

A review of Specialist Palliative Care provision and access across London

Mapping the capital

September 2015



A joint report by



Care and support
through terminal illness



Acknowledgements

This report has been jointly produced by the London Cancer Alliance, PallE8 and Marie Curie in collaboration with Specialist Palliative Care providers across London.

The **London Cancer Alliance** (LCA), formed in 2012, seeks to improve clinical outcomes for cancer patients, the experience of cancer patients and reduce variation in service provision for cancer patients across South and West London. The LCA's palliative care group was also formed in 2012, as an important cross cutting pathway to inform all tumour specific work across the LCA. The palliative care group aims to improve the access, experience and outcomes for patients requiring palliative care, irrespective of their diagnosis, across West and South London. The membership of the group brings together specialist NHS and voluntary sector expertise from primary, secondary and tertiary care, as well as service users, to enable the development of high quality patient-centred care. The group developed the methodology used in the mapping exercise that informs this report.

PallE8 is a clinically-led expert reference group for specialist palliative and end of life care for adults and children covering North Central London, North East London and West Essex. PallE8's membership includes all providers of specialist palliative and end of life care from across hospital, community and hospice teams within the region.

Marie Curie is a registered charitable organisation in the UK, providing care and support to people with terminal illnesses and their families. Marie Curie also takes a leading role in campaigning on behalf of people living with a terminal illness and their families, to make sure they can access the high quality care they need, when they need it most.

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1: Executive summary

The aim of this report is to provide more information on Specialist Palliative Care (SPC) provision in London. It is hoped that the data analysis in this report will be useful to both commissioners and SPC providers in their plans to improve care and reduce inequity in the quality of care for patients with life-limiting illnesses.

1.1 Background

For people with life-limiting illnesses and their family/carers, poor provision of services and support can add to the stress and confusion of an already-difficult time. Conversely, the right care and support at the right time can make all the difference.

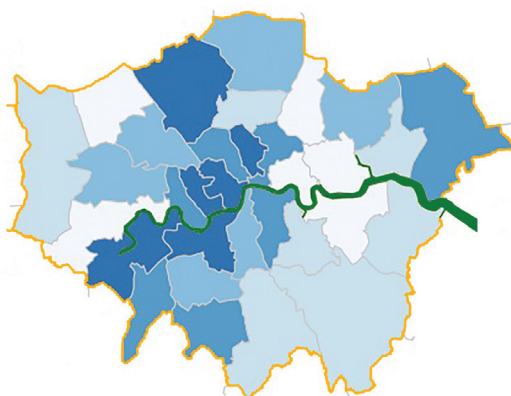
London contains some of the country's best care for people with life-limiting conditions but also some of the worst. For example, the latest national VOICES survey of the bereaved (2012), which covers the care of people within their last three months of life provided by SPC and other services, rated the Islington Clinical Commissioning Group (CCG) area second for quality in the whole of England whereas the Newham CCG area emerged as the worst.

Specialist Palliative Care (SPC) is defined as "the active, total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support"¹. SPC services should be available to all patients with cancer and non-malignant diseases on the basis of need.

To understand more about the provision of SPC in London, the palliative care group of the London Cancer Alliance (LCA) mapped SPC services across West and South London soon after its formation in 2012. A year later its counterpart, PallE8, used the same approach to map SPC services in North and East London.

Figure 1: Huge variation in overall quality of end of life care across London

The second best rated CCG in the UK is in London; and so is the worst.



% rating quality of care as outstanding or excellent

- 26.5 – 32.8
- 32.9 – 35.2
- 35.3 – 37.1
- 37.2 – 45.1
- 45.2 – 56.3

Reference:
Marie Curie Atlas (source: combined data from the ONS Survey of Bereaved People VOICES, 2011-12)

1 National Council for Palliative Care. Commissioning guidance for specialist palliative care: Helping to deliver commissioning objectives, 2012.

Now these two organisations, in collaboration with Marie Curie, have worked together to provide an updated picture of SPC provision across the whole of the capital, making such complete information available for the first time. This report is a synopsis of their joint findings and it includes recommendations for the commissioners of these critical services.

The report demonstrates that SPC services are provided at home, in hospital and in hospices across London, in weekday working hours. In keeping with the national picture, our SPC services see a disproportionate number of people with cancer, although the data we have analysed shows that more patients with non-malignant disease are accessing SPC services over time. Out-of-hours availability of SPC services has improved in the two years between the mapping exercises in South and West London (LCA areas) and in a small number of London CCG areas, this out-of-hours availability goes beyond the requirements of national guidance. In contrast, some deterioration in service availability was observed in North East and North Central areas.

Despite this, SPC services across London are still not fully meeting the out-of-hours service availability mandated by NICE guidance in 2004. These differences exist even within individual CCG areas, with some patients experiencing different levels of SPC access depending on where they live in the borough.

The London Cancer Alliance, PallE8 and Marie Curie have worked in partnership on this report. Our collective goal is to ensure that everyone, regardless of their condition, where they live or the services they use, gets the best possible specialist palliative care whenever they need it.

1.2 Methods

A template was designed by the London Cancer Alliance Palliative Care Group, building on the audit template design from 2012. This expanded on the established National Council for Palliative Care minimum data set to collect not only essential numerical, demographic and

diagnostic information for patients seen over the most recent 12-month period, but also the types and availability of SPC services provided across London.

Information was also collected on providers' staffing levels at one specified time point within the year and their use of clinical outcome measures.

The template was completed by all 50 adult SPC providers in London, as well as by paediatric SPC services in North Central and North East London, and covered services in hospitals, hospices and the community. The results were correlated, both by each organisation and by the 32 CCGs in the capital. Data was checked and cleaned, with detailed checking with providers for any missing or obviously incorrect data (including outliers), then provided back to each organisation in report format for final checking before being accepted as correct.

1.3 Key findings

- The report demonstrates that SPC services are provided at home, in hospital and in hospices across London, in weekday working hours.
- There was noticeable variation in out-of-hours availability of both hospital SPC and community SPC services across London in 2013/14. Availability of SPC services outside Monday to Friday, 9am to 5pm was a quality standard applied by NICE in 2004 for the specialist palliative care of cancer patients and this has now been endorsed by the latest government guidance for the care of all dying patients².
- SPC service providers across South and West London (ie the London Cancer Alliance areas) have improved their out-of-hours service availability somewhat since the 2012 audit; in contrast, some deterioration in service availability was observed in North East and North Central areas.

² Leadership Alliance for the Care of Dying People. One Chance to Get it Right. London: UK Government, 2014: 27, para.46.

- London SPC hospital advisory, community and hospice in-patient services saw more non-cancer patients in 2013/14 than national averages. The proportion of non-malignant referrals has also increased on average from a similar 2012 exercise. However, given that non-cancer deaths accounted for 71% of all deaths in 2014, this report indicates that London still has an unmet need concerning non-cancer patients accessing SPC services.
- The numbers of cancer deaths in each CCG area are a proxy for SPC need. It was found that, across London in 2013/14, there was a large variation in the ratio of patients who died with cancer to those who were seen by community SPC services. The same was true for hospice in-patient services. This variation should be further explored to understand the reasons underlying it.
- The report highlights variation in service provision within some CCGs with multiple providers.
- The data demonstrates clear variations between CCGs in the ratio of patients seen by community SPC services to patients seen in hospice in-patient SPC units, which again should be further explored to understand these differences.

1.4 Key recommendations for CCG commissioners

- Commissioners should be clear on SPC provision in their area, the characteristics of the services delivered and how each service has been tailored to meet the needs of their local population.
- Commissioners should improve collaboration with providers to ensure equity of SPC access and provision for all CCG residents.
- Both hospital and community SPC teams across London require further support to fully achieve the 2004 NICE quality standard for cancer. As a minimum, SPC services in hospital and the community should be supported to provide face-to-face visiting from 9am to 5pm, seven days a week, and telephone advice 24 hours a day, seven days a week.
- Commissioners should review staffing levels with their local SPC services to ensure they are in line with national recommendations.
- Commissioners should be aware of how their CCG performs against proxy measures for SPC need and outlying SPC services should be supported to understand why they differ from other services.
- It is recommended that CCGs from across London work with their local clinicians, patient groups, the voluntary sector, social care, public health organisations and local SPC services to understand need. The CCGs can then develop, fund adequately and evaluate appropriate, cost-effective SPC services. These services should meet the need for symptom control and psychosocial support of patients with advanced malignant or non-malignant diseases and their family/carer.

- When addressing local SPC needs, commissioners are asked to note that previous national guidance focused on the cancer patient population (NICE 2004), which often guided SPC service development at that time. Recent relevant guidance (eg NICE EOLC *Quality Standards*, 2011; *One chance to get it right*, 2014) has highlighted that SPC should be fully accessible for all adult patients with relevant complex needs, irrespective of their diagnosis. Therefore, commissioners may need to review their local SPC service capacity to accommodate this likely increase in demand.
- Given the generally ageing population and the likely increase over time in the percentage of people over the age of 65 from a Black, Asian and minority ethnic (BAME) background, it is recommended that CCGs look at their demographic projections and work accordingly with their local clinicians, community groups and their SPC services to develop, fund and evaluate appropriate, cost-effective services.
- While data quality for community SPC services and hospice in-patient services are generally robust, challenges around data quality for hospice day care services in particular and outpatient services mean that data related to these services would need to be considered with caution.
- It is difficult for us to make robust conclusions on equity of access to services on the basis of patients' BAME status. This is because the BAME status of patients accessing SPC services has been recorded with variable levels of quality, and the ethnic breakdown of BAME patients accessing those services does not necessarily correlate with the overall ethnic breakdown of a CCG which covers all age groups (given the average older age of SPC patients).

1.5 Key considerations

- This report covers the provision of SPC services in London and not the more general end of life care provided by in-patient acute wards, GPs, community nursing teams and care homes.
- Due to the lack of nationally accepted measures of SPC patient need, outcome or service quality, caution must be exercised when interpreting variances as best practice has not been defined.
- Data provided in the appendices only highlight services where 10 or more individuals were seen in that year. Furthermore, there are a number of patients who were not classified by CCG and this will have an impact on the accuracy of the data.

2: Scope

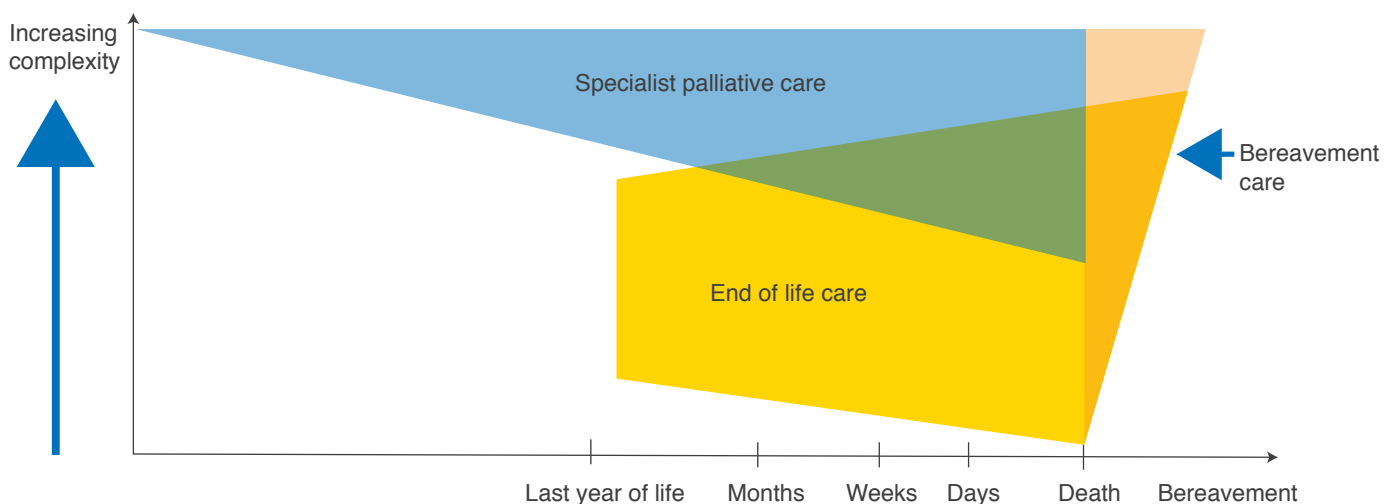
The scope of this report covers the provision of Specialist Palliative Care (SPC) services in London. SPC is defined as “the active, total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support”³.

“We want professionals to recognise this is often a traumatic period in our lives and a memory of a good death can support us as carers to feel consoled after they have died, whereas the memory of a death involving unnecessary suffering can often be a long-term painful memory.”

Brian Andrews, Chair of Lay Representatives, Board of the Pan-London End of Life Alliance

It is important to highlight that SPC is core to optimal end of life care delivery, although the majority of end of life care will be provided by generalists. Figure 2 below demonstrates the relationship between SPC and more general end of life care, and highlights the point that SPC tends to benefit more complex cases. Figure 3, on the next page, outlines the overlap in services delivered by SPC providers, recognising that some SPC providers also lead on end of life care locally. The categories of SPC service types covered by this report follow the National Council for Palliative Care’s definitions detailed in Appendix 1. SPC, unlike most of core healthcare delivery in the UK, is co-funded by the NHS and third sector. This has resulted in service development that is being driven as much, if not more, by individual providers rather than a national strategy.

Figure 2: Relationship between SPC and more general end of life care



³ National Council for Palliative Care. *Commissioning guidance for specialist palliative care: Helping to deliver commissioning objectives*, 2012.

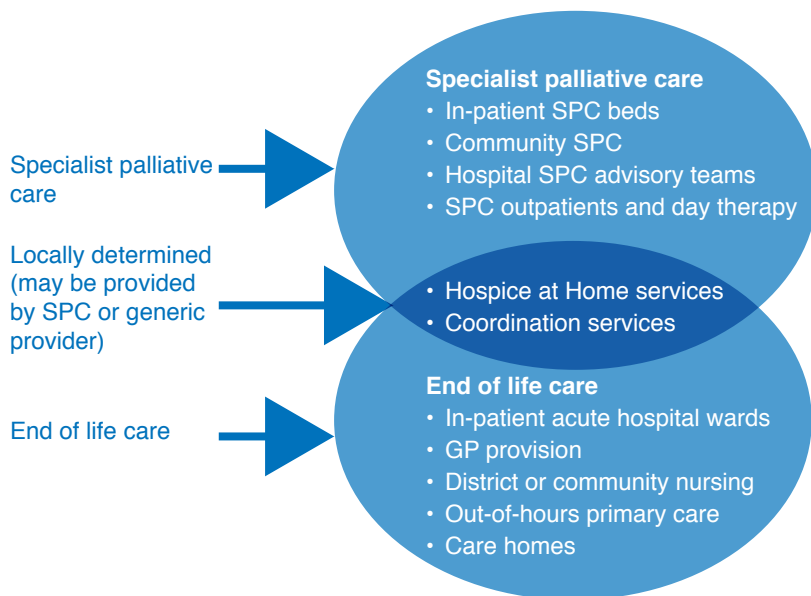


Figure 3: Outline of service types delivered by SPC compared to more general end of life care.

At present there are no nationally accepted measures of patient need, outcomes or service quality for SPC, although the Palliative Care Funding Review⁴, the upcoming NICE guidance⁵ and the Peer Review of Specialist Palliative Care Services⁶ have all considered the matter. By 2017, Public Health England aims to collect a national individual-level dataset from specialist palliative care services including demographic details, activity information and patient outcomes data.

The aim of this report is to provide more information on SPC provision in London. It is hoped that the data analysis in this report will be useful to both commissioners and SPC providers in their plans to improve care for patients with life-limiting illnesses and reduce inequity in their quality of care. However, because we are not measuring outcomes – due to the lack of nationally accepted measures of SPC patient need, outcomes or service quality – caution must be exercised when interpreting variances, as we cannot say what represents best practice.

It is worth noting that this report does not cover some services operating outside of London that support patients living within CCGs on the outskirts of London.

This report focuses on measuring a level of service activity as opposed to patient outcomes. However, it is also worth noting that there is comparative data from the VOICES and FAMCARE bereavement surveys which demonstrate that bereaved relatives report higher levels of satisfaction from SPC services than from non-SPC services⁷.

Table 1: Outline of data that has been reviewed for this report and what is out of scope

What is covered	What is out of scope
<ul style="list-style-type: none"> • All clinical services for SPC for adults across all settings in London, and paediatric palliative care across NE and NC London areas • NHS and non-NHS service delivery • Measures of service activity (individual patient counts only) • Service access • Patient specific characteristics – diagnosis (cancer/non-cancer), age bands and ethnicity, if recorded 	<ul style="list-style-type: none"> • Measures of need • Measures of quality • Patient outcome measures • Other service activity – education, governance and research (SPC clinical services provide substantial wider education, clinical governance and research services)

4 Hughes-Hallett et al. *Funding the Right Care and Support for Everyone – Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review*, 2011.
 5 NICE guidance for care of the dying adult, due to be published in December 2015.
 6 National Cancer Peer Review-National Cancer Action Team. *National Cancer Peer Review Programme Manual for Cancer Services: Specialist Palliative Care Measures*, 2012.
 7 Davies A, Peel T and Cox, S. *Bereaved relatives' satisfaction with the end of life care provided by specialist palliative care services in hospices, home, and hospitals: a service evaluation* by the Association for Palliative Medicine of Great Britain and Ireland, 2014. Awaiting publication.

3: Who are the populations we are trying to deliver services to?

3.1 Need-based rather than diagnosis-based approach

The World Health Organisation and National Council for Palliative Care definitions of SPC emphasise that SPC benefits patients on the basis of need rather than diagnosis.

However, defining the population in need of SPC presents a significant challenge, as unlike cancer populations, this group is not currently clearly defined. Therefore, while the number of cancer deaths can be used as a relative proxy measure for SPC need, it does not accurately reflect the true population need, especially considering only 29% of adult deaths in 2014 were from cancer⁸.

3.2 Cancer versus non-cancer need

The roots of the modern hospice and palliative care movements developed in response to the needs of people with cancer. Consequently, until recently, palliative care services mainly focused on identifying, assessing and supporting cancer patients, with limited focus on identifying the needs of non-cancer patients. As a result, referral to SPC and coordination of services is not as well developed for people with non-malignant diseases.

Over the last decade, there has been an increasing recognition within national policy and clinical guidance of the unmet palliative care needs of patients with non-malignant diseases⁹. This recognition was based on data demonstrating that the needs of patients with a non-malignant advanced disease (eg heart failure, COPD, MND and dementia) are as significant and varied as those of cancer patients^{10,11}. This research also estimated that 16.8% of patients with advanced non-malignant disease would benefit from SPC services.

A further study reported that patients with non-cancer conditions often experience community palliative care as inadequate and in need of planning and innovation¹².

In addition, a recent systematic review concluded that 'it is crucial that palliative care teams clearly define the roles of their professionals and increase capacity to deal with the uncertainty of non-cancer illness trajectories through effective interdisciplinary work'¹³.

This suggests that SPC services will need further resourcing to address the unmet need of the non-cancer population, although it is by no means certain that the needs of the cancer population are being met either.

8 National Council for Palliative Care. The end of life care strategy: New ambitions, 2014.

9 Department of Health. End of Life Care Strategy, 2008.

10 Addington-Hall JM. Specialist palliative care in non-malignant disease, *Palliative Medicine* 1998; 12: 417–427

11 Gomes B, Higginson IJ. Where people die (1974 – 2030): past trends, future projections and implications for care, *Palliative Medicine*, 22, 1, 33 – 41, 2008.

12 Addington-Hall JM, Hunt KJ. Non-cancer patients as an under-served group. In: Cohen J, Deliens L, eds. *A public health perspective on end of life care*. Oxford: Oxford University Press, 2012:151–9.

13 Oishi A, Murtagh FE. The challenges of uncertainty and inter-professional collaboration in palliative care for non-cancer patients in the community: a systematic review of views from patients, carers and health-care professionals *Palliat Med* 2014;28:1081–98.

3.3 London demographics

Current mortality figures for England show that around 451,000 people die per year, with the three leading causes of death consisting of cancer (29%), circulatory disease (28%) and respiratory disease (14%)¹⁴. Projections suggest that, by 2037, the mortality rate will rise by an additional 109,000 per year to 560,000 people each year¹⁵.

London CCG demographics are outlined in Appendix 2. It is clear there are significant local variations in demographics and deprivation across London, with numerous mobile, immigrant, multi-ethnic and homeless populations, as well as those who do not have English as their first language or are illiterate. It is likely that these factors will impact on access to SPC services¹⁶.

14 Office of National Statistics. Mortality Statistics, 29 October 2014

15 Office of National Statistics. National population projections (NPPs), 2015.

16 Dixon et al. Equity in the Provision of Palliative Care in the UK: Review of Evidence, 2015.

4: Specialist Palliative Care services accessed by CCG

4.1 Data analysis

The types of SPC provision available to adult residents of London's 32 CCGs have been identified, including who provides them and the number of patients who access each type of service (Appendix 3). It is not possible to say from the data whether appropriate numbers of patients are accessing specialist palliative care services in each CCG, but we have analysed this further in Chapter 6.

It should also be noted that it is possible that CCGs on the London borders will receive some service from providers outside the London Cancer Alliance or Palle8 areas. Non-London resident patients receiving services from the London providers were also included in the analysis.

Hospice in-patient services

- All of London's CCGs have access to in-patient hospice beds. These are provided by a total of 15 organisations of which only four belong to the NHS, the remainder being charitably owned and largely charitably funded.

Hospital services

- All the multi-speciality hospitals serving London have palliative care teams, and in all but one case, are funded directly by the NHS Trust concerned. The specialist centres, including The Royal Marsden, The Royal Brompton and Harefield, and Queen Square (this centre is covered by the CNWL UCLH SPC service) also have palliative care teams.
- Hospital teams mostly function in an advisory capacity to hospital clinicians in other specialties, who usually retain primary responsibility for their patient's care.

Community services

Community SPC services are subject to much greater variability than hospice in-patient services, both in their design and their availability.

- Community specialist palliative care in this report refers to teams of palliative care clinical nurse specialists with palliative medicine specialist support. They can visit patients in their own homes as well as provide telephone advice. All CCGs have access to this type of service during weekday working hours; however, Appendix 5 reveals that the facilities available at other times vary considerably between providers.
- Palliative care day therapy services provide a range of creative and rehabilitation activities for community patients as well as the opportunity to maintain and renew social interactions. Day care is available in most CCGs but exceptions exist, eg in Waltham Forest.
- Numbers attending day services as a proportion of those receiving community SPC (assuming that those counted under day services also received community SPC) vary substantially, e.g. about one in 17 in Hounslow, one in 10 in West London, one in eight in Newham and one in four in Bromley. It is unclear whether these differences result from issues of capacity or of the practicality of reaching the centre concerned (we also need to be cautious in interpreting this data as data quality for day care services is likely to be poorer).

- Palliative care services may provide outpatient clinic facilities for patients fit enough to travel, sometimes in response to the need for a specific professional intervention, eg from a doctor or a social worker, or, alternatively, as a potentially more efficient use of nursing resources than making a home visit the basis of every face-to-face encounter.
- SPC outpatient facilities are provided in all but five of London CCG areas (Hounslow, Merton, Sutton, Haringey and Islington) but the number of patients involved tends to be small compared with those receiving usual community SPC.
- A small number of CCGs have Rapid Response or Care Coordination services. The absence of an identified Rapid Response service does not mean that no such facility exists, as most community SPC teams adjust the speed of their response to a referral according to its degree of clinical urgency.
- Care Coordination services bring together SPC provision with generic end of life support and social care.
- Most SPC hospice in-patient services provide lymphoedema management for their own patients, and both hospice in-patient and community services provide bereavement support following the deaths under their care. These types of care are occasionally available to clients not otherwise known to the provider. When these types of care are not listed for a particular CCG, it does not mean that they do not exist in that area but just that they do not come from a SPC provider.

In addition to these common forms of community provision, a range of other types of service have been developed at the initiative of individual providers, with or without local commissioning support. Most of these services are intended to either prevent hospice in-patient or hospital admission, or to facilitate discharge from such settings:

- Hospice at Home (H@H) provides extra hands-on nursing care to complement the statutory district nursing service and the usual advisory role of the palliative care clinical nurse specialist¹⁷.
- 13 CCGs have a H@H-type service from one or more of seven providers. Some of these services cater only for patients already known to the provider's usual community SPC team while others, eg the North London Hospice Palliative Care Support Service, receive referrals directly.
- The large variation in the ratio of patients receiving H@H input to the total number of patients receiving usual community SPC, from around 1:25 in Richmond, to 1:6 (a fairly typical figure) in Harrow, to 1:1.5 in Greenwich, presumably reflects differences between localities in models of provision as well as in resources.
- The reason for this in the case of hospital palliative care teams is clear. According to specialty and sometimes locality, a CCG's residents are likely to enter different hospitals and their palliative care needs during an admission are dealt with by the SPC team of the hospital involved.
- In relation to community services, the reason for multiple providers is historic. Areas served by particular community SPC teams were delineated under a previous phase of NHS organisation and, indeed, were often separate from it. They therefore have boundaries that often do not match those of today's CCGs. This can also apply to the catchment areas of hospice in-patient units, which are likely to extend across all or parts of more than one CCG.

Multiple providers

The data indicates that there are numerous instances in which the same type of service for a single CCG is split between two or more providers (Appendix 3).

¹⁷ National Association for Hospice at Home.

- Of the 32 London CCGs, 19 have a single provider for SPC in-patient (ie hospice) services and 13 have a single provider for community SPC. For 12 CCGs, each type of service is provided by a single provider and, in 11 cases, this is the same provider for both service types.
- Other CCGs have up to four community SPC providers (eg Ealing, Camden) and three hospice in-patient providers (eg Islington, West London).
- The division of service between providers is rarely equal. In Brent, St Luke's Hospice and the Pembridge Palliative Care Unit respectively account for 49% and 47% of adult community SPC provision, but the remaining 4% is divided between two other providers. Likewise, St John's Hospice undertakes 49% of Westminster's hospice in-patient SPC but 37% is provided by the Pembridge unit and 14% by Trinity Hospice.
- It is unclear the extent to which multiple providers in a CCG overlap with each other and, if they do, who selects where a patient is referred to.

It is not necessarily either an advantage or a disadvantage to have multiple providers within a single CCG. However, the data for service availability in Appendix 5 reveals that community SPC services vary significantly in what they provide outside working hours.

Therefore, residents of individual CCGs can receive very different levels of community SPC support depending on the provider they are referred to (see Chapter 5). These inequities are not new and, in the areas where they exist, there is little evidence that the commissioning process has made effective progress in resolving them.

4.2 Recommendations for commissioners

- Commissioners should be clear on SPC provision in their area, the characteristics of the services delivered and how each service has been tailored to meet the needs of their local population.
- Commissioners should improve collaboration with providers to ensure equity of SPC access and provision for all CCG residents.

5: Specialist Palliative Care community and hospital advisory service availability

5.1 Data analysis

The service availability data from the 2014 mapping exercise for hospital advisory services and community services was compared with similar data in both LCA and PallE8 areas from 2012 and 2013 respectively. This data (on availability of 24/7 telephone advice and a 7-day face-to-face visiting service, in the community and hospital SPC services) is shown in Appendix 4.

The availability of community SPC, in each CCG, regardless of who provides it, is shown in Appendix 5.

Hospice in-patient SPC services all provide face-to-face support seven days a week at all hours and therefore are not shown separately.

Availability of SPC services outside Monday to Friday, 9am to 5pm was a quality standard applied by NICE¹⁸ in 2004 for the specialist palliative care of cancer patients. They specified the importance of provision of both telephone advice and face-to-face visiting.

“The (SPC) team should be staffed to a level sufficient to undertake face-to-face visits to all people with cancer at home or in hospital, 09.00-17.00, seven days a week. In addition, there should be access to telephone advice at all times (24 hours seven days a week). This is considered a minimum level of service. Provision for bedside consultations in exceptional cases outside the hours of 09.00-17.00, seven days a week is also desirable.”

This quality standard has now been endorsed by the latest government guidance for the care of all dying patients¹⁹.

These recommendations are also echoed by:

- the NICE guidance for end of life care²⁰
- Care Quality Commission²¹
- professional bodies in palliative and end of life care²²

For hospital SPC services across London in 2013-14:

- Only 9 of 30 services were able to provide seven-day visiting services.
- Four services do not provide telephone advice out of hours (Princess Alexandra Hospital, Barnet and Chase Farm Hospital Trust, North Middlesex Hospital and Whittington Hospital).
- Three services are providing a six-day visiting service.
- However, six services are providing face-to-face visiting all hours, which represents best practice (University Hospital Lewisham; King's College Hospital NHS Foundation Trust; Central and North West London – University College London Hospitals service; Central and North West London HCA Specialist Palliative Care Service; Royal Marsden NHS Foundation Trust; and Guy's and St Thomas' NHS Foundation Trust).

18 NICE. Improving supportive and palliative care for adults with cancer, 2004.

19 Leadership Alliance for the Care of Dying People. One Chance to Get it Right. London: UK Government, 2014: 27, para.46.

20 NICE. Quality standard 10: Specialist Palliative Care (QS13), 2011.

21 Care Quality Commission supports new vision for End of Life Care, 2015.

22 National Council for Palliative Care. Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives, 2012.

For community SPC services across London in 2013-14:

- 17 of 26 services are providing seven-day visiting.
- Five services are unable to provide telephone advice to professionals out of hours (St Clare Hospice, Royal Free Hospital, Haringey Community Team, Diana Team Newham [paediatric palliative care] and North East London NHS Foundation Trust's Redbridge Specialist Palliative Care Team).
- Six services are unable to provide telephone advice to patients or their families out of hours (as above, with the addition of University Hospital Lewisham).
- However, five services demonstrate best practice by providing face-to-face visiting at all hours (Saint Francis Hospice; Central and North West London – Camden; Central and North West London – Islington ELiPSe; Guy's and St Thomas' NHS Foundation Trust; and St Christopher's Hospice).
- There is a large variation in service availability of community SPC between CCGs, with some CCGs providing 24/7 specialist care visiting and others providing only Monday to Friday, 9am–5pm services.
- Some variation of service availability exists within CCGs as a result of CCGs having more than one provider, with some CCG residents receiving significantly greater service than others.

Data on service availability over time has been analysed for both the LCA area (between 2012 and 2014) and the PallE8 area (between 2013 and 2014). This shows some improvement in SPC service availability in the LCA area, but some deterioration in service availability between the two years in the PallE8 area.

Since this service mapping exercise, the authors are aware of some further services which have been able to implement seven-day, face-to-face visiting. Despite this, the data reveals that SPC service availability across London is still below the minimum service level set by NICE in 2004.

Additionally, there are inequities in SPC service availability within many CCGs as a result of CCGs commissioning from more than one provider. Both hospital and community SPC teams across London require further support to achieve the service availability recommended. There may be opportunities to share resources across providers to achieve this and to learn from services which are achieving or exceeding the quality standard.

5.2 Recommendations for commissioners

- Both hospital and community SPC teams across London require further support to fully achieve the 2004 NICE quality standard for cancer.
- As a minimum, SPC services in hospital and community should be supported to provide face-to-face visiting from 9am–5pm, seven days a week, and telephone advice 24 hours a day, seven days a week.

6: Correlation of community Specialist Palliative Care and hospice services to CCG proxy need measures

SPC should be provided according to need within populations of patients²³. It is important to ascertain whether current SPC services are providing care to all of the patients who need it.

However, we do not have a total for this population as there is no nationally accepted measure of patient need. For the purposes of this service evaluation, two ways of approximating need have been explored to allow us to compare what might be needed with current provision.

6.1 Ratio of cancer patients seen to cancer deaths (expressed as a percentage)

For the purposes of this analysis, the numbers of cancer deaths in each CCG have been used as a proxy for SPC need, while recognising the limitations of the proxy.

If it is assumed that the same proportion of the patients who die of cancer, need the same level of SPC input in each CCG, the number of patients with cancer in a given CCG, who were seen by an SPC service, could be divided by the number of cancer deaths in that CCG, to give a proxy for need. This methodology suggests that there is considerable variability in the percentage of patients in need who receive the service between CCGs. This is illustrated in Appendix 6.

In reviewing this data, it is important to remember that:

- cancer death figures by CCG are a proxy measure and not a direct measurement of need
- cancer death figures used are from 2012 and this service review is for 2013-14
- not all patients seen will die within the same year
- this percentage may not reflect the service to need ratio for the population with non-malignant diseases
- patients living in the boundaries of the LCA and PallE8 defined areas may be accessing SPC services outside the area of measurement in this study which may result in the ratio in those CCGs being underestimated

²³National Council for Palliative Care. Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives, 2012.

- there are a number of patients who were not classified by CCG and this will impact on the accuracy of the data

A deprivation measure is also shown in Appendix 6 as this may be an additional influence on the need for SPC. This analysis was made for community SPC and hospice in-patient specialist SPC.

For community SPC services across London in 2013-14

- There is a large variation by CCGs across London in the ratio of patients who were seen by community SPC services to those who died with cancer. This is especially the case in North East London (NEL) and North Central London (NCL).
- NEL also has higher deprivation scores suggesting that the gap between patients seen and patient need may be even higher.
- There are a few areas with high levels of patients seen compared to patient deaths in NEL and NCL such as Islington CCG and Camden CCG which suggests good provision of services.
- Hammersmith and Fulham CCG appears to be an outlier in North West London with fewer cancer patients seen per 100 cancer patient deaths.

For in-patient SPC services across London in 2013-14

- There is a large variation in the ratio of patients who died with cancer to those who were seen by in-patient services, with Barking and Dagenham CCG having the lowest ratio and Central London (Westminster) CCG the highest.
- CCGs with higher deprivation scores do not generally have a higher ratio, with Barking and Dagenham CCG having the lowest ratio.

6.2 Ratio of patients seen by community SPC to patients seen in hospice in-patient SPC units

For each CCG, a ratio was derived for patients seen by community SPC to patients seen in SPC hospice in-patient units. This gives a picture of the relative provision of community and hospice in-patient SPC services in each area. The results can be seen in Appendix 7.

In reviewing this data, it is important to remember that:

- there is no standard available for the appropriate ratio of SPC community to SPC hospice in-patient visits
- in some areas, commissioning and service models will impact on the relative availability and therefore activity of SPC community and SPC hospice in-patient teams

Across London in 2013-14

- The data reveal a wide variation in the ratio between patients seen by community SPC to patients seen in hospice in-patient SPC units. This raises questions about equity of access to the different types of SPC across London CCGs.
- Hillingdon appears to be an outlier, with a significantly higher ratio of patients seen by community SPC to patients seen in hospice in-patient SPC units.
- The four lowest ratios are all in North East London with City and Hackney and Waltham Forest CCGs demonstrating the lowest.

There is currently no way of measuring whether SPC services are responding to the population in need of SPC. Proxy measures such as the ones devised here can suggest variations in meeting need but should be interpreted with caution. Further examination of the reasons for variations noted is required.

6.3 Staffing

As part of reviewing provision of SPC services in London, providers submitted staff mix and staffing resource levels. We attempted to compare how SPC provision in each of the sectors across London in 2013/14 compares with the national recommendations for the minimum requirements of SPC provision outlined in the December 2012 publication, *Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives*, a guidance developed in partnership with the Association of Palliative Medicine, National Council for Palliative Care and Marie Curie²⁴. This data has not been included as part of this report for a combination of reasons:

- Commissioners commission a service, rather than the personnel quotas to provide it.
- Methodological challenges in applying the guidance meant that conclusions would have been unreliable. These challenges included:
 - The difficulty of comparing different CCG clusters when different types of service are split variously between different providers.
 - Organisations which provide more than one type of service differ as to how they allocate to each service the time of staff whose work pattern crosses service boundaries.
 - Variations in staffing mix or levels may reflect providers' choice of service model. Current evidence does not allow us to be definitive about which models of service are associated with the most favourable outcomes.

However, difficulties in application of the guidance notwithstanding, it is worth commissioners noting that the data indicate a likelihood that staffing levels in all types of SPC provision frequently fall short of national guidance and that this is a probable contributor to the service shortfalls that have been identified.

6.4 Recommendations for commissioners

- Commissioners should be aware of how their CCG performs against proxy measures for SPC need.
- Outlying SPC services should be supported to understand why they differ from other services.
- Commissioners should review staffing levels with their local SPC services to ensure they are in line with national recommendations.

²⁴ APM, Cons Nurse in Pall Care Ref Gp, Marie Curie Cancer Care, NCPC and Pall Care Section of RSM, 2012.

7: SPC service activity by care setting for cancer versus non-cancer diagnosis

7.1 Data analysis – cancer versus non-cancer patients

The analysis identified SPC service activity (patient counts) by cancer and non-cancer diagnosis for London-wide SPC services within three settings – hospital advisory, in-patient beds and community palliative care – and they were compared to previous service mapping data collected in 2012 and 2013 (Appendix 8). This data demonstrates that London services vary to some degree in the proportion of non-cancer patients they see.

Hospital advisory

- For a number of hospital advisory services, there are valid reasons for the cancer to non-cancer patient ratio observed being atypical.

For example, three hospital advisory services observed to have the highest percentage of cancer patients see limited non-cancer patients as they are primarily cancer centres.

- Discounting the above exceptions, 2014 data indicate that, of the patients seen by hospital advisory teams, the percentage with non-cancer diagnoses varied from 15% to 50%.
- 17 out of 23 (74%) services indicate they have increased non-malignant referrals from 2012 to 2014.
- 22 out of 28 (79%) services have a higher non-cancer patient rate compared to the national average for hospital advisory teams which is 25% ²⁵.

In-patient units

- 2014 data indicate that, of the patients seen by in-patient units, the percentage with non-cancer diagnoses varied from 5% to 30%.
- Nine out of 16 (56%) adult services increased their proportion of non-malignant referrals from 2012 to 2014.
- 14 out of 16 units (88%) increased their non-malignant referral proportion of non-cancer patients to adult in-patient units to a level higher than the national average.

Community palliative care

- 2014 data indicate that, of the patients seen by community palliative care teams, the percentage with non-cancer diagnoses varied from 10% to 35%.
- 16 out of 20 (80%) adult services which contributed relevant data increased their proportion of non-malignant referrals from 2012 to 2014.
- The Minimum Data Set data for 2014 showed that 17% of all referrals to community services nationally had a primary diagnosis which was not of malignancy. The study data indicates that 17 out of 23 (74%) adult SPC services in London accepted referrals for people with non-malignant illnesses.

In summary, this mapping exercise indicates that London SPC hospital advisory, community and hospice in-patient services, on average, see more non-cancer patients than national averages. In addition, the proportion of non-malignant referrals has increased on average from a similar 2012 mapping exercise.

However, given that non-cancer deaths accounted for 71% of all deaths in 2014, London still has a significant unmet need of non-cancer patients accessing SPC services.

7.2 Recommendations for commissioners

- It is recommended that CCGs from across London work with their local clinicians, patient groups, the voluntary sector, social care, public health organisations and local SPC services to understand need.

The CCGs can then develop, fund adequately and evaluate appropriate cost-effective SPC services. These services should meet the need for symptom control and psychosocial support of patients with advanced malignant or non-malignant diseases and their family/carer.

- When addressing local SPC needs, commissioners are asked to note that previous national guidance focused on the cancer patient population (NICE 2004), which often guided SPC service development at that time.

Recent relevant guidance (eg NICE EOLC *Quality Standards*, 2011; *One chance to get it right*, 2014) has highlighted that SPC should be fully accessible for all adult patients with relevant complex needs, irrespective of their diagnosis. Therefore, commissioners may need to review their local SPC service capacity to accommodate this likely increase in demand.

8: SPC service demographic characteristics

8.1 Age breakdown

In this study of London SPC services, we reviewed access to services across three age groups: under 65 years; between 65–84 years; and over 85 years; and in three settings – hospital advisory, community and hospice in-patient units in 2013/14 (Appendix 9).

The data illustrates that between:

- 40% and 90% of adult patients seen in a SPC hospital advisory service setting were over 65 years old; of which 6% to 8% were over 85 years old
- 60% and 80% of adult patients seen in a community SPC service setting were over 65 years old; of which 5% to 32% were over 85 years old
- between 60% and 80% of adult patients seen in a SPC hospice in-patient unit were over 65 years old; of which between 8% to 26% were over 85 years old

It is interesting to compare this data with the most recent national survey of patient activity data for SPC services which shows²⁶:

- 29% of referrals involved patients aged 25–64 years (deaths in this age group account for 13% of all deaths excluding external causes)
- 54% involved patients aged 65–84 years (who account for 46% of deaths overall excluding external causes)
- 16% involved those aged 85 and over (who account for 39% of deaths excluding external causes)

The relatively low proportion of eldest elderly (85 + years) receiving SPC services nationally, when compared to the mortality rates for each of the age groups, may indicate a disparity in access for this age group. There is evidence that patients over 75 years had the highest preference to die in a hospice and the least chance to receive it²⁷. The data from this study shows a similar picture for the London region.

This data illustrates that there is a disproportionately low representation of people over the age of 85 within London SPC settings compared to national mortality figures, but not when compared with national data for access to SPC services.

8.2 Ethnicity breakdown

In terms of equity of access to services on the basis of BAME status, it is difficult to make robust conclusions given that the:

- BAME status for patients accessing SPC services has been recorded with variable level of quality
- ethnic breakdown of BAME patients accessing SPC services would not necessarily correlate with the overall ethnic breakdown of a CCG covering all age groups, given the average older age of SPC patients. Only 4.8% of the England population aged over 65 years old are from BAME groups compared to the overall 14.6% BAME groups represented across all age groups²⁸

²⁶ Dixon J, King D, Matosevic T, Clark C, Knapp K. *Equity in the provision of palliative care in the UK: review of evidence*. Personal Social Services Research Unit, London School of Economics and Political Science, London, 2015.

²⁷ Gomes B, Calanzani N, Higginson IJ. *Local preferences and place of death in regions within England 2010*, Cicely Saunders International, London, 2011.

²⁸ Office of National Statistics. ONS census ethnicity by age, 2011.

It can be assumed that the need for SPC in these groups will increase over time as the BAME populations age. As such, it is imperative that SPC services are tailored to meet their needs.

A multivariate analysis on the recent VOICES bereavement survey²⁹ illustrates that, in terms of care experience, the respondents representing the decedents from BAME groups in this study felt they were less likely to receive help to allow their relative to stay at home during the final stages of their illness (at 95% rather than 99% significance level).

8.3 Recommendations for commissioners

- Given the generally ageing population and the likely increase over time in percentage of people over the age of 65 from a Black, Asian and minority ethnic (BAME) background, it is recommended that CCGs look at their demographic projections and work accordingly with their local clinicians, community groups and SPC services to develop, fund and evaluate appropriate, cost-effective services.

²⁹ Dixon J, King D, Matosevic T, Clark M, Knapp M. Equity in the *Provision of Palliative Care in the UK: Review of Evidence*, Marie Curie, 2015.

9: Conclusions

There is evidence of improvement since 2012 of SPC service access by non-cancer patients across London and in some out-of-hours service provision in West and South London (ie London Cancer Alliance areas). **However, SPC out-of-hours service availability across London still falls short of national guidance and accepted best practice.**

This report is limited by the lack of nationally accepted measures of SPC patient need, outcome or service quality to act as benchmarks. An analysis of provision of SPC against two proxies for need has been presented in the report but should be reviewed with caution. It was not possible to report on some of the information collected, including BAME populations, as a result of data quality issues.

The report makes a series of recommendations for commissioners on how they can implement the findings from this report to improve end of life care for residents in their area. However, without clear quality and outcome data, it is hard for commissioners to determine the best ways to use limited resources. **Nevertheless, to ensure 24/7 access to SPC telephone support and 9am to 5pm 7/7 access to face-to-face visiting, in line with national guidance, must be a priority.**

The anticipated launch of a national individual-level dataset in 2017 of SPC services including demographic details, activity information and patient outcomes data will be an important milestone towards providing evidence on outcomes, and (in the longer term) facilitating genuine equity of access across London.

LCA, PallE8 and Marie Curie believe everyone living with a life-limiting illness should have access to high quality care and support, which meets all of their needs.

Given that demands on existing stretched resources are only set to grow, we must tackle these issues and find solutions to avoid failing vulnerable people across London at the time they need us most. Monitoring the changing provision of SPC services across London is an important step along the road to improving care.

This report has been jointly produced by the London Cancer Alliance, PallE8 and Marie Curie in collaboration with Specialist Palliative Care providers across London.

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A joint report by

