of service was available or partially available. A wide range of different models of care was reported; such as dedicated ‘rapid response’ services set up for end of life care, or shared end of life care across organisational boundaries.

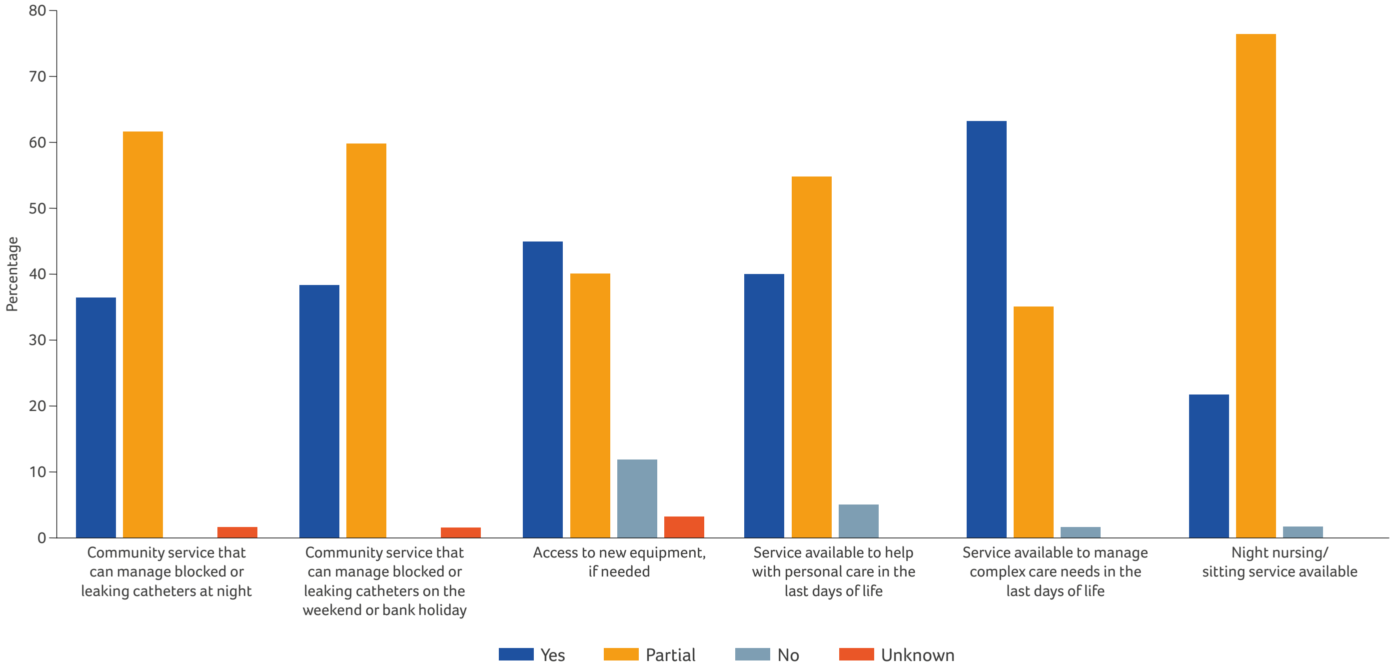


Figure 7: Responses about out-of-hours access to care and equipment, in the 60 UK areas surveyed

However, there were many reports of excess demand beyond availability or provision. Those interviewed reported being frustrated that they were unable to promise out-of-hours care and support to patients and families; “we can try but we can’t promise”. Another reported: “In terms of service delivery, it’s about what happens on the ground, and there is a big disparity in what we think we are doing compared to what we are actually doing”.

Respondents often recognised the growing need for palliative and end of life care, including for people with a much wider range of conditions beyond cancer. At the same time, they reported that it did not necessarily need to be specialist palliative care: “There is a need for more overnight care in all manner of respects, because it is a huge chunk of the week, and it is often when people feel vulnerable.”

Care packages were a particular challenge. One respondent articulated the issue very clearly: “Access to emergency carers or care packages is an issue, especially for patients being discharged home from hospital to die. [We] all struggle to get care packages in place. Often, it is the family who plug the gap until the care package starts. [… Yet sometimes,] if you are being discharged home and are under the palliative care team but not in the last days of life, you can get a care package quickly. This doesn’t make sense”. Many interviewees commented on the huge challenges of getting home care in place, often leading to delayed discharge/admissions from hospitals or hospices: “[there is] just not enough care provision in the community, particularly since the pandemic”.

Example of innovation

One palliative care support service in London has developed a rapidly responsive team who provide hands-on nursing care for people at home at the end of life requiring short-term (days) support to help them through a crisis. Healthcare assistants offer practical care with washing, toileting and assisting the family. Trained nurses offer practical care and can administer medications. Nurses visit for an agreed length of time, which varies from one hour to the whole night.

Access to new equipment was also possible in most areas, although those interviewed reported constraints on availability and access (especially in rural areas). As one interviewee said: “There are lots of issues in accessing equipment if needed, it is a struggle to get it. There should be provision to get urgent call-outs for equipment but there isn’t. It should be available within 24 to 48 hours, with 48 hours being the maximum that [patients] should be waiting”. Equipment was generally available out-of-hours, although more usually over weekends and bank holidays, rather than overnight. Interviewees reported specific challenges in access to equipment such as partial geographical coverage, unavailability of staff to provide this, challenges with electronic records/systems to enable this service, or initiatives to ensure equipment is available with only short-term funding.

Can patients and informal carers access specialist palliative care out-of-hours?

We asked if it was possible to access specialist palliative care nurse advice or support by phone or via video call out-of-hours if this was needed; this was widely available, with over 80% of areas reporting full or partial availability (Figure 8). A few interviewees reported workforce challenges; difficulty with appointing staff and hence challenges in covering out-of-hours rotas. Again, this service is often not available out-of-hours if the patient was not already known to the service; early recognition of palliative care needs and consequent referral to palliative care services is critical to gaining access to this support. In respect of home visits, specialist palliative care nurse visits at home tend to be between 9am and 5pm on weekends rather than overnight. This may be because of capacity issues. Sometimes specialist palliative care nurses were reported as only available 9am to 5pm, Monday to Friday.

In 73% of the areas surveyed, specialist palliative care nurses are available to visit during weekends and bank holidays. However, specialist palliative care nurse visits are much less common overnight; in

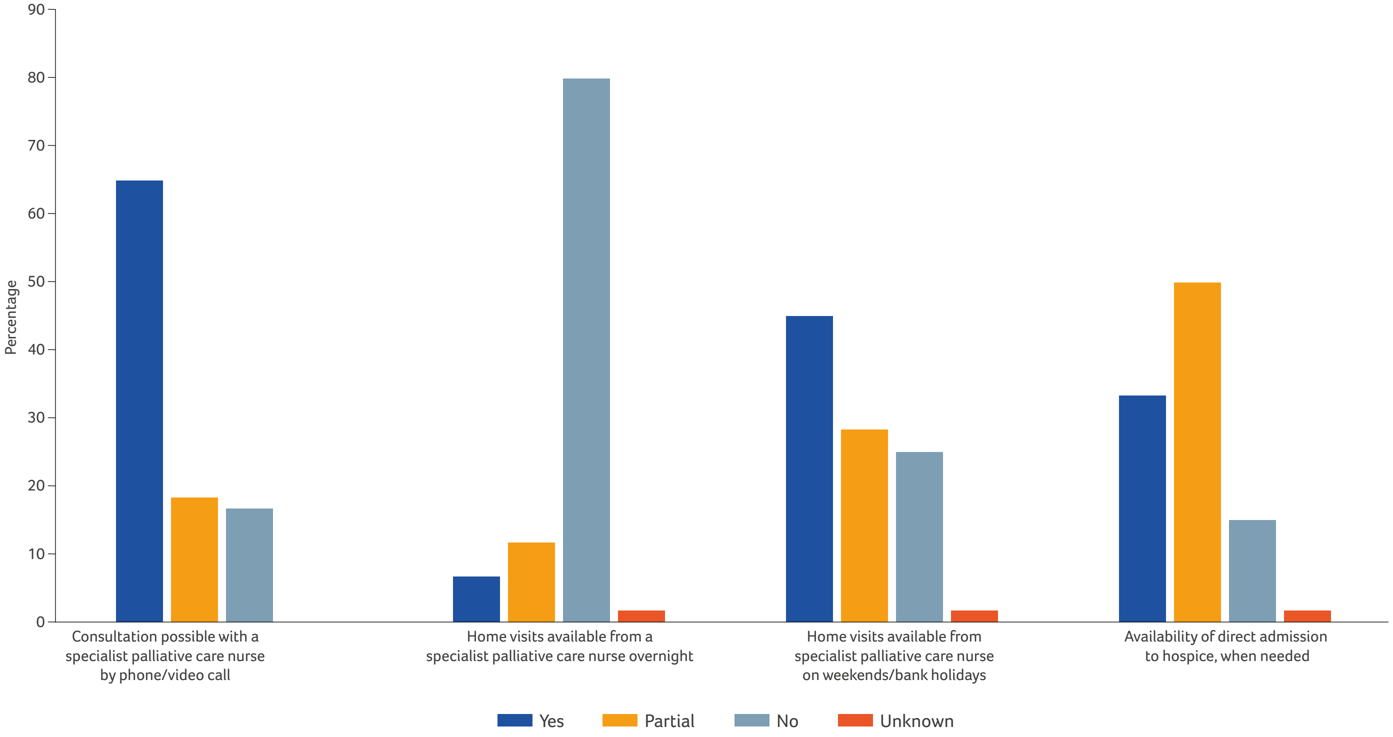


Figure 8: Responses about out-of-hours access to specialist palliative care, in the 60 UK areas surveyed

80% of areas, this service is not provided. In 83% of areas, direct hospice admission was possible when needed; this was not available in 15% of areas (and unknown in the remaining 2%). Those interviewed often spoke of limited bed availability; with delays in admission or redirection to other places (largely acute hospitals).

Examples of innovation

In one area of South-East England, patients have access to a 'cottage hospice'. The ten-bedded cottage hospice is a home environment away from home; it allows families the safe space to continue to provide care for their loved one but with staff on hand should they need additional support, respite, or for symptom control. An 'Informed Guide' (written and video materials) is easily available to help family caregivers provide care, and there are guest suites for additional family to stay, and cooking facilities. The cottage hospice is supported by Clinical Nurse Specialists, Staff Nurses, Specialty Doctors, Consultants, Hospice Paramedics and Nursing Assistants.

In the Orkney Islands in Scotland, the local hospital provides a designated ward for end of life care patients. Although not a formal inpatient hospice, patients can access specialist care there. All patients from across the Isles can access the hospital in theory although it can be complicated getting a patient across from more remote islands.

Do services work together out-of-hours?

Often there was a complicated configuration of interlinking out-of-hours services. Providers or commissioners had worked to ensure some level of comprehensive and coordinated provision, wherever possible, but a lot of local knowledge was needed to ensure optimal care. One respondent encapsulated how complicated this kind of configuration could be: "The clinical nurse specialists provide telephone advice and are available seven days per week. [The nights are] covered by different configurations of services. [. . .] During the daytime there is both telephone advice and a visiting service, and then overnight there is [a rapid response] service (8pm – 8am) which also offers telephone advice and visits. [. . . They] do have a gap in face-to-face provision for four hours. And then the consultant (doctor) on-call is accessible [. . .] for advice if required."

The importance of 24/7 coverage and integration of care was recognised as important for effective delivery: "The extension of the [service] to seven-day working is increasingly important as more and more people want to die at home and also for people not to be admitted to hospital to allow for equitable service. It is important to have the necessary services working seven days a week, 24-hours per day but this is not how it works currently".

We asked whether health and care professionals (such as GPs) could access urgent specialist palliative care advice out-of-hours; this was almost universally available, most often from senior palliative care on-call doctors. Some commented on the importance of learning and sharing between primary, community and specialist teams – with GPs, district nurses and community nursing teams often having a wealth of practical and hands-on experience, while the specialist palliative care teams bring expertise for more complex or challenging situations. One reported: "The overnight district nurses are really experienced at looking after patients with palliative care needs; that's their bread and butter." Others reported that GPs, district nurses and community nursing teams had – through the availability of specialist palliative care telephone advice – been enabled to continue leading the patients' care, resulting in fewer referrals to the specialist service.

Example of innovation

The Welsh Ambulance Service has recently appointed a team of dedicated palliative care paramedics to deliver specialist care to patients who are nearing the end of life; the first service of its kind in the UK. This team divide their time between the community and other settings and can help with administering palliative medicines. They can respond over the weekend and bank holidays between the hours of 8:00am and 6:30pm, and work closely with the district nursing team who provide 24/7 care.

We also asked about shared or integrated care records. These – in some form – were available in over 95% of areas, though in some areas challenges regarding access and use were reported: "It is a wish list really, but it would be useful to have one system that everyone can use as it is challenging with the multiple systems available. COVID-19 has pushed the use of technology into a helpful direction, which has opened a lot of new avenues."

Usually, some sharing of records between NHS and charitable hospice services was in place (often reported as 'partial'), although the extent to which this worked in practice was variable. The accuracy and speed of information flow between setting caused challenges; "In reality, documentation on discharge from the acute trust has not been as good as it could be".

The people's perspectives

This section is written by: Lynn Laidlaw, Rashmi Kumar, Jenny McAleese, Andy Woodhead, Cara Duggan, and Roberta Lovick.

"It is delays and lack of resources that gives the carer so much anxiety, so much worry and so much stress. When you want care, you want it now; tomorrow or next week is no good."

Introduction

We are a group of people with lived experience of caring for family members with palliative and end of life care needs. We have been involved in the Better End of Life programme from the start as valued members of the research team. Our aim is to ensure that the research reflects the priorities and perspectives of patients and their families/friends.

The findings from the interviews with commissioners, and health and care professionals presented in this report reflect on services that are currently available out-of-hours for people and their families/friends across the UK. In this section, we draw on insights from the actual experiences of people living with life-limiting illnesses, and their families/friends, of accessing out-of-hours care.

In May 2022, a PPI workshop was held with an independent facilitator, where people living with life-limiting illnesses and their informal carers were invited to share their experiences of out-of-hours care. 13 people attended, from England, Wales and Scotland. Ten participants were informal carers, one was a patient, and two people had a dual role. As members of the Better End of Life PPI team, we were present to listen to participants' experiences. We reflect here on what the workshop participants shared, what we learnt from their experiences, and how this relates to the research findings.

Care as imagined versus care provided

During the workshop, four themes came up again and again. Overall, these themes highlight a disconnect between the care described as available by service providers, and the real experiences of people living with life-limiting illness and their families and informal carers. Here, we describe these themes, illustrating them with quotes from the workshop.

A lack of out-of-hours support

While the findings in the report indicate that in many areas services are in place, workshop participants shared that many people are left without information, essential care and support. Services need to be useful, accessible, and convenient for patients and informal carers. They must reflect the needs of patients and informal carers, not just what service providers perceive these needs to be. They also need to be rapidly and reliably available.

"You are guaranteed a better death if you die between 9am and 5pm Monday to Friday, so I've asked my mum if this would be possible, just because you would have access to the people you need."

"It was hard to even get visits in hours, I didn't even try out-of-hours"

Recommendation: The priorities of people using services are often different to the people commissioning and providing the services. More involvement and better understanding of people who use palliative and end of life services in the commissioning process will help improve the relevance, access and appropriateness of services.

Emotional and practical labour

Caring for a family member/friend is a final act of love and it stays with the carer forever. When a person is coming to the end of their life, informal carers and family members want to be present with their loved ones and to support as best as they can. Unfortunately, emotional and practical labour resulting from a lack of formal support is distracting and disappointing, and takes them away from the moments that matter. This means they may not be able to provide the loving care they want to, which results in feeling that they may have let their loved one down.

"There have been times when I have thought Mum needs to die somewhere else, where I know the equipment is there and the people are there… That is against Mum's wishes, against all our wishes. We have done really well to keep her at home for so long despite everything, but it pushes you to that point where you feel out of control and frightened."

Informal carers spent lots of time and effort coordinating care, finding out information and trying to access equipment. This was described as physically, emotionally and financially exhausting, and above the emotional upset they already had to deal with when a loved one was dying.

"Ringing around takes too much time… Searching around in the dark for who to contact… One point of contact would be very helpful."

Recommendation: Service providers must recognise the psychosocial impact that care giving, and the impact of navigating the various health and social care services, has on the caregiver and their capacity to provide support. A single point of contact for informal carers to access support is essential.

Reactive not proactive services

Some workshop participants felt services reacted when things became critical or went wrong rather than planning ahead carefully for likely eventualities. This meant that the care received was often considered to have been "too little, too late". This lack of planning, of care and attention increased emotional and practical exhaustion for informal carers, with people waiting days for services such as overnight respite. In some cases, the loved one died before the service was provided.

"These weren't quick illnesses, there is plenty of time for healthcare professionals to get their ducks in a row, but it doesn't happen."

"When we said we needed help we were told nothing would be immediate…This was arranged in advance for the evening of the day he died. It was all too little, too late."

Participants also expressed concerns for people who have no family/friends to advocate for them, or who lack resources to provide care or buy equipment or care privately.

Recommendation: More resources must be directed towards palliative care services to enhance access and care provision. Better planning and recognition of patients' needs would mean the right care is provided for the right people at the right time. Services must assess and collect data (both quantitative and qualitative) to understand the outcomes and experiences of their users.

Equality, inclusivity and the impact on different communities

The workshop participants said they had found it difficult to find out what services and support were available. People raised issues of cultural and ethnic inequalities, and shared that they felt existing services were biased towards people living with cancer, and not for other advanced conditions. These issues heightened patients' and families' distress.

"There are incredible specialists in cancer care, but when it comes to dementia there is a real lack of knowledge."

"[Palliative care services] are not visible to the Asian community as an option and they wouldn't know who to contact".

Recommendation: Services must be developed and provided equitably, irrespective of socio-demographic characteristics (e.g. age, ethnicity) and geographical area. Further research is needed to understand how to best signpost palliative and end of life services across all cultures and socioeconomically diverse communities.

What next?

The experiences and reflections from the workshop highlighted above are not new. Indeed, many of these issues have been known for many years and it is disappointing that we are no further forward. There is undoubtedly a ‘postcode lottery’ across the UK when it comes to out-of-hours palliative and end of life services. However, a striking finding that has been highlighted in the workshop was the mismatch between what services may be available, and the experiences of patients and informal carers trying to access these services. The recommendations outlined above should be considered the bare minimum, and must be acted on by local commissioners, service providers and policy leads.

Dame Cicely Saunders said: “How people die remains in the memory of those who live on”. It is families, friends and loved ones who have to cope with the long-term failure of services that are not co-ordinated, do not meet people’s practical and emotional needs, or are not centred on the individual. We must refocus the attention away from avoiding death, for those at the end of their life, towards the quality of death and understanding what that means for each person.

Report recommendations

Out-of-hours palliative and end of life care must be valued and prioritised

- Our research highlights that out-of-hours palliative and end of life care provision is frequently inadequate and fragmented, and must be strengthened. The importance of effective, responsive, and timely out-of-hours care in improving the wellbeing of patients and their informal carers, and helping prevent emergency hospital admissions, must be recognised. **Services must be developed and provided equitably, irrespective of diagnosis, socio-demographic characteristics (e.g. age, ethnicity) and geographical area.**

- Our research re-iterates the extensive role of district nurses and community nursing teams in providing hands-on care out-of-hours, but also reflects the huge pressures on this workforce which limit the care that can be provided. A frequent theme in our interviews was that services were theoretically available to provide care, but in practice stretched beyond capacity. **Improved workforce planning and support for community providers of out-of-hours palliative and end of life care is essential.** The Royal College of Nursing similarly report unsustainable staffing pressures and major district and community nursing shortages across the UK[19-21]. Over 75% of district and community nursing teams reported insufficient staff to meet the needs and dependency of their patients[20].

- In a crisis, patients and their informal carers need to be able to access support and advice quickly. Our research highlights that some essential components of out-of-hours palliative and end of life care are often unavailable. For example, access to a designated telephone line for palliative and end of life care advice out-of-hours was recommended by the National Institute for Health and Care Excellence in 2011[45], and re-iterated in 2019[46] and 2021[25]. Our research finds that this is still not in place for one in four of areas surveyed. **A designated telephone line for people with palliative and end of life care needs and their informal carers should be available 24/7, in every part of the UK.**

Service development and planning must be actively informed by the voices of patients and informal carers, with meaningful engagement with patients and informal carers at its heart

- We already know the priorities of patients and informal carers[12]; out-of-hours care is top of the list. Listening to the experiences of those receiving out-of-hours palliative and end of life care tells us clearly what is working, and what is not. **Collaboration with patients and informal carers should – in every area – be used to drive improvements in out-of-hours care, shape service development and identify potential solutions to address gaps.**

- Those responsible for service provision must regularly assess their own provision according to patient and carer priorities. Our questionnaire is based on a Delphi study where patients, informal carers, members of the public and professionals reached consensus on the most important areas of out-of-hours care[40]. The questionnaire (see Appendix) can be used by those with commissioning responsibilities to understand and address gaps in service provision and priorities for improvement.

Integration between services is key to ensure high quality out-of-hours palliative and end of life care

- Participants in our study told us that more than any other area of care, out-of-hours care is a barometer of whether care is integrated or fragmented. Poor integration was highlighted between different out-of-hours services, and between in-hours and out-of-hours services. People with advanced illness and their informal carers deserve a coordinated, integrated and seamless approach. **Integrated Care Systems, Health Boards and NHS Trusts, Integration Joint Boards and NHS Health Boards, and Health and Social Care (HSC) Trusts across the UK need to strategically develop, enable and support greater integration and coordination of out-of-hours services.** A common theme in our data was that access to some out-of-hours services – for example designated telephone lines – is limited if people have not been referred to a specialist palliative care team. Similarly, without early recognition of deteriorating health, patients may not be involved in proactive discussion about wishes and preferences, or be provided with anticipatory medicines. Systems must be designed so that they facilitate collaboration and coordination between different out-of-hours services, to enable rather than hinder this access. **Everyone needs to have access to the services that they need, including those who might not have been identified as needing specialist support.** This includes proactive conversations about their needs, wishes and preferences for care, and provision of anticipatory medicines (if appropriate), to ensure personalised care. Routine use of patient reported outcome measures, such as Integrated Palliative care Outcome Scale (IPOS), could help identify deterioration and anticipate changing needs.

- Shared care records (including GP records, summary records, or electronic palliative care coordination system records) are a way of promoting integrated care. Shared care records do not guarantee delivery of high-quality out-of-hours care, but they help support the right care to be provided for the right people at the right time. **Availability and use of shared care records should be audited regularly to inform progress in overcoming the challenges identified in using and implementing these records across the UK.**

Research into out-of-hours care is essential for future service development

- Out-of-hours palliative and end of life care has been identified by the James Lind Priority Setting Partnership as a top priority for research[12]. In undertaking this work, we found relatively little research into out-of-hours care. Further research into out-of-hours care needs to be funded and delivered, with particular emphasis on evaluation of innovations and new models of care. Sharing good practice and consideration of supporting evidence for new innovations or models of care will help identify evaluation gaps and promote new research.

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Appendix

Part 1: Methods for UK emergency department analysis

Data was accessed through Trusted Research Environments. In England, data were provided by NHS Digital and accessed through the British Heart Foundation Data Science Centre. In Wales data were provided by the Secure Anonymised Information Linkage (SAIL) Databank. In Scotland data were provided by the National Records Office for Scotland. In Northern Ireland data were provided by the General Register Office for Northern Ireland (GRONI) and accessed through the Honest Broker Service.

Measure of area-based deprivation

We used the postcode from the decedent's place of residence to link to level of area-based deprivation. Deprivation was grouped based on quintiles, quintile 1 represents people living in the most deprived areas in each nation. In Scotland, quintiles were derived from deciles which were provided in the data.

The following measures of area-based deprivation were used: Index of Multiple Deprivation (IMD) for England (2019); Welsh Index of Multiple Deprivation (WIMD) 2019; Scottish Index of Multiple Deprivation (SIMD) 2020; Northern Ireland Multiple Deprivation Measure (NIMDM) 2017 in quintiles.

Age and sex standardisation

To help to compare rates between areas, we used the direct method of age and sex standardisation to remove differences in the age and sex structure. We used 10-year age bands from 0 to 100 (based on age at death), and the age and sex specific number of deaths in 2019 in each country as the standard population.

Geographical boundaries

The datasets for each nation are analysed separately, therefore cross-nation emergency department visits are not included. For example, if someone living in Wales visited an emergency department in England, this is not captured in the data. This is important when interpreting rates in different geographical locations and may be particularly important in areas situated on nation boarders such as the Powys Health Board in Wales, which is situated on the border with England.

Part 2: Questionnaire on provision of out-of-hours care across the UK

The questionnaire used in Part 2 of this research is overleaf and can be used by those providing out-of-hours services or with commissioning responsibilities to understand and address gaps in out-of-hours service provision and priorities for improvement. Please acknowledge the source (this report), and cite as:

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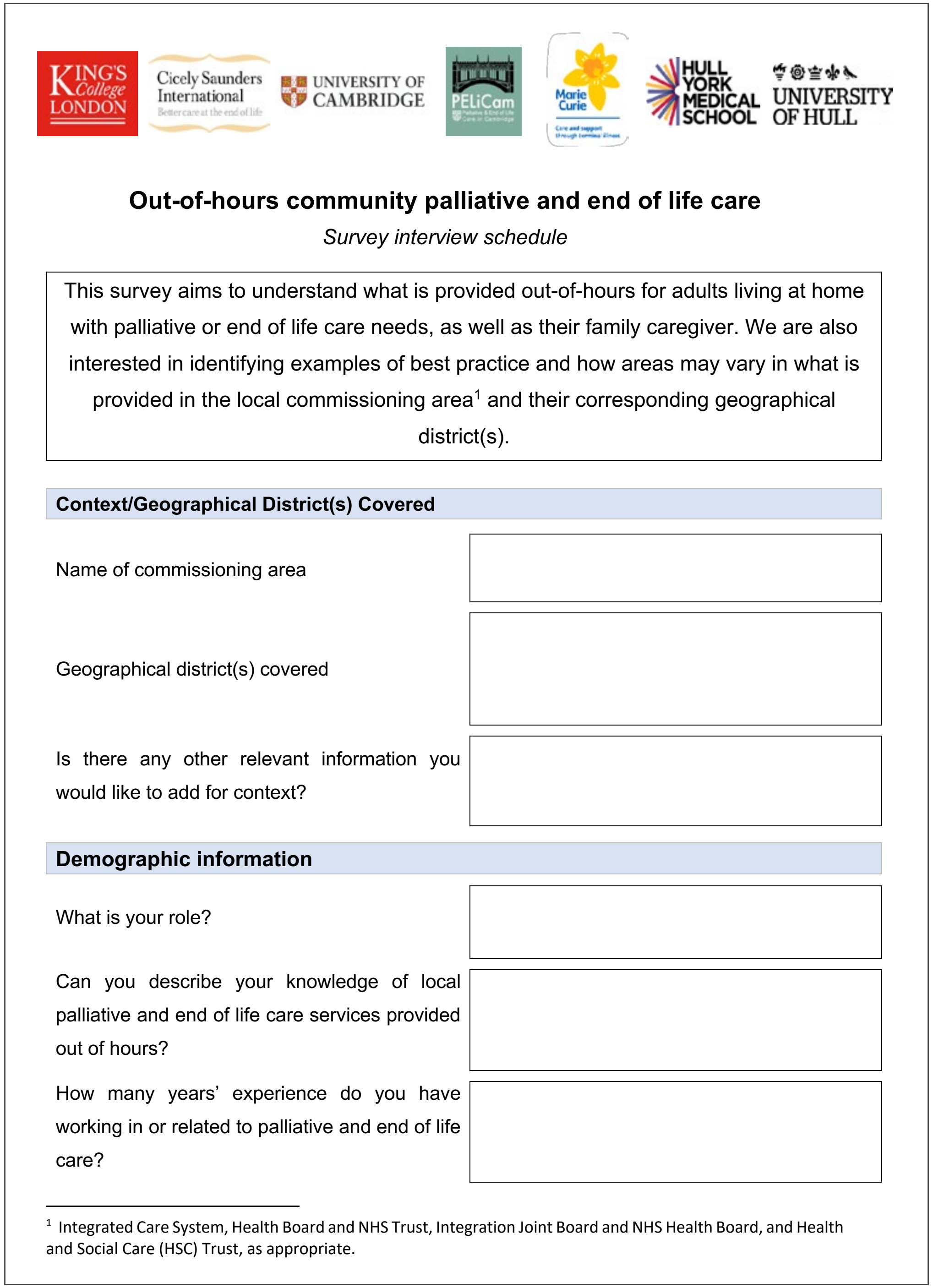

Out-of-hours community palliative and end of life care

Survey interview schedule

This survey aims to understand what is provided out-of-hours for adults living at home with palliative or end of life care needs, as well as their family caregiver. We are also interested in identifying examples of best practice and how areas may vary in what is provided in the local commissioning area[1] and their corresponding geographical district(s).

Context/Geographical District(s) Covered

Name of commissioning area	
Geographical district(s) covered	
Is there any other relevant information you would like to add for context?	

Demographic information

What is your role?	
Can you describe your knowledge of local palliative and end of life care services provided out of hours?	
How many years' experience do you have working in or related to palliative and end of life care?	

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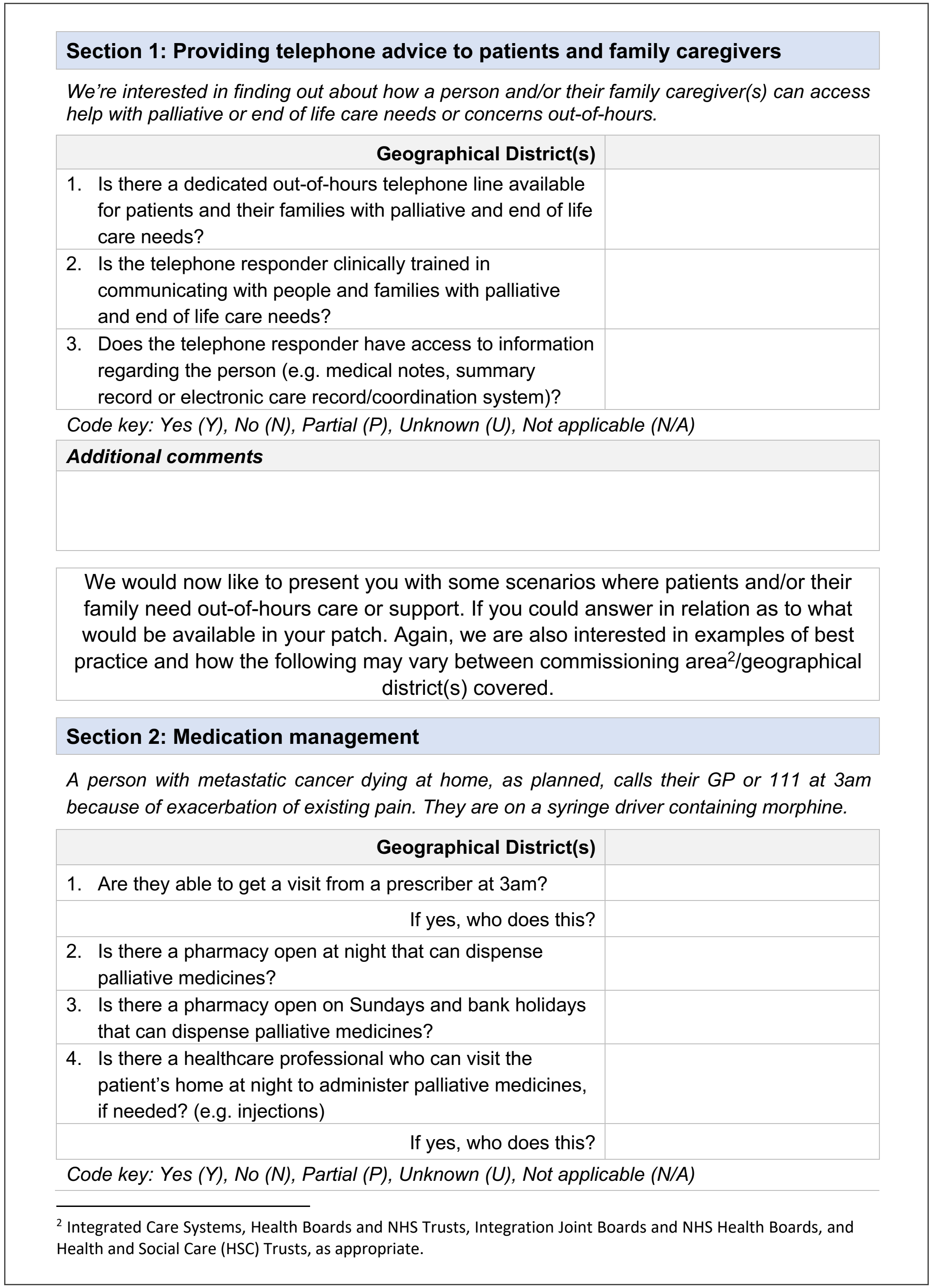
[1] Integrated Care System, Health Board and NHS Trust, Integration Joint Board and NHS Health Board, and Health and Social Care (HSC) Trust, as appropriate.



Section 1: Providing telephone advice to patients and family caregivers

We're interested in finding out about how a person and/or their family caregiver(s) can access help with palliative or end of life care needs or concerns out-of-hours.

Geographical District(s)	
1. Is there a dedicated out-of-hours telephone line available for patients and their families with palliative and end of life care needs?	
2. Is the telephone responder clinically trained in communicating with people and families with palliative and end of life care needs?	
3. Does the telephone responder have access to information regarding the person (e.g. medical notes, summary record or electronic care record/coordination system)?	

Code key: Yes (Y), No (N), Partial (P), Unknown (U), Not applicable (N/A)

Additional comments

We would now like to present you with some scenarios where patients and/or their family need out-of-hours care or support. If you could answer in relation as to what would be available in your patch. Again, we are also interested in examples of best practice and how the following may vary between commissioning area[2]/geographical district(s) covered.

Section 2: Medication management

A person with metastatic cancer dying at home, as planned, calls their GP or 111 at 3am because of exacerbation of existing pain. They are on a syringe driver containing morphine.

Geographical District(s)	
1. Are they able to get a visit from a prescriber at 3am?	
If yes, who does this?	
2. Is there a pharmacy open at night that can dispense palliative medicines?	
3. Is there a pharmacy open on Sundays and bank holidays that can dispense palliative medicines?	
4. Is there a healthcare professional who can visit the patient's home at night to administer palliative medicines, if needed? (e.g. injections)	
If yes, who does this?	

Code key: Yes (Y), No (N), Partial (P), Unknown (U), Not applicable (N/A)

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[2] Integrated Care Systems, Health Boards and NHS Trusts, Integration Joint Boards and NHS Health Boards, and Health and Social Care (HSC) Trusts, as appropriate.

Additional comments

Section 3: Crisis management (Community/district nursing)

A person has a long-term urethral catheter. They have several comorbidities (including prostate cancer) and complex care needs. At 3am their catheter becomes blocked.

Geographical District(s)	
Is there a community service that can visit the person's home to manage blocked or leaking catheters at night?	
If yes, who does this?	
Is there a community service that can visit the person's home to manage blocked or leaking catheters on the weekend or bank holidays?	
If yes, who does this?	

Code key: Yes (Y), No (N), Partial (P), Unknown (U), Not applicable (N/A)

Additional comments

Section 4: Care in the last few days of life

A person with advanced metastatic prostate cancer wishes to die at home. He is now increasingly drowsy, spending most of the day in bed. He is eating and drinking less, struggling to take oral medication, and is reaching the last few days of life. It is a weekend or bank holiday.

Geographical District(s)	
1. Is there access to new equipment (hospital bed, commode etc.) if needed?	
2. Is a rapid response service available to help with personal care in the last days of life?	
If yes, who is this provided by?	
3. Are rapid response trained nurses or Hospice@Home service available to manage complex care needs for the last days of life?	
If yes, who is this provided by?	
4. Is a night nursing/sitting service available (i.e. can stay with the patient)?	
If yes, who is this provided by?	
5. Is it possible to have a consultation with a specialist palliative care nurse on the telephone or via video call?	
6. Are home visits available from a specialist palliative care nurse at weekends and bank holidays?	
7. Are home visits available from a specialist palliative care nurse overnight?	
8. Is direct admission to hospice available when needed?	

Code key: Yes (Y), No (N), Partial (P), Unknown (U), Not applicable (N/A)

Additional comments

Section 5: Continuity of care and support for healthcare professionals

We are interested in how information is shared within and between multi-professional teams and different services to ensure continuity of care for people with palliative and end of life care needs. Additionally, we are interested in what support is available to healthcare professionals who require urgent palliative care advice (such as a GP).

Geographical District(s)	
1. Is there an electronic coordination system available to different healthcare professionals in different care settings?	
If no, are paper records available?	
2. If a healthcare professional (such as a GP) needs out-of-hours urgent palliative care advice is there a specialist telephone number available/accessible?	
If so, who do they call?	

Code key: Yes (Y), No (N), Partial (P), Unknown (U), Not applicable (N/A)

Additional comments

Thank you. Is there anything further you would like to add or more insight into these topics?

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The North East-Newcastle and North Tyneside 2 research ethics committee provided ethical approval for the CVD-COVID-UK/COVID-IMPACT research programme (REC No 20/NE/0161) to access, within secure trusted research environments, unconsented, whole-population, de-identified data from electronic health records collected as part of patients' routine healthcare.

The data used in this study are available in NHS Digital's TRE for England, but as restrictions apply they are not publicly available (https://digital.nhs.uk/coronavirus/coronavirus-data-services-updates/trusted-research-environment-service-for-england). The CVD-COVID-UK/COVID-IMPACT programme led by the BHF Data Science Centre (https://www.hdruk.ac.uk/helping-with-health-data/bhf-data-science-centre/) received approval to access data in NHS Digital's TRE for England from the Independent Group Advising on the Release of Data (IGARD) (https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/independent-group-advising-on-the-release-of-data) via an application made in the Data Access Request Service (DARS) Online system (ref. DARS-NIC-381078-Y9C5K) (https://digital.nhs.uk/services/data-access-request-service-dars/dars-products-and-services). The CVD-COVID-UK/COVID-IMPACT Approvals & Oversight Board (https://www.hdruk.ac.uk/projects/cvd-covid-uk-project/) subsequently granted approval to this project to access the data within NHS Digital's TRE for England. The de-identified data used in this study were made available to accredited researchers only. Those wishing to gain access to the data should contact bhfdsc@hdruk.ac.uk in the first instance.

The analysis using data in NHS Digital's TRE for England was performed according to a pre-specified analysis plan published on GitHub, along with the analysis code https://github.com/BHFDSC/CCU024_01).

This study makes use of anonymised data held in the Secure Anonymised Information Linkage (SAIL) Databank. We would like to acknowledge all the data providers who make anonymised data available for research. The responsibility for the interpretation of the information we supplied is the authors' alone[47-50].

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